ADVANCING THE HEALTH OF THE AMERICAN PEOPLE: ADDRESSING VARIOUS PUBLIC HEALTH NEEDS

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON ENERGY AND COMMERCE

HOUSE OF REPRESENTATIVES

ONE HUNDRED SEVENTH CONGRESS

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ADVANCING THE HEALTH OF THE AMERICAN PEOPLE: ADDRESSING VARIOUS PUBLIC HEALTH NEEDS

WEDNESDAY, JUNE 27, 2001

HOUSE OF REPRESENTATIVES,
COMMITTEE ON ENERGY AND COMMERCE,
SUBCOMMITTEE ON HEALTH,
Washington, DC.

The subcommittee met, pursuant to notice, at 1 p.m., in room 2322, Rayburn House Office Building, Hon. Michael Bilirakis (chairman) presiding.

Members present: Representatives Bilirakis, Upton, Greenwood, Bryant, Ehrlich, Pitts, Tauzin (ex officio), Brown, Barrett, Pallone, Eshoo, Stupak, and Green.

Also present: Representatives Stearns and Wicker.

Staff present: Marc Wheat, Majority counsel; Brent DelMonte, majority counsel; Kristi Gillis, legislative clerk; and John Ford, minority counsel.

Mr. BILIRAKIS. I see that Mr. Brown has entered the hearing room. You are the limiting factor, Sherrod, which means we can now get started.

I would announce at the outset that we were told that there will be a series of three votes that will take place at any time, so I've already alerted Mr. McMahon last night how very rude we can be to the witnesses up here, and you'll see that we will be rude because when those votes are announced we'll have to just break it off and run and cast our votes and then return afterwards.

The hearing will come to order. We have an ambitious agenda for our hearing today, and I will limit my opening remarks in the interest of time and would hope that all of the members of the subcommittee will do the same.

First, I do want to thank our many witnesses for joining us to testify on legislation that is very close to their hearts, and I know each of the proposals we will discuss today also means a great deal to, obviously, very many patients, many families, and I have followed the work of these advocates.

I also want to extend a special welcome, and I hope the rest of the witnesses won't mind my doing this, to Mr. Ed McMahon, who is testifying today is his capacity as National Vice President of the Muscular Dystrophy Association. I understand this is the first time he has testified before a congressional committee, and I understand he said he'll be nervous, can you imagine Ed McMahon being nervous publicly? But, I do want to—there go the notice on the votes—

I do want to reassure him that none of our witnesses today will be rated for their performances. In all seriousness, I've greatly enjoyed the opportunity to get to know Mr. McMahon. I was particularly impressed by his life story, which starting with a modest and difficult beginning, a Horatio Alger if you will, embodies the American ideals of determination, self-reliance and hard work. As a member of the Veterans Affairs Committee, I'm also pleased to note that Colonel Ed McMahon served his country, and I emphasize Colonel Ed McMahon, served his country in the United States Marine Corps as a fighter pilot during both World War II and the Korean War. Now, of course, he continues to serve others by bringing more attention and resources to fighting muscular dystrophy. We welcome you, sir, and thank you for your many contributions to our Nation.

Mr. MCMAHON. Thank you, sir.

Mr. BILIRAKIS. There are so many worthy pieces of legislation that we will be examining today, but I would like to highlight one bill that Congressman Brown and I have introduced to help address many of these concerns, and that is H.R. 1340, the Biomedical Research Assistance Voluntary Option, or as we like to call it, the BRAVO Act. Our bill would allow taxpayers to designate a portion of their Federal income tax refunds to support NIH research efforts. I believe that every dollar invested in research today will yield untold benefits for all Americans in years to come. Indeed, our own lives might some day depend on the efforts of scientists and doctors currently at work in our Nation's laboratories. Medical research represents the single-most effective weapon against diseases such as Duchenne Muscular Dystrophy and tuberous sclerosis. The advances made over the course of the last century could not have been predicted by even the most farsighted observers. It's equally difficult to anticipate the significant gains we may achieve in years to come to increase funding for further medical research.

I would ask all of these groups here today, whose research certainly needs help, we have committed some time ago, some 2, 3, 4 years ago, to doubling NIH funding over a period of 5 years, well, we are well on that path, but I know that we would welcome additional dollars and these income tax refund dollars, some of them chosen by people could be very helpful, but we need your help to get particularly the Ways and Means Committee to understand that and to allow that piece of legislation at least to see the light of day.

Again, I want to thank all of our witnesses for taking the time to join us. The members of this subcommittee, and the millions of American patients on whose behalf you will testify, are very grateful for your efforts. I'd like to try to get through the opening statements, if it's at all possible, before we run to vote. If not, we're just going to have to break and we'll return as soon as we can.

[The prepared statement of Hon. Michael Bilirakis follows:]

PREPARED STATEMENT OF HON. MICHAEL BILIRAKIS, CHAIRMAN, SUBCOMMITTEE ON HEALTH

The hearing will come to order. We have an ambitious agenda for our hearing today, and I will limit my opening remarks in the interest of time. First, I want to thank our many witnesses for joining us to testify on legislation that is close to

their hearts. I know each of the proposals we will discuss today also means a great deal to many patients, and I applaud the work of these advocates on their behalf.

I also want to extend a special welcome to Mr. Ed McMahon, who is testifying today in his capacity as National Vice President of the Muscular Dystrophy Association. I understand this is the first time he has testified before a congressional committee, and I want to reassure him that none of our witnesses today will be "rated" for their performances!

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There are so many worthy pieces of legislation that we will be examining today, but I would like to highlight one bill that Congressman Brown and I have introduced to help address many of these concerns: H.R. 1340, the Biomedical Research Assistance Voluntary Option or "BRAVO" Act. Our bill would allow taxpayers to designate a portion of their federal income tax refunds to support NIH research efforts.

I believe that every dollar invested in research today will yield untold benefits for all Americans in years to come. Indeed, our own lives might some day depend on the efforts of scientists and doctors currently at work in our nation's laboratories. Medical research represents the single most effective weapon against diseases such as Duchenne muscular dystrophy and tuberous sclerosis.

The advances made over the course of the last century could not have been predicted by even the most far-sighted observers. It is equally difficult to anticipate the significant gains we may achieve in years to come through increased funding for further medical research.

Again, I want to thank all of our witnesses for taking the time to join us today. The members of this Subcommittee—and the millions of American patients on whose behalf you will testify—are very grateful for your efforts.

Mr. BILIRAKIS. The Chair now recognizes Mr. Brown.

Mr. BROWN. Thank you, Mr. Chairman, and thank you, all the members of the panel. We appreciate very much your being here and discussing these bills.

I want to mention a couple of bills, as the chairman did, to highlight, although I think everything we are looking at today is pretty important. I want to thank Congressman Wicker and Congressman Peterson for introducing the Duchenne Muscular Dystrophy Child Assistance Research and Education Bill. I know a couple of our witnesses especially are interested in that issue. Muscular dystrophy is the world's No. 1 genetic lethal childhood disorder affecting generally only males with rare exceptions. It's estimated that one in 3,500 boys has Duchenne Muscular Dystrophy worldwide, results in muscle weakness which causes children to lose their ability to walk and ultimately in many cases lose their lives.

In 1987, the gene which causes DMD was identified and isolated, but unfortunately Federal research since then has been close to minimal. To the family of a child with DMD, this lost opportunity is hard to comprehend.

H.R. 717 would create three centers of excellence for DMD research in the National Institutes of Health, and three centers for epidemiology, data collection and surveillance at the Centers for Disease Control in Atlanta. This is a responsible next step to a remarkable discovery that science made a decade and a half ago.

I want to thank my colleague, Congressman Green, a member of this subcommittee, for his efforts to secure appropriate funding for research in juvenile diabetes. That disease strikes 13,000 children

a year, 35 each day. A 15-year old boy was in my office yesterday who was diagnosed, in my District, diagnosed with diabetes at the age of 2. He has 11,000 times pricked his skin because of that disease in those 13 years.

Chairman Bilirakis and I, with the help of many advocates including the Juvenile Diabetes Foundation, worked hard last year in passage of the Children's Health Act, which established a national commitment through research to research the issues of the uniqueness of juvenile diabetes as opposed to adult onset diabetes.

The Diabetes Research Working Group has called for an accelerated and expanded diabetes research program at NIH.

The last bill I want to mention is the one introduced with Chairman Bilirakis, that he mentioned, the Biomedical Research Assistance Voluntary Option Act, BRAVO, as the chairman said it would allow taxpayers to designate all or a portion of their tax refund for biomedical research conducted through NIH.

As the chairman said, I also applaud the doubling of the NIH budget. However, in large part because of a tax cut that this Congress did last year, and the chairman doesn't like it when I mention that, but as a result of the tax cut we did earlier this year this Congress has not planned to increase funding for the Centers for Disease Control. While we need to continue to do the high-tech research at NIH, we also need the public health aspect of the Centers for Disease Control, we also need the other work in education and research that the Centers for Disease Control does.

So, with that, I am pleased the chairman is having this hearing today. I'm pleased at the good work that he has done, and we've done together on these bills today, and I yield back the balance of my time.

Mr. BILIRAKIS. The Chair thanks the gentleman.

Mr. Upton.

Mr. UPTON. Thank you, Mr. Chairman.

Mr. BILIRAKIS. And, I would announce, after Mr. Upton's opening statement, we are not going to be able to get through before we have to cast that vote, so we'll break right after Mr. Upton's opening statement.

Mr. UPTON. Mr. Chairman, I'm going to introduce my opening statement as part of the record and just briefly summarize it.

I want to thank you and particularly my friend Mr. Wicker. I'm an original co-sponsor of the Duchenne Muscular Dystrophy Childhood Assistance Bill. I certainly know a number of folks that have that awful disease. I've always been a strong supporter of finding the necessary medical research dollars to combat so many of these different diseases, and I want to applaud you, Mr. Chairman, for your leadership in this effort every step of the way.

I, too, want to welcome my fellow Michigander, Mr. McMahon.

Mr. MCMAHON. Thank you, sir.

Mr. UPTON. I know he was there only 6 weeks, but I know he's been there since, for your leadership on this issue, and I also want to highlight a front-page story in today's Washington Post about a young lad at Children's Hospital who is making a difference in the fight on these diseases, and I would ask unanimous consent that this story be made part of the record.

Mr. BILIRAKIS. Without objection, that will be made part of the record.

[The Washington Post article follows:]

[Wednesday, June 27, 2001—Washington Post]

WITH POETRY, A SICK BOY LIFTS OTHERS

Young Hospital Patient Gets Book Published

By Tracey A. Reeves, Washington Post Staff Writer

At first, the young boy with the soft smile, wispy blond hair and gold wire-rimmed glasses too big for his face seemed startled by the swollen crowd and flashing cameras.

All around him, people were stepping over each other to get a glimpse of Matthew "Mattie" Stepanek, to hug his little body and shake hands with the young poet.

But being the fearless fighter that he is, Mattie remained calm, readjusting his slight frame in his motorized wheelchair as he delved into the role of celebrity.

The 10-year-old from Upper Marlboro, who has a rare form of muscular dystrophy that has claimed the lives of his three siblings, recently learned that his wish of becoming a published poet had come true.

Earlier this week, at a reception at Children's Hospital in the District, Mattie showed off his colorful new book, "HeartSongs," acknowledging those who made it happen.

"I want to thank all of my friends and all of my family and all of my kin," Mattie said, his words interrupted by the thick tube in his throat that puffs oxygen into his system. "I know I'm in the hospital and it's sad, but something good is happening."

If ever there was a wish that Mattie wanted to come true, this was it: to be lauded not for the medical struggles he has endured, but for how he has transformed those struggles into a body of work that even adults are at a loss to understand.

Cheryl Barnes—who with her husband, Peter, and their company, VSP Books, compiled Mattie's poems in paperback form—said she had a hard time believing that a child could write with such wisdom.

"He's bright beyond his years," Barnes said. "He is truly a remarkable child."

The book wish is actually Mattie's second to be granted.

Two weeks ago, volunteers arranged for him to speak by telephone from his hospital bed with former President Jimmy Carter, whom Mattie has long hailed as a role model since learning about him as a student at Mattaponi Elementary School in Prince George's County. Carter and the boy spoke for about 15 minutes about the importance of resolving conflicts in places such as Bosnia and Africa.

With his second wish now secured, Mattie is looking to make his third wish come true. He wants Oprah Winfrey and Rosie O'Donnell to read his poems on their shows.

"I'm going for them both," Mattie laughed. "I love them both."

Mattie's wishes might seem unusual indeed. Not at all like the requests for trips to Disneyland, cruises or chances to swim with dolphins that sick children often make.

But then Mattie has never been like other children, said his mother, Jeni Stepanek, 41, a researcher on leave from her job at the University of Maryland.

Stepanek said her son, a whiz kid who skipped two grades in elementary school before she decided to teach him at home, draws inspiration from stories of his older siblings—Katie, Stevie and Jamie, who, like Mattie, were born with dysautonomic mitochondrial myopathy, a disease that disrupts the body's breathing, processing of oxygen and heart rate.

