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JUVENILE DIABETES

HEARING

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE

ONE HUNDRED SIXTH CONGRESS

FIRST SESSION

SPECIAL HEARING

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TUESDAY, JUNE 22, 1999

U.S. SENATE,
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES,
COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:20 a.m., in room SH–216, Hart Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Harkin, Craig, Hollings, Reid, Kohl, and Murray.

Also present: Senators Connie Mack and Strom Thurmond.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

STATEMENTS OF:
HAROLD VARMUS, M.D., DIRECTOR
PHILLIP GORDEN, M.D., DIRECTOR, NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASE

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. The hearing of the appropriation's Subcommittee on Labor, Health, Human Services and Education will proceed.

This morning's hearing is a very unusual one as you have already noted from the presence of so many beautiful young Americans at our hearing which concerns diabetes in significant measure. Juvenile diabetes is a terrible malady which hits Americans of all ages but especially our younger people.

Today's hearing is designed to focus on what has been done on medical research and what should be done and what will be done in the future.

We have an outstanding panel of witnesses today—celebrities Mary Tyler Moore and Tony Bennett and Alan Silvestri are present along with Dr. Harold Varmus and Dr. Phillip Gorden from the National Institutes of Health. And our lead witness will be Senator Strom Thurmond who is opening the Senate at 9:30 in his capacity as President Pro Tempore but he will be joining us soon.

I want to express my regrets at some of the schedule shifts and a little delay here. But today is a very unusual day here for the Senate because at the same time this hearing will proceed, we're having four committees take up the issue of espionage in China and I'm on one of those committees.

We're having the appropriations committee of the Y2K problem. A little later the Sports Antitrust bill which is my bill will have a hearing down the hall and all of that is played against the panorama of the steel worker quota culture vote. And I've just come from a large rally of steel workers adjacent which shows you some of the panorama of problems which confront the Senate on any day.

I want to thank especially Priscilla Mack and Rosanne Dimenicia Hamburger for their help in putting this hearing together and, of course, my colleague Senator Betty Lee Taylor who is the stalwart here.

Just a word or two about the scope of the hearing before yielding to my colleagues for their opening statements.

Diabetes is a chronic disease which significantly impairs the body. Two major types—1, juvenile diabetes starting in childhood or adolescence and, type 2, an adult onset typically affects adults over 40.

Some 16 million Americans suffer from diabetes, 800,000 new cases a year, the 6th leading cause of death, the leading cause of adult onset blindness and a major contributor to kidney disease, heart disease, stroke, nerve disease, and amputations.

On the issue of funding for research, in fiscal year 1999 we had a $449 million appropriation which was a $62 million increase. Some 16 of the National Institutes of Health, where there are 22 institutes, 16 are involved in one way or another with diabetes.

The core problem which we're facing right now is how much money we're going to put up for medical research. The Senate of the United States voted 99 to nothing to double NIH funding over 5 years.

That was the sense of the Senate resolution. But when the time came to put up the hard cash, it wasn't there. Two years ago we had a negative vote of 63 to 37 against a significant addition. Last year it was 57 to 42 against a big addition and this year the vote was 52 to 48 against a big addition.

But the members of this subcommittee took the lead. Senator Harkin, a very strong fighter—he'll be here I think shortly, my ranking member. We took the lead with a very sharp pencil and found $2 billion to increase NIH funding last year and that means a lot for diabetes and juvenile diabetes.

And we're working now to see if we can't find the money again. It is difficult because of a budget agreement where we have caps and it is difficult because the health issue, the health research competes with education, workers safety and many other very, very important programs. But the kind of a turn out we have here today is a very strong signal to the Senate of the United States and the Congress of the United States that more has to be done.

My own view is that every single research grant application which is meritorious ought to be funded by the Federal Government, every single one.

We have a national budget of $1.7 trillion. And if we set our priorities right, there's no reason why the $15.6 billion cannot be increased this year by $2 billion and increased in the future.

Some say we can't afford it and I say we cannot afford it. But that's where the issue lies. And your support and your presence here today will make the difference.

We're going to proceed in our early bird rule in order of arrival. So I'll turn now to our distinguished Senator from Idaho, Senator Larry Craig, for an opening statement.

OPENING STATEMENT OF SENATOR LARRY CRAIG

Senator CRAIG. Mr. Chairman, thank you very much. You've recognized so many of the celebrities who have lent their name and their energy to this important cause.

But to all of you young people here today, let me visit with you for a few moments. You've been sitting here for quite a time and I hope that you understand why you're here.

It is extremely valuable for us who work in government on your behalf to put a face to what we do, to really understand why we do certain things. We have an important job but that job is to allocate America's resources for important reasons. And, as the chairman just said, there are a good many choices and there are a lot of very necessary causes.

But when all of you come and you are here and you visit with us or your Senators, you put a face to the need. That helps us a great deal.

In my State of Idaho a beautiful young lady I met this morning, Emily—hi, Emily. She has just put a face to the need in Idaho. And there are thousands of Emilies across the country and there are hundreds in Idaho who need our help because we can offer the resources in a way that no other entity in our country can and to the areas where the research can really mean something to make you all healthy or more importantly to allow you to live normal lives and that's why this hearing is here today and why we're here.

I'm pleased to be one of those Senators who is allowed to participate along with all of you in the first Juvenile Diabetes Foundation International Children's Congress. Because you're the first, that means that next year and the next year others like you will come and you need to continue to come to visit with your members of Congress to tell them how important those appropriations are to do the research, to do the funding, to allow you to live normal and healthy lives.

So thank you very much for being with us this morning and we thank all of you, the celebrities and the celebrities for lending your names and your energy to this important cause.

Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Craig. Senator Murray.

OPENING STATEMENT OF SENATOR PATTY MURRAY

Senator MURRAY. Thank you very much, Mr. Chairman, for having this hearing today. Welcome to all of you. It is great to have you with us this morning.

I want to thank the chairman for having this extremely important hearing about juvenile diabetes and its affect and join Senator Craig in saying having all of you here this morning and putting a face to this issue really does make a difference. I want to thank Nancy Stockton—Nancy, raise your hand—who is here with me from Washington State.

Nancy was diagnosed when she was 2 and she is now, I believe, 13 and has come all the way across the country from Washington State to Washington, D.C., and we're delighted to have you here. Thank you for the work you're doing.

So many families are touched by juvenile diabetes. I knew the word but I didn't know the meaning until my own niece was diagnosed several years ago as a young teenager. She has struggled throughout to gain control of her disease and I am so proud of the fact that Morgan Johns graduated from high school just a week ago after going through an awful lot in her life and helping me to understand what the diagnosis of diabetes means to hundreds and hundreds of young people like her.

So I am committed to this cause and I agree with the chairman that research is absolutely necessary. We need to find out all we can to control this disease but we also have to make sure that access is there. If we find a cure and people are denied access because their insurance won't pay for it, all the research in the world won't make a difference.

So I hope, Mr. Chairman, that we can deal with the patient bill of rights as well so that we can find a cure and make sure that all young kids have access to the care that they need.

Senator SPECTER. Thank you, Senator Murray. Senator Hollings.

OPENING STATEMENT OF SENATOR ERNEST F. HOLLINGS

Senator HOLLINGS. Thank you, Mr. Chairman.

Back in 1954 Bobby Kennedy, Ham Richardson and myself were 3 of the 10 men of the year. Ham Richardson was the tennis star, captain of the Davis Cup team. He suffered from juvenile diabetes. I became interested with my friendship with him and under the leadership of Mary Tyler Moore we launched the Institute of Diabetes at the National Institutes of Health and it has done a magnificent job and we've got to keep it going.

We're talking here, as the chairman has noted, not merely of just saving lives but saving money. We find from studies every dollar we invest in women, infants and children's feeding we save $3. Head start, $4.5. For Title I for the disadvantaged in education, $6.25. And for every dollar we invest in the National Institutes of Health we save $13.50.

So let's get about saving some money here this morning. Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Hollings.

SUMMARY STATEMENT OF DR. HAROLD VARMUS

We're going to proceed now with our second panel, Dr. Harold Varmus and Dr. Phillip Gorden. Senator Thurmond will be joining us in a few minutes. If we may, we'll interrupt the testimony to hear from Senator Thurmond at that time.

Our lead witness, Dr. Harold Varmus, has been the director of the National Institutes of Health since November 1993. At the University of California at San Francisco he earned the Nobel Prize for his work on the causative link between genes and cancer. He is a graduate of Amherst College, Harvard University and the Columbia Medical School.

Dr. Varmus, we thank you for your outstanding work and we welcome you here today and the floor is yours.

Dr. VARMUS. Thank you, Senator Specter.

Mr. Chairman, I appreciate your holding this hearing and your unstinting leadership to increase the budget for medical research in this country to benefit not only these delightful children who are sitting in front of us but children and adults with many other disorders as well.

As you have pointed out, the NIH through 16 of our institutes and centers supports research on diabetes mellitus and in a moment I will turn the microphone over to Dr. Phil Gorden, the director of the National Institutes of Diabetes and Digestive and Kidney Diseases, who will present the majority of the testimony.

As you know, research is proceeding at a great pace on many fronts and much of that is due to the very generous increases we've received from your committee last year in particular and previous years in addition. We are grateful to you for your support. That's the way in which our work can be most rapidly advanced toward our efforts to understand and to control and to ultimately eradicate this and many other disorders.

I also want to express my appreciation to the Juvenile Diabetes Foundation for helping to organize this hearing and for working with the NIH in such a collaborative and collegial fashion to assist our efforts to make progress against diabetes mellitus. Thank you.

Senator SPECTER. Thank you very much, Dr. Varmus.

SUMMARY STATEMENT OF DR. PHILLIP GORDEN

We turn now to Dr. Phillip Gorden who became director of the National Institute of Diabetes and Digestive and Kidney Disease at the National Institutes of Health in 1986, and had a very distinguished career there. He began in 1966 after earning his BA and MD at Vanderbilt University.

Thank you for joining us, Dr. Gorden, and we look forward to your testimony.

