S. HRG. 107–565

# CANCER CLUSTERS IN LONG ISLAND, NY

## FIELD HEARING

BEFORE THE

## COMMITTEE ON ENVIRONMENT AND PUBLIC WORKS UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

FIRST SESSION

ON

ASSESSING THE POTENTIAL LINKS BETWEEN ENVIRONMENTAL CONTAMINATION AND CHRONIC DISEASES

JUNE 11, 2001—GARDEN CITY, NY

Printed for the use of the Committee on Environment and Public Works

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ONE HUNDRED SEVENTH CONGRESS
FIRST SESSION

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[1]NOTE: On June 6, 2001, the majority of the Senate changed from Republican to Democrat when Senator James M. Jeffords, of Vermont, changed party affiliation from Republican to Independent. Senator Harry Reid, of Nevada, assumed the chairmanship of the committee.

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# CANCER CLUSTERS IN LONG ISLAND, NY

**MONDAY, JUNE 11, 2001**

U.S. SENATE,
COMMITTEE ON ENVIRONMENT AND PUBLIC WORKS,
*Garden City, NY.*

The committee met, pursuant to notice, at 9 a.m. in The Ballroom, Ruth Harley Student Center, Adelphi University, Garden City, NY, Hon. Harry Reid (acting chairman of the committee) presiding.

Present: Senators Reid, Clinton, and Chafee.

## OPENING STATEMENT OF HON. HARRY REID, U.S. SENATOR FROM THE STATE OF NEVADA

Senator REID. I'd like to call this meeting of the Committee on Environment and Public Works to order. My name is Harry Reid, I'm chairman of the Environment and Public Works Committee.

Today we're meeting in New York, and as appropriate, the Senator from the State of New York will conduct this hearing, Senator Clinton, a member of the committee.

[The prepared statement of Senator Reid follows:]

STATEMENT OF SENATOR HARRY REID, U.S. SENATOR FROM THE STATE OF NEVADA

I want to express my appreciation to Senator Clinton for holding this hearing, and for her leadership on the crucial issues that we will focus on today.

I have had the pleasure of working very closely with Senator Clinton on a number of important matters over the past 5 months, and want to take this opportunity to report that she is doing a tremendous job, both on the Environment and Public Works Committee and in the Senate at large. You are very fortunate to have her representing you.

Her service on both the Environment and Public Works Committee and on the Health Committee, her mastery of complex health and environment-related issues, and her commitment and vision in addressing those issues, contribute to her being an outstanding advocate for New Yorkers and for the Nation in addressing environment-related health problems of concern to citizens throughout the Country.

I also want to thank my colleague Senator Lincoln Chafee for being here today. Senator Chafee also serves on the Environment Committee and, like his father the late Senator John Chafee, Lincoln Chafee has been a true champion of many issues that American's hold most dear, including protection of our environment and public health.

I particularly want to recognize Senator Chafee's leadership in promoting research into the role the environment plays in the development of breast cancer, with the introduction last month of the Breast Cancer and Environmental Research Act, which Senator Clinton and I also have cosponsored.

This is the second hearing of the Environment Committee this year to focus on potential links between the environment and chronic disease, and how we can better understand and respond to disease outbreaks. In April Senator Clinton accompanied me for the first hearing, in my State of Nevada, in the city of Fallon.

The Fallon community is facing a tragic situation—14 children have been diagnosed with childhood leukemia in less than 2 years, where two cases would be sta-

tistically likely for this small community. In just the 2 months since the hearing, two more children have been diagnosed, and one child has died of the disease.

There are many theories as to possible causes or contributing factors, but at this point we simply do not know why so many children have been stricken with this terrible disease. Ongoing efforts by the Centers for Disease Control and the State Health officers include investigations into potential exposures to a number of environmental contaminants.

I look forward to learning more about progress in the Fallon investigation from the State of Nevada's epidemiologist, Dr. Randall Todd, who will testify on the first panel. Dr. Todd, I want to acknowledge your dedication in working on the Fallon investigation and to thank you for traveling such a long distance to be here.

As those of you here today well know, disease clusters are not confined to Nevada or New York. Communities throughout the United States are facing the same challenges and frustrations experienced in Long Island, in Elmira, and in Fallon, NV.

There is widespread concern among the citizens of this country about what environmental contaminants we are exposed to in our day-to-day lives, and what effect exposures may have on our health and the health of our families.

But, unfortunately, there is not a coordinated system in this country to support communities and States in responding to disease outbreaks, or to track chronic diseases so that we might better understand possible links to environmental exposure. Too often communities and States are forced to reinvent the wheel, and face these events alone, without the necessary resources, information or expertise.

While a number of Federal agencies are doing an excellent job supporting State and local officials in addressing community health concerns, the support system often seems uncoordinated, ad hoc, and too little too late.

There is a tremendous need to improve our understanding of the causes of chronic diseases and in turn to better protect public health through preventative measures. This need presents an opportunity that in my view we as a Nation cannot afford to pass up.

The time is long overdue for the Federal Government to craft a coordinated approach for rapidly and effectively responding to the needs of communities for support and guidance in identifying and addressing chronic disease clusters.

When we return to Washington, I look forward to working with Senators Clinton and Chafee, and other colleagues in the Senate and the House on both sides of the aisle, on legislation: (1) to bridge this critical gap in our knowledge concerning chronic diseases and related environmental factors, and (2) to establish a system to coordinate and support the investigation of and response to chronic disease outbreaks when they do occur.

I apologize in advance that I will not be able to stay for the entire hearing, as my duties as Assistant Majority Leader require that I get back to Washington. However, I will carefully review all of the testimony prepared for today's hearing.

I look forward to hearing from the witnesses.

Senator REID. Senator Clinton.

## OPENING STATEMENT OF HON. HILLARY RODHAM CLINTON, U.S. SENATOR FROM THE STATE OF NEW YORK

Senator CLINTON. Thank you very much, Chairman Reid.

Welcome to New York. I'm delighted that you and Senator Chafee from Rhode Island could join us for this important hearing. This is the second in a series of hearings about a very important issue, the potential link between our environment and chronic diseases and disease clusters, including especially here on Long Island, high rates of breast cancer.

I don't think I need to explain to anyone here at Adelphi, which has pioneered work on not only reaching out to breast cancer survivors, but also the investigation of environmental issues, that this is an issue that many of us live with and have very personal connections with.

While breast cancer incidence rates for New York State overall are below the national average, those for Long Island consistently exceed that national average. The hearing that Senator Reid convened in Fallon, NV, which I was very pleased to attend, focused

on childhood leukemia clusters, a problem that has just so affected that small community. At the time, I told Senator Reid about the high incidence of breast cancer here on Long Island and other cancers and chronic diseases that we have in clusters around New York, and that led to this hearing.

We all know that disease clusters and overall increases in the rates of chronic disease are not confined to New York or Nevada. We face these challenges around our country. According to the Centers for Disease Control, birth defects are the leading cause of infant mortality. Yet, the cause of about 70 percent of all birth defects is unknown.

The CDC also reports that from 1980 to 1984, cases of self-reported asthma increased 75 percent, an increase of epidemic proportions. New York has the second highest rate of people suffering from asthma, surpassed only by California. Asthma is the No. 1 cause of school absenteeism.

A recent report by the National Academy of Sciences estimates that 25 percent of developmental disorders in children is caused by environmental factors. Between 1986 and 1995, there was an almost 22 percent increase in endocrine and metabolic disorders, such as diabetes, a 20 percent increase in neurological disorders, such as Parkinson's, and nearly a 20 percent increase in respiratory diseases. We are totally in the dark as to how many children in this country are suffering from autism, yet we know that the numbers are increasing.

That's why we're here today looking for answers. We're looking for answers to the questions that many of you have asked yourself, "Why do I have breast cancer?" "Why does my child have leukemia?" "Why does my child have asthma or trouble learning in school?" "Is there something in my environment that is making me or my family sick?"

Well, we're going to be looking for those answers in a bipartisan way in both Houses of Congress this year. I'm looking forward to hearing from our witnesses, because we want to take this information and testimony back to Washington so that we can come together to determine what steps we need to take in order to do whatever is possible at the Federal level to try to aid in the search for answers to these unanswered questions.

Senator Reid and some of our colleagues and I are already working on legislation to address the problem of disease clusters. We want to establish ways to bridge the gap in our understanding of chronic disease and environmental factors. We believe our Nation needs to coordinate its support, investigation of and response to chronic disease outbreaks, with the ultimate goal of preventing them in the first place.

This hearing will add to the body of knowledge that we are acquiring. I want to thank all of you for coming, and I particularly want to thank my colleagues. First, my friend and our chairman, Senator Reid, who is also now the new Assistant Senate Majority Leader. I want to thank Senator Reid for giving us the opportunity to hold this hearing and for taking time off his even busier schedule to attend.

It's a pleasure and an honor working with Senator Reid. The service that he offers our entire country is something that I have

just marveled at. He seems to be absolutely tireless as he represents the people of Nevada and does the work that is required in the Senate. I want to thank him for his leadership and his friendship and for his dedication to addressing the shortcomings in our environmental protection and public health systems, so that we can find answers for the people in Fallon, Long Island and throughout America.

I also want to thank Senator Lincoln Chafee of Long Island for joining us. He has been a true leader on the environment, and in fact, is the lead sponsor of the Breast Cancer and Environmental Research Act, along with Senator Reid—legislation of which I am proud to be a cosponsor, which is carried in the House by our colleague, Nita Lowey.

Senator Chafee has been serving as the chairman of the Superfund Subcommittee, and he played a very significant role in the unanimous passage of the very first brownfields bill in the U.S. Senate. I have greatly enjoyed getting to know Senator Chafee, and look forward to a long and productive working relationship with him.

I also want to thank my colleagues from the House who represent Long Island. We are privileged to be in the district of Congresswoman Carolyn McCarthy. Carolyn has been a leader on many issues, in particularly on the issue of breast cancer, representing so many of her constituents, and I thank her for that. I would also like to welcome the other members of our delegation, Congressman Gary Ackerman and Congressman Felix Grucci, and to thank them and all the members of the New York delegation, including Senator D'Amato, for everything they've done to help us fight breast cancer here on Long Island and across America.

I want to thank our hosts today. I extend my appreciation to Adelphi University. The committee is very honored to be here, and to have a chance to hold this hearing at a university that is home to the Adelphi Breast Cancer Hot Line and Support Program. I want to thank President Robert Scott, Provost Marshall Walsh, Hillary Rutton, the director of the Hot Line and Support Program, and the many volunteers like my friend, Marie Kaplan, who are there day in and day out, answering 4,000 calls a year.

I would like to welcome any of the State officials who we have here. I know several of them were intending to come. Is Assemblyman Tom DiNapoli here? Tom, thank you for coming. Senator Michael Balboni, I appreciate greatly your being here and hope that we can have you address this important issue as well.

With that, I turn this hearing over to our chairman.

Chairman Reid.

Senator REID. Senator Clinton, thank you very much.

I have worked very closely with Senator Clinton these past 5 months. She's done a tremendous job as a member of this committee and a member of the Health Committee. She is someone who's a quick learner and she started the hearing we had in Fallon a short time ago.

I also want to take just a brief minute to note the presence of my friend, Lincoln Chafee. Every time, and I'm sure he gets tired of me saying this, but I had the honor of serving with his father. When we go through the list of great legislators in our country, his

father, John Chafee, certainly is on that list. I served with him from the time I came to the Senate and this committee, and he was an inspiration to me. We're happy to have his son, who has every indication of being just as good as his dad.

This is the second hearing, as Senator Clinton has indicated, that we're holding on this subject of a cancer cluster. In Fallon, NV, which is a community much different than this urban community that we have here in Long Island, NY, urban compared to Nevada, it's a community 60 miles south of Reno. We have in that little community a real, I don't want to call it a plague, but people are so frightened. The standard would be that about one and a half children would have childhood leukemia. We now have 15 children with childhood leukemia. We don't know the cause of that. We don't know whether it's caused by the naturally occurring heavy arsenic in the water. We don't know whether it's caused by the heavy application of pesticides and other things on the farms that they've had there for 100 years. We don't know if it's caused by the military base which is one of the largest military bases in the country—it's a Naval flying center—Fallon Naval Air Station. Top guns there use millions of gallons of fuel every year. We know that there have been some fuel spills.

We don't know if it's being caused by a virus. There's now a theory that it's being caused by a virus. British scientists believe that they can prove that some of the cancer that's been caused over is caused by heavy inflow and outflow of people into an area. Certainly, we have that there with the military base.

We don't know. Or is it a combination of those? We don't know. We cannot accept the answer that we've had in a number of these cancer clusters, it just happens. We don't know why this happens, we cannot let that happen. We need to establish a cause.

That's why I'm so thankful that Dr. Randall Todd, the State of Nevada State epidemiologist, is here with us today. He's going to be able to recount some of the things that are going on in Fallon.

One of the other things that we have in Fallon, we really don't know how many children are sick, because of the kids that have left that military base. We're doing our best to check it out, but we simply don't know.

Cancer clusters are not confined to Fallon, NV. That's why we're here in Long Island. Communities throughout the United States are facing these same challenges and frustrations experienced here in Elmira and in Fallon, NV.

I would just say in passing, in Nevada you always know where you are. In New York, I never know where I am.

[Laughter.]

Senator REID. There are towns, boroughs, cities—whatever else—but I'm glad we're here.

There's widespread concern among citizens of this country about environmental contaminants, and we've already mentioned a few of them. Kids get asthma, it's almost standard now for children. Why? We don't know. What effect do exposures have on our health and the health of our families? That's why Senator Clinton and Senator Chafee are here with us. There is a belief that our environment is causing some of these diseases.

We don't have a coordinated system in this country for how to respond to these disease outbreaks. So one of the things we're going to come up with, with these hearings, we're going to do it legislatively, the Federal Government, each time there's a cancer cluster, they have to re-establish how they're going to move into this area. We have the National Centers for Disease Control, National Institutes of Health, EPA, a number of Government agencies who in effect are stepping on themselves trying to figure out what to do. We want to have a protocol established, like when there's an airplane accident, with the National Transportation Safety Board, there is a way that they come in and the different agencies of the Federal Government react. We're going to do our best to do that.

The Federal Government agencies are doing their best. They're doing an excellent job of supporting State and local officials addressing community health concerns. But the support system many times seems to be uncoordinated, ad hoc, and simply too little too late. There is a need to improve our understanding of the causes of chronic diseases and in turn, to better protect public health through preventive measures.

Public health is something we don't talk about much in this country. We need to talk about it much more. The time is long overdue for the Federal Government to craft an orderly approach for rapidly and effectively responding to the needs of communities for support and guidance in identifying and addressing disease clusters.

When we return to Washington, I look forward to our continued work, that is, Senators Clinton and Chafee, others and I, on trying to come up with legislation to bridge this critical gap in our knowledge concerning chronic diseases and related environmental factors and establish a system to support investigation and response to chronic disease outbreaks when they do occur.

I want to extend my appreciation to members of the House for being here. Congressman Ackerman and I came to the House together. We were freshmen members of the House together. The other two Representatives I see and work with in Washington, we look forward to working with them even more closely as a result of this unfortunate occurrence of cancer we have in Long Island.

Senator CLINTON. Thank you very much, Chairman Reid.

Senator Chafee.

## OPENING STATEMENT OF HON. LINCOLN CHAFEE, U.S. SENATOR FROM THE STATE OF RHODE ISLAND

Senator CHAFEE. Thank you very much, Senator Clinton, for organizing this morning's forum. We're very grateful to you for doing that. It's a great deal of work, and I understand that. I'm anxious to hear the three panels that you've organized, and I know we're going to learn a lot. As Senator Reid said maybe a dozen times in his opening statement, "We don't know what causes these clusters, and that's why we're here, and we look forward to your testimony."

Thank you.

[The prepared statement of Senator Chafee follows:]

STATEMENT OF LINCOLN D. CHAFEE, U.S. SENATOR FROM THE STATE OF RHODE ISLAND

Good morning. I am pleased to be here today for this important hearing.

This hearing is very important for many reasons. The first and foremost is the fact that breast cancer mortality rates are up to 20 percent higher in Long Island than the national average. This is an alarming statistic, which deserves this close examination by the Environment and Public Works Committee.

Many scientists believe that certain groups of women have genetic variations that may make them more susceptible to adverse environmental exposures. A study recently conducted in Sweden showed that environmental factors may matter more than genetics in determining whether a woman is diagnosed with breast cancer. This study found that the environment—what we eat, breathe, drink, and smoke, including how we live and which chemicals we are exposed to—accounts for roughly twice the risk of cancer than genes do.

There is a reason so many women in Long Island are being diagnosed with breast cancer, and I believe that the environment here holds the key to this mystery.

I am particularly pleased to participate in this hearing today because of its relevance to legislation I recently introduced with Senator Harry Reid. We introduced S. 830, the Breast Cancer and Environmental Research Act this past May, and we are pleased that Senator Clinton is a primary cosponsor. S. 830 will establish research centers that would be the first in the Nation to specifically study the environmental factors that may be related to the development of breast cancer. The lack of agreement within the scientific community and among breast cancer advocates on this question highlights the need for further study.

This bill will enable scientists and researchers to conduct more comprehensive and conclusive research to determine the impact of the environment on breast cancer. S. 830 will require each Center of Excellence to collaborate with community organizations in the area, including those that represent women with breast cancer. Consumer advocates would also be involved in all phases of this program. While it is generally believed that the environment plays some role in the development of breast cancer, the extent of that role is not understood. Before we can find the answers, we must determine the right questions to ask. We need to step back and gather evidence before we come to conclusions, and that is the purpose of our legislation.

On that note, I would like to turn it over to the witnesses so we can hear their stories and learn from their expertise.

Senator CLINTON. Thank you.

Congresswoman McCarthy.

## STATEMENT OF HON. CAROLYN MCCARTHY, REPRESENTATIVE FROM THE STATE OF NEW YORK

Ms. MCCARTHY. Thank you, Senator Clinton. I want to thank Senator Reid and Senator Chafee and my colleagues here from Long Island. I have to say thank you to Dr. Scott from Adelphi. He had been wonderful in allowing us to use Adelphi on a number of occasions, and Hillary Rutton for the Breast Cancer Hot Line.

This is something that concerns all of us here on Long Island. I don't think there is anyone who doesn't know someone who doesn't have breast cancer or prostate cancer. But you know, as a nurse, I have to say, we have to look at all cancers, naturally we should be attacking it on every level of cancer. I'm sorry to say that I have three neighbors that I have grown up with, and all three, one, two, three, they're all suffering with lung cancer, all diagnosed within the last 3 months.

So this is something that concerns all of us, and our whole delegation. It doesn't matter whether it's here, doesn't matter whether it's in Gary's district, Peter King's, Steve Israel's, Felix Grucci's, it concerns all of us. I'm sure that when we start looking into the different causes, and we don't know all the causes, let's eliminate,

let's get some scientific evidence, and then start working on those areas that we can.

I want to thank Gary Ackerman and Felix Grucci. We're on a bill that will help breast cancer survivors be able to take their medications, open it up to other people that can buy into Medicare if they have breast cancer. This is another way of trying to do what we can to help the people in Long Island, NY, the whole country. This is something Senator Reid has said. We have to coordinate everybody, from the Federal level, so that we can attack this hideous disease. It's probably one of the most important things, in my opinion, that can help all Americans, and certainly the people of New York and Long Island.

Thank you.

Senator REID. Thank you, Congresswoman McCarthy.

Congressman Ackerman.

**STATEMENT OF HON. GARY L. ACKERMAN, REPRESENTATIVE FROM THE STATE OF NEW YORK**

Mr. ACKERMAN. Thank you very much, Madam Chair, Mr. Chairman, Senator Chafee. I appreciate the convening of this very critical hearing and I'd like to begin my comments by expressing my profound thanks for selecting Long Island for this very, very important hearing. When you think about one of the reasons, it's an honor that we'd rather not have. That is because we are in a place where we see one of the great hot spots, as they are called, in our country.

I'd also like to express my appreciation to the many soldiers in the battle against breast cancer. Many of them are here in this room right now, and too many to name. But their dedication and tireless efforts are critical, and they're so deeply appreciated by all of us.

We're here today to discuss the possible connection between the environment and chronic illnesses such as breast cancer. In addition, we need to explore what efforts should be undertaken by the Federal Government to address this problem. One of the legislative accomplishments of which I am most proud to have worked on is the establishment of the Long Island breast cancer study. As all here know, this is a multi-study effort to investigate whether environmental factors are responsible for breast cancer in Suffolk, Nassau, and Hardy counties in New York, as well as Connecticut. This historic investigation began in 1993, and is funded and coordinated by the National Cancer Institute, in collaboration with the National Institute of Environmental Health Science.

This comprehensive study consists of more than 10 studies that includes human population studies, the establishment of the Family Breast and Ovarian Cancer Registry and laboratory research. We all eagerly await the findings of this study, which should hopefully be released within the next few months.

Long Island's very high breast cancer rate, along with recent scientific studies, seems to suggest that there can be a connection between a person's environment and his or her risk of developing cancer. In the case of breast cancer, the question is, why do women on Long Island seem to be at greater risk of developing this disease? Someone said that Long Island is simply the unfortunate set-

ting for a convergence of known risk factors, such as socioeconomic and reproductive characteristics. However, others have suggested that local environmental contaminants are playing a key role in driving up the mortality incidents.

In October 1993, I had called for and asked to be convened and testified at a field hearing of the House Government Operations Subcommittee on Human Resources. The committee was then chaired by Congressman Ed Towns, who also attended. It was also attended by all of the representatives to Congress, the House, of Long Island, and also Senator D'Amato. The hearing focused on the possible link between cancer and the environment, and we discussed all of the factors.

I was first made aware of this problem after reapportionment had taken place and I was new to this part of our State, coming from Queens County, so far away. You have every right to be confused, Senator Reid, I don't know where I am half the time, either. I was first made aware of the problem by Karen Joy Miller, who is really an American hero. I remember our first conversation, it was Karen who convinced me that we needed to have such a hearing, because of these clusters. We didn't know whether or not and still don't that there was some causation that came from factors that might have been airborne, soilborne or waterborne, whether it was something that occurred from things that we did with the soil when this was a very rich farm land so many years ago. The hearing proved to be very interesting.

At the time I testified on the broader issue of how pollutants and contaminants in our environment act on our health, and at the time I predicted that the issue would become more important in the years to come. It's now 8 years later, and we're witnessing this as a national health problem. Long Island is not the only location in the country where such cancer clusters exist.

I want to commend Senator Clinton, Senator Chafee and Chairman Reid for examining this issue in Long Island today, as well as having convened a hearing in Nevada. This cross-country coverage serves to highlight the breadth and diversity of this health crisis that affects not only New Yorkers but all Americans. I look forward to the testimony of our panelists and to our colleagues here today. Thank you very much.

Senator CLINTON. Thank you, Congressman Ackerman.

Congressman Grucci.

## STATEMENT OF HON. FELIX J. GRUCCI, JR., REPRESENTATIVE FROM THE STATE OF NEW YORK

Mr. GRUCCI. Thank you, Senator. I'd like to thank the Senate Environment and Public Works Committee for hosting this event today. I think these types of hearings serve a very good and noble purpose for us to understand the issues and ways to resolve them. You know, there are approximately 3 million women that are diagnosed with breast cancer, a million of them don't know it yet. This year alone, 233,000 women will be diagnosed with breast cancer, and 40,000 of them won't be able to fight back the disease. That's a frightening statistic, a sad commentary for a Nation as rich and as good and as wholesome as this one is, that we have to find a cure for this dreaded disease.

My career in Congress isn't as long and as rich as some who are sitting at this table, but my fight for helping to find a cure for breast cancer dates from the time when I was a town supervisor. My municipality, the town of Brook Haven, was one of the first municipalities in Long Island to join in on the mapping program that was being done.

We also used some innovative concepts to help find funding dollars, much-needed funding dollars. When people would violate the ordinances of the town of Brook Haven, when we imposed the fines on them, I directed those fines be used by our local hospitals, it was St. Charles, Stonybrook or Brook Haven, to use that money to help find a cure for breast cancer, cervical cancer, prostate cancer and cancer of all types is a dreaded disease that affects this country and does such great harm to our citizens, to our families.

I know that we're preaching probably to the choir, because while you are all here, there are still a lot of chairs yet to be filled, and still a lot of people yet to reach. I think Congress has a responsibility to help meet that need, whether it's funding for environmental research, to see if indeed there is a connection and what that connection is between our environment and diseases that afflict us, whether it's to pass legislation to make the processes to finding a peaceful life more accessible, whether it's the overnight stays in the hospital, whether it's reconstructive surgery for women, whether it's finding the cure through more research dollars.

I'm proud to be a member of this Congress, and I'm proud to be sitting up here amongst this panel of individuals who have demonstrated their willingness to help find these cures. We've passed legislation, we're going to be pass legislation, we're going to be dealing with health care issues. All of this is going to be very important as the coming days arrive. I'm eager to hear from our panelists. I was reviewing their names and their backgrounds. It seems to me that we're going to get a great deal of knowledge from today's meeting.

I want to thank Senator Clinton and the Senators for being here. I think this is a very productive meeting and I look forward to its outcome. Thank you.

Senator CLINTON. Thank you, Congressman.

Congressman Israel.

**STATEMENT OF HON. STEVE ISRAEL, REPRESENTATIVE FROM THE STATE OF NEW YORK**

Mr. ISRAEL. Thank you, Senator. Let me also thank you for the leadership that you've shown on this profoundly important issue, and I thank your Senate colleagues for joining us this morning.

I appreciate the opportunity to testify on this issue, as a new Member of Congress. For 7 years prior to joining the House, I worked as a town councilman in Huntington with Karen Miller, whom Congressman Ackerman referred to and who will be testifying later, and the Huntington Breast Cancer Action Coalition in the local fight against breast cancer. One of the projects we initiated was a town-wide mapping and survey and analysis of breast cancer incidence. By chance, it just happens to be the map just behind me on the podium.

I learned something from those clusters that are so visible on those maps. Breast cancer cannot be categorized as a Federal issue or State issue or county issue or town issue. It extends across jurisdictions, boundaries, political parties. It extends to too many neighborhoods, too many families, too many women, too many streets throughout this area. In fact, Suffolk County has the dubious distinction of having more breast cancer cases than almost any other community in our Nation, 2,000 Suffolk County women are diagnosed with breast cancer every single year. What's worse is that we still don't completely understand why women in certain communities are more susceptible to this disease.

We have an obligation to them, we have an obligation to our families to work as partners toward the critical goal of eradicating breast cancer, and we need to start with the Federal budget. Congress and the Bush administration are just starting the annual wrangling over the budget. We can't allow this year's Federal investment in breast cancer research to be caught in that debate. We have to break breast cancer research out of this trap by building a broad base of support for legislation to increase this critical funding.

So I'm hoping that President Bush will support this year's budget and increase the breast cancer research. In addition to that, I want to thank Congressman King, who I believe is scheduled to be here later, for his Taxpayers Cancer Research Funding Act of 2001, which I have cosponsored. This legislation will add a new checkoff on the income tax return to allow for a $5 contribution to a special breast and prostate cancer research fund. That will enable all of us to work together as a country to increase the funding of the National Cancer Institute, which will in turn enable the NCI to increase their research grants to the medical community.

Each year, too many of our loved ones lose their lives to breast cancer. But with increased Federal investment in biomedical research, we will not only improve treatment for this debilitating disease, we will also find a cure. Our mothers, our daughters, our sisters and friends deserve no less. It is time to erase incidence of breast cancer on the map behind me.

Thank you.

Senator CLINTON. Thank you, Congressman. I'd like to ask the first panel to make its way to the table, and I'd like to ask for two brief comments from two of our local legislative leaders at the State level, Assemblyman Tom DiNapoli and Senator Balboni, if you would each like to make a brief comment while the panel gets settled.

## STATEMENT OF HON. MICHAEL BALBONI, STATE SENATOR FROM NEW YORK

Senator BALBONI. Senator Clinton, I'd like to thank you very much for the invitation to join you today. Members of the House and Senate, welcome to Long Island.

I know the strong advocacy in the House and I look forward to the results of this panel. I'd like to make a pitch that perhaps you may not have heard. Long Island presents certainly the challenges and the obstacles that come with being No. 1 in terms of the rate of cancer. But it also presents an opportunity. You will find here,

I would argue, more than any place in the Nation, a galvanized, energized electorate who understands the issue, because it's so personal to them, it affects them so pervasively.

What you also find here is a unique set of biotechnology opportunities where perhaps we can take the information that researchers and scientists present and turn it into cures. So I would ask that you would consider that when you step back from this hearing and consider all the information, consider also the need to move the information to a cure, and that's best done with our biotechnology.

Thank you very much.

Senator CLINTON. Thank you, Senator.

**STATEMENT OF HON. THOMAS P. DINAPOLI, NEW YORK STATE ASSEMBLY**

Mr. DINAPOLI. Good morning. It really is a pleasure to join with Senator Balboni in offering some brief comments. Senator Clinton, I'll leave some written testimony for your committee to deliberate on.

Welcome to Senators Reid and Chafee. It's always good to see our hard working Long Island delegation here, Congresswoman McCarthy, Congressman Ackerman, Congressman Grucci and Congressman Israel, and Congressman King as well. To Senator Clinton, we certainly want to express some particular words of appreciation. I know that last year we had many occasions to speak about the issues and concerns in the Long Island community. I know the voices have resonated most loudly and clearly with you are the voices of survivors of breast cancer and other health impairments on the island and their families. We all appreciate your bringing this very distinguished panel to Long Island to hear our concerns.

As Senator Balboni said, in so many places in New York State, Long Island has been the epicenter for activity and concern on this issue. I know you're going to hear from important scientific testifiers today, but certainly, I'm sure the most compelling testimony you will hear will be from the grass roots activists on Long Island, the women particularly who have kept this issue in the forefront.

I want to offer a few words of consideration for you to bring back some New York ideas to Washington as you complete your agenda there. Because in New York State, we have been grappling with the very important question of what are the environmental impacts as far as our public health, particularly with regard to cancer. Obviously, in all the years and all the studies going back to the original Stonybrook breast cancer study and the small area incident study the department of health was involved with at my request a number of years ago, this is still very much an open question.

So we certainly urge your continuing investment of Federal dollars in research through the ongoing national study. We could certainly use help as far as technical assistance and dollars to help with our State efforts to continue this research. A particular area is the effort to do mapping not only of the incidence of cancer and cancer clusters, but to do a coordination of the information that we have with sites of environmental contamination in proximity to cancer clusters.

As part of the written testimony I'm submitting, there are considerations in the pending Assembly bill A404 that provides spe-

cific requirements on our State Department of Health and Department of Environmental Conservation to coordinate these kinds of mapping and environmental facility contamination impacts. We could use your help in coming up with the dollars and seeing that we can adequately fund these studies.

Your colleague, Senator Schumer, was helpful in identifying a million dollars in aid through Federal EPA to help us map contamination of MTBE on Long Island. That's a very important issue to us, as the local representatives know, we depend for our drinking water supply on a sole source aquifer system. MTBE is certainly a pollutant and a possible human carcinogen, it has become ubiquitous in our environment and it is very important that we maximize our efforts to clean it up. Because while research is important, there are steps we can take to reduce our exposure to these kinds of harmful chemicals and substances.

Along that line, I would recommend to you that New York State will review once again the resolution that the State legislature sent to Congress back in 1999 calling for a Federal ban on MTBE, to eliminate it as an oxygenate in our gasoline. New York State was the first State to have adopted a State ban. I'm very pleased that it has held up in court so far. Certainly dealing with that particular contaminant, it's very important that there be a Federal response and Federal action.

I would also point out that New York State has enacted the first ever pesticide neighbor notification law, thanks to the efforts of many Long Island activists. It's a very important, common sense, right-to-know piece of legislation that helps people reduce their exposures to toxic substances and chemicals in the environment, also worthy of your consideration to be replicated on the national level.

I'll just conclude with the idea of a sentence that would be helpful to us as well. In the northeast region there are particularly health concerns about West Nile virus. Unfortunately, many of the funding programs put an emphasis on aerial spraying, creating other kinds of concerns about exposure to harmful toxic substances. We, in New York State, are trying to put more of a priority on non-spraying control techniques. We could use your help in terms of providing dollars to help us buy those kinds of incentives so localities can move in a different direction than traditional pest control has allowed for.

We're also working with the Long Island Breast Cancer Action Coalition. We're working on legislation this session to come up with a children's health incentive fund that will give dollars and grants to schools throughout our State, to give them extra money to help them move away from pesticides and other types of toxic substances when dealing with pest control. Again, an incentive-based approach will to help change the behavior, help promote best practices so we reduce harmful exposures. That again would be a program that would be aided by Federal support, certainly is worthy of your review and replication on a national level as well.

Again, thank you for coming to Long Island, certainly on behalf of Senator Balboni and myself, and all of our State legislative colleagues, recognize that this needs to be a partnership between the State government and the Federal Government and working with the local communities so we can get to the bottom of this very im-

portant question. I thank all of you, particularly Senator Clinton, for your interest on this issue. Thank you.

Senator CLINTON. Thank you very much, Mr. DiNapoli, for a very good list of issues that we should take back with us to Washington. I look forward to reviewing more closely your written testimony which has more details about this.

We've been joined by Congressman Peter King.

Congressman King.

**STATEMENT OF HON. PETER T. KING, REPRESENTATIVE FROM THE STATE OF NEW YORK**

Mr. KING. Thank you, Senator Clinton. I'll be very brief. I just want at the outset to thank Senator Clinton for convening this meeting and for the leadership she's shown, not just as a Senator, but in the previous Administration, where she worked so hard to focus public attention on breast cancer.

I also want to welcome Senator Chafee and Senator Reid, and of course all my other colleagues from Long Island.

There's probably not a person on Long Island that doesn't have a close family member or friend who suffers from breast cancer. There are clusters throughout Long Island. There seems to be an unusually high rate of incidence of breast cancer on Long Island. Certainly those of us in the Long Island delegation have always appreciated just how importantly this issue has been treated, totally in a bipartisan manner, with tremendous cooperation and certainly, from the time I've been in Congress, I give Congressman Ackerman so much of the credit for keeping the delegation united and working with us and fighting hard on this issue for more funding and for research. Certainly the Federal breast cancer study has been going on now for a number of years, and we await the findings of that. This hearing, I think, is one more very significant step to moving forward, trying to find reasons why, trying to understand why there are these unusually large numbers of breast cancer on Long Island, why we have these cancer clusters.

Senator Clinton, I thank you for convening this. I regret the fact that I could not get here sooner. I look forward to the testimony and again, I thank you for your leadership.

Senator CLINTON. Thank you, Congressman King.

The first panel we're going to hear from today consists of a number of people with first-hand experience as well as expert experience. The first witness is Dr. Phil Landrigan, professor of Pediatrics, and director of the Center for Children's Health and the Environment at the Department of Community and Preventive Medicine at Mount Sinai. The second witness is Dr. Randall Todd, Nevada State epidemiologist, who is here to tell us about how his State of Nevada is responding to the continuing challenge of the childhood leukemia cluster in Fallon, NV.

Next, we will hear from Mr. Jim Hare, a councilman from Elmira, NY, who will tell us about how Elmira has dealt with a potential childhood cancer cluster associated with a high school there. He will be joined by Mr. Tim Tobin, who is a parent of one of the students diagnosed with cancer at that school. I want to thank both Mr. Hare and Mr. Tobin, who had to take off from school to be

here. They're both teachers, and I appreciate their willingness to do that.

Finally, we'll hear from Karen Joy Miller, founder and president of Huntington Breast Cancer Action Coalition, someone who herself has been diagnosed with breast cancer, but has been a leader, as we've heard from several already, in the fight against breast cancer on behalf of us all.

I'd like to remind all of our witnesses today that everyone has a lot to say. We have a number of questions here that we want to be able to ask. So it would be helpful if you do your best to stay within the 5-minute guideline. You'll see these little lights up here, green means you're in good shape, yellow means you have a minute to go, and red means you're out of time. So do the very best you can. This is the same system we follow in the Senate.

I can remember as a very new beginning Senator having the then-chairman of the Health Committee gavel me to be quiet. So I know that it's hard to get everything you need to say in a short period of time. But we'll do our best to do that.

We have votes in the Senate tonight, so we'll need to make certain that this hearing is wrapped up no later than 1 p.m. in order for Senator Chafee and myself to make it back to Washington in time for the vote. Because of his added responsibilities as the new Assistant Majority Leader, Senator Reid will have to leave even earlier, because his responsibilities are such, he has to actually be on the floor when the Senate is in session.

We'll take no breaks during this hearing. After each panel, we'll allow one question from the members, if they have any, up here. Then we'll go on to the next panel.

Thank you very much for being here.

Dr. Landrigan, please proceed.

**STATEMENT OF PHIL LANDRIGAN, M.D., MSC., ETHEL H. WISE PROFESSOR AND CHAIRMAN, DEPARTMENT OF COMMUNITY AND PREVENTIVE MEDICINE, MOUNT SINAI SCHOOL OF MEDICINE**

Dr. LANDRIGAN. Thank you, Senator Clinton, Chairman Reid, Senator Chafee and members of the New York delegation. I'm delighted that you're taking this interest in cancer and chronic disease, and I praise you for your leadership in the issue.

Today the leading causes of illness and death in the American population are very different from those of 50 or 100 years ago. A century ago, the big diseases were the infectious diseases—smallpox, cholera, yellow fever, measles. Today, as you have said in your opening statements, the big diseases are asthma, which has doubled in frequency, certain birth defects and of course, cancer.

According to the American Cancer Society, more than a half million Americans, 550,000 Americans, are going to die this year of cancer. It's a major problem in our country, exceeded only by heart disease as cause of death. Breast cancer, as we've said multiple times already this morning, is an enormous problem. This year, across the United States, 182,000 cases of breast cancer will be diagnosed in American women, and also 1,400 new cases in American men. The incidence of female breast cancer has increased by 40 percent since we started keeping national records in the early

1970's. The actual rate has increased per million women by 40 percent.

I am a pediatrician, and I am very much concerned about pediatric cancer. Rates of incidence of pediatric cancer have increased in this country over the past three decades. There's a graph at the back of my testimony which shows that incidence has increased as mortality has gone down. The decrease in mortality is the good news. It reflects the fact that we've invested enormous dollars into devising treatments for cancer, but the bad news is the incidence is going up. Leukemia has increased by 12 percent since the early 1970's, brain cancer, which is the second most common form of cancer, has gone up by 30 percent. In young men between the ages of 15 and 30 years of age, there's been an almost 68 percent increase in the incidence of testicular cancer.

What are the causes of these increases that have made childhood cancer the third leading cause of death in childhood, exceeded only by unintentional injury and by homicide? What are the reasons? Some would argue that it's all due to better diagnosis, the fact that we have MRIs and CT scans enables us to detect cancers that otherwise we would have not picked up. I'm troubled by that argument. I've been practicing pediatrics for 30 years. My professional career spans the time in which this increase has occurred, and I really don't think we were missing a third of childhood cancers two and a half decades ago. This is a devastating disease, kids with cancer are terribly sick, they make it to the hospital, they come to medical attention. Perhaps better diagnosis has enabled us to pick up a few additional cases, but not 30 percent more.

So what could be the responsible factors? I'm sure that diet and lifestyle have contributed to some extent. The viral hypothesis is certainly receiving active consideration. I doubt that it's genetic change, genetic change just doesn't happen that quickly. So that brings us to the environment. We need to give very, very serious consideration to the notion that toxic chemicals in the environment have at least contributed to the increasing incidence of childhood cancer, female breast cancer, and other cancers in this Nation.

There are some 85,000 synthetic chemicals at loose in our environment today that did not exist in 1950. The chemical industry has been extremely ingenious at producing chemical substances. Unfortunately, they have not been nearly so good at testing these chemicals that they've produced. Fewer than half of the 85,000 chemicals that are out there have ever been tested to determine whether or not they have the capacity to cause toxicity or whether or not they have the capacity to cause carcinogenicity. Fewer than 10 percent of chemicals have ever been tested to determine whether they can be toxic to children and to human development. We need to do a much better job of chemical testing.

What are some of the other things we need to do? We need to invest heavily in what's been called disease tracking or disease surveillance. Senator Reid, you mentioned this. We need to have sophisticated, intelligent systems in this country that can plot trends in disease, that can plot the geographic occurrence of disease, that can enable us to spot clusters early. We need to put more money into research that elucidates the causes of cancer. The overwhelming majority of our cancer research dollars have gone into

determining and developing better treatments. Obviously money well spent, but now it's time to open a second front in the war on cancer and to identify the causes of cancer and seek ways to prevent cancer at its roots.

I think the bottom line here is that cancer is indeed, as Congresswoman McCarthy said, "a hideous disease," a terrible, devastating disease that destroys patients, destroys families, destroys communities. But it's also a preventable disease. We've not made the investment into cancer prevention that we must make in this country. It is time to do so. I commend you for convening this hearing today to look into the issue of cancer prevention. Thank you.

Senator CLINTON. Thank you, Dr. Landrigan.

Dr. Todd, thank you for coming all the way from Nevada.

**STATEMENT OF RANDALL L. TODD, M.D., STATE EPIDEMIOLOGIST, NEVADA STATE HEALTH DIVISION**

Dr. TODD. Thank you, Senator Clinton, Senator Reid, and other members of the committee, for inviting me here today to share some information about our State's investigation into a cluster of childhood leukemia cases in Churchill County. I would like to provide you with a brief background and description of what has happened and is continuing to happen in Nevada and share some of the lessons we are learning that may be useful here in New York or elsewhere in the country.

In July 2000, we were informed of concerns among the medical community in Churchill County that the number of recently diagnosed cases of childhood leukemia appeared to be unusually high. After confirming this, our initial investigation consisted of face-to-face interviews with each of the case families. We've also tested the water supply to each local residence where a case family lives or has previously lived. We used for these tests the battery of analyses that are required for public water systems under the Safe Drinking Water Act. Unfortunately, our water analysis to date has not revealed any results that would explain this cluster.

After our initial data gathering was complete, we convened a panel of national experts from Federal agencies and academia. We asked these experts to review our processes and data and provide us with advice on further steps to take this investigation hopefully to some definitive answers. They continue to be convened and are guiding our processes.

Given our rather bleak public health resources in Nevada, we found it was essential to utilize advice and resources provided through the Centers for Disease Control and Prevention as well as the Federal Agency for Toxic Substances and Disease Registry. I would like to comment on some obstacles that we have encountered and some lessons we are learning. A potentially serious obstacle to our ongoing investigation has come from the legal profession. We are now being challenged to provide copies of our data collection instruments as well as actual case data. These demands are coming at a time when we are just beginning to do what we call case-control studies. The danger here, aside from obvious concerns about confidentiality, arises when unofficial parallel investigators introduce informational biases into the study population that may blur

subtle distinctions between case and comparison families that would otherwise have provided us with important clues.

We have also experienced media sponsored investigations resulting in spurious connections among case families that are in our opinion over-interpreted, they are widely publicized and frequently result in panic among residents of the community at large. I believe these issues point to a need for some type of investigative privilege that would protect the scientific integrity of an ongoing public health inquiry.

Another phenomenon that arises in high profile cluster investigations is the emergence of self-proclaimed experts who promise to find answers more quickly than public health officials. These experts all have a tendency to tell the community what they want to hear, create distrust between the community and public health officials, and cause a waste of resources as health officials investigate and attempt to dispel myths and misinformation.

A lesson we have learned from this is that it is essential to keep the community well informed as to the progress of the investigation. Even seemingly mundane but necessary activities are of interest to the public and help concerned individuals to understand that the investigation is continuing. We conducted a public meeting for the community early on in the investigation, we established a toll-free hot line that people can call for information, and developed a web page with information that is specific to the investigation. These steps have not been enough. Consequently, we have begun to do weekly media briefings and last week conducted the first of what we expect will become a monthly open forum with the community. At our first open forum we had over 150 people in attendance asking questions for more than 2 hours. This is in a community with a little over 8,000 people. We also say that involvement of the local medical community in these meetings has been essential to building trust.

One common question that is frequently asked by the public is whether they should move away from the area. Unfortunately, we cannot provide them with a science-based answer at this time. We have, however, been able to obtain State emergency funds that have been used to increase staffing by local mental health professionals. This provides a mechanism for individuals to receive assistance in making decisions in the face of scientific uncertainty.

In closing, I would like to mention some things that might be done on a national level that could assist other communities facing a cluster of disease. First, because most children with cancer receive their definitive diagnosis and initial treatment at major cancer centers that may be located in a neighboring State, there can be significant delays in reporting to the central cancer registry in their State of residence. Some form of national cancer registration for childhood cancers at least would be very helpful in this regard.

Second, a standardized national protocol from agencies such as the CDC and the Agency for Toxic Substances and Disease Registry would allow them to respond to State and local concerns more quickly. It has been exceptionally difficult to explain to an impatient public why it should take so long to develop a scientific protocol, have it approved by the appropriate committees for the protection of human subjects, and then implement it in the field. Hav-

ing some things done in advance would go a long way toward minimizing this frustration in the community.

I hope these remarks have been helpful. I would be pleased to answer your questions.

Senator CLINTON. Thank you very much, Dr. Todd.

Mr. Hare.

**STATEMENT OF JAMES E. HARE, COUNCILMAN, CITY OF ELMIRA, NY**

Mr. HARE. Senator Reid, Senator Clinton, Senator Chafee and members of the House, I appreciate the opportunity to speak with you this morning.

I have been a teacher at Southside High School in Elmira, NY, for over 16 years. I was at the school when it opened, left of a short period and have been back there since 1986. My son attended the school and graduated in 1997, and as a former Mayor of Elmira and currently a city councilman representing, a south side district, many of any constituents have a direct connection with the school.

I believe there is a story to tell which should be of some interest to your committee. A logical question is why Southside now? The school stood there for 20 years, but for 20 years there have been questions, because the school is located on a former 83-acre industrial site, and the industrial site was demolished to build the school. There have been questions for years, but a number of things came together last year which made us decide to investigate.

Neighboring Scott Technologies, purchased the property and have conducted a 4-month, $900,000 voluntary cleanup of materials at the site. According to newspaper reports, "Tons of contaminated soil, storage tanks and equipment containing an alphabet soup of hazardous wastes were removed . . . that included removal of 2,000 cubic feet of contaminated soil, abandoned fuel and chemical storage tanks and electrical equipment containing polychlorinated biphenyls commonly known as PCBs." Other chemicals found and removed included arsenic, lead, zinc, cadmium and the solvents toluene, ethylbenzine and xylenes.

The site was given a clean bill of health by the State as the work was done under the supervision of the New York State Department of Environmental Conservation. It should be pointed out that the contaminated soil "did contain hazardous waste sometimes in levels 1,000 times higher than allowed by the conservation department." I have a copy of that report, this is the property right next to the school, and the school is on what used to be the rest of the plant.

Also last year, NYSDEC completed an investigation of petroleum contamination initially found in the vicinity of Miller's Pond, just to the east of the school. The investigation began after a sheen in Miller's Pond was reported to DEC in 1995. The contamination is believed to have resulted from the activity of industries that previously occupied the area. The source of contamination was found to be under the gym at Southside High School. Bioremediation is being used now to clean it up.

Finally, at a meeting of students in the school auditorium last year, organized to promote participation in the Relay for Life it was reported that six Southside students had cancer. That made 13

cases since 1997. I was stunned. I had known of cancer cases and two of my son's classmates were survivors, but six in 1 year was an eye-opener.

As a teacher in the building, a parent and councilman, I wrestled with what to do. What we did is we pull together an ad hoc committee in my living room, consisting of Mr. Tobin and his wife, whose son currently is a survivor of testicular cancer, the Patros family, whose son graduated with my son, he's a survivor of testicular cancer, Mike and Luann Smith, whose daughter graduated with my son, and he is the emergency management director for Chemung County, and Dan Royle, the other councilman from Southside who has had two sons graduate from Southside and has another son planning to go there.

We wrote a letter to the School Board posing some questions. Quite frankly, there had been discussions of this for years, and I was anxious as to why the school board didn't show any curiosity. But after our letter, they did, and they have been very positive in terms of their response.

We met with Tom Kump, who is the Chemung County health director and was also a member of the school board member at that time. He has since resigned the position on the school board because he felt that was a conflict of interest in terms of this issue.

One of the things that concerned us in the beginning, however, was the response of the New York State Department of Health, because as a quote from a staff member that said on April 14, "We get a myriad of calls of this nature. We respond to all of them. But in order to prioritize it we need to review the facts to determine if it's an unusual type of cancer, the same type of cancer, the timeframe, and are there any logical explanations for what is occurring." That was April 14.

On April 30, a State environmental expert commented that testing of the soil at Southside would begin for chemicals and contaminants similar to those found on the adjacent industrial site. Then one of the engineers stated that the conservation department never had any reason to believe there was metal contamination at the school.

On May 2, after a preliminary investigation, State health officials said that Southside High School was not a health hazard to students. Headlines read "High School Found Safe." These responses indicate that the bureaucracy has trouble responding, because they have to prioritize, that they have funds they have to come up with. Fortunately for Elmira, I think some quick pressure was put on, including a behind the scenes phone call by our chancellor of the Board of Regents, Carl Hayden.

Our committee decided that we needed some experts to ask the right questions. The school district didn't respond, we the city took the role of a non-partisan observer. The city council courageously stepped forward and hired an expert lawyer, Craig Slater, from Buffalo, who had been involved with Love Canal and had done some environmental work for us. Working with our committee, he was able to provide expert analysis of what was going on. Our new superintendent responded by forming an advisory committee, which Mr. Tobin will talk about, to investigate it. Quite frankly, the community I think came together in trying to investigate this

problem in a very open way. All meetings were open, the press covered it very well, surprisingly to some degree, the reporter doing the work was a former Southside student, our mayor is a former Southside student. So the community has come together, and as I think was perhaps alluded to previously, it has been a totally open process. While we can't answer questions the way many would like to have them answered, I do think the community feels a thorough investigation has been undertaken.

Senator CLINTON. Thank you very much, Mr. Hare.

Mr. Tobin.

**STATEMENT OF TIM TOBIN, ELMIRA, NY**

Mr. TOBIN. Senators Reid, Clinton and Chafee, members of the House of Representatives. My son, Michael, was diagnosed with testicular cancer on November 22, 1999. At that time, he was a 15-year-old sophomore who ran cross-country, track, and raced bicycles. Nothing I can say can describe the feelings his mother and I experienced when told, "Your son has cancer." Michael underwent immediate surgery. On January 1, 2000, we flew to Indianapolis for additional surgery at the center where Lance Armstrong was also treated.

Within a week of my son's diagnosis and first surgery, a parent whose son was diagnosed with testicular cancer 2 years prior contacted me. This father and I began a dialog about cancer and the oddities of this disease. It would not be long until a third young man would come to be diagnosed with testicular cancer. Researching National Cancer Institute Data, first to find information about the nature, treatments, and survivability of this cancer, and later to assess the "peculiarities" of testicular cancer cases among young men led me to a startling discovery.

The National Cancer Institute data for the occurrence of testicular cancer is between 3 to 4 cases per 100,000. Almost 70 percent of these cases occur in men in their mid-twenties to early forties. Rates for people of Hispanic descent, such as my son, are less. The National Cancer Institute statistics, in addition to with what I would later learn about chemicals used in industrial manufacturing, led me to this conclusion: I had a greater statistical likelihood of developing testicular cancer than my son, unless there was another factor at play. Coupled with the growing awareness of other cancer cases, this was cause for concern and inquiry.

Elmira, NY has been home to many former industrial sites typically found in northeastern cities. My son's high school was built on a site that had experienced 100 years of industrial use. During the years of manufacturing, some of the chemicals used and that are still present on the site include, but are not limited to PCBs, chromium, beryllium, arsenic, lead, nickel, zinc, phthalates and trichloroethylene. All of the above chemicals are known to, or believed to be carcinogenic.

In evaluating the site various criteria was used to determine safety. Many of the chemicals in the soils at the school and in the industrial site that still stands right next door exceed acceptable human exposure limits from either the EPA or the New York State Department of Environmental Conservation. However, they were still determined to be safe. In many cases, the New York State De-

partment of Health, in a preliminary draft of August 22, 2000, said exposure would not occur due to a "well established grass cover."

I have also read recent studies on phthalates that have indicated that exposure to this chemical causes "testicular lesions" in lab animals. This was from the Center for the Evaluation of Risks to Human Reproduction. I also must question the inherent contradiction that this area is safe when several experts have repeatedly stated that we could not build this facility here today as it would not pass industrial standards.

Nowhere in all of the data, studies, and reports from any of the different investigate or public health agencies, is there a mention that this site is on or directly contiguous to a DEC Class 2 Superfund site.

I would submit that clear-cut standards of chemical levels and exposure levels be implemented across the board. Further discussion, such as issues raised by the U.S. News and World Report in its June 19, 2000 edition or measures recommended by the Center for Environmental Justice in its study "Poisoned School—Invisible Threats, Visible Actions," needs to be engaged. Clean-up measures should be taken to meet these standards. Public notification of schools when an industrial cleanup takes place is a must.

In September 1999, such a cleanup was taking place during school hours at the site next door to my son's school. I can only imagine the chemical exposure that children were unknowingly subjected to from this activity.

I believe that industrial waste is a danger to humans. I believe that a more diligent, cooperative approach to fix the problem, rather than place blame, is needed. I believe that these substances are enhancing the risks and rates of cancer in our children. This is one risk that needs to, and can be, eliminated.

I would like to thank the city of Elmira and its elected officials for the position and leadership they have taken on this issue. I would further like to thank all of the members of the committee for your interest in this matter. Thank you.

Senator CLINTON. Thank you, Mr. Tobin.

Ms. Miller.

**STATEMENT OF KAREN JOY MILLER, FOUNDER AND PRESIDENT, HUNTINGTON, NY BREAST CANCER ACTION COALITION**

Ms. MILLER. There is no cancer-free zone. Our toxic environment affects each one of us, in fact, all of us.

I'm very nervous about the 5 minutes, so I'm going to go right on to my point and then I'll try to give you some testimony. On Long Island here we work as a cooperative, so a lot of people have provided it.

We're here to ask you, our valued representatives, to please take on some major new initiatives. There must be incentives to encourage environmental research. Breast cancer activists across the country have helped to raise multiple millions of dollars for research. But environmental researchers have been getting seriously shortchanged by funding agencies like the NCI. Breast cancer research must be more interdisciplinary and more focused on environmental contaminants.

That research must be done with the active assistance of the breast cancer community. Government must improve its data bases so that scientists can do their work properly. Today's cancer registries are woefully inadequate. They do not collect the many forms of information that are vital to researchers. Work with us to improve these registries.

We all need better information so that we can make healthier lifestyle choices. We need the Federal Government to provide information in a format that's easy to use and easy to understand.

We also ask our Government to speak openly about the precautionary principle. It's no longer as simple as saying, get our mammogram, while our environment is being tested. We need honesty at a Federal level about the health risks we face.

In 1994, the FDA recommended that doctors record in patient's files information to calculate the absorbed dose of radiation to the patient. Right now most doctors have no idea how much radiation their patients are exposed to. The fact that many of us see many different specialists compounds that problem. Please address this vital public health issue and remember that radiation is a proven environmental cause of breast cancer.

Additionally, we need medical coverage for routine testing of toxic buildup in our bodies. Coverage must include viable treatments to cleanse the body should the results be positive. The successful elimination of lead from children's blood, as well as from the environment, serves as a good example. It's time to replace the policy of acceptable risk in industrial practices with actual risk-reducing regulations that are fully protective of public health.

To date, the effects of groundwater on breast cancer have not been adequately researched. Many on Long Island are concerned that our water distribution systems increase our cancer risks, and this needs more attention.

The Senate, we hope, will ratify the international POPs treaty dealing with the Persistent Organic Pollutants such as PCB's, chlordane and dioxins. The elimination of these contaminants must begin without delay.

Good morning, I'm Karen Miller.

[Laughter.]

Ms. MILLER. I have lived on Long Island for 33 happy years raising three children with my husband Michael. In 1987, that was the year our peaceful existence was shattered by the news of my breast cancer diagnosis. Thanks to the wonderful support of my immediate family, I was eventually able to regain my stability.

Once on my feet, I was fortunate enough to find three other women in my town of Huntington who were willing to ask the vital question, "Why?" Together we started the Huntington Breast Cancer Action Coalition, whose first major project was to map the incidence of breast cancer within our township. We always knew that education equaled power, the power to create change. With that in mind, we set out to arm ourselves with solid information. We all read all we could, asked innumerable questions and along the way were lucky enough to meet the experts and learn from them.

Breast cancer is a disease that has been puzzling us for centuries. We have come a long way in solving this puzzle but it is an undeniable fact that we have just begun the serious research

into understanding the relationship between the toxicity in our environment and disease. Even though we are all hearing about the major breakthroughs in the fight against cancer, such as the completed Genome Project and the new wonder drug Gleevec, there is a long way to go before we can rest easy.

Our efforts of our Coalition along with many grass roots groups nationwide have laid the groundwork by increasing the public's awareness of breast cancer. The growing number of women who have had regular mammograms is proof of that very effort. Yet, despite all this, rates of breast cancer have jumped since 1973 almost 40 percent. That's very serious cause for alarm.

Earlier, I mentioned the mapping project initiated by our coalition. Please take a moment over here and look at the dots. Each of these dots, no matter what the color, represents a woman who is also asking the question, "Why?" She is willing to help any of the researchers with what they want to know. She is willing to disclose confidential information about herself, her medical history, her occupation, her lifestyle. She is one of the millions who want to know why.

Our high-tech world makes our lives more comfortable and convenient by the day, yet that very same world bears responsibility for our toxic pollution. Industrialization has been at the core of our success as a society, but the price has been much too high in terms of our health.

In the spirit of cooperation and community, we sincerely hope that your persistence and assistance during the next 4 years will make a real difference in the fight against breast cancer. When I learned I had breast cancer in 1987, I was devastated, my family was devastated. Improved methods of protection and cure are essential, but certainly they are not enough. We must get rid of the root causes of cancer, all cancer.

There is a growing body of evidence that supports our claims. Industrial toxins are killing us. Please help us to clarify our understanding and work with us to reduce our exposure to these awful chemicals that have become so pervasive in our community. In our hearts and in our minds, we know that change is possible, and we appeal to all of you in the next 4 years to give us those changes. Thank you.

Senator CLINTON. Thank you very, very much.

I want to thank all of the panelists. We just heard, I think, very eloquently how this is a problem and an issue that spans all of New York State and our entire country. Many other people who wanted to be here could not, and they have provided us with testimony that I can assure you will be read and analyzed.

For example, I want to thank the Elmira School superintendent for sending additional materials regarding Southside High School. All of those materials will be included in the official hearing record. The hearing record will be open for 2 more weeks, and anyone who wants to submit written testimony can do so. It will also be included in the official record. The address for sending in written testimony is posted outside the room today.

With respect specifically to Mr. Hare and Mr. Tobin's point, I have last week offered an amendment to the Education Act, which we are debating right now in the Senate, to do an investigation to

determine the safety of our schools, to really put some dollars behind a Government investigation to find out what factors in the school buildings that our children spend so much time in might possibly harm their health, whether it's very bad and clogged insulation and venting and air conditioning systems, or asbestos, or the industrial chemical problems that both Mr. Hare and Mr. Tobin spoke of. We need to know the facts, because we entrust our children into our schools and we should know exactly what conditions might be there that could affect their health and then take action to try to remedy that.

Now I'd like to turn to Senator Reid for his questions for this first panel.

Senator REID. Senator Clinton, thank you very much. The panel has been excellent.

Dr. Landrigan, it's true, is it not, that children's central nervous system in their bodies is generally more susceptible to these elements that we talk about, the arsenic, cadmium and all these other things in the environment that shouldn't be there?

Dr. LANDRIGAN. Yes, sir, that's absolutely true. From 1998 to 1993, I chaired a committee at the National Academy of Sciences that was given responsibility by the Senate to look at children's vulnerability to pesticides and other environmental chemicals. We concluded that children are not little adults in terms of their susceptibility to chemicals, and we said that we find that that susceptibility had a poor bases.

First, children are more heavily exposed than adults. Pound for pound, children breathe more air, they drink more water, they eat more food, so they take more toxins into their bodies. Then of course, kids play on the ground, when they drop a lollipop onto the rug, when the rug has been treated with pesticides, when they pick up and lick that lollipop, they take the pesticides directly into their bodies, practices that most adults don't engage in.

Kids are biologically more sensitive. Their nervous system is an extraordinarily complex entity. There are billions of cells, those cells have to move to their assigned positions, they have to establish literally trillions of connections. That whole developmental ballet, that whole choreography is extraordinarily delicate and easily disrupted. So if a child is exposed in the womb or in the first years of life to lead, to PCBs, to certain pesticides, to methyl mercury, the child can end up with loss of intelligence, altered behavior, and those effects can last lifelong.

Also, children don't have the metabolic machinery that enables them to break down and get rid of toxic chemicals like pesticides. So the chemicals stay longer in their bodies.

Last, the fourth reason why children are more susceptible is the simple actuarial fact that they've got more life ahead of them. They've got six, seven, eight decades of life ahead of them. So if the cells, for example, that are responsible for protecting the nervous system against Parkinson's disease, if those cells take a hit in infancy, nothing may show up for six decades. But the theory is now being actively explored that exposures earlier in life can lead to chronic diseases of the nervous system, such as Alzheimer's.

Senator REID. I knew the answer to the question, but I certainly couldn't articulate it as you have. Because when I was chairman

of the subcommittee on this committee a number of years ago, when we had the majority, we were able to look at lead-based paint and what a terrible devastating effect that has on children. We looked at products that had an impact on children, which was significant, but also adults, alar, that they used on peaches and grapes and apples. We were able to get that withdrawn.

I was so impressed with your testimony, because we had just started there on my subcommittee to look at how we handle chemicals in the environment. We so easily allow them to get into the environment, but it's almost impossible to get them out of the environment. If we determine a chemical is dangerous, we have no apparatus in the Federal Government, one that works well, at least, to get rid of that product. As you've indicated, there are tens of thousands of chemicals and we've only tested far less than 10 percent of them. So that's a real problem.

We also see this Southside High School, how large is it? How many students?

Mr. TOBIN. We have about 1,100 students.

Senator REID. I've read the testimony. It's interesting that, for those of you who may not be aware, there's a pool of water, a lake or whatever you want to call that, it's called the pool that never freezes, because it's so heavily laden with chemicals. That's really unfortunate. Even a layman would have to think some of the sickness of these children is related to this building. I certainly think we need to help it some way, in taking a look at this.

I'm also concerned about this tracking system we talked about, and Dr. Landrigan, you had mentioned it. With all the scientific apparatus we now have at our disposal, if there were directives from Washington saying that all cancer cases, and we could categorize them in some degree, had to be reported to a central system, that would help all you, isn't that true?

Dr. LANDRIGAN. Absolutely, sir. One of the problems we have in this country is that we have disease tracking systems for the infectious diseases that go back into the 1950's that are really pretty solid, for measles, for hepatitis, and more recently for AIDS. But by contrast, the tracking for chronic diseases, like cancer, like asthma, like birth defects, like developmental disabilities, is very scattered, weak and fragmentary. I would commend to you the report of the Pew Commission on Public Health, that Senator Wiecker chaired, the report was released a year or so ago. Dr. Lynn Goldman, who's going to be testifying later today, was staff to that commission. They've made some elegant recommendations about the importance of disease tracking in this country.

Senator REID. You would agree, Dr. Todd, that would be a tremendous help to this almost insurmountable problem you've found with the lack of resources in the State to do this heavy job that you have?

Dr. TODD. Yes, I would, Senator, it would be very helpful. The one caveat that I would mention is that some of the information that would be useful to us in public health in doing these investigations is infrequently collected in the illness care system and hospital system. It's all been useful to know what the occupation or the usual occupation of the patient was. That may or may not be

in the patient record. If it's not there, we can't abstract it and we can't generalize from the data as easily as we would like to.

Senator REID. One of the things I'm impressed with that is now beginning to occur in the State of Nevada, there's a very generous man in the State of Utah who's given more than a quarter of a billion dollars to the University of Utah Medical School. There's a cancer institute now established called Huntsman Institute. The reason I'm so impressed is that it shows a little bit of what can be done.

As you know, in Utah, the LDS church has collected hundreds of millions of names of people for genealogical purposes. But it's my understanding, one of the things the Huntsman Institute is doing, in this cancer that they're studying, they go back and check out what happened to the father, the grandfather, the great grandfather, and determine if there's any linkage as far as the types of disease from which that person died. Now, some things like that would be helpful, is that a fair statement, Dr. Todd, Dr. Landrigan?

Dr. TODD. Yes, absolutely, very helpful.

Dr. LANDRIGAN. Yes, sir, and the particular way in which they would help is that that kind of linkage study would enable researchers to look at the respective contribution of genetics and environment to the causes of cancer. Clearly, both contribute, most malignancy is probably a result of the combination of the two that occurs when a person with a particular genetic makeup is exposed to a particular environmental toxin. If you can trace back through the family and see that three generations ago, lots of toxic chemicals were not present, and compare that earlier experience with the experience today, the lessons could be profound, to really tell us what chemicals are doing.

Senator REID. Senator Clinton, can I ask a couple more questions, because I have to leave early? They can take my time.

I have a couple of other questions. Dr. Todd, one of the things that we're being criticized you and I, in the State of Nevada, is we're not moving quickly enough. How do you respond to that question?

Dr. TODD. Well, I sort of tell people that looking for causes, as we're doing, looking for scientifically, is something akin to trawling for fish out on a reef. You can only trawl so fast. We could put more power to the throttle and perhaps make the boat go 30 knots, but we wouldn't catch fish, if that was our objective.

Good science sometimes takes a while to accomplish and get the correct answer. We have other people out there that are promising answers. I have no doubt they can find answers. I have doubts that they'll be the correct answers. I have little doubt that the answers they find will be connected to deep pockets. If that's your objective, then yes, you can move more quickly. But we're trying to do this quickly as the state of science will allow us to move.

Senator REID. Also, the State of Nevada, like many State public health agencies, are tremendously understaffed and under-funded. Is that a fair statement? I know you don't want to get fired for saying this, but the fact is, that's true. I'll state it, you won't have to answer.

[Laughter.]

Senator REID. I would also ask Dr. Todd this. We now have the Centers for Disease Control, it's involved in the problems in the State of Nevada. We have the Agency for Toxic Substances and Disease Registry, we have the Environmental Protection Agency. From your contact with these entities, have they been helpful to you?

Dr. TODD. They've been extremely helpful. They are the best and they have access to some of the best scientists in the world to bring the appropriate analysis to bear on the situation. As I mentioned earlier, though, the frustrating part is that we're sort of inventing this as we go along. While there has to be a certain amount of customization for a particular situation, having some of these protocols prepared in advance so that it could be more quickly implemented in the field would be useful and would be appreciated by the community.

Senator REID. That's one of the things the House members and the Senators are going to work on. If something happens like in Fallon or Long Island, Federal agencies have a system whereby they move in the same way every time and are not reinventing the wheel, like we've had to do in Fallon.

Thank you, Senator Clinton.

Senator CLINTON. Thank you.

Senator Chafee.

Senator CHAFEE. Thank you very much, Senator Clinton. Probably the first warnings came in the early 1960's from Rachel Carson when she wrote her book "Silent Spring," on the dangers of toxins and pesticides to our health. Of course, she did die of breast cancer. So it's been a long time, it's been 40 years since then, we're still working on it.

Ms. Miller, you've asked a few things of us, and I'll in return ask one of you. That is, we do have a bill that Senator Clinton and Senator Reid mentioned. It's legislation that would establish research centers to study the environmental factors that may be related to the development of breast cancer. The bill would enable scientists and researchers to conduct more comprehensive and conclusive research in determining the impact of the environment on breast cancer.

Of course, all these bills have a number, this one is S. 830, and it would require centers of excellence to collaborate with community organizations in the area, including those that represent women with breast cancer. As you mentioned, it's important to have consumer advocates involved in all phases of the program, which this bill does require.

So I'll ask in return your help with S. 830, either in improving it, or if you're in agreement with it, in pushing it to make it law.

Ms. MILLER. Senator Chafee, thank you so much, Senator Reid and Senator Clinton. I am in agreement with that bill, but I would very carefully make sure that it is interdisciplinary. I am keenly aware, when we give money to research institutions that environmental researchers are seriously shortchanged. So I would ask you to really look at that issue and make sure that they get most of the pie. We have the technology now, we have the dynamics. We've got to keep the group working together. Thank you.

Senator CHAFEE. Very good. I will mention, it does appropriate $30 million over 5 years, and we'll take your advice on making it interdisciplinary, try to achieve that.

Also just note that as Senator Reid was saying earlier, that he's very unpopular with the farmers in Nevada. It just shows how difficult it is, because of course some of these chemicals are so helpful to them in growing their crops. It just shows some of the difficulties, as Dr. Landrigan said, they want to do more testing on some of these chemicals, but of course, there are those who are going to be opposed to that. That is some of the difficulty with what we're trying to accomplish.

Thank you very much for your testimony.

Senator CLINTON. Thank you very much, Senator Chafee.

Senator REID. I would just say also, there's a little bit of water involved in my unpopularity, also.

Senator CLINTON. Part of the challenge, though, it's sort of a chicken and egg issue. We have to have the tracking system so we can gather the information to make the case, so that people who might otherwise say, why are you singling me out or why are you asking me to do something with this chemical, they will themselves be able to see the results.

So I think that part of our real challenge is to get the information and then be able to make the case.

Mr. Hare.

Mr. HARE. I think that is important. A point I would like to make has to do with the investigation. When DEC came into Elmira, they did come in a little bit reluctantly. Their initial response, in my opinion, was somewhat cursory. It was the hiring of Craig Slater, I believe, by the city, that made the DEC more accountable and the school district.

Now, we do not have, technically, a cluster in Elmira. I need to make that point. But in the DEC investigation, they did not even do a phase one in terms of where the operation of this plan had been, and the metals and the processes in the various locations. The city did that for them. The school district undertook some of that.

I wanted to point it out, because we, in 1997, received a $200,000 brownfields demonstration title grant. The city has asked, and EPA Region II is considering a reallocation of a portion of the brownfields award to reimburse the city for part of its assessment.

I think that is something, if it's not a matter of policy, you might want to look at that would allow communities a little flexibility here. Because certainly the cost of these things is an issue. While you're talking about tracking illnesses after they've occurred, investigating more thoroughly the sites, part of this goes to that, as well as to what other uses that funding is for.

But I think helping to reimburse a community might make them more willing to undertake this. Because we have people in our community who are not directly impacted by the cancer issue who do believe maybe we've run the course here. We need to continue to push that.

Senator CLINTON. I appreciate your saying that. As I said when I introduced Senator Chafee, he played a major role in working out the bipartisan compromise on the brownfields legislation. He and

Senator Reid really carried that. I was pleased that one of my amendments that would prioritize based on disease presence in an area, would give people the first in line priority for these brownfields dollars. Because it's not just that there is a brownfield site that needs to be cleaned up, but if there is a Southside High School or another site that seems to be associated with a prevalence of disease, that that would be the site that would get the first call on those dollars. Because I think we have to start linking our environmental cleanup and disease clusters.

Congresswoman McCarthy.

Ms. MCCARTHY. Thank you. Thank you all for your testimony.

One of the curiosities that I always had, I'll go back Dr. Todd, when we see the clusters, not just the breast cancer, not just the prostate cancer, I'm often wondering, in those areas, because we know some of these chemicals can have different effects on different age populations, whether they're the youngest or the oldest. I'm just curious if we could do a tracking system in the future, that if you have a cluster of, say, breast cancer, how many kids do we have in that cluster also with leukemia? How many kids in that area? Then chemicals, this chemical.

I just got the report on my water in Mineola. It was great. It tastes great. I can't even pronounce three pages of the stuff in there that make my water good.

Now, I know all these things make my water better. How do I know if something in that ingredient is not having an effect on my body, because maybe I have an abnormality to that piece of material that's in there? This is where the legislation, as we're marking through, and through these hearings, I think we have to look. With the computers and the technology that we have today, I see no reason why we can't do the tracking.

Now, obviously we're going to have outcries from the chemical industries. Listen, all these chemicals were made for reasons, hopefully, to make our lives better. We didn't know. We have to look at prevention. Because we are finding the drugs to cure us. But what caused it? That hopefully, through the legislation, are things that we have to look at.

