

principal opponents of our campaign finance policies, the opportunity to argue his position before the ACLU's 83-member National Board. After hours of debate and discussion, Neuborne completely failed to shift the ACLU Board to his view. Many Board members in fact argued that Neuborne's position was in direct conflict with the First Amendment rights that form the foundation of our democracy. Ultimately, the one Board member who had offered a motion to radically alter our long-standing policy withdrew it rather than allowing it to come to a vote.

Yet our former ACLU colleagues persist, offering sweeping proposals that would constitute a wholesale breach of First Amendment rights and that ignore the real-world impact of limits on speech. They speak approvingly of efforts to impose "reasonable limits on campaign spending" without saying specifically what such regulations would do. But when we look at those consequences it becomes clear that current campaign finance measures would do immeasurable damage to political speech. The devil as the cliché goes, is in the details.

A key provision of both McCain-Feingold and Shays-Meehan would, for example, establish limits that effectively bar any individual or organization from explicitly criticizing a public official—perhaps the single most important type of free speech in our democracy—when the official is up for re-election within 60 days. If that kind of law had governed the recent New York City mayoral election, it would have effectively barred the ACLU (and other non-partisan groups) from criticizing incumbent Mayor Giuliani by name on the subject of police brutality in the wake of the horrific Abner Louima incident precisely during the pre-election period when such criticism is most audible. That prohibition would have gagged us even though the ACLU has never endorsed or opposed any candidate for elective office and is barred by our non-partisan structure from doing so. Similarly, anti-choice groups like the National Right to Life Committee would be effectively barred from criticizing candidates who support reproductive freedom. Yet such criticism of public officials is exactly what the First Amendment was intended to protect.

In contrast, there are many reform measures the ACLU supports that would protect and increase political speech. These include instituting public financing, improving certain disclosure requirements, establishing vouchers for discount broadcast and print electoral ads, reinstating a tax credit for political contributions, extending the franking privilege to qualified candidates and requiring accountability of and providing resources to the Federal Elections Commission. None of those proposed reforms would run afoul of the First Amendment.

Still, our former ACLU colleagues press proposals that would inevitably limit political speech. We continue to shake our heads, wondering how such measures can be regarded as "reforms" by anyone who is genuinely committed to the First Amendment.

REP. BELFANTI RECOGNIZED

**HON. PAUL E. KANJORSKI**

OF PENNSYLVANIA

IN THE HOUSE OF REPRESENTATIVES

*Monday, June 22, 1998*

Mr. KANJORSKI. Mr. Speaker, I rise today to pay tribute to my colleague and close friend, State Representative Robert E. Belfanti, Jr. Bob will be honored by the Susquehanna Valley Boy Scouts Council at the

Council's July 7 American Distinguished Citizen Dinner. I am pleased and proud to be able to participate in this prestigious event.

Mr. Speaker, Bob Belfanti represents parts of my congressional district in Northumberland County, Montour County, and Columbia County. I have been proud to work with him on numerous occasions since I was first elected in 1984. I consider him a close personal friend.

Born in 1948 to Robert and Rose Belfanti, Bob attended local schools in Mount Carmel, Pennsylvania, in what is part of the District he now represents. He was active in Scouting and became an Eagle Scout in 1961. He graduated high school in 1966 and enlisted in the United States Marine Corps the following July. Bob served in Vietnam and was decorated six times. Following his tour of duty in Vietnam, Bob attended the University of North Carolina on a special Inservice Program. In 1971, Bob received an honorable discharge from the Corps but remained active in a Reserve unit for another two years.

In 1972, Bob began electrician school and graduated as a journeyman in 1975. He operated his own contracting company prior to his election to the Pennsylvania General Assembly in 1980.

Active in numerous local organizations, Representative Belfanti is a member of the AmVets, N.E. Economic Development Council, Lions, Knights of Columbus, Veterans of Foreign Wars, American Legion, UNICO, and various Scouting organizations. Bob was listed in Who's Who in American Politics, received the Outstanding Young Men of America Award, National Young Democrat Award, and the National Leadership Award.