Dr. GORDEN. Thank you very much, Mr. Chairman. I appreciate very much the opportunity.

Mr. Chairman and members of the committee, consistent with the focus of today's hearing and the very special audience here, I will address my testimony towards diabetes in children, who in many ways suffer most from the disease.

Children with type one diabetes must have daily insulin injections to survive. They and their families must monitor blood glucose levels and adjust their diet and activities throughout the day. Although the value of blood glucose control is clear, this therapy is extremely difficult and must be made better and easier for everyone.

PACE OF RESEARCH ADVANCES

I'd like to emphasize several points that are central to present and future efforts to prevent and treat diabetes. We're witnessing rapid advances in genetics that underlie our effort to find the cause of many diseases, including diabetes. New discoveries of ways to manipulate the immune system have important implications for diabetes prevention and treatment. Key clinical advances have

shown how control of blood pressure and serum lipids and cholesterol is important for the comprehensive care of diabetic patients. The Diabetes Control and Complication Trial demonstrated that complications of diabetes affecting the eye, kidney and nerves can be ameliorated or prevented by careful blood glucose control.

These results have been extended and added to by recent studies using laser photocoagulation to treat diabetic eye disease and ACE inhibitors to treat diabetic kidney disease. Together, these advances represent major steps towards our continued quest for a cure. However, they further emphasize the urgent and compelling need to develop better technologies to both manage blood glucose levels and to treat complications.

We have the tools to identify individuals at high risk for type 1 diabetes and have demonstrated that diabetes can actually be prevented in animal models. These strategies are now being applied in a major, multi-center clinical trial designed to delay the onset of type 1 diabetes.

NEW RESEARCH INITIATIVES

We have sought the best advice possible from the scientific and voluntary diabetes community. We've accelerated and enhanced our efforts based on recommendations from the special trans-NIH workshop, which has been complemented by the recently completed Strategic Plan of the Diabetes Research Working Group. We have already initiated many recommendations and will continue to build upon them in the future.

We're exploiting the fruits of biotechnology with attention especially given to treatment and prevention. Initiatives have been launched to develop therapies to achieve normal glucose levels and to understand the mechanisms by which high glucose levels result in the late complications of diabetes.

We are embarking on a new and exciting initiative to restore insulin—producing capacity through islet cell transplantation. This research is being propelled by a remarkable series of advances.

Recent studies in primates have shown that both insulin-producing islet cells and kidneys can be transplanted using a highly selective method to control for immune rejection of the transplant.

Paralleling this initiative is a major new collaborative effort on immune tolerance within our intramural program. This effort is complemented by efforts across NIH from NIDDK and NIAID, along with the JDF, to broaden this effort into a network of major collaborative institutions around the country.

In closing, I would like to mention the productive research collaboration between the NIH and voluntary health organizations such as the Juvenile Diabetes Foundation. These partnerships span the gamut of basic research and clinical application across many institutes and centers.

Mr. Chairman, I've tried to emphasize that we at the NIH truly understand the heavy burden that diabetes places on families. At the same time, I want to share my feeling of great encouragement and hope because of the pace at which diabetes research is moving.

I believe our strong national research programs hold the key to curing this disease for all children and their families.

PREPARED STATEMENT

Mr. Chairman, the bottom line of my statement is that our work has made the health of the children in this room better. Our goal in the future is to continue that healthy direction and also to make their lives easier. I will be happy to answer any questions you may have.

Senator SPECTER. Thank you very much, Dr. Gorden.

[The statement follows:]

PREPARED STATEMENT OF DR. PHILLIP GORDEN

Mr. Chairman, I am Phillip Gorden, the Director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which has lead responsibility for diabetes research at the National Institutes of Health (NIH), within the Department of Health and Human Services. I appreciate the opportunity to testify before this subcommittee about NIH research to understand, treat, prevent, and ultimately cure diabetes.

In both human and economic terms, diabetes is an extremely costly disease. It affects an estimated 16 million Americans, including both genders, the young and the old, all races and ethnic groups, the rich and the poor. Consistent with the focus of today's hearing, I will address my testimony toward diabetes in children, who, in many ways, suffer most from the disease. They have the disease from an early age and must endure lifelong treatment. They must carefully adjust what they eat and everything they do—from schoolwork to sports—in order to manage their disease. Even with a continuous struggle to follow such rigorous regimens, they may still develop serious, long-term complications of diabetes.

Children with type 1 diabetes must have daily insulin injections to survive. They and their families must monitor their blood glucose levels throughout the day. While the value of maintaining blood glucose control is clear, this therapy is extremely difficult, and must be made better and easier for everyone.

Based on case reports and clinic-based studies, new information is emerging about children with type 2 diabetes. It appears that these children are not dependent upon insulin injections; however, their cells and tissues are resistant to insulin. Some may require insulin to maintain control of their blood glucose. The number of children with type 2 diabetes is increasing in our population and the age of onset is now occurring earlier. This is a special problem in racial and ethnic minority populations, who suffer disproportionately from diabetes, as well as from obesity—a major risk factor for type 2 diabetes. In most cases, type 2 diabetes in children appears as a complex, polygenic disease similar to that seen in adults. The NIDDK will be bringing together pediatric endocrinologists from across the United States to share information on the emerging problem of type 2 diabetes in children.

HIGHLIGHTS OF NIH-WIDE RESEARCH EFFORTS AND STRATEGIES

I would like to emphasize several points that are central to present and future efforts to treat diabetes effectively and ultimately cure it. The many institutes and centers of the NIH have a broad and multifaceted research agenda to treat, prevent and cure diabetes. The trans-NIH diabetes effort has led to major clinical advances in diabetes, and clues in the search for a real cure. We are witnessing rapid advances in genetics and genomics that underlie our goal to find and eliminate the cause of many diseases, including diabetes. Discoveries of mechanisms to manipulate the immune system have significant implications for diabetes prevention and treatment. Major new understandings of cell communication are critical to diabetes. Key advances in clinical research are showing how the control of blood pressure and serum cholesterol, as well as other lipids, is important in the comprehensive care of patients with diabetes.

The Diabetes Control and Complications Trial (DCCT) demonstrated that the complications of diabetes affecting the eye, kidney and nerves can be ameliorated or prevented. These results have been extended by the clinical progress achieved in treating diabetic eye disease with photocoagulation, and the use of drugs—such as ACE inhibitors—for the kidney disease of diabetes. Together, these advances represent major steps forward in our continued quest for a cure. However, they also further emphasize the compelling need to develop better technologies both to manage blood glucose levels and to treat complications more effectively and directly.

In the past decade, investigators supported by the NIDDK, the National Institute of Child Health and Human Development (NICHD), and the National Institute of

Allergy and Infectious Diseases (NIAID) have been able to establish immune, metabolic, and genetic screening tests to identify individuals at high risk for developing type 1 diabetes. In animal models and in preliminary human trials, researchers have also shown that low-dose insulin therapy may prevent or delay the onset of the clinical manifestation of type 1 diabetes. Thus, scientists can identify individuals at high risk for type 1 diabetes and intervene with a safe and possibly effective therapy. These tools are now being applied in a major multi-center clinical trial cosponsored by the NIDDK, NIAID, NICHD, the Juvenile Diabetes Foundation International (JDF) and the American Diabetes Association to prevent or delay the onset of type 1 diabetes. This trial is called the Diabetes Prevention Trial-1, or DPT–1. Another clinical trial, "Prevention of Cardiovascular Disease in Diabetes," will generate knowledge that will be important for preventing heart and vascular disease in early onset type 1, as well as type 2 patients. The National Heart, Lung, and Blood Institute (NHLBI) is sponsoring this trial, in conjunction with the NIDDK. We at the NIH join the children and families touched by diabetes in a shared effort to support vigorous, promising research aimed at the prevention, treatment and cure of this disease and have been pleased to collaborate with voluntary organizations, such as the JDF, in fruitful research partnerships.

To guide our diabetes research programs, we have sought the best advice possible from the scientific and voluntary diabetes community. For example, we have accelerated and enhanced our efforts based on a special trans-NIH workshop, entitled "Diabetes Mellitus: Challenges and Opportunities"—complemented by the Strategic Plan of the Diabetes Research Working Group. We have already initiated many recommendations from these processes and will continue to build upon them in the future. I am pleased to share with you today some of our most recent efforts, which relate to diabetes in children. A number of these have been undertaken in partnership with other NIH Institutes, other agencies, and voluntary organizations.

SPECIAL INITIATIVE ON TYPE 1 DIABETES

I am pleased to report progress on a special, NIH-wide initiative for innovative, clinically relevant and multidisciplinary research aimed at the treatment and cure of type 1 diabetes. This initiative is relevant to all of the scientific opportunities in type 1 diabetes research today, but especially to the development of more effective therapies, which can be easily administered and followed. Through this initiative, we are seeking the best research talent from diverse fields, the most promising research ideas, and the most technologically advanced research tools for combating type 1 diabetes. We are exploiting the fruits of the biotechnology revolution, with special attention to clinical issues.

Initiatives have been launched to develop therapies to achieve normal glucose levels in people with type 1 diabetes and to develop improved glucose sensors for regulating blood glucose. They also include expanded programs to understand the mechanisms by which high glucose levels result in the late complications of diabetes; to apply this information to the development of ways to prevent, limit or reverse complications associated with diabetes; and to understand the role of factors important in disease development.

This year special funds for type 1 diabetes research appropriated in the Balanced Budget Act of 1997 are being used to focus on the mechanisms by which the disease results in painful and disabling neuropathies and other neurological complications; identification of stem cells and factors that regulate development and differentiation of pancreatic beta cells through the establishment of a functional genomics resource in diabetes; and pilot studies for new therapies for type 1 diabetes and its complications.

INITIATIVE ON CELL-BASED THERAPIES FOR TYPE 1 DIABETES

We are embarking on a new and exciting initiative to restore insulin-producing capacity through transplantation of the whole pancreas, or of islets from the pancreas. This research is being propelled by an impressive series of advances. Recent studies in primates have shown that both insulin-producing islet cells and kidneys can be transplanted using a highly selective method to control for immune rejection of the transplant. This new technology involves what is referred to as "blockade of the co-stimulatory pathway." It allows for a selective form of immune tolerance and does not require suppression of the overall immune system, as is required by conventional therapy for organ transplantation.