Stepanek said doctors did not fully diagnose the problem until 1992, when she was told that she had the adult form of her children's disease. Worse, she had probably passed it on to her children.

"I get asked why we kept having children if we knew I had this," said Stepanek, who is divorced and uses a wheelchair. "I didn't get the genetic prognosis and diagnosis until all four children were born and the youngest was 2. We just didn't have the information we have now."

Mattie, who at 45 pounds and 49 inches is small for his age, takes his inspiration from the more mundane aspects of life.

In "HeartSongs," he writes of smelling noise, tree stars in the sky and snowflakes failing to the ground. In Mattie's eyes, dinosaurs smile and dandelions are beautiful yellow flowers, not weeds. In one poem, "Leaf for a Day," Mattie writes:

Today, I think I will be a tree.
Or perhaps, a leaf on a branch on the tree.
I will feel the gentle breeze,
And then I will 'plip' off my branch and my tree
And float in the wind.

At the media event for his book Monday, Mattie, a fan of Legos and X-Men action figures, soaked up the attention, receiving congratulations, gifts and heaps of lipsticked kisses. His doctors, nurses, fellow patients and friends from his muscular dystrophy camp had come for his debut, snapping up all 200 copies of the book.

Cheryl Barnes promised to print 500 more copies by Friday. In addition, she and her husband gave Mattie a contract to publish a second book.

On this evening, Mattie dressed up in black slacks, a white button-down shirt and skinny red tie. Even his wheelchair was in style, adorned with the words, "Mattie the Pokemon Monster."

As the crowd looked on, Mattie read a poem from "HeartSongs," his soft and breathy voice at times drowned out by the sounds of sniffles.

Later, he would tell the crowd, that he is certain a cure will be found for his disease. Maybe not in his lifetime, but in another child's lifetime.

The excitement was almost too much for Mattie, who has been confined to a bed in the intensive care unit for the past three months. By the time he locked eyes with a friend who had come to the hospital for the event, Mattie, pale and weak, could barely manage a smile.

"Hey Mattie," yelled Ben Mox, 10, of Upper Marlboro. "This is way cool, huh?"

Mr. UPTON. With that, Mr. Chairman, I yield back the balance of my time.

Mr. BILIRAKIS. The Chair thanks the gentleman. Since he used brevity, we will recognize Mr. Pallone for an opening statement.

Mr. PALLONE. And, thank you, Mr. Chairman, and I'll try to be brief.

I'm particularly interest in H.R. 293, the bill to elevate the position of the Director of Indian Health Service to an Assistant Secretary level within the Department of Health and Human Services.

Mr. Chairman, Indian country is united in its support for this legislative initiative for many reasons, but first and foremost because of the bill's recognition of the special relationship between the 546 federally recognized Indian tribes in the U.S. Government.

In 1976, Congress declared the policy of the Nation to the American Indian people to assure the highest possible health status for Indians, and this legislation will help make that policy a reality.

The Department of Interior recognized the special status of Indian people when it elevated the Director of the BIA to an Assistant Secretary in 1977. It's now time for comparable recognition to be given to the individual responsible for health care delivery to over a million American Indians and Alaska native people.

While Indian self-determination and recognition of a government-to-government relationship has been the policy of every administration since Nixon, within HHS decisionmakers have not always understood the implications of this uniqueness and the commitment to this special responsibility.

Just as an example, in '94 HHS, through the Health Care Financing Administration, approved waivers to State Medicaid plans for both Oregon and Washington, but it was only when tribes read in newspapers what was happening and began asking questions of both IHS and the states that a dialog began, and it was the initiative of the tribes to ensure that the rights of Indian patients to go to Indian health clinics, and the rights of Indian health programs to bill for services provided to Medicaid-eligible patients was protected.

I'm just using that as a story, Mr. Chairman, because I want to wrap up, about how the Department activity has led American Indians to view passage of H.R. 293 as critical. We need an advocate for Indian health at the highest level of the Department. It's not an option, it's a necessity.

If I could submit the rest of my statement for the record, Mr. Chairman.

I just did want to say, though, that although today's hearing and this bill is important, I hope that we might be able at some time to consider H.R. 1662, the Indian Health Care Improvement Act. This is another bill that basically reauthorizes the Indian Health Service that a lot of members of this committee and Congress on a bipartisan basis support.

And finally, I have a written statement, if I could submit for the record, Mr. Chairman.

Mr. BILIRAKIS. Without objection, the written statement of Mr. Stupak, and any other written statements of members of the subcommittee will be made a part of the record.

[The prepared statement of Hon. Frank Pallone, Jr. follows:]

PREPARED STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Thank you Mr. Chairman, for holding this important hearing today. Of the bills under consideration, I am particularly interested in H.R. 293—the bill to elevate the position of the Director of Indian Health Service to an Assistant Secretary level within the Department of Health and Human Services.

Indian Country is united in its support for this legislative initiative for many reasons, but first and foremost, because of the bill's recognition of the special relationship between the 546 federally-recognized Indian tribes and the U.S. government. In 1976, Congress declared it the policy of the nation to the American Indian people to assure the highest possible health status for Indians. This legislation will help make that policy a reality.

The Department of Interior recognized the special status of Indian people when it elevated the Director of the BIA to an Assistant Secretary in 1977. It is now time for comparable recognition to be given to the individual responsible for health care delivery to over a million American Indians and Alaska Native people. While Indian Self-Determination and the recognition of a government-to-government relationship has been the policy of every Administration since Nixon, within HHS, decision-makers have not always understood the implications of this uniqueness and the commitment to this special responsibility. Over the past months, I have traveled throughout Indian Country learning about the health care problems facing Native Americans. Inevitably, I hear of an example where this has been the case.

In 1994, HHS through the Health Care Financing Administration approved waivers to State Medicaid plans for both Oregon and Washington. These waivers allowed the states to require Medicaid patients to enroll in private-sector managed care health plans. Neither HCFA nor the states consulted with IHS or tribes to determine the impact this would have on Indian people or Indian health programs—programs that depend on Medicaid collection for 20-40% of their clinic operating budgets. Indian health programs were simply overlooked.

It was only when tribes read in newspapers what was happening and began asking questions of both IHS and the states that a dialogue began. It was the initiative of tribes that insured that the rights of Indian patients to go to Indian health clinics and the rights of Indian health programs to bill for services provided to Medicaid-eligible patients were protected. Had an Assistant Secretary for Indian Health Service been at the table when Department-level discussions of Medicaid reform took place, the impact on Indian Health programs and Indian people would have been foreseen and a great deal of time, money, and effort saved.

Unfortunately, I have heard many stories like this. Department activity has led American Indians to view passage of HR 293 as critical. An advocate for Indian health at the highest levels of the Department is not an option, but a necessity.

IHS is quite different from most Departments that primarily award money to states, or research organizations to carry out programs. IHS delivers direct health

care either through Federally-operated or tribally-operated programs. Someone knowledgeable of the Indian health care system must be at the table when key decision-making is taking place. To do otherwise is to leave Indian health care subject to inadvertent harm.

As you can see, Mr. Chairman, passage of this bill is not only necessary for consistency in government-to-government relationship between the United States and Indian Tribes; but it plays a role in the overall health of Indian Country. The leading position at IHS must be allowed full participation in *all* budget processes and the opportunity to be a strong advocate for *all* IHS proposals. I hope, Mr. Chairman, that working together we can achieve passage of HR 293 and extend equality to all Native Americans.

Today's hearing is important in terms of making progress on HR 293, but I would hope that it might also serve as a stepping stone for consideration of HR 1662—the Indian Health Care Improvement Act. I serve as an original cosponsor of this legislation which seeks to improve the care and education of Indian people by improving the services and facilities of Federal Indian health programs and encouraging maximum participation of Indians in such programs.

Thank you, Mr. Chairman. I look forward to hearing today's testimony.

Mr. BILIRAKIS. I'm sorry, I didn't mean to interrupt you.

Mr. PALLONE. That's fine. Thank you, Mr. Chairman.

Mr. BILIRAKIS. The Chair, 5 minutes, how much time will you take, Roger?

Mr. WICKER. Whatever your pleasure. I won't take very long at all, but I'll be happy to wait.

Mr. BILIRAKIS. Would you like to be heard now?

Mr. WICKER. Well, let me just say, if I may in about 2 minutes, Mr. Chairman.

Mr. BILIRAKIS. Well, we are going to have really run.

Mr. WICKER. That's fine, I'll wait. Really, you are the one who controls the traffic on this bill, and I want to do exactly what you think.

Mr. BILIRAKIS. We're going to wait then, because some of us don't move as fast as we used to.

We are going to just break for—it will be some time, because there are three votes, probably a good 25-30 minutes, maybe a little less than that because so much time is expired on the first vote.

Thank you.

[Brief recess.]

Mr. BILIRAKIS. The subcommittee will come to order.

Mr. Wicker is not a member of this committee or subcommittee, but has requested the courtesy of being able to sit in on the panel, at least for an opening statement, and hopefully he'll sit for a little longer than that, and the Chair is pleased to recognize him at this time.

Mr. WICKER. Well, thank you very much, Chairman Bilirakis, and also to Ranking Member Brown who was with us earlier, and who I'm sure will be back in the room shortly.

I'll be honest with you, Mr. Chairman, this is a thrill for me. And I can tell you that it is a very special day for many people in the audience, who have worked long and hard on the issue of Duchenne Muscular Dystrophy and childhood Muscular Dystrophy, for us to speak to you today, along with Pat Furlong and Ed McMahon, on behalf of H.R. 717, legislation which I introduced along with Representative Collin Peterson of Minnesota. This legislation will enhance our Federal research commitment to finding a cure for childhood Muscular Dystrophy.

Many people do not realize that Duchenne Muscular Dystrophy is the most common and most lethal of our childhood genetic disorders, and although the dystrophin gene which causes Duchenne Muscular Dystrophy was successfully identified and isolated by researchers as early as 1987, our Federal research devoted to potential treatment options for a cure has not been successful and has actually been minimal since that time.

I want to thank my colleagues for the overwhelming support they've given to H.R. 717, as evidenced by the huge list of original co-sponsors. Mr. Chairman, when we left the room before the break we had 304 co-sponsors out of the 435 Members of the House of Representatives. I'm pleased to say that we added to our numbers during the vote and we now have 305 co-sponsors and counting. So, hopefully, that will help the committee to look favorably upon this bill.

I also want to express my particular thanks to the scientists and researchers from the National Institutes of Health who came into my office, who helped us refine the language to make it more workable, and I certainly support the language which we developed along with them, and which will likely be offered as a substitute when this bill is considered by the committee.

So, thank you for allowing me to be here and to introduce the two witnesses who will testify. For your information, Mr. Chairman, Pat Furlong is President and Founder of the Parent Project Muscular Dystrophy. She has her own story which she will tell the subcommittee, but suffice it to say that she has been affected by this disease in a most personal and tragic way, and I believe her testimony will be instructive to the subcommittee. And then, of course, Ed McMahon, well, he's just Ed McMahon. As the chairman alluded, he is an American classic. He's one of our preeminent citizens in this country, and as the chairman also mentioned, as we approach our 225th anniversary of our independence, we are grateful to people of that greatest generation that Ed McMahon represents. He has been a leading spokesman throughout the Nation for Muscular Dystrophy research, and so I'm delighted to be here on behalf of the bill and to say thank you to our two outstanding witnesses.

Mr. BILIRAKIS. The Chair thanks the gentleman for being here and certainly thanks him for his legislation. You've worked on it, and I'm glad to see that we're finally getting around to moving it, Roger.

The Chair now recognizes the gentlelady from California, Ms. Eshoo.

Ms. ESHOO. Thank you, Mr. Chairman.

Good afternoon to you, and I want to be counted in amongst the colleagues of this committee in thanking you for having this hearing. It's an important one. I know you care about every single one of these issues, and we're very grateful to you for holding the hearing today and to all of the witnesses that are here. To Mr. McMahon, I can't help but think that as you announced so many winners in whatever that program was where you were announcing, that you would be able to go out and say that all of America is winning because of what the Congress has decided to do. I think that that could be really the most victorious message that comes

out of this very important subcommittee, where the first table is set for all of these issues.

There are a wide variety of issues that the committee is covering today, and that should be instructive to all of us and reinforce the tremendous scope and appreciation for that scope that this committee is responsible for. In one hearing, we are discussing a variety of bills and resolutions that deal with the public health issues that range from Muscular Dystrophy, to ensuring the availability of flu vaccine, it sounds kind funny that we have to do that, but I think the last thing that we can do in this country is to be complacent. We just assumed that there is a steady flow of what we need, and yet, here in the Congress, we in our seats are the ones that are going to assure that, and also to the issue of juvenile diabetes, to biomedical research at the NIH, which I have always called affectionately our "National Institutes of Hope," because they do speak of the hope and the dreams that the American people have, and we have to make good on that.