Bob's legislative efforts have ranged from employment issues to the environment. He has helped his district move beyond its coal mining heritage and toward the 21st century with millions in grant money for everything from technology to sewage treatment.

Mr. Speaker, Bob Belfanti is a proven leader, an able legislator, and a concerned citizen. I am proud to join with his wife Cece, his sons, his friends, and the community in paying tribute to his outstanding career and his dedication to his community. I am pleased to have had the opportunity to bring Bob's many accomplishments to the attention of my colleagues and I wish my good friend continued success, good health, and prosperity.

HONORING NEAL BROXMEYER

**HON. GARY L. ACKERMAN**

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

*Monday, June 22, 1998*

Mr. ACKERMAN. Mr. Speaker, I rise today to share with my colleagues in the House of Representatives the story of a man whose life, which ended all too soon in 1996 at age 43, was dedicated to the pursuit of truth.

Neal Howard Broxmeyer searched for truth with a great intensity. He was long immersed in spiritual work which brought tremendous peace. A beloved and respected leader of the School of Practical Philosophy, he played a major role in establishing its Abraham Lincoln School for Boys and Girls on the upper east side in Manhattan. His 9-year-old son is a student there, and is very proud of the role his Dad played. Indeed, it was one of Neal's pre-

cious dreams to see the school flourish and grow.

Neal's devotion to his family was exemplary. He naturally included within his family the many people whose lives intersected with his. In that sense, Neal's family included his associates and colleagues at Fairfield Properties, where he was a partner. His brothers have said that he was an excellent businessman, known for his honesty and his integrity. He was seen as the "heart and soul" of his business, and he was referred to as the "light of the office."

Neal Broxmeyer was a man who always looked beyond his own needs. He led his life in keeping with the maxim: Set no limits in service, and encouraged others to do the same. He was always available to others. He cherished the community in which he lived and was very happy to be part of the community association. He led the way in establishing the security patrol in the community, and always said "How could I not take it on?"

Neal was a simple man who was extraordinary. Always there, steady and balanced; never looking for faults in others, but instead finding the goodness in everyone. Everything and everyone who benefited from his attention, concern, insight, wisdom, counsel, and warmth understands that there was "absence of claim." Although not rigid, Neal was highly disciplined. His life, though very short, was filled with a quality beyond most. Nothing, it seems, was wasted.

Neal is survived by his loving family: His beloved wife Susan; their children, Dara, Jennifer, and David; by his parents, Muriel and Joseph; and by his brothers Mark and Gary.

June 23, 1998 will mark the inauguration of the Neal Broxmeyer Scholarship Fund. This fund will help to keep alive the memory and vision of this extraordinary man. Mr. Speaker, it is my privilege and distinct honor to bring the brief life of Neal Howard Broxmeyer to the attention of my colleagues and hope they will join me in paying tribute to an outstanding human being.

IN SUPPORT OF ADDITIONAL  
FUNDING AND AWARENESS  
ABOUT POLYCYSTIC KIDNEY DISEASE

**HON. JIM McDERMOTT**

OF WASHINGTON

IN THE HOUSE OF REPRESENTATIVES

*Monday, June 22, 1998*

Mr. McDERMOTT. Mr. Speaker, the Polycystic Kidney Research Foundation held a conference here on June 19–21. Four hundred patients, physicians, and researchers gathered to review the latest developments in research for a treatment and cure. Supporters visited members of the House and Senate to ask for a commitment to increased funding at the National Institutes of Health in research for this disease which affects 600,000 Americans. Polycystic Kidney Disease (PKD) is the most common life-threatening genetic disease and costs \$1.5 billion yearly in Medicare funding. Scientists are hopeful that with increased funding in research the disease can be treated or cured within the next five years.

Attached is an article which describes recent gains we've made in combatting PKD and how important continued research will be

to finding a cure. I urge my colleagues to take the time to read this article and learn more about this terrible disease.

[From Contemporary Dialysis & Nephrology, Sept. 1997]

#### GENETIC BREAKTHROUGHS TAKE CENTER STAGE IN ACCELERATING POLYCYSTIC KIDNEY DISEASE DRAMA

(By Michael D. O'Neill)

##### INTRODUCTION

"I believe the future holds the prospect of fundamental breakthroughs that will allow us to develop treatments that will change the basic biology of polycystic kidney disease (PKD)."