Paralleling this initiative is a major, new, collaborative effort on immune tolerance within the intramural program of NIH. The research partnership involves the NIDDK, the Warren Grant Magnuson Clinical Center, the Department of Defense, and the Diabetes Research Institute of the University of Miami. The strategy under

study is relevant to both the treatment of type 1 diabetes and kidney transplantation. Furthermore, there is a major, additional joint effort involving NIDDK, NIAID and the JDF to broaden this program into a network of collaborating institutions.

INITIATIVE TO ENHANCE MODALITIES OF TREATMENT

We are working diligently to develop a wide range of new and more effective therapies for avoiding the consequences of low blood glucose levels and for improving the treatment of diabetes. For example, the NICHD is supporting two comprehensive studies in adolescents on how low blood glucose levels affect learning skills and how the undesirable effects of multiple daily insulin injections affect compliance. We are also pioneering the development of glucose sensors and mechanical systems to facilitate insulin administration and thus ease the burden of this therapy for children and adults who are insulin-dependent.

One exciting recent advance may well have important therapeutic implications with respect to the immune system's attack on its own insulin-producing cells in type 1 diabetes. Researchers have shown that a protein called GAD, which is expressed by beta cells, controls the development of diabetes in an animal model of human type 1 diabetes. The demonstration that this protein initiates autoimmune diabetes builds on an earlier NIH-supported advance, which showed that cells specifically reactive against GAD directly produced beta cell injury in a mouse model. This avenue of research could have important consequences for the development of new therapies to prevent type 1 diabetes, provided these findings can be extended to human disease.

We also hope that new clinical advances will emerge from other NIH-supported investigations of pancreas and islet transplantation in animals. This work includes studies on ways to regenerate the pancreas; to develop methods to enable the protection and survival of implanted insulin-producing cells; and to discover innovative approaches to prevent graft rejection by induction of immune tolerance.

INITIATIVE ON PREVENTION AND TREATMENT OF COMPLICATIONS

Multiple NIH institutes are participating in a major initiative to combat the eye, nerve, kidney and vascular system complications of diabetes. These efforts include the search for genes that make individuals with diabetes particularly susceptible to developing one or more of these complications. Also featured is a new emphasis on understanding and treating diabetic nerve disease, and the inauguration of a major clinical trial aimed at reducing the cardiovascular complications of diabetes. These research areas have been identified as having high priority by the Diabetes Research Working Group.

INITIATIVE FOR DIABETES CLINICAL TRIAL NETWORK

One of the recommendations of the Diabetes Research Working Group is to establish a Diabetes TrialNet to foster clinical studies. In response, the NIDDK recently provided administrative extensions to the centers involved in the ongoing DPT–1, while a task force considers approaches for establishing such a network for future studies of prevention and treatment of type 1 diabetes. A component of this initiative will probably include support for the infrastructure for clinical researchers and nurses to conduct research; a central data coordinating center; central laboratories, mechanisms to review and prioritize research projects; and, databases of research volunteers, investigators and projects. Such a diabetes clinical research network would provide the necessary infrastructure for the efficient, rapid evaluation of promising new therapeutic approaches.

RESEARCH PARTNERSHIPS

In closing, I would like to mention just two examples of the many beneficial research collaborations between the NIH and voluntary health organizations, such as the JDF. The NIDDK–JDF centers of excellence program represents a productive research partnership and a model that has been adapted by several other NIH institutes. Also, the JDF and the NICHD are now co-funding a study of 12,000 infants who are at various levels of genetic risk for type 1 diabetes in order to detect the earliest evidence of immune attack on the insulin producing cells of the pancreas. These examples reflect the strong relationships the NIH and voluntary health organizations have formed to accelerate research progress.

Mr. Chairman, I am grateful for the opportunity to share with you recent and exciting NIH efforts focusing on diabetes in children. I have tried to emphasize today that we at the NIH truly understand the great burden diabetes places on families.

At the same time, I want to share my feelings of great encouragement and hope because of the pace at which diabetes research is moving. I believe that our strong national research programs hold the essential key to curing this disease for the benefit of all children and their families. I am pleased to answer any questions you may have.

STEM CELLS

Senator SPECTER. I begin with a question which is very sensitive but very important and that is the issue of stem cells as they may apply to a cure of juvenile diabetes.

At a previous hearing by this subcommittee, Dr. Douglas Melton, chairman of the Department of Molecular and Cellular Biology at Harvard University and a father of a 7-year-old diabetic son testified that: "the work with mouse stem cells is so encouraging that one is within a few years of being able to direct those cells to become pancreatic cells. He reiterated the importance of stem cell research in finding a cure for diabetes."

I bring this subject up because there is currently a prohibition for NIH funding on embryos. There has been a procedure adopted where private funds are used to extract stem cells from embryos and then NIH through the Council of Health and Human Services has said that it is appropriate under existing law to use Federal funding on the stem cells which have been extracted.

Now this is very similar to a problem which we had with fetal tissue where there was a concern that fetal tissue might cause abortions as opposed to the practice of using fetal tissue after the abortion had been completed so that the use of fetal tissue was not the cause of an abortion. Similarly these embryos are discarded. They are not to be used for in vitro fertilization or to create life.

Now the medical question that I have for you is a two-part question. How important are stem cells in the research to find a cure for diabetes, juvenile diabetes and how close are we with adequate funding? This is a question which we always get when we want to add $2 billion. What's the result?

I know scientifically it is hard to quantify. But we had testimony at an earlier hearing on Parkinson that we were within 5 years, 10 years at the outside of curing Parkinson. Now to what extent can you experts shed light on the question as to how close we are to curing diabetes, juvenile diabetes and to what extent is this stem cell research integral to that result?

Dr. VARMUS. Let me comment briefly, Mr. Chairman. I agree with Professor Melton's opinion. Dr. Melton is in the audience today and is a distinguished authority in this field and I would agree with his opinion that stem cell research is one of the most important leads we have to approaching a cure for juvenile diabetes.

As you heard on previous occasions, there is some difference of opinion about how long it would take to get to any end point, like, the cure of a certain disease.

I think it's fair to say that we should expect, if investigators are allowed to use Federal funds for the pursuit of stem cell research, that within the next 5 or 10 years we would at least learn how to differentiate those cells to make insulin producing cells. How easy it will be then to use those cells in transplantation experiments to

effect the amelioration of the cure of the disease that we all seek is, I think, difficult to estimate.

Senator SPECTER. While my yellow light is still on, are the stem cells very important to finding a cure for diabetes, juvenile diabetes?

Dr. VARMUS. Yes, they are very important. They are one of the several important leads including the efforts to control immune rejection that Dr. Gorden mentioned and a number of other possibilities that we haven't discussed here today. But I would say stem cells are among the three or four most promising leads we have toward finding an ultimate solution to juvenile diabetes.

OPENING STATEMENT OF SENATOR STROM THURMOND

Senator SPECTER. We've been joined by our distinguished President Pro Tempore Senator Strom Thurmond. Senator Thurmond, if you would come forward to the witness table, we will swear you in and hear your testimony.

Dr. VARMUS. Should we retreat, Senator, or should we just stay where we are?

Senator SPECTER. You may stay there.

Senator THURMOND. Thank you very much.

Senator SPECTER. For those of you who don't know, Senator Thurmond is the longest serving U.S. Senator. He opened up the Senate this morning as is the job of the President Pro Tempore in the absence of the Vice President who presides over the Senate constitutionally.

Senator Thurmond has had an extraordinary career as a candidate for President and Governor of South Carolina, a U.S. Senator for 45 years, chairman of the Judiciary Committee and chairman of the Armed Services Committee, was a leader in our battle to turn the tide on the use of fetal tissue for medical research.

Senator Thurmond, we welcome you here especially and look forward to your testimony.

Senator THURMOND. Thank you very much. I want to congratulate you for your fine work in the Senate.

Senator SPECTER. Thank you very much.

Senator THURMOND. Mr. Chairman, I am pleased to testify today in support of funding increases in the fight against diabetes. Diabetes is a chronic and often fatal disease affecting more than 16 million Americans. Billions of dollars is spent annually to care for those afflicted with this disease.

It is the sixth leading cause of death in the United States and a major cause of kidney disease, heart disease, amputation and adult blindness. Scientists tell us that medical research hold a cure for diabetes yet the problem persists.

Recent evidence indicates that we are on the verge of uncovering new prevention, screening and treatment procedures that will dramatically improve diabetes therapy and lead to a cure in the very near future.

I believe that at this critical juncture in the fight to end diabetes, it is imperative that we provide additional funding to our scientists who are on the verge of finding a cure. Every year over $100 billion is spent caring for the 16 million citizens suffering from the complications of this devastating disease.

A report released in February by the congressionally-mandated diabetes research working group has called upon the National Institutes of Health to substantially expand their support for diabetes research and has identified specific research recommendations as part of a new national plan to find a cure.

The report calls for a $827 billion investment for diabetes research in the National Institutes of Health in the fiscal year 2000. In light of the emotional and financial burden that diabetes brings to our country, I believe that this funding increase represents a prudent, invaluable investment in our nation's future.

PREPARED STATEMENT

I urge this committee to support this appropriation request so that we can end diabetes and end the pain that this disease brings to its sufferers and loved ones.

I wish to thank you, Mr. Chairman, and the members of the committee for your consideration.

[The statement follows:]

PREPARED STATEMENT OF SENATOR STROM THURMOND

Mr. Chairman, I am pleased to testify today in support of funding increases in the fight against Diabetes. Diabetes is a chronic, and often fatal, disease affecting more than 16 million Americans. Billions of dollars are spent annually to care for those afflicted by this disease. It is the sixth leading cause of death in the United States and a major cause of kidney disease, heart disease, amputation, and adult blindness. Scientists tell us that medical research holds a cure for diabetes, yet the problem persists.