I'd like to speak specifically about one of the bills we are discussing today, and I hope that we're all in agreement on the great need to pass Congressman Gene Green's resolution advising the Congress to increase the funding for diabetes research at the NIH over the next 5 years. I think some of my colleagues were visited by student delegates that have come to the Hill this week. I had two in my office yesterday, 9 and 12 years old, I believe, and one of them, the younger one, Mary, said to me, "I want you to know something. When we get a cure, if there isn't enough, I'll give mine up for someone else." Now, this is a 9-year old. And, you know, I mean her mother kind of turned the other way and was wiping the tears out of her eyes. So, I mean, look at the unselfishness of this child and what she expressed.

So, I think—I know that we can do this, I mean, this is a gathering of a good group of people here at this committee, so we should forthwith past that, and I'm proud, obviously, to support that.

Obviously, the legislation, we have legislation that provides the CDC the funds and the direction to ensure that states receive their flu vaccine orders from manufacturers and distributors in a timely manner. We have to make good on this, and so this is something else that the committee just forthwith I think needs to pass and to get to the floor, and I don't think anyone in this country could ever dream of being placed in the situation where we don't have the resources to do this.

And finally, another bill that I'm proud to support legislation introduced by our chairman, to allow taxpayers to designate part or all of their income tax refund to be paid over for use in biomedical research conducted through the NIH. And, I just got an idea, Mr. Chairman, when I get my $300.00 refund, which I don't think would take my family out to dinner, but better spent I'll donate that. It's a drop in the bucket, but at least it bears some significance in terms of where it's going.

So, I think that your idea is one that's long overdue, we should take action on that, and I want to thank everyone that's in the room here today and beyond this room that are the unswerving advocates on these issues. The Congress is a reactive institution. We

shouldn't be reactive, we should be long-term planners and thinkers, but truth be known we are reactive, and we reactive to the agenda and the hopes and the aspirations of the American people, and I don't think many things would be in front of us, or continue to be in front of us, were it not for your advocacy.

So, let's roll up our sleeves, let's get this stuff done. Thank you, Mr. Chairman, for your leadership and your vision, and to everyone that's here today. Thank you.

Mr. BILIRAKIS. And, I thank the gentlelady.

Mr. Greenwood, for an opening statement?

Mr. GREENWOOD. Thank you, Mr. Chairman. I'll be very brief. Thank you for holding this hearing. In the last Congress, as everyone will recall, we had a variety of bills that were aimed at children's health, and we were able to hold a hearing like this and then group those bills together into one children's health bill, which was one of the most useful things I think the last Congress did. And, I'm hopeful that this session will be able to package all of these bills together and move them as an adults' package that would help, not only adults, but children as well, and I think once we add my Lyme disease bill to that package it will be just about perfect.

I yield back the balance of my time.

Mr. BILIRAKIS. I thank the gentleman in the interest of time.

Mr. Green, we've had Greenwood, now we have Green.

Mr. GREEN. Thank you, Mr. Chairman. We just dropped off our name, we moved from Pennsylvania.

Mr. Chairman, I thank you for, one, holding the hearing today on the many issues that we have, but most importantly the bill H.C.R. 36 that I introduced with 80 plus co-sponsors which recognizes the burden of Type I Diabetes, known as Juvenile Diabetes. I'd like to take the opportunity to welcome both two friends, but also constituents here, Larry Balthazar and his family are from my district in Houston, and young Larry is back behind them. Isn't he the cutest young man that I think we have. I've been working with the Balthazars on this issue for several years, and Larry was diagnosed with Juvenile Diabetes, and I'm pleased that they are here today to share how Juvenile Diabetes has affected their family.

Juvenile Diabetes is a serious and life-threatening disease that affects more than 1 million Americans, many of whom like Larry are diagnosed as children or during their adolescence. This dreaded disease robs these children of their innocence and independence and forces them in a lifelong regimen of insulin injections, blood sugar tests and careful diet. Even with this careful regimen, people with diabetes face an increasing risk of dreaded complications, including blindness, lower limb amputation, kidney failure, heart disease and stroke. Some people don't understand the seriousness of diabetes or think it's a matter of just watching what you eat, but it's much more serious than that.

Can any of us imagine a childhood where we couldn't have our birthday cake, or where playing too much at recess causes us to pass out? As parents, we can't imagine having to hold our children down and giving them a shot of insulin. Unfortunately, there are daily battles that hundreds of thousands of Americans with Type I Diabetes must face. They can't take a day off from diabetes or

leave it at home when they go on vacation. They can only take their shots and monitor their blood sugar and diet, and hope and pray for a cure.

Fortunately, that cure is not too far away. Promising new research, such as islet cell transplantation, have offered hope to millions of Americans living with diabetes. Research on new treatments such as non-invasive blood glucose monitoring and insulin inhalers, at least offer people with diabetes a pain-free alternative to injections and finger pricks. But insufficient funding levels prevent researchers from achieving the breakthroughs that seem to be so close.

The Diabetes Research Working Group was established by Congress in 1997 to develop a comprehensive plan for diabetes research. This team of diabetes experts released a plan which would increase the effectiveness of NIH-funded diabetes research and identify areas where additional resources could result in better treatments and cure for this dreaded disease. But, in order to achieve the full potential of the Diabetes Research Working Group's recommendation, Congress must make a significant increase in research funding. In fact, the Diabetes Research Working Group recommends a $4 billion increase over the next 4 years, and I know with this increase in funding we could realize a cure for diabetes. That's why the message of H.C.R. 36 is so important. It recognizes the burden of Juvenile Diabetes and urges Congress to fully fund diabetes research at the level recommended by the Diabetes Research Working Group.

I'm pleased, Mr. Chairman, again, thank you for including this legislation, and I thank the 80 plus colleagues that have co-sponsored it, and I look forward to hearing the witnesses, and I yield back the balance of my time.

Mr. BILIRAKIS. I thank the gentleman, and thank you also for the hard work on that legislation. We certainly will plan to address it.

Chairman Tauzin, the chairman of the full committee.

Chairman TAUZIN. Thank you, Mr. Chairman. I want to commend you for this important hearing, which will consider a number of bills and resolutions that are aimed toward advancing public health. I especially want to commend you, Mr. Bilirakis, for calling a hearing that is going to partially focus on some diseases that, while known only to a very few, destroy the lives of those afflicted. For example, I imagine that only a very small number of Americans have ever heard of tuberous sclerosis, and yet every day two children will be born with this disease, and many of these children will develop epilepsy and autism.

The Congress needs to raise the awareness about this disease and declare its responsibility for supporting research into discovering the causes of genetic mutation that leads to tuberous sclerosis.

Further, while Reflex Sympathetic Dystrophy impacts the lives of the 7 million children and adults suffering with the disease, as well as their care givers, it's still fairly unknown to most Americans. Individuals suffering from RSD exhibit such painful symptoms as chronic inflammation, spasms, burning pain, stiffness, discoloration of the skin, muscles, blood vessels and bones. So, we are pleased that today's hearing will focus attention on this disease, and I want

to commend Mr. Barrett from Wisconsin for introducing the RSD resolution.

Tuberous sclerosis and RSD are just two matters which will be considered today. The committee will also turn its attention to bills and resolutions intended to better the lives of those suffering from Duchenne Muscular Dystrophy, Juvenile Diabetes and prostate cancer.

I'm pleased today to have co-sponsored my good friend, Mr. Wicker's, bill, that I understand the NIH is in broad support of. Further, we will hear testimony from witnesses who will advocate better access to the flu vaccine, support for drug-free communities, and elevating the Director of the Indian Health Service to the level of Assistant Secretary.

And last, Mr. Chairman, I'm very interested in learning more about legislation which would allow taxpayers to direct a portion of their tax overpayments directly to the National Institutes of Health, for the purpose of increasing biomedical research funding. The Congress as a whole has been working for years to increase NIH funding. I view your bill as a way of empowering Americans to join us in this cause.

My own wife serves on the board of the Children's Inn there, and so I know firsthand, not only of the great and generous work that citizens of America do in supporting that center, but the broad work of the NIH itself.

Mr. Chairman, I also want to mention to you that every day one of us becomes aware of one of these relatively unknown diseases. I became aware of one called Friedreich's Ataxia, because a young lady who has worked for me ever since I served in the Louisiana Legislature 30 years ago happened to marry a man of Cajun descent here in Washington, DC, and the combination of their genetic background produced a child with Friedreich's Ataxia, a disease that happens to impact the Cajun population in America, about 2.5 times the general population. There are all kinds of diseases like that we just don't know a whole lot about, that strike young people and children, and in this case that amazing young son of theirs, Keith, is growing into adolescence knowing that by the time he's 23 he'll lose all muscular control. He's already experiencing the ravages of that disease in many important ways in his life, and it's so sad to see him going through it and knowing that, you know, research is just around the corner that's going to produce a cure or find some way to prevent it, and we can only hope and pray for all the families of Americans who find their children born with these little-known, but devastating, diseases, that we have done all we can while we are here to try to promote research, and trials, and particularly the kind of cooperation in genetic research that we understand holds so much promise in finding causes and cures and eventual prevention.

So, this is an important hearing today. It is some of the most important work the Energy and Commerce Committee does. It touches real lives, and it creates real hope in people who today look upon the situation as hopeless.

And so, Mr. Chairman, thank you for calling it, I wish you well and God speed in this work, and I look forward to receiving the bills in the full committee.

Mr. BILIRAKIS. Thank you, Mr. Chairman, and thanks for being here and for your interest.

Mr. Barrett.

Mr. BARRETT. Thank you, Mr. Chairman, for convening today's hearings. I'm looking forward to hearing from all the witnesses and learning more about the health initiatives before us today.

In particular, I'm glad to see that there's a measure on the table in support of increased funding for Juvenile Type I Diabetes. Children's Hospital of Wisconsin in my district conducts very little research on Juvenile Type I Diabetes, which affects over 1 million Americans. Certainly more research dollars are needed to help cure this disease.

I'm also very pleased that the committee has the opportunity to hear from Debra Lundquist of the American Society of RSD, CRPS, who will explain why a House concurrent resolution which I introduced to increase awareness about Reflex Sympathetic Dystrophy is so desperately needed. I first learned about RSD through an impassioned letter from a teenage girl living in Milwaukee who suffers from this disease. At age 12, Betsy Herman contracted RSD after spraining her ankle. She complained of an excruciating burning and aching pain in her limbs, common in RSD patients, but because of a lack of understanding about this disease her condition went undiagnosed. In fact, Betsy was accused of faking and exaggerating her illness and was sent to psychological counseling. Proper diagnosis and treatment can lead to full remission if the disease is caught early enough. This, unfortunately, wasn't the case for Betsy who has undergone several surgeries and now must walk with the help of an implanted device, and while other kids her age played sports and attended dances, Betsy had to wait until classes were in session to walk the halls of her high school to assure that she wasn't bumped, because even the slightest touch can cause severe pain.

As Ms. Lundquist will tell you, it is estimated that about 7 million Americans are afflicted with this disease, more people than suffer from Parkinson's, AIDS and Alzheimer's combined, yet there's a serious lack of awareness about RSD which means research efforts are miserably underfunded and treatment can be woefully inadequate.

That is why Betsy, Deb Lundquist, and other RSD patients and care givers have called on Congress to take a proactive stance in raising awareness among medical personnel and the general population about this disease. In response, I have introduced a resolution designed to bring attention to RSD.

The measure recognizes that advocates have designated each May as National RSD Awareness Month, and applauds their efforts for bringing attention to the disease. The bill also encourages all Americans, including health care providers, to become familiar with the symptoms of RSD, since early detection is vital to a full recovery. In addition, the measure asserts that the Federal Government has the responsibility to work to increase funding for RSD research and to consider ways to improve patients' access to quality health care services.

With congressional support, we can help advocates direct attention and research dollars to treating and, hopefully, curing RSD, while increasing compassion for its sufferers.

Again, thank you for holding this hearing today. I look forward to hearing from Ms. Lundquist and all the witnesses present, and I would yield back the balance of my time.

Mr. BILIRAKIS. I thank the gentleman.

Mr. Ehrlich, the gentleman from Maryland, for an opening statement.

Mr. EHRLICH. Thank you, Mr. Chairman.

I have a prepared statement, but I do want to make a point or two, and I appreciate the full committee chairman, who is leaving the room now, for allowing this hearing to occur, and I appreciate your concern with regard to these issues.

Many of us have appointments today for those of you not used to Capitol Hill, so we are running in and out and going different places, but please know on particularly a day like today we read your testimony.

This is about as nonpartisan an issue, a subject, a hearing, as you can have in this place. I often think, there are two places that are nonpartisan on the Hill, one is the House gym and the other is with regard to these issues, and I'm serious about that.

As the chairman stated, these issues, these individual diseases, impact all of us. There are ways that we can, elected officials, help. One, obviously, is to lend our names, whatever credibility we happen to have, with respect to boards, fund raisers and the like, and we all do that, both sides of the aisle. Second, funding NIH, which has been a good, and popular, and right thing to do here, even in tough fiscal times. And third, manipulating the tax code and to increase, in various innovative ways, money going to research.