I happen to agree with you strongheartedly. Not only are we not diagnosing, but as a nurse, you're doctors, scientific people, kids are going to get sick, adults are going to get sick. We have an increase overall in what is causing it. I happen to think it could be a combination. Here on Long Island, it might be the water, maybe some planes flying overhead. We have to start looking at each and every and put them together. That's what the tracking, hopefully in the legislation that we can do on a Federal level.

We will have a battle. As you said, there will be lawsuits out there. But again, I always look at it this way, at what cost is it to our country on the health care system if we don't make the strives. As I said, I'm not blaming anyone on this. I just think technology has gone very fast, and we don't know the whole issue on the body.

Because I just see so much pain out there, breast cancer, prostate cancer, leukemia. Now we're seeing more and more higher levels of retardation. These things just come. There isn't a link. We

on this table have in my opinion a moral obligation to work with the scientists and everybody else to come up with the reasons.

So with that, I thank you again for hearing this committee and having a open dialog on this.

Senator CLINTON. Dr. Landrigan, did you want to respond?

Dr. LANDRIGAN. Just a quick comment, Congresswoman.

Thank you very much for those remarks. I think there are three things that the Congress can help us with that speak very directly to the issues you've raised. First, we've already discussed, disease tracking. Second, we need to track levels of chemicals in the blood of Americans. The CDC released a report this spring showing that most of Americans, and they tested 5,000 adults from all parts of the country, have traces in their bodies of at least 20 different chemicals.

Twenty-five years ago the first chemical that we started tracking was lead. As soon as we realized that 99 percent of children in this country had elevated levels of lead in their body, we took a deliberate action, that is to say, we got lead out of gasoline, based on chemical monitoring. What has resulted has been a better than 90 percent decline in the prevalence of lead poisoning in this country, due to that one bold regulatory action.

The third thing we need, and you spoke to it when you talked about the chemicals in drinking water, we need to have a right to know. People need to know what's in the air, what's in their food, what chemicals are being laid down in their communities and schools, neighbor notification laws, right-to-know legislation, analogous on a national scale to Proposition 65 in California.

Senator CLINTON. Thank you.

Congressman Ackerman.

Mr. ACKERMAN. I thank the panel for their great testimony. Following up on what you just said, Dr. Landrigan, the public does have a right to know. But what does the public do once they know? That's really an immediate problem that we face. Maybe I'll address this first to the members of the scientific community on the panel, both doctors.

When a young couple makes a determination of where they want to live, they consider a number of factors. They consider the job market, they consider the school system. We are going to be developing very quickly nationally, based on this conversation we're having from your panel, the ability to make a determination about these clusters all over the country. How seriously should people take this?

I know you're not in a policymaking position from this point, so I'll ask you a personal question, as a father, to another person, would you move into one of these communities that had very hot clusters of any numbers of things if you had a young family with young children?

Dr. LANDRIGAN. Well, I'm a pediatrician, a parent and now, thanks to the good work of my son and his wife, a grandparent. I'd be cautious. I realize that 99 percent of the time we never find a specific cause for a cluster. I've been involved myself when I worked at CDC in many cluster investigations. So I don't think the existence of the cluster per se means that the community is contaminated.

But I would certainly take it as an input to my decision. We give people information about lead in homes and radon in homes and asbestos in homes. We tell them where the nearest high tension power line is. I think it's at least reasonable to make this information available and trust that people will make intelligent judgments.

Mr. ACKERMAN. I think part of the problem is we're not able yet to make intelligent judgments because we don't know what the impact is. I think people would like to get some guidance, at some level or another, from somebody who knows, supposedly knows more than they do.

Senator CLINTON. Dr. Todd, what's your answer to that?

Dr. TODD. You bring up, Congressman, a very important point in the area of risk communication. When you get a little bit of information without a lot of ability to interpret it, it creates problems and it creates panic within a community.

In Fallon, for example, we have people that are considering moving to a neighboring community known as Fern Lake. It's maybe a half hour's drive away. It also is over a highway that has one of the worst collision rates on State roads. So they're trading a perception of lower risk by moving away from a cluster area for a higher risk on the highways as they make their commute.

These are difficult things, and there really aren't good scientific answers to help people make those kinds of decisions right now.

Mr. ACKERMAN. I realize that, and you said, good science takes a while. I wrote that down when you said that. Most people realize they have one life to live and want to make decisions in a proper manner. The situation, for example, in Love Canal, people were warned against that, but by the time they were warned against it, a lot of people, it was too late for them and their families.

I'd like to ask the advocates, starting with Ms. Miller, what they think about this. We certainly don't want to start a panic or a rumor that you shouldn't move into certain communities. That's not the idea, because every neighborhood is going to have some problem or another. But there are certainly hot spots, as we've determined.

Ms. MILLER. You know, I wonder if we're over-using the term cluster. Actually, I think if you give it any name, it might cause some problems and panic. But actually, if you look specifically at the Huntington community or communities across Long Island that have done breast cancer mapping, these are people that are willing to say, start with me, you can come into my home, I'll tell you all about my lifestyle, I'll tell you where I grew up, where I work, I'll let you live with me as long as you hopefully can prevent the next generation from getting this disease.

So basically, if we see a school or we see a block or a community, that's a really good place to start. We should downplay because cancer, while we're saying there might be areas of people that are wiling to be looked at and work with the researchers, that cancer has no boundaries. So we've got to go back to say, we live in a toxic environment, it's OK to say it, and the education has to come into how we can lower our risks in the air we breathe, the food we eat, the water we drink.

So I think if we improve education and teach people how to be more proactive, I think we'll do a lot over the next year.

Senator CLINTON. Gary, I'm going to have to let you off and let Mr. Tobin answer. We're going to have to move on to the next panel, I've just been told we have to move.

But I think it's fair to say we really appreciate what Karen just pointed out, that we find cancer everywhere. We find it in every kind of setting, along with other chronic diseases. I think the real key is to get the real information and not to, as Dr. Todd reminded us, create a panic.

Because part of, it's ironic that we know the leading cause of cancer in terms of an environmental causation is tobacco, we still sell it, we still permit it to be advertised. We know people freely go out and smoke, causing all kinds of cancer, and I believe second-hand cancer. So these are very complicated kinds of issues, and I think we have to look at that and in the next round, of course, I'll start with the members who didn't get to ask a question.

Mr. Tobin, how is your son doing?

Mr. TOBIN. Quite well, thank you. We expect a long, healthy life for him at this point in time, thank you for asking.

If I may just address a few things that were mentioned a few moments ago, Senator Reid mentioned possibly the concept of a national reporting system. In the situation in Elmira, one of the problems, we have a community where a lot of our best and brightest get up and leave, not to return. In the year and a half since this has been going on, we had a young man drive in from Florida, 26, with cancer, we had a young man, 25, living in Texas, they may not appear in the statistics at all. New York has a reciprocal agreement with Pennsylvania, we're just north of the border, maybe 8 or 10 miles. So I think Senator Reid's suggestion of some type of national reporting system would work well.

Ironically, some of the initial data that New York State put forth about the incident rates in Elmira, because of the nature or whatever of the reporting system, my son was not included in the statistics. He missed the cutoff date, I guess is what that would be.

The second point, to Congresswoman McCarthy, about rethinking possibly how we put aggregates of cancer data together, one of the things that gnaws at me when I listen to it now and again is when someone says, this cancer is statistically insignificant. It really offends me as a parent that someone's child is statistically insignificant. Sometimes we get caught up in the world of science and overlook human beings.

Following up on Congresswoman McCarthy's suggestion, if you look at, in our area, we've had a young man of 20 with colon cancer. We had a young man 28 with a rare brain cancer. We've had stomach cancers. They become statistically separate, because it's one case of this or one case of that. But if they become an aggregate, maybe there is something else. With the good doctors to my right here, that the young body does react differently, I think that also may be beneficial, to take both of your points. I would appreciate something with regard to that action. Thank you.

Senator CLINTON. I want to thank this first panel. It's done a wonderful job in setting the tone and providing us lots to think

about. We will look forward to continuing to followup this in our work.

Now I'd like the second panel to come and join. As they do, I'm going to be introducing them as they take their places. We're going to be hearing, on the second panel, from Dr. Marilie Gammon, who's the principal investigator for the Breast Cancer and Environment Study, part of the overall Long Island Breast Cancer Study project. She's here with us today from the University of North Carolina in Chapel Hill.

We'll also hear from Dr. Ruby Senie, who is the principal investigator for the Metropolitan New York Registry of Breast Cancer Families, also part of the study project. She's here with us today from Columbia University.

Gail Frankel is with us from Centereach, NY, representing the National Breast Cancer Coalition. Amy Juchatz is here from the Suffolk County Department of Health Services. We especially appreciate her participation. This is a wonderful opportunity for us to get a preliminary briefing about the breast cancer study project here on Long Island. But of course, the study's not finished. We know that there's a lot of data still to be analyzed. So I appreciate both Dr. Gammon and Dr. Senie coming to give us sort of a preliminary look at what they're finding.

Dr. Gammon, would you please begin?

**STATEMENT OF MARILIE GAMMON, PH.D., ASSOCIATE PROFESSOR OF EPIDEMIOLOGY, SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL**

Dr. GAMMON. Thank you, Senator Clinton, for your invitation to come speak. As mentioned, I am the principal investigator of the largest and most comprehensive of the projects in the Long Island Breast Cancer Study Project. The primary aims of that study are to look at several environmental contaminants, in relationship to the risk of breast cancer. In other words, we're trying to figure out, are there environmental contaminants that really can be linked to the cause of breast cancer.

We have two classes of compounds that we've been examining. The first is polycyclic aromatic hydrocarbons. These are combustion products from incomplete combustion. Sources would be diesel fuel, tobacco smoke, among those who are cigarette smokers, and also components of the diet. When you barbecue your food, it's that black junk on the meat and vegetables. They are known carcinogens in rodents, but their effect on the breast in humans is unclear.

The other class of compounds that we've been addressing is organochlorine compounds. These are persistent compounds that can be found in the body, they have a long half-life. They're things like DDT, its breakdown product DDE in the body. Another class of compounds that we're looking at is PCBs, which you've heard mentioned, and other pesticides including chlordane and dieldrin. All of those are measurable in the body, through blood samples. They're stored in the body's fat, and they have a half-life of about 10 years. So even though many of the compounds have been banned, they are still measurable in people's bodies.

So for the study, we assembled a multi-disciplinary team of scientists in New York City and on Long Island. What we did is over

a year period, we identified every case of breast cancer that was newly diagnosed in that year period. We identified some 2,000 women. We then got physician permission to approach the woman to interview her. We administered a 100-minute questionnaire in person. We also collected blood samples, urine samples, and samples of dust, water and soil among the subsample of women who had lived in their homes 15 years or longer.

Simultaneously, we identified a group of control women without a history of breast cancer. This would be our comparison group. Again, we call it frequency match, in other words, the distribution of cases of women who get breast cancer predominantly are over age 50, something like 75 to 80 percent of women who are diagnosed with breast cancer are over age 50. Because age is a predictor of cancer, you want to make sure that the age range of women that we use as our control group is the same.

So we made sure that the women that we randomly selected from the communities were of similar age distribution as our cases. We also administered the same questionnaire, collected their blood and urine samples, and among the subsample of women who were long-term residents of Long Island, we collected dust, soil and water.

Many of those data have been analyzed in a laboratory. We have submitted three papers for publication that address those primary hypothesis. We are continuing to analyze the data, because it's a wealth of multi-disciplinary data. It is pretty unique.

Another very unique aspect to this study is that we collaborated with the women activists on Long Island, including Karen Miller and many, many others in the group. That has been very interesting, and my first experience in working with activists and scientists.

Thank you.

Senator CLINTON. Thank you, Dr. Gammon.

Dr. Senie.

**STATEMENT OF RUBY T. SENIE, PH.D., PROFESSOR OF CLINICAL PUBLIC HEALTH, MAILMAN SCHOOL OF PUBLIC HEALTH OF COLUMBIA UNIVERSITY**

Dr. SENIE. Thank you very much for inviting me to the panel, to this hearing. I have prepared some slides and I would like to talk from them.

Senator CLINTON. I think they're going to drop a screen. There's a screen coming down.

Dr. SENIE. As principal investigator of the Metropolitan Breast Cancer Family Registry, I have had the privilege of working with many families on Long Island and Manhattan, and I will tell you, I'm very happy to have this privilege to tell you about the Family Registry and how it has five collaborating centers across, actually around the globe. Together, these six sites will be able to contribute greatly to studies of the environment and breast cancer.

In New York, we have recruited currently 1,500 families, and we've just recently been renewed for another 5 years. We plan to increase the number of minority families. I look forward to showing you the sites at which the other registries are located. Notice Huntsman, we heard about from Senator Reid, Melbourne, Australia, Northern California Cancer Center, Fox Chase in Philadel-

phia, in Toronto, the Cancer Control of Ontario. Here we are in New York.

The Metropolitan New York Registry includes the 1,500 families. Our goals from all the six sites have been to bank data and biospecimens as a resource for family-based gene-environment research, as compared to the case control study of Long Island. We recruit members of high-risk families through cancer registries, and through clinics. We're very careful to protect the confidentiality of our participants. We inform family members of our study findings and of additional research opportunities for them.

Each family is asked to include three or more participating relatives, males and females; 18 is the youngest age, with or without a history of cancer. Deceased relatives can be included by a proxy questionnaire and tumor tissue.

To enroll in the registry, we ask for maternal or paternal relatives to meet one of the following: a male with breast cancer, a female with breast or ovarian cancer diagnosed at a very young age, a female diagnosed with both diseases, or three or more relatives who are older in diagnosis.

We ask each to sign an informed consent. We have a family history form that asks for all relatives in the family and their cancer history. We ask for personal health history, dietary intake, and we collect blood and urine samples. We also do an annual followup creating a cohort of families.

These are some of our instruments used by the New York Registry. Each site has its instruments that overlap with the same questions.

We protect confidentiality by assigning coded identifiers. We removed all identifiers from the personal information. The data is entered into our secure computer system, and then transmitted to a central data base in California. All six sites send their data together. The genetic information is protected to prevent employment or insurance discrimination. We received an NIH certificate of confidentiality.

Benefits for participants include referrals for genetic counseling and testing, if they're interested. Participants are satisfied to be contributing to important studies. We distribute registry newsletters to participants with the latest research findings. I included one in the packet today. We hold seminars in Manhattan and on Long Island.

An Ashkenazi component was added by the NCI after the three founder mutations were identified. The NCI provided the funds for recruitment, testing and counseling. Four sites participated, including New York, Philadelphia Fox Chase, Toronto and Melbourne, the sites where most Ashkenazi Jews in the six sites live. It's interesting that only 25 percent of the New York families asked for genetic counseling and test results.

However, we do have quite a few carriers. This pedigree presents one family. Notice the family carries the mutation 6174delT. One tiny component of the BRCA2 gene was deleted, which led to this family having this mutation. Notice the patient with the yellow and red lines. She has sadly been diagnosed with three cancers. So far she's fine, after her pancreatic cancer has been treated. She has also been successfully treated for breast and ovarian cancer.

Notice her sister, a mutation carrier also, is free of any cancer. Her elderly paternal aunt, who is 83 years old, also has a mutation but no history of cancer. But that aunt's daughter has a mutation and was diagnosed with ovarian cancer. Another sister, an elderly woman at the time of diagnosis of ovarian cancer, is no longer living.

This is a complicated slide, but notice on the left the boxes with red around them indicate the carriers among the more than 2,400 Ashkenazi samples tested across the four participating sites. There were 336 individuals with a mutation, 46 men, 289 women. Of those, 130 have no cancer. It is quite amazing. You see, we all know that the risk of cancer is higher, but it isn't an absolute. Notice in the bottom left, 192 breast and ovarian patients who are among the carriers, 1 male and 191 females. But to the right, 886 breast and ovarian patients in our registry, 11 men, 875 women. None of these participants have one of the known Ashkenazi founder mutations.

We have the opportunity with the Registry to do much environmental research. We can compare Registry families of similar familial and genetic risks residing in very different geographic environments. We can study paired relatives who live apart as adults following shared childhood exposures. My sister lives in Paris, and sadly she's been diagnosed with breast cancer. We grew up in Rockville Centre, Long Island not far from here. I live in Manhattan and another sister lives in Florida. We don't understand what the factors are that affect risk in our family.

We can also assess the biomarkers of exposure in the stored specimens. We have blood, urine and tumor tissue samples that may provide clues to adverse environmental exposures that may have occurred many years earlier. As technology advances, we'll have a better way of understanding the effect of early exposures that can be measured today.

During our 5 years of renewal, fortunately we will be continuing until 2005, we will maintain the data base and the biospecimens we have, collect additional information for any new studies and assess additional exposures. We'll increase our minority family participation, expand the number of participants in each family, and conduct gene-environment studies, some of which are already underway. We will be expanding on those studies as new technology permits.

Thank you very much for this opportunity. I'm sure the Registry of all six sites will continue to contribute greatly to environmental research.

Senator CLINTON. Thank you very much, Dr. Senie, for a very informative description of the very complicated research you're doing. I appreciate that.

Ms. Frankel.

## STATEMENT OF GAIL FRANKEL, FIELD COORDINATOR AND ADVOCATE, ON BEHALF OF THE NATIONAL BREAST CANCER COALITION, CENTEREACH, NY

Ms. FRANKEL. Good morning. My name is Gail Frankel and I am from Centereach, and Brookhaven, Long Island, NY. I am an 8-

year breast cancer survivor. I am a volunteer with the Adelphi New York State Breast Cancer Hotline and Support Program.

I am speaking to you today as a proud member of the National Breast Cancer Coalition. I would like to thank this committee for holding this hearing, and I would like to thank Senator Reid, Senator Chafee, along with Representatives Lowey Myrick, for cosponsoring the Breast Cancer and Environmental Research Act. Thank you especially to my Senator, Senator Clinton, for your support of this legislation and your commitment to this issue. Thank you to all the committee members for inviting me here to testify today.

As you know, the National Breast Cancer Coalition is a grassroots organization dedicated to ending breast cancer through the power of action and advocacy. The Coalition's main goals are to increase Federal funding for breast cancer research and collaborate with the scientific community to design and implement new models of research, to improve access to high quality health care and breast cancer clinical trials for all women, and to expand the influence of breast cancer advocates in all aspects of the breast cancer decisionmaking process.

NBCC truly appreciates the fact that you are focusing on the issue of preventing this disease. We all wonder what causes breast cancer. I too have questions about what caused my breast cancer. Diagnosed at 53, I was told that even though my mother died at age 48 from the disease, my breast cancer was unlikely to be due to an inherited genetic defect since inherited cancer usually shows up at an earlier age in offspring. No other high-risk factors applied to me. Did my diagnosis have something to do with where I live? The sad truth is nobody knows. There is no conclusive evidence about what causes this disease.

As a volunteer for the Adelphi New York State Breast Cancer Hotline and Support Program, and as a breast cancer survivor myself, I understand all too well the concerns women in New York have regarding the possible link between the environment and breast cancer. While it is generally believed that the environment plays some role in the development of this disease, the extent of that role is not yet understood. NBCC believes that now is the time to focus our attention and public resources on developing an overall strategy to look at all aspects of this question. We can no longer afford to spend time, dollars and lives on isolated issues.

It is with that goal in mind that NBCC convened its first Environmental Summit in September 1998. This summit brought together more than 50 experts, including scientists, advocates, government officials, and policymakers to begin developing a comprehensive strategy for studying the potential links between breast cancer and the environment. Participants came to this summit with many diverse perspectives. Some felt strongly that the environment is to blame for breast cancer. Others thought the cause is purely genetic. A third group believed that breast cancer is caused by some combination of the two.

While the participants differed in their perspectives, they ultimately agreed that the lack of evidence about the environment and breast cancer highlights the need for further studies on this issue. Furthermore, the decision of which questions to research should not be made in a vacuum, rather it should be made as part of an

overall strategy of looking at all questions, prioritizing them, determining where we have some answers, and moving forward from that point.

That is exactly what the bipartisan Breast Cancer and Environmental Research Act is meant to achieve: a collaborative, coordinated, nationwide effort to address this issue.

This legislation recommends a responsible approach to the questions around this issue by authorizing $30 million per year for 5 years to allow the National Institutes of Environmental Health Sciences to create grants for the development and operation of collaborative research centers to study environmental factors that may be related to the development of breast cancer. Under a peer reviewed grant-making process, modeled after the incredibly successful Department of Defense Breast Cancer Research Program, the NIEHS director could award grants to public or non-profit entities for the development and operation of up to eight centers for the purpose of conducting multidisciplinary research on the links between breast cancer and the environment.

The legislation would require each center to be a collaborative effort of various institutions, companies and community organizations in the geographic areas where the research is being conducted, and includes consumer advocates. The enactment of such legislation would bring together a diverse group of entities, which would be able to take a broad look at the issue and develop a strategy based on differing perspectives. Like the support for the Department of Defense Breast Cancer Research Program, this legislation already has broad bipartisan support from across the political spectrum.

We recognize that this is a unique approach to looking at the environment and breast cancer. But time and time again, scientists, advocates and policymakers have told us that what is needed is a coordinated, responsible, innovative strategy. That is exactly what this bill offers. We appreciate that you, members of the committee, have the courage and vision to support this innovative approach.

Thank you again for the opportunity to testify today, and I would be happy to answer any questions.

Senator CLINTON. Thank you very much, Ms. Frankel.

Ms. Juchatz.

**STATEMENT OF AMY JUCHATZ, HEALTH PROGRAM ANALYST, SUFFOLK COUNTY DEPARTMENT OF HEALTH SERVICES**

Ms. JUCHATZ. Good morning. My name is Amy Juchatz. I am a toxicologist with the Suffolk County Department of Health Services, I'm in the Division of Environmental Quality. I'm somewhat new to the Suffolk County Department of Health. I apologize that Dr. Bradley, our commissioner, could not be here today, but I hope to answer your questions as best I can.

Basically, the role of the Suffolk County Health Department in evaluating cancer clusters and investigating cancer clusters and looking into possible environmental factors is primarily supportive in nature. It is primarily the State Health Department that actually conducts the investigations, looking at cancer incidence and whether there is a cancer cluster, and then our role at the local level is to look at local issues, help them by conducting site visits,

looking through county historical data, and if warranted, to conduct some environmental sampling.

A good example of that is the Long Island Breast Cancer Study. We analyzed, our laboratory analyzed approximately 700 drinking water samples and provided that analysis. We have a fairly extensive groundwater and drinking water monitoring program and we can analyze many contaminants, including over 100 pesticides and pesticide degradance, which is a big effort within our department.

I have also been asked to speak to you a little bit about a new task force that has been created in Suffolk County. Due to concerns of local citizens, the Suffolk County legislature created a rhabdomyosarcoma task force. I have brought with me my written testimony as well as the legislation and the resolution to establish that task force.

If you're like I was a few years ago, you may never have heard of rhabdomyosarcoma. I also brought along a packet of information here from the American Cancer Society that describes what it is and tells a little bit about it. But basically, it's a rare cancer of the soft tissues, and it's primarily a cancer in children. I think over 90 percent of the cancer cases of rhabdomyosarcoma are in people less than 20 years of age, and primarily at a younger age.

The resolution outlines various task for our Suffolk County rhabdomyosarcoma task force. One of the primary ones is to develop a survey so we can better understand the incidence of rhabdomyosarcoma in Suffolk County, and as well to investigate the history, the incidence and possible causes, environmental factors of rhabdomyosarcoma.

I hope that my brief presentation is helpful, and I would be glad to answer any questions you may have.

Thank you.

Senator CLINTON. Ms. Juchatz, how many children have been diagnosed with rhabdomyosarcoma?

Ms. JUCHATZ. It depends on what timeframe you're looking at. We have on average about two to three cases a year of rhabdomyosarcoma. There have been some years where there's been a little spike, and that of five cases. Overall, I think it really depends on when you start looking at that data.

Senator CLINTON. You've got now a task force formed to try to determine if there are any connections. Are you calling this a cancer cluster yet?

Ms. JUCHATZ. Not yet. From the preliminary analysis, it actually looks like there is not a cancer cluster, but that may just be that we haven't looked close enough and hard enough. That's what the task force, along with the State Health Department, is doing.

Senator CLINTON. I thought it was important that we hear from a local health department, because this is really going to have to be a concerted effort by local, State and Federal agencies working together in a way that we never have to track and report on chronic diseases like cancers. It's going to take a whole new mind set.

One of the previous witnesses, I think either Dr. Landrigan or Dr. Todd, pointed out that we have a good system when we're confronted by infectious disease. We have a reporting and tracking system, we have good cooperation between local, State and Federal health departments and agencies. We are only now focusing on the

fact we need to do a comparable job when it comes to the chronic diseases.

What someone like Ms. Juchatz does on the local level as a toxicologist is a necessary part of that chain of responsibility. So I thank you for being here.

I want just to ask Dr. Senie and Dr. Gammon, you're in the midst of this important study and I thought your slides were just really helpful, Dr. Senie. Basically, is it fair to say that in your crafting of the genetic patterns with families, you are finding that there are some patterns, but there are also some unanswered questions, why would one sister in a family which has BRCA1, BRCA2, the kind of genetic marker for breast cancer, develop the disease, and others wouldn't. Are you suggesting that there may then be environmental factors in addition to the genetic factors at work?

Dr. SENIE. Yes, I think precisely, in addition to the BRCA1 and BRCA2, we have many more common genetic factors, called polymorphisms, that I described in the written testimony that may be playing as important a role, if not more important. These may interact with BRCA1 and BRCA2 and potentially with environmental factors. I think we have to face the truth, that our bodies are very complex. Exposures that we can measure may be just scratching the surface, maybe there are a lot of things we haven't even thought about, and maybe some we really can't measure.

Senator CLINTON. Dr. Gammon, would you like to add?

Dr. GAMMON. Yes. Dr. Senie's project and my project in a sense are looking at very similar questions, but addressing them using different methodologies. By using the population base study like I'm doing, we take a sample of people, you're not selecting them thinking that they're going to have a genetic basis. Because although we believe that cancer is basically a defect of the genes, there are many things that come into play. They can be environmentally induced, they can just happen sporadically, we don't understand what's going on.

As we know, the BRCA1 and BRCA2 gene actually account for a very small percentage of breast cancers, it's under 10 percent. That would be a very high estimate. So we do believe that it's the smaller genetic polymorphisms, in other words, the variations in how the genes vary from person to person, interact with environmental exposures to bring on disease.

So strong components of both Dr. Senie's project and my own are to look at these interactions between what's happening genetically and what's happening environmentally. I think that's probably a very productive route to go, it's just a slow process.

Senator CLINTON. Senator Chafee.

Senator CHAFEE. Thank you, Senator Clinton, once again.

Dr. Gammon, you mentioned in your study that you benefit greatly from having experience of working with the activists in the field. I think that solutions to this insidious disease have been so elusive, that I think that's very important. Everybody that's been affected thus might have become an activist and highly motivated to find solutions and working with the scientists, I think is going to bear fruit. So I applaud you for that effort.

Thank you for all the testimony.

Dr. GAMMON. Well, thank you. It's really interesting, there is a survey done out of Harvard where they showed that over half of the American public thinks that cancer, particularly breast cancer, is caused by environmental agents. Yet only a very small fraction of scientists believe that. So I think that without the interest of the activists, it would be slow going.

People in the previous panel had stressed that environmental research, especially with regard to breast cancer, has not gotten much focus, and I think that's true. The effort of the Long Island Breast Cancer Study in general, all of the projects together, have been a major thrust in that area. So without the activists, I think we would be much further behind than we are now.

Senator CLINTON. I agree with that. I think the activists on breast cancer have changed our health care system for the better. Now we owe it to all of the survivors and everyone who is no longer with us to really do the work on the environmental connections that Ms. Frankel and others have spoken about.

Congressman King.

Mr. KING. Thank you, Senator Clinton.

I'd like to followup on this issue of the environment and issues that go beyond genetics or heredity. I know that personalized statements are not very scientific, I know anecdotal evidence is not very scientific. Just in my own case, I had grandparents that lived into their late 90's. I had aunts and uncles, 70's, 80's, 90's, there was not one incidence of cancer in our family. Yet my father and his two brothers died of cancer in their early 60's, my mother is a breast cancer survivor, I have a niece who has a problem with cancer.

Having said all of that, I've spoken with any number of other families who have similar instances where there was no prior history of cancer whatsoever, and starting maybe with the people who were born in the mid-teens, early 1920's, it seems that that generation has a disproportionate number of cancers compared with the previous generations. It's not just that they're living longer, it's not that they're being better tested.

It seems as the generations become more advanced, there's more incidence of breast cancer, prostate cancer, childhood cancers, rarer forms of cancer that haven't been heard of before. With all of the scientific testing that's being done on the breast cancer study on Long Island, and I'm certainly not trying to prejudge, I know all the work that's gone into it.

But I would certainly hope that we could find it. Whether it's disciplinary findings or grants research, cross-checking, whatever, there has to be some environmental factor. There has to be something, whether it's the food, the chemicals, the air, the radiation, any number of factors—something has changed. It's not just people living longer.

I ask if any of you can give us some concept about what you think this might be leading to or what you think might be there.

Dr. GAMMON. Let me clarify my statement about the interaction between genes and the environment, and maybe I could do a better job of explaining what I meant. My apologies.

Mr. KING. No need to apologize.

Dr. GAMMON. I think that as Dr. Landrigan pointed out, people's genetic makeups have not changed in that short period of time, that's impossible. But that certain people have a certain genetic makeup that may make them more susceptible. If the environmental exposure isn't there, then it doesn't matter if they're susceptible or not.

So I think all along, there's been variation on how people are susceptible to cancer or not. But if the exposure is not there, they're not going to get it. That's what I mean by interaction, both agents have to, both the environmental component has to be there and both the genetic component has to be there. Studying of the environmental components happens to be very, very difficult. It's extremely challenging. We don't have the technology in a lot of ways to be able to measure in people's bodies a lot of the exposures. We're concerned about long-term exposures. So we may have the capability of determining what you were exposed to yesterday, but we believe cancer takes 10 or 20 years to develop. So we don't have a good way a lot of times to measure what happened 10 or 20 years ago.

You're going to hear later testimony from the National Cancer Institute that one of the components of the Long Island Breast Cancer Study Project is a GIS mapping of historical exposures. We're hoping that by having this map, we'll be able to geographically recreate historically what a specific person were exposed to, and try to link that to their cancer burden. So part of the problem is that we're strapped by limits of technology, and as Dr. Senie said, as new technology develops, by having these banks of specimens and studies ready to go, we can capitalize on these new developments.

So that's what I think both studies are trying to do, is being able to draw on the new technologies developed. The GIS system, no one has done the kind of extensive work that the National Cancer Institute is now taking the lead on doing, specifically for the Long Island Breast Cancer Study.

Senator CLINTON. Dr. Senie, do you want to add anything to Congressman King's question?

Dr. SENIE. Yes, I think we focus a lot of our discussion on the external environment. We have to also think about changes in some of our own behaviors. Some of the medications we use, maybe even the natural ones we really don't know how many of these agents affect our bodies over the long haul. Some studies that have been reported may need to be redone each time a medication, for example, oral contraceptives, or hormone replacement therapy, are modified. These are constantly going through evolution. Every time they change the formulas, the drug may have a different effect on an individual woman. That is one of the problems. The genetic polymorphisms, that I mentioned earlier, may affect how our bodies use estrogen.

So for some women, the pill may have no adverse effect but for other women who carry a particular polymorphism, the pill may be harmful. This kind of association is now being studied in the registry of families. We even think pregnancy may have positive or negative effects on a woman's body.

Mr. KING. Thank you, Senator.

Senator CLINTON. Thank you very much.

Congressman Grucci.

Mr. GRUCCI. Thank you, Senator.

Senator, I do have with me also a study and a report, testimony actually from Dr. Elinor Schoenfeld, from Stony Brook University, that I would like to make part of this testimony being done here today. As we all know, Stony Brook University, in cooperation with Acadia National Laboratory is doing some great research work on cancer and breast cancer detection. So I think this report can be very helpful to us all in dealing with this terrible disease.

Ms. Frankel, I'd just like to ask you a question. Coming from Brookhaven, and as you probably remember, I was a supervisor there not too long ago, and we conducted a breast cancer study. I wasn't encouraged by the response that we got back, less than 40 percent of the surveys that were sent out, and I was told that we needed to have about 60 percent for it to have any kind of statistical reality to it.

I was just wondering how we in Washington might be able to help you all in getting the information so we could have the information, then open up to getting that out to the people. Is there any suggestion you have to help us do the job better?

Ms. FRANKEL. That's a tough question. Mainly because a lot of people are very private, and they don't want anybody to know anything about them or about their health. With the problem of privacy not being ensured, I don't know if you would get a lot of help.

I did get your questionnaire and I sent it back immediately. I was actually thrilled to have gotten it, because I said, here's a man who's going to do something about breast cancer on Long Island. I didn't know why, you have just explained why it died away. But I think we have to ensure people's medical privacy if we want them to divulge it.

Mr. GRUCCI. Then you probably remember from the survey that it was indeed drawn up by a medical professional and we tried to incorporate all those privacies into it. But this is a very significant issue, and we all really need to be prepared to do all that we can to make it happen, happen meaning finding a cure for this dreaded disease.

I was a cosponsor of the environmental legislation that's being talked about here today. I think it's important that we try to find that link. I guess anyone on the panel might, if they could answer this question for me. When we speak in terms of the environment, what areas are we focusing on? Are we focusing on just groundwater, are we looking at groundwater and air, are we looking at the origins where people would come from? What is the definition of environment in terms of these types of studies?

Dr. GAMMON. I think scientists define the word environment maybe more broadly than the public does. So that would include the groundwater, it would include air pollution, all those things that I think the public views as their environment.

But we also include things like dietary intake, medications you may have used, occupational exposures. So for instance, we did a migration study, and the migration studies have clearly shown that when women migrate from a low incidence area like Japan, where breast cancer is not very common, and the migrate to the United

States to a high incidence area like Los Angeles, that their incidence rates quickly, within a couple of generations, approach that that's going on with Caucasian women in the United States, indicating that it's not genes, it has to be environment, either environment as Dr. Senie alluded to, changes in their diet, or changes in their environmental exposures. It's probably both.

So that's to answer that question. I would also like to take the opportunity to comment on your comment, on several things that you said about confidentiality. As an epidemiologist, we're torn between the two worlds of wanting to have as much information as we can to be able to conduct our scientific studies, with as much heredity and accuracy as we can, and we also appreciate the patient confidentiality. So a lot of the laws that are getting passed or are being considered leave very restrictive and make it very difficult for epidemiologist to conduct research on the environment and cancer.

So there's two different things going on in Congress. One is that trying to protect patients' rights, which is a very laudable goal, but it also hems, the way some of them are written, it would make it very difficult to conduct the kinds of studies that we are conducting right now.

The other issue is wanting to figure out what causes cancer, and is it the environment. For that we will need registries. Registries record things a lot of people would consider invasions. So those two issues need to be brought together and resolved, both patients' rights taken into consideration and also the public's right to figure out what's causing cancer. So I wanted to comment on that.

I do want to thank you for bringing up the study from Stony Brook, because they are collaborating and they have a project as part of the Long Island Breast Cancer Study Project where they're looking at electromagnetic fields. The women to be interviewed in our study, they went back to their homes and they took electromagnetic field measurements. So this group of women has been incredibly, this is a group of women who's proven that they are interested and want to know what's going on, whether the environment is contributing to breast cancer.

Senator CLINTON. By electromagnetic studies, you're talking about power lines?

Dr. GAMMON. Yes, exactly.

Senator CLINTON. Congressman Israel.

Mr. ISRAEL. Thank you. I'll just make a quick comment about the Federal role and then a question. With respect to mapping and registries, it seems to me that if the Federal Government has found a way to return a $300 or $600 tax rebate check to every single income tax filer in America this fall, they can also find a way to make sure that the broadest number of Americans receives these kinds of surveys, and also the research that we're doing. Where there is a will, there is a way.

One of the running themes that's sweeping through both panels is that this challenge is so broad, and different organizations, research centers, scientists, are addressing it in so many different ways, breast cancer advocacy groups at Brook Haven, Huntington have done local geographic mapping. Dr. Gammon has conducted and is conducting her research as part of the Long Island Breast

Cancer Study. The Suffolk County Department of Health Services is doing its site visits and analyzing historic data.

I think it really points to the need to pass the Breast Cancer Environmental Research Act to create centers of excellence, and no region that I can think of is better poised for such a center than Long Island. We have SUNY Stony Brook, we have Cold Spring Harbor Laboratories, we have Adelphi, we have one of the strongest bases of biotechnology businesses in America. There is that unique convergence that would really benefit by these centers of excellence.

But an indispensable partner in all this is the Federal Government. My question to all the panelists is, are we doing enough? In 1991, we budgeted a total of $133 million for biomedical research into breast cancer. This year we're budgeting about $524 million. It sounds like a lot of money. The question, pure and simple, is, is it enough, can we do better in terms of Federal investments into biomedical research for breast cancer?

Senator CLINTON. Dr. Gammon, do you want to start?

Dr. GAMMON. It does sound like a lot of money. But research takes a lot of money. I think one of the issues that we need to address, biomedical is a broad area. We're addressing things like health care, treatment, trying to find the cure. We're talking about today more about trying to figure out what causes cancer. That kind of research just doesn't get the big fanfare that a lot of times the treatment studies do.

So I think that research costs a lot of money and it's very labor intensive. So yes, I think having more money is helpful. It costs a lot of money to do the Long Island study. Interdisciplinary research, research on a large scale, which gives it a greater validity, costs a lot of money.

Senator CLINTON. Dr. Senie.

Dr. SENIE. Truthfully, there needs to be some capped costs. We can't put all of our money into breast cancer, and yet obviously, many of us here are wishing that we had more to spend. I have to say that when you get into more complex studies such as ours, especially when genetics are involved, just to study BRCA1 and BRCA2 costs $1,200 under a special NCI-NIH arrangement with Mariann Genetics, per sample.

You take a family like the one I showed you, we could have chosen the wrong person to test, and we'd have a negative family. Just think of that, per family we get $1,200. I'm really torn about how to decide who in those 1,500 families to test. We will have somebody for genetic testing, but to do gene environment, you still have to know who are the carriers.

Then to look for the polymorphisms, they cost a lot less, but maybe about $200 per polymorphism. There are hundreds of them. Probably, we'll never figure out all of it. So it's a very complex area.

Senator CLINTON. Gail?

Ms. FRANKEL. Yes, of course we could always use more money. But I think under the circumstances, we have to use what money we can wisely. That's why we think the NIEHS will do such a great job, $30 million a year is not a lot in the scheme of things, and it would be used wisely. In fact, going back to Representative Grucci's question about what constitutes the environment; his question is

set up in the bill we're supporting. The plan is to start with what questions to ask, so we don't go all over the place and just throw the money away.

Senator CLINTON. Ms. Juchatz.

Ms. JUCHATZ. I'd like to reiterate again, we can always use more money. There's more things that we can do. But again, I think it is important that you look at it wisely and in a larger scheme and make sure we're refunneling it at the appropriate place.

But one thing to mention in terms of environmental factors, when we go in and take a sample of groundwater or soil or even a blood sample, we're kind of looking at a snapshot in time. As was mentioned, we're looking at cancer maybe taking 10, 20 years to develop with that latency period. So the question we really want to answer is what were they exposed to 10 or 20 years ago. That's a hard one, really, to get at.

I think maybe something that may develop in later time is more a perspective study when we start looking at people without breast cancer and looking at their environment and following them through and seeing who develops breast cancer and if there is some correlation then between environment. But it's a difficult thing to grab hold of.

Senator CLINTON. I want to thank this panel. It's been so helpful. One of the real issues that you've raised is how to direct scarce dollars toward different kinds of research. We have been very generous in funding the National Institutes of Health, NCI and other related agencies. But we haven't gotten enough dollars going into this kind of research. So we need to take a hard look at what we're doing and how better to direct the other research dollars we do spend.

I thank this panel, and now I'd like to introduce our third panel, which consists of representatives from a number of our Federal agencies. They are on the front lines and they also have specific ideas that go directly to Congressman Israel's question about, what we could do to better direct our dollars. How can we make this the national priority that it needs to be? One of the arguments that's being made now is that in addition to directing money at specific diseases like breast cancer, we need to put more money into general, basic scientific research and medical research. If you have a preordained idea about what you're looking for, you might miss some very good leads that come from more general scientific research.

So I think there are lots of issues about what we need to be doing here, and this final panel has, I think a lot of at least potential answers for us. I'm very grateful that all of you could be here. Some of you have traveled from long distances. I understand Dr. Jackson, who will be our first witness, changed his travel plans because he cares so much about this issue and what we should be doing as a Nation.

Our first witness will be Dr. Dick Jackson, director of the National Center for Environmental Health at the Centers for Disease Control and Prevention. He will be followed by Dr. Deborah Winn, acting associate director of the Division of Genetics and Epidemiology at the National Cancer Institute. Then we will hear from Dr. Sam Wilson, deputy director of the National Institute of Environ-

mental Health Sciences, and he will be followed by Dr. Lynn Goldman from the Bloomberg School of Public Health at Johns Hopkins University, who is part of a very important study done by the Pew Charitable Trusts about tracking chronic diseases.

Each of the panelists who appears on this third panel has devoted many years to public service and have taken some of the toughest jobs in our Government, trying to keep us healthy, trying to send up the warning signals when we weren't doing what we should be doing, grappling with very difficult issues. I personally want to thank each of you for your public service and for being part of our national public health system, which deserves more attention and more resources because of the job that it does.

So with that, let me call on first Dr. Jackson.

**STATEMENT OF RICHARD J. JACKSON, M.D., M.P.H., DIRECTOR, NATIONAL CENTER FOR ENVIRONMENTAL HEALTH, CENTERS FOR DISEASE CONTROL AND PREVENTION, DEPARTMENT OF HEALTH AND HUMAN SERVICES**

Dr. JACKSON. Good morning, Senator, good morning, members of the committee. Thank you for inviting CDC to testify at this important field hearing.

I'm joined in the audience by Dr. Marian Mandel, from the Division of Cancer Prevention and Control at CDC. If there are specific questions about the registries, I would ask for her to be able to join me at that time.

I will submit my full testimony for the record and just highlight comments that need to be added here.

The critical message that I want to convey here is that looking at cancer cluster risks in isolation from disease tracking and from environmental tracking will ultimately fail. It has to be a seamless system where this is all connected together.

Up until now, in many ways, we've had almost a chasm between the world of environmental tracking, and the world of disease tracking, between what is going on in the environment, what is actually going on in the environmental regulatory world of engineering and toxicology testing, and what is going on in the medical world. Studying environmental health hazards is very hard. I've done many of these field investigations, you go into communities that are very upset, rightfully so; they're very concerned and there's a lot of media presence. You're trying to answer questions about something that happened 5, 10, 15, 20 years before in terms of people's exposures.

A sister agency to NCEH, NIOSH, the National Institute of Occupational Safety and Health, have an advantage in the sense that they go into a workplace where there might be records of what people were exposed to, and they can find out who worked in that particular setting. When we go into an environmental investigation, oftentimes we're really trusting people's memories, there's very poor record keeping of what goes on. Oftentimes, people are suspicious of telling the Government where they were or what they were exposed to or what they did.

So these are very difficult investigations, but we've brought some new tools to it. I will touch on those as I go along.

One thing that's very hard to explain to the public as one gets into disease cluster investigations is that almost 90 percent of the time when you go into a cluster, it really is not a cluster. Cancer is a common disease, about one and a quarter million people develop non-skin cancer every year, about a half million die of it. So when you actually look at patterns in a population and compare it to the cluster you're looking at, the cluster kind of disappears.

For those clusters that are investigated and where we do identify a statistical increase, most of the time we still don't find an environmental cause. But that's interesting and in contrast to what the public believes. We human beings understand that when we see something, it's an effect of something around us. I'm convinced that in the public's mind, disease clusters are environmental until proven otherwise. Simply waving your hands and saying, "oh, well, it will never pan out," is completely unsatisfying to members of the public.

But also if you go into a disease cluster or cancer cluster investigation, you need to start the environmental investigation at the same time, and not wait months or even years to start the environmental investigation. That isn't to say clusters are all environmental, it is to say that environmental concerns are always a part of the community's concern. You have to deal with that concern and try to give answers to questions.

Now, the problem is that most State health agencies are very weak when it comes to environmental epidemiology. Senator, as you mentioned, the commitment I had today was to go to the State epidemiologists' meeting, and I will be going to that after this. State epidemiologist have voted in repeated resolutions about their need to have serious epidemiologic capacity in environmental health. It's great to have collected environmental data, it is great to have collected cancer data. But you've got to have someone smart, who can answer a question, who can speak in a language that human beings can understand, who is able to be that "intake" person. I was very impressed and have been very impressed with Dr. Todd of Nevada, that he's been able to stand these two very difficult roles very well. But these are not easy issues.

I would say that in the last five meetings, I've gone to the State epidemiologists, they have roundly pressured me and criticized CDC for not providing a training program, a pipeline for State epidemiologists, people who can understand both of these roles and speak the language of both sides. I think we at CDC owe it to the States to help them provide this.

We need different elements to deal with the environmental elements of the clusters. We've got to be able to track what's going on in the environment. I would assert that EPA has done a very good job of figuring out what's in the air, what's in the water and what's in the food. We know pretty well what's in the environment. We have been much weaker at knowing what's in human beings.

This is the report that CDC came out with in March; it is our down payment on a review of 100 different chemicals residing in the bodies of the American people. Every year CDC goes out and we test, actually put our hands on, 5,000 people, draw blood, urine and other specimens from them. This report from the 5,000 people we sampled in 1999 documents body burden levels of 27 chemicals

in the American people. It documents a 75 percent reduction in tobacco byproducts in non-smokers.

Senator CLINTON. That's good news.

Dr. JACKSON. It's very good news. In fact, having good data, real data on the population, will point us to some situations that are good news. In other situations, it's going to point where we need to put more strength. For example, we found higher levels of certain plasticizing agents, called phthalates, in women of reproductive age, higher levels than one would have predicted in advance of doing this study.

The second use of having this biologic data is that researchers, such as the individuals you just heard speak in the earlier panel, need to have background levels of what's in the population. Not to say that these chemicals are normal, but a community wants to know, are we different from any other community in America? You've got to have those levels on the overall population if you want to answer that question.

The third element is disease tracking capacity, such as cancer registries, birth defect registries. There again, you have to speed their getting in place. There are other disease registries around neurological diseases that I think the public is very interested and concerned in. I know we public health researchers are as well.

I think my closing comment is that I hope that whatever is done to address this issue of clusters, that it not be stovepiped, that there be an effort to connect these various elements together in a rational, useful way. It really makes a difference in people's lives when the local health departments work, they're the ones that were there in the cluster area long before it occurred, they're going to be around long after it occurred. The same is true with State health departments. Let's build that infrastructure, let's make those people more competent to deal with these problems.

I think that's the message I would like to leave with you today, and thank you for inviting me.

Senator CLINTON. Thank you very much, Dr. Jackson. I really appreciate, while we're waiting for the screen to come down, Dr. Jackson's pointing out the CDC biomonitoring study. Do you have any extra copies of that, Dr. Jackson? I think we want to be sure we get copies to at least all the members of the panel, so that they can see the work that is being done, to know what our internal environment looks like.

Dr. JACKSON. Yes, Senator, we'll get them.

**STATEMENT OF DEBORAH WINN, PH.D., ACTING ASSOCIATE DIRECTOR, EPIDEMIOLOGY AND GENETICS RESEARCH PROGRAM, DIVISION OF CANCER CONTROL AND POPULATION SCIENCES, NATIONAL CANCER INSTITUTE, NATIONAL INSTITUTES OF HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES**

Dr. WINN. I want to thank you for inviting me today and for giving me an opportunity to talk to you about NCI research on cancer, genes and the environment.

Today, I will cover NCI's approach to cancer surveillance, the Long Island Geographic Information System Project, and NCI's strategic plan for research investment in genes and the environ-

ment. Many chemical, physical and biological agents in the environment, such as ultraviolet radiation, toxic substances, and viruses, have the potential to increase the risk of cancer. However, the scientific community, as you heard earlier, usually thinks of the environment as having a much broader scope.

It includes, to us, not only the physical, chemical and biological environment, but also lifestyle behaviors, medications and occupation. People are often exposed to many factors simultaneously, or may be exposed to some carcinogens in many forms. For example, exposures to the carcinogen benzo(a)pyrene may come from air, tobacco, diet and occupation.

Geographic patterns of cancer occurrence may provide important clues to the environmental causes of cancer. NCI has two programs to help identify geographic areas of high cancer risk. The Surveillance, Epidemiology, and End Results Program provides a picture of cancer incidence, mortality and survival in 13 States and major metropolitan areas. The NCI's Atlas of Cancer Mortality, which you see here, contains maps, text, tables and figures showing the geographic patterns of cancer death rates throughout the United States from 1950 to 1994, for more than 40 cancers.

The NCI has used the atlases to generate leads for in-depth epidemiologic studies that have in the past shed light on factors contributing to cancer risks. We expect to develop new leads from the most recent cancer maps.

Here the slide from the atlas shows mortality rates from 1970 to 1994 by State economic area for cancer of the breast. The deepest red areas are those with rates in the top 10 percent of U.S. rates. The maps show very clearly the high breast cancer death rates among white women in the northeastern United States. The pattern is not the same for black women.

Dr. WINN. To understand the reasons behind these high breast cancer rates, the Long Island Breast Cancer Study Project was initiated. The Long Island Breast Cancer Study Project consists of more than 10 studies of breast cancer, including human population studies, the establishment of a family breast and ovarian cancer registry, and laboratory research. Earlier you heard from Dr. Senie and Dr. Gammon.

The project also includes the Long Island Geographic Information System (GIS–H). Geographic information systems are powerful computer systems for mapping and analyzing relationships over time and space between multiple layers of data. The Long Island GIS–H will include more than 80 data sets containing information on a wide range of environmental and health data for Suffolk and Nassau counties integrated into a single system. It will have researchers' tool boxes, with the software and statistical tools needed to analyze the data, and a web site including a mapping facility. The public mapping facility will be available early in 2002, if not before.

The system includes data on contaminated drinking water, hazardous municipal waste, electromagnetic fields, pesticides and other toxic chemicals, and indoor ambient air pollution.

The Long Island Geographic Information System will provide researchers a new tool to investigate relationships between breast cancer and the environment in Suffolk and Nassau counties, and

to estimate exposures to environmental contaminants. The public will be able to use the web sites to examine patterns of environmental exposures and breast cancer.

There is often a tendency in cancer research to focus on genes and cancer or the environment and cancer, but we're learning it's more complicated than that. Some cancers are associated with defects in one or a few genes. However, most cancers involve many genes. Individuals may inherit defects in these genes, or they may experience environmental exposures or other circumstances that cause gene mutations, which are changes in gene structure. If alterations occur in genes that control such functions as metabolism of carcinogens, DNA repair, or metabolism of nutrients, then cellular processes may become abnormal.

Even among individuals who have inherited cancer disposing genes, like the BRCA1 gene, the risk of developing cancers appears to be modified by genetic and environmental factors. So the interaction is important.

It then becomes important to understand the relevance of these complex interactions to people. Can we predict an exposed person's risk? What is the impact of predictive testing and cancer risk assessment on individuals and their families?

Opportunities now exist to determine how variations in genes combine with environmental and other factors to induce cancer in the general population. NCI has developed a strategic plan to discover the genetic and environmental and lifestyle factors and their interactions that define cancer risk, and develop new strategies for early detection and treatment.

Finally, the objectives of this initiative on genes and the environment are to identify new environmental risk factors and susceptibility to genes and determine their interactions in cancer causation, refine cancer risk models, and to develop other tools to conduct studies to address clinical and behavioral and societal impacts, such as whether women who inherit the BRCA1 gene should take hormone replacement therapy.

By marrying the study of the distribution and the environmental causes of cancer, and cutting edge genetic and related molecular technologies, we should be able to design new approaches to preventing cancer. Thank you.

Senator CLINTON. Thank you very much, Dr. Winn.

Dr. Wilson.

**STATEMENT OF SAMUEL H. WILSON, M.D., DEPUTY DIRECTOR, NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES**

Dr. WILSON. Thank you for inviting me to discus the influence of environment on human health. The goals of environmental health and environmental health research are establishing and maintaining a healthy, livable environment for humans and other species, and promoting an environment that improves well-being in all aspects of mental and physical health. This environment must be sustained into the future, and be a setting in which population growth and manufacturing and agriculture can thrive.

We all recognize that many important achievements have helped create a healthier, cleaner environment. Our past research strate-

gies have allowed many successes in understanding mechanisms of environmentally-linked diseases. To continue making strides in the future, we will need to focus on the interplay of genes and environment. It is this interplay, of gene-environment interactions, that holds the greatest promise in the fight to prevent and control environmentally-related diseases, including cancer and other chronic diseases.

This is the main point I want to make today, this point concerning gene-environment interactions. There are two recent advances in the field of human genetics on one hand and environmental health on the other that define our future research strategy. First, we now have the sequence of the human genome in hand. We are beginning to understand the individual to individual variations that modify susceptibility to disease.

Second, we are now working with an expanded definition or view of environmental exposures that includes diet, lifestyle, socioeconomic factors, and other factors including environmental pollutants. This expanded view of environmental factors will allow us to conduct more meaningful studies of environmental contributions to disease in the future.

The research model of understanding a relatively rare but strong disease gene or a strong environmental toxicant has served us very well in the past in defining the molecular biology of disease and in prevention. However, this model will not be sufficient to address the more common diseases, since only a small percentage of disease can be attributed to the rare dominant disease genes, or to the high level and very strong toxicants. Instead, new science and a new scientific tool box will be needed, along with more research involving common genes that modify an individual's response to environmental factors.

Fortunately, the genomics era will provide us with this new tool box. Along with the expanded view of the environmental factors, the field of environmental health research has an exciting new opportunity.

I will now very briefly describe some of the work pointing to the role of the environment in major diseases, and how understanding gene-environment interactions will improve our ability to prevent disease. In the past few years, we've seen a number of studies that illustrate the importance of the environment. For example, by comparing disease rates in twins, scientists have managed to tease apart the relative contributions of environment and genes.

We now know that environment accounts for over 50 percent of cancer risk, depending on the site of the cancer. Twin studies of Parkinson's disease reveal that environment accounts for 85 percent of the risk of the late onset cases of this disease. For autoimmune diseases, such as MS and Lou Gehrig's disease, environmental factors account for 60 to 75 percent of the disease risk.

But the environment, even though it is a major determinant, is not the only determinant. Two people with the same exposures and the same environmental history can have a very different outcome concerning diseases. Differences in susceptibility due to variations in genes, individual variations in a gene's coding for proteins that are critical in the body's response to environmental stress, account for these individual differences. These proteins include metabolism

enzymes, DNA repair enzymes, as we've heard, signaling molecules, and receptors, among others. Someone inheriting a gene that produces a weak or ineffective form of one of these proteins will be more susceptible than a second person inheriting a gene that makes a more effective protein. This is because the first person might be less able to break down or handle a toxicant and/or the repair of a specific cellular damage will be less efficient.

Thus, understanding the combination of these modifier genes and the specific environmental exposures is critical in understanding the causes of disease. Neither factor acts alone, but it is the two interacting or acting in concert.

In conclusion, I will say that preventing disease is now the most important service of public health policy. The most effective way to prevent disease is to understand the cause and change the conditions that permit it to occur. A key strategy to prevent many diseases will be to use the knowledge gained from gene-environment interaction research to estimate individual risks, and then to use this information to design approaches for better health and for better treatment.

Finally, we at the NIEHS have been working with a new model for research that provides for citizen participation. We believe that citizen participation in research will generate more relevant findings and will suggest better real world research questions, and will also serve to enhance communication for the participants in the entire research project and for the neighborhoods.

Thank you very much for this opportunity. I'll be happy to answer questions.

Senator CLINTON. Thank you, Dr. Wilson.

Dr. Goldman.

**STATEMENT OF LYNN R. GOLDMAN, M.D., M.P.H., PROFESSOR, ENVIRONMENTAL HEALTH SCIENCES, JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH, BALTIMORE, MD**

Dr. GOLDMAN. Senator Clinton, Senator Chafee, and members of the New York Congressional Delegation, thank you for the opportunity to provide perspective to this issue today. I'm a pediatrician and an epidemiologist, and I'm a professor at the Johns Hopkins University Bloomberg School of Public Health. Prior to coming to Hopkins, I served in the Clinton administration as Assistant Administrator at EPA for Prevention, Pesticides and Toxic Substances. Prior to that, I was State environmental epidemiologist for the State of California. In that position, I actually investigated a number of clusters and helped to write California's first handbook manual on how to do that.

At Hopkins, I serve as principal investigator for children's health for the Pew Environmental Health Commission, which was a blue ribbon independent panel charged with developing recommendations to improve the Nation's health defenses against environmental threats. Finally, I am also a member of the Environmental Defense Board of Trustees.

My perspective is that our public health service is falling short in terms of its duty to watch over the safety and health of Americans, and especially when it comes to chronic diseases. Chronic diseases are responsible for 7 out of 10 deaths in this country. More

than a third of our population, over 100 million men, women and children suffer from chronic diseases. These diseases cost our citizens and our Government $325 billion a year.

By 2020, chronic diseases are estimated to afflict 134 million Americans and cost $1 trillion a year. CDC estimates that 70 percent are preventable. But our Federal Government is not actively pursuing means to prevent these diseases.

You heard today from the personal perspective from people in Elmira, the people who have been involved with the Fallon and Long Island cancer problems, about the intense personal suffering, the community suffering that occurs with these clusters. I've experienced that myself in public health.

As a public health scientist, I'm aware that this is a problem that is repeated in communities across the country. In 1997, there were almost 1,100 requests by the public to investigate suspected cancer clusters. Many of these no doubt were preventable, most of them were not investigated. Even though we know about the importance of increasing our investigations of chronic diseases, and the staggering human and financial toll they have on our country, we do not have the systems in place to track chronic diseases, nor do we have the capacity to respond to these health crises.

Our agencies, as you have heard, are doing a great job tracking and responding to communicable diseases. This is a model that we know can be an effective model for preventing disease and encouraging public health.

Why is this the case? I think that part of what has happened is that we have simply failed to modernize our system as the health problems have changed over time. As a former chemical and pesticides regulator, I personally am appalled by the amount of ignorance that we have about chemicals in our environment, and our inability to be sure that we're doing the right thing to prevent chronic diseases.

In 1997, Environmental Defense looked at what we know about the most common chemicals in commerce, the 2,800 that are produced at at least a million pounds per year. They found an enormous amount of ignorance about those chemicals. When I was at EPA, we looked at them systematically. Only 7 percent had screening level information about toxicity and 40 percent had no information at all. We simply knew nothing about them.

There are efforts underway to increase the amount of information, but we're very much on the upward part of the curve on this. We also don't know very much about how many of these chemicals are in our bodies. We think that the work that CDC is doing to generate that information is a good start, but the reality is we don't know what's in breast milk, we don't know what's in the workplace, we don't know what's in the products that we are using or are that are in our homes, that are intended for our children.

With the Pew Commission, I wrote a report on birth defects. In this country, we do have some efforts to track birth defects. In that we found that 17 States did not track birth defects at all. Birth defects cause 22 percent of infant mortality, that's children under the age of a year. The State of New York does have a system, but it's a system that received a B on our report card. Why? Because the data are not comparable with the data that are collected in other

States. We cannot use the data to be able to make comparisons, to be able to say, these patterns in New York are unusual or not.

We know that 25 percent of developmental diseases, such as cerebral palsy, autism and mental retardation are caused by environmental factors, but only a handful of States track those. Asthma, we have an epidemic of asthma in this country. Again, we do not see tracking efforts for asthma. In fact, asthma rates have nearly doubled over the last decade and we still don't know why.

So the Pew Commission developed a number of recommendations to try to address the situation. First, though, we need to build a coordinated system of tracking diseases. We need to track diseases like asthma, the developmental diseases, the neurologic diseases, birth defects, cancers, diseases that are likely to be preventable. We also need to track exposures, exposures to heavy metals, pesticides, air contaminants, so that we know what are the chemicals to which people are actually exposed.

We need to have an early warning system that would alert communities of health crises such as lead poisonings or mercury poisonings. Our existing systems can be very slow to identify outbreaks like the West Nile or food illness outbreaks. We need to have systems that identify those more rapidly.

Third, we need to improve our response to identify disease clusters and other health crises. I think you've heard today about how those efforts need to integrate from the Federal to State all the way to the local level. One of the recommendations from the Pew Commission for the tracking network is about $275 million, less than $1 for every woman, man and child in the United States.

It's ironic that we have mapped the entire human genome but yet we do not know what are the environmental agents that can trigger the gene-environmental interactions that cause disease. We do have the technology, we have the know-how, we have the knowledge, but we have not put the same level of effort into identifying the triggers for disease as we have for identifying the genetic susceptibilities to disease.

Polling has been done on this issue, 63 percent of the American public feels that public health spending is more important than cutting taxes. Seven out of ten registered voters feel that public health spending is more important than spending on a national defense missile system. A recent public opinion poll by Princeton indicates that 9 out of 10 registered voters support the creation of a national health tracking system.

We know that the local agencies have faced declining funds, inadequately trained personnel, outdated laboratories, and we know that the CDC and ATSDR and NIH have not had the funding to give the States the guidance that they need, the standards that they need, the training, even on a very fundamental level, the laboratory support that they need in order to be able to do these investigations.

Who is guarding our health? The public health service has fallen short of its duty, lacking the troops, leadership and the tracking system. This is exactly where the Federal Government is needed. The Federal Government is essential to the success of State and local agencies in being able to address these problems. Yet, ironically, what we've seen is the proposed budget recommendations

have put forward severe cuts for the Nation's chronic disease prevention programs.

We need to be going in the opposite direction. We need to invest in preventing asthma, preventing cancer, preventing neurological problems in our children. There will be many more lives lost and much more suffering until we set out to do that.

Thank you again for this opportunity to testify.

Senator CLINTON. Well, it won't surprise you that I agree with her 100 percent.

[Laughter.]

Senator CLINTON. I so appreciate the panel's testimony. I just want to re-emphasize that there are many, many people in our public health system at all levels who are heroically struggling against great odds. We are not giving them the tools that they need to do the job that they want to do and that we expect them to do.

I think that the Pew Commission's recommendations are so on target about what we should do. We have a great capacity in our country to muster resources and set goals and achieve them. We now, because of the improvements in information technology and the mapping of the human genome, are at the point where we can make these investments, as Dr. Goldman and the others have suggested, and they will really pay off.

We couldn't have done it 10 years ago or 20 years ago. We really were strongly in the dark to just make sense of a lot of this. We now have the tools, and if we don't do it, then we have failed to do what we should do to protect our national health.

I would like now to call on Senator Chafee.

Senator CHAFEE. There are four doctors on this panel, and earlier Dr. Landrigan mentioned, if I recall, that there was some thought that there might be a virus associated with cancer. It's the first time I've heard that. What is the general consensus as we study disease, and the implication of a virus?

We'll start with Dr. Winn.

Dr. WINN. I believe you are referring to the potential cluster of leukemia in Nevada. There is a concern that a possible leukemia causing virus has been introduced there because it's an area with a lot of people moving in and out. I think that it will be a real challenge to try and investigate that theory further. There are epidemiologic methods that we use to try and model individuals interactions with one another, so that we might see if there is a potential for an infectious cause.

Certainly viruses are related to other cancers.

Senator CLINTON. Dr. Wilson.

Dr. WILSON. We know very well that virus infection is related to certain types of cancer, such as liver cancer, cervical cancer and so on. But the risk of developing cancer even after the viral infection is also influenced by environmental exposures. The evidence on this is very clear.

So we do know that viral infection is one of the factors in cancer etiology.

Senator CLINTON. Dr. Jackson.

Dr. JACKSON. Earlier speakers suggested looking at people today and going back 20 years or so ago to see what was in their blood. A study that was done jointly with the other agencies here, the lab-

oratory work was very interesting, a low-level increased risk for non-Hodgkins lymphoma if you had a certain chemical in your blood, but in fact if you had a certain herpes virus at the same time, instead of a fourfold risk, it was about a twentyfold risk.

So I think for many of these it's not going to be genes alone, it's not going to be environment alone, it's not going to be a specific chemical or a specific virus, it's probably all of them together.

Senator CLINTON. Congresswoman McCarthy.

Ms. MCCARTHY. Thank you. Thank you for the testimony. I see a number of, I hope I'm not the only one sitting here thinking, "Oh, my God, what a nightmare we have finding legislation to help all of you." It's not just a matter of getting the money. Let's be realistic about this. We have other forces that will try to stop us from trying to get the money.

I've seen here in New York State when we've tried to do something on just notifying the neighbors on pesticides, we had large corporations fighting us on that. I'm not saying it's the fault of the chemical companies. But let's be realistic as far as the politics. That's what we're going to be dealing with when we go back down to Washington. We are going to have so many groups after us not to do the research on environmental issues that we care very much about. That's where the grass roots across this Nation has to get involved, to have their voices heard. Because I don't think there is anyone here that wouldn't like to see more money go into the research that we need, especially in public health, going between the Federal, State and local. There's politics involved.

We will do our job. I hope that our committees find the right answers to help you do your job. But let's not kid ourselves. We've been talking about this for a number of years, and we've been stopped at every single turn. So with that, if any of you had a wish, where would you like to see us go as far as legislation?

Senator CLINTON. Dr. Jackson, do you want to start, please?

Dr. JACKSON. I really fear that the infrastructure of public health, knowing how the system works, it's pretty broken in the environmental arena. I think the way the funding comes in, it's so tightly circumscribed around a certain disease entity or a certain public health concern, that the system is really not working as well.

If I had one wish, it would be to see that, we're really looking at a systematic improvement and maybe not one more disease focus, disease focus, etc.

Senator CLINTON. Dr. Winn.

Dr. WINN. We have a critical need for biomarkers studies. Biomarkers are biochemical or molecular indicators of exposures or damage to tissues and cells. If we have better biomarkers of exposure, we might understand the mechanisms by which environmental agents produce cancer.

We also might have an early warning system so that you could identify individuals at risk before clinical disease actually occurs. So I think in that arena, biomarkers are very useful because we can't always undertake very large studies that go on for many, many years. We need indicators that give us answers much sooner.

Senator CLINTON. Dr. Wilson.

Dr. WILSON. I would answer that by following up on a point that Senator Clinton made earlier. That is that we need information, we need to get the information. That circumstance will allow us to implement the kinds of public health changes that we're all thinking about. So this topic of getting the information is the most important topic. As I said during my comments, I think we have a unique new opportunity at this point in time, given the new technologies and the Human Genome Project, given the new information technology resources, and given the increased enthusiasm and focus on gene-environment interaction and environmental health.

So I believe it's a unique point in this field and in the area of public health, where we can truly get the information, since for the first time we know enough to know what to do. That wasn't the case, as you said, earlier, 10 years ago.

Senator CLINTON. Dr. Goldman.

Dr. GOLDMAN. If I had to just ask for one thing, because there are so many things that need to be done, it would be for a bold stroke, and that would be the nationwide health tracking system. I think that is an effort that could receive broad public support. When Pew went around for support for the recommendations, we received a core of support from public health scientists and environmental health scientists and all the usual suspects, who realized how frayed the fabric of public health really is in this country.

But also we had support from medical groups, like the American Academy of Pediatrics, we had support from managed care organizations, we even had support from the American Chemistry Council, the industry organization. So I think that you could perhaps construct a broader tent around the public health agenda that could help in the future in terms of generating information, very specific information that might be needed for all those other things.

Senator CLINTON. In fact, if you look up there on the easel, that's one of the ads that Health Track is running, which shows that this is a national problem. I think, Carolyn, we could put together a very strong argument to bring together a political coalition that not only crosses party lines but geographic lines, industry lines and that sort of thing, we should try to do.

Congressman Ackerman.

Mr. ACKERMAN. Thank you very much, Senator. Thank you especially for everything that you've done, for finding Dr. Goldman for us. Thank you for putting her on last. I wish she was on a little earlier, you would have saved my blood pressure from going through the roof.

I am so frustrated, and I'm frustrated because of the lack of outrage that we have today at this hearing. I don't know why, but for some reason, I think that the medical community, the scientific community, should be banging their fists and pounding the table and making demands on us, rather than some of the things I've heard here today. Everybody I know is very well educated and very, very polite. I heard thank you for the $30 million to do this, and you're very generous, and we know that we have to accept political realities.

Nonsense. We make the political realities up here. We should be changing the political realities. Dr. Goldman talks about $275 million to do a nationwide tracking system that was suggested by the

Pew Foundation. Wouldn't that be marvelous? Two hundred seventy-five thousand dollars, what is that? I'm as strong on national defense as anybody else, but we spent a billion dollars a copy for a B1 bomber, and how many blew up when we were trying to make them? That's billion dollars, not million, billion.

Star Wars we're talking about now, trillions of dollars. Half of the scientific community says it's not going to work anyway, but we have to protect ourselves. Listen, more people died of cancer in the last 4 years than in World War I, World War II, the Korean War and the Vietnam War all together. I know that people are worried, but I know more people who have died this year of cancer than people who have died from a bomb falling on their head. Not that we shouldn't be concerned about both, but we have to get our priorities straightened out, and we're not doing that in our society.

I wish the scientific community had the same kind of table pounding initiatives that some of the women, especially that are here today, have done in my office making their demands. I heard from the scientific community today, it's a remarkable change from the hearing we had 8 years ago. Eight years ago, the Director of the National Institutes of Health said, "well, yes," to Senator D'Amato, when he testified at our hearing, we should be taking a look at the environment and basically it was what we would call in my scientific community pooh-poohed the whole notion.

After Senator D'Amato left, and 90 percent of the press corps with him, at the insistence of some of the advocates, I said, "Well, how much money are you going to put into this to take a look at this problem?" He said, "We don't have any money for it." Then we reconvened, if people here remember, we reconvened that meeting very quickly in Washington and basically read people the riot act, which resulted in almost everybody saying, "well," nobody said, "There's no connection." I think Dr. Jackson came as close to it, by saying that we really have to take another look, and the public is misinformed when they come to these very quick conclusions.

Nonetheless, I think everybody, yourself included, Dr. Jackson, I give you a lot of credit for that, and Dr. Wilson especially, that there has to be a coalition between the scientific community, the academic community and the people out there. My mother used to, God rest her soul, she used to have a great expression, she'd say, "If you want to help me, help me my way." We have to really help the people who instinctively know this issue and have called it to our attention. If the scientific community had the same kind of spirit that the advocates have shown, I think we would have gone a lot further than we have come at this moment.

One of the things that I heard earlier from the director of the Long Island study, and I think it was terrific, because "we've come a long way, baby," as they said in the commercial, the fact that just to get the community advocates involved with the scientific community in doing the project so they would have input was a huge fight. It was acknowledged here today that that is important by so many of the people who have just recently spoken, on this particular panel. There should be legislation that require any kind of project that proceeds, that the advocacy groups participate in some fashion.

I guess that was a pretty long question. So if anybody wants to respond, you have 30 seconds.

Senator CLINTON. Dr. Goldman.

Dr. GOLDMAN. Well, I obviously agree with what he said. I think in particular your last comment about involving the community is so important. In my experience, the community sometimes has very high hopes for what science can do for them and what scientists can find in doing these investigations. They need to be engaged from the very beginning so that their expectations are absolutely tuned with what can be done, but also so that they understand exactly what is being dedicated to look at the problem.

Sometimes communities are absolutely, as you pointed out, they're absolutely outraged when they find out the numbers of burdens that are on these agencies and the amount of prioritization that has to be done, so that something that perhaps deserves a comprehensive investigation gets a few weeks of somebody's time, which is an absolute outrage, and you're correct about that.

Senator CLINTON. Congressman King.

Mr. KING. Thank you, Senator Clinton. I'd also like to thank the panel. Really the clear inference of the testimony today, certainly this panel, is the interaction between genes and environmental factors, looking as Dr. Winn said, for biomarkers, early warning signs. It seems to me then what we're talking about somewhere in the future is that almost the ordinary annual checkup would be a system of cross tabs. We just wouldn't be looking for one thing, we'd be almost seeing what a person's experience has been, what the genetic factors are, and it would be much more complicated than it is today.

Now, are we talking about seeing that in our lifetimes? Is that around the corner? Is that within our grasp or are we still basically talking about individual advancements that hopefully will come together some time in the future? Can you put any time on it?

Also before you get to that, in answer to my good friend Gary, I think that national defense is very important, our defense budget is less than it was percentage wise before Pearl Harbor. Obviously, we have to do more. I would support any increased funding for environmental factors and others. But part of what we get paid for in Congress is to walk and chew gum at the same time. I think we can deal with national defense and hopefully advance health policy.