This hopeful message was delivered by Josephine Briggs, MD, director of the Division of Kidney, Urologic, and Hematologic Diseases in the National Institutes of Health's National Institute of Diabetes and Digestive and Kidney Disease (NIDDK), in her luncheon address at the 8th Annual Conference on PKD, sponsored by the Polycystic Kidney Research (PKR) Foundation, in Nashville, TN.

In 1982, Joseph H. Bruening and Jared J. Grantham, MD, founded the PKR Foundation to determine the cause, improve clinical treatment, and discover a cure for PKD. Today, the organization is the major funder of private PKD research grants and the disseminators of information about the disease worldwide to physicians, researchers, patients, and the general public.

Briggs' optimism was based on a continuing series of dramatic discoveries related to the genetics and molecular biology of PKD. These discoveries have come at an ever-increasing pace following identification of the PKD1 and PKD2 genes in 1994-1995 and 1996, respectively, and have roughly paralleled an increasing rate of PKD-directed research funding by both the NIH and the PKR Foundation.

##### ADDITIONAL ADVANCES

Additional advances in the last few months have generated even more excitement. Gregory Germino, MD, a nephrologist at The Johns Hopkins University School of Medicine, Baltimore, MD, has shown evidence that a two-hit mechanism initiates cyst formation in PKD and suggested that intervention to prevent the second hit may impact the course of the disease.

Germino has shown that the normal PKD1 and PKD2 proteins physically interact with each other in the cell membrane and probably participate in a common cellular pathway. This finding may explain why defects in either of these genes, located on different chromosomes, can cause the same clinical disease.

Briggs termed these discoveries "enormous, dramatic, and, in some cases, very surprising." She said that "have implications not only for PKD, but perhaps for other diseases as well."

Germino described his findings at one of the conference's many informative workshop sessions. Attendees also heard encouraging news about the prognosis for children with autosomal recessive PKD (ARPKD), and prenatal diagnosis of ARPKD. They also received updates on numerous other areas of PKD research and treatment.

In her address, Briggs also commented on the future of funding for PKD research and stressed the need for industry involvement on the parts of both the biotech and pharmaceutical industries.

##### PKD BACKGROUND

PKD is a systemic disease. The most common problems are associated with the kidneys, where fluid-filled cysts can develop and lead to End-Stage Renal Disease (ESRD). As

with other forms of ESRD, dialysis and transplantation are the available treatments.

There are two major forms of PKD—the more common, autosomal dominant (ADPKD) form that chiefly affects adults, and the much rarer autosomal recessive (ARPKD) form that affects children.

ADPKD affects an estimated 600,000 people in the U.S. and 12.5 million around the world. It is said to be the most common life-threatening genetic disease.

In the US, over 1,000 people die each year from PKD, and an additional 2,000 develop kidney failure. Costs to US taxpayers from dialysis, transplants, and treatment related to this disease are estimated at more than \$1 billion annually.

Defects in the PKD1 gene on chromosome 16 are responsible for 85% of ADPKD while defects in the PKD2 gene on chromosome 4 are responsible for about 15%. A third gene (PKD3), which has not yet been pinpointed, is defective in a small number of ADPKD families. The gene for ARPKD has not yet been identified, but it has been located within a small region of chromosome 6.

##### THE TWO-HIT MECHANISM

ADPKD patients are born with one defective PKD gene and one functional PKD gene. For PKD1-associated ADPKD, Germino has shown compelling evidence that cysts develop from a subset of kidney cells in which both PKD1 genes are defective.

Germino describes this as a two-hit mechanism. The first hit is being born with one broken PKD1 gene. The second hit is sustaining damage to the remaining functional PKD1 gene. This second hit leaves the cell with no way to produce the normal PKD1 protein, and that deficiency somehow leads to cyst formation.