Recent evidence indicates that we are on the verge of uncovering new prevention, screening and treatment procedures that will dramatically improve diabetes therapy and lead to a cure in the very near future. I believe that at this critical juncture in the fight to end diabetes, it is imperative that we provide additional funding to our scientists who are on the verge of finding a cure. Every year, over $100 billion is spent caring for the 16 million citizens suffering with the complications of this devastating disease.

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Senator SPECTER. Senator Thurmond, I think it might be of some interest to everyone and not intrusive to bring up the subject that you've had the problem with juvenile diabetes in your own family. So you've had personal experience with the terrible problem that is created here.

Senator THURMOND. I have a daughter.

Senator SPECTER. I might say for the record that when the issue came up about the use of fetal tissue that Senator Thurmond was a very strong advocate and really turned the tide on a favorable vote in the U.S. Senate and we thank you for your great contributions to America, Senator Thurmond.

Senator THURMOND. Thank you for your kind words.

Senator SPECTER. I know you have other duties. So we'll proceed now with the round of questioning for the doctors.

Senator THURMOND. Thank you very much.
Senator SPECTER. Thank you, Senator Thurmond.

OPENING STATEMENT OF SENATOR TOM HARKIN

I turn now to our distinguished ranking member, Senator Harkin.

Senator HARKIN. Thank you very much, Mr. Chairman. I apologize to you and to all who are here for being a bit late this morning. I just want to congratulate you, Mr. Chairman, on having this hearing and bringing us all together on this very important issue.

We're joined by a lot of distinguished guests. Perhaps the most distinguished of whom is Ms. Tyler Joe Carston who is here from Blairstown, Iowa. She is 11½ years old and has struggled with this juvenile diabetes since she's been 4 years old.

She wrote me a letter recently describing what it's been like for her living with diabetes. She said in her letter and I quote:

"People with diabetes never get a day off from it, even holidays. Diabetes is every single second of every single minute of every single hour of every single day of every year of your life."

But I want all of you to know that we are working hard. We are trying to find the resources necessary to fund the necessary research. I can assure you that Dr. Varmus and Dr. Gorden and their colleagues at the National Institutes of Health are doing all that they can to hasten the day when we have an intervention and a cure for juvenile diabetes.

I want to welcome also Mary Tyler Moore. Our visit was cut short a couple of weeks ago because of another meeting that we had because we were trying to get more allocations for our subcommittee to get the money to fight juvenile diabetes and a host of other illnesses that plague us. But we still have those battles yet to fight.

I have another quote here from the letter from Tyler Carston. She said, and I quote, "when we all die, we won't need money. So why can't we find a way to use it now and give people a chance to live."

I'll tell you, that's a lot of wisdom for an 11½-year-old. I tell you we can use that around here.

Last, on this issue of stem cell research. I recommend to all the report issued by the bioethics committee headed by Dr. Harold Shapiro of Princeton University and encourage all to read that portion in which they clearly outline an ethical way of approaching stem cell research. I believe we are doing it now. And I think to cut this short would be to doom, I think, a lot of people who suffer from diabetes and to put off that day when we can find an intervention and a cure.

I just believe that with the confluence—I've said this many times—of gene therapy and stem cell therapy if we can really put the money into this research, then Dr. Varmus' predictions that within the next decade of having some major breakthroughs, is more than a possibility. I think it's a hard reality.

This is not the time to back off or to back down or to short change the research we need in this country. We are on the verge of making great breakthroughs and I believe that stem cell therapy really holds one of the keys to it.

Again, I'm hopeful, Mr. Chairman, that we can find the money in our appropriations process or our allocation. I know you're working hard on that and your staff is working hard. Now is the time to make that final big effort to double NIH funding and to get the necessary money that we need to progress in stem cell and gene therapy research.

To all of you young people who are here, I really do believe that 10 years from now we're going to have a good intervention for this juvenile diabetes.

Thank you very much, Mr. Chairman.

Senator SPECTER. Thank you. We've been joined by Senator Reid and Senator Mack and we will be hearing from them as the round of questions proceed. We'll go in accordance with our early bird to Senator Craig.

Senator CRAIG. Mr. Chairman, for the sake of time and the anxiousness of young people, Doctors, I thank you for your testimony and your work. And I'll submit questions for the record.

Senator SPECTER. Thank you very much, Senator Craig. Senator Hollings.

Senator HOLLINGS. Dr. Varmus, the private effort of stem cell application to diabetes, can you describe that for the committee and its progress, its result, its promise?

Dr. VARMUS. Senator, as you know, the research that has been done on so-called pluripotent stem cells derived from embryos has been carried out with money from the private sector largely in academic labs with money from the private sector.

Because the money comes from the private sector, we actually don't know a great deal about what is specifically being done with cells but those cells using private resources. No doubt there are biotech companies that are pursuing some of the leads we've described here.

But it's my conviction and the conviction of many of my colleagues that this work is best conducted in the open with public money by investigators who are traditionally supported by the NIH. In conjunction with the ruling that Senator Specter mentioned we intend to begin funding that research as soon as we have our guidelines fully in place and they have been subjected to public debate.

Senator HOLLINGS. It's legal for this approach of stem cells. It's just a lack of money. Is that your situation?

Dr. VARMUS. The situation, Senator, is the following. There is an amendment in our appropriation bill that forbids the use of Federal funds from this committee for the funding of research that, with the embryo itself, that would lead to the derivative of the cells. Our council at HHS has ruled that it's legal for us to use those funds to support research with the cells themselves once they've been derived.

We intend to initiate such funding but we are in the process of setting our guidelines in place. They've been put in the Federal Register for public comment. We believe it's also very important because of the sensitivity of this issue to have the full public debate and allow everyone who has views on the matter of Federal funding for this research to have their views expressed.

I think we also have to hear very loud and clear from people such as those sitting in front of us who have very much to gain from this research. There are two sides to this issue and there are ethical concerns that have to be weighed in a very judicial manner.

Senator HOLLINGS. Thank you, Mr. Chairman.

OPENING STATEMENT OF SENATOR HARRY REID

Senator SPECTER. Thank you very much, Senator Hollings. We've been joined by Senator Reid of Nevada. Senator Reid.

Senator REID. Mr Chairman, thank you very much. I ask unanimous consent that a statement that I have prepared be made part of the record.

Senator SPECTER. Without objection, it will be included in the record.

Senator REID. Mr. Chairman, I'm very happy today to be here because I have three special Nevedans, 10-year-old Mollie Singer who we're going to hear from later today and her twin sister Jackie who accompanied her here. Also, from Reno, Nevada, in the northern part of the state we have Anna Zucker and her family. They traveled all the way here from Reno.

Doctors Gorden and Varmus, I have the same question I want to ask both of you and if you'd both respond, I would appreciate it.

PAST AND FUTURE PROGRESS IN DIABETES

First of all, what progress has been made in the last decade with juvenile diabetes and if you lop over into diabetes generally that would be acceptable? Also, what research is now in progress that is worth talking about to us and what do you expect in the next decade regarding the battle against juvenile diabetes and diabetes generally?

Dr. GORDEN. I think that a very brief summary would say that we understand one of the primary pathologic features, that is, the elevation of the blood sugar.

Senator REID. But tell us what's happened in the last 10 years. Will you do that?

Dr. GORDEN. We understand that careful clinical studies that control blood glucose levels have demonstrated marked benefits.

Senator REID. What is the marked benefits?

Dr. GORDEN. Marked benefits are a reduction in the complications of the disease, which have to do with the vascular system, the eyes, the kidneys and the nerves. We've seen that happen. We know it can happen.

We've had two major clinical trials in both type 1 and type 2 diabetes that prove that unequivocally. Now, the goal is to do two things: To prevent that blood sugar rise, which is part of the pathology in terms of causing the complications, and to find easier ways to ameliorate that rise if it occurs.

We are actually making considerable progress. Today I want to emphasize one of the newest areas of research. That is the area of immune tolerance, which gives us both the opportunity for prevention but, perhaps more directly now, the opportunity for new forms of treatment.

So, I think that—as we balance this off against the progress of biologic science in general and how we're doing clinically—we're

taking advantage of all the new technologies that are available for us.

I think children with diabetes are truly healthier, but we must make life easier for them in the future to maintain that good health. I think we're on the verge of that progress and we really have the machinery to achieve it.

Senator REID. Ten years from now, where do you think we'll be?

Dr. GORDEN. I think that 10 years from now we will clearly have a means to both prevent and treat hyperglycemia. I hope that we will understand a variety of causes by that time. We have reason to believe that there may be a multiplicity of causes for diabetes.

I hope and I believe that we will begin to make an important inroad into understanding those causes. Once we do that, we can apply specific therapies for each different form of this disease, whether there be one or a hundred.

The biotechnology revolution, bio-pharmacology, pharmacogenetics—all of these fields—are aiming directly at capitalizing on this tremendous science and increasing the specificity by which we can prevent and treat diseases like diabetes. I don't think any disease has more promise for both treatment and prevention than diabetes as we see it today.

Senator REID. Dr. Varmus.

Dr. VARMUS. I agree with my colleague about the various clinical advances that he's described. Let me just say one word about what I see as the vista in diabetes research. This vista is largely created by the investment that's been made very broadly across many fields of medical research and biology.

First, through the work on the human genome are coming to grips with the actual genetic determinants of diabetes that afflict all the children in this room and virtually everyone with diabetes. Within the next 5 years or so, we're going to know which genes contribute to the development of both type 1 and type 2 diabetes.

Second, efforts to understand the immune system have changed our perception of the bodily ingredients that both cause type 1 diabetes and allow us to treat it with transplants and fetal cell or embryonic cell therapy.

Third, approaches to our understanding of the biology of the cell—largely through studies of cancer—have given us a very clear picture of how insulin transmits its message to a cell. This knowledge has generated a number of important targets for developing new drugs for the treatment of both type 1 and type 2 diabetes. I believe these targets will result in a broadened set of drugs for the treatment of both types diabetes over the next 10 years.