Since I talk after Gary, I figured I'd take a shot at him, because he can't get back at me.

[Laughter.]

Mr. KING. In all seriousness, I go back to, what sort of timeframe are we talking about? Is there one as to when this can be brought together in a cohesive fashion, to bring it together where it actually is going to impact the ordinary person to give the early warning signs?

Senator CLINTON. Dr. Jackson.

Dr. JACKSON. Representative King, I was the lead person under the President's Executive Order on Children's Health and the environment. One of the reason it's important to focus on children is not just the reason Dr. Landrigan mentioned, but in fact, a lot of the issues were grappling with it's going to take a generation or two to really begin to put these responses together. First of all, lab-

oratory methods that we're analyzing not just 27 chemicals, but hundreds of chemicals, literally counting molecules in that little teaspoon of blood you get from an individual. That will actually come, but it's going to be 5, 10 years in the pipeline. We'll add about 25 chemicals a year.

The computational ability, you've got 40,000 genes, you've got 100, maybe 200 chemicals. To really do these studies, we need eventually to do some kind of longitudinal cohort, by that I mean a Framingham, where one would go forward, look at environmental chemicals, look at their genes and have the computer ability to look at thousands, tens of thousands of people. That kind of research capability twill come.

You don't want to be pushing tests on the public unless you have an ability to interpret them, whether it's a genetic test or a chemical test or any other kind. In fact, I worry that pushing tests on people where you really aren't sure what it means and you aren't sure you're going to do them some good is a trap we need to avoid.

Senator CLINTON. Dr. Winn.

Dr. WINN. I would agree with Dr. Jackson about what you do when you have information from tests, and how you communicate risks to individuals, and what can they do with that information. It will require a fair bit of research to understand how to do that and how to do it properly.

I think it's going to be a while before we can, in some systematic way, link major surveillance systems that look at cancer morbidity and mortality with surveillance systems that look at the environment. It's been an incredible challenge to create the Long Island geographic information system. It's a huge statistical and informatics effort. It will be important to try and develop systems like it more easily and develop systems to do that much better, so that they can be used much more broadly and provide information much more rapidly.

Senator CLINTON. Dr. Wilson, you answered this question, would you also respond a little bit to what Congressman Ackerman said about citizen-based participatory research, and maybe talk a little bit about what you're doing in your lab? I really do think that the women and the men of Long Island, particularly the breast cancer activists, created citizen-based participatory research. All the women in this room and so many others on Long Island has a major role in changing how we do medical research. So would you just comment on that?

Dr. WILSON. Let me comment on that first. I think this change in style of conducting research, if you will, is really a major step forward in the biomedical research community. In our experience at our institute at NIH, we have supported for some time 55 centers of excellence. We have worked to foster community outreach programs in these centers. All 55 of them currently have active community outreach programs.

In some of the centers, community groups are actually participating in the day-to-day conduct of research. The groups are helping to set priorities on what should be looked at, and helping in reviewing results and coming up with the models for publication of results. We're extremely impressed with the way this program is working and have begun to fund additional community-based pro-

grams to conduct research on their own, so to speak, without the direct linkage to a university.

This style of research, I think, is one of the most effective new techniques we have come across in the overall strategy of the best ways to deal with environmental-health science research.

Moving on to this question by Representative King, I think that the trend of individualized risk assessment, so that we would be able to take our individual risks under consideration as we make choices about lifestyle and environmental exposures and so on, is a trend that we're already seeing and we'll see much more of just in the next 5 years. I agree with Dr. Jackson and Dr. Winn that it will be some time beyond that time period before we truly understand this concept of gene-environment interactions, in order go be able to make more robust use of it.

But in the next 5 years, we will have this type of information on individual risk as a function of our individual gene makeup and our individual exposures that will make a big difference in how we conduct medicine and also how we make personal choices about lifestyle.

Senator CLINTON. Dr. Goldman.

Dr. GOLDMAN. Yes, first to the issue of the individual risk assessment, that's an area I think that is around the corner, as has been said by others. In fact, I think Congress is going to need to look at it very carefully in terms of making sure that this is done in a multidisciplinary way, and that the way the information is communicated to people is understandable to them and that they actually are encouraged by it to take the right actions to protect themselves.

I think that there are some real uncertainties about how this kind of information will actually be used by patients when it's provided to them. Then again, when we don't know what the triggers are, if you have information that maybe you have a genetic susceptibility, but you don't know what triggers it in the environment, what is that going to mean to you? What is that going to do in terms of influencing your behavior and how are you going to them change your lifestyle? Maybe people will throw up their hands and say, "I don't know what to do about it, since you're not telling me, well, then, what steps should I take to protect myself."

In terms of the public health issue, the issue of a national public health tracking system, much of that could be achieved in very short order. Much of it we know how to do. It's just a matter of deploying troops, putting in place the leadership, putting in place the methodology to do it. It's been more of a matter of not having those troops and that leadership and the efforts in place.

Dr. Jackson mentioned the fact that a lot of new laboratory procedures might need to be developed over time. There it's very difficult to predict. I remember 10 years ago when we were first talking about mapping the human genome as being a much longer term project than it was at the end of the day. I think it's very difficult to predict, when you allow scientists to be creative in coming up with solutions to the problem, how long it will take them to solve the problem. It could take a very long time by curing cancer, yes. But it could also take a shorter time than we think it will. I think what's important is getting people started on the task of trying to solve that, which we haven't done.

Senator CLINTON. Thank you very much. As Congresswoman McCarthy whispered to me, the privacy issues around this are very difficult, the insurance issues are mind-boggling. As we all learn that we are each of us susceptible to something, that means we are all uninsurable which of course leads me to suggest that we have insurance for everyone, but that's an issue for another field hearing in the future.

I also wanted to point out that in Senator Reid's and Senator Chafee's legislation on breast cancer and environmental research, it includes a specific provision for citizen participation. I think Gail Frankel had addressed that. So we're beginning to see some real results from a lot of this work. We just really have to accelerate our efforts, so we can get where we need to go a little faster.

Congressman Grucci.

Mr. GRUCCI. Thank you, Senator.

Dr. Winn, I'm looking at the chart that you have in your Power Point presentation. It's very striking that the northeast is an area of heavy concentration. The farther south you go and the farther west you go, there's less and less reported mortality rates for breast cancer.

When you go to the west, obviously you have the farm belt, and then you go down to the south and you have the oil fields and the oil refineries, and you move farther west, you have the area where we did our nuclear research, and explosions on surface and subsurface. In your opinion, why wouldn't you think there would be a bigger concentration out in those areas? I know one of the things we've always been concerned about here on Long Island is because it was a farming area, and it still is an agricultural area as you go farther out east. We were concerned about the chemicals that were being put on the ground to either ward off the pests or help grow the product.

Why wouldn't you think that there would be some more red in those areas of the country where I just pointed out?

Dr. WINN. If some of these chemicals are associated with breast cancer, it could simply be that there might be so much more land out there that some of the potential sources of toxic substances are less likely to be in contact with individuals compared to, say, the northeastern United States, which is very densely populated and potential exposures may be nearer to population centers. It could also have something to do with some of the reproductive patterns that are known to be associated with breast cancer as well. If women outside of the northeast are less likely to have some of the reproductive risk factors, then that might be a reason why there might not be an excess there.

Mr. GRUCCI. It just seems very striking that it's all concentrated up in the northeast, which leads me to believe that we have to work harder up here in order to convince our colleagues in the south and west that this is a priority issue and ought to be a priority issue. I just would point that out. In our dialog, as we go forward in determining how to spend the moneys that are coming into Washington, I think that we can do a lot with the resources that are there.

But as you look to the south and to the west, this issue doesn't rise to the top. We need to be more focused on making that happen.

I think working in concert with our other colleagues, Republicans and Democrats, to the south and to the west of us, would be very helpful in making that happen.

Dr. WINN. The maps are based on mortality rates and mortality rates are influenced by the stage at which cancers are diagnosed. If in the northeast women are diagnosed at a more advanced stage than women elsewhere, then the high mortality rates in the northeast may reflect that. So some of the factors that affect staging and treatment might also come into play.

Senator CLINTON. Dr. Goldman, did you want to respond?

Dr. GOLDMAN. Yes, I think there are two things to think about, and one is, as the ex-environmental epidemiologist from California, I'd like to point out that a couple of areas that look small on the map have a lot in them. There's San Francisco, there's Sacramento, the Los Angeles area, also share those higher rates.

But the other thing is that perhaps the exposures that are related to breast cancer are more intense in the northeast and Great Lakes area, and certain California areas. But that doesn't mean that those exposures aren't also responsible for breast cancer in other parts of the country. So by looking at places that are higher, that enables you to perhaps identify exposures that you can then use as a basis for fighting breast cancer in the whole country. It just so happens those are the places where you can really perhaps hone in and study those exposures, because you see higher rates there.

So that ought to be the way you have everybody be, and say, "yes, we want to prevent this disease," so let's look at it here.

Mr. GRUCCI. I totally agree with you, and I'm just suggesting that when others look at this map from around the country, the issues that we're seeing here, the clusters that we've having and the high rate of breast cancer, all cancer in general, if it's not being seen elsewhere, this is not going to be a priority. I would just suggest that we need to stay focused, that any help they can give us, whether it's supporting this legislation or additional legislation that needs to come down is going to be very important.

Senator CLINTON. Congressman Israel.

Mr. ISRAEL. Thank you, and because I'm last up, before I ask my question, let me again thank Senator Clinton for her leadership in bringing this hearing here. We will cross party lines on this issue.

Dr. Winn, in your testimony you discuss what you call a new NCI tool, the geographic information system to allow for the examination and tracking of cancer rates. I would just ask you to explain how that would fit into Dr. Goldman's recommendation for a nationwide health tracking system. Then I'll ask Dr. Goldman to comment on that.

Dr. WINN. This geographic information system links environmental exposures with health outcomes. We are very concerned about privacy. If you're looking at the web site and you're trying to analyze environment and cancer relationships you can't actually identify individual people, so this system is not really useful in a clinical setting or for helping an individual person with their health choices and helping them control their environmental exposures. It's more a system of surveillance and an analytical tool, rather than something that can be used to help specific individuals.

Dr. GOLDMAN. I think it very much would fit in. I think that just as we want to map the human genome, we want to map exposures and rates of chronic disease. That provides very valuable clues, just as with these breast cancer maps we see, some very valuable clues to what might be involved with causation of breast cancer.

I can also say that privacy protection was one of the recommendations of the Pew Environmental Health Commission, as part of the national health tracking system. The public health system has a very strong record of privacy protection. But if you're going to expand tracking, you need to expand those protections. There are ways to do that, to collect the information, to keep the information that can allow the identification of individuals out of the hands of anybody who might misuse it, whether it's an insurance company or a sales person or whoever.

Senator CLINTON. Well, I want to thank the panel very much. There may be additional questions that we will want to submit to the panelists, and particularly this last panel. There are a number of issues that I think may have arisen during the course of the hearing that we want further expert advice on.

I know that many of the issues that we've raised today are ones that are not easily answerable. But I don't think that excuses us from making our best efforts at trying to answer them. What has struck me since I've been looking into the whole question of chronic disease and cancer clusters is how little we really have done in a concerted way to try to find answers. We have had an under-resourced public health system, we have not given the kind of support on the chronic disease side that we did with respect to infectious and communicable diseases.

I think now is the time, and why this hearing is so important, and why the previous hearing in Fallon and the hearing I just participated in last week in the Senate on cancer clusters all are leading us to the awareness that now is the time for us to act. There are certain questions that rise to the level of urgency and you have to respond or then you're going to be, I think, accused of negligence or irresponsibility for failing to respond.

It just may be that all of the stars are in alignment, that these are the issues that we now can address and try to find solutions for. I personally think that the work that Dr. Goldman and her colleagues did with the Pew Trust Health Track Project gives us a good road map. That was a very long study. It looked at the resources available in the public sector and where we were lacking. I think that the delegation from New York, which does, as Congressman Grucci has said, has a very specific interest in this, we can lead the way.

But this is not just a New York or northeast problem. Although the intensity may be greater in some parts of the country, this is a national problem. Although cancer, and certain kinds of cancer, may be more prevalent in certain parts of our Nation, other chronic diseases are increasingly prevalent in other parts of our Nation. So this kind of mapping will give us information that will help everyone. Certainly as mobile a Nation as we are, as we move from place to place, this is information that citizens have a right to know.

So I really believe we can make the case that this is important for our entire country, important specifically for the needs of our

public health system, but most importantly for the well being and health of ourselves but particularly our children, since we've heard a lot today about the impact of all of these exposures and environmental factors when it comes to our children.

I think it's also important that we also set out what our individual responsibility might be and begin to think about approaching health from that perspective. It is an individual responsibility to stop smoking. It is an individual responsibility to be as careful as we can, insofar as we know, about our own diet. But an individual cannot really take responsibility for the exposures in our air and our water and our food that we don't have any direct control over. It's not something we in our individual family behind closed doors in our house can control.

So we have to have a very clear understanding of what we expect the individual to do as we gather information, and how we try to create some systems of accountability that will say to individuals, you know, if you are going to smoke and exposure yourself and your family members to tobacco, there is not only a risk but a cost associated with that. Then we have to do the best job we can to map out and get our more collective risks well know, so that we can take community action, national action against them.

I think it's very exciting that we're at this point where we can be actually thinking about this.

So I want to thank all of the panel members. If you have any last thoughts you'd like to leave us with, anyone have a last word?

Then we'll keep the record open for 2 weeks. Anyone who has additional testimony to submit, we welcome that. We will also be asking additional questions to clarify the record.

I want to thank my colleagues from New York who joined in this hearing. I want to thank especially our host, Congresswoman Carolyn McCarthy, Congressman Ackerman, Congressman King, Congressman Grucci and Congressman Israel. I particularly want to thank my two fellow Senators, Senator Reid, who is currently the Chairman of the Environment and Public Works Committee, but that may change in the next days, as it is likely that Senator Jeffords will chair this important committee. Senator Jeffords shares our concern about a lot of the issues.

I particularly want to thank Senator Chafee from one of our northeast neighbors, Rhode Island, where he has seen firsthand in this public service, having been in elective office, even though he looks so very young, in elective office for a long time, including being mayor of a city. He has seen the challenges to our public health system and takes very seriously the environmental concerns that we've been addressing.

So it's been a great pleasure to have you. I want to thank Adelphi for doing so much to make this important hearing possible, in addition to their ongoing educational mission, the breast cancer hotline and support program. They're on the forefront of doing a lot of environmental work, adding a masters in environmental studies, which is particularly appropriate for those who live on Long Island to be able to engage in this study right here at Adelphi.

Mr. ACKERMAN. Senator, if I can assume a prerogative, on behalf of the entire Long Island delegation, all of whom are here sitting right through the final gavel, to thank the Senate Committee for

coming here and bringing this hearing to Long Island. We especially want to thank you, and congratulate you first of all, I believe that this is the very first hearing that you have actually chaired as a member of the U.S. Senate. You have made us all very, very proud, and thank you for helping to make us all well.

[Applause.]

Senator CLINTON. The hearing is adjourned.

[Whereupon, the committee was adjourned, to reconvene at the call of the chair.]

[Additional materials submitted for the record follow:]

STATEMENT OF NYS ASSEMBLYMAN THOMAS P. DINAPOLI, THE ASSEMBLY STATE OF NEW YORK, ALBANY

I want to thank our own U.S. Senator, Hillary Clinton, the new Senate Majority Whip, Harry Reid, Senator Chafee, members of our Long Island congressional Delegation, and all of the members of the Senate "Cancer Coalition," for taking the lead in examining the possible connection between the quality of the environment and the health of the public.

I share your concern regarding the incidence of cancers and other serious medical conditions here on Long Island and across the country and their possible environmental connections. I applaud your efforts to address these concerns in forums and hearings such as this.

It is difficult to narrow down the environmental variables, which increase the possibility of greater health risk. However, it has been my privilege to work with so many dedicated and outstanding Long Island leaders and advocates—many will be addressing you today—who are fighting to address a number of issues which have environmental impact and which evidence strongly indicates have associated—often long-term—health impacts.

I would like to take a few minutes to talk about the steps that we are taking in New York State toward reducing the use of and exposure to potential harmful environmental conditions.

I believe many of these actions could be aided and supplemented by the Federal Government through the creation of a stronger partnership of public and private activities to address these growing concerns.

Last year, your colleague Senator Charles Schumer provided $1 million, through the Environmental Protection Agency (EPA), to enhance New York State efforts in mapping MtBE spills so that we can more effectively address these spills. This initiative was just the beginning of what needs to be done to map environmental hazards in New York State.

A few years ago, the New York State Legislature appropriated $1,000,000 to the State Health Department for cancer cluster mapping. Following a gubernatorial veto, the administration instead indicated it would provide cancer mapping administratively, through the Department of Health (DOH).

To many observers, the DOH process has produced maps that lack sufficient detail to provide the citizens of the State with usable and accurate cancer information.

The NYS Assembly subsequently introduced legislation (A. 404) mandating that the New York State Department of Environmental Conservation (DEC) and the Department of Health jointly develop a comprehensive computer-based environmental facility/cancer incidence map plotting system. The legislation requires these agencies to provide detailed information regarding environmental facilities and reported cancer incidences by census block throughout the State. Environmental facilities include sewage plants, hazardous waste facilities, factories and power plants that emit air pollution, and Superfund sites. This data will help researchers and the public look for, analyze and better understand the connection between environmental pollution and cancer rates in the general population.

There have also been efforts at the Federal level to provide accurate information regarding environmental facilities through environmental mapping web sites. The Federal Housing and Urban Development Agency and the EPA maintain environmental-mapping capabilities that identify environmental facilities including the facility name, address, environmental compliance history, chemicals released and permitted emission levels. These efforts are valuable models that could and should be implemented at the State level.

Currently the State Department of Environmental Conservation is attempting to implement a similarly informative web site service. The information available via the DEC web site is limited in that it only provides the identification of a facility

at a street address. It does not provide detailed information such as the facility name, type, what chemicals are being emitted, levels of emission, or compliance history.

We believe the Federal Government through funding and technical assistance could help New York develop a much-needed comprehensive mapping capability. This is an obvious compliment to the National Institute of Health's ongoing breast cancer study.

While these mapping and research efforts are developing, there are other activities that we can take to reduce exposure to contaminants and toxic materials in our environment.

An important issue where the Federal Government should join with New York—and California—is to immediately move to set a schedule toward banning the use of the gasoline oxygenate, MtBE.

In 1999, New York State sent a resolution to Congress, calling for a ban of this oxygenate, which is proven to pollute surface and groundwater supplies. While Congress has not yet acted, last year New York State passed the first law in the Nation that bans the use of this contaminant in gasoline sold in our State as of January 1, 2004.

The use of MtBE originated in the effort to reduce air pollution caused by motor vehicles. MtBE was listed as a possible human carcinogen, and unfortunately, as a result of numerous spills, leaks and atmospheric deposition, it has become a ubiquitous contaminant in surface and groundwater throughout New York. On Long Island, for example, it has been detected in 63 of Nassau County's monitoring wells, 55 public supply wells, and more than 250 private wells. The chemical has been discovered at approximately 500 sites on Long Island where spills and leaks involving gasoline have occurred.

This new law was challenged in court by the Oxygenated Fuels Association, but just last week we were pleased to hear that the Federal court upheld this law. (Federal District Court Judge Norman Mordue ruled that the Clean Air Act's preemption of State laws for the purposes of motor vehicle emission control does not apply to this New York State law, which is a public health measure designed to protect drinking water quality in the State.)

This is an important victory in our continuing efforts to protect drinking water in New York State as MtBE has been classified by EPA as a possible human carcinogen, and enters groundwater through leaking vehicle gasoline tanks, pipelines, overfilling of tanks, and automobile accidents. The sandy soils of Long Island are particularly vulnerable to MtBE contamination.

I stand before you today to once again call upon Congress to follow the path set by New York and California, and ban the use of MtBE in gasoline to prevent the serious public health, safety, and environmental and economic implications that are associated with continued long-term use of MtBE.

Last year—after 7 years of trying—New York enacted the most comprehensive pesticide notification legislation in the Nation. This law requires schools and daycare facilities to establish a pesticide application notification procedure, including notifying parents of their right to be informed 48 hours before pesticides are applied at these facilities. It also allows counties to adopt a local law requiring notification of neighbors before pesticides are commercially applied on adjacent properties and requiring homeowners to flag their yard after applying pesticides themselves.

As a society we need to move away from the widespread use of (several million pounds per year) pesticides and the dependence on toxic and hazardous chemicals in our quest for the greenest lawns, weed free gardens, and elimination of pests and insects. Alternatively, we must find ways, and provide the educational and financial resources to reduce our dependence on these chemicals (i.e. IPM programs) and move to non-toxic products, alternative mechanisms, and a greater focus on preventive techniques.

I am optimistic that through a number of provisions contained in the "Pesticide Neighbor Notification Act" the public will gain a better understanding of the chemicals and contaminants that make-up the pesticides, fertilizers, and herbicides that are being poured, placed, and sprayed around us. This type of public right to know legislation is worthy of replication throughout the country.

There are two other initiatives that are before the State Legislature that I believe people throughout the country, particularly our youngest and frailest citizens, would benefit from and which could be enhanced with Federal support:

Here in New York and throughout the northeastern region, local governments have been struggling to eliminate mosquitoes and control the spread of West Nile Virus. However, too many localities have focused too much of their efforts on aerial or ground spraying to control mosquito populations. More proactive methods of combating the spread of the virus including surveillance, public education, environ-

mental monitoring and non-spraying vector control have received inadequate attention.

If enacted, legislation (A. 7320) would provide a 75 percent match for county expenditures of up to $100,000 (from the current maximum of $5,000) for surveillance and monitoring and up to $200,000 (from the current maximum of $50,000) for non-spraying vector control activities.

As regions of the country have specific concerns where pesticide control is necessary, by providing an increased level of funding, the Federal Government can will help ensure that the health threat is addressed by providing an incentive to avoid the widespread spraying of pesticides when less toxic means are available.

The second bill that I would like to call to your attention also uses financial aid as an incentive to change current practices.

I am currently working with 1 in 9: The Long Island Breast Cancer Action Coalition on legislation (A. 8672) entitled, "The Children's Health Incentive Fund." This legislation would provide school districts with financial aid to help them move away from the use of harmful chemicals in the buildings where our children learn and on the fields on which they play. The bill is designed to offer State funds as an incentive for school districts to use non-toxic products and practices as alternatives to using potentially dangerous pesticides, fertilizers, and herbicides in and around our schools.

While many of the environmentally sensitive products are more expensive and some alternative practices take more time, by offering financial help to the 700 plus school districts in New York to use safer products and practices, our children, school personnel, and the environment will benefit from reduced exposure to potentially dangerous, toxic, and hazardous chemicals.

I thank you for your interest in this most important matter and I am grateful for your consideration and examination of the Long Island community.

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NEW YORK STATE ASSEMBLY BILL NO. 7320

2001–2002 REGULAR SESSIONS

MARCH 21, 2001

INTRODUCED BY M. OF A. DINAPOLI, WEISENBERG, GLICK, COLMAN, HOOPER, SCHIMMINGER, DAVIS, GALEF—MULTI-SPONSORED BY—M. OF A.A. COHEN, COLTON, GROMACK, JACOBS, MCENENY, SANDERS, WRIGHT—READ ONCE AND REFERRED TO THE COMMITTEE ON HEALTH

AN ACT to amend the public health law, in relation to amount of State aid given for mosquito control

The People of the State of New York, Represented in Senate and Assembly, Do Enact as Follows:

Section 1. Section 611 of the public health law, as added by chapter 901 of the laws of 1986, is amended to read as follows:

S 611. State aid; mosquito and vector control. 1. Where a county or municipal agency designated by the county health department or part county department of health conducts a mosquito and vector {control} surveillance program approved by the department OR CONDUCTS ENVIRONMENTAL MONITORING PURSUANT TO PARAGRAPH (C) OF SUBDIVISION FOUR OF THIS SECTION, it shall be provided State aid reimbursement at {the same percentage rate as basic public health services are reimbursed under paragraph (a) of subdivision two of section six hundred five of this article} A RATE OF SEVENTY-FIVE PERCENT, provided however that, the total State aid reimbursement provided pursuant to this section to such county or municipal agency shall not exceed {five} ONE HUNDRED thousand dollars. The reimbursement provided pursuant to this section shall be made from funds appropriated for the operation of local health departments pursuant to title one of this article.

2. Where a county or municipal agency designated by a county health department or a part-county health department conducts a mosquito and vector control program approved by the department, it shall be provided State aid reimbursement at {the same percentage rate as basic public health services are reimbursed under paragraph (a) of subdivision two of section six hundred five of this article} A RATE OF SEVENTY-FIVE PERCENT, provided however, that the total State aid reimbursement provided pursuant to this section to such county or municipal agency shall not exceed {fifty} TWO HUNDRED thousand dollars. The reimbursement provided pur-

suant to this section shall be made from funds appropriated for the operation of local health departments pursuant to title one of this article AND SHALL BE PROVIDED ONLY FOR THE FOLLOWING ACTIVITIES:

(A) ACTIONS UNDERTAKEN TO EDUCATE THE GENERAL PUBLIC ABOUT TECHNIQUES AND STRATEGIES THEY CAN TAKE TO CONTROL MOSQUITO AND VECTOR BREEDING ACTIVITIES ON PROPERTIES THEY OWN OR INHABIT AND ACTIONS UNDERTAKEN TO EDUCATE THE GENERAL PUBLIC ABOUT THE HEALTH AND ENVIRONMENTAL IMPACTS ASSOCIATED WITH PESTICIDE USED FOR MOSQUITO AND VECTOR CONTROL; OR

(B) ACTIONS UNDERTAKEN TO REDUCE MOSQUITO AND VECTOR BREEDING INCLUDING: THE USE OF BIOLOGICAL CONTROL AGENTS SUCH AS, BUT NOT LIMITED TO, MOSQUITO EATING FISH AND PREDATORY INSECTS SUCH AS DRAGONFLIES; THE MODIFICATION AND MANAGEMENT OF MOSQUITO AND VECTOR BREEDING HABITATS; THE USE OF LARVICIDES THAT ARE BIOPESTICIDES THAT ARE REGISTERED PURSUANT TO TITLE SEVEN OF ARTICLE THIRTY-THREE OF THE ENVIRONMENTAL CONSERVATION LAW; AND THE USE OF ALTERNATIVE TECHNOLOGIES SUCH AS, BUT NOT LIMITED TO, MOSQUITO TRAPS.

3. Under {emergency situations} A PUBLIC HEALTH THREAT DECLARATION, the department shall reimburse counties or municipalities at the same percentage rate as basic public health services are reimbursed under paragraph (a) of subdivision two of section six hundred five of this article for the cost of emergency vector control measures as approved by the department. {Such funds shall be made available from funds appropriated for the operation of local health departments, only to those counties or municipalities which have expended all other State aid which may be available for mosquito and vector control and surveillance programs.}

4. ANY FUNDS REIMBURSED BY THE DEPARTMENT FOR ACTIONS RELATED TO WEST NILE VIRUS PURSUANT TO PARAGRAPH (B) OF SUBDIVISION TWO AND/OR SUBDIVISION THREE OF THIS SECTION SHALL BE RELEASED ONLY UPON AN AFFIRMATIVE FINDING THAT:

(A) THE ACTIONS ARE CONSISTENT WITH THE NEW YORK STATE WEST NILE VIRUS RESPONSE PLAN;

(B) THE ACTIONS COMPLY WITH ALL PESTICIDE PERMITS, PRODUCT REGISTRATION AND LABELING PROVISIONS;

(C) THE ACTIONS ARE COUPLED WITH AN ENVIRONMENTAL MONITORING PROTOCOL THAT DOCUMENTS THE EFFICACY OF THE ACTION AND THE DEGREE AND TYPE OF IMPACTS THAT OCCUR IN HUMANS AND OTHER NON-TARGET SPECIES AND ENVIRONMENTAL QUALITY; AND

(D) NOTWITHSTANDING ANY PROVISION OF LAW TO THE CONTRARY, ANY ACTIONS THAT WOULD OTHERWISE REQUIRE AN AQUATIC PESTICIDE PERMIT OR FRESHWATER WETLAND PERMIT, SHALL BE CARRIED OUT PURSUANT TO SUCH PERMIT UNDER A PUBLIC HEALTH THREAT DECLARATION.

S 2. This act shall take effect immediately.

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NEW YORK STATE ASSEMBLY BILL NO. 8672

2001–2002 REGULAR SESSIONS

MAY 7, 2001

Introduced by Committee on Rules—(at request of M. of A. DiNapoli, Wright, Lavelle, Canestrari, Christensen, Colton, Davis, Eddington, Englebright, Gordon, Gromack, Hooper, Matusow, Mayersohn, McEneny, Millman, Nolan, Pheffer, Sidikman, Sweeney, Weinstein, Weisenberg)—read once and referred to the Committee on Health

AN ACT to amend the State finance law, in relation to establishing the children's health incentive fund; and making an appropriation therefor

The people of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Legislative findings. The legislature hereby finds that a significant amount of potentially dangerous chemicals are being used in and around our State's public schools. Exposure to environmental chemicals at school during critical developmental periods has been linked to childhood cancers, asthma, learning disabil-

ities, and hyperactive behavior disorders. Both synthetic pesticides and chemical fertilizers are being used in large quantities in and around our schools. Many of these chemicals are known to cause a variety of illnesses and effect the environment adversely. Absent an incentive-based program to use least toxic pesticides and low leaching fertilizers, our children will continue to be exposed to potentially dangerous chemicals. The children's health incentive fund will enable schools to transition to better management practices with least toxic products.

Cutting edge pest control products and natural fertilizers are now available on the market. However, these products are often more expensive to purchase and use. By offering incentives to school districts to adopt these products and practices, the children of New York State and the environment will have reduced exposure to potentially dangerous pesticides and fertilizers.

S 2. The State finance law is amended by adding a new section 83-a to read as follows:

S 83–A. Children's Health Incentive Fund.

1. There is hereby established in the custody of the State Comptroller and the Department of Environmental Conservation a fund to be known as the "Children's Health Incentive Fund" which shall provide a mechanism to reduce chemical exposure in schools. Such fund shall provide a monetary incentive to schools for the use of least toxic pest control products and fertilizers.

2. The fund shall consist of all monies appropriated for its purpose and shall be paid out on the audit and warrant of the State Comptroller on vouchers certified or approved by the Commissioner of the Department of Environmental Conservation for amounts up to ninety cents per full-time enrolled student annually for the purchase of least toxic pest control products and fertilizers by each school district, Board of Cooperative Educational Services, charter school, private school or parochial school. Annually, in order to qualify to receive monies from this fund, the school district, Board of Cooperative Educational Services, charter school, private school or parochial school shall submit receipts for these products and any other records or forms required by such department pursuant to rules and regulations.

3. The Commissioner of the Department of Environmental Conservation shall promulgate rules and regulations specifying products eligible to receive monies from this fund. Such products shall include only the following:

(A) Low-Water solubility and slow-release, fertilizers, soil conditioners and compost where low-water solubility means thirty percent or more of total nitrogen shall be water insoluble or controlled release. Fertilizers, soil conditioners and compost derived from or comprised of human sewage sludge or septage shall not be eligible to receive monies from this fund;

(B) Nonvolatile rodenticides in tamper resistant bait stations;

(C) Silica gels that do not contain synthetic pesticides or synergists;

(D) Pesticides classified by the United States Environmental Protection Agency as an exempt material under 40 C.F.R. PART 152.25;

(E) Boric acid; and

(F) Horticultural oils that do not contain synthetic pesticides or synergists and that are not petroleum-based.

S 3. The sum of three million dollars ($3,000,000), or so much thereof as may be necessary, is hereby appropriated out of any moneys in the State treasury in the general fund to the credit of the State purposes account not otherwise appropriated to the department of environmental conservation for the purpose of complying with the provisions of section two of this act. Such funds shall be payable upon the audit and warrant of the State comptroller on vouchers certified or approved by the commissioner of environmental conservation or his or her duly designated representative in the manner prescribed by law.

S 4. This act shall take effect immediately and apply to school years beginning on or after July 1, 2001.

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STATEMENT OF PHILIP J. LANDRIGAN, M.D., M.SC., ETHEL H. WISE PROFESSOR AND CHAIR, DEPARTMENT OF COMMUNITY AND PREVENTATIVE MEDICINE, PROFESSOR OF PEDIATRICS, DIRECTOR, CENTER FOR CHILDREN'S HEALTH AND THE ENVIRONMENT, MOUNT SINAI SCHOOL OF MEDICINE, NEW YORK, NY

Chairman Reid, Senator Clinton, and members of the New York congressional delegation, I am pleased to appear before you today to discuss rising rates of cancer and other chronic diseases in the American population and the linkages between cancer and the environment.

I would like also to discuss with you a blueprint for substantially reducing cancer rates in this Nation. The centerpiece of this plan will be the construction of a strong

national capacity in public health and preventive medicine that will enable us to locate, track, understand and prevent the environmental causes of cancer.[1]

My name is Philip J. Landrigan, M.D. I am Chair of the Department of Community and Preventive Medicine and Professor of Pediatrics at the Mount Sinai School of Medicine in New York City. I direct the Center for Children's Health and the Environment at Mount Sinai, a policy research center supported by The Pew Charitable Trusts. I am a pediatrician and epidemiologist.

RISING RATES OF CHRONIC DISEASE IN THE AMERICAN POPULATION

Today, the leading causes of illness and death in the United States are chronic diseases and injuries.[2] Rates of asthma have more than doubled. Incidence of certain birth defects of the reproductive organs such as hypospadias have doubled. Neurodevelopmental disorders such as dyslexia, attention deficit/hyperactivity disorder (ADHD) and autism are highly prevalent and cause untold misery to children and their families. Chronic diseases of the brain and central nervous system such as Parkinson's disease have increased in frequency.

Cancer is a particular problem. Cancer will kill approximately 550,000 people in the United States this year, according to the American Cancer Society. Cancer is the second leading cause of death, exceeded only by heart disease. It is the second leading cause of lost years of potential life.[3]

Breast cancer is a major problem in New York and across the Nation. An estimated 182,000 cases of breast cancer are expected to be diagnosed this year among American women, and about 1,400 new cases of breast cancer are expected to be diagnosed in men.[3] Rates of breast cancer have risen in the United States, and the cumulative increase in incidence since the early 1970's has been more than 40 percent.

Pediatric cancer is another major problem. An estimated 12,400 children and young people will be diagnosed with cancer in the United States in the year 2001. Cancer is the third most common cause of death in American children, exceeded only by unintentional injuries and homicide. Thus it is the leading cause of death from disease in our young people. The two most common forms of childhood malignancy are leukemia and brain cancer, and together these two diseases account for about two-thirds of pediatric cancer.[4] Although death rates for childhood cancer are down, thanks to early detection and vastly improved treatment, the reported incidence, i.e., the number of new cases of cancer per million children has increased over the past two decades please see attached graphs).[4]

For acute lymphoblastic leukemia (ALL), the most common pediatric malignancy, incidence increased from 23.1 cases per million children in the early 1970's to a peak of 28.2 per million in the 1980's, and then declined somewhat to a level of 26.8 per million in 1996. This represents an overall increase since the early 1970's of about 12 percent, an increase that is statistically significant.[4]

For primary brain cancer (glioma), a sharp and statistically significant increase in incidence has been noted from 23 cases per million children in the early 1970's to 29.0 per million in the late 1990's. This represents an overall increase in incidence over the past three decades of nearly 30 percent, an increase that is statistically quite significant.[3]

For testicular cancer, incidence in young men 15–30 years of age has increased over the past 30 years by 68 percent. This increase occurred entirely in white men, and was not seen in black men. It is statistically highly significant.[5]

The causes of these increases in cancer are incompletely understood Some have argued that better diagnostic detection and changing definitions of cancer may account for a major fraction of the increase.[6] I would agree that new diagnostic technologies have made some contribution to reported increases in cancer incidence, but I cannot agree that it is the whole story. I would point out that childhood cancer is not a subtle disease. Sadly, it is a devastating and extremely serious illness. It makes children terribly ill, arid it brings them to the hospital. Thus it seems unlikely to me that large numbers of children with cancer would have escaped medical detection only 25 years ago, at a time when many doctors of my generation were already practicing pediatrics.

A further argument against the notion that better diagnostic detection accounts for the entire reported increase in childhood cancer is that any increase due to better diagnosis would have produced only a temporary rise in reported incidence at the time of introduction of the new technology, reflecting diagnosis at an earlier stage of illness. That temporary increase would then be expected to be followed by a return to baseline. In fact, however, no such return to baseline incidence of childhood brain cancer has occurred in the United States over the past 30 years. In fact, the incidence rate for childhood brain cancer has continued to rise inexorably, and

this upward trend is seen in both boys and girls in all regions of the United States.[7] These facts argue that most of the reported rise in incidence of childhood cancer is a real increase.

It is highly likely that environmental toxins in air, food, dust, soil and drinking water have contributed to increasing rates of cancer in Americans of all ages, including our children. The known and suspected causes of childhood cancer include benzene, other solvents, radiation, arsenic, parental smoking, certain pesticides and certain chemicals in the environment that have the potential to disrupt the function of the endocrine system. Maternal consumption during pregnancy of cured meats containing nitrites, such as sausage and bacon has been shown to increase risk of childhood brain cancer. There are also protective factors. Maternal consumption of folic acid during pregnancy, and the practice of nursing an infant appear to be protective factors that can reduce incidence of childhood cancer. Those facts are signs of hope.

CANCER AND THE ENVIRONMENT—AN HISTORICAL PERSPECTIVE

Considerable progress toward cancer control has stemmed from the recognition that chemical agents in the environment can cause cancer.[8] In 1775, Sir Percivall Pott, a British surgeon, reported for the first time an association between childhood cancer and an environmental agent.[9] Pott noted that the "climbing boys of London", teenage lads employed as chimney sweeps, experienced a devastating incidence of cancer of the scrotum. He correctly attributed the development of those tumors to occupational exposure to soot. In 1895, Rehn noted a high frequency of cancer of the urinary bladder among workers in the aniline dye industry.[10] He attributed the causation of those tumors to aromatic amines. More recently etiologic associations have been recognized between benzene and leukemia,[11] asbestos and lung cancer,[12] bischloromethylether and lung cancer,[13] vinyl chloride monomer and angiosarcoma of the liver,[14] tobacco and lung cancer,[15] and chewing tobacco and cancer of the mouth.[16]

Toxicologic studies stimulated by those clinical and epidemiologic observations have led to fundamental advances in the understanding of cancer biology. Benzo(a)pyrene, a polynuclear aromatic hydrocarbon compound found in soot, has been found to induce skin cancer in experimental animals.[17] That finding provides a molecular basis for Pott's observations of the link between soot and scrotal cancer. Likewise β-naphthylamine, a chemical found in aniline dye manufacture, has been shown to cause cancer of the bladder in experimental animals, thus providing an explanation for the observation of Rehn.[18] Chemical carcinogens found in tobacco and tobacco smoke provide a biological basis for the observation that cigarette smoking causes lung cancer and that chewing tobacco causes cancer of the month and oropharynx.

Common themes that run through these tales of discovery are an (1) the importance of tracking data on cancer incidence, (2) an openness to the possibility that environmental factors can cause cancer and (3) a willingness to pursue clinical and epidemiologic observations to discover the biological mechanisms by which environmental agents cause malignancy.

The recognition of environmental carcinogenesis has had a profound influence on our understanding of human cancer. No longer must cancer be regarded as an inescapable consequence of aging or the result of unexplainable "natural forces." Quite the contrary. It is now realized that chemical carcinogenesis is not exceptional and that well over half of human cancers—perhaps as many as 80–90 percent worldwide—are caused by environmental exposures.[19] I should note that in this context "environmental factors" include not only exposures to industrial chemicals and pollutants but also exposures to such factors as diet, alcohol, tobacco, drugs, radiation and sexual behavior.

The concept that the environment is responsible for a great majority of human cancer received strong collaboration in a landmark study published recently from Sweden.[20] This study which examined patterns of cancer in 44,788 pairs of twins found sharp discrepancies in cancer incidence even between identical twins. These differences, even in persons of identical genetic composition, indicate that environment plays a major role in the causation of malignancy.

The most hopeful implication of the discovery of that many thousands of cancer cases are caused by exposures in the environment is that a very high proportion of all human cancer ought to be preventable. Prevention can be accomplished by reducing exposures to environmental carcinogens.[8]

CHEMICAL EXPOSURES IN TODAY'S WORLD

Americans today face environmental hazards that were neither known nor suspected a few decades ago. Americans today are at risk of exposure to over 85,000 synthetic chemicals, most of which have been invented since World War II. Americans are most likely to be exposed to the 28,000 high-production-volume (HPV) chemicals that the U.S. Environmental Protection Agency estimates are produced in quantities of over one million pounds per year.[21] These chemicals are the most widely dispersed in foods, household products, pesticides, air, food and drinking water. The National Academy of Sciences has found that children are the group within the American population most vulnerable to these chemical hazards.[22]

No basic toxicity information is publicly available for 43 percent of the high-production-volume chemicals according to the EPA. And although children are now recognized to be especially vulnerable to chemicals in the environment, only 7 percent of HPV chemicals have been examined for their potential toxicity to children or to human development.[21]

The percentage of cancer in Americans that is caused by toxic chemicals in the environment is not known We do, however, know that many chemicals are proven human carcinogens, that many more are suspected human carcinogens on the basis of animal testing, and that most chemicals have never been tested.

A BLUEPRINT FOR CANCER PREVENTION IN THE UNITED STATES

The following are elements of a comprehensive plan for the prevention of environmental cancer in the United States.

*Disease and exposure tracking.*—It will be essential to continue to provide support to the Centers for Disease Control and Prevention (CDC) and to the National Cancer Institute (NCI) to enable these agencies to monitor the number of cases of cancer and other chronic diseases that occur each year among Americans of all ages and in every part of the country.[1] The tracking of cancer, asthma, birth defects and other chronic diseases has lagged historically behind the tracking of infectious diseases such as measles and smallpox. Now, however, that the chronic diseases have become the major causes of morbidity and mortality in the United States, we must remedy this situation and aim ourselves with accurate information on the temporal and geographic distribution of cancer and other chronic diseases. Such information is essential for targeting prevention.

Also it will be essential to continue to provide support to the CDC to enable CDC to continue each year to monitor the levels of chemicals in the blood of Americans and to make this information available to the public. The combination of information on chemical exposure with data on cancer incidence will undoubtedly spark research that will identify specific preventable environmental causes of cancer and other chronic diseases.

A classic example of the importance of disease tracking to cancer prevention is provided by the story of oral cancer among women in the American South, In the early 1970's the National Cancer Institute published an Atlas of Cancer Mortality by County in the United States. Examination of the maps in this atlas revealed a strikingly high incidence of oral cancer among women across the southeastern United States from Virginia to Texas The cause of that increase was initially not known However, publication of the maps stimulated extensive research, and one of those studies was an epidemiologic investigation undertaken by Dr. Debra Winn. This classic study found an extremely strong association between oral cancer and the use of chewing tobacco.[16] Once this association had been discovered, programs of prevention were put in place. This represents a textbook example of how disease tracking can lead to discovery of the factors responsible for disease and then to prevention.

*Premarket testing* of the toxic and carcinogenic potential all new chemical compounds is a most effective approach to the prevention of environmental disease. Unfortunately, premarket testing has often not been undertaken. A 1984 analysis by the National Research Council showed that most chemical compounds have never been tested for their carcinogenic potential.[23] That unfortunate figure has not improved appreciably in the intervening years, and the number of new chemical substances released into the environment has increased substantially during that time.

In addition to doing more toxicity testing, we also need to develop more sensitive approaches to testing that can reliably detect the long-term consequences of exposures to toxic chemicals in early life. Extensive experiences demonstrated that infants and young children are uniquely vulnerable to certain chemicals that are relatively harmless to adults. To detect the unanticipated consequences of early exposures to such chemicals, it will be necessary to develop new approaches to assay prenatal, perinatal and childhood toxicity. For certain classes of chemicals it may, in

part, be necessary to undertake experimental studies in which chemicals are administered shortly after birth and the experimental subjects then followed over their entire life span.[22] This approach will replicate the human condition in which exposures in the earliest stages in life may produce disease only decades later. It may thus enhance detection of the environmental causes of late illness. Functional tests of neurotoxicity and of immune, endocrine and reproductive toxicity are also need to be much more widely applied then they are at present.

*Right-to-know* is the concept that American families have the right to be informed of the nature and toxic properties of the chemicals that they may encounter in their air, food, drinking water, schools and communities. It is a powerful took for cancer prevention, and it complements and extends the efficacy of regulation.

Right-to-know information empowers families and enables them to take intelligent decisions to reduce their own and their children's exposures to toxic substances Right-to-know has proven an extremely effective means for reducing toxic exposures. For example, EPA's Toxic Release Inventory (TRI) an annual listing of the nature and amounts of toxic chemicals released to the environment by polluting industries in the United States has highlighted those industries that are the worst actors and has resulted in many of these industries' taking aggressive steps to reduce their toxic emissions. Likewise Proposition 65 in California requires manufacturers to list hazardous materials on the labels of consumer products. This labeling requirement has resulted in the removal of many toxic products from the market in California and nationwide.

It will be necessary now to consider development of national right-to-know legislation in the United States that extends to consumers across this Nation the sort of knowledge now available only on the west coast.

*Regulatory standards* issued by the Environmental Protection Agency and the Occupational Safety and Health Administration are an extraordinarily important mechanism for the prevention of environmental cancer. These standards regulate permissible uses of carcinogenic chemicals and establish levels above which workers and the public may not legally be exposed. Standards have brought about substantial reductions in exposures to carcinogens, including asbestos, benzene, vinyl chloride and PCBs. All standards are however, inherently arbitrary—they imply safety when safety does not exist. There is no bright line between the level of exposure to a toxic substance that causes cancer and that which is safe; there is instead a continuum of toxicity. Standards therefore need continually to be re-examined in the light of new data, and when necessary revised.

Traditionally, regulatory standards in this Nation have been built on the assumption that the entire American population is comprised of 70-kilogram young adult males. Estimates of risks have been based on the exposures and the sensitivities of this "average" person, and standards have been set at levels to protect this person's health. The only Federal environmental law that specifically acknowledges the unique sensitivities of infants and children is the Food Quality Protection Act of 1996 This legislation, which governs the use of pesticides in agriculture, requires that standards be set at levels that will specifically protect infants and children from harm to their health In the years ahead, it will be necessary to extend the model of the Food Quality Protection Act to other environmental legislation so that all environmental standards are set at levels that will protect the health of the most vulnerable among us.

*Research.*—A vigorous national research program is an essential element of a comprehensive blueprint for cancer prevention. In this Nation we have traditionally directed the major portion of our cancer research portfolio into discovering new cancer treatments. This approach has yielded great benefits. Death rates from many cancers, in particular pediatric cancers and testicular cancer, have been substantially reduced. Thirty years ago when I was still a pediatric resident, every child with leukemia died of their disease. Today more than three-fourths of children with leukemia survive and live to play another day.

Now it is time to open a second front on the war on cancer. We need to increase substantially our investment in prevention oriented research. It maybe instructive to contrast our approach to cancer research with our approach to research on cardiovascular disease. The national portfolio on Cardiovascular Disease has long emphasized a search for the preventable causes of disease. This tradition began in 1948 when the U.S. Public Health Service established the Framingham Heart Study in Framingham, MA with the specific goal of identifying the preventable causes of heart disease and stroke. The study was initiated in the years after World War II when Americans had returned home to new prosperity, were eating a diet extremely high in cholesterol, were smoking at unprecedentedly high rates and experiencing massively increasing rates of heart disease and stroke. The Framingham Study and other studies like it identified the preventable environmental risk factors for heart

disease such as hypertension, cholesterol, obesity, cigarette smoking, diabetes and sedentary lifestyles. Once these risk factors had been identified, aggressive programs of prevention were put into place. The result has been a reduction in heart disease rates among American men and women of nearly 50 percent over the past five decades. That reduction represents one of the great triumphs of public health in the past half century. We need now to do the same for cancer.

CONCLUSION

Cancer is a complex, multifactorial, profoundly frightening and often deadly disease But also cancer is a preventable disease Many thousands of cancer deaths in this Nation every year are caused by toxins in the environment, and those are cases that can and should be prevented.

Cancer prevention requires a carefully orchestrated, precisely targeted series of programs in prevention and research. These programs can result in enormous reductions in cancer incidence, suffering and death. The challenge before us as a Nation is to craft such programs. We must track disease. We must test chemicals. We must educate and inform our citizens. We must commit to research in cancer prevention resources of the magnitude that we have historically committed to research in cancer treatment. Cancer prevention is cost-effective. Cancer prevention makes sense. And cancer prevention is the right thing to do.

Thank you. I shall be pleased to answer your questions.

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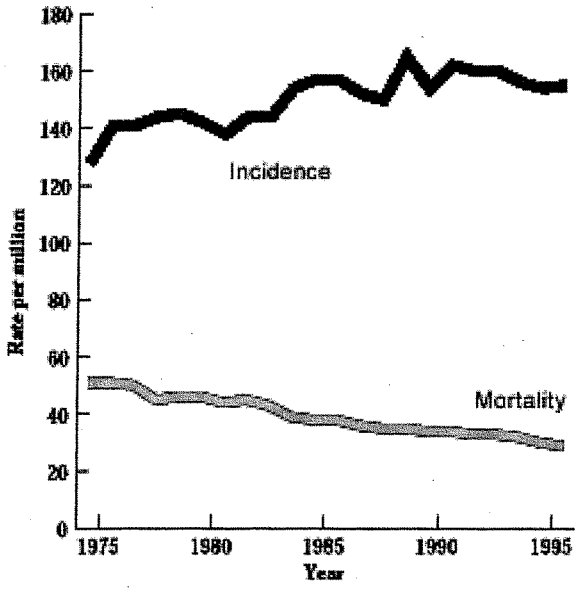
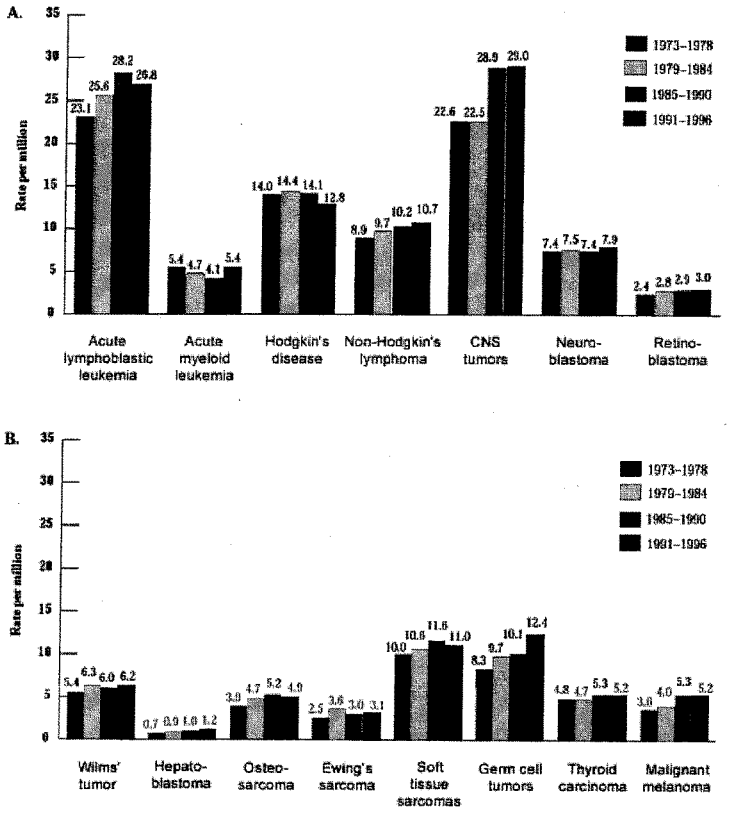
Childhood Cancer (Age 0-19), Age-Adjusted Incidence and Death Rates, 1975-1996




Source: American Cancer Society

ACS Statistics 2000 Cancer Facts & Figures Graphical Data Age-Adjusted Incidence Rates, Childhood Cancer (Age 0-19), By Period of Diagnosis, 1973-1996




Source: American Cancer Society

STATEMENT OF RANDALL L. TODD, M.D., STATE EPIDEMIOLOGIST, NEVADA STATE HEALTH DIVISION

Good morning Mr. Chairman. Thank you for the invitation to share information about our State's investigation into a cluster of childhood leukemia cases in Churchill County Nevada. I would like to provide you with a brief background and description of what has happened and is continuing to happen in Nevada and share some of the lessons we are learning that may be useful here in New York.

In July 2000, we were informed of concerns among the medical community in Churchill County that the number of recently diagnosed cases of childhood leukemia appeared unusually high. At the time we were first contacted there had been six cases diagnosed over a 5-month period of time. The usual rate of occurrence in a community of this size would be about 1 case every 5 years. Currently we have identified 8 cases of Acute Lymphocytic Leukemia (ALL) that were diagnosed in 2000. Another case had been diagnosed in 1999 and one case of Acute Myelocytic Leukemia (AML) has been diagnosed this year. For investigational purposes we have interviewed an additional 4 case families with recently diagnosed children having ALL and prior residence in Churchill County.

Our initial investigation consisted of face-to-face interviews with each case family. This involved a detailed review of residential history, sources of drinking and cooking water, in-home water treatment, chemical exposures, parental occupations, and medical history. We have also tested the water supplied to each local residence where a case family lives or has previously lived. About 50 percent of the case family residences were supplied with water from a regulated municipal source. The others obtained water from private domestic wells. We have tested all water, regardless of source, using the battery of analyses required for public water systems under the Safe Drinking Water Act.

Our water analysis to date has not revealed any results that would explain this cluster. There are high levels of naturally occurring arsenic. However, this has been present for throughout the history of the region and has not been specifically linked to the development of childhood leukemia. There are also some areas in which shallow and intermediate depth wells may exceed safe levels of uranium. This is also naturally occurring and is not found at all in the municipal water which comes from a much deeper aquifer. None of our water samples have detected significant levels of volatile or synthetic organic compounds.

After our initial data gathering was complete we convened a panel of national experts from Federal agencies and academia. These experts reviewed our processes and data. They also provided and continue to provide advice on further steps that should be taken to continue the investigation. I have included a copy of their initial report with the written copy of this testimony.

Although I am not familiar with the public health resources in New York, I suspect that Nevada has a somewhat leaner infrastructure. We have, therefore, found it essential to utilize advice and resources provided through the Centers for Disease Control and Prevention (CDC) as well as the Agency for Toxic Substances and Disease Registry (ATSDR).

I would like to briefly comment on some obstacles that we have encountered and lessons we are learning. A potentially serious obstacle to our ongoing investigation has come from the legal profession. We are now being challenged to provide copies of our data collection instruments as well as actual data. These demands are coming at a time when we are just beginning to do case-control studies. The danger, aside from obvious concerns about confidentiality, arises when unofficial parallel investigators introduce informational biases into the study population that may blur subtle distinctions between case and comparison families that would otherwise have provided important clues. We have also experienced media sponsored investigations resulting in spurious connections among case families that are over interpreted and result in panic among residents of the community at large. I believe these issues point to a need for lawmakers to provide some form of investigative privilege that would protect the scientific integrity of an ongoing public health inquiry.

Another phenomenon that arises in high profile cluster investigations is the emergence of self-proclaimed experts who promise to find answers more quickly than public health officials. Some of these individuals have legitimate scientific credentials from fields of study that are only tangentially related to the issues under study. Others are completely without scientific training. All of them have a tendency to tell the community what they want to hear, create distrust between the community and public health officials, and cause a waste of resources as health officials investigate and attempt to dispel myths and misinformation.

A lesson we have learned from this is that it is essential to keep the community well informed as to the progress of the investigation. Even seemingly mundane but

necessary activities are of interest to the public and help concerned individuals to understand that the investigation is continuing. We conducted a public meeting for the community early on in the investigation, established a toll-free hotline that people can call for information, and developed a web page with information specific to the investigation. We have begun to do weekly media briefings and last week conducted the first of what we expect will become a monthly open forum with the community. At our first open forum we had over 150 people in attendance asking questions for more than 2 hours. Staff to the investigation remained for an additional hour answering one-on-one questions. Involvement of the local medical community in these meetings is essential. One common question that is frequently asked by the public is whether or not they should move away from the area. Unfortunately, we cannot provide them with a science-based answer at this time. We have, however, been able to obtain State emergency funds that have been used to increase staffing by local mental health professionals. This provides a mechanism for individuals to receive assistance in making decisions in the face of scientific uncertainty and to deal with other stressful aspects of living in a community where a significant health concern is constantly the center of attention.

In closing, I would like to mention some things that might be done on a national level that could assist other communities facing a cluster of disease. First, because most children with cancer receive their definitive diagnosis and initial treatment at major cancer centers that may be located in a neighboring State, there can be significant delays in reporting to the central cancer registry in their State of residence. Some form of national cancer registration for childhood cancers would be very helpful in this regard. Second, when faced with a cancer cluster, the public attention invariably turns to the environment. There is a seemingly infinite number of possibilities when it comes to evaluating environmental concerns within the context of an emerging or ongoing cluster. A set of national recommendations for environmental surveillance would be helpful in this regard. Third, a standardized national protocol from agencies such as CDC and ATSDR would allow them to respond to State and local concerns more quickly. It has been exceptionally difficult to explain to an impatient public why it should take so long to develop a scientific protocol, have it approved by the appropriate committees for the protection of human subjects, and then implement it in the field. Having some things done in advance would go a long way toward minimizing this frustration in the community.

I hope these remarks have been helpful. I would be pleased to answer any questions the committee may have.

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ATTACHMENT

REVIEW AND RECOMMENDATIONS OF THE EXPERT PANEL DR. LESLIE L. ROBINSON, PROFESSOR, DEPARTMENT OF PEDIATRICS, SCHOOL OF MEDICINE, DIRECTOR, DIVISION OF PEDIATRIC EPIDEMIOLOGY AND CLINICAL RESEARCH, UNIVERSITY OF MINNESOTA CANCER CENTER; DR. THOMAS SINKS, ASSOCIATE DIRECTOR FOR SCIENCE, NATIONAL CENTER FOR ENVIRONMENTAL HEALTH, CENTERS FOR DISEASE CONTROL AND PREVENTION; DR. ALLAN H. SMITH, PROFESSOR OF EPIDEMIOLOGY, SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF CALIFORNIA, BERKELEY; DR. MALCOLM SMITH, HEAD, PEDIATRIC SECTION, CANCER THERAPY EVALUATION PROGRAM, NATIONAL CANCER INSTITUTE, NATIONAL INSTITUTES OF HEALTH; DR. MARY E. GUINAN, NEVADA STATE HEALTH OFFICER; DR. L.D. BROWN, DIRECTOR, NEVADA STATE HEALTH LABORATORY; DR. RANDALL L. TODD, NEVADA STATE EPIDEMIOLOGIST; AND DR. BURTON A. DUDDING, PROFESSOR, BEHAVIORAL PEDIATRIC AND ADOLESCENT MEDICINE, UNIVERSITY OF NEVADA SCHOOL OF MEDICINE

The expert panel was convened on February 15, 2001, in Reno, NV by Dr. Mary Guinan, Nevada State Health Officer. The panel reviewed the Nevada State Health Division's investigation of acute lymphocytic (lymphoblastic) leukemia (ALL) cases that had been diagnosed in Churchill County, NV. The panel considered possible follow-up actions and priorities by the Nevada Health Division. The meeting of the expert panel was attended by panel members and staff from the Nevada Health Division, University of Nevada School of Medicine, Nevada Governor's Office, U.S. Senate (Senator John Ensign's Office and Senator Reid's staff on U.S. Senate Committee on Environment and Natural Resources), and the Fallon Naval Air Base. This report summarizes the panel's review and recommendations.

The expert panel recognized the difficulty in evaluating and investigating excess occurrences of ALL. The panel members acknowledged that the cause(s) of ALL are insufficiently understood to single out a specific factor as explaining the observed excess in Fallon, NV. The panel members were familiar with previous investigations

of ALL clusters, all of which had failed to uncover an explanation of the cause of these excesses. At the same time, the panel members confirmed that the excess occurrence of ALL in Fallon, NV is unusual; not only because of its large number of observed cases among so small population-at-risk over a short time period, but also because further observed ALL cases had been diagnosed after the initial recognition of the ALL excess. The members of the expert panel acknowledged the excellent work of the staff of the Nevada Health Division on this investigation.

Scientific understanding of the biology of ALL prevented the committee members from predicting the cause of the observed excess of cases in Fallon. The committee is aware of at least three distinct sets of possibilities. The first set of theories collectively point toward a cancer causing chemical contaminant (e.g., human carcinogen) as the causal agent for the ALL epidemic. Theories about a chemical in the environment have received the greatest amount of public attention and community concern. The expert panel recognizes the need to address community concern regarding the presence of a hazardous chemical contaminant. However, the absence of cases of acute myeloid leukemia, the type of leukemia most commonly associated with toxic chemical exposure (1–3), argues against the Fallon cases being the result of toxic exposures. The panel members were skeptical that a chemical exposure could explain the excess cases of ALL in Fallon, NV. A second possible explanation relates to the theory of what is called *poulation mixing* in which clusters of ALL have been reported associated with unusual mixing of people, often in relatively isolated rural areas (4–11). The population mixing theory initially focused on the possibility of an unidentified infectious agent (i.e., a virus). However, the current consensus is that exposure to a variety of infectious agents (i.e., viral and bacterial) may trigger an unusual and rare reaction that affects a very small number of children within the susceptible population. The hypothesis suggests that ALL is not infectious, spreading from one person to another; but an unusual complication to a common infection within a susceptible population. The population-mixing theory is supported by the observation that excesses of ALL eventually subside, presumably because of increased population immunity. This theory requires further examination. The panel believes it reasonable to test this hypothesis by calculating rates of ALL in other rural areas of the United States having significant population mixing. However, such an effort falls outside the mandate of the Nevada Health Division. Finally, the possibility that the excess of ALL cases is due to random chance cannot be totally excluded as an explanation. The panel acknowledges, however, that the excess of ALL cases in Fallon, NV is not likely to represent a "chance" occurrence.

The expert panel recommends to the Nevada Health Division six follow-up steps in the investigation of the excess occurrence of ALL in Fallon, NV (see Table 1).

The purpose of these next steps are to: (1) efficiently expand case-finding efforts, (2) categorize the observed ALL cases by clinically relevant disease biomarkers, (3) identify potential excess environmental exposures unique to the community by a cross-sectional exposure assessment of selective contaminants and an evaluation of contaminant releases into the local environment with assessment of completed pathways for the case families, (4) collect and bank biologic specimens for future scientific investigations, (5) determine the time course and characteristics of population movements into the Fallon area for the period 1990 to 2000, and (6) maintain an expert panel to peer review investigative protocols and study results, consider future use of banked specimens, and provide ongoing consultation to the Nevada Health Division.

The expert panel also discussed the importance of high concentrations of arsenic in municipal and private drinking water supplies. The panel members expressed doubt that arsenic consumption in drinking water, by itself, could explain the observed ALL excess for several reasons: (1) The excess occurrence of ALL began in 1999, whereas the arsenic concentrations in drinking water have been consistently elevated for many years. (2) The case children who makeup the excess occurrence of ALL differ in respect to their consumption of arsenic contaminated drinking water. (3) Epidemiologic studies of arsenic exposed populations have not linked arsenic exposure with adult or childhood leukemia. One recent article suggests a weak association between childhood leukemia risk and exposure to low levels of arsenic in drinking water (12). The panel has reviewed the article and believes that the study is inadequate to support a conclusion that ALL is related to arsenic in drinking water. Each panel members expressed concern that the ongoing exposure to excess levels of arsenic in drinking water was a human health hazard, regardless of its relationship to the excess of ALL. The Fallon municipal water supply is contaminated with arsenic (As) at a level 10 times the EPA recommended standard for arsenic in drinking water. The panel was also aware that an unknown proportion of Churchill County drinking water wells, unregulated by the Federal Safe Drinking Water Act (SDWA), are at least as contaminated as the Fallon municipal water sup-

ply. Arsenic is recognized by the Report on Carcinogens of the National Toxicology Program as a known human carcinogen on the basis of epidemiologic studies that have linked arsenic exposure with an excess of skin, bladder, and lung cancers in exposed human populations.

The expert panel recommends that arsenic concentrations in the Fallon municipal drinking water be reduced to a level no more than that currently recommended by EPA (e.g.; 10 μg/L) as soon as possible. The panel strongly encourages the Nevada Health Division, and other State agencies, to proceed with recommendations for testing arsenic in all drinking water wells in Churchill County that are unregulated by the SDWA. The State health division should work to create a process providing this service when necessary and develop a set of recommendations for preventing arsenic exposure based on reported test results. The State health division should consider maintaining a listing of wells that have been tested along with test results.

TABLE 1.—INVESTIGATING THE EXCESS OCCURRENCE OF ACUTE LYMPHOCYTIC (LYMPHOBLASTIC) LEUKEMIA IN FALLON, NV: PHASE II RECOMMENDATIONS OF THE EXPERT PANEL (FEBRUARY 15, 2001)

*Priority: Task / Time frame / Collaborators*

1. Efficiently expand case-finding efforts. The panel members encourage the Nevada Health Division to continue limited case-finding strategies. The panel members recommended limited expansion of case-finding by linking to:

a. The national Childhood Oncology Group (COG) database(s) to identify all children with ALL having a residence at time of diagnosis in the State of Nevada. The purpose of this would be to evaluate completeness of the Nevada tumor registry and identify additional ALL cases from Churchill County.

b. An ongoing case-control study of ALL being conducted in California to review residential history of cases for previous residence in Churchill County, NV.

c. The California State Tumor Registry to identify any children with ALL with a Nevada residence at time of diagnosis.

*Time frame.*—These additional steps could be done within 2 months after satisfactory negotiations regarding patient confidentiality are completed.

*Potential Collaborators.*—Clinical Oncology Group, California Tumor Registry, California ALL research team.

2. Categorize the observed ALL cases by clinically relevant disease biomarkers. Cancer cells from each case-child have probably been collected and undergone immunophenotyping and cytogenetic testing. The health division should collect this information. If testing has not been done and tumor cells have been stored, the health division should secure samples and have them tested. These materials could be reviewed or tested at two independent laboratories. The distribution of these results among the case-children from Fallon can be compared against other children with ALL to determine if these distribution are similar or if the distribution among the Fallon case-series is unique.

*Time frame.*—The health division should proceed to determine availability of data or tumor cells as soon as possible.

*Potential Collaborators.*—Pediatric oncologists, Childhood Oncology Group, National Cancer Institute.

3. Identify potential excess environmental exposures unique to the community. The health division should conduct limited testing for *current* exposures in environmental media or human samples as well as evaluate contaminant releases into the local environment and assess the potential for human exposure to such contaminants. This analysis would be used to identify chemicals that are (and are not) elevated in the community and to consider if additional data collection is required.

a. A cross-sectional exposure assessment of selective contaminants would include examination of drinking water, human blood and urine of family members, and possibly dust collected from homes where case-children did and did not live. Testing should be limited to compounds for which normative data are available. The expert panel recommended testing for volatile organic compounds in drinking water and human tissues; radioactive isotopes in drinking water; selected heavy metals in drinking water, household dust, and human tissues; and pesticides in human tissues and in household dust.

b. An evaluation of contaminant releases into the local environment with assessment of completed pathways for the case families. The expert panel recommends collecting environmental releases data, including that from local industry and the Fallon Naval Air Station. An assessment of the potential for environmentally-released chemicals to result in human exposure should also be conducted, including potential for case-children to have been exposed.

*Time frame.*—These activities will require development of survey and sampling protocols and appropriate review of consent forms and confidentiality agreements. The committee anticipates start-up of these activities during the months of March or April and available results within 1 year.

*Potential Collaborators.*—National Center for Environmental Health, Centers for Disease Control and Prevention; Agency for Toxic Substances and Disease Registries; Jonathan Buckley (University of Southern California) for input on measuring house dust for pesticide residues, heavy metals, PAHs.

4. Collect and bank biologic specimens for future scientific investigations. The members of the panel recognize how limited our knowledge is of the cause(s) of ALL and the difficulty investigators have had in identifying the causes of similar ALL excesses. The panel members believe that collection of biologic specimens from case-children and family members may be useful for future research investigations into the cause(s) of ALL. A small amount of blood and urine, and perhaps buccal cells, should be collected, maintained, and made available for future research.

*Time frame.*—Collection of specimens could occur simultaneously with the exposure assessment (see 3A) or include samples taken during clinical care. a protocol for collection, storage, and access to samples must be developed and reviewed by an Institutional Review Board for compliance with human subject research.

*Potential Collaborators.*—Nevada Public Health Laboratory, National Center for Environmental Health, Centers for Disease Control and Prevention, National Cancer Institute as possible repositories for the tissue bank.

5. Determine the time course and characteristics of population movement into the Fallon area for the period 1990–2000. The expert panel recommends collecting demographic data concerning changes in the population of Fallon, specifically looking for evidence of large migration of new long-term residents into the community during this time period. The appended table illustrates the kind of first-level information that is relevant to this issue.

*Time frame.*—Initial data collection within 2 months.

*Potential Collaborators.*—Public school systems and Fallon Naval Airbase (for information concerning migration patterns), Drs. Les Robison and Malcolm Smith (for consultation to identify the specific data required).

6. Maintain the expert panel to peer review investigative protocols and study results, review proposals for future use of banked specimens, and provide ongoing consultation to the Nevada Health Division.

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STATEMENT OF JAMES R. HARE, COUNCILMAN, CITY OF ELMIRA, NY

Senator Reid and members of the Committee on Environment and Public Works:

I appreciate the opportunity to speak with you this morning. I have been a teacher at Southside High School in Elmira, NY, for over 16 years. I was at the school when it opened in 1979, then went to another school for 6 years and resumed in 1986 and have been there since. My son attended Southside for 4 years, graduating in 1997, and as a former Mayor of Elmira and currently a city councilman representing, a south side district, many of any constituents have a direct connection with the school.

I believe there is a story to tell about Southside which may be of some help to your investigation. For the last year the school and its grounds have been undergoing tests for hazardous wastes because of its location on part of an 83-acre former industrial site and the fact that there appears to be an inordinate number of cancer cases among the student body. (I have a timeline for use of the property for you).

A logical question is why now? Why after 20 years of use are these questions being raised? The fact is people have wondered about this site since the school was built. It has been stated publicly by NYSDOH and environmental officials that with today's standards the school would not be built on this site, but 20 years ago these standards and the sensitivity we have today were not present. Yet at least privately many have been troubled by the fact that part of the old plant remains standing and in use, right next door to the school and by reports of illness, specifically cancer over the years. (I have a letter from a retired teacher to that effect).

It all came together last year. Scott Technologies, Inc., of Mayfield, OH, who are the current owners of the property adjacent to Southside High School undertook a voluntary cleanup which took 4 months and cost $900,000. According to newspaper reports, "Tons of contaminated soil, storage tanks and equipment containing an alphabet soup of hazardous wastes were removed . . . that included removal of 2,000 cubic feet of contaminated soil, abandoned fuel and chemical storage tanks and electrical equipment containing polychlorinated biphenyls commonly known as PCB's". Other chemicals found and removed include, "arsenic, lead, zinc, cadmium and the solvents toluene, ethybenzine and xylenes" (Star Gazette, April 23, 2000). The site was given a clean hill of health by the State as the work was done under the supervision of the NYSDEC. It should be pointed out that contaminated soil "did contain hazardous waste some in levels 1,000 times higher than allowed by the conservation department. (Star Gazette, April 23, 2000) I have a copy of the Citizen Participation Plan for Remediation of the American LaFrance Facility prepared for Scott Technologies).

Also last year NYSDEC completed an investigation of petroleum contamination initially found in the vicinity of Miller Pond. The investigation began after a sheen in Miller Pond was reported to DEC in 1995. The contamination is believed to have resulted from the activity of industries that previously occupied the area. The source of contamination was found to be under the gym at Southside High School. DEC used a technique called bioremediation to address the fuel oil contamination. (DED Fact Sheet, April 2000).

Finally, at a meeting of students in the school auditorium last year, organized to promote participation in the Relay for Life it was reported that six Southside students had cancer. That made 13 cases since 1997. I was stunned. I had known of some cases and two of my son's classmates were survivors, but six in 1 year was an eye-opener.