With that being said, I am particularly interested in this hearing today with regard to, Mr. Chairman, Duchenne Muscular Dystrophy, and that has impacted the family of a close friend of the Ehrlich's, and we can all say that. As you know, all of you could say that, and most folks you stop on the street could say the same thing, it's the most common form of genetic childhood disease.

What's particularly frustrating, I guess, to some of us who have begun to follow this disease and are supporting this bill I'll get to in a second, is the fact that the gene was identified and isolated by researchers in 1987. My wife sits on the Cystic Fibrosis Board in Maryland, she was President, so I'm familiar with how important a development that is with regard to disease processes, but the research devoted and the dollars devoted to additional research has been rather minimal, and the numbers speak for themselves.

I do want to particularly commend my colleagues, Collin Peterson and Roger Wicker, who is here, I believe, for introducing H.R. 717, this CARE Act. The legislation will increase funding available for researching DMD, directing NIH's attention to solving this problem, and better educate the public with regard to this disease.

I also want to recognize Parent Project, and important organization for families of sufferers of DMD, a project I'm finding out more about myself, and thank them for their continued efforts to significantly increase the research dollars.

I ask all my colleagues in closing to support 717 and to support the families and children who wake up every day and must face this dreaded disease, and I yield back my time.

[The prepared statement of Hon. Robert L. Ehrlich, Jr. follows:]

PREPARED STATEMENT OF ROBERT EHRLICH, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MARYLAND

Mr. Chairman, thank you for holding this important hearing on legislative measures designed to address certain public health needs. I want to specifically call the Subcommittee's attention to a common childhood genetic disorder-Duchenne Muscular Dystrophy (DMD)—that affects approximately one in every 3,500 boys worldwide.

DMD is the world's most common form of genetic childhood disease. As the disease progresses, muscle deterioration in the back and chest exerts pressure against the lungs, making it difficult to breathe. By age 10, children born with DMD will lose the ability to walk. The deterioration process continues until it ultimately takes the boy's life, typically by the late teens or early twenties.

Although the gene that causes DMD was successfully identified and isolated by medical researchers in 1987, federal research devoted to potential treatment options or a cure since this initial discovery has been minimal. Of the $17.8 billion allocated for the National Institute of Health (NIH), only $9.2 million is invested in medical research specific to DMD. This limited federal support has resulted in minimal treatment options aimed at managing the symptoms, not treating the disease.

I want to commend my colleagues, Roger Wicker and Colin Peterson, for introducing H.R. 717, th DMD Childhood Assistance, Research, and Education (CARE) Act. This legislation will increase the funding available for researching DMD, direct NIH's attention to solving this problem, and better educate the public on this tragic disease. Also, I want to recognize Parent Project, an important organization for families of sufferers of DMD, and thank them for their continued efforts to significantly increase research at the federal level.

In closing, I ask all my colleagues to support H.R. 717, and to support the families and children who must wake up every day and face this dreaded disease. Thank you.

Mr. BILIRAKIS. I thank the gentleman for his opening statement. The opening statements of all members of the subcommittee are now terminated, and we will go on to the witnesses who have been very patient and understanding, and we appreciate that very much. You are all welcome.

[Additional statements submitted for the record follow:]

PREPARED STATEMENT OF HON. CHIP PICKERING, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MISSIPPI

Mr. Chairman, I want to thank you for holding this hearing and for your support for H.R. 717, the DMD Care Act of 2001. I also want to thank my friend and colleague from Mississippi, Mr. Wicker, for introducing the legislation we are considering today. I was proud to be among the original sponsors of this legislation with you and many other members of this Committee, and I note that the bill now has the co-sponsorship of 2/3rds of the House.

First of all, I would like to congratulate the Parent Project and all of the dedicated family members of children with this terrible affliction for their effective advocacy. I think they're truly made the case that the world's #1 lethal childhood genetic disorder deserves more than 1/2500th of the NIH budget. I am pleased to learn that when this legislation is marked up, it will reflect all muscular dystrophies, and I encourage the MDA's support.

The goal of this legislation is not to put muscular dystrophy at an advantage compared to other diseases of similar prevalence and severity, but rather to try to elevate it to a position of parity. Our Committee was instrumental last year in assuring the passage of a modest musculardystrophy title to the Children's Health Act calling for intensification of research on this disease. Since that time, NIH has offered a new Program Announcement of $5 million over three years. This is a positive development but more needs to be done. NIH must reorder its priorities to assure that developments in therapies to treat this disease are translated to clinical trials and to the patients.

I'm very pleased that our Committee is now poised to act on this legislation. I hope and trust that this legislation can be passed unanimously on the House floor before the August district work period, and that the other chamber will rapidly follow. I am very pleased to know that NIH officials have reviewed this legislation and they have suggested some changes which we can easily incorporate upon markup. It is clear that this is legislation that NIH can live with, and I would encourage NIH officials to go even further in their own efforts to escalate the pace of research into these diseases which take such a horrific toll on the lives of so many American children.

I look forward to the testimony of Ms. Furlong, as the mother of two boys who have succumbed to DMD, as well as the testimony of Mr. McMahon on behalf of the Muscular Dystrophy Association. Thank you.

PREPARED STATEMENT OF HON. CHIP PICKERING, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MISSIPPI

Mr. Chairman, thank you for having this important hearing on public health issues that affect all Americans. I would like to express my support for the bill H.R. 293, the legislation we are considering today that would elevate the position of the Director of the Indian Health Service (IHS) to Assistant Secretary of Health and Human Services (HHS).

This legislation will be beneficial to all Alaskan Natives and American Indians including the Mississippi Band of Choctaw Indians, led by Chief Phillip Martin, in my congressional district. I would like to ask unanimous consent to submit a letter of support for this legislation for the record from Chief Martin.

Mr. Chairman, as you know, the IHS is the lead agency in providing health care to the more than 550 Indian tribes in the United States. Services ranging from facility construction to pediatrics assist approximately 1.3 million American Indians and Alaska Natives each year.

The IHS currently falls under the authority of the Public Health Service within HHS. The IHS Director is the top administration official charged with carrying out the federal trust responsibility for IHS, but he does not report to the HHS Secretary.

Designating the IHS Director as an Assistant Secretary of Indian Health would afford IHS a stronger advocacy function within HHS, and allow for increased representation during the budget process. Similar legislation passed the Senate in 1999 by unanimous consent and there is no cost to the federal government associated with this bill.

Mr. Chairman, let me say thank you again for having this hearing today on a wide range of public health issues and I hope the Subcommittee will look favorably on H.R. 293. Thank you.

Mr. BILIRAKIS. The Chair now would recognize the gentleman from California, a gentleman of the world, Mr. Ed McMahon, National Vice President of the Muscular Dystrophy Association. Mr. McMahon, please proceed. We have a little clock here we set on 5 minutes. Obviously, if your statement would require a little more time than that we are certainly not going to cut you off.

STATEMENTS OF ED McMAHON, NATIONAL VICE PRESIDENT, MUSCULAR DYSTROPHY ASSOCIATION; PATRICIA FURLONG, PRESIDENT, PARENT PROJECT MUSCULAR DYSTROPHY; RAY MERENSTEIN, VICE PRESIDENT, PROGRAMS RESEARCH! AMERICA; CHARLES W. BLACKWELL, CHICKASAW NATION AMBASSADOR TO THE UNITED STATES; DAVID H. GREMILLION, MEMBER, BOARD OF DIRECTOR'S, MEN'S HEALTH NETWORK; WILLIAM J. HALL, PRESIDENT, AMERICAN COLLEGE OF PHYSICIANS-AMERICAN SOCIETY OF INTERNAL MEDICINE; DEBRA LUNDQUIST, ADMINISTRATIVE DIRECTOR, AMERICAN SOCIETY FOR REFLEX SYMPATHETIC DYSTROPHY/COMPLEX REGIONAL PAIN SYNDROME; LARRY BALTHAZAR; MICHAEL COBURN, PRESIDENT AND CEO, TUBEROUS SCLEROSIS ALLIANCE; AND JUDY CUSHING, IMMEDIATE PAST PRESIDENT, NATIONAL FAMILY PARTNERSHIP

Mr. MCMAHON. Thank you, Mr. Chairman, it will not. I will do it as quickly as I can, to give everybody else as much room as they need, but I appreciate being here. I'm honored by it. I'm fascinated by it, and it's quite a nice learning lesson for me.

I am here representing MDA and the 250,000 people that are afflicted with that disease, and though I'm not an expert in any sense of the word I have an expert behind me, this pretty lady right here, Doctor Sharon Hesterlee. You see her there? All right. She is our Director of Research Development, and all these pages I have, I only have three and a fifth right here, all these pages that I have could be summed up by what happened to me when I came into the building. I was waiting my turn to come through the security check, and as I came through the lady, security lady, said, "Well, what brings Mr. McMahon to our building?" I said, "Well, normally I give away money, here I'm trying to get some money." It's a different role for me, but for 50 years we have been funding this activity, Muscular Dystrophy Association, and we're almost a victim of our own success. We've been very successful over the years raising—last year we raised $55 million in a 21-hour period. It's quite remarkable that the American people get behind us so actively.

So, I'm here with hat in hand hoping that we can get a little money from the government. That's, essentially, what I'm doing here.

Let me just point out some things. For 50 years, MDA has been finding the top scientists in the world and funding their efforts to find what causes Muscular Dystrophy and how we can stop it. Now, we've made some very dramatic advances, 25 years of cellular biology, we've been able to locate genetic causes of almost all forms of Muscular Dystrophy.

Now, in just the past few years, MDA funded scientists have developed techniques that will allow us to attempt to fix genetic flaws that underline Muscular Dystrophy by inserting new genes into the human body. Now, these heroes of modern science are poised to test gene therapy for several forms of that disorder. The only thing that can slow our relentless pursuit and our advance toward treatments is money. So, until recently MDA has been able to handle this all by themselves, but now we need some help.

Muscular Dystrophy can result in a variety of different genetic mutations. Each mutation may require its own specific form of gene therapy. The cost of a clinical test of one genetic fix, for one particular disease, is $20 million. When you consider there are nine forms of Muscular Dystrophy, and some of those nine forms can result in many several different other defects, you can see why money is a major roadblock.

Now, in no way are we here to get money for us. The money is not for the Muscular Dystrophy Association. What we really want is money for the research centers that will be developed. Mr. Brown referred to this Article 717, and the CARE Act, 8105, I'd like to enter this into the hearing record if I may, Mr. Chairman.

Mr. BILIRAKIS. You learn quickly.

Mr. MCMAHON. Am I all right?

Mr. BILIRAKIS. Without objection.

Mr. MCMAHON. I remember this from high school.

Anyway, we are seeking $100 million, and that may seem like a lot of money to a lot of people and it is, but it's what we need so that people can walk again. Imagine what it's like for someone to have the ability to see their daughter down the aisle at her marriage, or to see a mother watch a child walk for the first time at 10 years old. Well, it's right here, it's waiting at the doorsteps. It's here for us. Money will make the difference.

So, rather than selling you something, I normally am selling. If you've watch television on any day for the last 53 years I've been selling something, from dog food, to beer, to automobiles, you name it, I've sold it, and I hope that I can sell this and make a point that this is something we need. We need your support, and we're going to sum it up by saying, help us find a cure, help us solve this problem. We need it, and it will be good for America.

Thank you.

Mr. BILIRAKIS. Thank you so much, sir. I would hope that you could help us with that BRAVO bill so we can get additional dollars coming from the public to NIH to supplement research, to complement the research.

Mr. MCMAHON. It was mentioned before, I was not aware of that, but if that can be put into the income tax system that would be wonderful.

Mr. BILIRAKIS. Yes. I'm going to get your address so we can help you out there.

Mr. MCMAHON. You have my help.

[The prepared statement of Ed McMahon follows:]

PREPARED STATEMENT OF ED MCMAHON, NATIONAL VICE PRESIDENT, MUSCULAR DYSTROPHY ASSOCIATION

Thank you Mr. Chairman and members of the Subcommittee. It's an honor to represent the Muscular Dystrophy Association and the 250,000 Americans affected by muscular dystrophy.

As you're aware, during my lengthy career in show business, besides hosting my own shows and spending a few years helping out some guy named Johnny, I've been a pitchman. Beer, dog food, insurance, magazines—you name it, I've helped sell it. Well, I'm here today to make a pitch to you. I don't want to sell you any products, but I do want you to buy something. What I'm selling is a dream—one you can make come true.

Obviously, I'm not trained as a physician or a researcher. I've got a pretty good layman's understanding of the nine forms of muscular dystrophy and where the research into finding treatments and cures is at the moment, but I don't pretend to

be an expert. That's why I've got Dr. Sharon Hesterlee, MDA's director of research development, here with me to handle any technical questions you might have. However, after spending more than 30 years serving as anchor of MDA's Labor Day Telethon with Jerry Lewis and doing my best to help the Association in any other ways I could, I do consider myself an expert on the human side of muscular dystrophy. Over the years, I've had the opportunity to meet and get to know many wonderful children and adults with MD. Unfortunately, many of them are not with us today. And that's why I am here today, and that's why I hope you're going to buy what I'm selling.