Senator REID. Finally, Mr. Chairman, in all these hearings where we're dealing with a specific disease, as we are here, the side effects in a positive vein are numerous, are they not? You indicated that studying cancer cells, you've learned a lot about diabetes. Studying diabetes, you're going to learn a lot about other disease, is that not true?

Dr. VARMUS. Yes. We believe that, in general, when we talk about disease-specific research, that's important. But we know that pursuing promising research leads has benefits that extend broadly in both directions.

Senator SPECTER. Thank you, Senator Reid.

OPENING STATEMENT OF SENATOR CONNIE MACK

Senator SPECTER. We're joined by Senator Mack. He used to be a member of the committee, a leader in research generally and cancer research, author of the Senate resolution to double NIH funding over 5 years.

Senator Mack, we would be pleased to accord you a round of questioning or comments.

Senator MACK. Thank you, Mr. Chairman, for the opportunity and I will be brief. And I just want to express my appreciation to you and to Senator Harkin and the committee for holding this hearing and say to the families, to moms and dads and the youngsters, thank you for being here.

I will say to you that we promise to remember you.

To Mary Tyler Moore, thank you for being the voice that has spoken to our hearts and hopefully it will open our wallets as well.

We have begun the effort to double the investment at NIH and I just want to say to both Senator Specter and to Senator Harkin that all of us appreciate the effort that you've been making even before the concept or the idea of doubling the investment. The two of you have worked together regardless of who has been chairman and who has been the ranking member. The two of you have worked together to try to see that the resources that are necessary are put into the fight against disease.

My wife Priscilla and I have been engaged in the fight against cancer. But I think what each of us experiences, regardless of what the disease is, is the impact on our loved ones. And I think that all of us, again regardless of what the disease is, recognize that we have come into a new age, if you will, an age of knowledge, knowledge about the specifics that affect the individual diseases.

Most of us believe that by putting more money into the effort, what we're doing is shortening the time when we will eventually find either a cure or some way to modify the effect of the disease on those that we love so dearly.

Again, Mr. Chairman, thank you for holding this hearing. I wish I could stay. I've got a markup in a finance committee that I'll be going to shortly. But, again, thank you for doing this. Dr. Varmus, thank you for your leadership at NIH.

Senator SPECTER. Thank you very much, Senator Mack. There's a great deal more we could explore, Dr. Varmus and Dr. Gorden. But we have quite a number of other witnesses.

We've had an extraordinary group of witnesses on the scene here. This is where the photographers usually congregate. And they've been extraordinarily patient and good. So we're going to try to move the proceeding along.

Thank you, Dr. Varmus. Thank you, Dr. Gorden.

We now turn to our panel with Ms. Mary Tyler Moore, Mr. Tony Bennett and then Mr. Alan Silvestri.

While our witnesses are coming forward, I might just comment about two matters that I heard of last week. My former executive director in Philadelphia reported to me—told me that his 13-year-old daughter had leukemia. My chief of staff here in Washington told me about a nephew who had a tumor on his shoulder blade of cancer which would have to be excised. We have letters in these

big mailbags written to Members of Congress from people who have been suffering from diabetes, juvenile diabetes.

When we see the specific children, the specific people who have been victims of these dreaded diseases, it just really emphasizes the necessity to leave no stone unturned and no dollar unspent where it can be directed helpfully to the cause of medical research and beyond.

NONDEPARTMENTAL WITNESSES

STATEMENT OF MARY TYLER MOORE, INTERNATIONAL CHAIRMAN, JUVENILE DIABETES FOUNDATION

Senator SPECTER. We now turn to one of America's leading advocates on the subject if not America's leading advocate. Ms. Mary Tyler Moore is probably best known for her television roles in the Dick Van Dyke Show and the Mary Tyler Moore Show. She received an Emmy in 1992 for her role in "Stolen Babies" and was nominated for an Oscar in "Ordinary People." Broadway honored Ms. Moore with a special Tony for "Whose Life Is It Anyway."

Ms. Moore has lived with diabetes for over 30 years and has worked to raise public and congressional awareness of this malady. She serves as the international chairman of the Juvenile Diabetes Foundation.

Welcome, Mary Tyler Moore, and we look forward to your testimony.

Ms. MOORE. Thank you very much, Mr. Chairman.

As the international chairman of the Juvenile Diabetes Foundation and on behalf of the hundreds of thousands of children with diabetes and their families who cherish them and guard their futures, I thank you for giving me and this first JDF Children's Congress the chance to appear before you today.

Diabetes is one of the most common chronic diseases of childhood. And, as all of the children and families here today know firsthand, it changes everything about a child's and a family's every day life.

To add to the day in and day out hassles of living with diabetes, the balancing of diet and exercise and insulin, the shots, the terrible episodes of low sugar, the debilitating feelings of high sugars is the knowledge that even if you do all you can to be normal, you're not. You're different and you face the uncertainty of an adulthood visited upon by early blindness, kidney failure, amputation, heart attack or stroke.

You know insulin is not a cure as will the 30,000 children who will be diagnosed this year with diabetes. What gives us all hope at JDF is the promise of research and the commitment of this committee and you, Mr. Chairman and Senator Harkin, to make doubling the NIH budget over the next 5 years a top priority.

Further, we appreciate last year's 15 percent down payment on that doubling and have confidence that you are up to the challenge of taking the next step, another $2 billion increase for NIH this year.

Of course, within that overall increase at NIH, we urge you to once again identify diabetes research as an area of great opportunity and need and a top priority at every NIH institute.

Mr. Chairman, the justification for increases in diabetes research has been provided by the recently released report of the Congres-

sionally Mandated Diabetes Research Working Group. The DRWG Diabetes Research Panel has put forward an accelerated and expanded diabetes research program at NIH. The panel recommends a fiscal year 2000 appropriation of $827 million for diabetes research.

The DRWG report identifies numerous major opportunities not being pursued because of lack of funds and focus. They include potential high impact initiatives in the genetics of diabetes, the biology of the beta cell, the treatment of diabetes-related eye disease, kidney disease, nerve disease, heart disease and the development of a vaccine for prevention of type one diabetes.

All of these initiatives were identified as high priorities by DRWG and are of particular importance to children with type one diabetes.

I want you to know that you are not the only one we are challenging to double research budgets. We've challenged ourselves at JDF. In 1998 we gave about $30 million to research; in 1999, $55 million. And in 2000 we will give more than $75 million and by 2002 we project giving more than $120 million to research. Now that's a doubling of every 3 years.

Mr. Chairman, you and the committee can take credit through your past commitments to NIH for having helped bring us to the threshold of this cure. And we at JDF have been proud to be your partners in this absolutely crucial endeavor.

We know that this is a particularly difficult year for appropriations but we cannot lose momentum, not now that we are so close.

So I ask you, Mr. Chairman, members of the committee, look around this room—look around once more. Listen to the voices of the children who will tell you their stories today. And when you retire to your deliberations, promise to remember them, to remember that more than 16 million people who like me have diabetes and promise to work with NIH to ensure that funding is provided so that all identified research opportunities in the DRWG report are explored.

PREPARED STATEMENT

At a minimum we need to be able to tell the children and their loved ones that we are investing the dollars necessary to find the cure. Thank you.

Senator SPECTER. Thank you very much, Ms. Moore.

[The statement follows:]

PREPARED STATEMENT OF MARY TYLER MOORE

As International Chairman of the Juvenile Diabetes Foundation and on behalf of the hundreds of thousands of children with diabetes and the families that cherish them and guard their futures, I thank you for giving me and this first JDF Children's Congress the chance to appear before you today.

Diabetes is one of the most common chronic diseases of childhood, and as all of the children and families here today know, first hand, it changes everything about a child's and a family's everyday life. And to add to the day-in, day-out hassles of living with diabetes—the balancing of diet, exercise, and insulin, the shots, the terrible episodes of low sugar, the weird feelings of high'sugars—is the knowledge that even if you do all you can to be as normal as possible, you're not, you're different, and you face the uncertainty of an adulthood visited upon by early blindness, kidney failure, amputation, heart attack or stroke. You know insulin is not a cure, as will the 30,000 children who will be diagnosed this year with diabetes.

What gives us all hope, at JDF, is the promise of research, and the commitment of this Committee, and you, Mr. Chairman and Senator Harkin, to make doubling the NIH budget over the next five years a top national priority. Further, we appreciate last year's 15 percent "down-payment" on that doubling and have confidence you are up to the challenge to take the next step—another $2 billion increase for NIH this year. Of course within that overall increase at NIH we urge you to, once again, identify diabetes research as an area of great opportunity and need, and of top priority at every NIH institute.

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The DRWG report identifies numerous major opportunities not being pursued because of lack of funds and focus. They include potential high impact initiatives in: the genetics of diabetes; the biology of the beta cell; the treatment of diabetes related eye-disease, kidney disease, nerve disease, and heart disease; and the development of a vaccine for prevention of Type 1 diabetes. All of these initiatives were identified as high priorities, by DRWG and are of particular importance to children with Type 1 diabetes.

I want you to know that you are not the only one we are challenging to double research budgets, or focus expenditures on better responding to public needs. We have also challenged ourselves. At JDF, in 1998, we gave about $30 million to research; in 1999, $55 million; in 2000, we will give more than $75 million; and by 2002 we project giving more than $120 million to research—that is a doubling every three years.

Mr. Chairman, you and this committee can take credit, through your past commitments to NIH, to having helped bring us to the threshold of a cure. And we at JDF have been proud to be your partners in this absolutely crucial endeavor. We know that this is a particularly difficult year for appropriations. But we cannot lose momentum. Not now that we are so close. So I ask you, Mr. Chairman, members of the committee, look around this room once more, listen to the voices of the children who will tell you their stories today, and when you retire to your deliberations, promise to remember them, promise to remember the more than 16 million people, who like me, have diabetes, and promise to work with NIH to ensure that funding is provided so that all identified research opportunities in the DRWG report are explored. At a minimum, we need to be able to tell the children and their loved ones that we are investing the dollars necessary to find a cure. Thank you.