I wrestled for a bit with my responsibility as an employee, a parent, and as a councilman and decided that questions needed to be asked. I called together an ad hoc committee to meet at my home. Tim and Margaret Tobin, whose son currently is a junior at Southside and is a cancer survivor, Andy and Julie Patros whose son graduated with mine and is a cancer survivor, Mike and Luann Smith, whose daughter graduated with mine and Mike is the Emergency Management Director for Chemung County and a former Southport Town Board Member, and Councilman Dan Royle who has had two sons graduate from Southside and has another planning to go there. We agreed to draft a letter to the Elmira City School Board, on

City Council stationery raising a number of issues, dated April 8 (I have a copy of that letter and another letter from our group).

We did not release our letter to the press, but it found its way there. The Elmira Star Gazette began what I believe to be one of its best journalistic endeavors investigating and reporting of the cancer issue at Southside. Margaret Costello, who did much of the reporting is a Southside graduate.

I must say that the school board which had shown no curiosity about this issue previously responded positively to our letter. Tom Kump, director of the Chemung County Health Department and a school board member met with us and the process of investigation got underway.

On April 14, Kris Smith of NYSDOH was quoted, "We get a myriad of calls of this nature. We respond to all of them. But in order to prioritize it we need to review the facts to determine if its an unusual type of cancer, the same type of cancer, the timeframe, and are there any logical explanations for what is occurring." (Star Gazette, April 14, 2000).

On April 30, it was reported that "State environmental experts would begin testing the soil at Southside . . . for chemicals and contaminants similar to those found on the adjacent industrial site". One of the environmental engineers stated that the conservation department never had any reason to believe there was metal contamination at the school (Star Gazette, April 30, 2000) HELLO.

On May 2, after a preliminary investigation State health officials said that Southside High School was not a health hazard to students. Headlines read "High School Found Safe". (Star Gazette, May 2, 2000).

These responses indicate that situations like ours face a mix of competing concerns which the State must react to based on time, resources, and bureaucratic inclination. This is tough to digest for those directly impacted and quite frankly raises the question about how thorough the State will be when they do investigate. What I believe we learned is that the more pressure that can be put on the State the better the investigation will be. But to be effective in applying pressure the local community has to know what questions to ask and to whom they should be directed.

At this point our committee recognized that we needed assistance, so that the issues would be qualitatively addressed. Our Mayor, Stephen Hughes (Southside graduate) and our City Manager recommended that we approach Craig Slater, an environmental attorney from Buffalo, who had done some work for Elmira, and has been involved with Love Canal. Courageously, the City Council authorized expenditure of $15,000 for Craig's services in the interest of protecting the public. In 1997, the City applied for and received a $200,000 Brownfields Demonstration Pilot Grant. The city has asked, and EPA Region is considering, a reallocation of a portion of the Brownfields award to reimburse city of Southside related assessment costs." With the advice of Craig Slater we also hired Barron and Associates/and Golder Associates as consultants to do a Phase I analysis. Craig, and our committee would serve as a third party separate from the interests of the school district and the State, we would represent the community. Craig's expertise positioned the public to be able to ask the right questions, challenge methodology used by the State and I think energized the school district to more aggressively seek answers.

I have for you Mr. Slater's response and comments on the investigation which has taken place at Southside. I believe his response should provide you with some insight about the nature of this investigation. For instance, he raises questions about the methodology of site investigation (they did no phase one, the City did), and he questions comparison values which appear to be "derived from generic residential exposure scenarios, and not site-specific exposure scenarios".

The Elmira School District also acted responsibly in my opinion. Once our new Superintendent, Laura Sherwood came on board, she met with Tim Tobin and myself for some historical perspective. The district hired a special attorney Rick Kennedy from Hodgson Russ Andrews Woods and Goodyear. She formed a reputable advisory committee, including Tim Tobin, Julie Patros, and Craig Slater as co-chair with the school attorney. In addition, the district hired their own consultants Brian C. Sendfelder, CHMM from Golder Associates and Dr. Rosalind Schoof from Gradient Corporation to analyze information. Also the school district voted to close the athletic fields until more could be learned. All committee meetings were open to the public and press Mr. Tobin will discuss the work of the committee.

WHAT ARE THE LESSONS WE HAVE LEARNED?

1. We have learned thus far that while the site raises serious questions it is difficult to make a direct link between what is in the soil and cancer.

2. We have resolved that the air and water quality in the building is safe and we have identified "hot spots" on the school grounds.

3. I believe we have demonstrated that a community can work together to search for the truth if the process is open and conducted professionally. We may disagree on the conclusions and unanswered questions remain, but a great deal of time and money has been spent to examine the problem.

4. The ability to access expert help serving the community interest was extremely important to the credibility of what was done. It made both the State and the school district assume more accountability.

5. The school district has undertaken an extensive survey of alumni to research health issues, particularly cancer, which have not surfaced and might shed more light on what has been investigated so far.

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Please Reply To: Buffalo
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April 12, 2001

**VIA E-MAIL AND U.S. MAIL**

Mark A. VanDeusen
Outreach Unit
NYS Department of Health
Center for Environmental Health
Environmental Exposure
Flanigan Square
547 River Street – Room 316
Troy, New York 12180-2216

Re: Elmira Southside High School
*Draft NYS DOH Health Consultation, dated February 23, 2001*
*Public Comment*
NYS DOH Site #808815N
Our File No. 31673.6

Dear Mr. VanDeusen:

Our firm represents the City of Elmira. This letter constitutes the City's response and comment to the Draft Health Consultation for the Southside High School ("SHS"), dated February 23, 2001 (the "Consultation"), prepared by the New York State Department of Health ("DOH"). We have subdivided our comments on the Consultation for ease of reference.

**A. General Comments:**

1. Final DEC Investigation Report: The accuracy, thoroughness and adequacy of the Consultation cannot be analyzed and meaningfully commented upon until the Final DEC Investigative Report is complete since the conclusions contained in the Consultation are wholly dependent upon the accuracy, thoroughness, and adequacy of DEC's investigation. We do not have a final DEC report on its investigation, thus the Consultation is not ripe for public review and comment.

2. Unified Site Investigation Report: DEC's own guidance on completion of environmental investigations (found in DEC TAGM's 4007 and 4025) mandates that investigation data be summarized in a comprehensive summary report. Also see, EPA OSWER Directive No. 9835.8A. That was not done here.

The City strongly believes that DOH must explain why it is acceptable to rely upon data and information which has not been reported or explained as required by or in compliance with state and federal directives and guidance. We believe that, under different circumstances, DOH would outright reject any risk analysis performed by a private party without a report that fully complied with TAGM's 4007 and 4025 upon which it relied. DOH needs to explain why it is acceptable here.

At a minimum, we believe a site investigation report containing the following elements is required:

- A detailed discussion of how the data was collected, including the design of the field investigation, the specific sample collection techniques and methods, the sepcific laboratory methods used to analyze the samples (including detection limits), and the QA/QC protocols used to examine the reliability of the data.
- A data validation report.
- All boring logs and field notes.
- All Sanborn maps and any "as-built" drawings for the school.
- A detailed discussion of the operating history at the site.
- A detailed discussion of the demolition, site preparation and construction at SHS.
- A discussion of the present use patterns and maintenance programs at SHS.
- A summary of the environmental conditions and remedial history of adjacent sites and properties, including the American LaFrance facility and the Miller Pond petroleum spill.
- A geographic location map.

3. Site Model/Exposure Route Model: Prior comments submitted on the 8/00 draft of the Consultation suggested that a site model/exposure route model be completed by DOH. That has not been done.

   We believe that it is critical that all of the data and relevant information developed by DEC in characterizing the nature, extent, and distribution of contaminants be utilized to produce a site conceptual model or exposure/pathway model. These types of models are necessary to thoroughly understand the interrelationships among the data developed

for the different media and is necessary to understand the correlation between contaminants in the soil and the extent to which the contaminants may be amenable to exposure pathways (groundwater, soil, or air). Contaminant sources, exposure pathways, and potential receptors must be included in the model.

4. Interim Public Health Hazardous Categories: There is insufficient explanation as to why the Department arrived at the conclusion that there is no apparent public health hazard under the interim public health hazard categories attached as Appendix D. We believe that a further explanation as to how the Department arrived at the determination it did under its guidelines would be appropriate.

   Appendix D of the Health Consultation lists the procedure used by DOH for evaluation of risks. The procedure includes various categories of risk and a corresponding qualitative descriptor. It is stated that increased cancer risks were estimated using site-specific information on exposure levels for the contaminant level of concern and then one of the qualitative rankings was used to rank risk from very low to very high. In this appendix, there is no mention of comparison values. Nor is it apparent that the procedure set out in Appendix D results in the comparison values or if this applies to some additional risk analysis.

   The basis of the Consultation conclusions are the comparison values that appear to be derived from generic residential exposure scenarios, not site-specific exposure scenarios. The qualitative descriptors listed in Appendix D do not appear to have been used anywhere in the Consultation.

   Clarification on how the procedures in Appendix D were applied is needed as is a discussion of the differences and similarities between the use of the comparison values and the risk assessment approach set out in Appendix D.

5. DEC TAGM Standards and DOH Assessment Comparison Values: We believe that there is also insufficient explanation and analysis of the difference between DEC TAGM soil and groundwater cleanup values and the public health assessment comparisons and how either affected or did not affect the public risk determination made in the Consultation. The public is, thereby, faced with reviewing soil sampling results which may indicate exceedances of DEC soil clean-up criteria but which DOH has concluded is insignificant from a public health perspective. A broader, more detailed, and reasoned analysis of this dichotomy would be appropriate.

   We also note that that there are other compilations of "screening" values that are used by the DEC and EPA which also are based on minimizing health risk and are far lower (sometimes by orders of magnitude) than the comparison values utilized for this site. Has DOH considered TAGM or EPA SSL's or PRG values in this assessment? We believe that there is a disconnect that needs to be explained between DOH comparison

values used here and screening guidelines used by other regulatory agencies (such as DEC TAGM values) which appear to be similar in concept and purpose to the comparison values but are far different in the actual values used.

**B. Specific Comments:**

1. Site History: As indicated above, we believe that the site history provided for in the consultation is inadequate for review and insufficient under applicable DEC TAGM guidance. Intensive heavy industrial operations and significant chemical use and disposal has been documented at this site for over 70 years. We believe that history is relevant, indeed critical, in determining any public health risk associated with the site. We do not believe that the Consultation in its present form adequately sets out, discusses, or identifies these operations or the contaminants of concern associated with these operations (which should be discussed in the background section of the Consultation).

2. Operational History: Similar to our comment above, we feel that a more detailed analysis of the site operational history should be set out in the Consultation.

   Based upon the City's investigation, industrial manufacturing operations have occurred at this site since 1887. Based upon the known industrial manufacturing operations between 1887 through 1935, many hazardous materials would have be used during this period of time, including degreasers, solvents, metals, and other potentially hazardous materials.

   More significant are the activities during Remington-Rand/Sperry Rand operations from 1937 through 1972. During this time, heavy manufacturing activities were being conducted throughout the 83 acre parcel, most concentrated, though, in the area of the present school location. Industrial activities during this time included metal cleaning; metal machining; metal finishing; plating; stripping; metal blackening; painting and coating operations; vapor degreasing; solvent power washes; the application of rust preventatives; use of soluble coolants from mechanic operations; painting and paint spray booths, organic paint stripping using phenolic compounds; applications of rust preventative in oil dip tanks; cyanide plating; cyanide heat treating; cyanide and nickel stripping; cyanide flux removal; chromium plating; nickel plating; sulfuric acid wire pickling; solid cyanide heat treating using solid cyanide; and cyanide and nickel stripping baths. Remington-Rand, as a result, used a broad range of hazardous chemicals during the processes including solvents, coolants, oils, degreasers, paint, cyanide, chromium (hexavalent and trivalent), zinc, nickel, petroleum, acids, sulfuric and others, and phenolic compounds.

   From a review of the Sanborn maps and as-built drawings, as well, it is clear that there were numerous transformers, tanks, vaults, settling ponds, and other concrete structures in use at the site during this time which may have contained waste. The Sanborn maps

and our investigation also show that there was raw product storage and intensive manufacturing activities being undertaken in the exact vicinity of the football and athletic fields.

It should also be noted in the site operational history, that Remington Rand utilized a waste water system which collected waste water from process areas through collection pipes from all points of the plants and directed the waste water to a holding pond (at American LaFrance) which then discharged directly into Miller Creek. This resulted in significant contamination to the Creek which has not been discussed in this report.

We believe that the operational history and a full discussion of the contaminants of concern which had previously been used at this facility should be included in the Consultation.

3. American LaFrance Facility/ Miller Pond Petroleum Spill: The Consultation should include an overview discussion of the environmental conditions at the American LaFrance ("ALF") parcel (located adjacent to the Southside High School) and associated with the Miller Pond Petroleum Spill. Since the ALF parcel was originally a part of the entire Remington-Rand 83-acre parcel and since the groundwater petroleum plume associated with the Miller Pond Petroleum spill is located under the SHS building, a discussion of whether and to what extent these areas of concern have caused contamination at SHS or pose a risk at SHS would be appropriate.

4. Exposed Soil Surface Areas: A key factor cited to support DOH's determination that the site poses no apparent health risk is the presumption that there is a 3-inch clean, uncontaminated layer of topsoil which acts as a barrier to exposure to the more significant contamination (found in "shallow" soils) found below the surface. In this regard, though, the Consultation refers to exposed soil areas which could act as pathways or conduits for risk exposure.

   Given this acknowledgment, we feel that it is important for the Consultation to discuss, quantify, and analyze the exposed surface areas, the steps that should be taken to assure barriers remain in place in these areas, and that a map of the exposed surface areas be provided.

5. Discolored Soils: The Consultation acknowledges that discolored soil was found in a number of soil borings. A map or table should be completed to show which borings contained discolored soils.

6. Maps/Data Representations: The Consultation should provide statistical analyses and graphic presentations of the data demonstrating the nature, extent and distribution of contaminants have been defined sufficiently to support DOH's conclusions, including the following: scaled maps; stratigraphy diagrams; isoconcentration maps; maps which designate sampling locations with respect to historic site structures, features, and use; "exposed soil" area and "discolored soil" location maps; and data arrays.

7. Ranges of Detection: The references in Tables 1 and 2, attached to the Consultation are to "ranges of detection" and "frequency of detection". We believe that this format of delivering information is insufficient, somewhat misleading, and hard to qualitatively analyze. This is particularly true since the "ranges of detection" show frequent exceedances of DEC's TAGM criteria (sometimes by orders of magnitude). In short, we believe that the format of Tables 1 and 2 are inadequate and insufficient to fully analyze and provide meaningful public comment.

8. Background Levels: In the Consultation, DOH refers to "typical background" (see page 6, for example) Please identify in the Consultation what DOH considers to be "typical background", the basis for that, and identify any samples you may have taken off-site to identify the "local or regional background" levels.

9. Cinders: The Consultation indicates that cinders were found "in most bore holes" in the surface soil zone. DEC soil boring logs also confirm the presence of cinders in most surface soil samples. Since the Department has acknowledged that the cinders could be associated with higher metal and PAH concentrations, we feel that it would be appropriate to discuss the nature, chemical composition, and the potential impact associated with cinders found in the surface soil area.

10. Surface Soils: DOH has relied upon the assumption that a clean, uncontaminated layer of topsoil at "surface" constitutes an institutional barrier to exposure in finding no public health threat (See, Conclusions). Yet, there are numerous and replete soil sample locations where levels of PAH's, chromium, zinc, and PCB's were found in excess of DEC TAGM soil cleanup criteria. Attached in this regard are maps prepared by Golder Associates identifying the location of surface soil samples where chromium, zinc, and PAH's were found in excess of DEC TAGM criteria.

    In light of this data, what rationale supports the DOH conclusion on page 11 that "the top foot appears to be topsoil"? Does DOH or DEC consider soils that contain metals and/or PAH's in excess of TAGM criteria to be clean topsoil? Would it be acceptable cover for a remedial action? Previous positions taken by DEC would indicate that DEC would reject such soils for cover or cap purposes and, if so, why is it acceptable for the athletic fields?

    On a similar issue, what constitutes native soil? What constitutes fill?

11. Chromium, Nickel, Zinc, and PAH's in Surface Soils: As indicated above, the Consultation confirms that chromium, zinc and PAH's were found in numerous locations in surface soils in the athletic fields in excess of DEC cleanup criteria in DEC TAGM 4046 and at levels the Consultation acknowledges are "...higher ...than would be expected from typical soils." Maps prepared by Golder Associates showing these locations are attached.

    How does DOH define "typical soils"?

Three of the surface soil samples exceed health comparison values (as well as DEC cleanup criteria) DOH has chosen. Why doesn't DOH recommend hot spot removal or capping for these areas?

The Consultation should identify the location of these soils and explain why the existence of these contaminants in surface soils in the athletic fields at levels in excess of DEC's TAGM soil clean-up criteria is acceptable.

12. PCB's in Surface Soils: The Consultation notes that PCB's were found in surface soils at an elevated level (pages 6-7) and some in excess of DEC cleanup criteria. Why was PCB data averaged when it was not in the original consultation?

13. Shallow Subsurface Lead Contamination: The Consultation notes a lead concentration in one location of 3940 ppm. Based upon our experience, that soil sample would fail the TCLP analysis and the material would be deemed to be hazardous under DEC criteria and would need to be remediated. The Consultation should discuss this fact and analyze the public health issues raised with respect to leaving hazardous soil materials in a shallow subsurface location below the SSH.

14. Hexavalent Chromium: It has been documented that hexavalent and trivalent chromium were used in large amounts by the prior industrial users of this property and disposed of at the site. The soil sampling analytical results confirm the pervasive and repeated disposal of chromium throughout this site. It is also clear that chromium was disposed of at the site in an aqueous condition resulting in significant on-site and off-site contamination. The report should discuss the impact of the known contamination of chromium pervasively throughout the location and, specifically, the relative public health risks associated with that and associated with the presence (or lack thereof) of hexavalent chromium.

15. Exposure Scenarios: On page 3 of the Consultation, numerous actual and potential users of the athletic fields are identified, yet the Consultation does not formulate different types of exposure scenarios to make reasonable assumptions on intake and exposure duration in calculating risk for these users. It would not be unreasonable to include various exposure scenarios in DOH's risk analysis.

16. Risk Associate with Exposure to Chromium: Inhalation was not considered for chromium as a risk factor. Inhalation of dust containing chromium particularly from the baseball fields and other areas devoid of vegetation are possible vectors of exposure that should be considered.

C. **Recommendations**

Basic facts about SSH mandate caution:

- Heavy industrial manufacturing operations occurred at the location of the SHS from 1887 through 1972.
- During Remington Rand operations at the site from 1937 through 1972, PAH-impacted ash, solvents, degreasers, acids, nickel and chromium and other metals, and other hazardous materials were used and disposed of on site.
- The DOH Health Consultation confirms that these past industrial operations resulted in contamination of the surface and subsurface soils at the school.
- The DOH Health Consultation confirms that chromium, zinc and various PAH's are not only present in surface soils in the athletic fields, but are found in numerous locations in excess of DEC cleanup criteria.
- Health concerns associated with present and past SHS students have been raised.
- The athletic fields continue to be used.

The City believes that we should act cautiously when we make decisions affecting our children's future and their health. The City does not believe we are doing so here. While we have questioned the basis upon which DOH has concluded that the documented existence of replete contamination in surface soils in the athletic fields in excess of DEC cleanup criteria is safe (or does not pose a health risk), we believe that the criteria that should guide our actions here are ones of a very different sort. What is the right thing to do? What is the cautious thing to do? Is marginalized safety enough for our children? Questions, no doubt, that can not be answered by a tabular reference to health comparison values, but rather must be answered by reference to quality of life values. Thus, while the City is not qualified to argue health risk with DOH, we do believe the data supports an appropriate, cautious and reasoned response that is in the best interest of our children.

We strongly recommend to the School District and the State of New York that application be made under the EQBA for funds necessary to cap the athletic fields with six (6) inches of clean, virgin, topsoil. We would request that DOH support this request and the State's funding of this remedy. As we have already said, while we cannot argue whether leaving contamination in surface soils in the athletic fields in excess of DEC cleanup criteria is safe or not, we do not believe it is acceptable. The right thing to do is to cap the fields with clean soils.

The City of Elmira and our office truly appreciate the extraordinary efforts DEC and DOH has gone to (the extra mile) in completing its investigation and analysis in such a timely and proficient manner. We hope that you find our comments to be helpful and that this discourse will enhance the value of the Consultation to the public at large.

Thank you once again for this opportunity to publicly comment on the Consultation. Of course, if you have any questions with respect to the above, please feel free to contact me.

Very truly yours,

HARTER, SECREST & EMERY LLP

Craig A. Slater

CAS:jp
cc: Samuel F. Iraci, Jr via fax
Mayor Steven Hughes
All Members of Citizen Advisory Committee via e-mail

## Southside High School property history

**1887-1909:**
B.W. Payne & Sons produces high-speed steam engines.

**1909-1935:**
Morrow Manufacturing Co. makes drill-chucks, machine parts and tools for machine trade.

**1935:**
Elmira Industries Inc. buys idle Morrow factory, offers it free to Remington Rand if the company will locate in Elmira.

**1936:**
Remington Rand begins manufacturing typewriter parts.

**1942:**
Under government order, Building 88

Source: New York state Department of Environmental Conser

# Digging for answers

This 83-acre property, straddling the city of Elmira/town of Southport border, has been used for manufacturing since 1887.

("N Plant") is built on south portion of property to manufacture World War II bomb sights designed by Carl L. Norden. This is currently the primary building left on the site.

**1946:**
Norden bomb sight production ends; Remington Rand moves some operations from northern part of property into N Plant.

**Late 1948:**
Remington Rand moves its adding machine assembly department to the N Plant.

**1963:**
Sperry Rand Corp. buys $1 million in equipment to modernize, redesign plant. Sperry Rand operations include cleaning, heat-treating, polishing, plating, stripping and metal-blackening.

**1972:**
Sperry Rand closes plant.

**1973:**
Sperry Rand deeds site to Chemung County Industrial Development Agency for $1.

**1974:**
Chemung County IDA leases site to Westinghouse Corp., which uses property primarily for warehousing.

**1977:**
IDA sells north portion of site to Elmira City School District. Construction begins on new Southside High School.

**1979:**
Southside High opens.

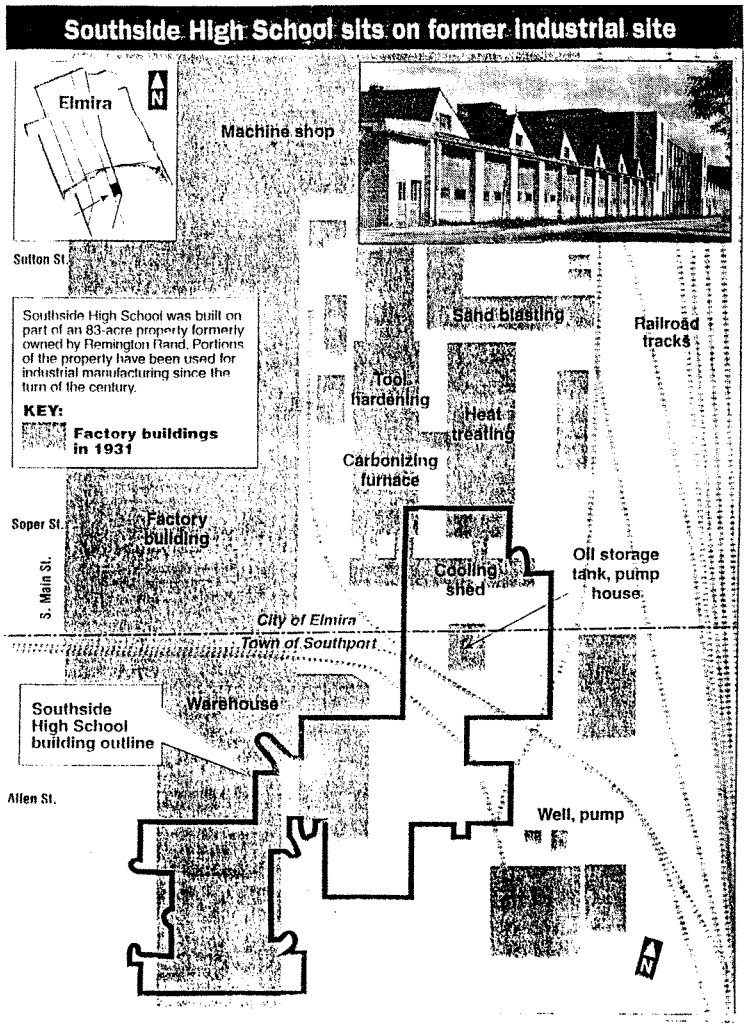
**1980:**
American LaFrance purchases Westinghouse's lease of the remaining 47.7 acres.

**1982-85:** American LaFrance manufactures, assembles fire engines at plant.

**1985:**
Figgie International, owner of American LaFrance, obtains title to its portion of property from the Chemung County IDA.

**1985-present:**
No major industrial use of site. Currently, property partially occupied by a wood pallet construction and reconditioning company, a bridge manufacturing company, a firm warehousing old rail cars and parts, and a business recycling computers.

**1987:**
U.S. Environmental Protection Agency lists the 83-acre parcel on its low-priority cleanup list after concluding it's a potential hazardous waste site. New York state Department of Environmental Conservation has listed site as potential candidate for inclusion on state's registry of inactive hazardous waste disposal sites.


Southside High School sits on former industrial site
Elmira
N
Machine shop
Sutton St.
Southside High School was built on part of an 83-acre property formerly owned by Remington Rand. Portions of the property have been used for industrial manufacturing since the turn of the century.
KEY:
Factory buildings in 1931
Sand blasting
Railroad tracks
Tool hardening
Heat treating
Carbonizing furnace
Soper St.
Factory building
S. Main St.
Cooling shed
Oil storage tank, pump house
City of Elmira
Town of Southport
Warehouse
Southside High School building outline
Allen St.
Well, pump
N

Date: June 11, 2000
To: Whom It May Concern
Re: Health Problems at Southside High School
From: Sylvia Roy, retired teacher.

I taught at the new Southside High School from the time it opened in 1979 until I retired in 1991. I was in room 207.

The first year that I was there I had an ear infection off and on all winter. I had never in my life had an earache until that time. There was such a constant rush of air that the noise level in the room made it very difficult to teach. The students could not hear me, and I could not hear them. Finally towards spring I got to the point where I could not stand the earache any longer. Carl Foreman was the vice principal. I told him that something had to be done or I was going to have to take sick leave. In a few days, the problem was remedied. I had suffered all year because there was no end on one of the air ducts.

At times paint fumes from the La France were almost unbearable, especial during warm weather.

Also there were times when I had breathing problems in that room. I

June 11, 2000

Dear Jim,

I am sending this to you because I know that it will arrive at the proper destination.

I had to have cancer surgery after I retired. I called the board of Health. They were supposed to call me back, but I have never heard a word from them.

I have read all of the articles in the paper, and I feel that there have been several things that are unhealthy in that building.

I appreciate the interest that you have shown in these problems, and my name is another one to add to the list.

Thank you.

Sincerely,
Sylvia Fry

P.S. If you need more information or have questions, please call me collect at 570-596-2695. It is best to call in the evening.

CITY OF ELMIRA
317 E. CHURCH STREET
ELMIRA, NEW YORK 14901

JAMES E. HARE
COUNCILMAN

April 8, 2000

Mrs. Deborah Pierce, President
Elmira School Board
818 W. Water St.
Elmira, N Y 14905

Dear Mrs. Pierce:

We are deeply concerned by the number of SHS students who have been stricken by cancer. What seemed to be a disturbing coincidence has become an alarming consistency. Families affected are distraught, parents of incoming ninth graders are fearful, there are currently students at SHS who will not drink the water. It appears to us that there are many unanswered questions about the situation. Little or no information has been provided the SHS community, parents who attended the Elmira School Board meeting on February 3rd, 2000, were unsatisfied with the explanation and the families with children affected have never been contacted by the district about the situation.

Those signing this letter are all parents of students who are attending, have attended and will be attending SHS. The Patros and Tobin families have had sons afflicted with testicular cancer. We are seeking some dialogue with the Elmira School District to seek a greater understanding of the situation and hopefully some answers to questions.

Are you aware that there are at least six students currently attending SHS who have been diagnosed with cancer this school year?

Are you aware that since 1997, at least thirteen SHS students have been diagnosed with cancer?

If the answer to the first two questions is yes then has the district undertaken any effort to develop statistical data to investigate if the incidence of cancer is greater than these numbers indicate?

Has the school district developed any statistical data to compare the incidence of cancer at SHS with other schools in the district or indeed with the community as a whole?

Will you provide us under freedom of information with copies of all environmental tests or other types of tests related to the air, ground water and soil surrounding SHS?

Has the school board been briefed on the afore mentioned tests and will you provide us with copies of the results reported to the board?

Will you explain why the SHS faculty has not been briefed about the situation with the open tanks under the gym and the apparent cleanup being undertaken?

Are you aware, and have you been briefed about environmental testing on adjoining properties to SHS?

It is not our purpose in this letter to accuse or threaten. We want to understand and if indeed there is a problem we want to work with you to find a solution. The anxiety of the SHS community is increasing and there needs to be a thorough and open discussion about the situation. We look forward to your response to these questions.

Sincerely,

James E. Hare
Sixth District Councilman
464 Cypress Street
Elmira, N.Y. 14904
733-7659

Dan Royle
Fifth District Councilman
729 Maple Avenue
Elmira, N.Y. 14904
734-4700

Andrew and Julie Patros
1127 Pennsylvania Avenue
Elmira, N.Y. 14904
733-9596

Timothy and Margaret Tobin
507 West Hudson Street
Elmira, N.Y. 14904
734-1178

Michael S. and Ann B. Smith
786 Cedar Street
Elmira, N.Y. 14904
732-4225

cc/Members of the Elmira School Board

Elmira City School District

**Joseph C. Farinola, Ed.D**
Interim Superintendent of Schools
(607) 735-3010

April 13, 2000

Mr. James E. Hare
Sixth District Councilman
464 Cypress Street
Elmira, NY 14904

Dear Councilman Hare:

Thank you for bringing your concerns to my attention. I have shared them with the Board and Dr. Farinola. As I indicated in our conversation, a meeting has been scheduled for Tuesday, May 2, 2000 at 7:00 p.m. at Southside High School. At the meeting a panel discussion will be moderated by Dr. Farinola which will address the issues raised in your letter. We may not provide closure, but will set the course for further community and State action by the official agencies. Please encourage any parents of stricken children to contact the County Health Department (737-2019), Mr. Kump, to share information for gathering statistical data which will aid in the official investigation.

I will be unavailable the week of April 14-16, 2000. Please feel free to call me the following week at home (732-5977) if you have any questions or suggestions for the meeting.

Sincerely,

Deborah W. Pierce

Deborah W. Pierce
President, Board of Education

DWP:sm

**Elmira City**
**School District**
951 Hoffman Street
Elmira, NY 14905
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CITY OF ELMIRA
317 E. CHURCH STREET
ELMIRA, NEW YORK 14901

JAMES E. HARE
COUNCILMAN

May 21, 2000

Mrs. Deborah Pierce, President
Elmira School Board
818 W. Water St.
Elmira, N.Y. 14905

Dear Mrs. Pierce:

We want to express our appreciation for your responsiveness to the concerns outlined in our first letter to you. Just this morning on WETM, your frank commitment to openness and seeking answers was reassuring. Your willingness to recognize responsible skepticism can be useful was also healthy. We see ourselves as playing the role of informed skeptics, sharing your goal of seeking and sharing answers as best we can.

The recent decision by the Board not to conduct a survey was disappointing. We agree that confidentiality is a concern. Therefore, perhaps what the Board should do is send a letter that alerts alumni and former staff of the issue and direct them to contact the Health Dept. with relevant information. We dispute cost as a factor. The District Newsletter which could be considered primarily a "puff piece" for the District, the recent speaker at the Conference Day and other expenses could also raise taxpayer questions. The letter we recommend serves a specific purpose. Each graduating class has a local contact person who has been involved in planning reunions and has active lists of addresses. Perhaps a staff person who has secretarial support could put a practical list together so that a mailing would be as efficient as possible. We also recognize that not all medical information, even cancer related, may be relevant, but the Health Dept. could be the judge of that.

During the WETM interview it was mentioned that a 1977 report was found that indicated oil in the ground, but that no other report has been located to indicate anything else. We would be interested in knowing the source of the 1977 report and obtaining a copy. Since the original contracters have not been forthcoming with information, has the school district made any effort to obtain records from them? Has the district made a search of its' own records on these matters?

Does the district have the original floor plan of the old factory? A number of people have called members of our committee to report that the plating operation was where the current building is. Apparently some of the worst potential pollution would have been generated there and could be under the building.

It seems to us that the documentation at the time of construction and the report not only on what has been found, but where on the campus tests have been made will be key to addressing the community concerns. In a conversation with Mr. Carlson, we indicated that we would be willing to participate in any preliminary review prior to a public meeting to work with you to make sure questions have been answered or at least addressed.

We appreciate your time and consideration of this matter.

Sincerely,

James E. Hare
Sixth District Councilman
464 Cypress St.
Elmira, N.Y. 14904
733-7659

Dan Royle
Fifth District Councilman
729 Maple Ave.
Elmira, N.Y. 14904
734-4700

Andrew and Julie Patros
1127 Pennsylvania Ave
Elmira, N.Y. 14904
733-9596

Timothy and Margaret Tobin
507 West Hudson St.
Elmira, N.Y. 14904
734-1178

# CITIZEN PARTICIPATION PLAN FOR REMEDIATION OF THE AMERICAN LAFRANCE FACILITY TOWN OF SOUTHPORT, CHEMUNG COUNTY, NEW YORK

**Prepared For:**

**STI Properties, Inc.**

**Prepared By:**

**URS Greiner Woodward Clyde**
**282 Delaware Avenue**
**Buffalo, New York 14202**

**June 30, 1999**

## 2.0 SITE DESCRIPTION

### 2.1 Physical Description

The ALF Site, located at 1051 South Main Street, Southport, New York (Figure 1-1), was originally part of an 83-acre parcel formerly owned by Remington Rand. Portions of the 83-acre parcel have been used for industrial manufacturing since the turn of the century.

The ALF Site occupies 47.7 acres and contains several industrial buildings with a total area of approximately 500,000 square feet. The northern portion of the site consists of a main building (Building 88) containing office and manufacturing space and several smaller buildings that were used by American LaFrance primarily for storage, sheet metal operations, and painting. The southern portion of the property is vacant property which includes a former parking lot and former picnic/recreation area. A non-functioning boiler house/coal storage building and incinerator are additional significant site features. ALF Site features are shown on Figure 2-1.

### 2.2 Operational History

As indicated, American LaFrance currently owns the southern 47.7 acres of a parcel that was originally 83-acres. The original parcel was used for manufacturing activities since 1887.

At the north end of the original 83-acre parcel, B.W. Payne & Sons produced high-speed steam engines between 1887 and 1909. From 1909 to 1935, the Morrow Manufacturing Company manufactured drill-chucks, machine parts and a line of tools for the machine trade. For the most part, both B.W. Payne & Sons and the Morrow Company conducted manufacturing activities north of the American LaFrance property.

Elmira Industries, Inc. bought the idle Morrow factory in 1935 and offered it free to Remington Rand if it would locate in Elmira. Rand accepted the offer and began manufacturing typewriter parts at the Site in 1936. During much of the period of Remington Rand's operation of the Site, the main manufacturing activities occurred North of the 47.7 acre property that was ultimately occupied by American LaFrance and not on the ALF site.

## 2.3 Topography, Geology, and Groundwater

The site is relatively flat with little vertical relief. A U.S. Geological Survey map of the area indicates the property has an approximate elevation of 850 feet above mean sea level (MSL). The closest bodies of surface water are Miller Pond located approximately 500 feet east of the site, Coldbrook Creek located approximately 250 feet east of the site, Seeley Creek located approximately 0.75 miles south of the site, and the Chemung River located approximately 1.25 miles north and east of the property.

According to the United States Department of Agriculture Soil Survey of Chemung County, New York (USDA, 1973), the soils at the site are classified as Made Land. This series is described in the Chemung County Soil Survey as excavated areas and areas modified by the placement of materials derived from various sources. The materials comprising this series typically consist of soil and rock fill material, material dredged from stream channels, rubble, trash, or refuse.

Chemung County lies in the glaciated portion of the Allegheny Plateau physiographic province. The entire county is underlain by bedrock, which is composed of sandstone and shale of Devonian age. Bedrock is estimated to have a relatively flat surface and occurs in the subsurface in the site area at approximate depths of 70 to 100 feet (Dames & Moore, 1988). Unconsolidated glacial deposits, consisting of till and stratified deposits of gravel, sand, silt, and clay, overlie the bedrock in most parts of the county. Based on test borings at the site, the geologic profile, generally, consists of 0.5 feet of soil underlain by an average of 5.0 feet of fill consisting of gravel, sand, silt, bricks, and trace amounts of cinders and ash. A heterogeneous mixture of gravel, sand, silt, and clay was encountered beneath the fill layer. Generally, the sand and gravel content in the subsurface increases with depth.

Groundwater supplies in the region are obtained from both the bedrock and overlying unconsolidated deposits. The highest well yields generally are from the unconsolidated sediments deposited within valleys and along stream channels. Groundwater quality of the area is considered to be acceptable for potable use, though, the hardness and iron content tend to be high.

American LaFrance purchased Westinghouse's lease of the remaining 47.7 acres in 1980, and used the Facility to manufacture and assemble fire engines from 1982 to 1985. American LaFrance conducted the majority of its manufacturing and assembly operations in Building 88 (the N-Plant). American LaFrance generated paint sludge, paint solvents, waste cutting oils and waste coolants during its operations. American LaFrance staged these wastes in an area east of the N-Plant and disposed them off-site. Figgie International, the owner of American LaFrance, obtained full title to the property from the Chemung County Industrial Agency in 1985, shortly before ceasing manufacturing activities at the property. Since 1985, the Site owned by American LaFrance has not been used for major industrial purposes. Significantly, the ALF Site has not been substantially used since 1985, when Figgie International curtailed all of its manufacturing activities at the site. Since then, this facility has been under-utilized, and currently is partially occupied by a wood pallet construction and reconditioning company, a bridge manufacturing company, a company warehousing old rail cars and parts, and a company recycling computers.

On April 10, 1987, the United States Environmental Protection Agency (USEPA) conducted a Potential Hazardous Waste Site Preliminary Assessment of the entire 83-acre parcel and subsequently listed it on the CERCLIS as a low priority site. Although the 83-acre parcel currently is not listed in the NYSDEC Registry of Inactive Hazardous Waste Disposal Sites, the NYSDEC has designated the entire parcel as a "P" site, indicating that it is a potential Registry candidate.

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Subsequently, the ALF Site was included on the inventory list of the NYSDEC Hazardous Substances Waste Disposal Site Study report submitted to the New York State Legislature (the "Hazardous Substances Sites Study"). Sites included in the Hazardous Substances Sites Study were those which NYSDEC reported to the Legislature would not, or should not be dealt with under the inactive hazardous waste disposal site program. The Legislature is reviewing the Hazardous Substances Sites Study to determine whether it is appropriate to enact new legislation to deal with the sites listed in the study.

**TABLE 3-1**
**HAZARD CHARACTERISTICS OF SELECTED CHEMICALS DETECTED AT THE AMERICAN LAFRANCE FACILITY**

| Substance | Toxicity/Carcinogenicity | Permissible Exposure Limits (PELs)* |
|---|---|---|
| Polynuclear Aromatic Hydrocarbons (PAHs) | Many PAHs are toxic by inhalation and easily absorbed by the skin. Prolonged exposure may result in tissue injury, dermatitis, and chemical burns. Inhalation of high concentrations can result in bronchial irritation, cough, hoarseness, and pulmonary edema. Acute doses are toxic to many tissues, but the thymus and spleen are particularly sensitive. Some PAHs are confirmed human carcinogens. | There are no established PELs for PAHs as a group. Some PAH compounds have no PELs while some have a PEL of 0.2 mg/m³. |
| Polychlorinated Biphenyls (PCBs) | Highly toxic. Suspected human carcinogen. | Control exposure to lowest feasible limit (NIOSH). |
| Beryllium | Highly toxic, especially by inhalation of dust. A known OSHA carcinogen. | 0.002 mg/m³<br>0.005 mg/m³ (Ceiling)(1) |
| Chromium (Dust and salts) | Highly toxic, especially by inhalation of dust or fume. A known OSHA carcinogen. Ingestion usually induces a strong emetic action. | 0.5 mg/m³ (Trivalent)<br>0.1 mg/m³ (Ceiling)(1)(Hexavalent) |
| Lead (Inorganic dust and fumes) | Toxic by ingestion and inhalation of dust or fumes. Three types of lead poisoning include alimentary, neuromotor, and encephalic. Some lead compounds are experimental carcinogens of the lungs and kidneys. | 0.05 mg/m³ |
| Nickel (Elemental) | Poison by ingestion, intratracheal, and intravenous routes. May cause dermatitis. Experimental carcinogen. | 1.0 mg/m³ |
| Zinc (Zinc oxide dust) | Low toxicity. Zinc chromates and arsenates are experimental carcinogens. | 10 mg/m³ (Total)<br>5 mg/m³ (Respirable) |

* PELs are 8-hour Time-Weighted Averages (TWAs) unless otherwise noted.

NEW YORK STATE
DEPARTMENT OF HEALTH

NEW YORK STATE
DEPARTMENT OF
ENVIRONMENTAL CONSERVATION

MAY 2000

# FACT SHEET - SOUTHSIDE HIGH SCHOOL

## Introduction

On April 8, 2000, the Elmira City School Board received a letter from parents expressing concern about an unusual number of cancers among current and former students at Southside High School. The school board asked the New York State Department of Environmental Conservation (DEC) and the New York State Department of Health (NYSDOH) to attend the May 2, 2000 school board meeting to address concerns about cancer among students and provide information about environmental conditions in the area. This fact sheet was prepared by the NYSDOH and DEC to summarize the planned evaluation of cancer occurrence, the ongoing environmental testing at and near the Southside High School, and the proposed plans for the future.

## Cancer Occurence

Cancer is a rare disease in children when compared with its occurrence in adults. Still, cancer will affect one in every 300 children by the time they reach the age of 20. The types of cancer that are most common in children are leukemia, cancers of the brain and other parts of the nervous system, and lymphomas, including both Hodgkin's disease and the non-Hodgkin's lymphomas.

Public concern has arisen over reports of an unusual number of cases of cancer among current and former students at Southside High School. Much of this concern centers on reports of three cases of testicular cancer (cancer of the testes). Although testicular cancer is relatively uncommon for males of all ages taken together, nationally it is the second most common type of cancer among white males ages 15-19, and the most common type of cancer among white males ages 20-35.

The NYSDOH will review and evaluate all available information on cancer in current and former students at the Southside High School. This will include any information that may be provided by members of the public and school and local officials, as well as information obtained from the New York State Cancer Registry. As mandated by law, the New York State Cancer Registry obtains information on all cases of cancer diagnosed and/or treated in New York State. Information on cancers in New York residents who are treated in other states is also obtained through agreements with many other state cancer registries, including Pennsylvania's. Characteristics of confirmed cases of cancer will be examined in order to identify any unusual patterns in the numbers and types of cancers found, and their timing and geographic distribution that would indicate the possibility of a common source. The results of this evaluation will determine what, if any, additional study is needed.

## Air and Water Testing at Southside High School

In 1995, fuel oil contamination was discovered on Miller Pond, east of Southside High School. A DEC investigation (described in the next section) indicates that the contamination extends underneath the high school. The contamination is approximately 15 feet below ground. No one is coming in direct contact

(exposure) with petroleum wastes at the school. To be affected by chemicals in these wastes, a person would have to be exposed to the chemicals. To determine exposure to a chemical you must consider not just the presence of the chemical, but how you might be exposed. Exposure requires direct contact with contaminated material by swallowing it (ingestion), breathing vapors (inhalation), or by absorbing it through the skin (dermal contact) following direct contact. In this situation, the most likely route of exposure would be through inhaling petroleum vapors. In order for indoor air to be affected by the petroleum contamination, several steps must occur: (1) the petroleum must migrate near or under the school, (2) vapors from the petroleum must travel through the soil and then (3) be drawn into the school through openings in the foundation.

DEC conducted air sampling at the high school in 1997 to assess possible air quality impacts. The results of this air testing do not show a general indoor air contamination problem at the school. The majority of the air samples collected within the school showed levels of volatile chemicals that are typically found in indoor air. One sample collected from the library contained toluene at a level four to five times what is typically found in indoor air; other chemicals were within typical ranges. Toluene is a common chemical found in inks, glues and nail polish, as well as petroleum. Since some products that contain toluene, such as glues used in libraries, finding toluene above background levels is not surprising. Although we do not know the exact source of the toluene, the risk of experiencing health effects at the level reported in 1997 is minimal. Recently, an additional air sample was taken in the library and those results will be available shortly.

To address current concerns about the high school, DEC conducted additional indoor air testing in the school on April 19, 2000. The NYSDOH will evaluate these results when they are available. Additionally, DEC took tap water samples from inside the school to verify water quality. The drinking water at the school is provided by the Elmira Water Board, which supplies the City of Elmira and some of the surrounding area. The main sources of the water are the Chemung River and several supply wells located near the river. The Elmira Water Board routinely tests the water, and it meets all state and federal requirements for drinking water quality. DEC also used ground-penetrating radar to find out if underground storage tanks exist on school property. Results from this testing do not show underground storage tanks on the school property. On April 27, 2000, DEC installed soil gas probes under the foundation of the school to determine if petroleum vapors are present in the soil gas under the school. The NYSDOH will monitor these probes to determine if vapors are present that may affect the school.

## Environmental Investigations:

**1) Miller Pond/ Former Remington Rand Oil Spill:**

In 1995, an oil sheen on Miller Pond was reported to DEC. DEC began an investigation, starting along the shoreline of Miller Pond, eventually including Southside High School property and the nearby residential area.

DEC installed 29 groundwater monitoring wells to determine groundwater flow direction and to determine the source of the petroleum contamination. In addition to the indoor air sampling mentioned above, DEC tested for petroleum from more than 30 soil borings and several test pits (small excavations to look for underground tanks or contamination). The investigation indicated that a plume of fuel oil contamination exists in groundwater within the area bounded by Southside High School to the west and Miller Pond to the east (see figure 1). The plume is located approximately 15 feet below ground. The investigation did not detect any petroleum-related surface soil contamination throughout the project area.

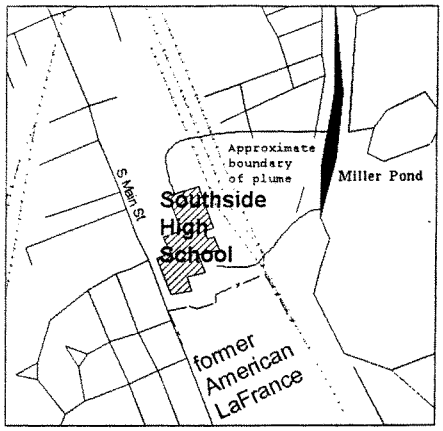
The fuel oil contamination is believed to have resulted from the activity of industries that previously occupied the area. The Remington Rand Corporation and other companies used property, including the parcel where Southside High School now stands, for a variety of industrial purposes until 1973. Records indicate that underground petroleum storage tanks existed on the site when it was an industrial property. However, investigations to date have not revealed any tanks remaining on the property.

***How Will the Fuel Oil Contamination be Addressed?***
DEC plans to use a technique called bioremediation to address the fuel oil contamination. Pure oxygen will be injected into the groundwater to stimulate naturally occurring soil organisms. The organisms will break down the fuel oil, mainly into carbon dioxide and water.

Initially, oxygen will be injected through a series of injection points drilled immediately behind Southside High School. The injection points will be connected underground to oxygen-generating equipment. There should be no disruption of school activities. The oxygen-generating equipment will be stored off of school property, so there will be no above-ground equipment on school property once the system is operating.

It is expected that field work will begin within two to four weeks and be completed in two to three months. Groundwater will be tested periodically to determine the effectiveness of the system. As the cleanup progresses, more injection points will be added toward the east, in the direction of Miller Pond. DEC collected groundwater samples from all site monitoring wells in March 2000. The results will be used as a baseline for evaluating the effectiveness of the bioremediation technology. DEC also will take additional soil samples during the installation of the oxygen injection points to test for non-petroleum related substances.

Figure 1




**The Former American LaFrance Voluntary Cleanup Site:**
The former American LaFrance site is located at 1051 South Main Street, south of Southside High School (figure 1). The site has been used for a variety of industrial purposes. American LaFrance, Inc., produced fire engines at the site between 1982 and 1984. No significant manufacturing has taken place at the property since then. Between 1991 and 1997, American LaFrance conducted environmental investigations on the property. The results indicated soils from the surface to a depth of 2 feet were contaminated with polynuclear aromatic hydrocarbons (PAHs). PAHs are a group of chemicals that are found in petroleum products and can form during incomplete burning of petroleum, garbage, wood or other organic substances like tobacco or charbroiled meat. Metals, including cadmium, chromium, and lead, were also found in low concentrations in surface soils, with elevated concentrations in a few isolated locations. Investigations have not shown contamination in groundwater at the site.

In 1999, the current owner of the site, Scott Technologies, Inc., signed a voluntary agreement with DEC to excavate and remove PAH contaminated soil up to three feet below the ground surface. This work included the removal of soil with higher concentrations of metals. The excavation was completed in December 1999.

***Could Southside High Students and Staff be Exposed to Contaminants from the Former American LaFrance Site?***
Since the areas with elevated PAHs in soil were located within a fenced portion of the property, these areas were not readily accessible to students and staff of the high school. During the excavation work, dust levels

were monitored at the perimeter and showed that the efforts to minimize dust had been effective. Since any contamination at the surface and near surface has been removed, people are not being exposed to contaminants at the American LaFrance site.

Additionally, as part of the voluntary agreement with DEC, Scott Technologies has agreed to restrict future uses of the property to industrial or commercial purposes.

## What are the Next Steps?

Because of the concerns raised by parents, NYSDOH will evaluate the occurrence of cancer among students at the high school. The results of this evaluation will determine what if any additional cancer investigations are warranted. NYSDOH will also evaluate the results of the indoor air tests that will be conducted at the school. As our investigation progresses, the DEC and NYSDOH may perform additional investigations to assess potential exposures of the students and staff to contaminants. If any exposures are identified, the DEC and NYSDOH will evaluate ways to reduce them.

As mentioned above, the NYSDOH will monitor these probes and determine if vapors are present that may affect the school. To begin the remediation (clean-up) of the underground petroleum DEC will begin the process of oxygen injection system within a few weeks.

Results of the work being performed by the DEC and NYSDOH will be shared with the public as soon it is available.

## For More Information:

Documents related to the oil spill site and the former American LaFrance site are available at the Southside Branch Library, 328 S. Main Street, Elmira, (607) 733-4147. Please contact the following if you have questions about:

**Health Concerns**:
Dawn Hettrick, Assistant Sanitary Engineer, NYSDOH (800) 458 - 1158, Ext 27860; or
Mark VanDeusen, Outreach Coordinator, NYSDOH (800) 458-1158, Ext. 27530

**Cancer Concerns**:
Aura Weinstein, Director, Cancer Surveillance Program (518) 474-2354

**Miller Pond/Former Remington Rand Oil Spill:**
Scott Rodabaugh, DEC Horseheads Office (607) 739-0809

**Former American LaFrance Voluntary Cleanup Site:**
M.D. Mehta, DEC Avon Office (716) 226-5354
Meaghan Boice-Green, DEC Avon Office (716) 226-5326

New York State Department of Environmental Conservation

# FACT SHEET

August 2000

## SOUTHSIDE HIGH SCHOOL

**Introduction**

In response to concerns raised at a May 2, 2000 public meeting, the New York State Department of Environmental Conservation (NYSDEC), in consultation with the New York State Department of Health (NYSDOH), initiated an environmental sampling program at the Southside High School and nearby adjacent properties. Southside High School is located in Elmira, New York, has approximately 1300 students and was built in the late 1970's on property used for industrial manufacturing from approximately 1880 to 1974. The purpose of this fact sheet is to update you on the status of this environmental sampling program.

**Background**

Between May and August 2000, 135 samples were collected to provide environmental data on soil, groundwater, surface water and sediment at and near Southside High School. Sampling locations are shown on Figures 1 and 2. Investigative efforts were extensive, with emphasis on the school property, and greatly exceeded the amount of sampling typically involved in an environmental investigation, especially in the time frame in which this investigation was conducted. Sampling locations were carefully selected and were based upon available information, requests received from the public, consultation with the NYSDOH, and best professional judgement. Resampling occurred at select locations after review of initial analytical results. These additional data provide confidence relative to the extent and magnitude of the chemicals found.

Samples included different media (soil, sediment, groundwater, and surface water) for a wide range of analytical parameters. Forty-one surface soil samples, seventy-nine subsurface soil samples, eight groundwater samples, two surface water samples and five sediment samples were collected. Analytical parameters evaluated for this project were extensive and included volatile organic compounds (VOCs), semi-volatile organic compounds (SVOCs), metals, pesticides and polychlorinated biphenyls (PCBs). NYSDOH and NYSDEC had previously performed air testing. NYSDOH's Health Consultation concludes that, based on the air monitoring data, the indoor air at the Southside High School poses no apparent public health hazard.

**Discussion of Results**

Southside High School Property

Volatile organic compounds (VOCs) are chemicals that easily evaporate. Some VOCs are chlorinated solvents which have a variety of uses in various industrial operations including equipment degreasing and cleaning. Eighty-nine soil samples collected across the school property were analyzed for thirty-six VOCs. Results were compared to the NYSDEC recommended residential soil cleanup objectives which are used as guidance in the evaluation of inactive hazardous waste disposal sites. In these analyses, there were two exceedances of NYSDEC recommended residential soil cleanup objectives detected in the subsurface of the football field that NYSDEC believed warranted further evaluation. One soil sample

collected at the north end of the football field contained one volatile organic compound called trichloroethene (TCE), a common industrial solvent, at 110 parts per million (ppm) at the 2-4 feet depth and 11 ppm at the 6-8 feet depth. The NYSDEC recommended residential soil cleanup objective for TCE is 0.7 ppm. Resampling at this location on August 14, 2000 did not detect any TCE. This resampling reinforces the presumption that any contamination is sporadic and not widespread. Trichloroethene was detected in downgradient groundwater monitoring wells at or near the NYS drinking water standard of 5 parts per billion. Results ranged from 1 to 9 ppb. Groundwater is at a depth of approximately 15 feet. There is no exposure to this groundwater because public water is supplied to the school which meets all state and federal standards. While TCE appears to be sporadically present in the subsurface on the school property, analysis of surface soil samples did not detect any VOCs on the school property in excess of the NYSDEC recommended residential soil cleanup objectives. Given the fact that VOCs were not detected in the surface soils above the NYSDEC recommended residential soil cleanup objectives and the water supply is uncontaminated, there is little potential for exposure. The infrequency and low concentration of detections indicates there is no widespread TCE contamination.

Several semi-volatile organic compounds (SVOCs) were detected at various locations above NYSDEC recommended residential soil cleanup objectives in soils on school property. Most of the SVOCs detected at this site are typical constituents of combustion byproducts and asphalt pavement. Generally, these compounds were detected in the subsurface where exposure is limited. SVOCs were detected in all seven groundwater samples but at very low concentrations and none exceeded NYS groundwater standards. The NYSDOH Health Consultation developed for this site concludes that the subsurface SVOC levels in soil at Southside High School pose no apparent public health hazard.

Metals were also detected above the NYSDEC recommended residential soil cleanup objective in several locations across the school property. Several metals were detected above typical background concentrations in surface and subsurface soil samples. The NYSDOH Health Consultation prepared for Southside High School concludes that the site does not pose an apparent public health hazard. Metals concentrations detected in the soil are likely a result of past industrial operations and do not represent an environmental threat. Metals do not readily migrate in the subsurface and exposure is limited. Water from four monitoring wells located downgradient from the school property was analyzed and no NYS groundwater standards for metals were exceeded.

There were no exceedances of the NYSDEC recommended residential soil cleanup objective for pesticides in any of the seventy- four soil samples taken on the school property. No pesticides were detected in any of the seven groundwater samples.

Polychlorinated biphenyls (PCBs) are synthetic chemical compounds which are oily-type substances that are no longer manufactured. They were widely used as coolants, insulating materials and lubricants in electrical equipment. There were no PCB exceedances of the NYSDEC recommended residential cleanup objective in any of the twenty surface soil samples. PCBs were detected above the NYSDEC recommended residential soil cleanup objective in four of the fifty-seven subsurface locations sampled on the school property. Exceedances were found as follows: on the football field one to three feet below the surface, near the northwest corner of the school at four to five feet below the surface, near the northeast corner of the school at four to six feet below the surface and on the east side of the school at one to three

feet below the surface. While there are exceedances of NYSDEC recommended residential soil cleanup objectives for PCBs, exposure is limited by the soil and grass cover which acts as a barrier to public contact. Additional sampling near these locations did not replicate these concentrations indicating PCBs concentrations above the NYSDEC recommended residential soil cleanup objective are not widespread on the school property. PCBs tend to remain adsorbed to soil and do not readily migrate. Monitoring of downgradient groundwater did not detect any PCBs.

Off-site Properties

Investigation was also performed at selected off-site locations. Please refer to the attached figure. Based on available information, the New York State Electric and Gas (NYSEG) property east of the school is hydraulically downgradient of the school. Analytical results from sampling on the NYSEG property did not identify any contaminants of concern. As discussed above, TCE was detected in groundwater at or near the NYS standard. Two surface water samples were collected from the outflow of the pond located on the north end of the Former American LaFrance property. No contaminants of concern were identified from the surface water sampling. Sediments in the unnamed tributary connecting the pond to Coldbrook Creek were also sampled. Elevated levels of SVOCs, metals, and PCBs were detected and warrant further evaluation to determine the nature and extent of contamination and appropriate remediation. Soil and groundwater were also sampled on the Former American LaFrance recreation area. Elevated levels of metals and SVOCs were detected and warrant further evaluation.

**Conclusion**

While exceedances of NYSDEC recommended residential soil cleanup objectives or NYS groundwater standards were detected in a few samples at different locations across the site, consequential amounts of hazardous waste were not identified. Evaluation of the data does not indicate that a significant threat to public health or the environment exists on school property. This site does not qualify for inclusion in the New York State Registry of Inactive Hazardous Waste Disposal Sites because there are no consequential amounts of hazardous waste and there is no significant threat to public health or the environment. The NYSDOH Health Consultation concludes that Southside High School poses no apparent public health hazard. Some off-site areas (the unnamed tributary of Coldbrook Creek and portions of the Former American LaFrance site) warrant further investigation. NYSDEC will follow-up on both off-site areas.

Next Steps

A more detailed presentation of this sampling program and its results will be given at the upcoming public meeting. This meeting is scheduled for 7:00 pm on August 23, 2000 and will be held at the Southside High School auditorium. Additional information can be obtained by contacting:

Health-related issues
Mark Van Deusen
NYSDOH
547 River Street
Troy, NY 12180
800-458-1158 ext 27530

Environmental issues
Mary Jane Peachey, P.E.
NYSDEC
6274 E. Avon-Lima Road
Avon, NY 14414
716-226-5353

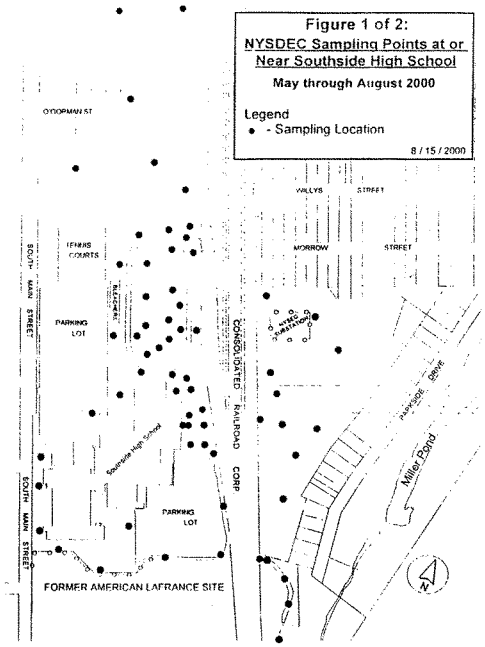
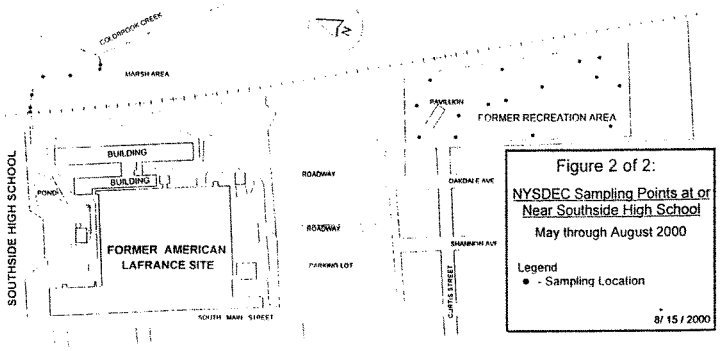


Figure 1 of 2:
NYSDEC Sampling Points at or Near Southside High School
May through August 2000
Legend
• - Sampling Location
8 / 15 / 2000
O'DOPMAN ST
WALLYS STREET
MORROW STREET
TENNIS COURTS
PARKING LOT
SOUTH MAIN STREET
CONSOLIDATED RAILROAD CORP
Southside High School
PARKING LOT
Miller Pond
FORMER AMERICAN LAFRANCE SITE
N


COLDBROOK CREEK
MARSH AREA
PAVILION
FORMER RECREATION AREA
BUILDING
BUILDING
POND
ROADWAY
ROADWAY
PARKING LOT
OAKDALE AVE
SHAMROCK AVE
CURTIS STREET
SOUTHSIDE HIGH SCHOOL
FORMER AMERICAN LAFRANCE SITE
SOUTH MAIN STREET
Figure 2 of 2:
NYSDEC Sampling Points at or Near Southside High School
May through August 2000
Legend
• - Sampling Location
8/ 15 / 2000

DOH

**FACT SHEET**
**August 23, 2000**

**INVESTIGATION OF CANCER AMONG STUDENTS AT THE SOUTHSIDE HIGH SCHOOL, ELMIRA, NEW YORK**

The New York State Department of Health conducted an investigation of cancer among students attending the Southside High School in Elmira, New York. This investigation was spurred by reports of an unusual number of students diagnosed with cancer during the 1999-2000 school year and also among students attending the school since 1997. The community also expressed concern about fuel oil contamination in the ground beneath the school, and the nearby American LaFrance industrial site, where a voluntary environmental clean-up recently took place.

**Cancer among current and former students**

Case confirmation: Community concerns focused on reports that at least six students attending Southside High School were diagnosed with cancer during the 1999-2000 school year. There were also reports that 13 students were diagnosed with cancer since 1997. To confirm these reports, information about current and former students believed to have cancer was collected from community members. This information was compared with various data sources available to the Department of Health. These include contacts with hospitals and physicians, as well as the New York State Cancer Registry (NYSCR), which collects information on all individuals diagnosed with cancer in New York State, as required by law.

**46 students reported as having cancer**

**35 confirmed with illnesses**

- 25 had cancer
  - 3 diagnosed before entering Southside High School
  - 22 diagnosed while attending or after leaving Southside High School
- 10 had health conditions other than a reportable cancer

**11 unable to confirm**

- 8 moved out of state prior to reported date of diagnosis
- 3 not enough information to confirm diagnosis

A total of 46 students who attended Southside High School were reported to us as having cancer. We were able to confirm 25 of them as having cancer and 10 as having health conditions other than a reportable cancer (the most common types of skin cancer are not reportable to the NYSCR). Of the 25 individuals confirmed with cancer, three were diagnosed with cancer before attending Southside High School. Among the remaining 22, the most common types of cancer found were leukemias and lymphomas (including Hodgkin's disease and non-Hodgkin's lymphomas). Other types of cancer found included testicular, cervical and brain cancers. (To protect patient confidentiality, if fewer than six people were diagnosed with a particular type of cancer, we cannot provide the exact number.)

Of the 11 students not confirmed, eight moved out of state prior to their diagnosis. Sufficient information that would allow us to confirm a cancer diagnosis was not available for the remaining three.

Of the seven students reported to have cancer while attending Southside High School in 1997 or later, fewer than six were confirmed as actually having cancer. The total number confirmed includes individuals who were diagnosed prior to entering high school. Those not confirmed as having cancer were confirmed to have other health conditions.

The types of cancer diagnosed among students attending or who attended Southside High School are similar to those expected in this age group. Leukemia, lymphoma, and brain cancer are the most common types of cancer among children ages 15-19. Testicular cancer is one of the most common cancers in males ages 15-34 years.

Comparison with expected: The community also had concerns about whether the number of cases of cancer among students who have attended Southside High School was unusual. To address this concern, the number of cancer cases that were confirmed was compared with the number that would be expected among all students who ever attended Southside High School. Enrollment figures from the time the school opened in the fall of 1979 through the 1999-2000 school year were used to determine how many students attended Southside High School and how old they would be at different points in time. From this, we calculated that 48 students would be diagnosed with cancer between 1980, when the first class graduated, and June 2000 (this number is referred to as "expected cases"). Thirty-nine of these students would be expected to be diagnosed with cancer between 1990 and 2000. (This is because cancer becomes more common as people age and the number of people who ever attended Southside High School was larger.) The total number of people confirmed as having cancer was less than the total number of people expected to be diagnosed with cancer in the time since the high school opened. This was also true for the most recent 10 years, when the majority of the confirmed cases were diagnosed. Looking at the most common types of cancer separately, the numbers of confirmed cases were not statistically greater than what would be expected in either time period for any particular type of cancer.

**Among students who had ever attended Southside High School**

22 reported and confirmed as being diagnosed with cancer 1980-2000

48 cases expected 1980-2000

39 cases expected 1990-2000

**Geographic study**

Cancer incidence in the geographic area served by Southside High School was also examined. This allowed us to take into account people with cancer who may not have been reported by community members. Using the NYSCR, children ages 0-19 who were diagnosed with cancer since 1980 and who lived in ZIP Codes 14904 (Elmira), 14871 (Pine City) and 14894 (Wellsburg) at the time of diagnosis were identified (please see accompanying map). The total number of children with cancer in this group, as well as the number with each type of cancer, were compared to the numbers expected. The expected numbers were calculated based on the number, age and sex of children living in the three ZIP Code areas and the rates of specific types of cancer for children in New York State, excluding New York City.

**Cancer cases diagnosed 1980-1998 among children living in ZIP Code areas 14904, 14871, 14894**

Children ages 0-19
22 cases observed, 23 cases expected

Children ages 15-19
6 cases observed, 7 cases expected

A total of 22 children living in the three ZIP Code area were diagnosed with cancer from 1980 to 1998. A total of 23 cases was expected. In examining specific types of cancer, the most commonly observed types were leukemia (9 cases observed, 6 expected), cancers of the brain and other parts of the nervous system, and lymphomas. No particular type of cancer was found to be statistically higher (or lower) than expected.

We also looked at the 15-19 age group, the group corresponding to those attending high school or having just graduated. Six young people were diagnosed with cancer, compared with seven expected. There were no statistically significant differences between observed and expected numbers of cancer cases for any particular type of cancer in either males or females.

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**Cancer since 1997**

Community members expressed particular concern over the number of cases of cancer among students attending the high school since 1997. To address this concern, we combined information from the geographic study and the case confirmation study for people ages 15-19. The total number of students diagnosed with cancer was less than six, but greater than the number expected (approximately one case). The difference between the total number of students actually diagnosed with cancer and the number expected was not statistically significant. This means that it could have occurred by chance. Looking at specific types of cancer, however, the majority of the students diagnosed in this time frame were diagnosed with testicular cancer. The number of young men diagnosed with testicular cancer was statistically significantly greater than the number expected.

**Summary**

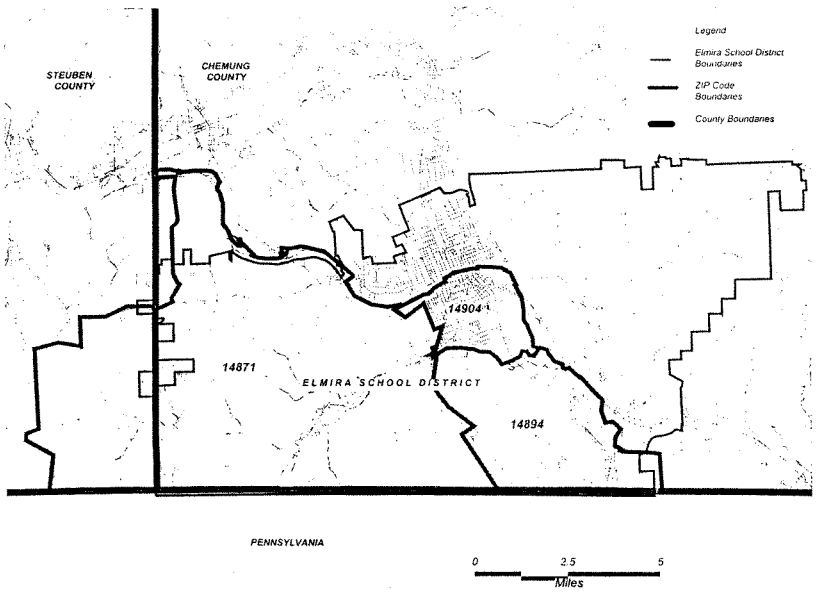
Looking at the overall time period since Southside High School opened, we did not find an unusual pattern of cancer among current and former students. No unusual pattern of cancer was found among children living in the area served by the school. The numbers and types of cancers diagnosed were similar to what would be expected for this age group. There was a perception that a large number of people attending or who attended Southside High School since 1997 have been diagnosed with cancer. This may be explained by a small number of students diagnosed with cancer while attending Southside High School, combined with students diagnosed with cancer before attending the high school and others diagnosed with health conditions other than cancer. Finally, although the actual number of cases is small, the study did confirm an unusual number of young men diagnosed with testicular cancer since 1997.

**Next steps**

The New York State Department of Health will continue to monitor cancer incidence among students at Southside High School and in the three ZIP Code area. We will continue to receive and investigate reports of cancers among current and past students. We will also examine the finding of an unusual number of young men diagnosed with testicular cancer in greater depth. We will look into the medical histories of these young men to determine if they have any known or suspected risk factors for the disease.