For more than 50 years, MDA has been funding the top scientists in the world in an effort to find out what causes muscular dystrophy and how we can stop it. With the dramatic advances made in the past 25 years in cellular biology, we've been able to locate the genetic causes of almost all the forms of muscular dystrophy. In just the past few years, MDA-funded scientists have developed techniques that will allow us to attempt to fix the genetic flaws that underlie muscular dystrophy by inserting new genes into the human body. These heroes of modern science are poised to test gene therapy for several forms of the disorder. The only thing that can slow our relentless advance toward treatments and cures is money. Until recently, MDA managed to fund all the research into muscular dystrophy that was scientifically justified. That's no longer the case.

The problem is that some forms of muscular dystrophy can result from a variety of different genetic mutations. Each mutation may require its own specific form of gene therapy. The cost of a clinical trial to test one genetic fix for one particular disease-causing flaw is $20 million. When you consider that there are nine forms of muscular dystrophy and that some of those nine forms can result from any of several different defects, it's easy to see why money is a major roadblock to testing this potential treatment. Despite the incredible generosity the American people show for MDA each year, there's no way a nonprofit organization like ours can possible afford to fund this vital research. For the first time in the history of the Muscular Dystrophy Association, we're asking the federal government to help in this fight. We don't ask for a penny for ourselves, but for an annual increase of $100 million in National Institutes of Health funding for muscular dystrophy research—money that will be distributed directly to the researchers trying to make treatments and cures for these devastating disorders a reality.

I've never tried to sell anything that cost $100 million before, but I've never had a product that I believed in as much as I do this one. Treatments and cures for muscular dystrophy would be a bargain at many times this price. We're talking about diseases that rob people of the ability to walk, to dress themselves, to feed themselves, eventually, even to breathe. We have to ask ourselves, how much is a human life worth? How much are tens of thousands of lives worth? Can you place a value on the smile on a mother's face when she sees her child walk for the first time at 10 years old? Or set a price on the pride a father feels at walking his daughter down the aisle on her wedding day because he was able to beat a disease that tried to steal his life? No product ever sold can offer so many benefits of such great value.

What do I get out of making this sale? I get some sense of peace from knowing that I've played a small part in fulfilling the promise that all of us at MDA made long ago—that we wouldn't quit until treatments and cures for muscular dystrophy are a reality. Each time I'm reminded of a special friend lost to this terrible disease—and believe me, after this many years it happens often—I can whisper, it wasn't in vain my friend. You helped us get here. You helped us make the dream come true.

When legislation calling for increased NIH funding for muscular dystrophy research comes before you, I hope that you'll remember the quarter of a million Americans waiting for a miracle, and that you'll decide to make a difference, to save lives, to make this dream come true.

Thank you from all of us who still believe in miracles.

Mr. BILIRAKIS. Ms. Pat Furlong is the President of Parent Project Muscular Dystrophy, located in Middletown, Ohio.

Ms. Furlong, please proceed.

STATEMENT OF PATRICIA FURLONG

Ms. FURLONG. Thank you.

I'd first like to express my appreciation to Chairman Bilirakis, Ranking Member Sherrod Brown, and members of this committee,

for the opportunity to testify. Boy, what a day for the Muscular Dystrophy community.

I want to express my special thanks to Representatives Roger Wicker and Collin Peterson. They have been our champions, and we are very, very grateful.

I represent Parent Project Muscular Dystrophy, a voluntary health organization comprised of parents and grandparents whose children have been diagnosed with Duchenne or Becker Muscular Dystrophy. We wish to expedite a treatment and cure for this disease. It is a heartbreaking disease.

Mr. Chairman, today I'm here to testify in support of legislation introduced this year with respect to Duchenne Muscular Dystrophy. Let me take a moment to say that Duchenne Becker Muscular Dystrophy represents 90 percent of the muscular dystrophies. This is the reason that we are here on the Hill.

For years, families have been smothered in public information that states we are almost there, we are around the corner, shortly there are answers. We are not quite there. Although emerging strategies leading to treatment and therapy in the future are in the works, Federal investment in Duchenne Muscular Dystrophy research has been minimal. We have to commit adequate resources to support the prognosis to see significant change in Duchenne Muscular Dystrophy.

My commitment to the Duchenne Muscular Dystrophy community stems from two convictions. My two boys were diagnosed in 1984, they died at ages 15 and 17. Second, my role with the Parent Project Muscular Dystrophy as President and Founder.

On a sunny day in June in 1984, a physician said to me, your sons have Duchenne Muscular Dystrophy, there is no hope, there is no help. Your daughters may be carriers. I'm not sure your family will survive. I wondered at that point why the sun still shined.

The barriers to progress on this disease says little for us as a society and a Nation, that due to significant lack of resources clinical outcomes for this disorder are predictable and remained unchanged. Boys die before reaching 20, before reaching adulthood, before experiencing life.

One day long ago, my son Patrick was trying to convince me of something a little bit crazy, which was pretty par for the course for Patrick. He said, pretend I'm in a mid-life crisis, in fact, he was 8 years old, and it was his mid life. Duchenne Muscular Dystrophy is the most common lethal childhood genetic disorder. It affects one in 3,500 males. There is a German study that would change the incidence and prevalence of this disease down to about one in every 2,500. This disease can be inherited through X-linked recessive transmission within families, although one third of this disease is spontaneous mutation. That means every person here, every Member of Congress, every member of this country and this world, is subject to the risk of this disease.

Children who are born with DMD follow a predictable clinical course. Young children develop difficulty walking and begin falling due to muscle weakness, and by 8 to 10 years of age the muscle weakness has progressed so that children often are not walking. By late teens, most Duchenne children have died from this disease, usually as victims of respiratory failure. This rather clinical expla-

nation does not clearly reflect the disorder. The children with Duchenne Muscular Dystrophy experience a lifetime of medical intervention. By the age of 12, most boys have lost their ability to walk and for the rest of their life will require the wheelchair. In an effort to prevent spinal curvature and respiratory compromise and bone loss, long-leg braces are utilized in combination with hours in standers.

Hand in hand with loss of function is loss of independence. The child will need help with ordinary things, lifting a fork, rolling over in bed, hugging someone they love. By the age of 15, the breathing apparatus of these children completely fails and is severely compromised. At that point, most children need invasive ventilation.

Finally, young men with Duchenne Muscular Dystrophy are often forgotten in that muscle is not just for moving bones, muscle comprises our—smooth muscle comprises our digestive tract, the heart is a muscle. These muscles fail, there is no muscle that escapes degeneration in Duchenne Muscular Dystrophy.

The diagnosis of Duchenne Muscular Dystrophy is accompanied by a lifetime of progressive loss of function, loss of independence, dependence on family and care givers. It's an extraordinary physical, mental, psychological, spiritual and financial burden to the families.

Finally, the loss of these boys, their absence diminishes us as a society. This great country is less than what it should be without these boys.

Before his death, my son Christopher said to me, "If you won't fight for me, who will?" It is for this reason we founded Parent Project Muscular Dystrophy. It is for this reason that we began in 1997 efforts and advocacy, and I must say it's a good day because the Muscular Dystrophy Association has now joined our efforts and together as a community we can see miracles for these boys.

Our advocacy program has now developed into a comprehensive Federal advocacy program, and it's been a truly remarkable year and a remarkable experience for Parent Project Muscular Dystrophy to see Congress take such a proactive, leading commitment to support the entire Muscular Dystrophy community has been spellbinding. On Valentine's Day of this year, H.R. 717, the Duchenne Muscular Dystrophy Childhood Assistance Research and Education Act, was introduced in the House of Representatives by Representatives Wicker and Peterson, and now today 304 co-sponsors. We are delighted.

As you know, this bill takes significant steps toward increasing Federal research dollars to find a cure for Duchenne and other forms of Muscular Dystrophy. Specifically, H.R. 717 has some key steps involved: increased coordination of research: building upon Title 23 of the Children's Health Act, H.R. 717 expands, intensifies, and coordinates research activities related to muscular dystrophy by establishing the Muscular Dystrophy Interagency Coordinating Committee. Centers of Excellence: In order to ensure a focused research effort on muscular dystrophy, H.R. 717 establishes up to three Centers of Excellence at NIH to support and expand basic and clinical research on various forms of muscular dystrophy. Centers of Excellence at CDC: To begin to analyze existing data and formulate linkages between the epidemiological aspects of this dis-

ease—particularly the high incidence of genetic mutations—with the research being conducted H.R. 717 also authorizes up to three Centers of Excellence within the CDC. The National Muscular Dystrophy Surveillance Program: The bill provides grants to public and nonprofit entities for implementation of a National Muscular Dystrophy Surveillance Program. And finally, Dissemination of Education to Medical Professionals and Promotion of Public Awareness: one of the profound problems in Duchenne Muscular Dystrophy is the range of care across this country and across the world. There is benign neglect to very aggressive care, and at each individual center it varies. We need to have consistent guidelines, standards of care. We need to make sure we maximize and optimize the lives of these children right now, as we push forward the emergence of treatments.

Much to the delight of the Parent Project Muscular Dystrophy and the entire muscular dystrophy community, the Senate soon followed the House's lead by introducing a consensus version of the House bill, S. 805. It was introduced and now has 32 co-sponsors. We are so thankful for the support of this Congress, and thankful that the face of this disease will soon change forever.

[The prepared statement of Patricia Furlong follows:]

PREPARED STATEMENT OF PATRICIA FURLONG, PRESIDENT, PARENT PROJECT MD

On behalf of the Parent Project for Muscular Dystrophy Research, Inc. (otherwise known as the Parent Project MD), I would like to express the organization's sincere appreciation to Chairman Michael Bilirakis, Ranking Member Sherrod Brown and Members of this Committee for the opportunity to testify before you today.

I represent the Parent Project MD, a nonprofit voluntary health organization comprised of parents and grandparents whose children have been diagnosed with Duchenne muscular dystrophy or its milder form, Becker muscular dystrophy. The Parent Project MD's mission is quite simple and straightforward: To mobilize people in the USA and Worldwide in collaborative efforts, enabling people with Duchenne and Becker Muscular Dystrophy to survive, thrive and fully participate into adult age. We wish to expedite treatment and a cure for this heartbreaking muscle disorder by increasing support for research.

Mr. Chairman, today I am here to testify in support of legislation introduced this year with respect to Duchenne Muscular Dystrophy. I'd like to take a moment though and first reflect on some of my own impressions of Duchenne and its impact on families. For years, families have been smothered with public information stating that we are 'almost there' or 'around the corner'. Answers are on the horizon -or are they? Mr. Chairman, we are not there. Although emerging strategies leading to treatment and therapy in the future are in the works, federal investment in DMD research has been abysmal until only recently. We have to commit adequate resources and support before the prognosis of DMD will see significant change.

My commitment to the Duchenne muscular dystrophy community stems from two convictions: first, from my experience as a mother of two children who died from Duchenne; second, my role as founder and President of the Parent Project Muscular Dystrophy. I have to be honest here in saying that if given the choice, I would rather just be a normal mom with two sons and two daughters, both of my sons being alive still and healthy. Unfortunately, this was not the plan for my family. On a sunny June day in 1984, my sons were diagnosed with Duchenne muscular dystrophy. To this day, I recall the exact words: "Mrs. Furlong, your sons have Duchenne muscular dystrophy, you are therefore a carrier, one or both of your daughters will perhaps be carriers. Your marriage will fail and your daughters will suffer due to the amount of care you will necessarily provide for your boys. Do you have any questions?" I wondered why the sun was still shining.

THE INJUSTICE OF DUCHENNE

It simply isn't fair to be bright, handsome, and full of potential. To be well adjusted in a good family, having so much to give the world, to be so loved and then to die so young. Worse, is to both see and feel the life force deteriorate slowly, fi-

nally and completely—until there is nothing left. Mr. Chairman, we live in a proactive, positive world, though children with DMD are ultimately powerless.

The barriers to progress on this disease says little for us as a society and as a nation—that due to a lack of significant resources, clinical outcomes of this disorder are predictable and remain unchanged. Boys die before reaching 20, before reaching adulthood, before experiencing life. One day, long ago, my son Patrick was trying to convince me about one of his crazy ideas and I recall smiling at his comment "Mom, pretend I am having a midlife crisis.[[Sadly, age 8 was midlife for Patrick—his argument was sound.

Duchenne Muscular Dystrophy (DMD) is the most common lethal childhood genetic disorder in the world, affecting 1:2328 male newborns worldwide (1997 German study). The disease can be inherited through X-linked recessive transmission within families, or it may be caused by a spontaneous mutation in individuals. In fact, one-third of Duchenne cases are not inherited but are caused by a gene mutation. Children who are born with DMD follow a predictable clinical course. Young children develop difficulty walking and begin falling due to muscle weakness, and by 8-10 years of age the muscle weakness has progressed to the point where most children must rely on wheelchairs. By their late teens, most DMD children have succumbed to their disease, usually as victims of respiratory failure.