STATEMENT OF TONY BENNETT, ENTERTAINER

Senator SPECTER. We turn now to Mr. Tony Bennett, a World War II veteran who fought in the Battle of the Bulge, and a singer with more than 24 top 40 hits including "Because of You" and "I Left My Heart in San Francisco." His music has brought smiles to my generation, and the fact that he also sings for the MTV generation just proves that his talent is timeless.

His concern for this disease has resulted in the establishment of the JDF Tony Bennett Diabetes Research Fund in honor of his grandson who has diabetes.

Mr. Bennett, we appreciate your being here and look forward to your testimony.

Mr. BENNETT. Thank you. Good morning, Mr. Chairman and distinguished members. I don't consider myself an expert on diabetes but I had enough first-hand experience with those who have suffered its consequences to know what havoc it can wreak on the human body.

In the course of my career I was fortunate to be very close friends with two wonderful performers, Ella Fitzgerald, America's first lady of song, and a cornet player and also Glen Miller's first guitar player, Bobby Hackett who played such beautiful music with Jackie Gleason, and sold millions of records of mood music for

Jackie Gleason. I witnessed how this terrible disease took a toll on them and how they suffered from the complications caused by diabetes.

Millions of Americans, almost 16 million to be exact, are living with diabetes and their future is uncertain. Although insulin is a treatment, it is not a cure and it doesn't prevent the onset of complications from the disease. It can be just as debilitating as the disease itself.

I could read this and we've all been doing this this morning. I must say I've come to Washington for the last 50 years as a performer and I've always loved it here. It's such a thrill to be in Washington, D.C., and it's such an up beat. There are so many wonderful things to see here.

But of all the times I've ever been here, Mary, to see these children, you know, it's just not enough of an accident, I think, as an American citizen that we stress the fact that every move we make is an investment for the future of our children so that we save our great country.

PREPARED STATEMENT

I think that we should today not let down these children that were nice enough to come here and show them that they did something right. And so that when they grow up they can be proud of their country they live in. Thank you very much.

Senator SPECTER. Thank you, Mr. Bennett, for your statement and I think your emotion carries more than words.

[The statement follows:]

PREPARED STATEMENT OF TONY BENNETT

Good morning, Mr. Chairman and distinguished members: I don't consider myself an expert on diabetes, but I have had enough first-hand experience with those who have suffered its consequences to know what havoc it can wreak on the human body. In the course of my career, I was fortunate to be close friends with two wonderful performers—Ella Fitzgerald and the coronet player Bobby Hackett. Through the years that I knew them, I would witness how this terrible disease took their toll on them, as they suffered from the complications caused by diabetes.

Millions of Americans—almost 16 million to be exact—are living with diabetes. Their future is uncertain and although insulin is a treatment it is not a cure and it does not prevent the onset of complications from the disease that can be just as debilitating as the disease itself.

It has been a very positive experience, through my involvement with the Juvenile Diabetes Foundation, to see how much can be accomplished when support is made available for research. In know that the future of all these children here today and across our country can be much more promising if we can increase our efforts to find a cure. I offer my personal appreciation to the members of this Subcommittee who have made funding for medical research a top priority. None of us must forget that we do not have a cure yet—and we owe it to our children to ensure that every possible scientific opportunity in diabetes research is funded so that there will be no delay in bringing home the cure.

STATEMENT OF ALAN SILVESTRI, COMPOSER

Senator SPECTER. When you see these children with diabetes, juvenile diabetes, when you hear the stories one by one of people suffering from cancer or Alzheimer or Parkinson or heart ailments and to know that this rich powerful country can prevent it is something that we just have to do.

This subcommittee has very sharp pencils out to see if we can find the $2 billion this year. And it's a battle because other worth-

while projects will have to receive the eraser end of the sharp pencil. But when it comes to medical research and maladies which can be prevented, there is just no excuse for a wealthy country like America not doing it and we intend to do it.

We turn now to our third panelist. Mr. Alan Silvestri composed scores for movies like "Back to the Future," "The Body Guard" and "Forest Gump." He's worked to raise awareness and concern for diabetes since 1992 when his son Joseph was diagnosed with juvenile diabetes. Let us express our regrets, Mr. Silvestri, that we didn't get a hold of you for the photo op earlier but we'll have another chance. The floor is yours.

Mr. SILVESTRI. Thank you, Mr. Chairman.

As the chair dad of the 1999 Children's Congress, I would like to begin by thanking all the ladies and gentlemen of the committee for allowing us to have the opportunity to come and tell our story to the American people.

Before I begin, I would like to direct your attention to these gray mailbags you see here. These contain thousands of letters that have come from the communities, families and friends of the children. They are all appeals to the Members of Congress to increase funding for the NIH to help us find a cure.

As you may recall, in the end of "Miracle on 34th Street" in the trial of Santa Clause, the judge finally ruled that because the U.S. Postal Service believed that these letters belonged to Santa Clause, well, then he must, in fact, really be Santa Clause.

We would like to think here today that if we can convince the Members of Congress that this cure is possible, then, in fact, it will be a reality and it will be possible. And we look at this as our miracle on Capitol Hill.

Like most parents, I want to do what's best for my kids so they can live, thrive and look forward to the realization of their most precious dreams and their most precious futures.

Not too long ago after writing the score for "Forest Gump," my wife and I found ourselves going to lots of places and meeting lots of people we had never met before.

Once while the introductions were going around the room, the small talk turned to that famous ice breaker question what do you do for a living. And I said I was a film composer. Someone said they were a teacher. One said I'm a homemaker. And when it became my wife's turn, she said I am a pancreas.

As the parent of an infant with diabetes, one must literally take over the tasks of one of the body's most complicated and at the same time most miraculous organs. Sandra was very clear about the job description which I will briefly relate.

6:30 a.m. time for Joe's blood test.

7 o'clock Joe's shot.

7:30 breakfast carefully weighed to balance his insulin.

10 o'clock another blood test.

10:30 a snack.

12 o'clock blood test.

12:30 lunch adjusted for blood sugar and insulin.

3 o'clock blood test.

3:15 a snack once again adjusted for blood glucose levels.

5 o'clock blood test.

5:30 dinner and insulin shot.
8 o'clock blood test. 8:30 snack.
9 o'clock story time.
10:30 blood test and evening shot usually while the child is asleep.
2 a.m. a blood test.
6 a.m. the alarm rings and one gets to begin all over again.

As one of our young delegates said, never a day off. In Sandra's case her first day on this job happened when she happened to be seven months pregnant with our third child. So this addresses the living and thriving part of parenting but what about that third part, the part that concerns their future.

As parents who look down the road for our children trying to safely guide them as they walk into their future, the scientific community and those who have lived with diabetes have reported back to us from down that road and they tell of a future no parent wants for his child.

We know that the cure we are finally so close to is the only thing that will give these children here today and those children all across the country the future that every child deserves. We know that we desperately need your help to accomplish this.

PREPARED STATEMENT

One of the great cinematic moments was that moment when Ebenezer Scrooge awakened from a nightmare and he realized that it was not too late to change the future for one child. Today we are asking the American people to awaken to these bright beautiful faces before us here filled with hope and see that for my son Joe and for all of these kids the moment to change their future is now. I thank you.

Senator SPECTER. Thank you, Mr. Silvestri, for that very touching message from the heart for your son and we have the message and we will deliver it.

Mr. SILVESTRI. Thank you, sir.

[The statement follows:]

PREPARED STATEMENT OF ALAN SILVESTRI

As the Chair "Dad" of the 1999 Children's Congress, I would like to begin by thanking the ladies and gentlemen before me for the opportunity to bring our story to the people of our country. Like most parents, I want to do what's best for my kids so they can live, thrive, and look forward to the realization of their most precious dreams in their most precious futures.

Not too long ago, after writing the score for *Forrest Gump*, my wife and I found ourselves being invited to lots of places with lots of people we didn't know. Once, while introductions were going around, the small talk turned to that great ice-breaker question . . . "What do you do for a living?" "I'm a film composer." "I'm a teacher." "I'm a homemaker.". . . and so it went. When it was my wife's turn she calmly replied.. "I'm a pancreas."

As the parent of an infant with diabetes, one must literally take over the tasks of one of the body's most complicated and miraculous organs.

Sandra was very clear about the job description.

6:30 am Joe's blood test
7:00 am Joe's shot
7:30 am breakfast, carefully weighed to balance his insulin
10:00 am blood test
10:30 am snack—adjusted for blood sugar and insulin
Noon blood test—if his blood sugar is high then an insulin shot
12:30 pm lunch, adjusted for blood sugar and insulin

3:00 pm blood test
3:15 pm snack, adjusted for blood sugar and insulin
5:00 pm blood test
5:30 pm dinner and insulin shot
8:00 pm blood test
8:30 pm snack
9:00 pm Bed time
10:30 pm Blood test and evening shot
2:00 am Blood test
6:00 am Wake up and start all over again.

In Sandra's case, her first day on the job happened to be when she was 7 months pregnant with our third child.

This addresses the living and thriving part of parenting but what about the third part, the part that concerns the future.

As parents, we look down the road for our children, trying to safely guide them as they walk into their future. The scientific community and those who have lived with diabetes have reported back to us from down that road and they tell of a future no parent wants for his child.

We know that the cure we are finally so close to is the only thing that will give our children the future every child deserves.

We know that we desperately need your help to achieve this.

One of the great cinematic moments was that moment when Ebenezer Scrooge awakened from a nightmare and realized that it was not too late to change the future for a small child. Today we are asking the American people to awaken to these bright, beautiful faces, filled with hope, and see that, for my son Joe and all these kids, the moment to change their future is now.

Senator SPECTER. Our children have been extraordinarily patient. We have another round of children. Does somebody have some questions they want to ask of this panel?

Senator REID. I just briefly have a statement I want to make.

Senator SPECTER. Senator Reid.

Senator REID. I don't want to be ahead of anyone else.

Senator SPECTER. Go ahead. I think you're the last voice here on this panel.