*For more information on the cancer investigation please contact Aura Weinstein or Janice Rocklin of the Cancer Surveillance Program of the New York State Department of Health at (518) 474-2354 or (800) 458-1158 (ext. 23454). The complete report on this investigation will be available the first week of September. Copies may be obtained by calling the Cancer Surveillance Program at the numbers listed above or by calling Thomas Kump, Chemung County Health Department, at (607) 737-2019.*

ZIP CODES 14904, 14871, 14894
CHEMUNG COUNTY, NEW YORK



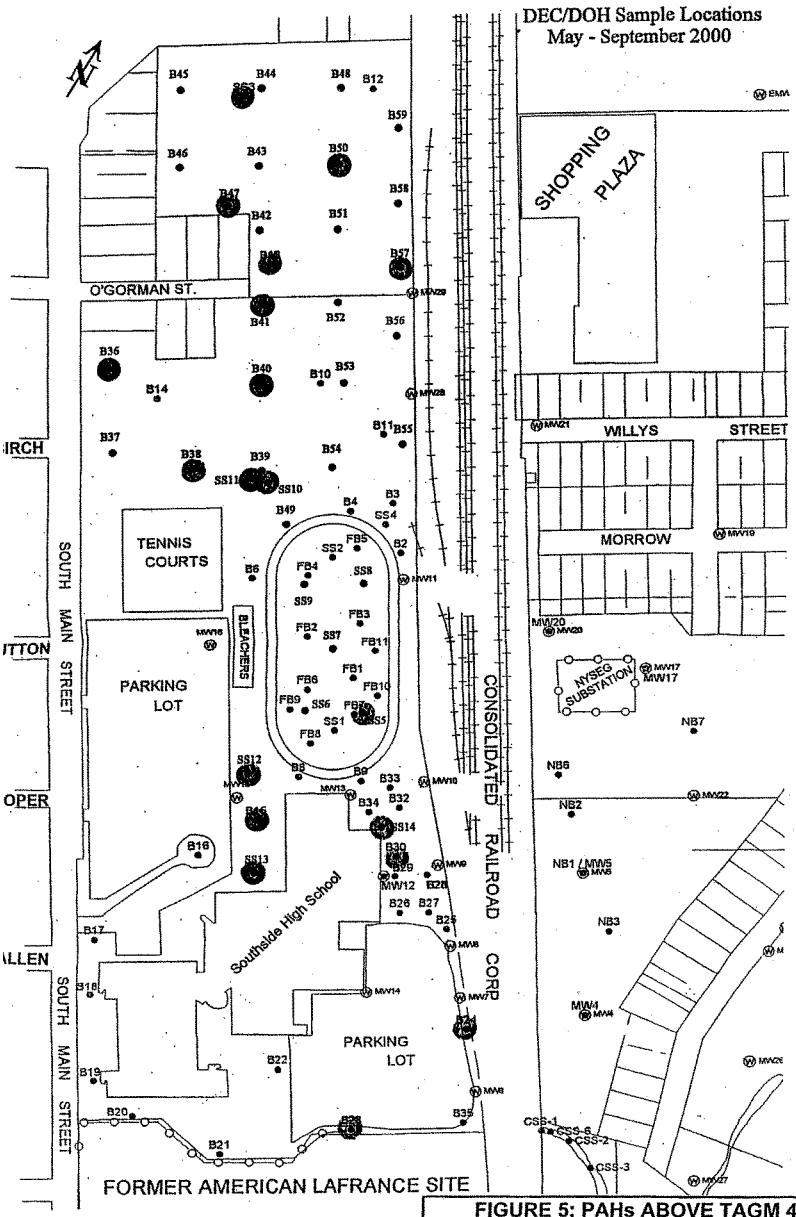



**FIGURE 5: PAHs ABOVE TAGM 4046 SURFACE SOIL: 0 TO 6"**

**Southside High School**

● PAHs Present

**NOT TO SCALE:**
**FOR PRESENTATION PURPC**

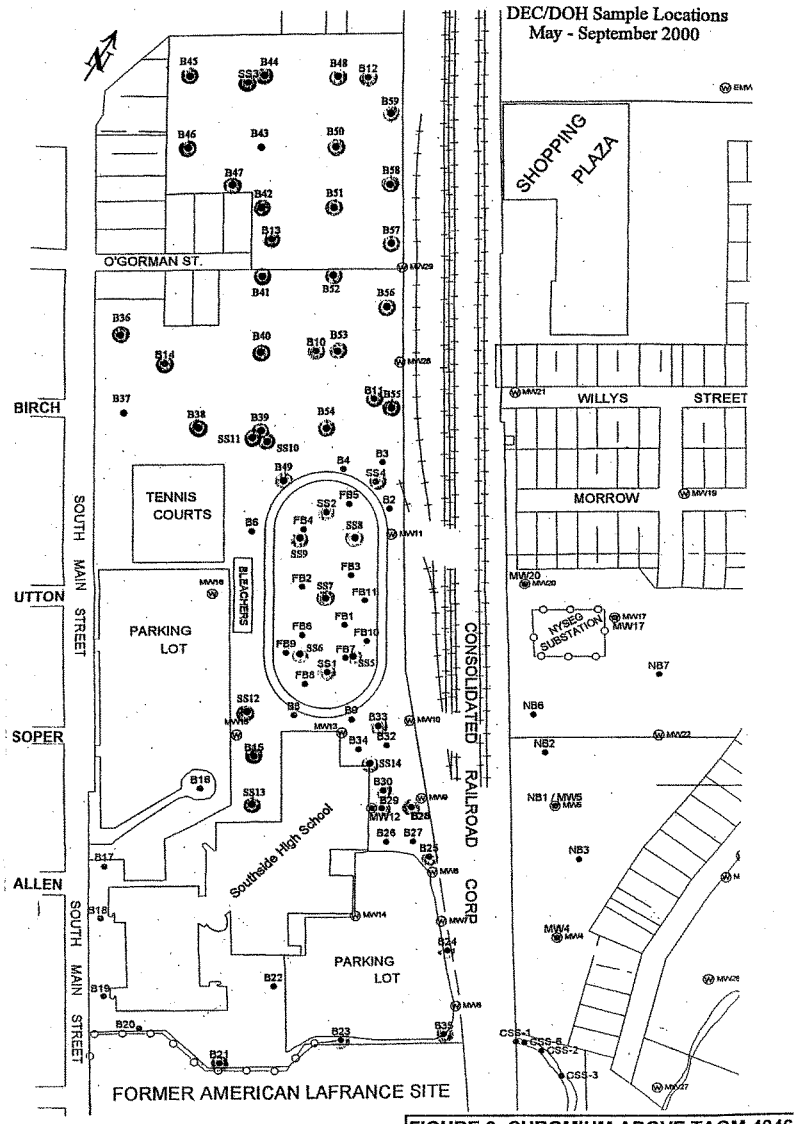



**FIGURE 6: CHROMIUM ABOVE TAGM 4046 SURFACE SOIL: 0 TO 6"**

**Southside High School**

Total Chromium Present

NOT TO SCALI
FOR PRESENT ES ONLY

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**SOUTHSIDE ADVISORY COMMITTEE**
**ELMIRA, NEW YORK**
**Listed Alphabetically**

DRAFT
ATTACHMENT #2
Hodgson, Russ, Andrews, Woods & Goodyear, LLP

**September 27, 2000**

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JUN-09-2001 09:42 SOUTHSIDE HIGH SCHOOL 607 735 3299 P.02

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**ELMIRA, NEW YORK**
**Listed Alphabetically**

**September 27, 2000**

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STATEMENT OF TIM TOBIN, ELMIRA, NY

My son, Michael, was diagnosed with testicular cancer on November 22, 1999. At that time, he was a 15-year-old sophomore, who ran cross-country, track, and raced bicycles. Nothing I can say can describe the feelings his mother and I experienced when told "your son has cancer". Michael underwent immediate surgery. In January 2000, we flew to Indianapolis for additional surgery at the center where Lance Armstrong was treated.

Within a week of my son's diagnosis and first surgery, a parent whose son was diagnosed with testicular cancer 2 years prior contacted me. This father and I began a dialog about cancer and the oddities of this disease. It would not be long until a third young man would come to be diagnosed with testicular cancer. Researching National Cancer Institute Data, first to find information about the nature, treatments, and survivability of this cancer, and later to assess the "peculiarities" of testicular cancer cases among young men led me to a startling discovery.

The NCI data for the occurrence of testicular cancer is between 3 to 4 cases per 100,000. Almost 70 percent of these cases occur in men in their mid twenties to early forties. Rates for people of Hispanic descent, such as my son, are less. The NCI statistics, in addition to with what I would later learn about chemicals used in industrial manufacturing that are in the ground where my son attends school, lead me to this conclusion—I had a greater statistical likelihood of developing testicular cancer than my son, unless there was another factor at play. Coupled with the growing awareness of other cancer cases, this was cause for concern and inquiry.

Elmira, NY has been home to many former industrial sites typically found in northeastern cities. My son's high school was built on a site that had experienced 100 years of industrial use. During the years of manufacture, some of the chemicals used and that are still present on the site include, but are not limited to PCB's, chromium, beryllium, arsenic, lead, nickel, zinc, phthalates and trichloroethelene. All of the above chemicals are known to, or highly likely, to be carcinogenic.

In evaluating the site various criteria was used to determine safety. Many of the chemicals in the soils at Southside High School and in the industrial site that still stands right next door exceed acceptable human exposure limits from either the EPA or the NYSDEC. However, they were still determined to be safe. In many cases, the NYSDOH stated that exposure would not occur due to a "well established grass cover" (NYSDOH Preliminary Draft August 22, 2000)

I have also read recent Federal studies on phthalates have indicated that exposure to this chemical causes "testicular lesions" in lab animals. (Center for the Evaluation of Risks to Human Reproduction). I also must question the inherent contradiction that this area is safe when several experts have repeatedly stated that "we could not build this facility here today as it would not pass industrial standards." And no where in all of the data, studies, and reports from any of the different investigate or public health agencies, is there a mention that this site is on or directly contiguous to a DEC Class 2 Superfund site. This information, taken directly from DEC files by NYPIRG, was published in the Elmira Star-Gazette on May 30, 2001.

I would submit that clear-cut standards of chemical levels and exposure levels be implemented across the board. Further discussion, such as issues raised by the U.S. News and World Report on June 19, 2000 or measures recommended in "Poisoned School—Invisible Threats, Visible Actions," needs to be engaged. Clean-up measures should be taken to meet these standards. Public notification of schools when an industrial cleanup takes place is a must. In September 1999, such a cleanup was taking place during school hours at the site next door to my son's school. I can only imagine the chemical exposure that children were unknowingly subjected to from this activity.

I believe that industrial waste is a danger to humans. I believe that a more diligent, cooperative approach to "fix" the problem, rather than place blame is needed.

In particular, I believe that these substances are enhancing the risks and rates of cancer in our children. This is one risk that needs to, and can be, eliminated.

I would like to thank the city of Elmira and its elected officials for the position and leadership they have taken on this issue. I would like to thank all of the members of the committee for your interest in this matter.

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STATEMENT OF KAREN JOY MILLER, FOUNDER AND PRESIDENT, HUNTINGTON, NY, BREAST CANCER ACTION COALITION

Good morning. I am Karen Joy Miller from Huntington Long Island and I'd like to begin by thanking this esteemed panel for allowing me to testify today. Senator Reid, Senator Clinton, Congressman Ackerman, Congressman King, Congress-

woman McCarthy, Congressman Grucci and Congressman Israel, you have all been very supportive of grassroots efforts to put an end to breast cancer and this hearing is evidence of your concern.

I have lived on Long Island for 33 happy years raising three children with my husband Michael. 1987 was the year when our peaceful existence was shattered by the news of my breast cancer diagnosis. Thanks to the wonderful support of my immediate family. I was eventually able to regain my breath. Once on my feet, I was fortunate enough to find three other women in my town who were willing to ask the vital question: WHY? Together we started the Huntington Breast Cancer Action Coalition, whose first major project was to map the incidence of breast cancer within our township. I always knew that education equaled power . . . the power to create change. With that in mind, I set out to arm myself with solid information. I read all I could, asked innumerable questions and along the way was lucky enough to meet the experts and learn from them.

Breast cancer is a disease that has been puzzling us for centuries. We have come a long way in solving this puzzle but it is an undeniable fact that we have just begun the serious research into understanding the relationship between the toxicity of our environment and disease. Even though we are all hearing about the major breakthroughs in the fight against cancer, such as the completed Genome Project and the new wonder drug Gleevec, there is a long way to go before we can rest easy.

The efforts of our Coalition along with many grassroots groups nationwide, have laid the groundwork by increasing public's awareness of breast cancer. The growing number of women having regular mammograms is proof of that very effort. Yet, despite the heightened awareness and vigilance, breast cancer rates have jumped by 40 percent since 1973. THAT IS SERIOUS cause for alarm!

Earlier I mentioned the mapping project initiated by our coalition Huntington Breast Cancer Action Coalition. Please take a moment to look at the dots. Each of these dots, no matter what the color, represents a woman who is ALSO asking the question why? She is willing to provide any answers the researchers want to know. She is willing to tell you confidential information about herself. She is one of the millions who want to know WHY?

Our high-tech world makes our lives more comfortable and convenient by the day, yet that same world bears responsibility for toxic pollution. Industrialization has been at the core of our success as a society, but the price has been much too high in terms of our health.

Breast cancer activists as well as informed people everywhere believe that toxins in the environment may be just as responsible for creating genetic abnormalities, as are inherited factors. Widespread and cumulative exposure to toxic agents in the air we breathe, the water we drink, the food we eat and the constant radiation our bodies absorb, may be causing dangerous alterations to the healthy cells in our bodies. Our immune system simply cannot fight them all off and ultimately cancer takes hold.

I am here to ask you, our valued representatives, to PLEASE take on some major new initiatives:

• There must be incentives to encourage environmental research. Breast cancer activists all across this country have helped raise multiple millions of dollars for research. But environmental researchers have been getting seriously short-changed by funding agencies like NCI. Breast cancer research must be more interdisciplinary and more focused on environmental contaminants. And that research must be done with the active assistance of the breast cancer community.

• Government must improve its data bases so that scientists can do their work properly. Today's cancer registries are woefully inadequate. They do not collect many forms of information that are vital for researchers. Work with us to improve these cancer registries.

• We all need better information so we can make healthier lifestyle choices. We need the Federal Government to provide that information in a format that is easy to use and understand.

• We also ask that our government speak openly about the precautionary principle. It is no longer as simple as telling the public to "Get a Mammogram". While our environment is being tested, we need honesty on a Federal level about the health risks we face.

• In 1994 the FDA recommended that doctors record in patient's files information to calculate the absorbed dose of radiation to the patient. Right now most doctors have no idea how much radiation their patients are exposed to. The fact that many of us see different specialists, compounds the problem. Please address this vital public health issue and remember that radiation is a proven environmental cause of breast cancer.

• To date, the effects of groundwater on breast cancer have not been adequately researched. Many on Long Island are concerned that our water distribution systems increase our cancer risks, and this needs greater attention.

• The Senate must ratify the international POPS treaty dealing with the Persistent Organic Pollutants such as PCB's, chlordane and dioxins. The elimination of these contaminants must begin without delay.

It is high time to reverse these trends, and with your help it can be done.

In the spirit of cooperation and community, we sincerely hope that your persistence and assistance during these next 4 years will make a REAL difference in the fight against breast cancer. . . . When I learned that I had breast cancer in 1987, I was devastated. My family was devastated. Improved methods of detection and cure are essential, but they are not enough. We must get at the root causes of breast and other cancers. There is a growing body of evidence that supports our claims.

Industrial toxins are killing us. Please help us to clarify our understanding of risks and work with us to reduce our exposure to these awful chemicals that have become so pervasive in our communities. In our hearts and minds, we know these are possible and we appeal to you to speed up that process.

Thank you.

# RESULTS OF THE HUNTINGTON BREAST HEALTH SURVEY DATA

May 2001

Erin O'Leary, PhD
Roger Grimson, PhD
Forward by Mimi Galgano and Karen Miller

for

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## CHAPTER I. Summary of HBCAC Survey Data

- The number of women who responded to the HBCAC survey was 23,777. The estimated response rate to the survey for the Town of Huntington was 37%. The response rate varied by 5-digit zip code, from 17 - 52%.

- Response rates by age show that, on the average, response rates were lowest in the 25-44 year old category and were highest in the 45-54 year old category.

- The breast cancer prevalence rate ranged between 4% - 7% in 5-digit zip codes. Breast cancer prevalence rates should be considered in light of the response rates by 5-digit zip code.

- The average age of survey respondents was 51.4 ± 13.3 years (median was 50 years old), and the average age was similar across 5-digit zip code categories.

- The average age at diagnosis of breast cancer was 53.0 ± 11.7 years (median was 52 years old), and the average age at diagnosis was similar across 5-digit zip code categories.

- The average number of years at the current address was 17.3 ± 12.4 years (median is 15 years), and the number of years at the current address was similar across 5-digit zip code categories.

- The average age at the time the women responded to the survey was significantly older in women who ever had breast cancer (mean age ± standard deviation 60.5 ± 11.6) compared to women who never had breast cancer (mean age ± standard deviation 50.9 ± 13.1).

- The average number of years at the current address was significantly higher for women who ever had breast cancer (23.0 ± 12.7 years) compared to women who did not (17.0 ± 12.3 years). The reason for this difference was women who ever had breast cancer were, on average, 10 years older than women who never had breast cancer.

- Women who ever had breast cancer gave birth to their first child at an older age, were more likely to have any relative with breast cancer (mother, sister, daughter, aunt, niece, cousin, grandmother, father, and/or brother), and were more likely to have had radiation therapy (other than that for breast cancer) compared to women who never had breast cancer. Additional information on radiation therapy, such as why they had it (health condition), year they had it, and if they had it prior to breast cancer diagnosis would have been helpful to clarify this finding.

## CHAPTER II. History of HBCAC Breast Health Survey

In the fall of 1992, the Huntington Breast Cancer Action Coalition was founded by four young women concerned about the incidence of breast cancer in their town. Its first major effort, the BREAST HEALTH SURVEY, was created (1) as an educational tool to encourage women to become responsible and accountable for their own breast health (2) to shed light on why Long Island has a higher incidence of breast cancer than some other regions of the country, (3) to determine what was the actual state of breast health among Huntington's women and (4) hopefully assist research scientists in determining possible environmental links to the disease. It was also designed to try to search for geographic patterns of breast cancer in Huntington. However, no questions in the survey asked specifically about environmental exposures.

The survey was directed to female residents over the age of 25 who reside in the Town of Huntington (TOH). The TOH was established in 1689 and is located on 94 square miles in Suffolk County, Long Island, New York. The survey was written by Roger Grimson, PhD, biostatistician at the Department of Preventive Medicine at the University Medical Center at Stony Brook, physicians at Huntington Hospital and local breast health activists. In fact, the term "breast health" was first used by volunteer Paul Langer.

The TOH survey contained questions similar to those on a survey conducted in the Village of West Islip by the West Islip Breast Cancer Coalition. In September 1993 the HBCAC Breast Health Survey (written in both English and Spanish) was mailed to all households in the TOH sponsored by Huntington Hospital which donated the funds for printing, and with the support of Town officials and many community volunteers. In the early 1990's the TOH population was 189,956 (90% white, 4% black, 2% Asian, 4% Hispanic), with an estimated 63,000 households according to the 1990 U.S. Census and LILCO (local electric company) figures. The survey was publicized in community newspapers, radio and television stations, the Pennysaver, and also at PTA, civic and religious meetings. The initial response to the survey was overwhelming; over 15,500 surveys were filled out and returned in 1993 and early 1994. The surveys were mailed back to Huntington Hospital, who then forwarded them to HBCAC. Even a few men with breast cancer filled out the survey. In 1993, the national statistic of men with breast cancer was 2%.

A second mailing of the survey sponsored by The Junior League of Long Island and Suffolk County Health Partnership, was made in June 1994 to those households who did not respond the first time. Another 9,000 surveys were collected. A similar third mailing was completed in July 1996 which brought in another 5,000 completed surveys. In October 1997, HBCAC mailed a four-page informational newsletter also containing the survey to all residents. Also during that time Huntington Hospital, Town Hall, libraries, doctor offices, beauty parlors, etc., were utilized as distribution and collection sites of the survey form. As a result, an additional 5,000 completed surveys were collected. The final effort was the Neighbor-to-Neighbor Campaign, where volunteers visited specific homes to encourage non-responders to fill out the survey. An additional 1,300 surveys were collected.

Meanwhile, volunteers at the HBCAC office processed the surveys for data entry. Each survey was reviewed, assigned a record number, and assigned a 9-digit zip code (zip+4) if not provided. Nine-digit zip code (zip+4) was obtained manually from US Postal Zip Code books. The surveys were batched in groups of 25. It took 1 to 1½ hours to enter a batch into the computer database. The initial data entry program was written in 1993 by volunteer Mike Deulio in DOS.

***March 25, 1995, Preliminary Report of Breast Health Survey Released***

A meeting at Huntington Town Hall was held on the evening of March 25, 1995, presenting preliminary statistics of the 18,955 Breast Health Surveys received up to that date. The GIS map produced by Ray Thierrin at Greenman-Pedersen Inc. of Babylon, showed 5,421 respondents indicating members with breast cancer in their family (1:3.5) and 939 respondents indicated they had breast cancer at some time in their life (1:20). Presentations were made by Roger Grimson, PhD, biostatistician from SUNY Stony Brook and Ray Thiernin of Greenman-Pedersen.

In 1995 a new volunteer programmer, Beth Goodman, updated the data entry program to FOXPRO, and then to ACCESS in 1997-8. Data entry continued at the HBCAC office at 900

Walt Whitman Road, Melville, NY, by trained HBCAC volunteers with two computers donated by the community. Two other sites were also used for inputting data: Cold Spring Harbor High School and Career Blazers, a nearby employment service. Both sites were donated and had banks of many computers. Thus, many volunteers could enter data at one time. The volunteer data entry supervisors for these venues were Stephanie and Paul Sakson TOH Receiver of Taxes Ester Bivona and her volunteer staff also did a large volume of data entry. The remaining data entry was completed by a small dedicated volunteer staff at office space (with no phone for interruptions) donated by Jay Bender in Huntington Village.

The next huge project was to reorganize and box the thousands of surveys by their assigned record numbers. This was organized by Mimi Galgano and Irwin Fishberg with the help of an additional corps of volunteers.

When the survey data were transferred from DOS to FOXPRO unfortunately some entries were lost and had to be re-entered. The date-of-birth field was lost on thousands of surveys and had to be re-entered. A volunteer nursing student, Jennifer Runnals, who needed community service, accomplished this massive task during many, many evening and weekend sessions at the HBCAC office.

Because the surveys were collected over a period of five years, the database was searched for duplicates. Once identified, duplicates were removed from the database. This detailed task took approximately 75 hours and was accomplished by volunteers Irwin and Terry Fishberg. They reviewed printouts of the survey responses in date-of-birth and zip-code order to identify duplicates. Several thousand duplicate surveys were removed from the database. Although only those women with a change of diagnosis were asked to fill out another survey, apparently, many other women forgot they had filled out a survey in the past, and filled out a second, and sometimes even a third survey.

Verification of the survey data under the guidance of our epidemiologist, Erin O'Leary, PhD, initially consisted of a 10% verification of the entire database with records chosen by computer-generated random selection. This was accomplished by comparing the data entered into the

computer with the hard copy of approximately 2,500 surveys. Additionally, the records of all women who indicated they had breast cancer were verified for accuracy by comparing the data entered into the database with the hard copy . Then, birth-dates for all records were checked with the hard copy and corrected if necessary. Also, the nine-digit zip code (zip+4) field was double checked for accuracy. A programming error affecting Record Nos. 25,768 to 30,384 in the Years-at-Residence field was corrected. The number of women 25 years and older in the TOH who answered the survey was 23,777.

The result of the 10% verification indicated a data entry error rate of ≤ 1%, and were therefore considered for analyses, for the responses to the following questions: current address, city, state, zip, number of years at the current address, number of years residing in Suffolk County, previous residents of your home had breast cancer, occupation, number of years worked in your occupation, date of birth, ever/never had breast cancer, date (month/year) of breast cancer diagnosis, family member with breast cancer, males in your family had breast cancer, have you ever had radiation therapy other than as treatment for breast cancer, age at first menstruation, have you ever been pregnant, how old were you at your first pregnancy, how many times have you given birth, number of years used birth control, and menopausal hormone use.

The responses for the following questions were not considered for analyses because data entry or programming errors were found for more than 2% of the selected surveys: years at previous address, has any member of your family had cancer of any kind, have you ever had a mammogram, date of mammogram, reason did not have mammogram, date of breast cancer biopsy, did you ever breast feed, months of breast feeding, have you reached menopause, and reason for menopause.

In addition, logic checks were performed by Erin O'Leary. The internal consistency of responses to questions were checked. For example, age at interview should be less than the number of years at the current residence; women indicating a family member with breast cancer, but the response to relative was missing; any woman indicating her age at first birth less was than 13 years of age or any responses of more than 10 children. These and other logic checks were then sent to Mimi Galgano, who either explained why certain variables were missing or corrected the

data by viewing the data on the hard copy of the questionnaire and then updating the database. This was done several times. Therefore, we are confident that the data and subsequent data analyses are accurate.

We would like to thank the women who responded to the surveys and the many volunteers who entered and checked data. Without the response from the community, we would have never been able to conduct this study.

## CHAPTER III. Summary of Survey Results

### A. Introduction

The American Cancer Society estimated that 182,800 American women would be diagnosed with invasive breast cancer, and about 40,800 women would die of the disease in 2000 (1). It is the most commonly diagnosed cancer among women, other than non-melanoma skin cancer. It is the second leading cause of cancer death in women, after lung cancer (1). At this time, there is no way to prevent breast cancer. There are some risk factors, listed below, that increase a woman's chance of getting breast cancer. However, many women with breast cancer do not have any of these risk factors, and many women with these risk factors never get the disease. Therefore further research into the causes of breast cancer are needed (1).

Breast cancer risk factors that have been found to be related to breast cancer include:

1. age, the older you are the higher your risk for breast cancer;
2. ethnicity: white women have a higher incidence of breast cancer compared to black women and women in North America and Northern Europe have higher rates compared to Asian and African countries;
3. genetic mutations (BRCA1, BRCA2) account for less than 10% of cases;
4. family history (mother, sister, or daughter) is a slight increase in risk;
5. personal history of breast cancer;
6. previous breast/chest irradiation (atomic bombs from Hiroshima and Nagasaki; previous radiation treatment for Hodgkin's Disease and Non-Hodgkin's Lymphoma; and treatments for other diseases (fluoroscopy);
7. reproductive factors such as late age at first birth or never having children increases your risk slightly; early age at menstruation and late age at menopause increases your risk slightly (hypothesis: longer duration of exposure to estrogen);
8. current oral contraceptive use;
9. hormone replacement therapy;
10. not breast feeding;
11. alcohol use; and
12. obesity in postmenopausal women.

Factors needing further study include environmental pollution and physical inactivity (1).

The known breast cancer risk factors account for less than 50% of breast cancer cases. Therefore it is imperative that we continue to study the causes of breast cancer and investigate areas of research that have not been so. One such area is environmental factors. Serum levels of pesticides have been studied, however, the effect of actual exposures and relation to disease have not been. It is important to consider the exposures to many chemicals at once, since this is how we are exposed. This area of research has only begun to be studied. The integration of a geographic information system in locating point sources of pollution should enable researchers to study this problem in a much more comprehensive way. The idea of studying these factors in both time and space is very important and should lead to clues as to the causes of this deadly disease.

## B. Objectives

The overall objective of the Huntington Breast Health Survey was to educate and encourage women to be more responsible for their breast health; describe breast cancer prevalence in the TOH, and to help researchers understand the reasons for higher incidence of breast cancer on Long Island compared to the rest of New York State and other areas of the U.S..

The specific study objectives included in this report are:

1. Response rates to the survey and how they varied by 5-digit zip code
2. Response rates by age
3. Prevalence of breast cancer by 5-digit zip code and comparison to other communities
4. Characteristics of survey respondents by zip+4
5. Description of characteristics of survey respondents
6. Comparisons of characteristics of survey responses by women who ever and never had breast cancer.
7. Comparison of characteristics of women who lived in their current residence for 15 years or more

## C. Response Rates

The response rate is the number of women who responded to the survey (23,777) divided by the number of women in the town of Huntington (63,665). The number of women in the town of Huntington was estimated using census data provided by Roy Fedelem in the Suffolk County Department of Planning in Hauppauge. The overall response rate was 37% (23,777 / 63,665) X 100)). This was higher than that of the South Fork study (2), which was 15%, and that of the study in Onondonga County in Upstate New York (3), which was 29%.

There was variation of the response rates by 5-digit zip code (Table 1). As shown, response rates were lowest in zip code 11725: Commack (17%); zip code 11724: Cold Spring Harbor (22%); zip code 11740: Greenlawn (27%); and zip code 11746: Huntington Station, South Huntington, and Dix Hills (33%). Response rates were higher in zip code 11731: East Northport and Elwood (38%); zip code 11747: Melville (43%); zip code 11768: Fort Salonga, Northport, Asharoken, Eaton's Neck (44%); zip code 11743: Huntington Bay, Huntington, Lloyd Harbor, Halesite (51%); and zip code 11721: Centerport (52%).

At the start of the study, Roger Grimson, PhD, biostatistician, recommended that 35,000 surveys, or approximately 50% be returned for the study to be scientifically valid. Ideally, we would like to see response rates of 70% or more, however, it is difficult to achieve high response rates to mailed surveys. Results from surveys with low response rates may not be representative of the distribution of risk factors or the geographic distribution of cases. Areas where we would need to be careful about drawing any conclusions regarding geographic patterns would be Commack, Cold Spring Harbor, and Greenlawn.

Map 1 shows the geographic distribution of the survey responses by 5-digit zip codes. As shown, the geographic distribution of the lower and higher response rates are random and do not show any regional patterns.

Table 2 shows the estimated response rates by age groups (25-44; 45-54; 55-64; and ≥ 65) by five-digit zip code. Overall, the response rates were lowest in women ages 25-44 (27%), highest

in women ages 45-54 (48%), 46% in women ages 55-64 and 43% in women ≥ 65 years old. This pattern was similar in most of the 5-digit zip codes, with the exception of Melville (zip code 11747), where the highest response rates were in the ≥ 65 years of age. Since the response rates are relatively low in the 25-44 year old group (27%), we would need to be careful that the survey results may not be representative of the true distribution of risk factors or the geographic distribution. Perhaps the lower response rates in younger women were because these women are in the age group with the lowest prevalence of breast cancer.

**D. Incidence vs Prevalence Rates**

The incidence of breast cancer as reported by the New York State Department of Health, NYS Cancer Registry, between 1993-1997 for all of New York State, is 102.1 / 100,000. The rate for Nassau County is 115.3 / 100,000 and the rate for Suffolk County is 115.7 / 100, 000 (4). This is the first time that the rate for Suffolk County surpassed that for Nassau County. One explanation for this observation may be that Suffolk's population has been steadily increasing and is becoming as high as Nassau's. The approximate number of observed number of breast cancer cases between 1993-1997, using the New York State Surveillance Improvement Initiative, Breast Cancer in New York State by Zip Code data, is 700 (5). These rates are called incidence rates, and focus on newly diagnosed cases. The formula for incidence is

$$\text{Incidence} = \frac{\text{\# of new cases of disease}}{\text{population at risk}}$$

Incidence cases are used to study causes of disease, since they are the best representation of all cases of a disease.

The HBCAC Breast Health Survey accrues prevalent breast cancer cases, which focuses on breast cancer survivors or women who ever had breast cancer at a point in time (when they filled out the survey). Prevalence indicates the number of women in the population affected by the disease.

$$\text{Prevalence} = \frac{\text{\# of existing cases of a disease (women who ever had breast cancer)}}{\text{Total population}}$$

at a point in time (when they filled out the survey).

These prevalent cases are more likely to include earlier stages of breast cancer (less aggressive; e.g. stage I or stage II breast cancers) than later stages (more aggressive, e.g. stage III or stage IV), since these are the women with breast cancer who are more likely to survive. Women reported their breast cancer diagnosis date between the years 1951 and 1998.

## E. Geographic Distribution of Breast Cancer

The overall breast cancer prevalence rate in the survey for women over the age of 25 in the TOH is 1218 existing cases / 23,777 respondents = 5%, or 1 out of 20. The breast cancer prevalence rates from other community surveys are:

| Town | Prevalence Rate | Median Age, 1990 |
|---|---|---|
| • Great Neck, Nassau | 7% | 40.0 |
| • Babylon, Suffolk | 4% | 33.0 |
| • West Islip, Suffolk | 3.5% | 33.0 |
| • South Fork, Suffolk | 7% | 39.0 |
| • Huntington, Suffolk | 5% | 36.0 |

The lower breast cancer prevalence rates are in the areas with the lower median age (West Islip, Babylon), and the higher prevalence rates are in the areas with the higher median age Great Neck and South Fork), with Huntington in the middle.

Table 3 shows that the breast cancer prevalence rates vary somewhat by 5-digit zip codes, but this variation is not different from what we would expect by chance. The prevalence rate for Centerport (11721) and Commack (11725) is 4%; for East Northport and Elwood (11731), Huntington, Huntington Bay, Halesite, Lloyd Harbor (11743); and Huntington Station, South Huntington, and Dix Hills the rate is 5%; for Greenlawn (11740), Melville (11747), and Northport, Fort Salonga, Asharoken, Eaton's Neck (11768) the rate is 6%; and for Cold Spring Harbor (11724), the rate is 7%. The higher rate for Cold Spring Harbor could be explained by the low response rate (22%), and that perhaps more women who ever had breast cancer responded to the survey. Map 2 shows the geographic distribution of the breast cancer prevalence rates. The lower and higher response rates are randomly distributed, no one area has all high rates or low rates.

To estimate how representative of all breast cancer cases diagnosed in the TOH between 1993 – 1997 the breast cancer cases accrued by the survey data were, we divided the number of women in the survey who said they were diagnosed with breast cancer between 1993-1997 (n=279) by the approximate number of observed breast cancer cases between 1993-1997, using the New York State Surveillance Improvement Initiative, Breast Cancer in New York State by Zip Code

data (n=700). The tumor registry captures most breast cancers, and was used as the gold standard (4). We estimate that 279 / 700 or 42% of cases in the survey were also in the NYS Tumor Registry. It is possible that some of the cases reported in the survey are not included in the tumor registry data. In fact, the Onondaga County Breast Cancer Survey stated that they would match the cases identified in their survey with the tumor registry to measure the completeness of the NYSDOH Cancer Registry (3).

The percent of all breast cancer cases between 1993-1997 in the survey and in the tumor registry data were calculated for each 5-digit zip code. The percentages ranged between 32% - 67%. For 11721: 38%; 11724: 36%; 11725, approximately 36% (not all of 11725 is in the TOH); 11731, 31%; 11740, 47%; 11743, 43%; 11746, 42%; 11747, 67%; and 11768, approximately 32% (not all of 11768 is in the TOH).

**F. Characteristics of Zip+4**

A zip+4 is a small area within a 5-digit zip code, usually the length of one-side of a street. We decided to geocode, or assign a coordinate to a zip+4 rather than to individual addresses since it would require a significant amount of time to put each individual street address into a format suitable for geocoding. The zip+4s are small enough to look at spatial statistics, but large enough so that geocoding can be done easier. In fact, over 99% of addresses were geocoded into a zip+4.

There are a total of 8548 zip+4 with one or more respondents to the survey. Approximately 36% of these zip+4 contain only one respondent; 23% contain 2 respondents, 15% contain 3 respondents, 10% con'ain 4 respondents, 6% contain 5 respondents, 3% contain 6 respondents, 2% contain 7 respondents, 2% contain 8 respondents, 1% contain 9 respondents, and the remaining 1.5% contains 10 and over respondents. Approximately 87% of zip+4 do not have any respondents who were breast cancer cases; 360 (4%) are zip+4's with 1-20% respondents ever having breast cancer; 141 (2%) are zip+4's with 21-25% respondents ever having breast cancer; 412 (5%) are zip+4's with 26-50% respondents ever having breast cancer; and only 2% are zip+4's with 51-100% respondents ever having breast cancer. Most of the zip+4's with 100% cases include only one survey respondent. Map 3 shows the percentage of respondents that ever had breast cancer per zip+4. We plan to do further analyses by zip+4 to see if any geographic patterns emerge showing areas with more women who ever had breast cancer.

Table 4 shows the number and percentage of prevalent breast cancer cases in each zip+4 by 5-digit zip code for all respondents and for respondents over 25 years old, respectively. Between 84-90% of zip+4s did not have any respondents who ever had breast cancer; between 3.7 - 7.1% of zip+4s had over 0 and less than or equal to 25% of respondents who ever had breast cancer; between 4.0 - 6.3% of zip+4s had over 25% and less than or equal to 50% of respondents who ever had breast cancer, < 1% of zip+4s had over 50% and less than or equal to 75% of respondents who ever had breast cancer, and between 1.1 – 3.4% of zip+4s had over 75% - 100% of respondents who ever had breast cancer. The difference of these percentages between 5-digit-zip codes is of borderline significance, with Cold Spring Harbor and Greenlawn with over 3.0%

of their zip+4s with all respondents reporting ever having breast cancer and the remaining 5-digit zip codes with 2.1% or less with all their respondents reporting ever having breast cancer.

## G. Characteristics of Survey Respondents

Table 5 shows the mean (average), standard deviation (measure of variance) and the median (the middle value) of some of the variables in the survey. The mean age of survey respondents was 51, and the median was 50. The mean number of years at the current residence was 17, and the median was 15. The mean number of births was 2, and the median was 2. The mean age at first birth is 25 and so is the median. For women reporting ever having breast cancer, the mean age at diagnosis is 53 and the median is 52.

Table 6 shows the number and percentage of women who responded yes to various questions on the survey, and the number of women responding to that question on the survey. The percentage of women who lived at their current residence for 15 years or more was 52.7%. The percentage of women with a family history (defined as a mother, sister, daughter, aunt, niece, cousins, grandmother, father, and/or brother with breast cancer) was 29%. The number of respondents reporting a male relative with breast cancer was 127 or 0.5%. The number of women reporting that their daughters were diagnosed with breast cancer is 83 or 0.3%. The number of respondents reporting ever having radiation therapy other than that for breast cancer treatment was 687 or 2.9%. The number of respondents reporting ever been pregnant is 21081 or 88.7%. The number of respondents reporting ever use of birth control pills is 11742 or 49.4%. The percentage of women reporting that previous residents of their current residence had breast cancer is 747 or 3.1%.

## H. Comparison of Variables by Ever/Never Had Breast Cancer

Table 7 shows the mean and standard deviation of survey variables for women who ever had breast cancer and women who never had breast cancer, and the p-value for the t-test. The t-test is a statistical test to see if the mean values of continuous variables (age, # of years at the residence, etc.) are similar or different in the two groups (women who ever had breast cancer and women who never had). The p-value is the probability that the difference is due to chance. If the p-value is less than 0.05, then the means of that particular response to a question by ever and never had breast cancer are statistically significantly different from each other (i.e., the differences are not likely to be due to chance).

Women who ever had breast cancer were older at the time they filled out the survey and lived in their current home longer than women who never had breast cancer. After data were divided into 10 year age-categories, no difference in years at current residence among the two groups was seen. Therefore, the longer number of years of residence in women who ever had breast cancer compared to women who never had breast cancer is because the women who ever had breast cancer were older at the time they filled out the survey compared to women who never had breast cancer.

For reproductive variables, women who ever had breast cancer had slightly more births (p=0.02), and were slightly older at the time of the birth of their first child (p=0.007) compared to women who never had breast cancer. The percent of women ever pregnant, average number of births and age at first menses were similar in women who ever had breast cancer and women who never had breast cancer.

Table 8 shows the number and percent of women who answered yes to the following survey questions and the total number of women who responded to the question. The p-value for the chi-square test is also shown. The chi-square test is a statistical test to see if the proportion of women who answered yes to a particular question is similar among women who ever had and women who never had breast cancer. This is similar to the t-test as described above. If the p-value is less than 0.05, then the proportions are statistically significantly different in the two groups and this difference is not likely to be due to chance. Women were asked if they had a

family history of breast cancer (defined as having a mother, sister, daughter, aunt, niece, cousins, grandmother, father, and/or brother with breast cancer). Thirty-eight percent of women who ever had breast cancer and 29% of women who never had breast cancer reported a family history of breast cancer. A second question was asked to ascertain if women had any male relative with breast cancer. Only 0.6% of women who ever had breast cancer and 0.5% of women who never had breast cancer reported any male relative with breast cancer.

The percentage of women who had ever been pregnant was similar among women who ever had breast cancer and women who never had breast cancer. Women were also asked if they ever used birth control pills. Approximately 38% of women who ever had breast cancer and 50% of women who never had breast cancer reported ever using oral contraceptives (OCs). When these data were divided into 10-year age categories, no difference in ever use of OCs among the two groups was seen. At first, it would appear that women who used OCs were less likely to have ever had breast cancer. However, since women who ever had breast cancer were ten years older, on average, than women who never had breast cancer, women who ever had breast cancer were less likely to have ever used birth control pills. The reason for this is that since many women were older than reproductive age when OCs came into widespread use. Therefore, after adjusting for age, we see no difference in OC use among women who ever had and women who never had breast cancer.

Women were asked if they ever had radiation therapy other than as treatment for breast cancer. Twenty-five percent of women who ever had breast cancer and 2% of women who never had breast cancer reported having radiation therapy. This question did not ask the woman to specify if the treatment was before her breast cancer; what part of the body she had the radiation therapy, what year she had it, and for how long. These data would be helpful in understanding which type of radiation therapy these women were exposed to. Future surveys should include more detailed questions on radiation therapy to pinpoint the type of radiation therapy that may be related to breast cancer.

Women were asked if any previous residents of their home had breast cancer. Over 7% of women who ever had breast cancer and 3% of women who never had breast cancer reported this.

Also, women who reported having a relative with breast cancer and ever having breast cancer were more likely to have a previous resident of their home with breast cancer.

The Huntington Breast Cancer Action Coalition is interested in studying women who did not have breast cancer themselves, but reported their daughters were diagnosed with breast cancer. Eleven women who ever had breast cancer and 72 women who never had breast cancer reported that their daughters were diagnosed with breast cancer.

We ran additional analyses on a subset of women who lived in their current residence (residence where they filled out the survey) for 15 years or more. We chose to look at this subset of women because if exposures related to household residence or its location are related to the initiation or promotion of breast cancer, then any search for geographic patterns due to environmental aspects is enhanced by studying women who lived in an environment long enough to have developed breast cancer through that environment. For example, a woman who lived in a home in the TOH for 1 year and was diagnosed with breast cancer that year probably acquired it at an earlier time. The latency period (time of initiation and promotion of breast cancer to breast cancer diagnosis) is not known and may vary among breast cancer cases. However, a cutpoint of 15 years is often used in epidemiologic studies.

Women who lived in their current residence for 15 years or more were older at the time the survey was filled out and older at time of diagnosis than women who lived < 15 years in their current residence. However, results for number of births, age at first birth, percent with family history of breast cancer, male relative with breast cancer, daughter with breast cancer, radiation therapy other than that for breast cancer, ever been pregnant, ever used birth control pills, previous resident of current residence had breast cancer were similar in women who lived in their homes > 15 years and all residents.

## I. Conclusions

The overall response rate to the survey was 37%, ranging from 17-52% among 5-digit zip codes. The breast cancer prevalence rate was 5% (1 out of 20), ranging from 4-7% among 5-digit zip codes. The average age of women who responded to the survey was 51, and the years at the current residence was 17. Average age at diagnosis for women reporting ever had breast cancer was 53.

Women who ever had breast cancer gave birth to their first child at an older age, were more likely to have a relative with breast cancer, and were more likely to have had radiation therapy compared to women who never had breast cancer. Because these variables were found to be significantly related to breast cancer and they are considered known risk factors for breast cancer, we therefore feel more confident that the women responding to the survey are representative of all breast cancer cases. However, since women who ever had breast cancer are, on average, 10 years older at the time they answered the survey than women who never had breast cancer, careful analysis of the data by 10-year age groups was necessary to draw the correct conclusions.

We recommend that future community surveys include more detailed questions on radiation therapy, such as when it was administered (year), the part of the body it was administered to, and for what disease or health problem, to pinpoint the type of radiation therapy given to survey respondents.

## J. Future Directions

Additional analyses of the survey data include running analyses to check for geographic patterns of breast cancer cases in the Town of Huntington.

We will run SatScan, a statistical program that searches for clusters of cases, taking into account age, response rates, and year diagnosed with breast cancer. It is very important to take into account year of diagnosis of the case, since women who ever had breast cancer reported being diagnosed between 1951 - 1998, and women diagnosed in the 1950s and 1960s may have different exposures (environmental, etc.) than women diagnosed in the 1970s and 1980s. We also plan to explore prevalence of breast cancer in relation to proximity to point sources of pollution using a Geographic Information System (GIS), taking into account the above factors.

**Table 1**
**Number of participants by 5-digit zip code, estimated number of residents by 5-digit zip code, and estimated response rate by 5-digit zip code, HBCAC survey, women ≥ 25 years old[1]**

| Zip Code | Towns | # of Participants | Estimated # of Residents[2] | Estimated Response Rate |
|---|---|---|---|---|
| 11721 | Centerport | 988 | 1896 | 52% |
| 11724 | Cold Spring Harbor | 377 | 1678 | 22% |
| 11725 | Commack | 703 | 4191 | 17% |
| 11731 | East Northport, Elwood | 3915 | 10388 | 33% |
| 11740 | Greenlawn | 1207 | 4452 | 27% |
| 11743 | Huntington Bay, Huntington, Lloyd Harbor, Halesite | 5611 | 11012 | 51% |
| 11746 | Huntington Station, South Huntington, Dix Hills | 6887 | 20954 | 33% |
| 11747 | Melville | 1760 | 4131 | 43% |
| 11768 | Fort Salonga, Northport, Asharoken, Eaton's Neck | 2329 | 5333 | 44% |
| **Total** | | **23777** | **63665** | **37%** |

[1] Participants who could not be assigned a zip+4 are excluded.
[2] Estimated from the 1990 Census.

Map 1 - Survey Response Rates by 5 Digit Zipcodes

Breast Cancer Prevalence Study 1993-1998

Huntington, Long Island, New York

Highways
- Limited Access Highway
- Primary Road
- Secondary Road
- Long Island Railroad

Zip Codes
- 11721
- 11724
- 11725
- 11731
- 11740
- 11743
- 11746
- 11747
- 11768
- Long Island Sound
- Suffolk County

Geographic Information System Acknowledgements:

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**Table 2**
**Estimated response rates by age and 5-digit zip code, HBCAC survey, women ≥ 25 Years Old[3]**

| Zip Code | Towns | Estimated Response Rate Ages 25-44 | Estimated Response Rate Ages 45-54 | Estimated Response Rate Ages 55-64 | Estimated Response Rate, Ages ≥ 65 |
|---|---|---|---|---|---|
| 11721 | Centerport | 40% | 69% | 62% | 57% |
| 11724 | Cold Spring Harbor | 16% | 33% | 20% | 29% |
| 11725 | Commack | 13% | 19% | 21% | 19% |
| 11731 | East Northport, Elwood | 27% | 49% | 50% | 42% |
| 11740 | Greenlawn | 20% | 38% | 36% | 25% |
| 11743 | Huntington Bay, Huntington, Lloyd Harbor, Halesite | 37% | 67% | 62% | 58% |
| 11746 | Huntington Station, South Huntington, Dix Hills | 24% | 43% | 42% | 38% |
| 11747 | Melville | 30% | 51% | 51% | 64% |
| 11768 | Fort Salonga, Northport, Asharoken, Eaton's Neck | 31% | 59% | 52% | 52% |
| **Total** | | **27%** | **48%** | **46%** | **43%** |

[3] Participants who could not be assigned a zip+4 are excluded.

**Table 3**
**Number of prevalent breast cancer cases by 5-digit zip code, number of participants by 5-digit zip code, and percentage of cases by five-digit zip code, HBCAC survey, women ≥ 25 Years Old[4]**

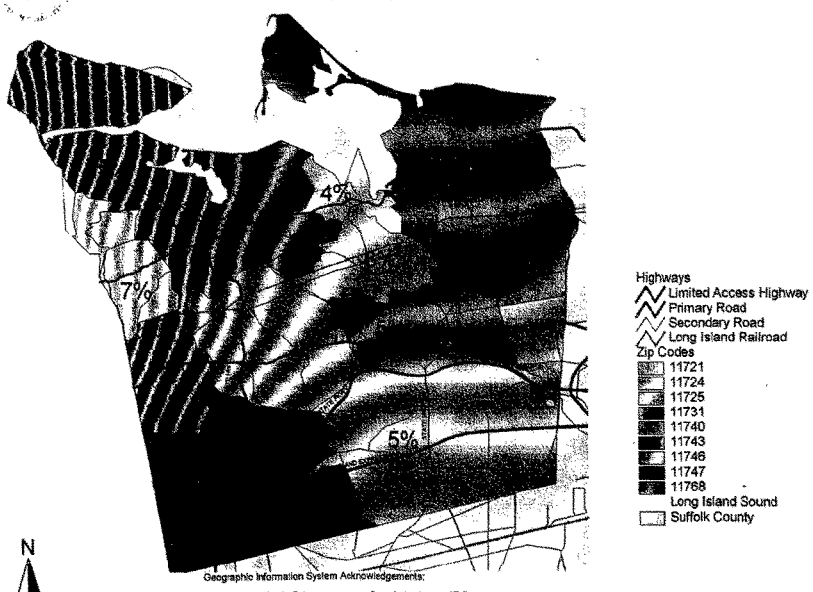
| Zip Code | Towns | # of Prevalent Breast Cancer Cases | # of Participants | Percentage of Prevalent Breast Cancer Cases |
|---|---|---|---|---|
| 11721 | Centerport | 44 | 988 | 4% |
| 11724 | Cold Spring Harbor | 26 | 377 | 7% |
| 11725 | Commack | 28 | 703 | 4% |
| 11731 | East Northport, Elwood | 180 | 3915 | 5% |
| 11740 | Greenlawn | 76 | 1207 | 6% |
| 11743 | Huntington Bay, Huntington, Lloyd Harbor, Halesite | 291 | 5611 | 5% |
| 11746 | Huntington Station, South Huntington, Dix Hills | 342 | 6887 | 5% |
| 11747 | Melville | 98 | 1760 | 6% |
| 11768 | Fort Salonga, Northport, Asharoken, Eaton's Neck | 133 | 2329 | 6% |
| **Total** | | **1218** | **23777** | **5%** |

[4] Participants who could not be assigned a zip+4 are excluded.

map 2

# % of Prevalent Breast Cancer Cases by 5 Digit Zip Codes

Breast Cancer Prevalence Study 1993-1998
Huntington, Long Island, New York




Geographic Information System Acknowledgements:

Map Development Services:
Greenman-Pedersen, Inc.
Institute of Sustainable Development
Long Island University at Southampton

Mapping Data:
Geographic Data Technology
Suffolk County
Town of Huntington

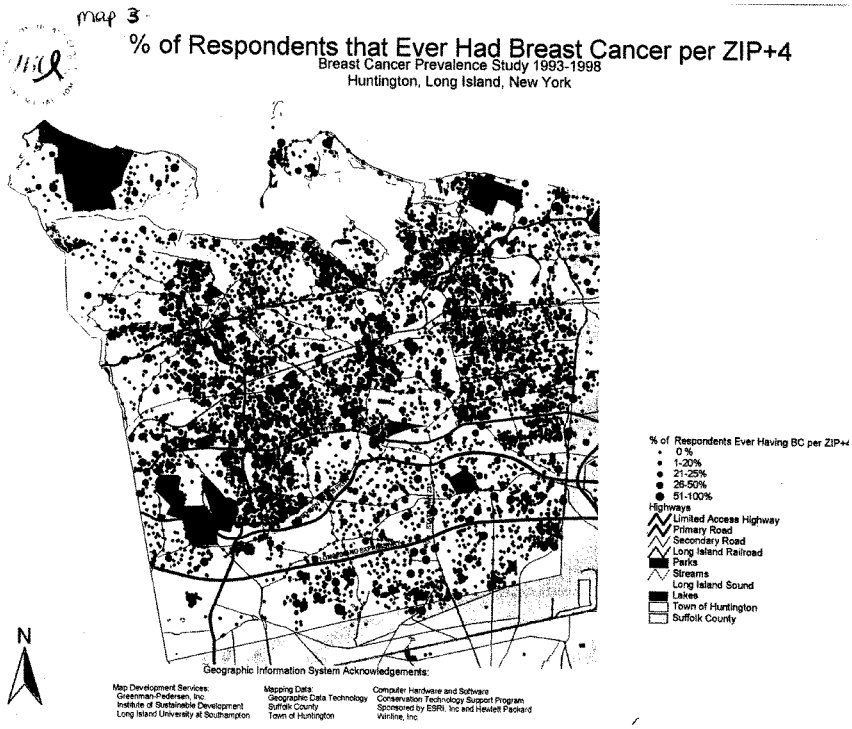
Computer Hardware and Software
Conservation Technology Support Program
Sponsored by ESRI, Inc and Hewlett Packard
Vimlina, Inc.

**Table 4**
**Number and percentage of prevalent breast cancer cases in each zip+4 by 5-digit zip code, HBCAC survey, women ≥ 25 Years Old[5] (n=8548)**

| Zip Code | 11721 Centerport | 11724 Cold Spring Harbor | 11725 Commack | 11731 East Northport, Elwood | 11740 Greenlawn | 11743 Huntington Bay, Huntington, Lloyd Harbor, Halesite | 11746 Huntington Station, South Huntington, Dix Hills | 11747 Melville | 11768 Fort Salonga, Northport, Asharoken, Eaton's Neck |
|---|---|---|---|---|---|---|---|---|---|
| **% of prevalent cases** | N<br>% | N<br>% | N<br>% | N<br>% | N<br>% | N<br>% | N<br>% | N<br>% | N<br>% |
| **0** | 311<br>88.6 | 153<br>87.4 | 241<br>89.9 | 1224<br>88.1 | 358<br>84.0 | 1767<br>87.2 | 2126<br>87.8 | 544<br>86.1 | 746<br>86.9 |
| **≤ 25** | 21<br>6.0 | 8<br>4.6 | 10<br>3.7 | 81<br>5.8 | 27<br>6.3 | 120<br>5.9 | 143<br>5.9 | 45<br>7.1 | 46<br>5.4 |
| **> 25 - ≤ 50** | 14<br>4.0 | 8<br>4.6 | 13<br>4.9 | 64<br>4.6 | 27<br>6.3 | 97<br>4.8 | 108<br>4.5 | 29<br>4.6 | 52<br>6.1 |
| **> 50 ≤ 75** | 1<br>0.3 | 0<br>0.0 | 0<br>0.0 | 2<br>0.1 | 1<br>0.2 | 2<br>0.1 | 2<br>0.1 | 1<br>0.2 | 4<br>0.5 |
| **> 75 - ≤ 100** | 4<br>1.1 | 6<br>3.4 | 4<br>1.5 | 18<br>1.3 | 13<br>3.1 | 40<br>2.0 | 43<br>1.8 | 13<br>2.1 | 11<br>1.3 |

[5] Participants who could not be assigned a zip+4 and participants with a missing date of birth or less than 25 years of age are excluded.

map 3


% of Respondents that Ever Had Breast Cancer per ZIP+4
Breast Cancer Prevalence Study 1993-1998
Huntington, Long Island, New York
% of Respondents Ever Having BC per ZIP+4
0 %
1-20%
21-25%
26-50%
51-100%
Highways
Limited Access Highway
Primary Road
Secondary Road
Long Island Railroad
Parks
Streams
Long Island Sound
Lakes
Town of Huntington
Suffolk County
N
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Wildline, Inc

**Table 5**
**Descriptive statistics for age at interview, number of years at current residence, number of births, age at first birth, for all survey respondents (n=23,777) and age at diagnosis for women who ever had breast cancer (n=1,177), women ≥ 25 years old[6]**

| Variable | Mean ± SD<br>N | Median | Range |
|---|---|---|---|
| | | | |
| Age at interview (years) | 51.4 ± 13.3<br>23,777 | 50.0 | 25 – 98 |
| | | | |
| Number of years at current address (years) | 17.3 ± 12.4<br>23,777 | 15 | 0 – 81 |
| | | | |
| Number of births | 2.2 ± 1.4<br>23,777 | 2 | 0 – 23 |
| | | | |
| Age at first birth (years) | 25.1 ± 4.7<br>20,201 | 25 | 10 – 44 |
| | | | |
| Age at diagnosis (women who ever had breast cancer, years) | 53.0 ± 11.7<br>1,177 | 52 | 19 – 91 |
| | | | |

[6] Participants who could not be assigned a zip+4 are excluded.

**Table 6**

**Number and percentage of survey respondents who lived at their current residence for ≥ 15 years, with a family history of breast cancer, a male relative with breast cancer, a daughter diagnosed with breast cancer, radiation therapy other than that for breast cancer, ever been pregnant, ever used birth control pills, with a previous resident of their current residence had breast cancer, women ≥ 25 years old[7]**

| Variable | n (%) |
|---|---|
| Years at current residence ≥ 15 years | 12499 (52.7) n=23719 |
| Family history of breast cancer[8] | 6867 (29.0) n=23,777 |
| Male relative with breast cancer | 127 (0.5) n=23,777 |
| Daughter diagnosed with breast cancer | 83 (0.3) n=23.777 |
| Radiation therapy other than that for breast cancer | 687 (2.9) n=23,777 |
| Ever been pregnant | 21081 (88.7) n=23,777 |
| Ever used birth control pills | 11742 (49.4) n=23,777 |
| Previous resident of current residence had breast cancer | 747 (3.1) n=23,777 |

[7] Participants who could not be assigned a zip+4 are excluded.

[8] Defined as any relative with breast cancer, including a mother, sister, daughter, aunt, niece, cousins, grandmother, father, and/or brother.

**Table 7**
**Comparison of characteristics of survey respondents by ever had breast cancer (n=1218) or never had breast cancer (n=22559), and p-value for the t-test, women ≥ 25 years old[9]**

| Variable | Ever Had Breast Cancer Mean ± SD | Never Had Breast Cancer Mean ± SD | p-value[10] |
|---|---|---|---|
| Age at interview (years) | 60.5 ± 11.6<br>n=1,218 | 50.9 ± 13.2<br>n=23,777 | < 0.0001 |
| Number of years at current address (years) | 23.0 ± 12.7<br>n=1,218 | 16.8 ± 12.3<br>n=23,777 | < 0.0001 |
| Number of births | 2.3 ± 1.5<br>n=1,218 | 2.2 ± 1.4<br>n=23,777 | 0.02 |
| Age at first birth (years) | 25.6 ± 4.7<br>n=1049 | 25.1 ± 4.5<br>n=19,152 | 0.0007 |
| Age at first menstrual period (years) | 12.7 ± 2.7<br>n=1,167 | 12.7 ± 2.2<br>n=21,857 | 0.65 |
| Number of years used birth control pills (years) | 4.5 ± 4.6<br>n=451 | 4.9 ± 4.4<br>n=12,039 | 0.09 |

[9] Participants who could not be assigned a zip+4 are excluded.
[10] P-value for the t-test.

**Table 8**
**Comparison of characteristics of survey respondents by ever had breast cancer (n=1218) or never had breast cancer (n=22559), and p-values for the chi-square test, women ≥ 25 years old[11]**

| Variable | Ever Had Breast Cancer n (%) | Never Had Breast Cancer n (%) | p-value[12] |
|---|---|---|---|
| | | | |
| Family history of breast cancer | 462 (37.9) n=1,218 | 6405 (28.4) n=22,559 | < 0.0001 |
| | | | |
| Male relative with breast cancer | 7 (0.6) n=1,218 | 120 (0.5) n=22,559 | 0.84 |
| | | | |
| Daughters diagnosed with breast cancer | 11 (0.9) n=1,218 | 69 (0.3) n=22,559 | 0.0005 |
| | | | |
| Ever been pregnant | 1084 (89.0) n=1,218 | 19997 (88.6) n=22,559 | 0.70 |
| | | | |
| Ever used birth control pills | 452 (37.1) n=1,218 | 11290 (50.1) n=22,559 | < 0.0001[13] |
| | | | |
| Radiation therapy other than that for breast cancer | 311 (25.5) n=1,218 | 376 (1.7) n=22,559 | < 0.0001 |
| | | | |
| Previous resident of current residence had breast cancer | 89 (7.3) n=1,218 | 658 (2.9) n=22,559 | < 0.0001 |
| | | | |

[11] Participants who could not be assigned a zip+4 are excluded.
[12] P-value for the chi-square test.
[13] No difference between women who ever and who never had breast cancer when stratified by age.

## APPENDIX A HBCAC Breast Health Survey

# Breast Health Survey

**All women over the age of 25** who live in the hamlets of Asharoken, Centerport, Cold Spring Harbor, Commack, Dix Hills, Eatons Neck, East Northport, Elwood, Fort Salonga, Greenlawn, Halesite, Huntington Bay, Huntington Station, Huntington Village, Lloyd Harbor, Lloyd Neck, Melville, Northport, South Huntington, West Hills, Wincoma, are eligible. If you have not already filled out this survey or have had a change of diagnosis, ***please*** **complete this survey now and return it to *Huntington Hospital*.**

***Be good to yourself and your neighbors. Please fill out this survey and return it as soon as possible. Place your answers in the boxes below.***

What is your present address? _____
*¿Cual es su direcion ?* Number and Street Address

*(Calle, cuidad/pueblo, estado, zip code)* _____
Town, or Village, State, Zip Code (Zip + 4)

How many years have you lived at this address? ☐
*¿Cuantos años ha vivido usted en su direcion?*

How many years have you lived in Suffolk County? ☐
*¿Cuantos años ha vivido usted en el condado de Suffolk?*

What was the town and state of your last address?
*¿Cual era su direcion anterior (cuidad/pueblo y estado)?* _____

How many years did you live at your last address? ☐
*¿Cuanto tiempo vivido?*

To the best of your knowledge, have any previous residents of your home had breast cancer? ☐
*¿Ha usted tenido conocimiento de que alguna persona que haya residido, antes de usted, en su vivienda ha tenido cancer del seno?*

What is your occupation? If retired, what was your former occupation?
*¿Cual es su ocupacion?* _____

Years worked in your occupation? ☐
*¿Cuantos años lleva en su trabaja actual?*

What is your date of birth? (Month/Year) ☐
*¿Cual su fecha de nacimiento? (Mes/Año)*

Do you have or have you had breast cancer? ☐
*¿Ha padecido usted de cancer del seno?*

If yes, when was the breast cancer discovered? (Month/Year) ☐
*¿Si contesto que se. Cuando le descubritron el cancer? (Mes/Año)*

Has any member of your family had breast cancer? ☐
*¿Tiene usted algun familiar con cancer del seno?*

If yes, what relative? (example: maternal grandmother, mother, etc.)
*¿Si la respuesta anterior es si, cual es la relacion? (madre, hija, tia, etc.)* _____

Have any males in your family had breast cancer? ☐
*¿Algun hombre en su familia ha tenido cancer del seno?*

Has any member of your family had cancer of any kind? ☐
*¿Algun miembro de su familia ha tenido algun tipo de cancer?*

Have you ever had a mammogram? ☐ Date of last mammogram. (mo./yr.) ☐
*¿Se ha hecho usted una mamog. 1a?* *¿Cuando fue su ultima mamografia? (M/A)*

If not, what was the reason(s)? Fear *Miedo* | Saw no need *Vio no necesidad* | Cost *Costo* | Inconvenience *Inconviniencia*
*¿Si no se ha hecho mamografia, porque?*

Have you ever had a breast biopsy? ☐ Date of last breast biopsy. (mo./yr.) ☐
*¿Se la ha practicado a usted, una biopsia del seno?* *¿Cual es la fecha de la ultima biopsia del seno? (M/A)*

Have you ever had radiation therapy other than as treatment for breast cancer? ☐
*¿Ha usted recibido terapia de radiasion?*

How old were you at your first menstruation? ☐
*¿Que edad tenia usted cuando tobo de su menstruasion?*

Have you ever been pregnant? ☐
*¿Ha estado usted embarazada alguna vez?*

How old were you at your first pregnancy? ☐
*¿Que edad tenia usted en su primero embarazo?*

How many times have you given birth? ☐
*¿Cuantos niños ha tenido?*

Did you breast feed your children? ☐ For how many total months? ☐
*¿Lacto usted sus niños?* *¿Por cuantos meses?*

Have you ever used birth control pills? ☐ For how many years? ☐
*¿Ha usted usado pastillas anticonceptivas?* *¿Por cuantos años?*

Have you reached menopause? ☐
*¿Ha usted alcanzado la menopausa?*

Reason for menopause? Natural *Natural* | Surgical *Cirurgica* | Other *Etc.*
*¿Razón para su menopausa?*

Have you ever used menopausal hormones? ☐
*¿Ha usted usado hormonas para la menopausa?*

Would you be willing to answer more questions to elaborate on this survey? If so, please provide:
*¿Estaria usted despuesta a contestar mas preguntas para elaborar en esta encuesta?*

Signature _____ Telephone _____

**The Huntington Breast Cancer Action Coalition is a not-for-profit community service group. The Coalition is composed of volunteers working to promote community awareness and action necessary to obtain public and private funding of breast cancer research. For information, or to volunteer your time, please contact: HBCAC, 900 Wait Whitman Road, Melville, NY 11747. Phone 516-547-1518.**

Huntington Hospital has a dedicated Breast Care Center available to the community, including the only Stereotactic Breast Biopsy Unit in Suffolk County. For more information call 516-351-2564.

Thank you for taking the time to complete this questionnaire. Please mail as soon as possible to:
*Gracias por contestar este questionario. Por favor envielo lo mas pronto posible.*

**The Huntington Breast Cancer Action Coalition**
**c/o Huntington Hospital**
**270 Park Avenue**
**Huntington, NY 11743**

**References**

1. American Cancer Society. Cancer Facts and Figures-2000. Atlanta, GA: American Society 2000. Website: www.cancer.org.

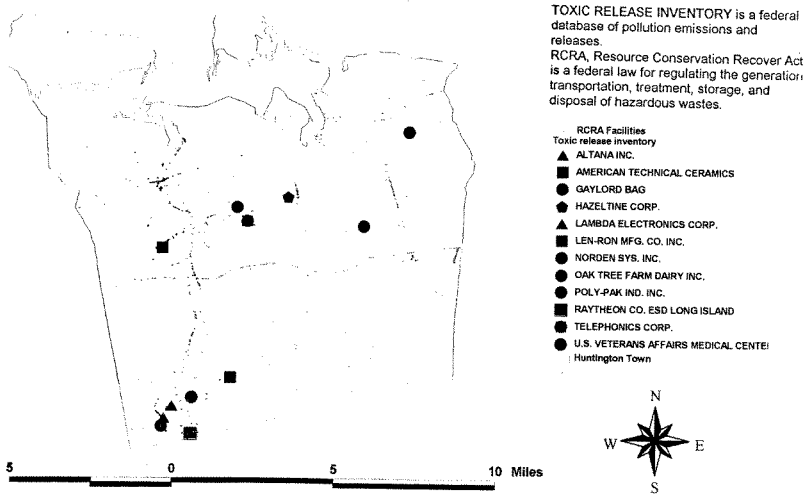
2. Breast Cancer Results from the Survey of the South Fork Breast Health Coalition. Grimson R and O'Leary, E.

3. The Breast Cancer Mapping Project in Onondaga County, New York. Novick, L and Farrell, M. November, 1999.

4. New York State Department of Health, New York State Cancer Registry, Cancer Incidence and Mortality by County. Volume 1. 1993-1997.

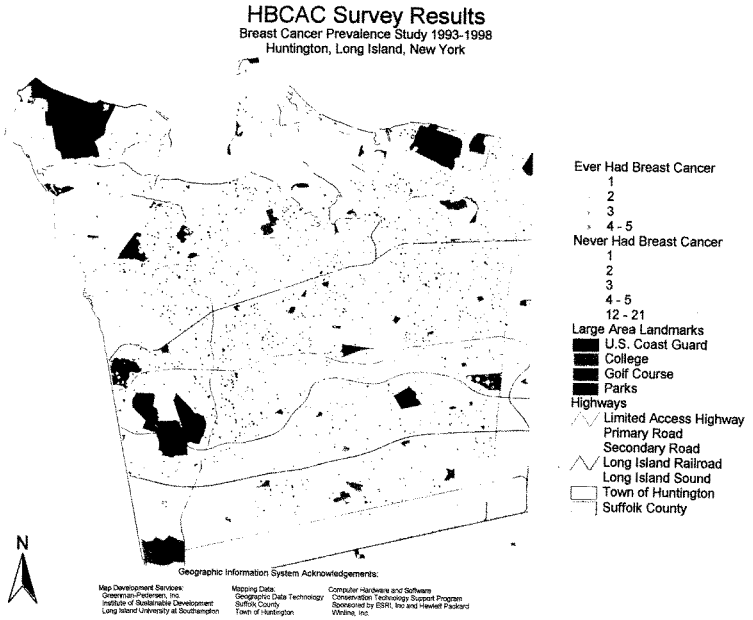
5. New York State Cancer Surveillance Improvement Initiative. New York State Department of Health. 1999-2000.

# TRI and RCRA Sites




TOXIC RELEASE INVENTORY is a federal database of pollution emissions and releases.
RCRA, Resource Conservation Recover Act is a federal law for regulating the generation, transportation, treatment, storage, and disposal of hazardous wastes.

RCRA Facilities
Toxic release inventory
- ALTANA INC.
- AMERICAN TECHNICAL CERAMICS
- GAYLORD BAG
- HAZELTINE CORP.
- LAMBDA ELECTRONICS CORP.
- LEN-RON MFG. CO. INC.
- NORDEN SYS. INC.
- OAK TREE FARM DAIRY INC.
- POLY-PAK IND. INC.
- RAYTHEON CO. ESD LONG ISLAND
- TELEPHONICS CORP.
- U.S. VETERANS AFFAIRS MEDICAL CENTE
- Huntington Town


HBCAC Survey Results
Breast Cancer Prevalence Study 1993-1998
Huntington, Long Island, New York
Ever Had Breast Cancer
1
2
3
4 - 5
Never Had Breast Cancer
1
2
3
4 - 5
12 - 21
Large Area Landmarks
U.S. Coast Guard
College
Golf Course
Parks
Highways
Limited Access Highway
Primary Road
Secondary Road
Long Island Railroad
Long Island Sound
Town of Huntington
Suffolk County
N
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FIRST INTERNATIONAL CONFERENCE ON THE RADIOLOGICAL PROTECTION OF PATIENTS
Malaga, Spain March 25 - 30, 2001

The problem of secondary cancers as a result of radiation was actively discussed by 800 scientists (from 88 countries) at this landmark conference. The opening session was a round table I chaired discussing advocates' expectations and concerns - an innovative and welcome approach to a highly scientific meeting, and one which seemed to have an important impact on most the scientists present.

**CONCERNS:** It was notable that everyone present was deeply concerned about patient protection. Fifteen European countries have adopted principles relating to radiological procedures and at least two (France and the Netherlands) have people hired by the government to see that these are followed. These principles are based on the concepts of justification and optimization - legal requirements that each radiological procedure be justified (necessary) and administered with maximum effectiveness and least harm. There was a lot of talk about risk/benefit ratios, but no one has a formula for measuring them. It was repeatedly emphasized that each procedure should be individualized depending not only on the medical problem but on the patient's age, weight, etc. In several sessions the importance of knowing a patient's previous history of radiation treatment was emphasized to avoid radiation burns to an over-treated area.

**DOSAGE:** Some questions were raised about the problems of monitoring dosage - there are three areas that can be measured and they would not be meaningful if they were mixed. ( I have not yet been able to learn why any one area couldn't be designated the one to consistently

where there is a paucity of financing and care). As technology and knowledge develops standards will require periodic change, and should be flexibly regulated; there should be mechanisms to adjust regulations to reduce risk and improve delivery. Training of personnel should be part of a quality assurance program.

Finally, it was recommended that "stakeholders" (including consumers) be involved in developing and implementing regulations.

**SUMMARY:** Medical radiation accounts for about 95% of doses from "man-made" sources; it is the largest radiation source other than natural background. The task is to provide enough dose for the task, but no more. Newer equipment needs acceptance testing; older equipment needs to be properly maintained. More attention has to be paid to reducing specific organ dose, and decreasing exposure to unintended targets.

Knowledge of a patient's prior procedures is essential to avoiding injuries.

***Justification*** ( is the procedure a) necessary and b) the best for the job), ***optimization*** (is the benefit to the patient maximized while the risk to the patient is minimized) and ***quality assurance*** (trained personnel, monitored equipment) are the watchwords in radiation treatment.

The presence of an advocate on groups or committees, especially those that deal with policy implications, was stressed but only partially accepted by the scientists present..

# # #

The conference was organized by the International Atomic Energy Agency and co-sponsored by the European Commission, the Pan American Health Organization and the World Health Organization, hosted by the Government of Spain in cooperation with the International Commission of Radiological Protection and the United Nations Scientific Committee on the Effects of Atomic Radiation.

Malaga.wpd

STATEMENT OF MARILIE GAMMON, PH.D., ASSOCIATE PROFESSOR OF EPIDEMIOLOGY, SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

Good morning Chairman Reid, Senator Clinton, and distinguished members the committee. I am Dr. Marilie Gammon, of the University of North Carolina at Chapel Hill; formerly of Columbia University in New York. I would like to thank you for inviting me to talk with you about how our environment may influence our cancer risk.

I am the principle investigator of the Breast Cancer and the Environment on Long Island Study[1], which is the cornerstone of the Long Island Breast Cancer Study Project (LIBCSP). The LIBCSP, funded by the National Cancer Institute (NCI) and the National Institute for Environmental Health Sciences (NIEHS), is a multistudy investigation of possible environmental causes of breast cancer on Long Island, and is a collaborative effort of New York City and Long Island researchers. My study is investigating whether certain environmental contaminants increase risk of breast cancer among women in Nassua and Suffolk counties. The primary aims are to determine if organochlorine pesticides, including DDT, polychlorinated biphenyls (PCBs), dieldrin, chlordane, and polycyclic aromatic hydrocarbons (PAH), a ubiquitous pollutant caused by incomplete combustion of various chemicals including diesel fuel and cigarette smoke, are associated with risk for breast cancer.