This rather clinical explanation does not clearly reflect the disorder. Children with DMD experience a lifetime of medical intervention. As toddlers, boys with DMD look quite normal. At diagnosis—informed physicians refer to baseline studies, night splints, AFO's and PT—an excessive barrage of medical lingo that will soon become a second language for the family. As a mechanism to prevent contractures of the Achilles tendon, hamstrings and ileotibial bands, gait changes, lordosis, walking on their toes and finally loss of ambulation, boys with DMD require aggressive physical therapy, ankle-foot orthosis (AFO's), and long leg braces.

By the age of 12, most boys have lost their ability to walk and, for the rest of their life, will require an electric wheelchair. In an effort to prevent spinal curvature, respiratory compromise and bone loss—long leg braces are utilized in combination with several hours of upright posture in 'standers'. Hand in hand with loss of function is loss of independence. The child will need help with ordinary things: associated issues related to schooling, toileting, lifting a fork, turning in bed.

By the age of 15, the breathing apparatus of these children is severely compromised. When laying flat in bed, these children do not have sufficient respiratory effort to exhale, blow off CO2; hence mechanical (noninvasive) ventilation is instituted. They sleep with a mask over the nose and mouth (BiPap ventilation), which provides forced air into the lungs and therefore enhances their ability to exhale.

Finally, the young man with DMD will require invasive ventilation -tracheotomy and ventilators due to extraordinary weakness of the pulmonary apparatus. Often we forget that muscle encompasses much more than moving bones—the heart is a muscle as is the digestive tract, which is comprised of smooth muscle. No muscle escapes degeneration in Duchenne. Children with Duchenne have cardiomegaly (enlarged heart), decreased cardiac output and congestive heart failure in their late teens. During the late teens or early 20's, young men with DMD are unable to manage oral secretions, have difficulty with digestion and require manual removal of stool.

The Diagnosis of DMD is accompanied by a lifetime of progressive loss of function, loss of independence, dependence on family/caregivers and extraordinary physical, mental, psychological, spiritual and financial burden for the family and for all of us, as a society. Finally, the loss of these boys—their absence—what we miss as parents, siblings, relatives, communities as a society is great. This greatest country on earth is diminished by our irreverence for the lives of these children.

PARENT PROJECT MD & ADVOCACY

Before his death, my son Christopher asked, "if you will not fight for me, than who will?" I was devastated at this question, for one feels completely defeated when they cannot help protect their own child, instead having to simply watch the child suffer this long, agonizing death. Parents from around the US, indeed the world, wanted to advocate for their child, for this disease. Our children are not out of their warranty period before they wear out, our children will never have the adult status to advocate on their own behalf, our children's degeneration sends ripples of pain and dysfunction through generations of families. As a result, in 1994 a small group of parents founded Parent Project Muscular Dystrophy, a national nonprofit dedicated to expediting research and a cure for DMD/BMD.

In 1997, Parent Project MD members initiated its first advocacy agenda. Initially, we wrote letters to representatives—please on behalf of our sons. In 1999, the

House Labor/HHS Appropriations Subcommittee heard our testimony. Last year, the Senate Appropriations Committee graciously included strong DMD report language in its conference report, ensuring a greater commitment to coordination within the National Institutes of Health. We were further blessed by the efforts of your Committee last year when muscular dystrophy was granted a separate Title in the Children's Health Act of 2000—the first time in history there has been a federal mandate on Duchenne and other forms of Muscular Dystrophy.

Our advocacy program has now developed into a comprehensive federal advocacy program, and it has been a truly remarkable year for the Parent Project Muscular Dystrophy, and for the entire muscular dystrophy community as a whole. To see Congress take such a proactive, leading commitment to supporting the entire muscular dystrophy community has been completely spell-binding. On Valentine's Day of this year, H.R. 717, the Duchenne Muscular Dystrophy Childhood Assistance, Research and Education Act (commonly referred to as the DMD CARE Act), was introduced in the House of Representatives by Representatives Roger Wicker, Collin Peterson and 90 original co-sponsors. Today, this bill boasts of 290 cosponsors, showing the tremendous support of the Congress in increasing federal research efforts towards Duchenne muscular dystrophy.

MERITS OF H.R. 717, THE DMD CARE ACT

As you know, this bill takes significant steps towards increasing federal research efforts to find a cure for Duchenne and other forms of muscular dystrophy. Specifically, H.R. 717 takes five key steps towards improving the federal commitment to muscular dystrophy:

- **Increased Coordination:** Building upon Title 23 of the Children's Health Act of 2000, H.R. 717 expands, intensifies, and coordinates research activities related to muscular dystrophy by establishing the Muscular Dystrophy Interagency Coordinating Committee.
- **Centers of Excellence at NIH:** In order to ensure a focused research effort on muscular dystrophy, H.R. 717 establishes up to three Centers of Excellence at NIH to support and expand basic and clinical research on various forms of muscular dystrophy, including investigations into the diagnosis, early detection, prevention, control, and adequate treatment of various forms of muscular dystrophy.
- **Centers of Excellence at CDC:** To begin to analyze existing data and formulate linkages between the epidemiological aspects of this disease—particularly the high incidence of gene mutations—with the research being conducted, H.R. 717 also authorizes up to three Centers of Excellence in muscular dystrophy epidemiology through the Centers of Disease Control and Prevention (CDC).
- **National Muscular Dystrophy Surveillance Program:** The bill provides grants to public or nonprofit private entities for the implementation of a National Muscular Dystrophy Surveillance Program.
- **Dissemination of Education to Medical Professionals and Promotion of Public Awareness:** H.R. 717 establishes and implements a program to provide information and education on muscular dystrophy to health professionals and the general public, including information and education on advances in the diagnosis and treatment of muscular dystrophy and training and continuing education through programs for scientists, physicians, and other health professionals who provide care for patients with muscular dystrophy.

CONCLUSION

Much to the delight of the Parent Project MD and the entire muscular dystrophy community, the Senate soon followed the House's lead by introducing a consensus version of the House bill. S. 805, the Muscular Dystrophy CARE Act, was introduced in May and now has 30 cosponsors.

The enormous support this bill has generated in such a short amount of time speaks volumes not only about the significant external support of the legislation, but also to the integrity of our Congressional leaders who have listened with open hearts and open minds to their constituents and families of children with Duchenne muscular dystrophy. Our earnest hope is that you never have to understand firsthand the devastation of Duchenne muscular dystrophy. Your leadership in addressing this important legislation reminds us that Congress does care and Congress does act to ensure our national resources are appropriately directed.

Respected Members of the Subcommittee, today, our battle is against Duchenne and other forms of muscular dystrophy. My personal story is a collective story about all the children diagnosed with Duchenne who, and following their exposure to myriads of medical intervention, lose all independence and finally their lives. Mr.

Chairman, in this, NOTHING has changed in the last 100 years, the story remains unchanged and will remain so without increased investment in DMD research. In this remarkable land of medical miracles, we should all hide our faces in shame on that one statistic; let alone the harsh reality of this progressive, heartbreaking degenerative process known as Duchenne.

We ask that you listen now to the voices of these young men, as their voices will surely fade before they reach adulthood. We urge you to provide this legislative direction for research that will investigate the territory of this devastating disease and the weaponry needed to win this war. Without your help, our children will continue to have the same prognosis for another 100 years. Mr. Chairman and distinguished members of the Committee, we are honored to appear before you today, and grateful for this opportunity to testify.

Mr. BILIRAKIS. Thank you very much, Ms. Furlong. You do your sons proud.

Our next witness is Mr. Ray Merenstein, who is the Vice President for Programs of Research!America.

Mr. Merenstein, you are recognized to testify.

STATEMENT OF RAY MERENSTEIN

Mr. MERENSTEIN. Thank you.

Mr. Chairman, distinguished members of the subcommittee, I thank you for your leadership and tireless dedication to the longevity, quality of life and health of your constituents. It is with great honor that I testify before this subcommittee, the very one chaired by another distinguished gentleman from Florida, Paul Rogers, who is now Chair of Research!America.

I testify on behalf of Research!America, the Nation's largest advocacy organization for the full spectrum of medical and health research. We are a leader in the movement to double funding for NIH, and ensure strong, sustainable support for its sister health and science agencies.

One hat I wear is Director of the 435 project, a national outreach campaign bringing research closer to home. There is a story to be told in all 435 Congressional districts, as we just heard, about the progress and promise of medical and health research. The research enterprise is about access to answers, not just answers to scientific hypotheses, but answers of accountability that show the money is spent wisely, the science is done justly, and results are producing constantly.

It is your vision as a subcommittee, and those who join the cosponsors of H.R. 1340, BRAVO, that should be commended. One thing I've learned traveling the Nation listening to focus groups and patient testimonials over the past decade, is that no commitment can be too great if it saves even just one life and reduces suffering. The return of the investment on research in terms of economic impact and quality of life is a remarkable one. So, while some questions of the fast growth of agencies are aquarius to what's next after doubling may arise, there's a three-part equation I offer to justify the funding: the will of the people, the opportunity of science, and the reality of politics. We must enhance the book of knowledge so that discovery expands and delivery provides, and we must continue authorizing novel ideas like the BRAVO Act.

As early as 1995, Research!America's polls asked the following question: if you could check off a box on your Federal income tax return to have some of your tax refund be donated specifically for

medical research, do you think you would? In Florida, for example, 56 percent of those surveyed answered affirmatively.

In 2000, just shy of 94 million people received refunds. This translates, according to our polls, to 52.6 million citizens willing to donate some of their refund. If every person willing to donate just put in $1.00 of his or her refund it would garner over $50 million in extra funding. Based on the average size of an NIH grant, that is more than 160 new research ideas. If ever there was a doubt that Americans are willing to pay for more research out of their own pocket, just look at the breast cancer stamp. The .40 cent stamp in its first 9 months raised $6.6 million for breast cancer research.

But, what makes BRAVO even more appealing is it does not specify any particular disease. So, if discoveries are made researching one area, they might have benefits for another area. The tax refund affords peer reviewed science the opportunity to identify the greatest chance in science for researchers, clinicians, fellowships, and trainees all across America, which brings me to the opportunity in science.

Earlier this year, Lasker/Funding First partnered with JAMA to give a spectacular glimpse into the crystal ball of a healthier America. Lasker/Funding First also published exceptional returns in economic study from economists on the impact of medical and health research. Today's headline noting, "Decreases in heart disease, cancer, AIDS, stroke," those are the kind of cost impacts that allow us to put more money back into research. A 17-year investment of just $56 million produced a 91 percent cure rate for testicular cancer with a return now annually of $166 million.

A new NIH report titled, "Investments, Progress and Plans," categorically points out the success stories of the past few years in oral health, nursing, aging, childhood illness, mental health, orphan diseases known to few, and Alzheimer's, Parkinson's and others known to millions. The NIH report also notes progress, controlling emergent infectious diseases that I know the ranking minority member has a certain championing for, building on the human genome, advancing technologies, and understanding health disparities. In other words, research saves lives and research saves money.

Despite such progress, we still only fund about two out of every five meritorious grants. Training grants for clinicians are too small and sometimes new scientists struggle to make a career. This Nation must not warehouse solutions. BRAVO will make a difference. Can we spend the money wisely? What will happen after doubling? What about public health in the physical sciences? Evidence is provided by the young boy or girl who is a part of the 80 percent cure rate in childhood leukemia, the elderly woman whose eyesight has been restored, the father who has survived heart disease and the diabetic whose hope for a cure is greater than ever. Last year should be the greatest of all indicators of where there's a will there's a way, a championed bipartisan agreement resulted in a 14 percent increase for NIH, 13 percent for NSF, 31 for the Agency for Health Care Research and Quality, 25 for CDC, and a 7 percent increase for the VA Medical Research and Prosthetics budget. The strides and success of yesteryear are the breakthroughs and brain

child of tomorrow. Those surveyed in our prevention research initiative, Congress, media, public health professionals, academic leaders, and perhaps most importantly survivors, all expect a great deal of progress over the next 10 years in disease prevention and health promotion, and they, too, support a tax checkoff to help fund this research, so much that it's above the 70 percent level 5 to 6 years after we began surveying on this.

To the chairman and members of the subcommittee, you truly are, as this hearing is entitled, advancing the health of the American people. The public is on your side and so is scientific opportunity, and without question you have the political will.

As Chairman Rogers said earlier this month when the plaza in front of NIH, Building 1, was dedicated in his honor, "Without research there is no hope."

Thank you to the subcommittee and to all of your colleagues for making hope all the greater.

[The prepared statement of Ray Merenstein follows:]

PREPARED STATEMENT OF RAY MERENSTEIN, VICE PRESIDENT, PROGRAMS, RESEARCH!AMERICA

From the introduction of the National Cancer Act to the reauthorization of the Agency for Healthcare Research and Quality, this subcommittee has always been an outspoken personification of Congressional commitment to the health of our nation's citizenry. Chairman Bilirakis, and distinguished members of this subcommittee, I thank you for your leadership and tireless dedication to the longevity, quality of life and health of your constituents, your state, your country, not to mention globally. It is with great honor that I testify before this subcommittee, the very one that was once chaired by another leader from the great state of Florida, and now chair of Research!America, the Honorable Paul G. Rogers.