Senator REID. I, like everyone else, appreciate very much each of you testifying and I say lending your support is extremely important.

I say to Tony Bennett in 1973 when I was lieutenant governor of the State of Nevada, I came to one of your performances. I think it was the Riveria Hotel. We had a symphony orchestra backing you up and gave you an award from the State of Nevada of how much you had done. That was almost 25 years ago and you're still doing things and I appreciate very much your being here.

But I do want to say this while you very prominent people are at the podium here. There is a lot of talk around Washington. The No. 1 item some people are talking about are tax cuts. But I have to say is I don't know how in the world we can even consider tax cuts and not give proper funding for medical research especially for these beautiful children down front here.

I would hope that when we keep this shrill voice going about tax cuts and how important it is, I hope it doesn't drown out the voices of these beautiful children here about how important medical research is. I would hope that you would join in that debate which will take place here in Washington in the next few months.

Senator SPECTER. Senator Hollings.

Senator HOLLINGS. Twenty-five years ago I flew in—45 years ago—in 1954 to Las Vegas in the Flamingo and I hadn't seen you

in 45 years personally. But, Tony Bennett, I've been your admirer ever since.

Mr. BENNETT. Thank you very much, sir.

Senator HOLLINGS. I appreciate your dedication over these many, many years not just the entertainment but, like you and Mary Tyler Moore, your endurance. Now really the notice to come up here—and everybody agree because everybody has agreed. What we disagree about are the priorities. And having been up here a few years, the question is which should take priority? I know I can find $2 billion in the intelligence budget.

Senator SPECTER. We accept.

Senator HOLLINGS. We didn't even know the Russians were coming down the road. I know I can find $2 billion in the defense budget because each of the services one another play in and everything else like that—in fact, we added on already $6 billion.

I happen to be on the authorization for space and that's a very, very dynamic program and development. But as between the opportunity in space and the opportunity in health care, Mr. Chairman, we ought to get this front and center. Thank you very much, Mr. Chairman.

Senator SPECTER. We've been joined by our distinguished colleague Senator Kohl from Wisconsin. Senator Kohl—no statement? Fine.

Well, we thank you very much, Ms. Moore, Mr. Bennett and Mr. Silvestri. We hear you loudly and clearly. Thank you.

We now turn to our very distinguished panel of children—Zephyr Straus, Stockton Morris, LaNisha Patterson, Mollie Breana, and Will Smith. If you, ladies and gentlemen, would take the seats, please.

In an extraordinary hearing with celebrated celebrities and celebrated doctors and a celebrated senator, Senator Thurmond, we now come to the real stars of the show.

STATEMENT OF JIM STRAUS

We start first with Zephyr Straus, 2 years old, diagnosed with diabetes in August of 1988 when she was 15 months. In January of this year she became the youngest child in the United States to use an insulin pump, accompanied by her father Jim who was diagnosed with type one diabetes in 1971. The Strauses are from Emerald Hills, California.

Mr. Straus, thank you for joining us and we welcome a statement on behalf of Zephyr.

Mr. STRAUS. Thank you. She is waking up here. She didn't find the testimony quite as fascinating as I did.

Again, my name is Jim Straus. This is our 2-year-old daughter Zephyr. I've had to live with diabetes since I was ten. It is difficult but nothing compared with living with the knowledge that I've passed diabetes on to my daughter.

As you stated, she was 15 months old when I realized that she was demanding more and more fluids and saturating more diapers and becoming increasingly listless. Finally, her symptoms hammered through my denial and I squeezed some urine out of her diaper onto a test strip.

I was in shock as I watched the strip turn brown indicating a very high level of sugar and ketones in her urine. I grabbed my own blood glucose test kit, pricked her heel and waited for the longest 30 seconds in my life. And I was just devastated when I watched how high—the meter couldn't read how high her blood sugar was.

That first blood test took as much courage as I could have and now we test her eight to ten times a day. And, as you mentioned, she is one of the youngest people in the United States to be using an insulin pump. When we ask her for a test and ask her which finger and she'll hold out which finger she wants to be tested with.

This may seem like a blessing but part of me wants her to keep fighting because passive acceptance of diabetes and insulin therapy will not lead to a cure.

Mostly I don't ever want Zephyr to have to set her alarm and get up every couple of hours during the night and check her child's blood sugar. I don't want her to have to lie awake at night wondering if her child is having a low blood sugar reaction because she gave her too much insulin or not enough food and not have to wake up in the middle of the night and feed her child food because she was right and have something go wrong there. Too much insulin or low blood sugar can lead to a coma or death for the child there.

PREPARED STATEMENT

With your support, hopefully we can increase the funding for the NIH and help develop a cure for both myself and for our daughter here and for all the other 16 million Americans with diabetes.

Senator SPECTER. Thank you very much, Mr. Straus. You have a beautiful daughter there and we will do our best to help her have a healthy life.

Mr. STRAUS. Thank you.

[The statement follows:]

PREPARED STATEMENT OF JIM STRAUS

My name is Jim Straus and this is my 2-year-old daughter, Zephyr. I have had to live with diabetes since I was 10 years old. It is difficult, but it is nothing compared to living with the knowledge that I have passed diabetes on to my daughter.

Zephyr was 15 months old when I realized that she was demanding more and more fluids, saturating diapers and becoming increasingly listless. Finally her symptoms hammered through my denial and I squeezed some urine out of her diaper onto a test strip. I was in a state of shock as I watched the strip turn brown, indicating a very high level of sugar and ketones in her urine. I grabbed my own blood glucose test kit, pricked Zephyr's heel and waited for the longest 30 seconds of my life. Can you imagine how I felt when I realized her blood sugar was too high for my meter to read? That first blood test took so much courage.

Now we poke her 8 to 10 times per day and she is one of the youngest people in the world to use an insulin pump. She actually chooses which finger we are going to use. Maybe this seems like a blessing, but part of me wants her to keep fighting it. Passive acceptance of diabetes and insulin therapy will not lead to a cure.

I don't ever want Zephyr to have to set her alarm and get up every 2 hours to check her child's blood sugar. I don't want her to lie awake all night between the alarms fearing that she's given her child too much insulin, too little food or too much exercise during the previous day, which could lead to a coma or even death. I don't want Zephyr to have to wake her sleeping child in the early hours of the morning and force her child to eat because her fears were correct.

With your support and an increased focus on curing diabetes at the National Institutes of Health, we can cure diabetes for me and Zephyr and 16 million other Americans.

STATEMENT OF STOCKTON MORRIS

Senator SPECTER. Now we have 9-year-old Stockton Morris, Bryn Mawr, Pennsylvania, goes to the third grade at Coopertown School, diagnosed with type one diabetes when he was 20 months old.

Stockton, the microphone is yours.

Mr. MORRIS. OK. I'm Stockton Morris from Haverford, PA. At 20 months old I was diagnosed with diabetes. What a shock to my parents, even though my mom is a nurse. I am 9 years old and in the third grade at Coppertown School in Bryn Mawr, PA. I have had this dumb disease for 8 years. I can never remember not having diabetes.

I stick myself 8 to 10 times a day. My last stick of the day is at 1 a.m., I am asleep and dad does it. I do the others myself. My fingers get so sore that I put medicine on them before I go to bed. Even though I check my blood sugars a lot, I've had seizures. We really need a cure. I don't want to ever have seizures again.

Everyone thinks my insulin pump is a beeper. It comes in real handy when my blood sugars are high. I don't need three to five shots a day because I have the insulin pump.

Sometimes I'll miss school due to high blood sugars. 200 to 500. I just hurt or feel too tired. My vision gets blurry. I can't concentrate and my school work does not get done.

On school trips when a lot of them just jump on the bus, I have to take my machine, strips and food. Besides that, I also have celiac disease where I can't eat wheat. Sometimes I feel like there's nothing to eat. When I play tennis, sometimes I go very low because of the running around I do.

I get dizzy, go limp and can't get up. They tell me this will have a bad effect on my body down the road. Low blood sugars is not good for my brain. It will be awesome for a cure. I'd love not having to do blood sugar tests.

PREPARED STATEMENT

Any money that could be given for research will make the cure come soon. I don't want to have complications with my eyes, heart or kidneys. When a cure comes up, I want to thank JDF researchers and scientists, a big thank you, for your promise to remember me and all children with diabetes.

Thank you for allowing me to speak today.

Senator SPECTER. Thank you, Stockton. You handled those speaking cards like a professional.

[The statement follows:]

PREPARED STATEMENT OF STOCKTON MORRIS

My name is Stockton Morris from Haverford, Pennsylvania. At 20 months I was diagnosed with Diabetes. What a shock to my parents, even though my mom is a nurse. I am 9 years old and in the 3rd grade at Coopertown School in Bryn Mawr, PA. I have had this dumb disease for 8 years now. I can never remember not having diabetes.

I stick myself 8 to 10 times a day. My last stick of the day is at 1:00 am. I am asleep and Dad does it, the others I do myself. My fingers get so sore that I put medicine on them before I go to bed. Even though I check my blood sugars a lot, I have had seizures. We really need a cure! I don't want to ever have seizures again!

I stick myself 3 to 4 times at school. It eats up time and I miss schoolwork. Everyone thinks my insulin pump is a beeper. It comes in really handy when my blood sugars are high. I don't need 3–5 shots a day because I have a pump.

Sometimes I'll miss school due to high blood sugars (200–500). I just hurt or feel too tired. My vision gets blurry, I cannot concentrate and my schoolwork does not get done.

On school trips, I just can't jump on the bus. I have to take my blood sugar machine, strips, and food.

Because I also have celiac disease and I cannot eat wheat, sometimes I feel like there is nothing I can eat.

When I play tennis sometimes I go very low because of the running around. I get dizzy, go limp and cannot get up. They tell me this will have bad effects on my body down the road.

My first overnight scouting trip was great but at 2:00 in the morning I had a bad low. My mother said "38." That is very low!