For this population-based study, all women in Nassau and Suffolk counties who were newly diagnosed with breast cancer during a 1-year period that ended mid-1997 (cases) were invited to participate. A comparison group (controls) of women who did not have breast cancer were randomly selected from the two counties. Altogether about 1,500 cases and 1,500 controls participated. The study participants completed a questionnaire administered by interview in their homes, and provided pre- and post-treatment blood samples and urine samples. In addition, a random sample of participants who had resided in their homes for at least 15 years participated in a study in which house dust, tap water, and yard soil samples were collected (home study). About 340 cases and 340 controls participated in this component of the study.

Blood and urine samples from 400 of the cases with invasive cancer, 200 of the cases with in situ disease, and 400 of the controls were randomly selected from the study population and analyzed. Laboratory analyses were conducted to measure organochlorine pesticides and PAH-DNA adducts in blood (PAHs bind to DNA), and urinary markers of estrogen metabolism. For the home study, samples were assayed for pesticides and PAHs.

The blood and urine samples of all African-American study participants were analyzed to increase the data available for this group. Further, all African-American women participants who had lived in their homes for at least 15 years were invited to be part of the home study.

Statistical analyses of the questionnaire data are now in progress. These data will be coupled with the results of the laboratory analyses to assess the risk for breast cancer associated with organochlorine pesticides and PAHs. Findings addressing the two primary hypotheses are expected to be published later this year.

Newly undertaken research includes examination of the possible interaction between susceptibility markers and environmental risk factors on risk for breast cancer. Further, tumor and blood markers of estrogen and PAH metabolism are being studied, and the laboratory analyses are now underway. Results from these newer efforts are expected in the year 2002.

I would be pleased to answer any questions you may have.

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STATEMENT OF RUBY T. SENIE, PH.D., PROFESSOR OF CLINICAL PUBLIC HEALTH, MAILMAN SCHOOL OF PUBLIC HEALTH OF COLUMBIA UNIVERSITY

Mr. Chairman and members of the committee: My name is Ruby T. Senie and I am a member of the faculty in the Department of Epidemiology of the Mailman School of Public Health and Principal Investigator of the Metropolitan NY Registry. Breast cancer has been the focus my research for more than 25 years. I wish to thank you, Mr. Chairman, and members of the committee, for convening this hearing on Long Island to discuss the potential influence of environmental exposures on breast cancer risk. Although increased susceptibility to breast and ovarian cancer has been associated with genetic mutations of BRCA1 and BRCA2, researchers have recognized that risk is also influenced by environmental exposures, lifestyle factors,

[1] The study is sometimes referred to as the Columbia case-control study, because Dr. Gammon began the study while at Columbia University, New York, NY.

health behaviors, and other components of the genome. A major challenge to investigators is the ability to quantify the risk associated with potentially harmful environmental exposures that may have occurred many years in the past; however, new technology has enabled the establishment of the field of molecular epidemiology. With these advanced tools, investigators are investigating potentially harmful exposures; reduction or avoidance of such exposures may eventually provide avenues for primary prevention of breast cancer.

I appreciate the opportunity to describe the purposes and achievements of the Metropolitan NY Registry and the five other sites contributing to the Cooperative Family Registry for Breast Cancer Studies [CFRBCS]. The initial goal of the CFRBCS, funded by the National Cancer Institute in 1995, was to encourage participation of key members of cancer-prone families. The families invited to join the Registry have been identified through high-risk clinics and population-based cancer registries. The role of family-based research for etiologic studies, specifically of the interactions of genetic risk with environmental exposures, was defined and potential multidisciplinary projects were described.

A major challenge for the CFRBCS Steering Committee was to develop a universal consent form to meet the Institutional Review Board [IRB] criteria of the six CFRBCS international sites. The consent form appropriately informs participants of the interdisciplinary research that will be conducted using the data and biospecimens they contribute and that findings from these studies may benefit their own families as well as society at large. The consent form also assures the protection and maintenance of confidentiality of all family members while minimizing any risks that may be associated with their participation.[1]

Each participant has been asked to provide medical history, family and lifestyle information as well as blood and urine samples. Permission to obtain sections of tumor tissue is also requested of participants with a history of breast or ovarian cancer or whose affected relative is deceased. These data and biospecimens provide a valuable resource for qualified scientists who are studying avenues to prevent, diagnosis, and treat breast cancer. To ensure the appropriate use of the invaluable and limited biospecimens, senior breast cancer researchers of the Advisory Committee evaluate the merits of each submitted research proposal. Approved projects are then assessed by the Research Monitoring and Ethics Review Panel to assure that standards of medical ethics are maintained and the confidentiality of data is guaranteed.

Family-based genetic studies necessitate the participation of three or more relatives per family; therefore, women and men with and without a history of cancer are included. Although the need for enrollment of families rather than isolated individuals within families has created a sense of community among participants who share our common goals, some individuals have hesitated to encourage their relatives to participate. Some hesitancy has been due to the perception that genetic studies are qualitatively different from other types of medical research contributing to fear of genetic discrimination. To reassure participants and to protect their privacy a Certificate of Confidentiality has been obtained from the Department of Health and Human Services prohibiting names or identifying characteristics from ever being released for any purpose.

Due to the rapid progress of scientific research, especially in the field of genetics, the exact nature of future studies using the Registry resources could not be fully described to individuals considering participation. Therefore, a commitment was made by the CFRBCS team of investigators to inform Registry participants of ongoing research and results through biannual newsletters and educational seminars. [Current issue from NY is attached] Through these mechanisms participants are also advised of additional research opportunities in which their active participation might provide personal benefit while contributing to cancer prevention options, improved screening modalities and enhanced therapeutic modalities.

Our international CFRBCS now includes more than 6,000 families of whom 1,150 were recruited by the New York Registry team. To identify a diverse population of cancer-prone families from the New York metropolitan area, several of the researchers contributing to the Long Island case-control study also collaborated in forming the NY Registry. Families at high risk were defined as having one or more first or second degree relatives with: early onset breast cancer, a history of both breast and ovarian cancer, male breast cancer, or three or more older aged relatives with breast or ovarian cancer. These criteria for the NY Registry have enabled recruitment of

[1] Daly, M.B., Offit, K., Li, F., Glendon, G., Yaker, A., West, D., Koenig, B., McCredie, M., Venne, V., Nayfield, S., Seminara, D., Participation in the cooperative family registry for breast cancer studies: issues of informed consent. J. Nat. Cancer. Inst. 92:452–6 (2000)

a genetically diverse cohort of families with a spectrum of risk with potentially inherited susceptibility to breast cancer.

Data and biospecimens are collected from all participating relatives using common instruments and laboratory protocols. Coded personal health information, dietary intake, treatment for breast and/or ovarian cancer, and pedigree data are routinely transmitted to CFRBCS Informatics Center. Biospecimens including blood and tumor tissue samples are banked at each collaborating site following rigid quality control procedures. Annual followup with all participants has been conducted to maintain an accurate record of cancer history and current status of participating family members as well as those who have not agreed to join.

Data files from all six Registry sites are merged and made available to approved investigators by the CFRBCS Informatics Center. Code numbers enable linking of family and personal history data with genetic analyses; personal identifiers are never available. The development of research proposals has progressed concurrently with family recruitment. The banked data and specimens are now being used by New York colleagues as well as investigators across the country in many interdisciplinary studies to assess the risk of breast cancer and breast cancer prognosis associated with susceptibility genes and the interaction of these genes with environmental exposures.

Familial aggregation of breast cancer has been recognized for centuries; however, the identification of BRCA1 and BRCA2 indicated the importance of having a cohort of families for studies linking genetic and environmental factors for breast cancer studies. Following identification of specific mutations in BRCA1 and BRCA2 among members of breast cancer families of Ashkenazi heritage, supplemental funds were awarded to four of the six CFRBCS sites including the New York Registry. These funds enabled enhanced recruitment efforts and offer genetic counseling and test results to interested members of this subgroup.

Genetic testing assessed the presence of the three founder mutations including 185delAG and 5382insC on BRCA1 and 6174delT located on BRCA2. A total of 336 mutations carriers among men and women of Ashkenazi heritage have been identified in the 1,417 Ashkenazi families currently participating in the CFRBCS. Of the 1,078 Ashkenazi participants with a history of breast or ovarian cancer, 18 percent were found to have inherited one the founder mutations. More than 1,220 blood samples from 93 New York Ashkenazi families have been tested for the founder mutations. Of these, 144 carriers have been identified including 120 women and 24 men. In addition to breast and ovarian cancer, some carriers have reported malignancies of other sites including prostate, colon, and melanoma. Sixty-one, eighteen men and forty-three women, found to have a mutation of either BRCA1 and BRCA2 have not been diagnosed with any cancer; however, most are younger than age 60 and remain at elevated risk. Although genetic counseling with provisions providing genetic test results was offered to all participants of Ashkenazi heritage, approximately 25 percent requested these services. However, during followup calls, additional family members are now expressing interest in learning their carrier status.

Although a large increase in disease risk has been associated with inheritance of mutant alleles of the two known breast cancer susceptibility genes, BRCA1 and BRCA2, these genetic mutations account for only a small proportion of breast cancer cases. Investigators are now recognizing the contribution of "low-risk" genetic variations to breast cancer risk. Single nucleotide polymorphisms (SNPs) which occur frequently in the regulatory and coding regions of genes, may confer an increase in cancer risk or modify the cancer risk induced by other factors. The common occurrence of SNPs in the population could contribute more to cancer incidence than the BRCA1 and BRCA2. SNPs may interact with environmental exposures modifying their independent effects disease risk. Studies of many SNPs are currently being conducted by CFRBCS investigators.

Enrollment of family members is often complicated by the geographic dispersion of living relatives necessitating much recruitment by phone and mail. However, this dispersion may be an asset for studies of suspected environmental contaminants. The metropolitan area includes regions of downstate New York as well as counties of New Jersey and Connecticut close to Manhattan. More than 300 participating families residing on Long Island have a first degree relative living outside the metropolitan area. To assess the impact of geographic dispersion that may implicate environmental exposures in breast cancer patterns within families, studies of paired sisters and parent-offspring sets may provide unique opportunities to assess cancer risk among individuals with shared exposures during formative years and differing geographic environments later in life. In addition, the more than 6,000 enrolled CFRBCS families are widely dispersed geographically providing the opportunity to assess breast cancer risk in relation in environmental exposures, BRCA½ mutation status and SNPs. As technology advances enable reliable measures of environmental

contaminants, Registry sites could collect additional data and biospecimens to enhance currently banked samples in order to assess risk in relation to the interaction of specific genetic factors and suspected adverse exposures.

The Metropolitan NY Registry and 5 collaborating sites of the CFRBCS have recently been awarded an additional 5 years of support indicating the importance placed on this project by Dr. Richard Klausner, director of the NCI, and Dr. Barbara Rimer, director of the Division of Cancer Control and Population Sciences. These funds will support additional recruitment, specifically of minority families, in order to provide adequate numbers for subgroup multidisciplinary studies. Disparities in risk and prognosis of breast cancer will be studied in relation to genetic, environmental, and treatment factors. Continuing followup interviews will be conducted providing opportunities to assess specific environmental exposures suspected of increasing breast cancer risk as well as changes in exposures reported at entry to the Registry.

The NY Registry and the collaborating sites of the CFRBCS provide a unique resource for current and future studies of breast cancer risk associated with genetic factors, environmental exposures, life style factors, and personal behaviors. During the next 5 years the Registry should contribute greatly to identifying avenues for reducing the incidence and enhancing prognosis of breast cancer. I feel privileged to be leading the New York Registry team and to be contributing to breast cancer research supported by the National Cancer Institute.

METROPOLITAN NEW YORK
REGISTRY
Ruby T. Senie, PhD Principal Investigator Winter 2001 1-888-METRO 08

# Happy New Year! Happy Millenium 2001!

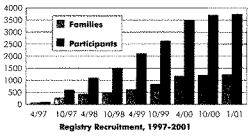
## From Dr. Ruby T. Senie

As Principal Investigator of the Metropolitan New York Registry, I wish you all the best in the new year. The staff of the Registry joins me in thanking you for your generous contributions and commitment to our research project. We all wish you good health and happiness during 2001!

I am currently a Professor of Clinical Public Health at Columbia University's Mailman School of Public Health. The epidemiology of breast cancer has been my focus for twenty-five years. I am proud to lead the Registry as we create a unique resource for research into this disease.

Our Registry is now 5 years old. We received our initial funds from the National Cancer Institute in September 1995 along with 5 other international sites forming the Cooperative Family Registry for Breast Cancer Studies [CFRBCS]. In March 2000 we reapplied for federal funds to continue our project. In our renewal application we indicated that we had surpassed our CFRBCS recruitment goal with 6,125 families and more than 18,000 individuals participating. Our Metropolitan NY Registry has contributed 1,180 families with 3,786 individuals.

We are very happy to tell you that the National Cancer Institute has awarded all CFRBCS sites, including New York, an additional 5 years to accomplish two goals: expand participation, and follow-up on all current Registry participants. This commitment from the National Cancer Institute indicates confidence in the role of the CFRBCS as an invaluable resource for current and future breast and ovarian cancer research studies. Our goal is to identify avenues for prevention.



Registry Recruitment, 1997-2001

In this issue of our newsletter you will learn about some of the studies using the CFRBCS resources that are being conducted by New York researchers as well as by scientists across the United States and around the world. We will describe several modifications to the Metropolitan NY Registry that will enable us to be more efficient while maintaining confidentiality of all the private information you have given us. Finally, we have included several brief summaries of recently published studies that may be of special interest to you.

## Centralization

To improve efficiency of record keeping and to coordinate follow-up, the Metropolitan NY Registry is now consolidated at Columbia University. All mail and phone contacts are being handled by the Registry team listed on the cover of this newsletter. If you originally spoke with a Registry Coordinator based at Memorial Sloan-Kettering Cancer Center, Mount Sinai Medical Center, Beth Israel Medical Center, NYU Medical Center or Stony Brook Medical Center, you will now be contacted by another friendly Registry Coordinator at Columbia. All updating of your family information and future family recruitment will be conducted by this smaller team of Columbia Registry

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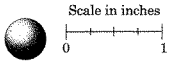
# Effectiveness of Mammography

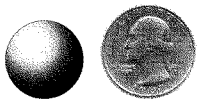
### Size of Tumors Found by Mammography, by Clinical Exam, and by Breast Self-Exam



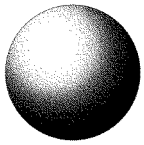

Average-size lump found by regular mammograms: 0.43 inches

Average-size lump found by first mammogram: 0.59 inches

Average-size lump found by clinical exam: 0.78 inches



Average-size lump found by women practicing monthly BSE: 0.81 inches



Average-size lump found by women accidentally: 1.40 inches

*Adapted from material from the Susan G. Komen Breast Cancer Foundation*

## Current Work in Breast Ca

### Recently Published Studies of Breast Screening

The American Cancer Society and many other organizations have emphasized the link between successful breast cancer treatment and the size of the tumor at diagnosis. That is why we encourage Registry families to take advantage of **all** early detection methods: monthly self-examination, frequent clinical examinations, and annual mammograms. The diagram at left shows the average size of cancers found by different methods. Several recently published studies emphasize the complementary nature of these screening modalities.

A recent Canadian study of women ages 50 years and older by Miller and colleagues was published in The Journal of the National Cancer Institute [JNCI 2000]. The authors noted that smaller tumors were detected among women who received annual screenings of both clinical exam and mammography compared to those who received annual clinical examinations without mammography. However, survival rates 12 years after diagnosis did not differ by screening modality. The Canadian Screening Trial also included careful instruction in self-examination, which was also shown to contribute to improved survival.

Accuracy of mammograms has been the focus of several recent studies. Several noted that the timing of mammography in the menstrual cycle can be important for premenopausal women. Screening mammograms should be scheduled during the early phase of the menstrual cycle, before ovulation, when breast tissue is least dense. In the case of postmenopausal women, a study in the Journal of the American Medical Association [JAMA 2001] by Rutter and colleagues reported that hormone replacement therapy [HRT] taken by many postmenopausal women increases breast tissue density. The authors suggested that the accuracy of mammography may be decreased among women taking HRT.

### Other Published Research of Special Interest

**Oral Contraceptives**

Use of oral contraceptive [OCs] before 1975 by women with a family history of breast cancer appeared to increase their subsequent risk of developing the disease. However, current OCs contain lower levels of estrogen and progesterone and may not have this adverse effect on breast cancer risk. The authors also noted OCs have also been found to protect women including those at genetic risk for developing ovarian cancer. [D. Grabrick, et.al., JAMA 2000].

**Physical Activity**

Several studies have found that women who were more physically active during adolescence have a lower risk of developing breast cancer as adults. Preliminary findings reported by Dr. Mary Clare King suggests that young women with a BRCA1 and BRCA2 genetic mutation may lower their risk of breast cancer by strenuous exercise around the time of puberty and young adult years. This protective effect of physical activity appears to be stronger among women who maintain a lean body weight. [Bernstein, et. al., JNCI, 1994 and Verloop, et. al. JNCI 2000]

**Cancer on Long Island**

A recent study by Stellman and colleagues has shown that no relationship appears to exist between past exposure to organochlorine pesticides such as DDT and breast cancer among women living on Long Island. [Cancer Epidemiology Biomarkers & Prevention 2001]. Other studies are currently underway to add to our understanding of pesticides and breast cancer risk.

Copies of these articles and of other current research are available at the Metropolitan New York Registry office, call 1-888-METRO 08.

## The Metropolitan NY Registry at Work

### Introducing Members of the New York Research Team

Dr. Habib Ahsan is studying the link between differences in metabolism of estrogens and the risk of breast cancer among paired relatives. Although mother-daughter pairs and paired sisters share many of the same genes, some small differences in their genetic make-up are known to occur. Dr. Ahsan is studying several estrogen metabolizing genes, reproductive history and estrogen use in more than 400 paired first degree relatives participating in the Metropolitan NY Registry. Blood samples from relatives with and without breast cancer are required for this investigation.

Dr. Grazyna Motykiewicz is investigating whether the risk of developing breast cancer is associated with an individual's ability to repair genes that may be damaged by environmental exposures. For her study Dr. Motykiewicz is analyzing DNA samples donated by paired sisters from families in the Metropolitan NY Registry. Although sisters are likely to have similar genetic make-up, their ability to repair damaged DNA may differ leaving one sister more susceptible to breast cancer. For her study, Dr. Motykiewicz is using blood samples from more than 400 pairs of sisters from the Registry.

Some studies suggest that alcoholic drinks may influence the risk of developing breast cancer. Dr. Mary Beth Terry is using blood samples from paired sisters to study a potential association between genetic susceptibility to alcohol, reported alcohol consumption at different ages and breast cancer risk. This study will contribute to an important area of research, as little is known about the role of alcohol intake and breast cancer risk among women with a strong family history.

Dr. Hank Juo is searching for new genes causing familial breast cancer. Two breast cancer genes, BRCA1 and BRCA2, have been found; however, they only explain a limited proportion of breast cancer patients who have strong family history. Dr. Juo has reported evidence of a novel breast cancer gene from studying the Scandinavian populations. He will analyze the DNA samples of the Ashkenazi breast cancer families participating in the Metropolitan NY Registry. This study will be conducted under the collaboration with Columbia University Genome Center.

*"I am a 3rd generation cancer patient and have an 18 1/2 year old daughter. My mother and sister are both still living (breast cancer survivors). In addition, my paternal Aunt died of breast cancer in her 30's. As my daughter continues to get older my concerns for her health increase. I would be honored (as would my daughter) to participate in any testing you might be doing to further the education of genetics and breast cancer."* - A Concerned Registry Participant

The Metropolitan NY Registry has many families in which either family history, questionnaires or blood samples have not yet been received. Without a complete file, the family or individual participant cannot contribute to ongoing studies, like those described above. Please complete your participation today!

## Askenazi Study

Approximately 2.5% of men and women of Ashkenazi Jewish heritage in the general population have a mutation of on one of two genes linked to breast cancer: BRCA1 and BRCA2. Almost all Ashkenazi BRCA1 or BRCA2 mutation carriers have one of three mutations called 'founder' mutations. The Metropolitan NY Registry is a resource to study the relationship between these mutations and various forms of cancer.

Among the nearly 1200 recruited families in the Registry, 46% noted they were of Ashkenazi heritage. Since our families in the NY Registry were invited to join because of a family pattern of breast and ovarian cancer or the young age at diagnosis, they are at higher risk of disease, and therefore do not represent the general Ashkenazi population. To carry out the research proposed by the NY Registry and our international colleagues, BRCA1 and BRCA2 analyses are conducted on blood samples from Ashkenazi Registry participants. All results are coded and kept strictly confidential.

So far, more than 1220 samples have been tested, and 141 [12%] men and women have been found to carry a mutation. These carriers represent 89 of the more than 500 families tested. While nearly two thirds of those with a mutation did have a history of cancer of some kind (mostly breast and/or ovarian cancer), more than a third of those who carry a mutation had no cancer at all. These unaffected men and women at genetic risk are of great importance to the studies currently underway. They will help us understand what factors may be protective against cancer development. Interestingly, some members of the families which carry genetic mutations have been diagnosed with other cancers, such as prostate, stomach and colon cancer. Researchers are investigating how the mutations known to contribute to breast and ovarian cancer may contribute to these other cancers as well.

## NY Registry Goals

### Complete Data & Specimen Collection

We have several important goals to accomplish in the years ahead. One goal of our Registry Coordinators will be to encourage you to complete all aspects of data and biosample collection. Many studies depend upon a linkage of questionnaire data with laboratory findings. Therefore, some studies are waiting for completed questionnaires or blood samples before the research can progress. Our Registry Coordinators are available to work within your time schedule to assist you in the completion of all Registry items. Please do not hesitate to call them to discuss the best way for you to complete your Registry questionnaires.

### Ethnic Diversity

Another important goal is to increase the racial and ethnic diversity of the Metropolitan NY Registry. Our recruitment goals will focus on expanding the number of participating African-American, Asian-American, and Hispanic families. Current research can be limited by the under-representation of minority groups. Expanding the Registry's recruitment of minorities will help researchers study breast cancer in diverse populations and provide more accurate data on the biologic behavior of the disease.

### Larger Families

Several researchers need biosamples from multiple family members with and without a history of cancer in order to conduct their projects. We encourage each participating family to include at least four members. Therefore, if you have relatives who are considering joining and have questions regarding their participation, please have them call 1-888-METRO-08.

## Registry Has Patient Advocate

Ms. Alice Yaker serves as patient advocate and community outreach director for the Metropolitan NY Registry. Previously she was Executive Director of SHARE, a self-help organization in NYC for women diagnosed with breast or ovarian cancer. She has represented patient advocates on the Steering Committee of the Cooperative Family Registry for Breast Cancer Studies by advising the research team on programs and outreach effort to enhance Registry participation. Ms. Yaker has contributed to the development of

questionnaires and newsletters, has spoken on behalf of the Registry at community meetings, and has interfaced with clinicians on behalf of the project.

## Resources Available

### Research, etc.

Copies of the publications mentioned in this newsletter are available from the Registry office at Columbia Presbyterian Medical Center. If you would like more information on the latest breast cancer research, call the Registry office at 212-305-8856. We also have many useful publications from the National Cancer Institute, the American Cancer Society, and other organizations. Topics include breast physiology, genetic testing, mammography, and more.

### MAMM Magazine

MAMM magazine was launched in October 1997 to meet the needs of women diagnosed with breast and other reproductive cancer. Many articles provide a resource for readers guiding their understanding of treatment options and the impact therapy may have on their quality of life. A subscription to MAMM can be arranged over the phone by calling 212-242-2163, or on the internet at www.mamm.com.

### Contribute to NY-Based Breast Cancer Research

Several states, including Massachusetts and California, have allocated tax dollars to establish breast cancer research programs. Since 1996 New York State has provided the opportunity for taxpayers to donate income tax refunds to the NY State Breast Cancer Research and Education Fund. To date more than $2.4 million has been donated to NY State breast cancer researchers. On October 30, 2000, Governor George Pataki enacted a new law providing state funds to match the donated dollars. "Every dollar that New Yorkers contribute to this fund helps support and advance the ground breaking research of our scientific community- - research that will someday lead to better diagnosis, treatment, and hopefully a cure for breast cancer," said Dr. Antonia Novello, NY State Health Commissioner. "Through this new legislation New Yorkers now have an opportunity to double the amount allocated to the Breast Cancer Research and Education Fund to fight this disease that affects 12,000 New Yorkers each year." Soon New York State residents will receive income tax forms in the mail and be able to donate to the state-based program.

# COMMENTARY

## Participation in the Cooperative Family Registry for Breast Cancer Studies: Issues of Informed Consent

*Mary B. Daly, Kenneth Offit, Frederick Li, Gord Glendon, Alice Yaker, Dee West, Barbara Koenig, Margaret McCredie, Vicki Venne, Susan Nayfield, Daniela Seminara*

No universal surveillance system collects information on all cases of cancer in the United States. Instead, cancer data are assembled in a variety of ways. Several very good population-based registries collect data in a fairly uniform manner, but different hospital-based registries often have different formats for data reporting, collection, coding, and analysis. Outcomes of interest include estimates of incidence, prevalence, and mortality; the identification of risk factors through epidemiologic analyses; the evaluation of patterns of care; and financial and resource planning. Few of the registries, however, have any genetic information. The recent identification of genes associated with high penetrance for breast cancer has brought a new focus to the study of cancer genetics—one that emphasizes the identification of families with heritable patterns of cancer—and has created the need for the development of registries that are defined by familial cancers.

### The Cooperative Family Registry for Breast Cancer Studies

The Cooperative Family Registry for Breast Cancer Studies (CFRBCS) is an international consortium established in 1995 as a resource for research on the epidemiologic, clinical, and genetic aspects of breast cancer. Funded by the National Cancer Institute (NCI), six sites (Northern California Cancer Center [Union City], Ontario Cancer Genetics Network, Cancer Care Ontario [Canada], University of Melbourne [Australia], Fox Chase Cancer Center [Cheltenham, PA], Metropolitan New York Registry, and Huntsman Cancer Research Center [Salt Lake City, UT]) collaborate to enroll a total of 5000 families at high risk for breast cancer into a family-based registry. The purpose of the CFRBCS is twofold: 1) to collect pedigree information, epidemiologic data, and related biologic specimens from patients with a family history of breast cancer in order to provide a registry resource for interdisciplinary studies on the etiology of and survival from breast cancer and to encourage translational research in this area and 2) to better characterize populations at high risk for breast cancer who could benefit from new preventive and therapeutic strategies.

Individuals with a personal or family history of breast cancer are identified according to a standardized set of eligibility guidelines. An attempt is made to enroll each proband, her first-degree relatives, and her affected second-degree relatives. Participants are asked to provide detailed family-history data as well as epidemiologic, medical, and lifestyle information. Blood samples are obtained from participating family members, and tumor specimens are requested from those with a cancer diagnosis. These resources are then made available to the research community for studies approved by an external advisory board of scientists and patient advocates.

The principal investigators from the participating sites and the leadership of the NCI recognized immediately the need to address the unique aspects of participation in a family-based registry with an emphasis on genetic research. The Informed Consent Working Group was created to identify issues of primary interest in the informed-consent process as it relates to involving families in an ongoing process of data collection, evaluation, and analysis and to develop a model informed consent document. This commentary presents the results of its deliberations and discusses those issues of particular significance to registry participation.

### History of the Consent Process

Beginning with the publication of the Nuremberg Code in 1949, the realization of the need to involve research participants in voluntary consent has been a growing and evolving process. Although written consent forms for therapeutic research were introduced at the National Institutes of Health (NIH) in 1953 (*1*), it was not until the 1970s that the research community, in partnership with the federal government, began to develop formal guidelines for the ethical conduct of medical research. The Code of Federal Regulations published in 1975 created the system of Institutional Review Boards (IRBs) that were charged with safeguarding the rights and well-being of research subjects and guaranteeing that appropriate informed consent is obtained (*2*). The purpose of the consent form is to apprise the prospective research subject of the nature of the study and to disclose the potential risks and benefits associated with participation. IRBs have become an integral part of the medical research environment, and the process of obtaining informed consent has become part of the standards and guidelines in the conduct of medical research involving human subjects.

General agreement has been reached about the required con

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*See* "Notes" following "References."

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tent items in the standard consent form (Table 1). This model, which has been the prototype for clinical trials research for the past 20 years, is now, however, being challenged in the face of the growing genetic revolution in science. Powerful new molecular technologies are making possible the ability to map the entire human genome and to identify genes responsible for a host of human diseases. The fear that genetic information may be used to stigmatize or to discriminate against individuals or groups has led to the perception that genetic research is qualitatively different and more risky than other types of medical research and, therefore, requires an expanded process of disclosure and informed consent. Several professional and governmental agencies, including the NIH, the Centers for Disease Control and Prevention (CDC), the American Society of Human Genetics (ASHG), the American College of Epidemiology, and the American Medical Association, have recently published diverse and sometimes conflicting recommendations for obtaining appropriate informed consent for the conduct of genetic research. The members of the Informed Consent Working Group were fully cognizant of this ongoing debate when they developed the informed-consent process for the CFRBCS.

## Content of the Proposed Consent Form

The members of the Informed Consent Working Group clearly identified the need to consider informed consent as a process that is based on a trusting relationship between study participants and investigators and reflected in both verbal and written formats. The goals of the consent process are to ensure respect for the participants, to guarantee participant autonomy, and to facilitate informed decision-making. As a first step, the group identified seven core content items necessary for inclusion in the consent form.

1) Study purpose: The rationale for the collection of information and biospecimens from a cohort of defined-risk families into a multisite registry should be stated as clearly as possible. This is particularly important, since the registry is a resource for future research projects and not a research project itself. While the individual research projects that will use these resources will, at the time of informed consent, be undefined, the general categories of research (e.g., new gene discovery, risk factor identification, and gene–environment interactions) can be described to emphasize the potential value of the resource being developed. The rationale for including data from multiple sites should also be explained. It is important that participants be made aware that the outcome of research is always uncertain but that knowledge may be gained as a result of their participation in the registry.
2) Eligibility: Individuals agreeing to participate in a family-based cancer registry should have a clear understanding as to what role they play in the potential research and what personal and family characteristics make them eligible for participation. This information helps to explain the need to enroll the family as a whole, rather than isolated individuals within the family, and fosters a sense of community and common goals with other participating families.
3) Procedures: The nature and extent of commitment to the registry should be understood before a potential participant agrees to participate. It is especially important that the proband understand that she will be responsible for providing access to and encouraging participation by other eligible family members. The type and quantity of data to be collected must be clearly specified. The following items should be included: the number, content, and frequency of the study questionnaires; the frequency of follow-up contact; and the frequency of blood collection and amount of blood typically collected. When appropriate, the need to obtain tumor specimens and pathology reports should be explained, and consent should be obtained. The possibility of recontact for specific study needs and the need to identify proxy informants to supply information for family members who are deceased should also be made explicit.
4) Use of registry data: The consent form should describe how investigators apply to use registry resources and explain that their requests are peer-reviewed. Participants should be aware of the nature of prospective research results and when and how they will be reported and shared, how new research findings will be added to the registry database, and the process to be followed when research findings appear to have potential clinical benefit. (Of particular relevance here is the mechanism by which clinical benefit is determined.) The estimated duration of DNA banking should be stated.
5) Property rights: Biospecimens and any products thereof are the property of the registry. Participants are assured, however, that the specimens they provide will be used only for the purposes described in approved study projects. Participants may be rightly concerned about the fate of biosamples that they provided when the original project is completed and funding ends. In most registries, specimens are saved indefinitely, since one of the goals is to be responsive to new research directions, but participants retain the right to withdraw from the registry and to request that their samples be destroyed and deleted from the registry database.
6) Risks, benefits, and costs: Risks referred to in traditional consent forms usually pertain to physical effects associated with different treatment modalities. In the case of participation in a family cancer registry, however, risks are more likely to be psychological or social and may involve changes in established family dynamics. Participants should be informed that they or other family members may discover things about themselves that they did not really want to know or are unsure how to react to. The risk of genetic discrimination by virtue of participation in a cancer family registry, particularly by insurers or employers, should be mentioned as a possibility, albeit a remote one. The benefits to society of each individual's participation (education and information received, the benefit to future generations, etc.) should also be stated.
7) Confidentiality: Participants should be informed how the data and biosamples that they provide will be protected from violations of confidentiality. Methods of coding, encryption, physical storage and security, and transmittal of data, especially electronic information transfer, should be described. Biosamples stored in a central repository should be coded

**Table 1.** Components of a standard consent form

| | |
|---|---|
| A. Nature of study | F. Confidentiality |
| B. Study procedures | G. Costs |
| C. Risks | H. Withdrawal |
| D. Benefits | I. Termination |
| E. Alternatives | J. Significant findings |

with identifiers removed prior to storage so that the ability to identify samples is left only with the site from which they originated.

The Informed Consent Working Group agreed that all information should be conveyed to potential participants in language that is clear and suitable to their ages, educational levels, and cultural backgrounds. They recognized that many research subjects are interested in receiving even generalized or preliminary research project results, and another decision emerging from these discussions was the commitment to publish a regular newsletter to keep participants informed about the development of the registry, about ongoing research projects, and about general research results as they are reported.

## Content Areas of Particular Significance for Registry Participation

Some aspects of consent to participate in a family-based registry for the purpose of genetic research deviate from the more traditional individual-focused clinical research protocols and require special consideration. The communication of data from multiple, international sites to a central data repository requires special safeguards. Uncertainty about the nature of the research projects that will be conducted by use of the registry's resources is common. The extent to which other family members may be affected by either registry participation or registry research findings is also unclear. And finally, the delicate distinction between research results and clinically significant findings may be especially difficult to define in the case of genetic data.

### Privacy and Confidentiality

At the core of the ethical issues associated with the involvement of human subjects in medical research are the issues of privacy and confidentiality. Privacy pertains to the extent to which others can gain access to information about an individual. Privacy issues may arise in research when information is obtained about individuals without their specific consent to divulge or to disseminate that information. Of particular significance is the case of family-based studies, where one person often provides information about the medical histories of family members without their explicit consent. The creation of a family pedigree may reveal previously unknown relatives or may uncover patterns of disease of which the family was unaware.

It has been suggested that publishing family pedigrees poses the risk of invasion of privacy *(3)*. Individuals may experience pressure from other family members to provide information so that the pedigree is complete. While recognizing that there is no clear consensus on this issue, the Office for Protection from Research Risks (OPRR) of the U.S. Department of Health and Human Services has stated that IRBs can consider the collection of pedigree information to be acceptable as long as the nature of the risks involved is defined *(4)*.

Although the identification of the size of the family by the proband is a necessary first step in the creation of a pedigree, the subsequent recruitment of additional family members to a family cancer registry should be done without coercion and with sensitivity to the needs and concerns of each family member. The strategy taken by the Informed Consent Working Group was to request specific written permission from the proband for the registry's staff to contact each additional family member. This policy gives the proband the opportunity to consult with other family members to decide whether withholding permission to contact some family members is in their best interests. At the same time, it removes the burden of actual recruitment from the proband and allows individuals contacted by registry staff to decline to participate without fear of recriminations from family members.

In genetic research, issues of confidentiality equal privacy issues in importance. Confidentiality pertains to the handling and use of data provided by an individual for the purpose of scientific research. Appropriate mechanisms must be in place to prevent the improper disclosure of information and to limit the use of the data to the purposes prescribed in the consent process. Special confidentiality concerns arise in family studies because of the unique nature of genetic data and the implications that information about one family member may have for other family members.

The assurance of confidentiality in genetic studies has two components. First, participants in the registry should be clearly informed as to the physical security of their data and biospecimens, including methods of coding and removal of identifiers, encryption techniques, and quality-assurance policies. Second, participants should be informed about the process of releasing data to future investigators as it relates to maintaining confidentiality. To address the latter issue, the CFRBCS has been constructed as a functionally anonymous data bank that uses an informatics structure that maintains linkages to personal identifiers for the purposes of long-term follow-up but blinds individual investigators to these identifiers.

### Use of Data and Biospecimens by Investigators Outside the CFRBCS

Storage of biospecimens in a tissue repository for the purpose of future research creates an archive of biologic samples. The use and reuse of archived tissues are areas of growing debate, particularly when they involve the banking of genetic material. IRB guidelines developed in 1993 by OPRR indicate that investigators should attempt to disclose plans for subsequent use or reuse of data or biospecimens at the time of consent. The dilemma is knowing how to disclose to prospective registry participants the potential risks resulting from research when the nature of future research projects is unknown, and the current pace of genetic research challenges our ability to adhere to the OPRR's recommendation.

The Informed Consent Working Group considered under what circumstances the investigator should be required to obtain a new consent for use of the specimens stored as part of registry participation, a process that may put undue burden on the research subjects or compromise the research effort. Several documents address this issue.

By federal regulation *(5)*, research using stored tissue samples is exempt from IRB review if the tissue samples already exist when the research is proposed and the ability to identify the research subjects is not available to the research team. In cases where samples can be linked to individuals, renewal of consent may be waived when 1) it is judged that there is minimum risk to the subjects, 2) the rights or welfare of the subjects will not be jeopardized, 3) the research could not feasibly be carried out without the waiver, and 4) subjects will receive information about their role in the research when appropriate *(4,6,7)*.

The Genetic Privacy Act, a proposal for federal legislation, recommends a stringent set of consent mechanisms for genetic research, including the restriction of access to DNA samples to persons clearly authorized by the subject at the time of consent and the requirement to destroy the sample upon completion of the specifically authorized genetic analyses unless retention is clearly authorized or the specimens are made anonymous *(8)*. This proposal is based on the premise that genetic information is qualitatively different from other types of medical information, since it provides information about the health of the individual's family and has, historically, served as a means of discrimination.

A workshop convened by the NIH and the CDC in 1994 determined that all investigators, including those not directly involved in the participant's care, should be bound, in most cases, by the limits of the original consent and that, given the potential for risk involved in genetic research, individuals have the right to determine how their samples are used. This principle implies that renewal of consent would be necessary for research projects that are not described in the original consent form. The workshop participants made an exception for samples that were made irretrievably anonymous, since renewal of consent would be impossible *(9)*.

The ASHG, on the other hand, takes a somewhat more flexible view regarding samples that are identifiable. Its statement maintains that subjects providing samples for prospective studies should be informed about the nature of the research proposed, its possible limitations and outcomes (including the possibility of unexpected findings), and the steps that will be taken to assure confidentiality. The ASHG supports renewing consent by subjects for new studies but offers criteria that allow recontact to be waived and that are based on the level of risk involved and the practical constraints imposed by the process of renewing consent *(10)*.

All of the statements and guidelines published to date recognize the uncertainty of many issues pertinent to genetic research and recommend continued debate both within the scientific community and within society at large. Given these limitations, the Informed Consent Working Group recognized the need for an oversight body to monitor the use of the resources stored in the CFRBCS. With the agreement of the entire steering committee, it was decided to expand the advisory committee to include individuals with expertise in the legal and bioethical aspects of genetic research and to give the committee the responsibility to include the issue of renewing consent in their evaluation of research projects. The existence and function of this Research Ethics and Monitoring Panel (REMP) are made explicit in the consent form so that potential registry participants are made aware of the nature of the decision-making process as it relates to their biosamples.

### Communication of Registry Research Results

Traditionally, data from studies in research laboratories have not been communicated to the individuals who provided samples for the project. This policy is based on the assumption that results generated in a research laboratory may be subject to less stringent reliability criteria than those originating from a clinical laboratory that is subject to the strict quality-control conditions set by the Clinical Laboratories Improvement Act. Even under the conditions set by this act, many people have questioned the clinical utility of genetic tests that predict the probability of future diseases for which there are no efficacious protective interventions. Although the specific purpose of enrolling families into the CFRBCS was not to perform genetic tests on individual family members, the Informed Consent Working Group appreciated the likelihood that many proposed research projects would include mutation analyses for the major genes associated with breast and ovarian cancers, thereby creating a dilemma regarding the communication of these test results. If results were not communicated to CFRBCS participants, they might be deprived of the potential benefits of knowing their carrier status and taking (or not taking) preventive actions indicated by the results of their tests. On the other hand, giving research results to individuals who had not specifically consented to be tested for a particular mutation—and who may not want the information—raises many other ethical problems.

After much deliberation, it was decided that the consent form would indicate that, when information of potential clinical benefit was obtained as a result of research performed with CFRBCS resources, participants would be notified collectively and offered the opportunity to seek individual genetic testing in a clinically approved laboratory. The definition of clinical benefit would be determined by the full advisory committee, including the members of the REMP, and would be based on the accuracy of the test results, the magnitude of the potential threat posed to the research subject, and the magnitude of the potential benefit to be derived from receiving the information. While this compromise was thought to be reasonable, it was appreciated that it does not address the financial barriers to genetic testing in the clinical setting.

### Process Issues

In the process of developing a model consent form, the Informed Consent Working Group identified two process issues that could affect the final form and style of the consent document at each site: 1) legal and regulatory issues for multiple sites and 2) geographic and cultural issues.

**Legal and regulatory issues for multiple sites.** IRB approval of research protocols remains a local prerogative and is subject to the history, philosophy, and legal constraints of each board. The Informed Consent Working Group recognized the possibility that individual state laws may jeopardize the acceptance of its model consent form and would necessitate local modifications. New York State law does not, for example, allow genetic test results generated in a research setting to be used to inform individuals, because an informed-consent process specific to the exact test being performed is required, and testing must be performed in a state-approved clinical laboratory.

**Geographic and cultural issues.** The ability to study diverse populations in different countries served by different health care systems is a tremendous strength for the CFRBCS in terms of research opportunities. It provides some challenges, however, with regard to standardization of the informed-consent process. Although there is international agreement on the basic principles of the process, there is also a need to respect the community milieu and the cultural context in which the research is conducted. For example, scientists and identified social leaders within a Native-American tribe collaborated to develop a protocol for genetic research that relies on communal decision-making as opposed to individual determinism *(11)*. And geneticists in China are far more supportive than scientists in the United States of enforced government-initiated genetic-screening programs *(12)*.

With reference to CFRBCS members, one of the major differences between the U.S. sites and sites in Canada and Australia is the organization of health care. While there are millions of uninsured and underinsured individuals in the United States, where health care is a complex mixture of private and public programs, both Canada and Australia have National Health Services that guarantee basic health care to all citizens. This situation translates into major differences in the litigious climate and in individuals' perceived and real levels of vulnerability with regard to confidentiality and how it affects the availability of health care to them. In the United States, one of the major reasons cited for not participating in genetic testing research protocols is fear of discrimination by insurance companies *(13)*. Residents of Canada and Australia, in contrast, do not share that risk and are likely to view genetic research with less concern. [Although in Canada the lack of a common law tort of discrimination precludes civil action against an insurer for discrimination, human rights legislation may provide limited protection from the use of genetic tests in underwriting insurance policies *(14)*.]

### Impact of Other Regulatory and Advisory Bodies

A growing number of academic, governmental, and political bodies are attempting to set policy with regard to genetic research and privacy, confidentiality, and discrimination issues. Their goals and agendas differ and change repeatedly to try to keep pace with the speed of genetic discovery and application. This changing environment makes it particularly difficult to address the concerns of all these organizations while developing and maintaining guidelines for informed consent for participation in the CFRBCS.

## Conclusion

In order to promote and to preserve the public trust, which is essential to the success of genetics-based research, it is imperative that investigators maintain the highest ethical standards regarding informed consent and, at the same time, remain sensitive to cultural and social norms of scientific research. Genetic research in the current environment emphasizes the tension between the preservation of individual autonomy and the potential reward to the individual of contributing to genetic discovery. We recognize that the balance achieved and represented while explaining the CFRBCS to potential participants must reflect societal values and must strive to maximize benefit and minimize risk. The Informed Consent Working Group has extended the debate on informed consent by 1) considering the competing needs of the individual, the family, and the public; 2) recognizing the need for special expertise in ethics and law in the guidance of the CFRBCS; 3) anticipating the need for flexibility in the consent process as genetic knowledge moves ahead at unprecedented speed; and 4) acknowledging the responsibility of the investigators to include research participants in the dissemination of research results. It is hoped that these efforts may have relevance to others in the field of genetic research.

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## Notes


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## STATEMENT OF GAIL FRANKEL, FIELD COORDINATOR AND ADVOCATE, ON BEHALF OF THE NATIONAL BREAST CANCER COALITION

### BACKGROUND AND INTRODUCTION

Good morning. My name is Gail Frankel and I am from Centereach, NY. I am an 8-year breast cancer survivor. I am also a volunteer with the Adelphi Breast Cancer Hotline and Support Program.

I am here today as a proud member of the National Breast Cancer Coalition (NBCC).

Thank you Chairman Reid (D-NV), for holding this hearing, and along with Senator Chafee (R-RI), Representative Lowey (D-NY), and Representative Myrick (R-NC), for cosponsoring the Breast Cancer and Environmental Research Act. Thank you also to my Senator, Senator Clinton (D-NY), for your support of this legislation and your commitment to this issue. And thank you to all the committee members for inviting me here to testify today.

As you know, the National Breast Cancer Coalition is a grassroots organization dedicated to ending breast cancer through the power of action and advocacy. The Coalition's main goals are to increase Federal funding for breast cancer research and collaborate with the scientific community to design and implement new models of research; improve access to high quality health care and breast cancer clinical trials for all women, and; expand the influence of breast cancer advocates in all aspects of the breast cancer decisionmaking process.

NBCC truly appreciates the fact that you are focusing on the issue of preventing this disease. We all wonder what causes breast cancer. I too have questions about what caused my breast cancer. Diagnosed at 53, I was told that even though my mother died at age 48 from the disease, my breast cancer was unlikely to be due to an inherited genetic defect since inherited cancer usually shows up at an earlier age in offspring. No other high risk factors applied to me. Did my diagnosis have something to do with where I live? The sad truth is nobody knows; there is no conclusive evidence about what causes this disease.

### THE ENVIRONMENT AND BREAST CANCER

As a volunteer for the Adelphi Breast Cancer Hotline and Support Program, and as a breast cancer survivor myself, I understand all too well the concerns women in New York have regarding the possible link between the environment and breast cancer.

While it is generally believed that the environment plays some role in the development of this disease, the extent of that role is not yet understood. NBCC believes that now is the time to focus our attention and public resources on developing an overall strategy to look at all aspects of this question. We can no longer afford to spend time, dollars and lives on isolated issues.

It is with that goal in mind that NBCC convened its first Environmental Summit in September 1998. This Summit brought together more than 50 experts, including scientists, advocates, government officials, and policymakers to begin developing a comprehensive strategy for studying the potential links between breast cancer and the environment.

Participants at this Summit brought many diverse perspectives. Some felt strongly that the environment is to blame for breast cancer. Others thought the cause is purely genetic. A third group believed that breast cancer is caused by some combination of the environment and genetics. While the participants differed in their perspectives, they ultimately agreed that the lack of evidence about the environment and breast cancer highlights the need for further studies on this issue. Furthermore, the decision of which questions to research should not be made in a vacuum, rather it should be made as part of an overall strategy of looking at all questions, prioritizing them, determining where we have some answers, and moving forward from that point. That is exactly what the bipartisan Breast Cancer and Environmental Research Act is meant to achieve: a collaborative, coordinated, nationwide effort to address this issue.

### PEER-REVIEWED ENVIRONMENTAL BREAST CANCER RESEARCH—A MODEL FOR OTHER DISEASES

This legislation would take a responsible approach to the questions around this issue by authorizing $30 million per year for 5 years to allow the National Institutes of Environmental Health Sciences (NIEHS) to make grants for the development and operation of collaborative research centers to study environmental factors that may be related to the development of breast cancer.

Under a peer-reviewed grant-making process, modeled after the incredibly successful Department of Defense Breast Cancer Research Program, the NIEHS Director could award grants to public or non-profit entities for the development and operation of up to eight centers for the purpose of conducting multi-disciplinary research on the links between breast cancer and the environment.

This legislation would require each center to be a collaborative effort of various institutions, companies and community organizations in the geographic areas where the research is being conducted, and would include consumer advocates. The enactment of such legislation would bring together a diverse group of entities, which would be able to take a broad look at the issue and develop a strategy based on differing perspectives.

And, like the support for the DOD BCRP, this legislation already has broad bipartisan support from across the political spectrum.

CONCLUSION

We recognize that this is a unique approach to looking at the environment and breast cancer. But time and time again, scientists, advocates and policymakers have told us that what is needed is a coordinated, responsible, innovative strategy. That is exactly what this bill would be. We appreciate that you, Members of the committee, have the courage and vision to support this innovative approach.

Thank you again for the opportunity to testify today, and I would be happy to answer any questions.

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STATEMENT OF AMY JUCHATZ, M.P.H., SUFFOLK COUNTY DEPARTMENT OF HEALTH SERVICES

Good morning. My name is Amy Juchatz. I am a toxicologist with the Suffolk County Department of Health Services, in the Division of Environmental Quality.

The Suffolk County Department of Health Services is often asked to become involved in the investigation of cancer cluster investigations. Typically, our role is supportive to the New York State Department of Health, which investigates suspected cancer clusters. The State health department maintains a Cancer Registry. Access to the cancer registry data, especially in regard to small area analyses, is restricted due to confidentiality concerns.

In concert with the State health department activities, the Suffolk County Department of Health Services provides support at the local level such as conducting site visits, meeting with concerned citizens, reviewing historical health department records and information pertaining to each situation or by conducting related environmental sampling. In addition to these support activities the Suffolk County Department of Health Services also perform extensive monitoring of groundwater and drinking water for a wide range of contaminants, including over 100 pesticides and their breakdown products.

Recently, the Suffolk County Department of Health Services performed such tasks following an investigation by the State health department of a cancer cluster identified among former students at a local high school.

The Long Island Breast Cancer Study, being conducted by the National Cancer Institute, is another good example of our supportive role. We transported and analyzed approximately 700 drinking water samples from residences of breast cancer cases and controls. These samples were analyzed for an array of possible contaminants, including inorganics, volatile organic chemicals, heavy metals and chlorinated pesticides.

Recently, the Suffolk County Legislature passed a resolution creating a task force to investigate the occurrence of a rare childhood cancer known as rhabdomyosarcoma. Specifically, this resolution created the Suffolk County Rhabdomyosarcoma Task Force for the purpose of developing a comprehensive survey, intended to better identify the incidence of rhabdomyosarcoma in Suffolk County. The Task Force has just recently formed and had our first meeting in March.

Local citizens initially raised concern about rhabdomyosarcoma incidence. The State Health Department has examined the rhabdomyosarcoma incidence data to see if any potential cancer cluster was evident. To date, the State has not been able to observe any geographical clustering, but are re-evaluating the State data base along with supplemental data provided by the concerned citizens.

I hope that the information that I have provided is helpful to this committee in its deliberations of cancer clusters and the possible role of the environment. I would be glad to address any questions you may have.

Thank you.

STATEMENT OF RICHARD J. JACKSON, M.D., M.P.H., DIRECTOR, NATIONAL CENTER FOR ENVIRONMENTAL HEALTH OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Good morning. I am Dr. Richard Jackson, director of the National Center for Environmental Health (NCEH) of the Centers for Disease Control and Prevention (CDC). I would like to thank the committee for inviting me here today to discuss how environmental exposures can potentially affect the public's health, and the role that the public health community can play in addressing these issues.

OVERVIEW

It is well known that short-term, high-level exposures to environmental chemicals can cause adverse health effects. Much of what is known about these types of exposures is based on occupational exposure research involving individuals or small groups of people who have been potentially exposed to environmental chemicals. However, less is known about the effects that long-term low-dose exposures can have on people's health, particularly when the potentially exposed population is large. Health effects such as birth defects, developmental disorders, neurological and immunological diseases, and cancer are often attributed to environmental exposures. When the suspected exposure source is found in a specific location, or community in a higher number than would be expected when compared to comparable locations, people in the community become concerned that there is a disease "cluster". Furthermore, people are also worried that something in their environment is causing the cluster.

DISEASE CLUSTERS

Disease clusters, such as cancer clusters, can have a devastating impact on individuals, families, and communities. From a public health perspective, the "perception" of a cluster in a community may be as important as, or more important than, an actual cluster. Public concern increases quickly when people think there is a cancer cluster in their community and that they and/or their children will be harmed. These situations deserve prompt and effective public health attention.

In the public's mind, cancer clusters are caused by something in the environment until proven otherwise. While certain clusters may result from environmental exposures, we need to consider many possible explanations before drawing conclusions. When searching for the cause of a cancer cluster, public health workers will have the opportunity to review the unique environmental aspects of a community and identify existing known environmental hazards. If public health workers identify a public health hazard, they should quickly remedy the situation. Public health action to remove a known human health hazard should not be delayed.

Cancer cluster reports are common because cancer is common. The American Cancer Society predicts that this year 1,220,000 Americans will be diagnosed with non-dermatologic cancer; and over 553,000 Americans will die this year because of all types of cancer. Fortunately, we are making progress in preventing and controlling cancer. CDC recently reported good news from California where lung cancer incidence fell 14 percent between 1988 and 1997. The reported decline may be related, in part, to the significant declines in smoking rates as a result of California tobacco control programs. We also know that early detection of cancer through cancer screenings saves lives. But, the preventible causes of many cancers remain elusive.

I can assure you that CDC and Agency for Toxic Substances and Disease Registry (ATSDR) are committed to a public health system that can quickly identify and respond to community concerns about cancer clusters. Cancer cluster activities must be integrated into the broader public health approach to cancer prevention and environmental hazard control. A community suspects that a cancer cluster exists when more cases of cancer have occurred than are expected and when there is a possibility that the cases share a common cause. A few cancer cluster investigations have led to the discovery of preventable causes, but this is the exception rather than the rule. These investigations involved astute researchers and physicians who identified an excess of extraordinarily rare cancers among their patients (e.g.; adenocarcinoma of the vagina and diethylstilbestrol; Kaposi's sarcoma and HIV virus; liver angiosarcoma and vinyl chloride monomer) or who identified a cluster of certain cancers known to have a single preventable cause (e.g.; mesothelioma and asbestos).

Approximately 85 to 90 percent of investigations of suspected cancer clusters find no increased cancer incidence. Even though 10 to 15 percent of investigated clusters do show that the study population has a higher than expected cancer risk, this increased risk, may be due to the random distribution of cancer within a population (i.e. chance). The causes of the remaining clusters are unknown. Routine analysis

of cancer registry data to identify cancer clusters can increase the number of chance clusters. Statistical tests of cancer registry data cannot separate observed clusters caused by chance from those due to an unrecognized common cause.

Although cancer clusters rarely provide a scientific opportunity to identify a new cause of cancer, public health agencies require the capacity and technical expertise to support a staged response to public inquiries about cancer clusters. Public health agencies require the scientific and technical expertise to identify when an excess cancer has occurred and to reassure communities when it does not. Cancer clusters are reported throughout the United States. A survey by the Council of State and Territorial Epidemiologists found that 41 State health departments reported 1,900 cancer inquiries in 1996. We don't know the total number of reported cancer clusters because there is no national tracking system to identify suspected or confirmed clusters.

MEASURING ENVIRONMENTAL EXPOSURES

Our challenge is to address the public's fear that something in their "environment" is causing the cluster. To effectively determine the public health impact of a chronic environmental exposure, three things are tracked. First, we cannot know the hazards of chemicals in humans unless we monitor what chemicals actually are in the environment. Tracking toxic chemicals in the environment must include the amount, concentration, and geographic distribution of known and potential toxic chemicals. Some systems for tracking this type of data already exists, for example, within the U.S. Environmental Protection Agency's (EPA) *Toxic Release Inventory* which collects data down to the local level. There are also EPA and State data bases for water, air, and pesticide environmental contaminants.

Second, actual human exposure levels are tracked through measurement of chemicals in human blood and urine through a process known as "biomonitoring." CDC released the first annual *National Report on Human Exposure to Environmental Chemicals*. This first edition of the Report presents levels of 27 environmental chemicals measured in the U.S. population. These chemicals include metals (e.g., lead, mercury, and uranium), cotinine (a marker of environmental tobacco smoke exposure), organophosphate pesticide metabolites, and phthalate metabolites. An example of what we have observed so far is a decline from 71 percent in the early1990's to 32 percent in1999 for non-smoking Americans exposed to environmental tobacco smoke. We are expanding the Report to include 100 environmental chemicals. Chemicals under consideration for future Reports include carcinogenic volatile organic compounds, carcinogenic polyaromatic hydrocarbons, dioxins, furans, polychlorinated biphenyls, trihalomethanes, haloacetic acids, carbamate pesticides, and organochlorine pesticides. This data will be collected annually and the number of chemicals tracked will increase, but this data is currently only available on a national level.

Finally, health outcomes are to be tracked over time. Specifically, both disease events and trends in health risk behavior need to be monitored over time through tracking systems such as vital statistics, health surveys, and disease registries. As we build a comprehensive disease tracking system in the U.S. that can provide data on a range of chronic conditions at the national, State, and local levels, it will be designed so that the data collected can be linked to the data from the other two tracking components. A comprehensive, nationwide exposure and disease tracking system is the only means to access the magnitude and nature of health risks from environmental exposures.

A STAGED RESPONSE TO CLUSTERS

I will now describe the components of a staged response to clusters which includes the multi-level, multi-agency public health response that is required to address potential health problems and public concerns related to potential environmental exposures.

THE STATE ROLE

Cancer cluster concerns should be addressed by State health departments working as closely as possible to the affected community. A staged response is called for, and this requires that State and local agencies establish a set of core competencies. The first competency is the ability to determine if a cancer cluster represents an excess cancer risk for the community. The second competency is the ability to respond to a cancer cluster concern. A third competency is the ability to link information about environmental contamination with cancer registry data.

Most State health departments have developed protocols for responding to cancer clusters, however, these approaches and capacities vary from State to State.

High quality, population-based cancer registries are a critical tool for health departments to address cancer cluster concerns. CDC currently supports statewide, population-based cancer registries in 45 States, three territories, and the District of Columbia through the National Program of Cancer Registries (NPCR). The National Cancer Institute includes the remaining five States as part of its Surveillance, Epidemiology, and End-Results Program. These registries systematically collect and analyze cancer incidence and mortality data to identify and monitor cancer trends over time, guide cancer control activities, and suggest leads for further research. CDC's NPCR represents a unique opportunity to strengthen cancer reporting and registration in the United States. The NPCR collects information on cancer cases for 96 percent of the nation's population. Since 1997, the number of NPCR-supported State cancer registries that have been certified for quality by the North American Association of Central Cancer Registries has increased from 9 to 29.

Data collected by State cancer registries can be used to guide planning and evaluation of cancer control programs; help set priorities for allocating health resources; and advance clinical, epidemiologic, and health services research. Cancer registry data is essential to be able to determine cancer patterns among various populations, to monitor cancer trends over time, and to identify and evaluate suspected clusters of cancer.

To maximize the benefits of State-based cancer registries, CDC is developing the NPCR-Cancer Surveillance System for receiving, assessing, enhancing, aggregating, and disseminating data from NPCR programs. This system will provide valuable feedback to help State registries improve the quality and usefulness of their data, and the system could support important data linkages with other cancer data bases. Availability of data on a regional and national level will also facilitate studies in areas such as rare cancers, cancer among children, cancer among racial and ethnic minority populations, and occupation-related cancer.

Effective State health departments are reliant on experience staff who can access and use cancer registry information, interpret these data and act appropriately upon the results. CDC is currently exploring various strategies to meet these needs.

When we are able to identify environmental health hazards in affected communities and link cancer registry information with environmental exposure data, states well be able to better address community concerns.

THE CDC AND ATSDR ROLES

CDC and ATSDR respond to cancer clusters by providing infrastructure support, national leadership, and technical assistance to States. Technical assistance has included peer review and consultation, field investigations, and assessment of environmental exposures. CDC has enhanced State infrastructure by funding State-wide population-based cancer registries that enable health departments to review cancer incidence data and assess reported cancer clusters. In 1989, CDC sponsored the National Conference on the Clustering of Health Events; the proceedings appear in a supplement to the *American Journal of Epidemiology* (volume 132, July 1990). In addition, CDC published *Guidelines for Investigating Clusters of Health Events* in July 1990. The guidelines can be accessed at: http://www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm CDC continues to review these documents and the current science to be able to revise guidelines as appropriate.

ATSDR and CDC are involved in responding to cancer clusters. I have already mentioned CDC's support of State-wide cancer registration. CDC conducts exposure assessments and epidemiologic studies that evaluate how people are exposed to environmental hazards and that identify preventable environmental causes of cancer. CDC's environmental health laboratory measures known and suspected cancer-causing agents in human blood and urine. CDC also addresses exposures to cancer causing-agents in the work place by conducting laboratory science and epidemiological investigations. CDC also responds to requests from employers, employees, and other government agencies for investigations involving possible work-related cancer.

ATSDR includes selected cancers among its seven priority health outcomes. ATSDR has responded to requests for cancer cluster investigations, especially those near hazardous waste sites. In addition, ATSDR educates concerned communities about cancer causes and prevention and publishes *Toxicologic Profiles*, a series of 137 monographs about cancerous and other health effects of hazardous substances, chemicals, and compounds found in waste sites. ATSDR also has been involved in research projects about the relationship between environmental exposure and the development of selected childhood cancers.

NEXT STEPS

CDC and ATSDR are working toward a number of activities to assist State health departments respond to cancer cluster and other inquiries related to potential health risks from environmental exposures. CDC is establishing a single point of contact through which all of these disease cluster inquiries might flow. This office would coordinate the CDC and ATSDR response, drawing upon needed expertise throughout CDC and ATSDR and other Federal agencies. CDC, in coordination with State and local health departments will develop recommendations or guidelines for responding, identifying, and following-up on disease cluster inquiries.

We are in the process of developing a public health system that is capable of monitoring exposure to chemicals linking the monitoring data to actual health outcome information, and utilizing the results to identify and respond to disease cluster inquiries. This will require a partnership among CDC, ATSDR and State health departments. Disease cluster investigations have rarely led to new discoveries into the causes of cancer, developmental disabilities, and other health outcomes. However, other positive public health outcomes can result. One example comes from a community in California. At this site, a pesticide investigation did not find any causal links between environmental exposure and disease; however, it did lead to the implementation of many positive public health actions such as increased health insurance coverage, pesticide tracking and better working conditions.

CDC and ATSDR will continue to work with States on their disease registries and help provide public health professionals with the knowledge and skill to use these systems to respond to the public. CDC and ATSDR are working with the States to build their environmental public health capacity. Through comprehensive, coordinated efforts and in partnership with many governmental, nongovernmental and community-based organizations we will continue to improve America's environmental public health will be assured.

Thank you for the opportunity to testify before you today. I would be happy to answer any questions you might have.

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STATEMENT OF DEBORAH WINN, PH.D., ACTING ASSOCIATE DIRECTOR, EPIDEMIOLOGY AND GENETICS RESEARCH PROGRAM DIVISION OF CANCER CONTROL AND PREVENTION, NATIONAL CANCER INSTITUTE, NATIONAL INSTITUTES OF HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Good morning. I am Deborah Winn, Ph.D., acting associate director, Epidemiology and Genetics Research Program, National Cancer Institute (NCI). Thank you, Senator Clinton and distinguished members of the committee, for inviting me to talk with you about NCI research on cancer, genes, and the environment. Conceptual and technical breakthroughs and the often breathtaking pace of scientific discovery have engendered among cancer researchers a tremendous sense of optimism that new avenues will be found to prevent, detect, diagnose, and treat cancer. Nowhere is the sense of promise greater or the potential more profound than at the interface of epidemiology and genetics. By marrying the study of the distribution and causes of cancer in human populations with cutting-edge genetic and related molecular technologies, we will, over time, be able to design new approaches to health and cancer care based on an understanding of how genes modify and interact with environmental exposures.

THE ENVIRONMENT, GENES AND CANCER

The term "environment" refers not only to air, water, and soil, but also to substances and conditions in the home and workplace. It includes dietary components; the use of tobacco, alcohol, or drugs; exposure to chemicals, and sunlight and other forms of radiation; and infectious agents. Lifestyle, economic, and behavioral factors are all aspects of our environment. To date, we know that tobacco is the environmental exposure most significant to the cancer burden. Factors that are absent from our environment, as well as those that are present, influence our cancer risk.

Cancer susceptibility is another critical piece of the puzzle. For example, why does one person with a cancer-causing exposure develop cancer, while another does not?

Genes may be the key. We know that disruption of fundamental cellular processes contributes to the development and progression of the more common, non-hereditary forms of cancer. Yet even among individuals who have inherited cancer-predisposing genes, the risk of developing cancer appears to be modified by other genetic and environmental factors. There is mounting evidence that a person's genetic make-up may influence susceptibility or even resistance to cancer-causing exposures.

Some cancers are associated with defects in one or a few genes. An example is the Li-Fraumeni syndrome, which involves an inherited tumor suppressor gene and is associated with familial occurrences of breast cancer and certain other cancers. However, most cancers involve many genes. Individuals may inherit defects in these genes, or they may experience environmental exposures or other circumstances that cause gene mutations, which are changes in gene structure. Most mutations do not affect the normal processes of cells in which they occur; but if alterations occur in genes that control such functions as metabolism of carcinogens, DNA repair, metabolism of nutrients, hormones and other factors, cell cycle control factors, or immune function, among others, cellular processes may become abnormal. Cancer arises through the accumulation of multiple mutations in genes resulting from multiple exposures over a period of years or decades.

Understanding the interaction of genes with other genes and environmental factors in the development of cancer is critical. Gene-environment interactions are evident when the risk from an environmental exposure varies depending on individual genetic make-up. For example, the CYP family of genes controls metabolism of some carcinogens. Each of us has CYP genes, but the exact structure of the genes varies from person to person. People with specific variants face a higher risk, by two to ten fold, of developing tobacco-related cancers such as lung cancer, esophageal cancer, and cancer of the oral cavity, than those individuals who have other CYP gene variants. This risk increases as the level of exposure to tobacco smoke increases. Furthermore, certain combinations of CYP variants, and variants of another gene, GSMT1, interact, resulting in even greater risks of these cancers.

NCI APPROACH TO THE STUDY OF GENE-ENVIRONMENT INTERACTIONS

The NCI has greatly expanded its efforts to identify the genetic and environmental risk factors leading to cancer susceptibility in individuals, families, and populations; evaluate the interactions of these risk factors; assess the relevance of these risk factors to clinical practice and public health; and address the diverse and complex scientific, ethical, legal, and social issues associated with this research. The NCI has identified the study of genes and the environment as a high priority research area with great potential for discovery. As our knowledge base expands in this critical area, we will be able to quantify the cancer risks associated with specific environmental and genetic factors and their interactions, and design new approaches to health and cancer care based on an understanding of how genes modify and interact with environmental exposures.

NCI's investment in the study of genetics has yielded enormous dividends. For example, NCI's Cancer Genome Anatomy Project has resulted in the discovery of approximately 40,000 new genes. New technologies have permitted scientists to determine which genes are active in normal or in cancerous tissues. There has been an exponential increase in the pace of identifying genes that maintain the integrity of our genetic material, regulate cell growth and development, and determine our response to hormones and other chemicals produced by the body or in the environment. Related discoveries have enabled us to characterize the function of hundreds of new genes and pathways. Vast public data bases contain millions of entries describing gene sequences and their location in the human genome.

NCI has expanded the tools available to the cancer genetics research community through the World Wide Web. Through the Genetic Annotation Initiative of the Cancer Genome Anatomy Project, scientists have identified more than 20,000 genetic variations, and they expect to expand that number to nearly 500,000 by 2002. Researchers are using sophisticated computer programs to identify variations in specific genes in people with cancer to determine which variants are associated with certain types of cancer and whether some variants occur more often in some populations. New technology development through the Innovative Molecular Analysis Technologies Program is also improving our ability to effectively analyze the large volumes of samples and data in these population-based studies.

Members of the Mouse Models of Human Cancers Consortium (MMHCC) are developing and validating mouse models—mice with cancers similar to the major human cancers that can be inherited. These models will be made available to scientists for research. Composed of 20 groups of investigators from institutions across the country, the MMHCC uses Web-based discussion forums and other communication tools to integrate emerging knowledge about cancer susceptibility from animal models with studies on human populations. The MMHCC also supports a repository for models of key cancers caused by specific gene variants.

We have gained tremendous insight into risks for cancer by examining the personal and medical histories of high-risk families and investigating how cancer-predisposing genes are modified by other genes and environmental factors in these fam-

ilies. For example, through the Cooperative Family Registries for breast/ovarian and colorectal cancers, we have collected clinical, epidemiological, and pathological data as well as biospecimens for over 8,000 high-risk families. Analysis of this information may lead to targeted approaches for the prevention, detection, and diagnosis of cancer.

Establishing significant and valid evidence for gene-environment interactions requires studies of large populations over long periods of time. In cohort studies, information on exposures to factors that might affect cancer risk and biologic samples are collected from individuals in large population subgroups. By systematically following these people over time to determine who develops cancer and who remains cancer free, scientists can understand the risk of developing cancer for those with specified exposures and genetic profiles. In this way, early detection can be directed to those at greatest risk, and diagnosis and treatment can be tailored to individual needs. NCI is establishing a Cohort Consortium of investigators from around the world to facilitate the pooling of data on very large numbers of people, foster collaborative links among resources, and organize collaborative studies. Another type of large population study is case-control studies, which retrospectively examine exposure histories and genetic profiles of people who already have cancer (cases) and compare them with those of people who have not developed cancer (controls). NCI is assembling a Case-Control Consortium to support large-scale studies of gene-environment interactions for less common cancers.

LONG ISLAND BREAST CANCER STUDY PROJECT

One illustration of NCI's approach to the investigation of the relationship between genes and the environment in the development of cancer is the Long Island Breast Cancer Study Project (LIBCSP): a multistudy research initiative examining the possible role of environmental factors in breast cancer in Suffolk, Nassau, and Schoharie counties in New York and Tolland County, Connecticut, where rates of breast cancer incidence are elevated. The LIBCSP used a full array of scientific approaches to study breast cancer on Long Island, and consisted of more than 10 studies that include human population (epidemiologic) studies, the establishment of a family registry for breast and ovarian cancer, and laboratory research on mechanisms of action and susceptibility in breast cancer development.

Originally conceived as part of the LIBCSP, a new tool has been created by NCI to help overcome the frustrations associated with studying geographic variations of disease: a prototype computer system called the Geographic Information System for Health (GIS-H). The GIS-H allows examination and tracking, over time and space, of cancer rates with any geographically defined factor that might contribute to the cancer burden. It is the largest and most comprehensive system of its type developed for the study of breast cancer. The GIS-H is a new approach for researchers to use in investigating relationships between breast cancer and the environment, and to estimate exposures to environmental contamination. The GIS-H data layers will include geographic data for precise mapping and geographic location of features in all data layers. Demographic data on health care facilities, health care surveys, breast cancer, and the environment will also be included. The environmental data will include information on contaminated drinking water; sources of indoor and ambient air pollution, including emissions from aircraft; electromagnetic fields; pesticides and other toxic chemicals; hazardous and municipal waste; and radiation. The system will rely chiefly on existing data bases obtained from Federal, State, and local governments, and private sources—including historical information on environmental exposures from residents—with emphasis placed on high-quality data. More than 80 data bases are slated to be included in the system. The GIS-H provides the opportunity to apply a powerful emerging technology to the study of environmental causes of breast cancer and is anticipated to be ready for investigator-initiated pilot studies this year.

ATLAS OF CANCER MORTALITY

Because geographic patterns of cancer may provide important clues to the causes of cancer, the NCI has, for over 30 years, studied geographic patterns of cancer mortality across the United States. Our most recent effort in this area is an updated atlas of cancer mortality. The new Atlas of Cancer Mortality in the United States, 1950—1994, prepared and published by the NCI, is a book and website of maps, text, tables, and figures showing the geographic patterns of cancer death rates throughout the United States for more than 40 cancers, and features 254 color-coded maps that show the geographic variations during 1970–94 compared to those during 1950–69. The color maps make it easy to pinpoint geographic areas with average, below average, or elevated rates. The Atlas, and related information, can be ex-

plored at http://www.nci.nih.gov/atlasplus/. The website allows the user to tailor the data interactively, to produce maps by race, gender, time period, age group, State, State economic area, or county level; and to develop bar charts and trend line graphs. The site also provides links to related sites. The Atlas has been designed so it is accessible not only to researchers, but to the public, consumer advocates, and everyone who is working to improve public health.