Today I am here to testify on behalf of Research!America, the nation's largest unified advocacy voice for medical and health research. Research!America is a recognized leader in the movement to double funding for NIH by fiscal year 2003 while ensuring strong and sustainable growth for its sister health and science agencies. Our membership now represents more than 400 voluntary health agencies, teaching hospitals, academic institutions, industries, philanthropies, professional societies, state-based organizations and trade associations.

My title is vice president of programs, but perhaps more appropriate to today's hearing, I also serve as director of the 435 Project®—a national outreach campaign dedicated to bringing research closer to home. There is a story to be told in all 435 Congressional district, hence the 435 Project®, about the remarkable progress and the endless promise brought about by medical and health research. After all, it is the taxpayer, the consumer, the shareholder and the philanthropic donor that make research possible in this country. The research enterprise is about access to answers—not just answers to scientific hypotheses, but answers of accountability that show the money is spent wisely, the science is done justly and the results are producing constantly.

H.R. 1340

Chairman Bilirakis, it is your vision, and those who join you as co-sponsors of H.R. 1340, the BRAVO (Biomedical Research Assistance Voluntary Option) Act, that should be commended in particular. If there is one thing I've learned traveling the nation for nearly a decade listening to focus groups, patient testimonials, scientific projects and economic impact as they relate to medical and health research, it is that no commitment can be too large if the research leads to the end of suffering for millions of Americans. Research does make a difference.

Even with the movement to double the budget of the NIH, one for which we owe gratitude to all of you on the subcommittee, there is still less than a nickel of every health care dollar going to medical research. That's why the work of your subcommittee is so important. It continues to look at a health system—Medicaid and Medicare, research, patient care and more—with a cost of over one trillion dollars. It is your subcommittee that tries to figure out how to make that system more effective in terms of quality and in terms of cost. As my testimony covers later, you will

find the return on the investment in research—in terms of economic impact and quality of life—a remarkable one.

To those wondering if it is justified to find yet another funding stream for NIH on top of the generous budget increases set forth the past few years, the stories of survival from citizens across American should cure such doubts. No other Federal investment can bring better treatments, stronger cures and improved prevention of disease than support of our national research agencies. So while some question the fast growth of agencies or query as to what's next after doubling, there is a tripartite equation I offer to justify the funding: the will of the people, the opportunity of science and the reality of politics. Each of these I will address, and each ends in a resounding indication that ramped up investment in medical and health research is economically, physically and politically the right thing to do.

If as a nation—whether legislators in the halls of Congress or scientists in the labs of universities—we are to make a difference in the people's health, this country must financially and scientifically ensure that research enhance the book of knowledge so that discovery expands and delivery provides. We must continue funding increases through appropriations and we must continue authorizing novel ideas like the ever successful breast cancer stamp or the visionary BRAVO act. Such leadership will ensure more diseases are being prevented, new scientists are being funded, more dollars are being saved, and more ideas are being generated.

Public Opinion

When it comes to taxpayer-supported research, the public is on your side. As early as 1996, Research!America in its statewide polls asked the following question: "If you could check off a box on your federal income tax return to have some of your tax refund be donated specifically for medical research do you think you definitely would, probably would, probably would not or definitely would not consider doing this." Fifty six percent of those surveyed answered affirmatively.[1] This question was followed then by asking those who would donate to tell how much they would donate. The answers ranged from 15 percent of those favoring the idea willing to donate $5-10 dollars and even 2 percent willing to apportion $100-500 of their refund. Here's the difference that it would make. In 2000, just shy of 94 million people received refunds.[2] Based on the survey, fifty six percent of those would donate meaning 52.6 million citizens. Even if every person willing to donate gave only $1 of his or her refund (far less than the median response on the survey), it would garner over $50 million in extra funding for future treatments, cures and preventions. Based on the average size of an NIH grant, this is more than 160 new research ideas.[3]

The public's overwhelming support for research has been tested by Research!America numerous ways. When people say they will put some of their refund or some of their stamp money into research, they aren't just responding in idealistic or altruistic fashion. They have hope, they have expectation and they have belief in science. For example, when Research!America has asked if the federal government should invest in research even if it has no immediate benefit, more than 78 percent answered yes. It is our nation's role to be a leader in medical and health research. In fact, more than 86 percent of those surveyed say it is important that the U.S. maintains its role as a world leader in medical research.[4]

If ever there was doubt that Americans would be willing to fund more out of their pockets for research—beyond what they already support—just look again at the breast cancer stamp. In the first nine months of the special 40-cent stamp, $6.6 million was raised for breast cancer research. Demand was so high and people's willingness to pay more for research so great, that an initial second printing of the stamps had to be completed. Does it make a difference? Certainly. In 1999 the FDA approved 15 treatments for cancer and cancer pain alone.

What makes BRAVO even more appealing, is it does not specify any one disease toward which the money should be directed. The tax refund as a complementary funding source—and I note complementary, as it should not supplant the necessary increase in funding from appropriations—will afford the peer-reviewed science to identify the greatest opportunities and to fund researchers, clinicians, fellowships and trainees all across America. More funding will also play a key role in sustaining the growth of opportunity. For with the review, implementation and evaluation of every idea comes the need for strong management, administrative and infrastruc-

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[1] Research!America. Floridians Speak Out About Medical Research. February 1996: Alexandria, VA

[2] www.irs.gov

[3] http://silk.nih.gov/public/cbz2zoz.@www.charts.avgr01.pdf

[4] http://www.researchamerica.org/opinions/2000polls.generalversion.html

ture support. Opportunity must be met, and it must be managed. Additional funding will help fulfill the opportunities. Which brings me to the second area of accountability for medical and health research: the opportunity in science.

The Opportunity of Science

Recently Lasker/Funding First commissioned a series of papers published earlier this year in the *Journal of the American Medical Association.* The papers provide a spectacular glimpse into the crystal ball of a healthier America. Alzheimer's disease and osteoporosis are strong candidates for disease prevention. It should be noted that a five-year delay in the onset of Alzheimer's can save more than $50 billion annually.[5] Chronic diseases such as Parkinson's and arthritis will be brought under control even more than they are today. According to a study by Ken Manton out of Duke University, there is evidence that research has led to a decline in disability rates of elderly, thereby saving a tremendous toll on the healthcare costs of tomorrow.[6] As Katie Couric said in receiving an advocacy award from Research!America, many cancers will be read about in history books rather than text books. Already a 91 percent cure rate of testicular cancer, based on an investment of just $56 million over 17 years is more than paying for the research with a return of $166 million in *annual* savings.[7] Such savings in cancer and other disease is reiterated by studies from economists compiled by Lasker/Funding First.[8]

I want to point out a recent compilation of success and promise that NIH has put together to highlight the impact of the dramatic rise in funding. Just recently they issued "Investments, Progress and Plans: Selected examples from FY 1999-2003."[9] This categorically points out the amazing success stories of just the past few years in oral health research, nursing research, research into aging and research into childhood illness, research in mental health, research in orphan diseases known to few, and research in AIDS, cancer, heart disease and stroke known to millions. Perhaps more pertinent is the NIH report also notates the potential for progress. Controlling re-emerging infectious disease like tuberculosis—a disease I know ranking member Brown continues to target, is within our grasp. The human genome has provided us with a set of keys and a series of doors that lead to new treatments and even cures for cystic fibrosis, heart disease and so much more. Advanced technologies depend on ever-increasing funds in order to catalyze partnerships with NSF, DOD and DOE. New understanding of health disparities have us on the verge of translating the discovery of NIH to the delivery of CDC and the quality and cost control of AHRQ for those populations most in need. In other words, research saves lives and research saves money.

Hence, BRAVO and other innovative ways to sustain strong funding for NIH—and its sister agencies—are vital. The promise of research doesn't draw to a close in fiscal year 2003 when we all hope the NIH "double in five" movement has been accomplished. Science has made dramatic progress as I've noted before, but the yellow brick road it's paving has some curves to still negotiate and some hills to climb. Today, despite funding increases, our nation still only supports less than two out of every five meritorious research ideas. Training grants for clinicians to study research—physician, dental and nursing researchers—are too small to serve as an incentive and thus this nation risks a decreasing research workforce. Young scientists still sometimes struggle to make a career in research for fear that a project might not get funded. Increased funding is making a difference. A 65 percent increase in funding for first time NIH-funded scientists occurred between 1995 and 1999; success rates for young scientists submitting ideas grew from one in seven, to one in four, over the same period. But this still means the majority aren't getting funded. Too many ideas are out there becoming lost opportunities. This nation must not warehouse solutions. Supplemental funds from ideas like BRAVO will make a difference.

The Reality of Politics

With the great growth of NIH have come a series of questions. Can the money be spent wisely? What will happen after doubling? What about public health and the physical sciences? These are all questions that ought to be asked, and they are all questions with answers that ought to be heard. The money, as NIH's new report shows, is being spent wisely. But even more evidence is provided by the young boy

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[5] Alliance for Aging Research, "Putting Aging on Hold: Delaying the Diseases of Old Age". Washington, DC

[6] Manton, K., et al, *Proceedings of the National Academy of Sciences,* Vol. 94, pp. 2593-2598, March 1997.

[7] http://www.aamc.org/adhocgp

[8] http://www.laskerfoundation.org/reports/pdf/exceptional.pdf

[9] http://www.nih.gov/about/investments.htm

or girl who is a part of the eighty percent cure rate in childhood leukemia, the elderly woman or man whose eyesight has been restored as a result of new technology and greater understanding of the function of vision, the mother or father who survived heart disease because of progress in bypass surgery or success of automatic defibrillators, the diabetic whose hope for a cure is greater than ever because of potential with stem cells, islet cells and other new knowledge gleaned from research. This is the proof that increased funding does make a difference.

As to what will happen after doubling, I urge all of you to recognize that even in times of certain budget cuts, scientific opportunity should become political reality. It was less than a decade ago when science agencies were going to be slashed by 20-25%, but the leadership of those like Senator Mark Hatfield, the Appropriations chair at the time, carved out near double digit increases for NIH because the science warranted such a funding level. And last year should be the greatest of all indicators of the "where there's a will there's a way" adage. A bipartisan agreement resulted in a 14 percent increase for NIH and a 13 percent rise for NSF, a 31 percent increase for AHRQ, a 25 percent increase for CDC and a 7 percent increase for the VA research and prosthetics research budget.

Research!America recently polled survivors of preventable diseases on a national scale as part of our prevention research initiative. To no surprise, survivors are very supportive of research. Yet even though their survival is testament to research's progress, 85 percent still feel preventable diseases and injuries in this country are a major health problem. Meanwhile more than 65 Members of Congress and senior staff polled at the same time confirmed the same with 95 percent citing it as a major health problem.[10] The strides and success of yesteryear, lead to the brainchilds and breakthroughs of tomorrow. From basic research to behavioral science, more can and will be done if supported at the level of the public's desire and of science's capability. This is why majorities of all those surveyed—Congress, media, public health professionals, academic leaders, survivors and the general public—expect a great deal of progress to be made in health promotion and disease prevention research in the next 10 years. With continued growth in support for NIH, alongside AHRQ, CDC, NSF, VA and others, this expectation will become reality.

Chairman Bilirakis and members of the subcommittee, you truly are, as this hearing says, "Advancing the Health of the American People and Addressing Various Public Health Needs." Feel good about what you're doing. The public is on your side and so is scientific opportunity and political will. As Chairman Paul Rogers says often and said earlier this month when the plaza outside building one at NIH was dedicated in his honor, "Without research there is no hope." Thank you for making hope all the greater and better health all the likelier.

If you could donate some of your tax refund specifically for medical research, do you think you would?