It will be awesome to find a cure. I would love not having to do blood sugar tests. Low blood sugars are not good for my brain. Any money that can be given for research will make the cure come sooner. I really don't want to have complications with my eyes, heart or kidneys. When a cure comes, I want to thank JDF researchers, scientists and doctors. A big thank you for your "Promise to Remember Me" and all the children with diabetes. Thank you.

STATEMENT OF LA NISHA PATTERSON

Senator SPECTER. We now call on LaNisha Patterson, 10 years old from Germantown, Wisconsin, diagnosed with juvenile diabetes when she was 4 years old.

Thank you for being here, LaNisha, and we look forward to hearing from you.

Ms. PATTERSON. My name is LaNisha Patterson and I am 10 years old. I've had diabetes for almost 6 years. Juvenile diabetes is a deadly disease. People can get blind and have other problems from juvenile diabetes. I always hoped that diabetes would go away like a cold but it doesn't. Sometimes kids tease me and call me diabetes girl but I don't show my anger. I just don't say anything.

I used to cry when I got finger pokes and shots. My mom and dad used to cry and we would all pray together. I have had convulsions because my blood sugar level went low while I was sleeping. It is very scary. We should be able to sleep through the night without being afraid.

I hate diabetes but I don't get mad because I have it. Sometimes having diabetes brings me emotional problems but I just go pray with my mom and dad when this happens.

I really, really hope that there will be a cure. If there's not a cure, I will find a cure. I want to be a medical researcher. I want to make sure that no other child has to go through the same pain that I go through every day.

The last thing I would like to say is that the one thing that could keep me from fulfilling my dreams and goals is if diabetes ends my life before I achieve them.

PREPARED STATEMENT

So, please, promise to remember me and all the children suffering from diabetes and help find a cure for me and others.

Thank you and may God bless you and keep you.

Senator SPECTER. That's terrific, LaNisha. We will keep it going so that you can be a researcher, too. We'll keep you going and the whole process going.

[The statement follows:]

PREPARED STATEMENT OF LANISHA PATTERSON

My name is LaNisha Patterson and I am 10 years old. I've had diabetes for almost 6 years.

Juvenile diabetes is a deadly disease. People can get blind and have other problems from juvenile diabetes. I always hoped that diabetes would go away like a cold but it doesn't.

Sometimes kids tease me and call me diabetes girl but I don't show my anger I just don't say anything.

I used to cry when I got finger pokes and shots. My mom and dad used to cry and we would all pray together.

Sometimes I am hungry but I have to wait to eat because my blood sugar is high. Sometimes I am not hungry but I have to eat because it is time.

I have had convulsions because my blood sugar level went low while I was sleeping. It is very scary. We should be able to sleep through the night without being afraid.

I hate diabetes but I don't get mad because I have it. Sometimes having diabetes brings me to emotional problems but I just go pray with my mom and dad when this happens.

I really, really hope that there will be a cure. If there is not a cure I will find a cure. I want to be a medical researcher. I want to make sure that no other child has to go through the same pain that I go through everyday.

The last thing I would like to say is that the one thing that could keep me from fulfilling my dreams and goals is if diabetes ends my life before I achieve them. So, please promise to remember me and all the children suffering from diabetes and help find a cure for me and others.

Thank you and may God keep you and bless you, good bye.

STATEMENT OF MOLLIE SINGER

We now look forward to hearing from Mollie Breana, 10 years old, goes to Catholic school in Las Vegas, Nevada.

Ms. SINGER. Hi. My name is Mollie Singer. I am 10 years old and I have had diabetes since 1993. In the past 5½ years I have taken 8,395 shots of insulin and I have poked my fingers 20,987 times.

Everything I do is planned around my diabetes—eating, sleeping, playing, and even homework. If things are not planned exactly, my blood sugar levels can go out of control.

I have been embarrassed in school because I couldn't read when my eyes were blurry when my blood sugar was high and I've been told that diabetic kids are a hassle.

A year after I got diabetes I had open heart surgery and I had a real bad time. When I was in the hospital no one knew how to handle a child with diabetes and I got the wrong amount of insulin and the wrong food.

My twin sister Jackie is my best friend and my guardian angel. When she was seven, she saved my life by getting help in the middle of the night when my blood sugar went too low. Jackie does not have diabetes. And because I know how hard it is, I hope she never ever gets it.

Finding a cure for diabetes is all I think about every hour of every day. I try to be brave but sometimes I get very sad and cry myself to sleep. I dream of what it would be like when I take my last shot of insulin and no longer have to poke my fingers.

At night Jackie and I pray for everyone who is sick and we ask God to help the doctors to find a cure for diabetes and other terrible diseases.

PREPARED STATEMENT

We, also, pray for important people like you and I hope that after hearing about my life that you will promise to remember me by giving researchers the money needed to cure diabetes.

Thank you for listening.

Senator SPECTER. Thank you very much, Mollie. Thank you.

[The statement follows:]

PREPARED STATEMENT OF MOLLIE SINGER

Hi, my name is Mollie Singer. I am 10 years old and I have had diabetes since 1993. In the past 5½ years I have taken 8,395 shots of insulin and I have poked my fingers 20,987 times. Everything I do is planned around my diabetes—eating, sleeping, playing and even homework. If things are not planned exactly, my blood sugar levels can go out of control.

I've been embarrassed in school because I couldn't read when my eyes were blurry because my blood sugar was high and I've been told that "diabetic kids are a hassle." A year after I got diabetes, I had open-heart surgery and I had a real bad time. When I was in the hospital no one knew how to handle a child with diabetes and I got the wrong amount of insulin and the wrong food.

My twin sister Jackie is my best friend and my Guardian Angel. When she was seven, she saved my life by getting help in the middle of the night, when my blood sugar went too low. Jackie does not have diabetes and because I know how hard it is, I hope that she never ever gets it.

Finding the cure for diabetes is all I think about every hour of every day. I try to be brave but sometimes, I get very sad and cry myself to sleep. I dream of what it will be like when I take my last shot of insulin and no longer have to poke my fingers. At night Jackie and I pray for everyone who is sick and we ask God to help the doctors find the cure for diabetes and other terrible diseases. We also pray for important people like you and I hope that after hearing about my life that you will promise to remember me by giving researchers the money needed to cure diabetes.

Thank you.

STATEMENT OF WILL SMITH

Senator SPECTER. We now have Mr. Will Smith, 13 years of age, lives in New York City and was diagnosed with type 1 diabetes way back in 1991. Will.

Mr. SMITH. Hi. I'm Will Smith the 7th grader at the Collegiate School in New York City. I was diagnosed with juvenile diabetes when I was 7 years old. I'm now 13.

Sports have always been a big part of my life. I love to play soccer, basketball and particularly baseball where I still dream of a professional career. But because of this incurable disease, I have to worry about my future in athletics.

If I couldn't play baseball because of many possible complications of diabetes from poor hand-eye coordination to blindness or amputation, I would be crushed. This has been one of my biggest concerns since I was diagnosed.

I am also embarrassed about having to test my blood sugar and sometimes take an insulin shot around my baseball team. Some of my teammates seem uncomfortable at the sight of all the needles and test equipment and few have asked me why I need to do that in front of them.

It's also painful not to have the freedom of eating whatever I want. While other kids can eat pizza or cheeseburgers whenever they're hungry, I have to consider how those might push up my blood sugar readings too high.

At a minimum I have to take extra insulin for some foods and others such as cake or candy are out of the question. In the past

year my doctor has warned me that my blood sugars have been running too high as it is. I try very hard to manage my diabetes and I know that we are close to a cure.

PREPARED STATEMENT

I can only dream of that day that I can eat what I want and do not have to worry about what my blood sugar number is and not worry about what it will do to my eyesight or coordination.

While I can only dream about that day, you can make it happen. Thank you.

Senator SPECTER. Thank you very much, Will.

[The statement follows:]

PREPARED STATEMENT OF WILL SMITH

Hello. I am Will Smith, a seventh grader at The Collegiate School in New York City. I was diagnosed with juvenile diabetes when I was 7 years old; I'm now 13.

Sports have always been a big part of my life. I love to play soccer, basketball, and particularly baseball, where I still dream of a professional career. But because of this incurable disease, I have had to worry about my future in athletics. If I couldn't play because of the many possible complications of diabetes—from poor hand-eye coordination to blindness or amputation—I would be crushed. This has been one of my biggest concerns since I was diagnosed.

I am also embarrassed about having to test my blood sugar and sometimes take an insulin shot around my baseball team. Some of my teammates seem uncomfortable at the sight of all the needles and test equipment, and a few have asked why I need to do that in front of them.

It's also painful not to have the freedom of eating whatever I want. While other kids can eat pizza or cheeseburgers whenever they're hungry, I have to consider how those might push up my blood-sugar readings too high. At a minimum, I have to take extra insulin for some foods; others such as cake or candy are usually out of the question. In the past year my doctor has warned me that my blood sugars have been running too high as it is.

I try very hard to manage my diabetes; and I know that we are close to a cure. I can only dream of the day that I can eat what I want and not have to worry about what my blood-sugar number is, and not worry about what it will do to my eyesight or coordination. Though I can only dream about that day, you can help make it happen. Thank you.

Senator SPECTER. Thank you and all on this panel and thank the children. We thank you for coming from all 50 States. This has been a most extraordinary hearing.

I want to conclude with a recommendation that we move forward from this hearing to persuade the Congress to put up the money to conquer diabetes and juvenile diabetes. The hearings are fine but they have a reach only to an extent.

You can identify the 63 Senators who voted no 2 years ago and the 57 Senators who voted no last year and the 52 Senators who voted no this year on increased funding. And with 50 States represented, we have the muscle here to influence those folks.

So that it is more than a hearing. It is a lot of very hard work of establishing the priority. We have a Federal budget of $1.7 trillion and that's enough to provide the doubling for NIH in the 5 years and the $2 billion this year. But it won't happen by itself.

So I urge you to carry forward the fight. Thank you all very much.

CONCLUSION OF HEARING

Thank you all very much for being here. That concludes our hearing. The subcommittee will stand in recess subject to the call of the Chair.

[Whereupon, at 10:45 a.m., Tuesday, June 22, the hearing was concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]

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