The Atlas does not provide information about why death rates may be higher in certain localities than in others, but it can generate leads for in-depth epidemiologic studies that may shed light on factors contributing to cancer risks. Possible risk factors include tobacco use, occupational exposures, dietary habits, ethnic background, and environmental exposures from the air or water. In addition, geographic differences in mortality rates may reflect differences in access to medical care, such as screening, diagnosis, or treatment. We anticipate that many of the leads provided by the new Atlas will guide further epidemiologic and public health activities aimed at preventing cancer.

The NCI is encouraging research proposals for new interdisciplinary studies that use the GIS-H and the Atlas of Cancer Mortality to explore geographic variations of cancer incidence and mortality and speed the process of scientific discovery and application. To date, about 30 applications have been received in response to this new initiative.

## NEW RESEARCH DIRECTIONS

Now, more than ever before, opportunities exist to determine how variations in genes combine with environmental and other factors to induce cancer. NCI has identified key priority areas for research on genes, the environment, and cancer, and designed a strategy to capitalize on the opportunities before us. We intend to focus expanded effort on identifying and characterizing gene variations involved in molecular pathways important in cancer development, and new environmental risk factors—and determining their interactions in cancer causation. We are planning initiatives that will develop new ways to assess and measure environmental exposures for use in population studies; develop new experimental models that parallel human cancer-related genes, pathways, and processes; and identify cancer-predisposing genes in high-risk families and investigate how expression of these genes is modified by other genes and environmental factors.

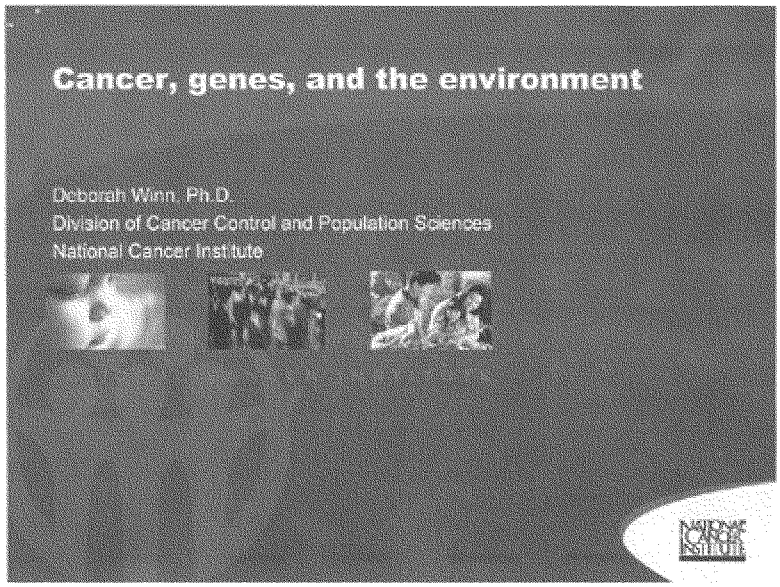
New insights into genetic susceptibility, environmental carcinogens, and their potential interactions can be incorporated into cancer risk prediction models that can in turn be used to estimate individual risk. We now want to refine cancer risk prediction methods and models to integrate genetic and environmental determinants of cancer.

Clinical trials involving genetically high-risk individuals can increase our understanding of the clinical, behavioral, and societal issues associated with cancer susceptibility. We plan to expand enrollment of genetically high-risk individuals into clinical protocols and conduct studies to address the clinical, behavioral, and societal issues associated with cancer susceptibilities.

## CONCLUSION

More than two hundred years ago, as our ancestors abandoned the theory that cancer was the result of an imbalance of bodily humors, scientists first observed that cancer could be linked directly to an environmental agent. As the 21st century dawns, scientific discovery is occurring at a pace that would have astounded our forebears. We have known for a long time that our environment, including our lifestyle choices and economic circumstances, influences our risk for developing cancer; but we have not understood exactly how, or why some people are more susceptible to these influences than others. Over the past decade, there has been an explosion of information on the fundamental nature of cancer, and with the rapid development of dazzling new technologies and tools, we grow closer every day to solving these mysteries that have long confounded us. Success is within our grasp. So, while the questions are complex and our progress has been hard-won, our hope is strong and our dedication is unwavering for a simple reason that each of us here today understands: our goal is to eradicate cancer and save the lives of those who would otherwise be lost to us.

Thank you for this opportunity to tell you about NCI's work. I would be pleased to answer any questions you may have.

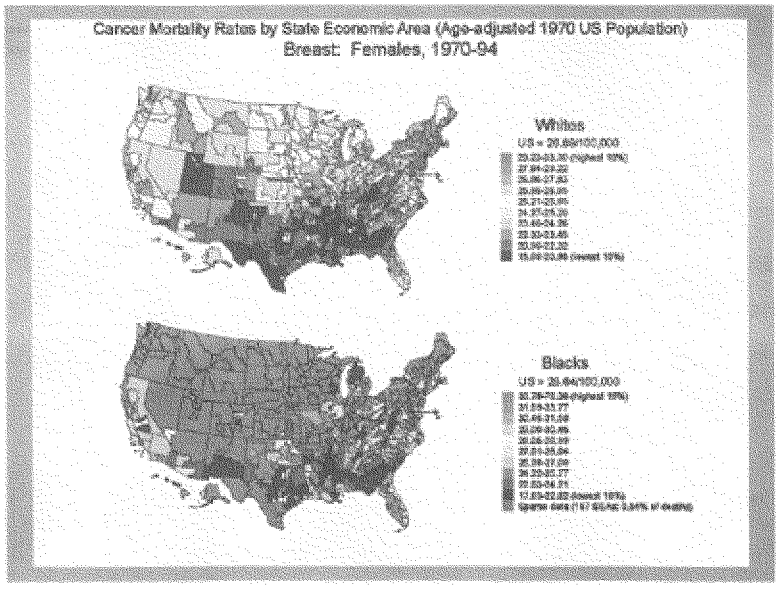

Cancer, genes, and the environment
Deborah Winn, Ph.D.
Division of Cancer Control and Population Sciences
National Cancer Institute

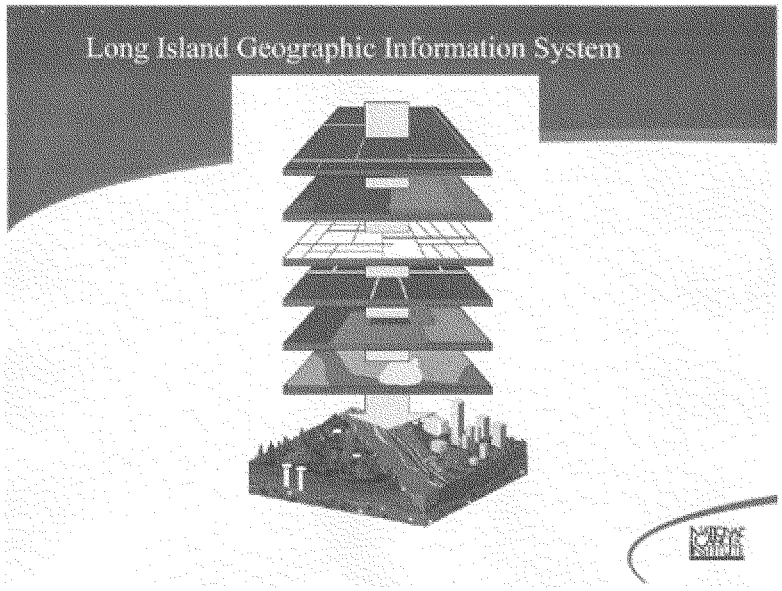
**National Cancer Institute: Research on cancer, genes, and the environment**

- Cancer Surveillance
- The Long Island Geographic Information System project
- NCI's strategic plan for research investment in genes and the environment

## Environment

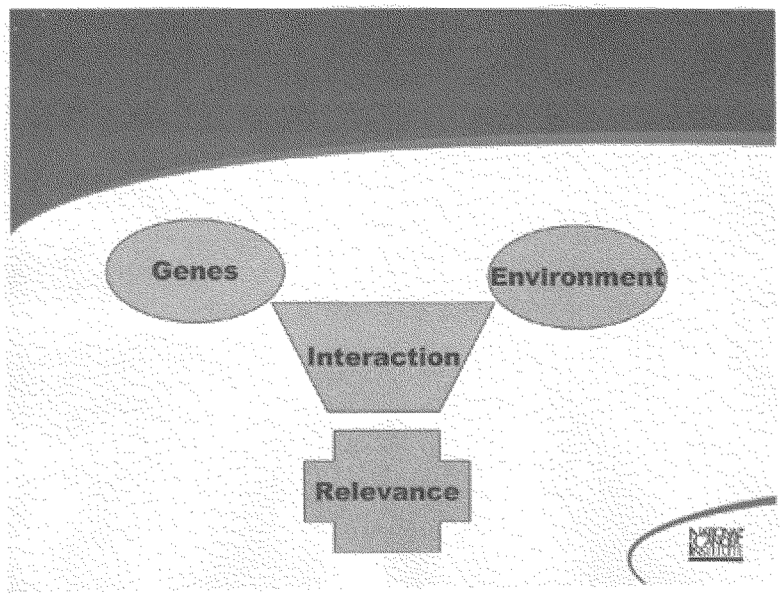
- Physical, chemical, and biological agents
- Lifestyle behaviors
- Occupation
- Medications


Cancer Mortality Rates by State Economic Area (Age-adjusted 1970 US Population)
Breast: Females, 1970-94
Whites
Blacks


Long Island Geographic Information System

## Long Island Geographic Information System

- Will provide researchers a new tool to investigate relationships between breast cancer and the environment in Suffolk and Nassau counties, and to estimate exposures to environmental contaminants
- Public will be able to use the website to examine patterns of environmental exposures and breast cancer


Genes
Environment
Interaction
Relevance

## Opportunities for research on genes and the environment

- Strategic plan for research investment
- Goal is to discover genetic, environmental, and lifestyle factors and their interactions that
  - define cancer risk
  - inform the development of new strategies for prevention, early detection, and treatment

## Objectives of genes and the environment initiative

- Identify new environmental risk factors and susceptibility genes and determine their interactions in cancer causation
- Refine cancer risk models and develop other tools
- Conduct studies to address clinical, behavioral, and societal applications

STATEMENT OF SAMUEL H. WILSON, M.D., DEPUTY DIRECTOR, NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES

I appreciate this opportunity to talk with you about environmental influences on our health. This subject is timely because here at the beginning of a new century we are assembling the tools that will enable us to detect environmental triggers of disease more precisely and more meaningfully. This ability will come about because of advances in an entirely different field, that of genomics which is the study of genes and of what genes do. The Human Genome Project, which has been the topic of much recent press coverage, was initiated in part to determine what genes are important in disease development. What we are finding, though, is that few genes serve as major determinants of disease risk. Instead, it is the interaction of our genes and our environmental exposures that sets the stage for the majority of disease development. Indeed, for many diseases, our genetic makeup by itself accounts for only a small part of our disease risk. It is our environment, acting in concert with our particular genetic susceptibilities, that confers a major part of our disease risk. Thus gene-environment interaction is where our attention must focus and where the major strides in environmental health research will be made in the future. In my testimony I will (1) describe some of the work that illustrates the significant role of environmental factors in major diseases, (2) describe how understanding gene-environment interactions will improve our ability to identify the precise environmental triggers of diseases, and (3) give examples of some of the research that NIEHS has initiated to address these topics. I will also touch on our expanded view of what constitutes "environment" and how diet and socioeconomic status must be included in this view.

The past few years have seen a remarkable number of studies that have identified the importance of environment in major diseases. By comparing rates among fraternal and identical twins, scientists have been able to tease apart the relative contributions of genes and of environment for several major diseases. Based on twin studies in Scandinavia, we now know that environment accounts for more than 50 percent of cancer risk, with genes accounting for the remainder of risk. Twin studies on Parkinson's Disease reveal that environment accounts for 85 percent of the risk in the late-onset cases of this disease. For autoimmune diseases such as multiple sclerosis and Lou Gehrig's Disease, environmental factors account for 60 percent to 75 percent of disease risk. Clearly, then, our environment is a major determinant of our health and of our relative risk for disease. It also spans a broad number of diseases and disorders. To give you an example, at the National Institute of Environmental Health Sciences we are investigating environmental triggers for cancer, Parkinson's Disease, birth defects, infertility, autoimmune diseases, hypertension, asthma and other respiratory disorders, learning and behavioral disorders, and uterine fibroids.

Although many people think of "environment" in terms of pollutants and industrial by-products, environmental factors encompass a much larger universe. They include diet and nutrients, pharmaceuticals, infectious organisms, natural compounds such as aflatoxin found in grains, herbal formulations, and our socio-economic environment. It is this totality of environmental factors that is proving to have a major role in human health and in disease development.

Environment, though, is not the total answer in disease development. Two people with the same exposure can have very different outcomes. Obviously not everyone who smokes cigarettes gets lung cancer, nor does every asthmatic respond to dust mite and cockroach allergens. We all have different susceptibilities to environmental agents. Many of these differences in susceptibility appear to be due to variations in genes coding for proteins critical in the body's response to environmental agents.

These proteins include metabolizing enzymes, DNA repair enzymes, cell cycle control proteins, cell signaling proteins, and receptor proteins. Someone inheriting a gene that produces a weak or ineffective form of one of these critical proteins will be more susceptible than someone inheriting a gene that produces a more effective form. That is because the first person might be less able to break down or excrete environmental compounds or to repair cellular damage caused by environmental agents. Thus understanding gene-environment interactions is critical in defining the environmental contribution to disease. Neither acts alone. It is the two acting in concert that lays the foundation for disease and dysfunction.

For these reasons the National Institute of Environmental Health Sciences (NIEHS) established the Environmental Genome Project (EGP). The EGP is a survey of the important genetic variants that affect people's responses to environmental agents. The EGP is a natural outgrowth of the Human Genome Project. In fact, understanding gene-environment interactions will be the only way to extract the full benefit from our investments in the Human Genome Project. That is because only

a few, relatively rare, diseases are caused by defects in a single gene. A large number of diseases and disorders result from inadequacies in common environmental response genes and can only lead to disease in the presence of a particular exposure.

The Environmental Genome Project ushers in a new era for environmental health science research. Previously individual variation in responsiveness to exposures generated a high "background noise" that could often mask the contribution of environmental agents to disease risk, particularly at the low levels to which most of us are exposed. Now, as we identify important genetic variants that alter response to environmental agents, scientists can better control for the confounding variable of individual susceptibility when they study environmentally caused diseases. In the future, we expect to be able to followup on results of twin studies by identifying the actual environmental components that comprise the major part of disease risk.

It should be noted, though, that timing is everything for environmental exposures. Certain stages of life impart a much greater vulnerability. Early human development, infancy, and childhood are among these stages. The carefully orchestrated events by which a fertilized cell develops into a sentient being offer many opportunities for environmental interference and disruption. In fact, children can suffer adverse effects from environmental exposures at doses that cause no apparent problems in adults. We are greatly interested in the potential of birth registries and prospective cohorts to decipher the genetic and environmental contributions to many diseases, particularly in children. We have joined with the Norwegian government on a study of cleft palate, a common birth defect. Norway has one of the highest reported rates of cleft palate in the world, as well as a highly organized birth registry that records these defects. For this study, both genetic samples and data on environmental exposures of mothers and infants are being collected. When completed, this study will provide the largest and most comprehensive collection of data ever obtained on the genetic and environmental components of this birth defect.

The NIEHS is also building on plans currently under way in Norway to recruit 100,000 pregnant women and their children. These families would be followed in a lifetime cohort study of health. NIEHS will collect and store blood and urine of these women for the purpose of assessing environmental and other exposures during pregnancy. This information on exposures of the fetus will be used to study the effects of environmental factors during this crucial period on birth defects, developmental problems, childhood diseases, and even diseases of adulthood that result from exposures early in life. In addition, NIEHS, CDC, and the National Institute of Child Health and Human Development have the lead for a similar longitudinal study on environmental influences on children's health in this country. This study was recommended by the President's Task Force on Environmental Health Risks and Safety Risks to Children in 1998 and mandated by the Children's Health Act of 2000.

Another study under design at NIEHS is the Sisters Study of breast cancer. This study would examine environmentally associated risks of breast cancer by recruiting women who have a sister already diagnosed with breast cancer. Because these women are at increased risk of breast cancer, twice as many breast cancer cases are expected as would be identified in any other cohort of similar size. Biologic specimens will be collected and stored at recruitment, and extensive questionnaires will be submitted regularly. Breast cancer risk will be assessed in terms of exposure to natural hormones, environmental hormone disruptors, growth factors, dietary components, and environmental contaminants such as pesticides and solvents. This study will also assess the importance of gene-environment interactions.

Studies continue to validate the importance of nutrition in maintaining health and preventing disease. Whole grain foods, for example, have been identified in NIEHS rodent studies as being protective against breast cancer and have been shown to protect against stroke in a NIH-supported longitudinal study of nurses. Nutrition is a major environmental risk component of many diseases. For this reason, the NIEHS has partnered with the NIH Office of Dietary Supplements (ODS) to fund a Center for Phytochemical and Phytonutrient Studies. This center is currently investigating the ability of dietary phytochemicals to prevent or treat prostate cancer, the role of phytoestrogens in altering immune response and possibly predisposing some women to autoimmune diseases, and the capacity of bioflavonoids to protect brain tissue from oxidative damage.

One of the major environmental challenges we face is that of exposure assessment—that is, defining exactly what chemicals are in our environment and how much is absorbed in our bodies. This type of information is invaluable to the NIEHS in designing relevant epidemiologic and laboratory studies that can determine the types of effects that can arise from environmental exposures. The NIEHS collaborates with the United States Geological Survey and the Centers for Disease Control and Prevention to use their expertise and data bases to develop a better under-

standing of common environmental exposures in this country. We are also collaborating with our sister agency, the National Cancer Institute, on the Agricultural Health Study. In this study we are assessing exposures common to agricultural settings and evaluating their influence on risk of developing conditions such as cancer, Parkinson's, infertility, birth defects, respiratory dysfunction, and other problems.

In conclusion, I would like to make the case that preventing disease is one of the most important services of our public health network. Protecting people from avoidable illness and death saves money, spares suffering, and improves the quality of life for society. The most effective way to prevent disease and disability is to understand the cause of an illness and change the conditions that permit it to occur. A key strategy to prevent many diseases or delay disease progression is to minimize or eliminate adverse effects of chemicals in the environment. This preventive strategy underlies the field of environmental health and is a core principle guiding NIEHS-funded research.

Because of its emphasis on prevention, environmental health science research is rarely played out in the high-tech, treatment-oriented arena of modern clinical centers. Rather, some of our most important work is done in agricultural fields, among migrant workers, in inner-city neighborhoods, and in public schools. The practice of environmental health science often requires engaging the efforts of our most disadvantaged citizens. NIEHS has been experimenting with new models of research that provide for citizen participation. It is our feeling that citizen-based participatory research will generate more relevant findings, will suggest better real-world research questions, and will serve as a communication tool for the participants and their neighbors.

I would be pleased to answer any questions.

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STATEMENT OF LYNN R. GOLDMAN, M.D., M.P.H., PROFESSOR, ENVIRONMENTAL HEALTH SCIENCES, JOHN HOPKINS BLOOMBERG SCHOOLS OF PUBLIC HEALTH

Chairman Reid, Senator Clinton, and members of the New York Congressional Delegation, thank you for the opportunity to come to New York to provide real perspective to our nation's ability to respond to crises in our communities.

My name is Dr. Lynn Goldman and I am a pediatrician and an environmental epidemiologist. I have an extensive background in the area of pesticide health and environmental effects and environmental risks to children. Between 1985 and 1992 I served in various positions in the California Department of Health Services, most recently as Chief of the Division of Environmental and Occupational Disease Control. Among other things, I was responsible for the conduct of a number of epidemiological investigations of the impacts of environmental exposures to health, especially the health of children. I carried out several investigations of childhood cancer clusters. In 1993 I was appointed by President Clinton and confirmed by the Senate to serve as Assistant Administrator for Prevention, Pesticides and Toxic Substances at the U.S. Environmental Protection Agency (EPA).

In that position, I was responsible for the nation's pesticide and toxic chemicals regulatory programs at the EPA. In January 1999 I left the EPA and joined the Johns Hopkins University where I presently am Professor at the Bloomberg School of Public Health. I served as the principal investigator for children's health for the Pew Environmental Health Commission—a blue ribbon independent panel charged with developing recommendations to improve the nation's health defenses against environmental threats. I currently am a member of the Environmental Defense Board of Trustees.

Our public health service is falling short in its duty to watch over the safety and health of Americans, particularly when it comes to chronic diseases that may be associated with environmental factors.

Chronic diseases are responsible for 7 out of 10 deaths in this country. More than a third of our population, over 100 million men, women and children suffer from chronic diseases. These diseases cost our citizens and government, $325 billion a year. By 2020 chronic diseases are estimated to afflict 134 million Americans and cost $1 trillion a year. And the CDC estimates that 70 percent are preventable.

But our Federal Government is not actively pursuing how to prevent this epidemic of chronic diseases.

As a Nation, we have been increasing our research into how to treat disease. As a result, we have some good news here. More children with leukemia survive today than ever before. We have also seen some success with reducing exposure to tobacco and the marketing of tobacco to our children. But there is bad news. The rates of a number of non-smoking related cancers—childhood brain cancer, breast cancer, non-Hodgkin's lymphoma, liver cancer, myeloid leukemia, thyroid cancers and a sev-

eral other tumor types—have been steadily rising for the past two decades. A review of the National Cancer Institute Atlas of Cancer Mortality shows clear geographic differences in rates of a number of cancers, differences that should serve as clues for followup studies and efforts to prevent cancer. As a Nation, we have not invested in preventing chronic diseases.

You heard today from those who have experienced firsthand the tragic cluster of childhood leukemia in Fallon and the breast cancer epidemic on Long Island. These crises are tragedies on both the personal and community level. My heart goes out to these communities. But as a health scientist, I am aware that this is problem that is repeated in communities all across the country. In 1997, there were almost 1,100 requests by the public to investigate suspected cancer clusters. Many of these are preventable diseases; preventable tragedies and our public health resources are insufficient to effectively respond to these challenges. In too many cases, there was not the capacity to investigate these problems.

Even though we know about the increasing importance of chronic diseases and the staggering human and financial toll they have on our country, we have no systems in place to track chronic diseases nor do we have the capability to respond to these health crises. Our Federal, State, and local agencies only systemically track and respond to infectious diseases such as polio, yellow fever and typhoid. These are diseases that a national tracking and response system helped to eradicate back in the late 1800's.

Over a century later, we never modernized our public health system to respond to today's health threats. As a result, we are hamstringing our health specialists from finding solutions and effectively taking action—regardless if it's childhood cancer or a nationwide asthma epidemic.

As a former chemical and pesticide regulator, I am appalled by the lack of information to make wise decisions about chemicals in the environment and our inability to be sure that we are doing what we should be doing to prevent chronic diseases. In 1997, Environmental Defense looked at what we know about chemicals in commerce at high volume (greater than a million pounds a year) in the United States. They found surprising and disturbing gaps in the information available to government and the public, a finding later confirmed both by EPA and by industry. Indeed, EPA's analysis indicated that that only 7 percent have screening level information about toxic effects and more than 40 percent have no information at all. To compound our ignorance, we do not know which chemicals are winding up in our bodies and the bodies of our children. For example, which contaminants are in breast milk? This is basic information that is needed, both to understand the risks and more importantly to make the right decisions to protect the public from harmful exposures.

Clearly, we cannot make wise decisions about the risks of chemicals given this state of ignorance. Incentives need to be created to generate information about hazards and exposures to industrial chemicals that are in our food and water, products used in the home and intended for children, and in the workplace.

Further, we also need this tracking information so that we can carry out the studies that will identify what might be causing high rates of chronic disease in communities in the United States. Let me give you an example of our scattered State health tracking systems.

• With the Pew Commission I wrote a report on birth defects that rated the State's efforts to monitor birth defects. Even though birth defects are the No. 1 cause of infant mortality, 17 States do not track birth defects. The Pew Commission gave Nevada and the 16 other States an F in its report, "Healthy from the Start" which was released in late 1999. New York received a "B", meaning that while there are good efforts underway the registry does not collect data that are compatible with the national standard set by the CDC. As a result, data from New York can't necessarily be compared to those from other States, hindering the ability of scientists to determine patterns of diseases and their causes.

• Whereas the National Academy of Science estimates that 25 percent of developmental diseases such as cerebral palsy, autism and mental retardation are caused by environmental factors, only a handful of States have any efforts at all to track these diseases.

• Cancer registries in many States have been severely neglected for years. Even in California, when I was there, we saw support deteriorate to the point where the registry could collect the data, but not analyze it or use it to take action to respond to cancer threats.

The Pew Environmental Health Commission based out of the Johns Hopkins School of Public Health studied our nation's capacity to identify and respond to chronic disease clusters for 2 years and proposed creating a nationwide Health Tracking Network to solve this problem.

The Nationwide Health Tracking Network is based on four principles: (1) building a coordinated system of tracking chronic diseases and associated environmental factors; (2) providing the resources and training to local health departments to analyze the data; (3) immediately responding to health problems identified through the system; and (4) providing the national leadership to coordinate health and environmental activities throughout the Federal Government so that these programs do not operate in isolation of one another.

The Nationwide Health Tracking Network consists of five components:

1. Establishing essential data collection systems: The first component builds on existing health and environmental data collection systems and establishes data collection systems where they do not exist. The Network will coordinate with the local, State and Federal health agencies to collect this critical data. In all fifty States, the Network would track:

- Asthma and other respiratory diseases;
- Developmental diseases such as autism, cerebral palsy, and mental retardation;
- Neurological diseases such Alzheimer's, multiple sclerosis, and Parkinson's;
- Birth defects; and
- Cancers, especially in children.

The Network also would track exposures to:

- Heavy metals such as mercury and lead;
- Pesticides such as organophosphates and carbamates;
- Air contaminants such as toluene and carbamates;
- Organic compounds such as PCB's and dioxins; and
- Drinking water contaminants, including pathogens.

Building upon the existing systems for infectious diseases, the Federal Government will establish the standards for the health and exposure data collection necessary to create uniformity throughout the system. With Federal resources such as funding, training and lab access, State and local public health agencies will collect, report and analyze the data.

2. Creating an Early Warning System: The second component is an Early Warning System that would immediately alert communities of health crises such as lead, pesticide and mercury poisonings. The existing system of local health officials, hospitals and poison centers that alert our communities to outbreaks like food illness and the West Nile virus would also alert our communities to these health crises.

3. Improving response to chronic disease emergencies: The third component consists of improving our response to identified disease clusters and other health crises. The Network would coordinate Federal, State and local health officials into rapid response teams to quickly investigate these health problems, providing the teams with trained personnel and the necessary equipment.

4. Addressing unique local health problems: The fourth component is a pilot program consisting of 20 regional and State programs that would investigate local health crises and clusters that are currently not part of the nationwide Health Tracking Network. These programs would alert the public and health officials to new developing disease clusters outside of the nationwide Health Tracking Network. These pilots programs also would serve as models for tracking systems for inclusion in the Network.

5. Creating community and academic partnerships: The fifth component establishes relationships with five Academic centers and with our communities. Our community relationships would ensure that the tracking data is accessible and useful on a local level, and our research relationships would train the work force, analyze data, and develop links between the tracking results and preventive measures.

(The background and basis for this Network and other Commission findings and recommendations are attached as part of the written testimony. These are also available on the *Commission's website.*)

This Network would provide our communities, scientists, doctors, hospitals and public health officials with missing data on where chronic diseases are clustering and associated environmental factors that would enable us to develop prevention strategies. Over thirty key health organizations have endorsed this recommendation, ranging from Aetna U.S. Health Care to the American Cancer Society to the American Academy of Pediatrics to the Association of State and Territorial Health Officers (ASTHO).

Developing prevention strategies are critical to reducing the $325 billion a year Americans spend on chronic diseases. As noted above, the estimated cost of chronic disease is predicted to rise to $1 trillion in less than 15 years. The estimated cost of the Network is about $275 million or less than 1 dollar per every man, woman and child.

It is ironic that we have mapped the entire human genome and yet we don't have the most basic information about the diseases that are killing us. We are learning

about the genetic susceptibilities in the population but we do not have a clue which chemicals might be triggering these genes to create disease. We have learned how to spend millions upon millions to treat chronic diseases like asthma and cancer but the Federal Government has not identified the reasons why asthma and rates of certain cancers are rising. We need to spend our tax dollars more effectively by identifying which chronic diseases are increasing and which exposures may be impacting our health.

The most cost effective use of tax dollars today would be to invest in preventing the leading killers in this country. And the American public agrees. The American public is so concerned about this issue that 63 percent feel that public health spending is more important than cutting taxes. Seven out of ten registered voters (73 percent) feel that public health spending is more important than spending on a national missile defense system.

A recent public opinion poll by Princeton Survey Research Associates revealed that nine out of ten (89 percent) registered voters support the creation of a national system.

Most local health departments face declining funding, inadequate training for staff, limited or no laboratory access, and outdated information systems. CDC and ATSDR have not been able to adequately help. For instance, there is no Federal funding for an environmental health specialist or even chronic disease investigator almost all States. Nor does CDC or the Agency for Toxic Substances and Disease Registries (ATSDR) give States written guidance, standards or protocols on how to investigate the cancer clusters.

On a Federal level, there are a few programs that relate to chronic diseases, but do not track and respond to the increases in rates of chronic disease. The irony is the Administration's proposed budget recommends severe cuts for the nation's chronic disease prevention programs. We need to be going in the exact opposite direction. Health defense should be the country's No. 1 commitment.

Who is guarding our health? The answer is that the public health service has fallen short of its duty—lacking the tracking, troops and leadership. This is exactly where our Federal Government is needed—to develop the tracking and monitoring systems, supply the troops and offer the leadership to prevent chronic disease.

To modernize our public health resources so that we can identify clusters before they grow, we must take rapid action to control their spread and find solutions to prevent diseases. CDC must be given the direct mandate to aggressively respond to communities' concerns like those on Long Island and in Fallon, with modern tools and health-tracking systems. And Congress must prioritize $275 million per year, less than a dollar per person to make this happen. It is just a tenth of 1 percent of the overall spending of health care dollars in this country.

Without this type of investment, we will only watch asthma, certain cancers and other chronic disease rates continue to rise. There will be many more lives lost to preventable diseases. And that will be the greatest tragedy of all.

Thank you for the opportunity to testify today.

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STATEMENT OF ELINOR SCHOENFELD, M.D., ASSOCIATE PROFESSOR, STONY BROOK UNIVERSITY SCHOOL OF MEDICINE

My name is Dr. Elinor Schoenfeld and I am an associate professor in the Department of Preventive Medicine at the School of Medicine, University of New York at Stony Brook. On behalf of the University at Stony Brook, I would like to thank you for giving us the opportunity to be a part of these hearings. The research community at the University at Stony Brook is engaged in many aspects of environmental research and the impact the environment has on health. With the University's close collaborations with many other organizations on Long Island, the University would be an ideal resource for research collaborations to study the impact of the Long Island environment on community health. We are the only medical school located in Suffolk County. The Health Sciences Center houses the schools of Medicine, Nursing, Health Technology and Management, Social Welfare and Dentistry. Each school provides for the teaching of health professionals to serve the health care needs of the community. In addition, each school provides for the development of researchers in many fields of basic and clinical sciences.

The Department of Preventive Medicine within the School of Medicine has an outstanding team of epidemiologists and occupational medicine specialists with a special interest in cancer and the environment. We have a long-standing relationship with the community to investigate concerns about possible disease clusters on Long Island. In addition, we have a strong interest and involvement with breast cancer research on Long Island. Currently, we are conducting the Electromagnetic Fields

and Breast Cancer on Long Island Study, which is investigating the possibility that electromagnetic fields increase the risk of breast cancer. This EMF study is federally funded and is one of the studies of the Long Island Breast Cancer Study Project.

The EMF and Breast Cancer on Long Island Study is a population-based case-control study of women in Nassau and Suffolk Counties, New York. Women were eligible for this study if they participated in the Long Island Breast Cancer Study Project case-control study, were either diagnosed with breast cancer between August 1, 1996 and June 20, 1997 or were population-based controls accrued through random-digit dialing (women ages 30–64) or HCFA files (over age 65), and lived in their current residence for 15 years or more.

The measurement protocol for the study was based on the results of a comprehensive pilot study. The measurement protocol included spot measurements (at the front door, bedroom and most lived in room), 24-hour measurements (bedroom and most lived-in room). Participants were queried on their use of electrical appliances, age of the home, number of years in the home, occupational history, electric train travel, and light-at-night. At a second visit, the wiring around the home was diagrammed by trained technicians. Results from this study will be available later this year.

Another potential resource for evaluating the impact of the environment on health for the local community is the Long Island Cancer Center, which appointed it first director, Dr. John Kovach, this past year. The goal of the Long Island Cancer Center is to provide comprehensive cancer care to all Long Islander's while providing an environment to conduct both clinical and basic research into the causes and treatment of cancer.

There are many features of University at Stony Brook and the School of Medicine which present a unique opportunity to develop a truly comprehensive cancer program which integrates the best of academic research at a basic and translational level with clinical trials, patient care, community hospitals, community physicians and the community at large. The special aspects of the program are:

1. University at Stony Brook Department of Preventive Medicine and Epidemiology has a 20-year history of working with the State Department of Health, the State of New York, and the Federal Government in studying the cancer problem on Long Island. This includes mapping potential toxic sites throughout the Island, the study of "hot spots" of breast cancer on Long Island as part of the federally funded Long Island Breast Cancer Project, and cancer education in the schools, communities at large and community physicians. To facilitate these Long island epidemiology studies, the Department of Preventive Medicine has established mechanisms for data collection, storage, retrieval and analysis while assuring confidentiality of the data. This is a unique resource for a cancer center poised to apply advances in molecular biology and genomics to the problem of human cancer. The special opportunities available to Stony Brook and to the citizens of Long Island are to develop a population-based cancer data base focusing initially on breast and prostate cancer, two leading cancers in men and women respectfully in the United States.

2. University at Stony Brook and the School of Medicine currently receive over $10 million annually in total support form the National Cancer Institute. This level of support is above the median support received by the 68 Comprehensive Cancer Centers in the United States.

3. The University Stony Brook and the School of Medicine already possess four program grants from the National Institutes of Health. These attest to the quality and the integration of multiple investigators into cohesive programs, the hallmark of comprehensive centers. The awards include two program grants to explore environmental causes of genetic damage; a third grant in Tumor Virology and a fourth grant supporting General Clinical Research Center.

4. The School of Medicine possesses outstanding expertise in all clinical aspects of cancer diagnosis and treatment. These include outstanding cancer surgery for brain, lung, gastrointestinal, breast and ovarian cancer; exceptional radiation oncology with state-of-the-art equipment; and excellent medical oncologists for children's cancers and adult cancers. The physicians consistently receive accolades from the public regarding their compassion and thorough care.

5. The University at Stony Brook and Brookhaven National Laboratory have exceptional resources in computer sciences, applied mathematics, statistical genetics and biostatistics. Such depth in these areas is rarely found in a single comprehensive cancer center. These disciplines are increasingly important to medical research which relies more and more the receipt, storage, retrieval and analysis of massive amounts of data.

6. Strong working research relationships and a single graduate/raining program between Cold Spring Harbor Laboratory and University at Stony Brook and the

School of Medicine provide special opportunities to bring basic biological research relevant to the cancer problem to an international level of quality. Cold Spring Harbor Laboratory has a cancer center grant from the National Cancer Institute for its basic science programs. With the completion of the Human Genome Project, an ability to relate variations in human genetic sequence to specific disease promises to provide un-paralleled insights into the causes of disease and lead to new mechanisms of disease prevention and cure. Cold Spring Harbor will benefit by access to physician scientists being recruited to the cancer center at Stony Brook.

7. The close relationship between Brookhaven National Laboratory and Stony Brook University provides unique resources for the cancer center such as access to the synchrotron light source for structural studies and to expertise relevant to development of advanced imaging capabilities. Dr. Nora Volkow, director of Clinical Research at Brookhaven National Laboratory and Dr. Linda Chang, the new medical director of Brookhaven National Laboratory are national experts in advanced imaging procedures.

Imaging research is aided enormously by the capability of Brookhaven National Laboratory to generate a variety of short-lived isotopes useful for the labeling of proteins and for positron emission tomography (PET). Additional strength was added recently with the recruitment of Dr. Helene Benveniste from Duke University. She is an internationally recognized expert in micro-magnetic resonance imaging (MRI) in the mouse. The State of New York recently provided $900,000 to establish for Dr. Benvenistea state-of-the-art micro-MRI instrument.

8. Over the past 6 months, the Cancer Center has invited investigators from other institutions with the kind of expertise needed to enhance the comprehensive nature of the Long Island Cancer Center at Stony Brook. Eleven speakers have presented seminars to one or another of the focus groups of the cancer center. The consensus of these investigators, who are already well funded from the National Cancer Institute, is that there is outstanding science at the center and that the setting at University at Stony Brook is ideal from an academic standpoint.

Other University resources for the evaluation of the impact of the environment on health include the Long Island Groundwater Research Institute (LIGRI) which was established in 1994 to marshal the resources and expertise of the University for the study of groundwater hydrology and chemistry. One of the Institute's goals is to bring the results of scientific research to bear on the region's most pressing groundwater problems. Inquiries on all aspects of groundwater hydrology and chemistry are welcome.

The resolution of hydrogeological and groundwater pollution problems requires basic and applied research from a broad array of disciplines. The Institute coordinates and expands the existing potential for research by faculty, staff and students in groundwater hydrology. The Institute maintains close communication with ground-water professionals in the government and private sector in Long Island. Through the University's Center for Regional Policy Studies, a distinguished Advisory Council has been established with representation of agencies with management responsibilities. In 1997 the Institute was formally established by legislative act.

The Institute has become a member of ECAC joining the Maxwell School and College of Engineering and Computer Science at Syracuse University, the New York Water Resources Institute at Cornell University and the Darrin Fresh Water Institute at the Rensselaer Polytechnic Institute. The purpose of this group is to assist local communities to access institutional expertise and resources to provide outreach, education and support to government agencies through this State-wide effort. As part of this effort, the Institute has been asked to provide technical information to community groups (ABCO, NEARS) concerned with contamination at Brookhaven National Laboratories. The Institute also provided testimony for a joint legislative assembly hearing on water quality and quality issues sponsored by the Commission on Water Resource Needs, the Environmental Conservation Committee and the Task Force on Food, Farm and Nutrition.

Given the community's awareness and the importance of cancer on Long Island, we applaud today's hearing. As scientists studying the link between cancer and the environment, we recognize the need for a special effort and initiative in this area. We are prepared to lend our efforts to meet the challenge to improve the health of the population on Long Island.

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STATEMENT OF MARK SEROTOFF, TOWNLINE CIVIC ASSOCIATION, ENVIRONMENTAL CARCINOGENS ON LONG ISLAND, NY

The importance of addressing the epidemic of cancer on Long Island cannot be overemphasized. One-in-nine incidence of breast cancer, high levels of pancreatic,

esophageal, brain cancers, leukemia, lymphoma, lung, testicular, colon, stomach, melanoma, multiple myelomas, liver, kidney, bladder cancers and more are common. Such diverse presentations result from varied causes: ingestion by mouth, skin, and respiration.

Ingestion includes exposure to chemicals in food and water. An inspection of the year 2000 water quality statement from South Huntington Water District reveals permissible levels of: 1,1,1-Trichloroethane, Tetrachloroethane, Trichloroethene, Bromodichloromethane, Chlorodibromomethane, 1,1-Dichloroethane, 1,2-Dichloropropane, nitrates (fertilizers); all carcinogens. Most other water district reports have similar levels of "acceptable" carcinogens. Farming on Long Island is the largest dollarwise in the State and carcinogenic residues may be found on the produce, again, within "acceptable" government standards.

There are five incinerators distributed around Long Island and over a dozen power plants, with potentially a dozen more due to deregulation. All use fossil-fuel and emit millions of pounds a year of carcinogens in the form of particulate matter and volatile organic compounds. Because these are on an ISLAND, there are very few suitable locations for minimum impact on the population and environment. In some neighborhoods, more than one of these major stationary sources are side-by-side. Some existing, or proposed, are close to homes, schools, hospitals and parks.

The unique topography and meteorology of Long Island result in numerous stagnant days, especially in the ozone season (May to October). Exposure to the aforementioned carcinogens as well as other pollutants is significantly higher to the general population during such times. Furthermore, the dearth of mass transit has resulted in an extraordinary number of vehicle and truck (high-polluting diesel) trips that add carcinogens and other pollutants to the air. In fact, the DEC has classified Long Island for over 8 years as a "non-attainment region" for ozone. That also implies high levels of the other pollutants that cause heart/lung damage and cancer.

The proliferation of cellular communications has resulted in countless cell towers and antennas that dot the Long Island landscape. These are suspected of have carcinogenic effects. Some towers with dozens of stations (antennae) are adjacent to dense residential clusters. In addition, the same applies to high tension fines. Both will become more prevalent with time.

Blessed with hundreds of miles of shoreline, sunbathers have ample opportunity of sun exposure which is associated with melanoma.

The nature of a carcinogen is such that there is no safe limit of exposure. The Delaney Amendment prohibited chemicals, compounds or additives in food or drugs that showed any laboratory cancer causation. It has since been repealed under industry pressure as too costly. The next question is, "To what degree will these carcinogens be removed from the environment?" or better, "How much are we prepared to spend?" The current situation is unacceptable; additional (and more costly) steps must be taken: If we want improved health and quality-of-life, we must pay for it.

Residue on food can be reduced or eliminated by organic methods of farming and more thorough cleaning. People will have to be educated to accept good produce with cosmetic defects. Enact stricter standards for residue.

Activated charcoal filters of greater sensitivity and more stringent water purification and standards must be used until chemicals are non-detectable in the potable water. Greater enforcement and stricter regulations must be in place to prevent contamination of the sole-source aquifer water supply. Less strict standards can be in place for industrial processes, which may cut costs. Suffolk County Sanitary Code Article 7 is a good example of a law meant to protect the aquifer by prohibiting bulk storage of hazardous chemicals over deep-recharge zones. However, it needs to be updated and is being challenged by power producers, for example, that want to store hundreds of thousands of gallons of hazardous liquids over prohibited aquifer recharge zones.

A relatively simple solution exists regarding the incinerators: shut them ALL down. New York City has done it, with a considerably larger population than Long Island. Turn the incinerators into refuse-concentrating and recycling centers, and follow the NYC method of disposal.

Regarding the absurdly high number of proposals for generators on Long Island, mostly by out-of-state companies, a regional energy plan must be formulated that will allow only the number of new power plants that will be needed to meet expected demand, AFTER much greater effort is made using renewables, efficiency and conservation. Any new generators must be placed at existing sites, or as far from vulnerable populations as possible. Tighten industrial emission standards.

Highly polluting diesels in heavy trucks may have their effects reduced by night deliveries, with stricter and frequent inspections to assure peak engine operation. A light rail line on, under or above the LIE could lessen commercial traffic. Reinstate the "luxury" tax to discourage gas guzzlers, with tax credits for economical ve-

hicles. Another possibility is to use the waterways and barge trucks or goods to distribution depots. Rethink uncontrolled growth, development and sprawl. The more there is, the more power plants and vehicle trips are required.

Cell towers and antennae must be isolated from homes and schools if possible. Satellite communication is an alternative, as well as a highway antenna wire using lower power, as in the tunnels. Melanoma from sun exposure can be reduced by public education including sunscreens and body examinations.

The highest standard of living in the world has been achieved in America with Long Island as a microcosm, but it has come with a price, an epidemic of cancer. The solutions are known. Proven methods and technology exist to greatly ameliorate the problem, but will we pay the bill?

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FEINGOLD ASSOCIATION OF THE UNITED STATES,
*Alexandria, VA, June 3, 2001.*

Committee on Environment and Public Works,
*U.S. Senate,*
*Washington, DC.*

DEAR COMMITTEE MEMBER: On behalf of the Feingold Association, I would like to express our deepest gratitude for the work of this committee to focus attention on the possible links between environmental contamination and chronic diseases. We are most appreciative of the inclusion of food in defining environment, in light of the purposes of our organization which are to generate public awareness of the potential role of foods and synthetic additives in behavior, learning and health problems, and to support members in the implementation of the Feingold Program. The Feingold Program is based on a diet eliminating certain salicylate-containing foods, all synthetic colors, synthetic flavors, and the preservatives BHA, BHT, and TBHQ.

Additionally, we appreciate the opportunity to provide information which we hope will be valuable in our shared search for answers. As an organization, we have been helping people for the past twenty-five years and feel we can offer insight into possible connections between foods, synthetic food additives and preservatives, other chemicals, the body's processes of sulfation and salicylate metabolism, the immune system, and chronic diseases such as ADHD, autism, and asthma.

The attached document was submitted previously to the Institute of Medicine and the National Vaccine Advisory Committee in an effort to address the need for further research into previously mentioned areas as they may relate to concerns about vaccines and mercury more specifically. It is vital to note that a positive response to the Feingold Program may serve as a marker for those at risk for diseases or damage from vaccines and/or vaccine ingredients. We feel this information may also assist you in considering broader issues related to the environment and chronic diseases. The need to identify the role of diet is crucial and may provide the baseline for exploring and determining root causes.

Your commitment to collaborative efforts in order to find answers is most commendable and appreciated. It is our hope that you will be taking a leadership role in identifying the way such work will be coordinated. This should include the work of other government agencies and officials, such as Senator Dan Burton, who similarly are obtaining valuable input regarding chronic diseases such as ADHD, autism, and asthma. We respectfully request the opportunity to participate in ongoing dialog about these issues, which are of personal and professional concern for those we serve. Thank you again for your sensitive and proactive work to improve and ensure our public health.

Sincerely,

SHERRI LUTHER PALMER,
*President,*
*The Feingold Association of the Northeast.*

KATHLEEN BRATBY, M.S.N., R.N.,
*President,*
*The Feingold Association of the United States.*

FEINGOLD ASSOCIATION OF THE UNITED STATES,
*Alexandria, VA, June 3, 2001.*

Committee on Environment and Public Works,
*U.S. Senate,*
*Washington, DC.*

DEAR COMMITTEE MEMBER: The Feingold Association of the United States, Inc., founded in 1976, is a non-profit organization whose purposes are to generate public awareness of the potential role of foods and synthetic additives in behavior, learning and health problems, and to support its members in the implementation of the Feingold Program.

The program is based on a diet eliminating certain salicylate-containing foods, all synthetic colors, synthetic flavors, and the preservatives BHA, Bill, and TBHQ.

We in the Feingold Association realize that the program is one of many "puzzle pieces" in addressing behavior, learning, and health problems such as those associated with autism and ADHD. It is often a cornerstone of multimodal therapy for such children, and we feel that more research into what is happening in the body's sulfation system, in salicylate metabolism, or in other areas in which diet may play a role should be important for improved treatment and prevention of ADHD and autism.

Research in England and elsewhere (Harris et al, 1998; Waring & Ngong, 1993; O'Reilly & Waring, 1993; Alberti, 1999) has shown that children with late-onset autism are very low in the enzyme PST (phenol sulfotransferase) and appear to have major problems in sulfation. This appears to be related to food sensitivities (Scadding et al., 1988; O'Reilly & Waring 1993; McFadden 1996) and common food additives (Bamforth et al, 1993) as well. We ask for research to determine if: (1) these may be the children at risk for autism or ADHD if vaccinated, or (2) the vaccines suppress the sulfation system in any way, which would put at risk all those who are below some threshold yet to be determined.

Since many children with autism or ADHD respond to the Feingold diet (Arnold, 1999; see also www.feingold.org/research—adhd.html and www.feingold.org/research—autism.html), we would like to know why—whether it could be an impact of some vaccination which creates the problem that the diet can help, and/or whether the child has such a problem naturally so that identifying this would screen for those who may be at risk of actual damage by vaccine chemicals. In other words, is the Feingold diet a treatment for some form of damage and/or would the response to the Feingold diet be a marker to determine which children are at risk?

In related work, Dr. Mary Megson has shown that children with autism and/or ADHD have a defect in the G-Protein, and she is able to identify them by family profile. This should be studied as a preventive measure to identify those children at risk before vaccinating. Also, according to Dr. Megson, there are ways to prevent or even correct such damage in these children, and further research should be done based on her work and any possible relationship to Feingold diet responders. (See www.treatmentchoice.com/megson.html)

Additionally, research has shown that synthetic food additives suppress levels of zinc (Brenner, 1979; Ward 1990, 1997), hormones and enzymes (Bamforth et al 1993) and the immune system (Koutsogeorgopoulou 1998). We ask for research to be done on all the ingredients in vaccines to determine any impact on zinc levels, zinc metabolism, enzymes, hormones, and the immune system—and, conversely, whether these reactions to synthetic additives would be markers to identify children potentially at risk to develop ADHD or autism with (or without) further vaccination.

The following statement was signed by attendees at the 25th Annual Conference of the Feingold Association on September 22, 2000: We the undersigned strongly suggest that vaccines containing mercury be stored until such time that the effects of mercury buildup in multiple vaccinations is better understood. If the effect is statistically minimal, the vaccines may be used at a later date. If the high doses of mercury are harmful, the vaccines can later be destroyed. Meanwhile, current stores of mercury-free vaccines can be used and data gathered about the effect of mercury-free vaccines.

A copy of this signed statement will accompany the hard copy of this letter (by mail), and the original was submitted to the office of the Surgeon General. We further call for research to recognize those children who may be harmed by or have difficulty detoxifying such toxins as mercury, phenol, formaldehyde, or other ingredients in vaccines so they can be identified and protected.

When research is done on the hypothesis of whether vaccines are related to autism and ADHD, the connection between vaccines and the metabolic pathways involved in response to the Feingold diet should not be ignored. We have identified areas for further research which we hope will contribute to finding the answers we

all need for the sake of our future, our children. Thank you for the opportunity to provide these materials, and we ask to be involved in ongoing dialog and efforts to address public health issues such as these currently commanding national attention.

Sincerely,

KATHY BRATBY, MSN, RN,
President.

JANE HERSEY,
National Director.

SHULA EDELKIND,
Research Librarian.

PAT PALMER,
Board Member Emeritus.

COLLEEN SMETHERS, CRNP (RETIRED)
President, Feingold Assn. of Southern California.

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WE THE UNDERSIGNED STRONGLY SUGGEST THAT VACCINES CONTAINING MERCURY BE STORED UNTIL SUCH TIME THAT THE EFFECTS OF MERCURY BUILD-UP IN MULTIPLE VACCINATIONS IS BETTER UNDERSTOOD. IF THE EFFECT IS STATISTICALLY MINIMAL, THE VACCINES MAY BE USED AT A LATER DATE. IF THE HIGH DOSES OF MERCURY ARE HARMFUL, THE VACCINES CAN LATER BE DESTROYED. MEANWHILE, CURRENT STORES OF MERCURY FREE VACCINES CAN BE USED AND DATA GATHERED ABOUT THE EFFECT OF MERCURY FREE VACCINES.

Jacob Greenberg, PhD
Nancy Masucci
Thomas Pelly
Leslie Fowler
Raja Jaber MD
Donna Mastel
Dorothy Lucchesi
Virginia Goerg
Susan Williams
Marilee K. Jones
Marina L Torre
Cara Penny
Eileen A Breen
Stuart A Penny
Lorraine Minichiello
Margaret L Harris
Catherine C White

Paul Ipsen RN.
Lisa Hofman teacher
Linda Marshall
Heid Huwaw
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Ann E. Jardin MA-CCC/sp.
Nancy Dartnell Ph.D.
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Ann Gray
Barbara Kirk
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Loretta Goldsand
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Colleen Smeckers 10246 Juniper Rd Mira Loma Ca 91752 909 685-0924
Kathy Bradley
[illegible]

ELAINE MARIE COBIS,
*Islip, NY.*

Committee on Environment and Public Works,
*U.S. Senate,*
*Washington, DC.*

DEAR SENATOR HILLARY CLINTON: Thank you for invitation to have the opportunity to experience some of the efforts of your hard work. I attended the Senate hearing at Adelphi University in Garden City, NY on June 11, 2001. I felt humbled being in the presence of persons dedicated to helping humanity. I have my own testimony of human suffering which I believe can be attributed to the pollutants of the environment.

As a Registered Nurse, I had the opportunity to care for patients on the Oncology Unit which help me attain the expertise for caring for patients afflicted with cancer. I applied my skills to caring for patients in the home who required infusion therapy such as chemotherapy, TPN and several forms of intravenous therapy.

In 1991, while working for HMSS, an infusion therapy company, I cared for a 21-year-old student with a diagnose of leukemia. She lived in a dorm for 2 years which was located at Stoney Brook University on Long Island, NY. The dorm she lived in was closed down by a team of epidemiologist of New York State in July 1991. The reason cited in a Newsday column was that the cases of Leukemia, over the years, were too numerous not to suspect problems with the building.

In 1992, I held a young girl in my arms till she breathed her last labored breath. She was 23. Her killer was breast cancer. She lived in Brentwood, Long Island. Her doctors, from Columbia Presbyterian Hospital in Manhattan, suspected that she had breast cancer since age 16. A tumor on her right shoulder was discovered during a routine physical examination for college at age 20. Her age alone raises suspicion that the breast cancer was linked to the pollutants in the environment. Brentwood, Long Island is home to Pilgrim Psychiatric Center. This hospital has acres of land surrounding it, some of which are the pine barrens. It is also home to a toxic dumpsite located on the grounds of Pilgrim Psychiatric Center.

In 1989, I took tare of a 21-year-old male with advanced testicular cancer. He lived in Brentwood, Long Island.

In 1991, an 11-year-old girl, my daughter's first cousin, was diagnosed with thyroid cancer. She still is fighting this cancer with yearly exams and treatments at Sloan Kettering Hospital. Thyroid cancer, in a child, is extremely rare and is highly suspect to be directly linked to environmental hazards.

I hope my testimony contributes to the many and will help attain the honorable goal of establishing a national cancer reporting agency. This will help gather information so that action can be taken to heal this wounded Nation. We were once a clean and healthy land. Efforts must be made to bring that health back to our noble land.

Sincerely,

ELAINE MARIE COBIS,
*Registered Nurse.*

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MICHAEL CONTI,
*Oceanside, NY, June 16, 2001.*

Committee on Environment and Public Works,
*U.S. Senate,*
*Washington, DC.*

TO WHOM IT MAY CONCERN: On Monday, June 11, 2001, at Adelphi University I attended a hearing on environmental health concerns chaired by Senator Clinton. Many prominent scientists were asked to speak about their research efforts that were aimed toward investigating the causes of cancer and other human illnesses. Unfortunately, none of the scientists who spoke are doing research in an area that I feel needs investigating.

Since the title of the hearing was Environmental Health Concerns, it was very appropriate for the scientists to be asked to define environment and to give examples. Environment was described as the material things around us that we can see as well as the invisible things. Therefore, the scientists would study the water and air for pollutants as well as electromagnetic radiation. Their definition for environment meant that they would be looking outside the human body. Herein lies the problem.

I want the Senate Committee on the Environment and Public Works to investigate the toxic microenvironment that exists in the mouths of many Americans who

have metallic filling materials in their teeth. For hundreds of years teeth have been restored with a material commonly called a silver filling or silver amalgam. This material is the end result of mixing approximately equal parts of elemental liquid mercury and an alloy powder composed chiefly of silver, and tin, and sometimes smaller amounts of copper, zinc, palladium, or indium. However, the composition of this amalgam has recently changed with the addition of greater amounts of copper. According to scientific evidence high copper amalgams are very deadly. A typical adult will usually have one or more crowns containing some gold, silver, and palladium. Some other metals such as chrome and nickel might also be present in a person who is also wearing a removable partial denture. As you can see the mouth can be a microenvironment of toxic metals which will leach into the body and have the potential for causing disease. Besides poisoning the body, microelectric currents are set up between these dissimilar metals which is also harmful to the human body.

Teeth lie on meridians according to Chinese medicine. Chinese medicine claims that problems associated with first molars are related to breast cancer. I've been told this is true. I want the Senate to put a team of people together to see if there is any truth to this statement.

Finally, I would ask all members on this health committee to become informed with the literature that is already available linking dental work with human disease. I am enclosing a list of publications that you must read before making any decisions. I urge you to read these books rather than relying on the scientists from whom you heard on June 11.

I just want to include a short paragraph from my first e-mail to Mrs. Clinton dated Thursday, May 3, 2001.

"I was pleased to hear on Monday and today in Paul Harvey's broadcast of the news that the State of Maine has a bill before the State legislature banning the use of mercury dental amalgam in pregnant women. I would like you to initiate a similar bill for New York State."

I thank you in advance for the effort I know the committee will put toward better health for Americans. Please keep me informed of your decisions.

Sincerely,

*Michael Conti.*

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Books Available Through Dams (See Guide to the Books for Descriptions of Contents)

| | Price/book [In dollars] |
|---|---|
| GENERAL OVERVIEW, DENTAL-HEALTH ISSUES | |
| DAMS Information Booklet (part of the information packet) | $4.00 |
| DAMS Information Packet (includes DAMS booklet, list of practitioners, etc.) | 7.00 |
| Uninformed Consent: the Hidden Dangers in Dental Care, by Hal Huggins, DDS & Levy, T | 17.00 |
| Whole Body Dentistry, the Missing Piece to Better Health by Mark Breiner, DDS | 21.00 |
| Tooth Truth, by Frank Jerome, DDS | 22.00 |
| The Key to Ultimate Health, by Richard Hansen, DMD and Ellen Brown, JD | 22.00 |
| Elements of Danger, the Hazards of Modern Dentistry by Morton Walker, DPM | 16.00 |
| Mercury Free, by James E. Hardy, DDS | 19.00 |
| Dentistry Without Mercury, by Sa am Ziff, Michael Ziff, DDS | 8.00 |
| Solving the Puzzle of Mystery Syndromes (with patient stories!) by Mary Davis | 7.00 |
| SAFE REMOVAL OF MERCURY AMALGAM FILLINGS and HEAVY METAL DETOXIFICATION | |
| A Guide for the Patient (Specific detox protocols, including IV-C) by Queen & Queen | 15.00 |
| Standards of Care for Amalgam Removal, by Paul J. Pavlik, DMD | 15.00 |
| Dental Mercury Detox—by Ziff, Ziff & Hanson | 8.00 |
| Detoxification by Hal Huggins, DDS, MS | 15.00 |
| Protocol for Amalgam Removal and Dental Revisions by Hal Huggins, DDS, MS | 18.00 |
| ROOT CANALS | |
| Root Canals, the Good, the Bad and the Ugly, by Gary Strong, DDS | 2.00 |
| CAVITATIONS Chronic Pain & Jaw Bone Cavitation, by Gary Strong, DDS | 2.00 |
| Beyond Amalgam, the Hidden Hazard of Jawbone Cavitations by Susan Stockton | 15.00 |
| SCIENTIFIC SUMMARIES: | |
| Infertility and Birth Defects (also, auto-immune effects) by Sam Ziff & M. Ziff, DDS | 17.00 |
| The Missing Link: Heart Disease as it Relates to Mercury, by Ziff & Ziff | 14.00 |
| Toxic Metal Syndrome (links to mental illness) by H.R. by H.R. Casdorph & M Walker | 17.00 |
| HEALTH RESOURCES Winning the War against Asthma & Allergies, EW Cutler, DC | 20.00 |
| Fluoride, the Aging Factor by John Yiamouyiannis, Ph.D. | 17.00 |

Books Available Through Dams (See Guide to the Books for Descriptions of Contents)—Continued

| | Price/book [In dollars] |
|---|---|
| What Your Doctor May Not Tell You About Menopause, by John R. Lee, M.D. ..... | 16.00 |

DAMS Memberships-quarterly newsletter. $25/year, $15 for low income Contributions to DAMS are tax deductible. Above prices including shipping at book rate. Add $1 per book for 1st class shipping Subtotal and $2 per book for priority shipping (call for quantity shipping rates). For Canadian orders, please add 1.00 per book. Send check or money order or credit card information with this form to: TOTAL DAMS, Inc. P.O. Box 7249 Minneapolis, MN 55407–0249. Please make checks or money order payable to: DAMS, Inc. You may also call to check on availability of titles and to order by credit card by calling (800) 311–6265. For general questions, please call (612) 721–1144.

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STAR FOUNDATION,
*East Hampton, NY, June 20, 2001.*

Committee on Environment and Public Works,
*U.S. Senate,*
*Washington, DC.*

Re: Environmental Carcinogens on Long Island, NY

These comments are submitted on behalf of STAR, Standing for Truth About Radiation, a grassroots organization with 4,000 members concerned about the toxic effects of nuclear radiation. We promote public awareness, medical and scientific investigation, institutional accountability, independent oversight, and responsible public health and environmental policies. STAR actively promotes' alternative and renewable energy technologies, as the available solution to nuclear generated power.

Rising cancer rates oh Long Island are a great public concern. Efforts to look for a cure to cancer are, laudable, but as a society, we must also be looking to identify and minimize the man-made causes. On Long Island, there are numerous issues of concern. Pesticide contamination and industrial solvents have polluted large areas of groundwater around the island. There are old, dirty power plants that are "grandfathered" from the Clean Air Act that desperately need to be replaced our up-graded. These issues deserve serious attention.

However, when looking at the cancer risks to the public, the most widely ignored issue has been man-made radiation. Primarily, this has resulted because the atomic program was a creation of the Federal Government. The Federal Government promoted "Atoms for Peace" and widely subsidized and promoted the inception of nuclear power. Therefore, the issue has escaped objective, inclusive and transparent analysis and public discourse. It is well settled that radiation causes cancer, the debate is over at what level of exposure do cells start to mutate. Radiation protection standards have been changed seven times since their inception. However, as a society, we have been slow to come to terms with the true costs associated with the atomic age. It was not until last year, that a White House draft report linked 14 Department of Energy (DOE) sites with increased rates of a variety of cancers and other occupational illnesses. This is highly significant because it is the first time that our government has acknowledged that people got cancer from radiation exposure at Department of Energy facilities. Indeed, after fifty years of disputing the fact, the Federal Government is now recognizing "credible evidence of increased risks due to ionizing radiation exposure and chemical and physical hazards" at DOE facilities.

As a Nation, we must objectively analyze the public health consequences of man-made radiation from nuclear reactors.

I. REACTOR EMISSIONS & HEALTH

Nuclear power reactors have been producing electricity since the first unit began operations in 1957. Currently, 103 reactors are operating in the U.S., producing about 20 percent of the nation's electricity and about two-thirds of Americans live within 100 miles of at least one nuclear reactor with approximately 42 million people living downwind from commercial reactor.

Startup of new reactors and increased use of existing ones have caused the net generation of electricity from reactors to nearly triple (248 million to 727 million gigawatt hours) from 1980 to 1999. Moreover, about half (51) of the reactors now licensed have been operating for at least 24 years; Big Rock Point, in northern Michigan, had the longest life span (34 years) before closing. Present trends suggest that use of nuclear power reactors may proliferate in the future. The U.S. Nuclear Regulatory Commission has received applications to extend the licenses of 43 reactors from 40 to 60 years. In addition, the Nuclear Energy Institute announced a goal of 50 new nuclear reactors at its annual meeting in May 2001.

Rising use of aging nuclear reactors present health & safety issues that needs to be addressed:

1. Do routine emissions of radioactivity into the air that are inhaled and ingested, result in increased disease risk?

2. Does the buildup of nuclear waste from reactor operations pose a threat to the health of local residents?

Because radioactivity can cause damage to the human immune, genetic, and hormonal systems, an accurate assessment of risk to the public is warranted. However, current regulatory policies do not include any such assessment. The U.S. Nuclear Regulatory Commission has approved the first five applications for reactor license extension, with no consideration of disease rates among the local population.

## II. NUCLEAR POWER REACTORS AND HEALTH

Only one national study has been done on disease rates near nuclear power plants. In 1990, at the insistence of Senator Edward M. Kennedy, the National Cancer Institute published data on cancer near nuclear plants. While the study concluded that there was no connection between radioactive emissions and cancer deaths, rates near many reactors rose after reactor startup. Since 1990, the Federal Government has undertaken no health studies of disease rates near nuclear power plants.

However, the non-profit Radiation and Public Health Project (RPHP) has undertaken the first-ever study that measures radioactivity in the bodies of persons living near nuclear power reactors. In 1996, RPHP launched the Tooth Fairy Project, which uses the same methodology of calculating levels of Strontium–90 in baby teeth employed in the St. Louis study during the 1 950's and 1960's.

Sr–90 is just one marker for the 100–200 radioactive chemicals that are released in nuclear reactor operations, and it is a critical one. Like calcium, Sr–90 attaches to the bone and teeth when it enters the body, where it remains for many years due to its slow rate of decay (half life of 28.7 years). It kills and impairs bone cells, and penetrates the bone marrow, which is where the red blood cells critical to immune function are formed. Of all man-made radioactive isotopes, Sr–90 was the one that caused the greatest health concern during the atmospheric bomb test years in the 1 950's and 1960's.

To date, RPHP has collected over 3000 baby teeth, mostly from areas near reactors in California, Connecticut, Florida, New Jersey, New York, and Pennsylvania. Strontium–90 concentrations have been measured in nearly half (1463) of these teeth that have been tested by an independent laboratory.

The average current concentration of Sr–90 is similar to that in St. Louis in 1956, in the midst of the period of atmospheric nuclear weapons testing. Results of the Tooth Fairy Project have been published in three peer-reviewed medical journals. (27–29)

The largest number of teeth (563) have been measured for residents of Suffolk County New York. Results show that the average level of Sr–90 has steadily increased 40 percent from the early 1 980's to the mid-1990's. Because above-ground bomb testing ceased in the early 1960's, and old bomb fallout is decaying steadily, this trend indicates that a current source of radioactive emissions is contributing to the buildup of Sr–90 in teeth. This source can only be nuclear reactors.

| Year of Birth | No. of Teeth | Avg. Sr–90+ | Percent Change |
|---|---|---|---|
| 1981–84 | 38 | 1.10 | ..... |
| 1985–88 | 157 | 1.38 | ..... |
| 1989–92 | 258 | 1.41 | ..... |
| 1993–96 | 45 | 1.54 | +40.0 |

+Average picocuries of Strontium–90 per gram of calcium in baby teeth at birth.

In the same time period, cancer diagnosed in Suffolk County children less than 10 years old steadily rose a nearly identical 49 percent. The data supports the theory that exposure to radioactive emissions from nuclear reactors increases the risk of cancer, especially in young persons.

Children are not the only humans affected by the radiation-cancer connection. However, since the rapidly developing fetus and infant are most sensitive to toxic exposures to radiation and other chemicals, immediate adverse effects are most likely to occur. A latency period of up to several decades between exposure and manifestation of cancer may be necessary in adults.

| Period | Age 0–9 Cancer Cases | Avg. Pop. | Cases per 100,000 Pop. | Percent Change |
|---|---|---|---|---|
| 1981–84 | 92 | 182,441 | 12.61 | ..... |
| 1985–89 | 115 | 182,463 | 15.76 | ..... |
| 1989–92 | 129 | 185,050 | 17.43 | ..... |
| 1993–96 | 146 | 194,498 | 18.77 | +48.9 |

III. LONG ISLAND—CHILDHOOD CANCER IN HIGH-RADIATION AREA

In the late 1990's, anecdotal news of an unusually high number of cases of Rhabdomyosarcoma in northwestern Suffolk County children began to surface. The usually rare soft tissue cancer was discovered in 23 children living in a small area. Parental concerns of victims prompted the Suffolk legislature to authorize a RMS Task Force in the fall of 2000 to investigate the extent and cause of the outbreak.

While the cause(s) of rhabdomyosarcoma are generally unknown, radiation exposure has been identified as a risk factor. Over one-quarter of laboratory mice who had Sr–90 rubbed on their skin were later diagnosed with rhabdomyosarcoma or a related cancer and pregnant women who receive a pelvic X-ray are twice as likely to bear a child who will be diagnosed with the disease. The RPHP Baby Teeth Study has collected 57 teeth from the area of Suffolk County in which most children with rhabdomyosarcoma live. The average concentration of Sr–90 in teeth is the highest in Suffolk County, at 1.48 picocuries of Sr–90 per gram of calcium. Teeth in other areas, such as the north and south forks of Long Island and the middle of Suffolk County have barely half that amount. RPHP is now conducting a case-control study, in which it tests teeth from children with rhabdomyosarcoma to further establish the link between the disease and environmental radiation. However, this relationship deserves further study.

IV. CLOSING REACTORS—EIGHT U.S. NUCLEAR POWER PLANTS

When nuclear power reactors cease operations, there is an immediate removal from the diet of all radioactive products that decay quickly, and a more gradual removal of those that decay slowly. The reduction should be greatest in nearby areas downwind of closed reactors; the majority of airborne emissions are propelled in the downwind direction, where radioactive gases and particles can be inhaled and are introduced into the diet via precipitation. Since 1987, eight nuclear power plants have closed, leaving at least a 70-mile-radius with no operating reactors. In downwind counties within 40 miles of all eight of these, the death rate among infants under 1 year of age plunged in the first 2 years after closing. RPHP is collecting baby teeth near one of these areas (Rancho Seco, near Sacramento CA) to establish that the improvement in health is accompanied by a declining level of in-body radioactivity.

| Reactor, Closed | Infant Death | | Live Births | | Deaths/1000 | | Percent Change |
|---|---|---|---|---|---|---|---|
| | Before | After | Before | After | Before | After | |
| LaCrosse WI, 1987 | 36 | 30 | 3507 | 3452 | 10.27 | 8.69 | −15.4 |
| Rancho Seco CA, 1989 | 418 | 390 | 44500 | 49414 | 9.39 | 7.89 | −16.0 |
| Ft. St. Vram CO, 1989 | 83 | 72 | 9725 | 9977 | 8.53 | 7.22 | −15.4 |
| Trojan OR, 1992 | 253 | 204 | 30320 | 29799 | 8.34 | 6.85 | −17.9 |
| Big Rock Pt. MI, 1997 | 25 | 6* | 2922 | 1529* | 8.56 | 3.92* | −54.2 |
| Me. Yankee ME, 1997 | 19 | 10* | 3841 | 2201* | 4.95 | 4,54* | −8.3 |
| Pilgrim MA, 1986 | 97 | 76 | 12956 | 13412 | 7.49 | 5.67 | −24.3 |
| Millstone CT, 1995 | 166 | 130 | 22261 | 21093 | 7.46 | 6.16 | −17.4 |
| TOTAL 8 AREAS | 1097 | 918 | 130032 | 130877 | 8.44 | 7.01 | −16.9 |

| Reactor, Closed | Infant Death | | Live Births | | Deaths/1000 | | Percent Change |
|---|---|---|---|---|---|---|---|
| | Before | After | Before | After | Before | After | |
| U.S. AVG 2-YR CH, 1986–98 | ..... | ..... | ..... | ..... | ..... | ..... | −6.4 |

*Only 1998 data are available for post-shutdown periods for Big Rock Point and Maine Yankee.

V. POLICY IMPLICATIONS

Since the end of the cold war a decade ago, nuclear weapons are no longer manufactured or tested. However, the production of electricity from American nuclear reactors has reached an all-time high, and some utility companies are considering a large-scale expansion of the industry. These developments indicate that the protection of humans from the potentially harmful effects of exposure to radioactive emissions in the environment will be critical. To that end, we urge Congress to take the following actions:

1. Conduct hearings examining the current knowledge on the impact of environmental radiation on public health, including cancer.
2. Establish and support an independent medical and scientific commission to evaluate the impact of environmental radiation on public health, including cancer.
3. Institute a systematic program measuring radioactivity levels in bodies of persons living near to and distant from U.S. nuclear power reactors.
4. Conduct or support routine, periodic studies tracking disease patterns and trends among persons living near to and distant from nuclear power reactors. Studies should identify infants and children separately from adults, and should focus on cancer.
5. Direct policymakers and regulators to include consideration of disease patterns and trends within the local population when making decisions to extend licenses of existing nuclear reactors.
6. Direct policymakers and regulators to include consideration of potential health effects when making decisions to grant operating licenses for new nuclear reactors.
7. Require that in-body radioactivity levels be evaluated in all federally funded programs that investigate possible causes of elevated cancer rates in the U.S.

In sum, it is irresponsible for the Federal Government to continue to ignore the long-term health consequences of nuclear power. Available information indicates that nuclear power increases regional cancer rates and the long-term ramifications must be afforded much greater attention. Thank you for your attention to this important issue.