This two-hit model is particularly attractive because it offers an explanation for two fundamental puzzles of PKD, namely the highly variable course of the disease and the focal nature of cyst formation (in PKD, only one out of every 100 or 1,000 nephron tubule cells actually goes on to become a cyst—the vast majority of these cells are completely normal).

This argument proposes that the cysts develop only from those cells that experience second hits and that the variable disease course might be traceable to variable frequencies of the second hits in different individuals.

##### CELL MEMBRANE INTERACTION

The second dramatic finding, reported in the June 1997 issue of Nature Genetics, is that the normal PKD1 and PKD2 proteins interact in the cell membrane and probably work together in a common cellular pathway. As noted earlier, this finding may explain why defects in either of these genes can cause the same clinical disease.

"By understanding pieces of this cellular pathway and the steps involved, we hope that we can one day design safe and effective therapies for PKD," Germino said.

##### HOPE FOR ARPKD PATIENTS

Encouraging news concerning ARPKD was reported by Lisa Guay-Woodford, MD, a pediatrician and assistant professor of Medicine at the University of Alabama-Birmingham.

"Still, in 1997, there is a sense among the general medical community that ARPKD is a universally fatal disease," she remarked. "The answer is that it is not. While it's true that 30%-50% of these children will not survive the newborn period, results from two recent studies have shown that, if a child with ARPKD can survive the first year of life, that child has a reasonably good prognosis."

Guay-Woodford said that, if sufficient family information is available, it's possible to

carry out prenatal diagnosis for this disease, using DNA-based genetic linkage analysis. With collaborators, Guay-Woodford has performed such diagnoses in a number of cases where the fetus was known to be at risk for ARPKD.

##### NIH AND PKD FUNDING

In her luncheon address, Briggs stressed the urgent need for the biotech and pharmaceutical industries to become more involved in the funding of PKD research. She noted that the estimated cost of taking a single drug to market is \$270 million, which exceeds the entire NIH budget for kidney disease research.

"If we are going to eventually see new drugs for PKD, we also need pharmaceutical and biotech investment," she said.

While noting that NIH funding for PKD research had increased significantly—from \$70,000 (one grant) in 1982 to \$7.3 million (46 grants) in 1996, Briggs, a nephrologist and kidney researcher, expressed her desire for increased NIH funding in the area of PKD research. The PKR Foundation has previously stated that annual NIH funding for PKD research has trailed allocations for diseases that affect fewer people. Cystic fibrosis, for example affects 30,000 people in the US and received \$61 million in annual funding from the NIH in 1996 while PKD affects 600,000 and received only \$7.3 million.

In 1996, the PKR Foundation funded \$536,000 in PKD research and will fund \$750,000 by the end of this year.

"We directly fund individual investigators at major teaching and research institutions and heavily promote the need for increased PKD investigation at the federal level," according to Dan Larson, PKR Foundation president. "We plan to work closely with Dr. Briggs and the appropriations committees to add a zero to the current PKD research allocation of \$7.3 million."

#### GIVE THEM AN ADULT WHO CARES

#### HON. DONALD M. PAYNE

OF NEW JERSEY

IN THE HOUSE OF REPRESENTATIVES

Monday, June 22, 1998

Mr. PAYNE. Mr. Speaker, as youngsters we're taught about pride and humility and how we must use them if we are to serve well and succeed in life. Today, proud and humble, I would like to join others as they honor and recognize my brother, William, for his work as a New Jersey State Assemblyman representing the 29th Legislative District. Tomorrow at an event at the prestigious law firm of Gibbons, DelDeo, Dolan, Griffinger & Vecchione in Newark, New Jersey, family, friends, colleagues and supporters will gather to thank and further encourage Assemblyman Payne on the leadership he has continuously exhibited to benefit the lives of those less fortunate among us.

Assemblyman Payne is serving his first term where he is a member of the powerful Appropriations Committee. My brother, Bill, is no stranger to the political process. He was the first African American elected as District Leader in Newark's North Ward in 1955. He unsuccessfully sought municipal elected office in 1962 when he lost by 399 votes a run-off election for Councilman-at-Large. He ran a spirited race for South Ward Councilman in 1966 which was also unsuccessful. Over the years he has assisted numerous citizens in their