Sincerely,

SCOTT M. CULLEN,
*Counsel.*

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BRENTWOOD/BAY SHORE BREAST CANCER COALITION,
*Brentwood, NY, June 24, 2001.*

Committee on Environment and Public Works,
*U.S. Senate,*
*Washington, DC.*

Ref: Statement for Hearing at Adelphi University, Garden City, Long Island, June 11, 2001

HONORED COMMITTEE MEMBERS: As a rule, prevention is the 1st principle of public health, but this is not so in the case of Cancer. Information of known and possible environmental causes is not brought to bear on real world practices. This information is not available to the public in a systematic way to enable people to make daily decisions protective of their health and that of their families. Yet, reducing exposure to toxins is an important Pt step to reducing cancer. This can be done. I offer the example of reducing lead levels in children's blood. It begins with testing all preschooler's blood for lead levels. When blood levels are high, we go back to the home and community to trace the source or sources of the lead. There is then remediation to remove the source of exposure. The child's blood is chelated (cleansed) of the lead at the same time. As a society we have removed lead from gasoline and track it to other sources for removal. We should follow the same approach for exposure to toxins that are known or suspected of causing cancer. Animal studies and weight of evidence are enough for me to exercise the precautionary principle. The key to the

success of the lead program is its specificity. It identifies the danger for the child at risk, before serious health damage and points the way to medical and environmental correction.

Routine testing to measure current levels of toxic body burdens must be funded. A testing program would help to recognize and pinpoint possible causes. Currently, one cause of toxin exposure is by nursing mothers who unknowingly pass their stored toxins to their infants via breast milk. This testing would allow a woman to take action, to have the opportunity to cleanse their bodies before beginning to nurse. Surely her infant is the last person she would want to expose to toxins. This is her dearest one, at a most vulnerable time of life. Testing can prevent this from ever happening.

This brings us to the question of risk evaluation. The current "Acceptable Risk" method that is based on a young healthy 70-kilogram male and 1 chemical, and 1 route of exposure at a time is not health protective. It does not deal with especially vulnerable people such as children or those with illness, or impaired immune systems (such as prior cancer treatment). It does not consider exposure to a variety of toxins. One size risk doesn't fit all. We need a "reducing risk" regulatory policy, which continually reduces the levels of exposure. As in the case of lead, we need to follow the toxins to their sources and use this information to justify cleanups and changes in industrial practices. There should be financial incentives for transitions to non-toxic methods. Models, education and technical advise for non-toxic alternatives should be funded.

Mounting a scientific study for cancer can take years. The asthmatic child and parents can tell you that right now there is something in that school room that can be measured, that triggers that child's shortness of breath, that may in time be the cause of cancer of many people. Now it seems like our children are as canaries in the mine, pointing the problem out but at a terrible cost! We must react and seek out the cause of their asthmatic symptom and remove it.

We have to deal with poisons whose health effects are not as simple as dose and immediate death. These impact immune and hormonal systems, but the cancer result appears after long periods of time, making it very difficult to show direct cause and effect. Teaming up an open system of access to this information, along with grassroots participation, can help account for toxic effects on health and the environment. The individual then making an informed decision to protect health should expect the same of the government. We all have a stake in promoting public health. We need the process to do this together. Fund putting the work of science out in the field to identify contaminants and their concentrations. Make this the first line of defense for the prevention of disease.

Sincerely,

ELSA FORD,
*BBBCC President.*

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STATEMENT OF CAROL S. KOPF, LEVITTOWN, NY

WATER FLUORIDE CHEMICALS LINKED TO CANCER

Arsenic levels high enough to pose a cancer risk are detected in drinking water treated with, tooth decay preventing, fluoride chemicals, which also contain trace amounts of other contaminants such as lead, barium and beryllium (1). Over 60 percent of U.S. communities purposely add impure fluoride into residents drinking water and virtually 100 percent of us consume foods and beverages made with this tainted water.

No discussion about the environment and health can be complete without looking at the science behind water fluoridation and human health—even at the low levels of fluoride added to U.S. water supplies. While environmentalists fight to get legislators to clean up toxic chemicals accidentally, or without forethought, injected into the environment, water engineers across the country are purposely adding cancer-causing industrial waste products into our nation's water supply.

According to the National Sanitation Foundation (NSF), the only three chemicals certified for fluoridation are: Hydrofluosilicic or Fluosilicic acid, Sodium Fluoride, and Sodium Silicofluoride . . . the most common contaminant detected in these products is Arsenic," reports NSF. "The other significant contaminant found is Lead," they report[1] "All of the fluoride chemicals used in the U.S. for water fluoridation, sodium fluoride, sodium fluorosilicate, and fluorosilicic acid, are byproducts of the phosphate fertilizer industry" wrote Tom Reeves, National Fluoridation Engi-

[1] http://www. fluoridealert.org/NSF-letter.pdf

neer, U.S. Centers for Disease Control CDC). "Arsenic . . . had an average of 0.43 parts per billion (ppb) in the drinking water attributable to the fluoride chemical," he reports.[2]

Also, CDC's "Water Fluoridation A Manual for Engineers and Technicians," (Reprinted 1991) reads, "sodium silicofluoride is widely used as a chemical for water fluoridation. As with most silicofluorides, it is generally obtained as a by product from the manufacture of phosphorus fertilizers." (page 15)

But dentists don't seem to know or admit this. However, legislators trust them. The media cites them as fluoride experts. But dentists are not experts on toxicology. And, too often, they spend more time denigrating those opposed to fluoridation rather than reading up on the science behind fluoridation.

In a newspaper interview, American Dental Association fluoridation spokesman, Michael Easley, DDS, who promotes fluoridation via his National Center for Fluoridation Policy and Research website at the University of Buffalo, NY, was quoted as saying,". . . there are the contrived arguments that claim fluoride is a chemical pollutant, a toxic byproduct . . . There is no scientific basis for any of these claims."[3]

The American Water Works Association is worried about arsenic-contaminated fluoride chemicals. If arsenic's maximum contaminant level is reduced to 5 ppb, "90 percent of the arsenic that would be contributed by treatment chemicals is attributable to fluoride addition," according to their journal, "Opflow."

Arsenic in drinking water causes bladder, lung and skin cancer, and may cause kidney and liver cancer. Lead poisoning can cause learning disabilities, behavioral problems, and at high levels, seizures, coma and even death.

Some experts say safe levels for arsenic or lead don't exist.

Arsenic levels as high as 1.66 ppb have been found in hydrofluosilicic treated drinking water (1), which, according to the National Academy of Sciences, is a cancer risk.[4].

Also studies show that children who live in silicofluoridated communities have higher blood lead levels than children who live in sodium-or non-fluoridated communities.[5]

Fluoridation began with the discovery that residents who drank and ate foods irrigated with natural calcium fluoride had lower rates of tooth decay but teeth that were yellow, brown and chipping (dental fluorosis). Early researchers erroneously assumed that, since fluoride discolored teeth, fluoride must also be the reason the teeth were less decayed. They forgot to factor in the calcium. The U.S. is the most artificially fluoridated country in the world (water, food, air and dental products). Dental fluorosis is growing in our child population. Yet, tooth decay is rampant in our poor and minority populations, some of whom also display fluoride overdose symptoms (dental fluorosis) and who, most often, live in fluoridated communities.

Fluoridation is especially a burden to the poor who can't afford to buy bottled water and who are harmed the most by fluoride chemicals, studies show. Calcium is the antidote to fluoride poisoning because it binds with the fluoride to carry it safely out of the body.

Less fluoride is available to the body when one drinks calcium fluoride. The fluoride contained in the phosphate fertilizer industry's waste products usually dissolves partially, leaving free fluorine to bind with the calcium the body needs then carries it out of the body.

The best solution is to stop fluoridating U.S. drinking water. Fluoride is neither a nutrient nor essential to health and is ubiquitous in the food supply. Unlike essential vitamins and minerals, ingesting slightly above recommended doses of fluoride causes serious adverse health effects including death. The best way to have great teeth is to eat properly—something our poor and immigrant populations have trouble doing. Nourish the child and their teeth will prosper and the only side effects will be healthier children.

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STATEMENT OF LORRAINE PACE, FOUNDER OF THE BREAST CANCER MAPPING PROJECT AND CO-PRESIDENT, BREAST CANCER HELP, INC.

My name is Lorraine Pace. I am a breast cancer survivor, activist and founder of the breast cancer mapping project. I have resided in the same zip code of West Islip for 45 years. I am an active member in the following organizations:

- Division for Women's Advisory Council

[2] http://www.fluoridealert.org/ifin–230.htm
[3] http://www.buffalo.edu/reporter/vol30/vol30n17/n5.html
[4] http://www.nrdc.org/water/drinking/arsenic/chap1.asp
[5] http://www.dartmouth.edu/~news/releases/marol/fluoride.html

- Charter Member of the Suffolk County Breast Health Partnership
- Cornell Ad Hoc Advisory Board
- National Breast Cancer Coalition
- Vice President of Promote Long Island
- Environmental Committee of the Long Island Association
- New York State Breast & Cervical Cancer Advisory Board
- Department of Health Cancer Surveillance and Early Detection Board
- NYS Breast Cancer Network

I was also on the following peer review boards:

- Department of Defense
- Health Research Science Board
- For the Breast and Prostate Cancer Detection, Treatment and Research Act funded by the cigarette tax in California

The first 50 years of my life were filled with family, a career in real estate, and a return to college where I earned a bachelor and masters degree. I am a mother of three, but nothing in those years prepared me for my 50th year in 1992—the year I discovered that the lump I had been feeling in my left breast for many years was what I had feared all along—it was cancer and it spread to my lymph nodes. That is when, I, Lorraine Pace, until then a typical suburban woman, became an activist. I never smoked in my life and as far as drinking, I am an occasional social drinker. I was not on hormone replacement therapy and on birth control pills for only 2 months. I had all my children, John, Lisa and Greg before the age of 30. I was in excellent health with good eating habits and exercised regularly. Neither grandmother nor my mother had breast cancer. I did everything that I was supposed to do for early detection, including having regular mammography views since my early 30's. I knew there had to be another reason why I developed breast cancer.

I went to New York City to a breast cancer specialist. I went to him every 6 months for many years, during which time I complained to him about this change I felt in an old scar located in my left breast.

I was told repeatedly, "Not to worry, it was only scar tissue"; and since nothing showed up in all my mammography's, I was told to come back in 6 months which I did. A month before my 50th birthday my radiologist called to tell me that I would have to come back for more views since they saw something suspicious in both breasts. I figured that the lump that had been bothering me for years had finally showed up in my mammography's. I went back to my radiologist and had more views taken. I was then told to go for surgery on both sides of my breasts. They discovered calcifications in the right breast and a suspicious lump in the left breast.

After surgery the results of the tissue samples from both breasts came back benign and I was told again not to worry. With stitches still on both breasts, I went on to celebrate my 50th birthday. After all, I had a lot to celebrate. I returned to my doctor to have my bandages and stitches removed, but noticed the lump on my left side, which was in a 6 o'clock position was still there. Since I was told that my breasts were fine, I did not worry about the lump.

Eight months after my surgery when I was on an airplane I started to talk to the person next to me. He happened to be a mortician from Suffolk County. During our conversation he informed me of all the young women who lived on the east end of Long Island who were brought to his funeral home who had died of breast cancer.

The very next day I went to see my breast cancer surgeon and asked him to remove this so-called scar tissue. He agreed to remove it and did a frozen section after many more mammography views. Within a few minutes he came back with the results; yes, it was what I feared—cancer and I would need additional surgery and an axially dissection. He didn't seem concerned about the results of the dissection, but neither was he concerned about the lump that I felt for many years. He assured me that the lump, though malignant, probably had not spread cancer to my lymph nodes. I received a call a week later to find out that it had indeed spread to 3 of my lymph nodes. This is what spurred me to become an activist, since I did not want other women to experience what I did.

Mammography screening is the best tool we have presently for the early detection and diagnosis of breast cancer. But it is not always effective for young women or women with dense breasts. We must therefore find a more precise and accurate method of screening women for breast disease. After all, we have the technology to put a man on the moon, surely we can find a better way to diagnose breast cancer. As it is now, by the time a tumor is found in the breast, it has been there for approximately 8–10 years. After all we have a blood test for prostate why can't we have one for breast cancer?

Awhile after I was diagnosed with breast cancer, it struck me that 20 other women I knew had also been diagnosed. After a great deal of thought, the one thing

I could see that we had in common was that most of us lived on dead-end streets. I started to think about what this could mean.

Our community was lovely fresh air water views. The only thing that was odd about this environment was that occasionally my tap water was rusty. I began to wonder, if possibly, the metals that made the water rusty could have anything to do with the breast cancer rate in my neighborhood and the rest of Long Island. I read that the Center for Disease Control was to come to Long Island. I testified before them and showed my rusty water and asked them if there was any connection between my breast cancer and my rusty water. Newsday took a picture of me that appeared on the front page in the spring of 1992 titled, "Asking for Answers." Joan Swirsky of the New York Times wrote several articles after this article appeared. During this time I was undergoing chemotherapy and shortly after radiation. NJ Burkett of Channel 7 Eyewitness News did a series on breast cancer mapping and was awarded the Folio Award for his coverage.

Once I began to suspect the culprit might be the water, I looked around at other communities and at other environmental factors that could be involved. I found that New York City has a much lower rate of breast cancer than Long Island. Yet they are so close to us-just a few miles. Is that because they get their water from upstate reservoirs? Or they don't have lawns that they obsessively fertilize-dumping every kind of killer chemicals into the underground aquifer that is our sole source of water? Or is it because their wires are buried underground instead of overhead like they are in parts of the suburbs?

And it's not only the chemicals that are put on our lawns that are poisoning our water, but the chemicals put on our golf courses as well. Older industries are also to blame that have dumped hazardous chemicals into the ground for years.

When there appeared to be no answers to my questions, I asked my oncologist, Dr. Michael Feinstein to help me prove a theory I had about dead-end water mains. My concern was that if you lived on a dead-end street the water did not circulate as well as if you lived in the middle of the block and you were exposed to more contaminants. He offered his help to see if this theory could be proved. On his days off we met with former Suffolk County Health Commissioner, Dr. Mary Hibberd and the head of the Suffolk County Water Authority, Michael LoGrande to develop a survey. After these initial meetings, I and my friend Pat approached our Congressman Tom Downey. He in turn sent us to Angie Carpenter for a quote on printing the survey. She in turn sent me to Ted Shiebler who worked in public relations at Good Samaritan. He then called Lou Grasso, editor of Suffolk Life Newspaper. Lou Grasso and Dave Wilmott, publisher of Suffolk Life contacted me and they in turn printed the survey on their front page and this is how the breast cancer mapping originated. Liz Tonis of Suffolk Life kept the community apprised of the results of the surveys with ongoing articles in Suffolk Life. My radiation oncologist, Dr. Allen G. Meek encouraged me to pursue the mapping project. With the help of Maria Diorio and many other volunteers from the neighborhood we put the responses from the survey on to a map. This was done from my dining room table every day for 18 months. The map showed clusters of breast cancer with definite patterns of concentration in certain areas. This data was then analyzed by Dr. Roger Grimson, a biostatistician from SUNY, Stony Brook. Without the help of the volunteers this couldn't have been accomplished. After the mapping was completed we received a 69 percent response from the community and that was due partially to efforts by people in the community such as Father Thomas Arnao of Our Lady of Lourdes Church in West Islip. He was the first priest to get involved in the breast cancer movement. He and other priests from the community encouraged their parishioners to complete the surveys.

In 1992 I started the West Islip Breast Cancer coaltion. My husband, John Pace formed the corporation and 501(c) 3 pro bono. He also did the same for Breast Cancer Help, Inc. and for the Carol M. Baldwin Breast Cancer Research Fund. Meanwhile, the idea of mapping has caught on across Long Island, New York State, nationwide and abroad. I received calls from women in Huntington, Great Neck, Babylon, Southampton, Brookhaven, etc. asking for assistance on how to do mapping in their towns. New York State Senators Owen Johnson and Caesar Trunzo gave a grant to the West Islip Breast Cancer Coaltion to study the map. The State legislature should be applauded for passing legislation requiring cancer mapping for all of New York State. In fact the NYS Department of Health was awarded the "Gold" Certification from North American Association of Central Cancer Registries due to Governor George Pataki's 4 million dollar increase in funding.

After leaving the West Islip Breast Cancer Coalition I started Breast Cancer Help, Inc. with Father Thomas Arnao, who is now co-president of Breast Cancer Help, Inc. We and our members are proud of our many accomplishments, some of which are listed below:

• Our Vice President spearheaded the national campaign to create the first breast cancer awareness stamp. My daughter-in-law painted a pink twisted ribbon as a possible example of this stamp. Our group also supported the creation of the breast cancer research stamp.

• Originating the breast cancer mapping project and helping other coalitions to do mapping locally, nationally and abroad.

• Initiating the move to establish the toll-free Cancer Helpline at Stony Brook Hospital.

• Leading the effort to organize and establish the annual "Walk for Beauty" in Stony Brook.

• Supported the petition that resulted in President Clinton's commitment to a National Action Plan to fight breast cancer and a $250 million increase in Federal funding for breast cancer research.

• Initiating the change in Federal regulations that provides insurance coverage for stem-cell infusion therapy for Federal employees and their spouses who have breast cancer.

• Support the passage of the NYS law that ends the practice of drive-through mastectomies.

• Initiating the move to update and expand the NYS Breast Cancer Registry.

• Leading the move to create the check-off for breast cancer research and education on the NYS income tax form and supported the subsequent legislation that authorizes the State to provide a dollar-for-dollar match for each contribution made to breast cancer research and education.

• Helping to launch the Long Island Breast Cancer Study Project.

• Advocating the establishment of the NYS Pesticide Registry.

• Testifying at local, State and Federal hearings on the environment and the possible link to breast cancer

• Raising breast cancer awareness by generating local, regional and national media coverage as well as by contributing to public service programs, educational symposiums and fund-raisers

• Supported the Neighborhood Notification Bill

• Charter member of the Suffolk County Breast Health Partnership

• Member of the National Breast Cancer Coalition ò Initiated the Carol M. Baldwin Breast Cancer Research Fund at Stony Brook

• Keynote speaker at the first breast cancer rally in Suffolk County on the steps of the H. Lee Dennison Building in Hauppauge. Suffolk County Executive Robert Gafthey supported this rally.

• Supporting passage of the NYS Adoption Bill that allows breast cancer patients to adopt children.

In conclusion one of the most important things that need to be done is to have a unified national cancer registry that includes residential history and occupational history. This will give the scientists a better way to track cancer for a possible link between the environment and breast cancer. Residential history is important because if a woman who is a lifelong resident of New York moves to Florida and is shortly thereafter diagnosed with breast cancer she is on the Florida cancer registry as having been diagnosed in Florida. This is misleading; in reality she developed the tumor in New York. Occupational history should also be included in the cancer registry. For instance if a person is exposed to chemicals in their workplace, and is then diagnosed with cancer, could the diagnosis be work related?

We need to have all the hazardous waste sites cleaned up, and the people of Long Island should use pesticides that kill insects without harming the environment. A population-based study should be done that studies bio-markers such as the blood to determine what the possible environmental cause(s) of cancer on Long Island are. We also need the most advanced technology in our hospitals for the treatment and diagnosis of cancer patients on Long Island. We need to find out why so many young women are being diagnosed with breast cancer on the East End of Long Island where there is a high incidence of this disease. We owe it to the future generations to find the cause(s) and the cure of breast cancer.

STATEMENT BY RESEARCH ASSOCIATES JAY M. GOULD, PH.D., DIRECTOR; ERNEST J. STERNGLASS, PH.D., CHIEF SCIENTIST; JERRY BROWN, PH.D.; JOSEPH MANGANO, M.P.H., M.B.A.; WILLIAM MCDONNELL, M.A.; MARSHA MARKS, A.C. S.W., L.C.S.W.; JANETTE SHERMAN, M.D. AND WILLIAM REID, M.D., RADIATION AND PUBLIC HEALTH PROJECT, NEW YORK, NY

## I. INTRODUCTION

The Radiation and Public Health Project (RPHP) is an independent, non-profit research and educational organization. The focus of RPHP's work is to assess the health effects of exposures to radioactive chemicals released into the environment by nuclear weapons tests and nuclear reactor operations. Founded in 1985, RPHP maintains a staff of professionals from the fields of radiation physics, toxicology, epidemiology, and statistics. Its members have published numerous medical journal articles and books on the radiation health issue (see Appendix).

RPHP researchers understand that incidence of certain diseases and conditions with potential environmental causes have risen in the U.S. in the 1980's and 1990's. Infants and children may be hardest-hit, suffering from increased rates of cancer, asthma, underweight births, and ear infections. RPHP is attempting to document the contribution of environmental radiation to these growing problems.

RPHP has documented substantial evidence linking environmental radioactivity with increased cancer risk. Perhaps the strongest evidence is the correlation of levels of radioactive Strontium–90 in baby teeth with risk of childhood cancer in Long Island. The following testimony outlines these findings and considers implications for public policy.

## II. NUCLEAR REACTOR EMISSIONS AND HEALTH

Currently, 103 nuclear power reactors are operating in the U.S., producing about 20 percent of the nation's electricity.[1] These reactors are located at 72 plants (sites) across the country. About two-thirds of Americans live within 100 miles of at least one nuclear reactor. Operating utilities have permanently closed a total of 22 reactors. In addition, 128 reactors that were proposed by utilities to Federal regulators were later canceled before commencing operations.[2]

Startup of new reactors and increased use of existing ones have caused the generation of electricity from reactors to nearly triple (248 million to 727 million gigawatthours) from 1980 to 1999. (1) Moreover, about half (51) of the reactors now licensed have been operating for at least 24 years; the now-closed Big Rock Point reactor in northern Michigan, had the longest life span of any U.S. reactor (34 years).

Present trends suggest that use of nuclear power reactors may proliferate in the future. The U.S. Nuclear Regulatory Commission has received applications to extend the licenses of 43 reactors from 40 to 60 years. In addition, the Nuclear Energy Institute announced a goal of starting 50 new nuclear reactors at its annual meeting in May 2001.

Increasing use of aging nuclear reactors present environmental health issues that need to be addressed, namely:

1. Do operations of reactors, which routinely emit man made chemicals into the air that are inhaled and ingested in diet, result in increased disease risk, including cancer?
2. Does the aging of reactors increase the chance of a serious accident?
3. Does the buildup of nuclear waste from reactor operations pose a threat to the health of local residents?

The focus of RPHP's work is primarily issue #1, health effects of routine emissions of radioactive chemicals into the environment.

Because radioactivity can damage human health, an accurate assessment of risk to the public is warranted. However, current regulatory policies do not include any such assessment. The U.S. Nuclear Regulatory Commission has approved the first five applications for reactor license extension, with no consideration of disease rates, including cancer, in persons living closest to reactors.

RPHP has investigated health effects of exposures to reactor emissions, and wishes to present a summary of findings to the Senate Committee on the Environment and Public Works, as it considers the issue of environmental health.

## III. ATOMIC BOMB TESTING—PRECURSOR TO REACTORS

Nuclear reactors employ fission of uranium atoms to generate electricity. The fission process creates 100 to 200 radioactive chemicals not found in nature, which may damage the immune, genetic, and hormonal systems. These products include strontium, plutonium, iodine, and other carcinogenic isotopes. The only other source

of these manmade chemicals is nuclear weapon explosions. Most fission products generated by reactors are contained as radioactive waste, but a fraction is emitted into the local air and water.

The detonation of many atomic weapons above the ground (100 in the Nevada desert and 106 in the south Pacific) from 1946–62 represented the first time in history that Americans were exposed to fission products. The total output of these tests was equivalent to that of about 10,000 Hiroshima bombs, while Soviet tests in this period approximated another 30,000 Hiroshima bombs.[3] Levels of radioactivity in the American diet rose sharply. Radioactive Strontium–90 reached an average concentration of 30.3 picocuries per liter in U.S. milk in May 1964, compared to about 5 in 1957.[4]

The 1963 Limited Test Ban Treaty prohibited atmospheric bomb tests by the United States, Soviet Union, and Great Britain. President John F. Kennedy made health effects of fallout, especially on children, a focus of a speech urging Senate ratification of the treaty:

". . . the number of children and grandchildren with cancer in their bones, with leukemia in their blood, or with poison in their lungs might seem statistically small to some, in comparison with natural health hazards. But this is not a natural health hazard—and it is not a statistical issue. The loss of even one human life, or the malformation of even one baby—who may be born long after we are gone—should be of concern to us all."[5]

The period of atmospheric weapons testing was marked by minimal or negative progress for several infant and child health measures. The 13 percent drop in the death rate for children under 1 year from 1951–65 was the slowest of the 20th century. Cancer diagnosed in children under age 20 rose 29 percent (and leukemia rose 41 percent) from the late 1940's to the early 1960's in Connecticut, the only State that operated a cancer registry at that time.

Recent public reports have acknowledged the harmful effects of making and testing atomic bombs:

- The National Cancer Institute published a study estimating that radioactive iodine in the above-ground atomic bomb tests caused as many as 220,000 Americans to develop thyroid cancer.[6]
- The Institute of Medicine documented elevated rates of death from prostate cancer, nasal cancer, and leukemia among 70,000 soldiers exposed to bomb blast fallout in Nevada.[7]
- The U.S. Department of Energy acknowledged that 600,000 workers at 14 nuclear weapons plants suffered from excessively high rates of 22 types of cancer due to occupational exposures.[8]

## IV. NUCLEAR POWER REACTORS AND HEALTH

There has been a dearth of scientific, peer-reviewed studies evaluating disease rates near U.S. nuclear power plants. Only one national study has been done. In 1990, at the insistence of Senator Edward M. Kennedy, the National Cancer Institute published data on cancer near nuclear plants. While the study concluded that there was no connection between radioactive emissions and cancer deaths, rates near many reactors rose after reactor startup.[9] Since 1990, no Federal agency, including the Environmental Protection Agency and Nuclear Regulatory Commission, has undertaken any studies of disease rates near nuclear power plants.

The worst accident of any U.S. nuclear power reactor occurred at Three Mile Island PA in March 1979. Substantial amounts of radioactive gases and particles were released during the crisis, prompting the Pennsylvania Governor to advise that pregnant women, infants, and small children evacuate the 5-mile radius of the stricken reactor. Subsequent studies of persons residing within 7.5 miles of Three Mile Island showed that rates of leukemia, lymphoma, lung cancer, and colon cancer jumped between 25 and 60 percent in the 7 years after the accident.[10]

Childhood cancer is generally believed to be one of the diseases most affected by radiation exposure. In the U.S., only two articles have documented elevated childhood cancer near nuclear power reactors.[11–12] By contrast, there are at least 11 articles on childhood cancer in areas near various power plants in the United Kingdom[13–23], plus additional studies in other nations.

The lack of health studies near American nuclear reactors is complemented by a lack of measurements of in-body levels of radioactivity for persons living near nuclear reactors. Government-supported programs to measure Strontium-90 in St. Louis baby teeth[24] and in New York City and San Francisco bones[25] were terminated in 1976 and 1982, respectively. Both primarily measured the effects of bomb test fallout rather than nuclear power reactors.

*Long Island—Sr-90 and Childhood Cancer Increases Are Similar*

RPHP is attempting to address the shortage of information on radiation's health effects by documenting radioactivity levels in the human body and comparing them with cancer and other health trends.

RPHP researchers have undertaken the first-ever study that measures radioactivity in the bodies of persons living near nuclear power reactors. In 1996, RPHP launched the Tooth Fairy Project, which uses the same methodology of calculating levels of Strontium–90 in baby teeth employed in St. Louis during the 1950's and 1960's. The chemical enters the baby teeth through the mother's diet during pregnancy and through the mother's bones.

Sr-90 is just a marker for the 100–200 radioactive chemicals that are released in nuclear reactor operations, but it is a critical one. Like calcium, Sr–90 attaches to the bone and teeth when it enters the body, where it remains for many years due to its slow rate of decay (half life of 28.7 years). It kills and impairs bone cells, and penetrates the bone marrow, which is the red blood cells critical to immune function are formed, making it a risk factor for all cancers. Of all man-made radioactive chemicals, Sr–90 was the one that caused the greatest health concern during the atmospheric bomb test years in the 1950's and 1960's. In 1956, Presidential candidate Adlai Stevenson remarked that Sr–90 was "the most dreadful poison in the world."[26]

To date, RPHP has collected over 3000 baby teeth, mostly from areas near reactors in California, Connecticut, Florida, New Jersey, New York, and Pennsylvania. Strontium–90 concentrations have been measured in nearly half (1463) of these teeth by Radiation Environmental Management Systems (REMS) Inc., an independent laboratory in Waterloo Canada.

The average current concentration of Sr–90 is similar to that in St. Louis in 1956, in the midst of the period of atmospheric nuclear weapons testing. Results of the Tooth Fairy Project have been published in three peer-reviewed medical journals.[27–29]

The largest number of teeth (563) have been measured for residents of Suffolk County New York, site of the Brookhaven National Lab and surrounded by nearby reactors. Results show that the average level of Sr-90 has steadily increased 40.0 percent from the early 1980's to the mid-1990's. Because U.S. above-ground bomb testing ceased in the early 1960's, and old bomb fallout is decaying steadily, this trend indicates that a current source of radioactive emissions is contributing to the buildup of Sr–90 in teeth. This source can only be nuclear reactors.

Trends in Average Concentration of SR-90, Suffolk County, NY Baby Teeth, 1981-1996

| Year of Birth | No. of Teeth | Avg. Sr–90+ | Percent Change |
|---|---|---|---|
| 1981–84 | 38 | 1.10 | ..... |
| 1985–88 | 157 | 1.38 | ..... |
| 1989–92 | 258 | 1.41 | ..... |
| 1993–96 | 45 | 1.54 | +40.0 |

+Average picocuries of Strontium–90 per gram of calcium in baby teeth at birth.

In the same time period, cancer diagnosed in Suffolk County children less than 10 years old steadily rose a nearly identical 49 percent.[30] The data support the theory that exposure to radioactive increases the risk of cancer, especially in young persons.

Trends in Cancer Incidence Age 0–9, Suffolk County, NY, 1981–1996

| Period | Age 0–9 | | Cases per 100,000 Pop. | Percent Change |
|---|---|---|---|---|
| | Cancer Cases | Avg. Pop. | | |
| 1981–84 | 92 | 182,441 | 12.61 | ..... |
| 1985–89 | 115 | 182,463 | 15.76 | ..... |
| 1989–92 | 129 | 185,050 | 17.43 | ..... |
| 1993–96 | 146 | 194,498 | 18.77 | +48.9 |

Children are not the only humans affected by the radiation-cancer connection. However, since the rapidly developing fetus and infant are most sensitive to toxic exposures to radiation and other chemicals, immediate adverse effects are most likely to occur. A latency period of up to several decades between exposure and manifestation of cancer may be necessary in adults.

*B. Long Island—Childhood Cancer Outbreak in High-Radiation Area*

In the late I990's, news of an atypically large number of cases of rhabdomyosarcoma in northwestern Suffolk County children began to surface. This soft tissue cancer was diagnosed in 23 children living in a small area, when one or two cases would normally be expected. Publicly aired concerns of parents of victims prompted the Suffolk legislature to authorize a Task Force to investigate the extent and cause of the outbreak.

While the cause(s) of rhabdomyosarcoma are generally unknown, radiation exposure has been identified as a risk factor. Over one-quarter of laboratory mice who had Sr–90 rubbed on their skin were later diagnosed with rhabdomyosarcoma or a related cancer.[31] Pregnant women who receive a pelvic X-ray are twice as likely to bear a child who will be diagnosed with the disease.[32]

The RPHP Baby Teeth Study has collected 57 teeth from the area of Suffolk County in which most children with rhabdomyosarcoma live. Teeth from this region have the highest average concentration of Sr–90 in Suffolk County, at 1.48 picocuries of Sr–90 per gram of calcium. Teeth in other areas, such as the north and south forks of Long Island and the middle of Suffolk County have barely half that amount. RPHP is now conducting a case-control study, in which it tests teeth from children with rhabdomyosarcoma to further establish the link between the disease and environmental radiation.

*C. San Luis Obispo, CA—Effects of Opening Reactors*

Demonstrating a radiation-cancer link requires collection of valid data on exposures. One relatively simple way of evaluating health effects of exposures is to study children living near a recently opened reactor, before and after the opening.

RPHP has collected 34 teeth from children born in San Luis Obispo County in California, which is the site of the Diablo Canyon reactors (started 1984 and 1985). Average Sr-90 levels for the county's children born after the reactors began operations increased 49.6 percent. While more teeth are needed to make results more significant, the finding provides preliminary evidence of added environmental radioactivity actually entering human bodies.

Trends in Average Concentration of Sr-90, San Luis Obispo County, CA Baby Teeth, 1979–1994

| Year of Birth | No. Teeth | Avg. Sr-90+ | Percent Ch. |
|---|---|---|---|
| 1979–85 (before startup) | 15 | 1.35 | ..... |
| 1986–94 (after startup) | 19 | 2.02 | +49.6 |

+Average picocuries of Strontiuxn–90 per gram of calcium in baby teeth at birth.

Several years after the startup of Diablo Canyon, cancer death rates among children living in San Luis Obispo and adjoining Santa Barbara County began to rise. The rate for children 19 and under was 74.5 percent higher in the 1990's than it was in the late 1980's.[33] Again, these data support the theory that radiation exposure increases the cancer burden in children (allowing several years between initial exposure and death; many children who die of cancer live several years after diagnosis).

Trends in Cancer Mortality Age 0–19, San Luis Obispo and Santa Barbara Counties, CA, 1985–1998

| Year of Death | Deaths | Total Pop. | Deaths/ 100,000 Pop. | Percent Ch. |
|---|---|---|---|---|
| 1985–89 | 16 | 742,569 | 2.16 | ..... |
| 1990–98 | 57 | 1,515,911 | 3.76 | +74.5 |

Reactor startups have adverse effects on all local citizens, not just children, Thyroid cancer in two Connecticut counties increased dramatically after nuclear reactors opened in the late 1960's.[34] Thyroid cancer is especially sensitive to exposure to radioactive iodine, which is present in the "cocktail" of chemicals in nuclear reactor emissions.

*D. Closing Reactors—Eight U.S. Nuclear Power Plants*

When nuclear power reactors cease operations, there is an immediate removal of all locally generated radioactive chemicals that decay quickly, and a more gradual removal of those that decay slowly. The reduction is greatest in nearby areas downwind of closed reactors; the majority of airborne emissions are propelled in the downwind direction, where radioactive gases and particles can be inhaled and are introduced into the diet via precipitation.

Since 1987, eight nuclear power plants have closed, leaving at least a 70 mile radius with no operating reactors. In downwind counties within 40 miles of all eight sites, the death rate among infants under 1 year plunged in the first 2 years after closing.[35] RPHP is collecting baby teeth near one of these areas (Rancho Seco, near Sacramento CA) to establish that the improvement in health is accompanied by a declining level of in-body radioactivity.

Trend in Infant Mortality, Downwind Counties Near Closed Nuclear Reactors, Two Years Before vs. Two Years After Closing

| Reactor, Closed | Infant Death | | Live Births | | Deaths/1000 | | Percent Change |
|---|---|---|---|---|---|---|---|
| | Before | After | Before | After | Before | After | |
| LaCrosse WI, 1987 | 36 | 30 | 3507 | 3452 | 10.27 | 8.69 | −15.4 |
| Rancho Seco CA, 1989 | 418 | 390 | 44500 | 49414 | 9.39 | 7.89 | −16.0 |
| Ft. St. Vrain CO, 1989 | 83 | 72 | 9725 | 9977 | 8.53 | 7.22 | −15.4 |
| Trojan OR, 1992 | 253 | 204 | 30320 | 29799 | 8.34 | 6.85 | −17.9 |
| Big Rock Pt. MI, 1997 | 25 | 6* | 2922 | 1529* | 8.56 | 3.92* | −54.2 |
| Me. Yankee ME, 1997 | 19 | 10* | 3841 | 2201* | 4.95 | 4.54* | −8.3 |
| Pilgrim MA, 1986 | 97 | 76 | 12956 | 13412 | 7.49 | 5.67 | −24.3 |
| Millstone CT, 1995 | 166 | 130 | 22261 | 21093 | 7.46 | 6.16 | −17.4 |
| TOTAL 8 AREAS | 1097 | 918 | 130032 | 130877 | 8.44 | 7.01 | −16.9 |
| U.S. AVG 2-YR CH, 1986–98 | ..... | ..... | ..... | ..... | ..... | ..... | −6.4 |

*Only 1998 data are available for post-shutdown periods for Big Rock Point and Maine Yankee.

## V. POLICY IMPLICATIONS—RADIATION HEALTH AND NUCLEAR REACTORS

Since atomic bombs were first manufactured and used during World War II, exposure to man-made fission products has been a critical environmental health issue. The relative novelty of these chemicals in the environment underscores the need for thorough and objective studies.

Since the conclusion of the cold war a decade ago, nuclear weapons are no longer manufactured or tested. However, the production from American nuclear power reactors has reached an all-time high, and utility companies (supported by the Bush Administration) are considering a large-scale expansion of the industry. These developments indicate that protection of humans from the potentially harmful effects of exposure to radioactive emissions in the environment will be critical. To that end, we urge Congress to take the following actions:

1. Conduct hearings examining the current knowledge on the impact of environmental radiation on public health, including cancer.
2. Establish and support an independent medical and scientific commission to evaluate the impact of environmental radiation on public health, including cancer.
3. Institute a systematic program measuring radioactivity levels in bodies of persons living near to and distant from U.S. nuclear power reactors.
4. Conduct or support routine, periodic studies tracking disease patterns and trends among persons living near to and distant from nuclear power reactors. Studies should identify infants and children separately from adults, and should focus on cancer.
5. Direct policymakers and regulators to include consideration of disease patterns and trends within the local population when making decisions to extend licenses of existing nuclear reactors.
6. Direct policymakers and regulators to include consideration of potential health effects when making decisions to grant operating licenses for new nuclear reactors.
7. Require that in-body radioactivity levels be evaluated in all federally funded programs that investigate possible causes of elevated cancer rates in the U.S.

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## APPENDIX

### RECENT PROFESSIONAL PUBLICATIONS RADIATION AND PUBLIC HEALTH PROJECT

#### RECENT BOOK PUBLICATIONS

1. Gould, J.M. and members of RPHP. The Enemy Within: The High Cost of Living Near Nuclear Reactors. New York: Four Walls Eight Windows, 1996.
2. Brown, J. and Brutoco, R. Profiles in Power: The Antinuclear Movement and the Dawn of the Solar Age. New York: Twayne Publishers, 1997.
3. Mangano, J.J. Low-Level Radiation and Immune System Damage: An Atomic Era Legacy. Boca Raton, FL: Lewis Publishers, 1998.
4. Sherman, J.D. Life's Delicate Balance: Causes and Prevention of Breast Cancer. New York: Taylor and Francis, 2000.

#### RECENT MEDICAL JOURNAL ARTICLES

1. Gould, J.M. et al. Strontium-90 in deciduous teeth as a factor in early childhood cancer. International Journal of Health Services 2000; 30(3):515–39.
2. Mangano, J.J. et al. Strontium-90 in newborns and childhood disease. Archives of Environmental Health 2000; 55(4):240–4.
3. Gould, J.M. et al. The Strontium-90 baby teeth study and childhood cancer. European Journal of Oncology 2000; 5(suppl. 2):119–25.
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NEW YORK STATES COALITION OPPOSED TO FLUORIDATION, INC.,
*Old Bethpage, NY, June 13, 2001.*

Committee on Environment and Public Works,
*U.S. Senate,*
*Washington, DC.*

Re: Testimony on Fluoride's Role In Environmental Pollution, Systemic Health and Dental Health Problems, and a Practical Solution

DEAR CHAIRMAN AND COMMITTEE MEMBERS: Members of our organization attended the hearing on environmental health concerns at Adelphi University on Monday, June 11, 2001. Senator Hillary Clinton was an excellent Chair of the hearing, along with Senators Henry Reid and Lincoln Chafee. The participating legislators offered valuable input, as did the panel participants. The discussions on breast cancer, testicular cancer, leukemia clusters, birth defects, asthma, and other health problems were very important. However, we believe the value of the hearing would

have been still more enhanced had an opportunity been provided for those in the audience who wished to make a brief statement or ask a pertinent question.

There was a missing factor that is important to bring to your committee's attention. A number of the professional and civic participants expressed their concern about the lack of controls, allowing arsenic to enter our drinking water. Other panelists expressed the disturbing fact that numerous chemicals are not even tested. Still others talked about the concerns about lead exposure, etc. The Precautionary Principle was pointed out by another panelist. Yet a missing factor, a common denominator, could well be the role that fluoride chemicals in our public water supplies play in the environmental picture.

Fluoride is a cumulative enzyme poison. Fluoride is a prescription drug when obtained at a pharmacy, yet is carelessly added to fluoridated water supplies in order to try to reduce tooth decay. Fluoride is classified as a contaminant by the Environmental Protection Agency (EPA). Fluoridation deliberately adds hundreds of thousands of tons of toxic nonbiodegradable fluoride chemicals to our already endangered water supplies. The synergistic effects of fluoride with other substances is not fully known. Fluoride accumulates in the body like lead, and, in fact, is more toxic than lead and almost as toxic as arsenic.

The public is being subjected involuntarily to fluoride ingestion and exposure because of total fluoride intake that is now out of control. Once fluoride is added to public drinking water, it is impossible to control dosage. The fluoride enters our cooking water, and, in fact, fluoride concentrates upon boiling. It enters the foods and beverages grown in or processed in fluoridated areas. It is in our toothpastes, rinses, medications, among other sources. It is even breathed in from humidifiers. Dental fluorosis has become rampant in our country. The problem is fluoride excess, not fluoride deficiency.

Our government agencies are working at cross purposes. There is an increasing emphasis on *reducing* the pollution of our water supplies and we are spending millions of dollars trying to clean up our environment. Then we permit an increase in water pollution by the deliberate addition to our drinking water of toxic fluoride (mostly hydrofluosilicic acid, a waste by-product of the phosphate fertilizer industry) with no regard to the amount of water consumed, the amount of fluoride stored in the body, or the amount tolerated. Children and adults with kidney and urinary tract disorders, and other dietary and medical problems, require the ingestion of large quantities of water, and fluoridated water compounds their problems.

Opposition to fluoridation is shared by no less than the Environmental Protection Agency's (EPA) Headquarters Union, representing over 1500 EPA professionals. They include toxicologists, biologists, chemists, engineers, lawyers and other professionals). This EPA professional union is in sharp disagreement with their own EPA agency that promotes fluoridation. Dr. J. William Hirzy, chemist, represents the EPA union. He has pointed out that their members are "charged with assessing the safety of drinking water" and that their judgments are based, in part, on animal studies and human epidemiology studies indicating "a causal link between fluoride/fluoridation and cancer, genetic damage, neurological impairment and bone pathology. Of particular concern are the recent studies linking fluoride exposure to lower IQ in children."

Studies, including Government studies, report on populations that are unusually susceptible to the toxic effects of fluoride: the elderly, those with kidney, bone and cardiovascular problems, high water consumers, the newborn, the nutritionally deficient, and others. (U.S. Public Health Service, "The Toxicological Profile for Fluorides" 1993, etc.) Published studies report an increase in hip fractures in the elderly and osteosarcoma in young males in fluoridated areas.

In Western Europe, where there is only perhaps 2 percent of the population fluoridated, as opposed to over 60 percent in our heavily fluoridated country (mostly without informed consent and at times even without the knowledge of the public), dental health is essentially as good as or better than in the United States. In Europe, industrial fluosilicates are recognized for the problematical by-products of industry.

Documents show that fluoride added to water also contains lead, arsenic, antimony, cadmium, and other undesirable substances. In fact, health agencies now concede there has been no safety testing of the silicofluoride acid chemicals most commonly used to fluoridate public drinking water, largely from phosphate fertilizer. Incredibly, these fluoride products have not been tested as safe for human consumption. That is why several U.S. Congressmen have contemplated hearings or already initiated hearings.

Proponents of fluoridation are trying to downplay the important research of Professor Roger Masters, which shows increased blood lead levels in children in the artificially fluoridated water supplies where fluosilicic acid is used. This should be given the most careful and serious attention by our public health authorities.

Former Chairman of the Senate Environment & Public Works Committee, Senator Bob Smith, has asked the EPA to review its standard for fluoride in drinking water. Senator Crapo included a presentation by Dr. William Hirzy of the EPA's Union of professionals at Headquarters in Washington at his June 29, 2000 hearing, where Dr. Hirzy reported on fluoridation's detrimental effects. U.S. Representative Sensenbrenner, former Chairman of Committee on Science, also commenced an investigation, as did U.S. Representative Calvert, former Subcommittee Chairman of because of their safety concern.

Many letters and petitions went to the aforementioned committees from citizens and community groups throughout the country, and from other countries as well. The work had only begun. We respectfully ask that you continue the investigation for the good and the protection of the public.

Finally, the panelists at the June 11th meeting were concerned because of the difficulty in ridding our environment of known toxic chemicals. In contrast, with fluoridation, the answer is a simple matter of turning off the fluoride valve. This was done in Riverhead, Levittown, Carle Place, and Rouses Point, New York, areas within the Water Authority of Western Nassau County, and many places throughout the State, the country and abroad. Fluoridation was discontinued for a variety of reasons, including health, pollution and freedom of choice concerns, as well as accidental misfeeds, malfunction of the fluoridation system, and human error, resulting in illness, hospitalization, and even fatalities.

While we realize there could be multiple environmental factors involved in the increase of chronic diseases, it is our strong position that your efforts, genuine and vigorous as they are, would not be complete without the inclusion of the fluoride factor. In this regard, there are professionals of world-class caliber ready and willing to discuss this matter with you, to meet with you, to appear before your committee, to participate in your efforts with other members of the scientific and medical fields, in your laudable search for answers.

We would appreciate the opportunity of discussing such participation with you. We look forward to a constructive response.

Sincerely,

PAUL STEPHEN BEEBER,
*President and General Counsel.*

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U.S. HOUSE OF REPRESENTATIVES,
COMMITTEE ON SCIENCE,
*Washington, DC, September 7, 2000.*

Paul Beeber,
*Old Bethpage, NY.*

DEAR MR. BEEBER: Thank you for communicating with me regarding the Environmental Protection Agency's (EPA) position on fluoride in drinking water. It is my goal to ensure that all decisions made at the EPA are based on sound science and are done in the proper risk-based context.

The EPA spends millions of dollars on health and safety research into substances that naturally occur or contaminate our drinking water, including arsenic and radon, as well as substances that are added to drinking water, including compounds that result from the breakdown of chlorine, a chemical used for disinfection. Fluoride falls into each of those categories—it is both naturally occurring and a drinking water additive. Most of the research data that I have seen concerns the safety of using sodium fluoride (NaF) as a fluoridation agent. However, many of our nation's fluoridated water supplies use different fluoridation agents, such as hydrofluosilicic acid or sodium silicofluoride. Much less is known about these compounds. A research program by EPA into the safety of all of the fluoride compounds we add to our drinking water is overdue. That is not only sound science, it is common sense.

Thank you again for sharing your views, on this important issue with me. I would invite you to follow this and other issues of importance to you on the Science Committee web site at *www.house.gov/science.*

Sincerely,

F. JAMES SENSENBRENNER, JR.,
*Chairman.*

[From the National Treasury Employees Union, Chapter 280]

## FLUORIDATION HAZARDS

### WHY EPA'S HEADQUARTERS UNION OF SCIENTISTS OPPOSES FLUORIDATION

The following documents why our union, formerly National Federation of Federal Employees Local 2050 and since April 1998 Chapter 280 of the National Treasury Employees Union, took the stand it did opposing fluoridation of drinking water supplies. Our union is comprised of and represents the approximately 1500 scientists, lawyers, engineers and other professional employees at EPA Headquarters here in Washington, DC.

The union first became interested in this issue rather by accident. Like most Americans, including many physicians and dentists, most of our members had thought that fluoride's only effects were beneficial—reductions in tooth decay, etc. We too believed assurances of safety and effectiveness of water fluoridation.[1]

Then, as EPA was engaged in revising its drinking water standard for fluoride in 1985, an employee came to the union with a complaint: he said he was being forced to write into the regulation a statement to the effect that EPA thought it was alright for children to have "funky" teeth. It was OK, EPA said, because it considered that condition to be only a cosmetic effect, not an adverse health effect. The reason for this EPA position was that it was under political pressure to set its health-based standard for fluoride at 4 mg/liter. At that level, EPA knew that a significant number of children develop moderate to severe dental fluorosis, but since it had deemed the effect as only cosmetic, EPA didn't have to set its health-based standard at a lower level to prevent it.

We tried to settle this ethics issue quietly, within the family, but EPA was unable or unwilling to resist external political pressure, and we took the fight public with a union *amicus curiae* brief[2] in a lawsuit filed against EPA by a public interest group. The union has published on this initial involvement period in detail.[1]

Since then our opposition to drinking water fluoridation has grown, based on the scientific literature documenting the increasingly out-of-control exposures to fluoride, the lack of benefit to dental health from ingestion of fluoride and the hazards to human health from such ingestion. These hazards include acute toxic hazard, such as to people with impaired kidney function, as well as chronic toxic hazards of gene mutations, cancer, reproductive effects, neurotoxicity, bone pathology and dental fluorosis. First, a review of recent neurotoxicity research results.

In 1995, Mullenix and co-workers[2] showed that rats given fluoride in drinking water at levels that give rise to plasma fluoride concentrations in the range seen in humans suffer neurotoxic effects that vary according to when the rats were given the fluoride—as adult animals, as young animals, or through the placenta before birth. Those exposed before birth were born hyperactive and remained so throughout their lives. Those exposed as young or adult animals displayed depressed activity. Then in 1998, Guan and co-workers[3] gave doses similar to those used by the Mullenix research group to try to understand the mechanism(s) underlying the effects seen by the Mullenix group. Guan's group found that several key chemicals in the brain—those that form the membrane of brain cells—were substantially depleted in rats given fluoride, as compared to those who did not get fluoride.

Another 1998 publication by Varner, Jensen and others[4] reported on the brain- and kidney-damaging effects in rats that were given fluoride in drinking water at the same level deemed "optimal" by pro-fluoridation groups, namely 1 part per million (1 ppm). Even more pronounced damage was seen in animals that got the fluoride in conjunction with aluminum. These results are especially disturbing because of the low dose level of fluoride that shows the toxic effect in rats—rats are more resistant to fluoride than humans. This latter statement is based on Muilenix's finding that it takes substantially more fluoride in the drinking water of rats than of humans to reach the same fluoride level in plasma. It is the level in plasma that determines how much fluoride is "seen" by particular tissues in the body. So when rats get 1 ppm in drinking water, their brains and kidneys are exposed to much less fluoride than humans getting 1 ppm, yet they are experiencing toxic effects. Thus we are compelled to consider the likelihood that humans are experiencing damage to their brains and kidneys at the "optimal" level of 1 ppm.

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[1] For a history of how drinking water fluoridation began, see "Fluoride, Teeth and the Atomic Bomb," by investigative reporters Joel Griffiths and Chris Bryson, available on-line at http://www.ia4u.net/~sherrell/bomb.htm

[2] On-line at http://www.rvi. net/~ftluoride/amicus.htm

In support of this concern are results from two epidemiology studies from China[5,6] that show decreases in I.Q. in children who get more fluoride than the control groups of children in each study. These decreases are about 5 to 10 I.Q. points in children aged 8 to 13 years.

Another troubling brain effect has recently surfaced: fluoride's interference with the function of the brain's pineal gland. The pineal gland produces melatonin which, among other roles, mediates the body's internal clock, doing such things as governing the onset of puberty. Jennifer Luke[7] has shown that fluoride accumulates in the pineal gland and inhibits its production of melatonin. She showed in test animals that this inhibition causes an earlier onset of sexual maturity, an effect reported in humans as well in 1956, as part of the Kingston/Newburgh study, which is discussed below. In fluoridated Newburgh, young girls experienced earlier onset of menstruation (on average, by 6 months) than girls in non-fluoridated Kingston.[8]

From a risk assessment perspective, all these brain effect data are particularly compelling and disturbing because they are convergent.

We looked at the cancer data with alarm as well. There are epidemiology studies that are convergent with whole-animal and single-cell studies (dealing with the cancer hazard), just as the neurotoxicity research just mentioned all points in the same direction. EPA fired the Office of Drinking Water's chief toxicologist, Dr. William Marcus, who also was our local union's treasurer at the time, for refusing to remain silent on the cancer risk issue.[9] The judge who heard the lawsuit he brought against EPA over the firing made that finding—that EPA fired him over his fluoride work and not for the phony reason put forward by EPA management at his dismissal. Dr. Marcus won his lawsuit and is again at work at EPA. Documentation is available on request.

The type of cancer of particular concern with fluoride, although not the only type, is osteosarcoma, especially in males. The National Toxicology Program conducted a 2-year study[10] in which rats and mice were given sodium fluoride in drinking water. The positive result of that study (in which malignancies in tissues other than bone were also observed), particularly in male rats, is convergent with a host of data from tests showing fluoride's ability to cause mutations (a principal "trigger" mechanism for inducing a cell to become cancerous)[e.g., 11a, b, c, d] and data showing increases in osteosarcomas in young men in New Jersey,[12] Washington and Iowa[13] based on their drinking fluoridated water. It was his analysis, repeated statements about all these and other incriminating cancer data, and his requests for an independent, unbiased evaluation of them that got Dr. Marcus fired.

Bone pathology other than cancer is a concern as well. An excellent review of this issue was published by Diesendorf et al. in 1997.[14] Five epidemiology studies have shown a higher rate of hip fractures in flucridated vs. non-fluoridated communities.[15a, b, c, d, e]. Crippling skeletal fluorosis was the endpoint used by EPA to set its primary drinking water standard in 1986, and the ethical deficiencies in that standard setting process prompted our union to join the Natural Resources Defense Council in opposing the standard in court, as mentioned above.

Regarding the effectiveness of fluoride in reducing dental cavities, there has not been any double-blind study of fluoride's effectiveness as a caries preventative. There have been many, many small scale, selective publications on this issue that proponents cite to justIfy fluoridation, but the largest and most comprehensivestudy, one done by dentists trained by the National Institute of Dental Research, on over 39,000 school children aged 5–17 years, shows no significant differences (in terms of decayed, missing and filled teeth) among caries incidences in fluoridated, non-fluoridated and partially fluoridated communities.[16] The latest publication[17] on the 50-year fluoridation experiment in two New York cities, Newburgh and Kingston, shows the same thing. The only significant difference in dental health between the two communities as a whole is that fluoridated Newburgh, NY shows about twice the incidence of dental fluorosis (the first, visible sign of fluoride chronic toxicity) as seen in non-fluoridated Kingston.

John Colquhoun's publication on this point of efficacy is especially important.[18] Dr. Coiquhoun was Principal Dental Officer for Auckland, the largest city in New Zealand, and a staunch supporter of fluoridation—until he was given the task of looking at the worldwide, data on fluoridation's effectiveness in preventing cavities. The paper is titled, "Why I changed My Mind About Water Fluoridation." In it Colquhoun provides details on how data were manipulated to support fluoridation in English speaking countries, especially the United States and New Zealand. This paper explains why an ethical public health professional was compelled to do a 180 degree turn on fluoridation.

Further on the point of the tide turning against drinking water fluoridation, statements are now coming from other dentists in the pro-fluoride camp who are starting to warn that topical fluoride (e.g. fluoride in tooth paste) is the only significantly

beneficial way in which that substance affects dental health.[19, 20, 21] However, if the concentrations of fluoride in the oral cavity are sufficient to inhibit bacterial enzymes and cause other bacteriostatic effects, then those concentrations are also capable of producing adverse effects in mammalian tissue, which likewise relies on enzyme systems. This statement is based not only on common sense, but also on results of mutation studies which show that fluoride can cause gene mutations in mammalian and lower order tissues at fluoride concentrations estimated to be present in the mouth from fluoridated tooth paste.[22] Further, there were tumors of the oral cavity seen in the NTP cancer study mentioned above, further strengthening concern over the toxicity of topically applied fluoride.

In any event, a person can choose whether to use fluoridated tooth paste or not (although finding non-fluoridated kinds is getting harder and harder), but one cannot avoid fluoride when it is put into the public water supplies.

So, in addition to our concern over the toxicity of fluoride, we note the uncontrolled—and apparently uncontrollable—exposures to fluoride that are occurring nationwide via drinking water, processed foods, fluoride pesticide residues and dental care products. A recent report in the lay media,[23] that, according to the Centers for Disease Control, at least 22 percent of America's children now have dental fluorosis, is just one indication of this uncontrolled, excess exposure. The finding of nearly 12 percent incidence of dental fluorosis among children in un-fluoridated Kingston New York[17] is another. For governmental and other organizations to continue to push for *more* exposure in the face of current levels of over-exposure coupled with an increasing crescendo of adverse toxicity findings is irrational and irresponsible at best.

Thus, we took the stand that a policy which makes the public water supply a vehicle for disseminating this toxic and prophylactically useless (via ingestion, at any rate) substance is wrong.

We have also taken a direct step to protect the employees we represent from the risks of drinking fluoridated water. We applied EPA's risk control methodology, the Reference Dose, to the recent neurotoxicity data. The Reference Dose is the daily dose, expressed in milligrams of chemical per kilogram of body weight, that a person can receive over the long term with reasonable assurance of safety from adverse effects. Application of this methodology to the Varner et al.[4] data leads to a Reference Dose for fluoride of 0.000007 mg/kg-day. Persons who drink about one quart of fluoridated Water from the public drinking water supply of the District of Columbia while at work receive about 0.01mg/kg-day from that source alone. This amount of fluoride is more than 100 times the Reference Dose. On the basis of these results the union filed a grievance, asking that EPA provide un-fluoridated drinking water to its employees.

The implication for the general public of these calculations is clear. Recent, peer-reviewed toxicity data, when applied to EPA's standard method for controlling risks from toxic chemicals, require an immediate halt to the use of the nation's drinking water reservoirs as disposal sites for the toxic waste of the phosphate fertilizer industry.[24]

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[From Dartmouth College, March 15, 2001]

DARTMOUTH RESEARCHERS WARNS OF CHEMICALS ADDED TO DRINKING WATER

HANOVER, NH—In a recent article in the journal, *NeuroToxicology*, a research team led by Roger D. Masters, Dartmouth College Research Professor and Nelson A. Rockefeller Professor of Government Emeritus, reports evidence that public drinking water treated with sodium silicofluoride or fluosilicic acid, known as silicofluorides (SiFs), is linked to higher uptake of lead in children.

Sodium fluoride, first added to public drinking water in 3945, is now used in less than 10 percent of fluoridation systems nationwide, according to the Center for Disease Control's (CDC) 1992 Fluoridation Census. Instead, SiF's are now used to treat drinking water delivered to 140 million people. While sodium fluoride was tested on animals and approved for human consumption, the same cannot be said for SiFs.

Masters and his collaborator Myron J. Coplan, a consulting chemical engineer, formerly Vice President of Albany International Corporation, led the team that has now studied the blood lead levels in over 400,000 children in three different samples. In each case, they found a significant link between SiF-treated water and elevated blood lead levels.

"We should stop using silicofluorides in our public water supply until we know what they do," said Masters. Officials at the Environmental Protection Agency have told Masters and Coplan that the EPA has no information on health effects of chronic ingestion of SiF-treated water.

In their latest study published in a special December 2000 issue of *NeuroToxicology*, Masters, Coplan and their team analyzed data on blood levels from more than 150,000 children ages 0 to 6. These tests were part of a sample collected by the New York State Department of Children's Health, mostly from 1994 to 1998 in comparable non-fluoridated and SiF-treated public drinking water in communities with populations of similar size. Socio-economic and demographic risk factors for high blood lead were also considered using information from the 1990 U.S. Census, The researchers found that the greatest likelihood of children having elevated blood lead levels occurs when they are exposed both to known risk factors, such as old house paint and lead in soil or water, and to SIF-treated drinking water.

"Our research needs further laboratory testing," added Masters. "This should have the highest priority because our preliminary findings show correlations between SiF use and more behavior problems due to known effects of lead on brain chemistry." Also requiring further examination is German research that shows SiFs inhibit cholinesterase, an enzyme that plays an important rote in regulating neurotransmitters.

"If SiFs are cholinesterase inhibitors, this means that SiFs have effects like the chemical agents linked to Gulf War Syndrome, chronic fatigue syndrome and other puzzling conditions that plague millions of Americans," said Masters. "We need a better understanding of how SiFs behave chemically and physiologically."

Currently, a bill before the New Hampshire House of Representatives would impose more stringent testing on fluoridating chemicals added to public drinking water. On March 7, 2001, Masters and Coplan testified in favor of the bill, HB 754, The Fluoride Product Quality Control Act, at a public bearing. Masters contends that bill's requirement for testing the silicofluorides is vital but needs to be complemented by further research on neurotoxicity and behavior.

Masters and Coplan note that their recent studies contain the most extensive empirical evidence of the health and behavioral costs of these chemicals. "If further research confirms our finding;" Masters added, "this may well be the worst environmental poison since leaded gasoline."

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## IS FLUORIDATION SCIENTIFICALLY DEFENSIBLE

(By John R. Lee, M.D.)

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Therefore, fluoridation of community water supplies is a failed concept and should be abandoned.

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[From the Mesa Tribune, Arizona, December 5, 1999]

FORMER FAN OF FLUORIDATION NOW WARNS OF ITS PERILS

(By Barry Forbes, Tribune Columnist)

"Why'd you do it, Doc? Why'd you toss the fluoride folks overboard?"

I had just tracked down Dr. Hardy Limeback, B.Sc., Ph.D. in Biochemistry, D.D.S., head of the Department of Preventive Dentistry for the University of Toronto, and president of the Canadian Association for Dental Research. (Whew.)

Dr. Limeback is Canada's leading fluoride authority and until recently, the country's primary promoter of the controversial additive.

In a surprising newsmaker interview this past April, Dr. Limeback announced a dramatic change of heart. "Children under three should never use fluoridated toothpaste," he counseled. "Or drink fluoridated water. And baby formula must never be made up using Toronto tap water. Never."

Why, I wondered? What could have caused such a powerful paradigm shift?

"It's been building up for a couple of years," Limeback told me during a recent telephone interview. "But certainly the crowning blow was the realization that we have been dumping contaminated fluoride into water reservoirs for half a century. The vast majority of all fluoride additives come front Tampa Bay, Florida smokestack scrubbers. The additives are a toxic by-product of the super-phosphate fertilizer industry."

"Tragically," he continued, "that means were not just dumping toxic fluoride into our drinking water. We're also exposing innocent, unsuspecting people to deadly elements of lead, arsenic and radium, all of them carcinogenic. Because of the cumu-

lative properties of toxins, the detrimental effects on human health are catastrophic."

A recent study at the University of Toronto confirmed Dr. Limeback's worst fears. "Residents of cities that fluoridate have double the fluoride in their hip bones vis-a-vis the balance of the population. Worse, we discovered that fluoride is actually altering the basic architecture of human bones."

Skeletal fluorosis is a debilitating condition that occurs when fluoride accumulates in bones, making them extremely weak and brittle. The earliest symptoms?

"Mottled and brittle teeth," Dr. Limeback told me. "In Canada we are now spending more money treating dental fluorosis than we do treating cavities. That includes my own practice." One of the most obvious living experiments today, Dr. Limeback believes, is a proof-positive comparison benveen any two Canadian cities. "Here in Toronto we've been fluoridating for 36 years. Yet Vancouver—which has never fluoridated—has a cavity rate lower than Toronto's."

And, he pointed out, cavity rates are low all across the industrialized world—including Europe. which is 98 percent fluoride free. Low because of improved standards of living, less refined sugar, regular dental checkups, flossing and frequent brushing. Now less than 2 cavities per child Canada-wide, he said.

"I don't get it, Doc. Last month, the Centers for Disease Control (CDC) ran a puff piece all across America saying the stuff was better than sliced bread. What's the story?"

"Unfortunately," he replied, "the CDC is basing its position on data that is 50 years old, and questionable at best. Absolutely no one has done research on fluorosilicates, which is the junk they're dumping into the drinking water."

"On the other hand." he added, "the evidence against systemic fluoride in-take continues to pour in."

"But Doc, the dentists."

"I have absolutely no training in toxicity;" he stated firmly. "Your well-intentioned dentist is simply following 50 years of misinformation from public health and the dental association. Me, too. Unfortunately, we were wrong."

Last week, Dr. Hardy Limeback addressed his faculty and students at the University of Toronto, Department of Dentistry. In a poignant, memorable meeting, he apologized to those gathered before him.

"Speaking as the head of preventive dentistry. I told them that I had unintentionally mislead my colleagues and my students. For the past 15 years, I had refused to study the toxicology information that is readily available to anyone. Poisoning our children was the furthest thing from my mind."

"The truth," he confessed to me, "was a bitter pill to swallow. But swallow it I did." South of the border, the paradigm shift has yet to dawn. After half a century of delusion, the CDC, American Dental Association and Public Health stubbornly and skillfully continue to manipulate public opinion in favor of fluoridation.

Meantime, study after study is delivering the death knell of the deadly toxin. Sure. fluoridation will be around for a long time yet, but ultimately its supporters need to ready the life rafts. The poisonous waters of doubt and confusion are bound to get choppier.

Are lawsuits inevitable?" I asked the good doctor "Remember tobacco." was his short, succinct reply.

Welcome. Dr. Hardy Limeback, to the far side of the fluoride equation.

It's lonely over here, but in our society loneliness and truth frequently travel hand in band.

Thank you for the undeniable courage of your convictions.

AN INTRODUCTION TO FLUORIDE

• The chemicals used in 90 percent of U.S. water fluoridation programs are industrial-grade hazardous wastes captured in the pollution-control scrubber systems of the Fluorine recovery in the fertilizer industry-a review. *Phosphorus & Potassium No. 103,* Sept./Oct. 1979.

• "Our water department calculates that we would be buying 33 tons of chemicals/year . . . The kickerto this scheme is that the amount intended for the targeted children is only 16 pounds of that 33 tons." Councilman Keith Beier, city of Escondido Council Meeting, March 24, 1999.

• All three fluoridation chemicals are more toxic than lead and just slightly less toxic than arsenic. 100 times more fluoride is added to drinking water than is le LD50 data. RE. Gosselin et al, *Clinical Toxicology of Commercial Products*. 5th ed., 1984.: U.S. EPA Maximum Contaminant Levels (MCL) EPA/NSF Standard 60.

• Regarding the silicofluorides used in 90 percent of U.S. fluoridation programs, EPA states, "In collecting the data for the fact sheet, EPA was not able to identify

chronic studies for these chemicals." *Letter of June 23, 1999*, from EPA Asst. Adm. J. Charles Fox to U.S. Representative Ken Calvert, Chairman, Subcommittee on Energy and the Environment, Washington, DC.

• Water fluoridation mass medicates at a level higher than the prescription schedule for your children. For example, the schedule's dose for infants under 6 months is "None." *J. Am. Dental Assoc.* Dec. 1995.

• 66.4 percent of U.S. schoolchildren in so-called "optimally" fluoridated communities have at least one tooth that displays the permanent visible signs of fluoride-overdose . . . dental fluorosis: white spots, stains, opaque, chalky and brittle enamel. K.E. Heller, et al, *J of Public Health Denistry*. Vol. 57: No. 3 Summer 1997.

• African-American children experience twice the prevalence of dental fluorosis as white children and it tends to be more severe. National Research Council, *Health Effects of Ingested Fluoride*. 1993, p. 44.

• "This was the only contaminant up to this time that we knew had a human health effect. Other drinking-water contaminants (approx. 80) were recognized by the results of (high-dose) animal studies only." EPA drinking-water analyst, David Schnare. *The Progressive.* Dec. 1990.

• "Our members' review of the body of evidence over the last 11 years, including animal and human epidemiology studies, indicate a causal link between fluoride/fluoridation and cancer, genetic damage, neurological impairment, and bone pathology. Of particular concern are recent epidemiology studies linking fluoride exposure to lowered IQ in children." *Letter of July 2, 1997,* from J. William Hirzy, Ph.D. to Jeff Green. The union (now NTEU, Chapter 280) consists of and represents all of the toxicologists, chemists, biologists and other professionals at EPA headquarters, Washington, DC.

• Melatonin, the main pineal gland hormone now thought to act as a 'body clock', is inhibited by fluoride causing early onset of sexual maturation in study animals. The mean age of menstruation for girls in fluoridated test city Newburgh, New York, in 1956, was 5 months earlier than non-fluoridated control city, Kingston. Low melatonin levels have been linked to both breast and prostate cancer. *Caries Research*, Vol. 28, p. 204 1994. *J Am Dent Asso, March* 1956. *Breast Health* Charles Simone, Princeton oncologist.

• In a survey of over 280,000 Massachusetts children, Dartmouth researchers found that where silicofluorides were used to fluoridate water, children w above the danger level of 10 μg/dL. *Dartmouth News*. Office of Public Affairs, Hanover, NH. Aug. 31, 1999.

• Filters and water purifiers do not remove fluoride. Reverse-osmsis or distillation will, but are impractical for showers and bathing. G. Whitford, Intake and Metabolism of Fluoride, Adv Dent Res 8(1):5–14, June, 1994.

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FLUORIDE INFORMATION ON THE WEB (PARTIAL LIST)

www.fluoridation.com
www.fluoridealert.org
www.citizens.org
www.orgsites.com/ny/nyscof
www.garynull.com/issues/fluoride/fluorideactionfile/htm
emporium.turnpike.net/p/pdha/health.htm
www.bruha.com/fluoride
www.fluoride-journal.com
www.zerowasteamerica.org/fluoride.htm
www.penweb.org/issues/fluoride/index.html
www.npwa-freeserve.co.uk (United Kingdom)
www.voice.buz.org/fluoridation/index.html (Ireland)

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STATEMENT OF BARBARA J. BALABAN, SOMERS, NY

*Problem 1.* Studying the environment is difficult.

Suggestion. We need interdisciplinary studies to bring together the various specialists to put their expertise to work on the multi-faceted problem. The Breast Cancer and Environmental Research Act (S. 830) will provide such a framework.

*Problem 2.* We need advocates, scientists and industry to work on these problems.

Suggestion. Re-authorize the National Action Plan on Breast Cancer, which is no longer functioning.

Suggestion. Research funded by the Federal Government should require the participation of consumers in the design and oversight of requests for proposals and protocols, except in the case of those unsuitable, highly scientific, laboratory studies.

*Problem 3.* Why focus on breast cancer rather than all diseases/other diseases?

Suggestion. Because we have laid the groundwork for breast cancer/environment studies we should view breast cancer as a model for studying other diseases. What we learn will be applicable to other illnesses.

*Problem 4.* Definition of clusters. Epidemiologists deny the presence of cancer clusters.

Suggestion. We need a new definition of clusters. The one we use is derived from studies of infectious diseases and not relevant to cancers and other chronic diseases.

*Problem 5.* Cancer is not caused by any single exposure.

Suggestion. We need special emphasis on studying exposures prenatally through young adulthood, when the body's cells are undergoing the most rapid changes and are thought to be most vulnerable to insult.

Suggestion. We need to study chemicals that are not labeled carcinogenic, and to study chemicals in combination, not just individually. It is possible that a non-carcinogenic chemical can become carcinogenic when combined with another chemical.

*Problem 6.* We do not yet understand what environmental components are linked to various diseases.

Suggestion. We need a national Geographic Information System to record environmental conditions and be kept up to date. These can then be accessed by researchers to better study various geographic areas.

*Problem 7.* Retrospective studies are not reliable. They rely on (possibly faulty) memory. Also, many exposures are not able to be detected in the body after a period of time.

Suggestion. Prospective studies should be financed.

*Problem 8.* Lacking specific evidence, what can we do to minimize people's exposures to potentially dangerous environmental factors?

Suggestion. Insofar as is practical, invoke the Precautionary Principle. When we have reason to suspect that a substance might be dangerous, curb its use while further studies are carried out. Chemicals should be proven safe before being allowed to be used, rather than using them until they are proven dangerous.

*Problem 9.* Exposure to electro-magnetic fields are thought to be dangerous.

Suggestion. Schools should incorporate a unit on electro-magnetic fields. Students could be trained to use a gause meter to measure the emfs in their schools and try to reconfigure classroom use to minimize exposure. This would bring immediate benefit to the students as well as providing an educational experience they can apply to other areas of their lives.

*Problem 10.* Radiation is a proven cause of cancer.

Suggestion. Exposure to the medical uses of radiation can be minimized. Authorize a comparative study in several hospitals to devise ways of reducing patient exposure to medical radiation.

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