(Percent saying would consider)

	%
Alaska (1997)	56
Oklahoma (1997)	55
Pennsylvania (1997)	56
Wisconsin (1997)	54
California (1996)	59
Florida (1996)	56
Texas (1996)	51
National (1995)	60
Kentucky (1994)	61
Virginia (1994)	75

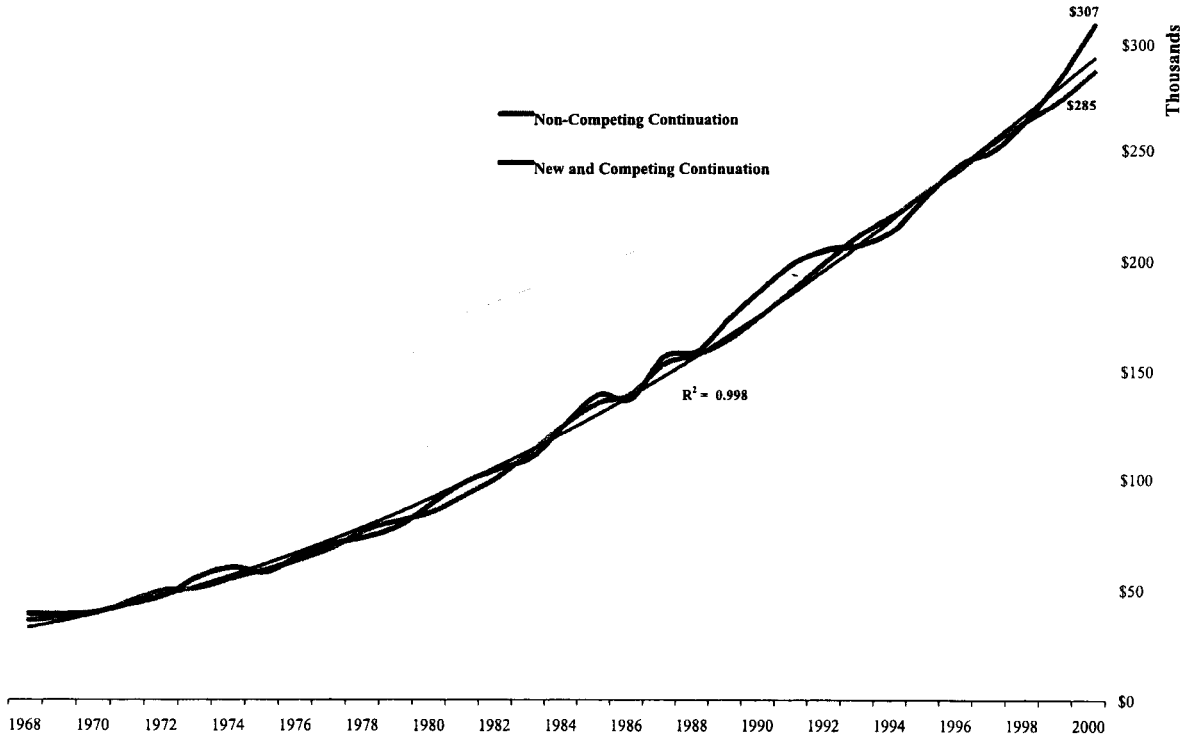
Source: Research!America

[10] http://www.researchamerica.org/programs/pri/roper.html

Table 10 -- Number of Internal Revenue Refunds Issued, by Internal Revenue Region and District, Fiscal Year 1999 [1]

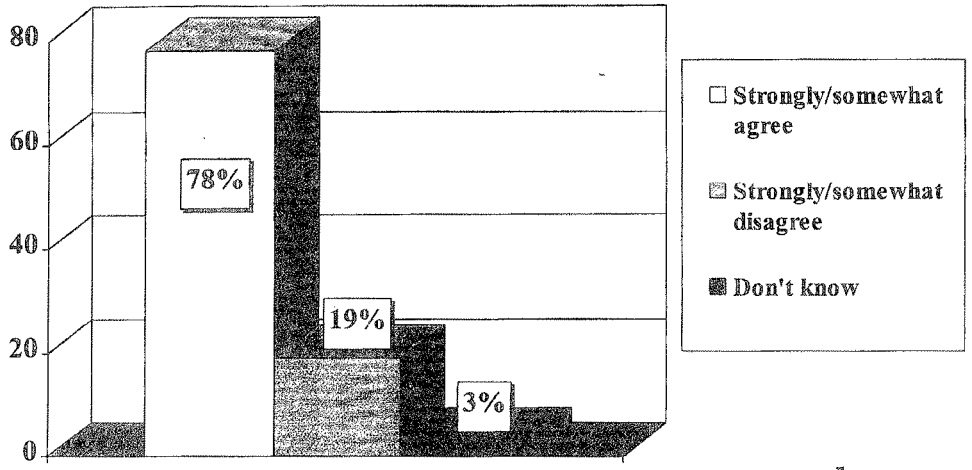
Internal Revenue region and district	Total Internal Revenue refunds [1]	Number of refunds of-- Corporation income tax [2]	Individual income tax [3]	Employment taxes [4]	Estate tax	Gift tax	Excise taxes [1]
	(1)	(2)	(3)	(4)	(5)	(6)	(7)
United States, total	**96,520,042**	**542,857**	**93,919,447**	**1,971,456**	**19,197**	**3,759**	**63,326**
Northeast Region	**26,559,452**	**194,789**	**25,851,381**	**490,629**	**5,932**	**1,224**	**15,517**
Brooklyn	2,375,848	6,233	2,321,552	46,378	573	91	1,021
Connecticut-Rhode Island	1,570,231	8,972	1,529,336	32,255	556	104	1,008
Manhattan	1,464,839	9,134	1,408,304	46,780	760	319	1,562
Michigan	3,584,000	20,883	3,498,203	62,697	597	101	1,719
New England	3,384,384	17,166	3,298,936	65,133	868	172	2,109
New Jersey	2,923,798	12,264	2,845,540	62,827	861	149	2,157
Ohio	4,428,752	100,770	4,257,834	67,000	623	131	2,394
Pennsylvania	4,394,629	12,503	4,308,278	72,685	680	112	2,393
Upstate New York	2,432,971	9,044	2,387,400	34,914	414	45	1,154
Southeast Region	**27,248,808**	**109,466**	**26,552,251**	**563,962**	**4,386**	**997**	**17,596**
Delaware-Maryland	2,377,836	10,740	2,320,214	44,864	573	83	1,362
Georgia	2,765,872	12,398	2,692,764	58,457	300	87	1,886
Gulf Coast	3,940,819	15,919	3,841,576	79,697	483	94	2,870
Indiana	2,238,101	7,200	2,191,754	37,484	285	77	1,301
Kentucky-Tennessee	3,354,940	11,545	3,275,732	64,352	494	94	2,723
North Florida	3,013,676	10,410	2,932,784	67,998	511	92	1,893
North-South Carolina	4,150,912	17,195	4,050,483	79,960	597	103	2,574
South Florida	2,338,361	11,212	2,251,548	73,280	593	295	1,433
Virginia-West Virginia	3,068,289	12,847	2,995,396	57,870	550	72	1,754
Midstates Region	**21,660,149**	**120,236**	**21,066,703**	**451,992**	**3,490**	**738**	**16,990**
Arkansas-Oklahoma	1,977,369	9,782	1,923,556	42,115	236	54	1,626
Houston	1,699,935	9,827	1,648,291	40,292	260	82	1,183
Illinois	4,382,488	20,386	4,254,712	83,601	822	181	2,786
Kansas-Missouri	2,620,645	16,030	2,745,498	56,601	499	90	1,927
Midwest	3,527,337	26,313	3,430,025	67,706	550	86	2,648
North Central	2,149,337	13,550	2,088,824	43,916	347	69	2,831
North Texas	2,781,575	15,602	2,691,769	71,192	475	126	2,411
South Texas	2,341,463	8,746	2,284,228	46,569	292	50	1,578
Western Region	**20,174,672**	**113,110**	**19,598,279**	**446,335**	**5,264**	**825**	**13,059**
Central California	2,092,739	11,444	2,036,134	43,390	613	78	1,080
Los Angeles	2,487,260	12,992	2,416,174	55,523	774	173	1,624
Northern California	2,877,073	17,084	2,796,623	60,250	1,284	120	1,712
Pacific-Northwest	3,743,561	24,707	3,624,263	90,530	800	152	3,089
Rocky Mountain	3,005,275	19,825	2,904,655	77,876	514	98	2,307

Average Competing and Non-Competing NIH R01 Award and Trend
Fiscal Years 1968 - 2000



The Public Supports Basic Research

Even if it brings no immediate benefits, basic science research which advances the frontiers of knowledge is necessary and should be supported by the Federal Government.



Source: Aggregate 2000
Charlton Research Company for Research!America

Research America
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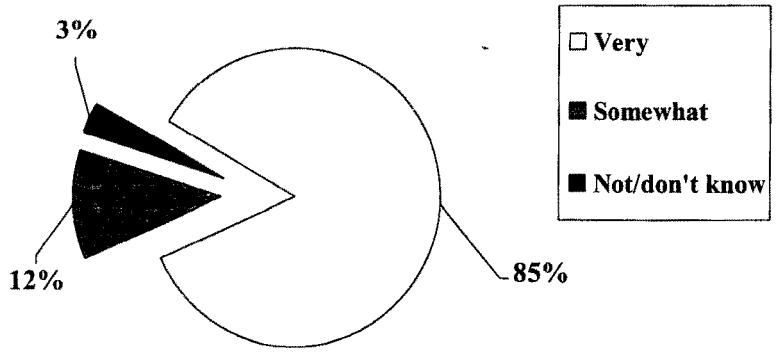
The U.S. Should Remain a World Leader in Medical Research

How important do you think it is that the U.S. maintains its role as a world leader in medical research?



Source: Aggregate 2000
Charlton Research Company for Research!America

Research!America
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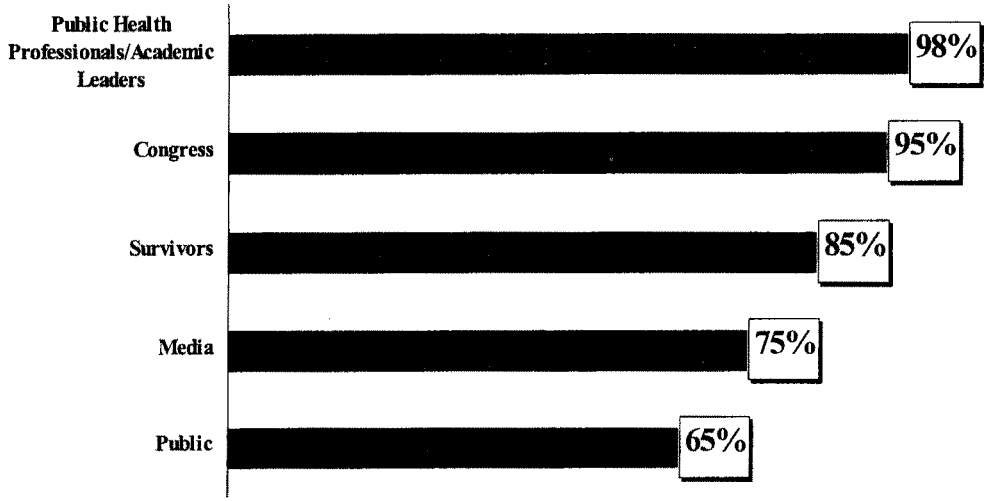
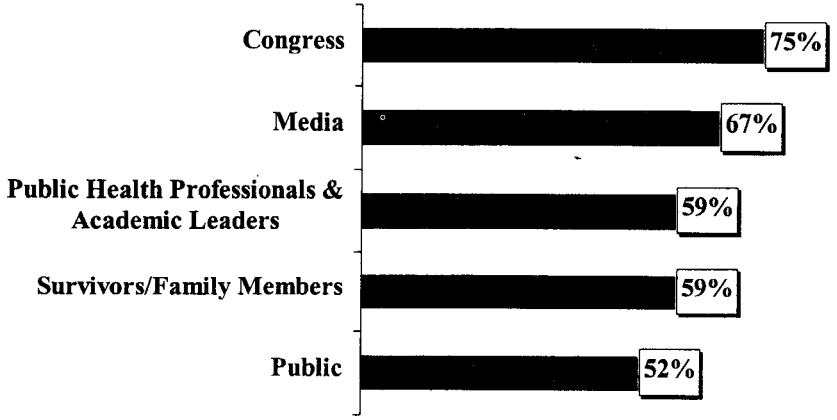
Q: Are preventable diseases and injuries in this country today a major health problem, a minor health problem, or not a problem?
(percent saying "a major health problem")



Source: R!A Prevention Research Initiative
2000 Harris Interactive, Inc.

Research America
AN ALLIANCE FOR DISCOVERIES IN HEALTH

Q: How much progress do you expect to be made in health promotion and disease prevention research in the next 10 years? A great deal, some, not much or none at all? (percent saying "*a great deal*")



Source: R!A Prevention Research Initiative
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Mr. BILIRAKIS. Thank you, Mr. Merenstein, for your testimony. We appreciate it.

Next, we'll turn to Mr. Charles W. Blackwell, who is the Chickasaw Nation Ambassador to the United States. We are pleased to have you here, Mr. Blackwell, and you are recognized to testify.

STATEMENT OF CHARLES W. BLACKWELL

Mr. BLACKWELL. Thank you, Mr. Chairman and members of the committee. It is an honor, a little bit of an overwhelming honor, to be here as one voice, and I want to make it clear, I'm only one Indian among the almost 2 million in the country who are, I would say to the person supportive of H.R. 293, the reasons are outlined in my written testimony which I submit in revised form for the record, and without repeating that I will tell you that my honor in doing this began on July 30, 1942 when I was born in an Indian hospital, Concho Indian Hospital in western Oklahoma, and it continues to this day, not only as a teacher and a lawyer, but now as a tribal diplomat, but more importantly for my own family.

In my family, from the day I was born, we have dealt with the ravages of diabetes, from my grandfather, to now my granddaughter, and while there is little rhyme or reason for that, as a spokesman for the American Indian community and for my family here today, we are willing to do what is necessary for ourselves to overcome the ravages of this disease.

Last Friday, when I received the invitation to testify before you today, I was reminded of another invitation I received about 4 years ago, a call from the White House to serve on the President's Advisory Council on HIV-AIDS. I served on that, and whenever the call came from the White House I told the young man who asked me, I said, "I appreciate the honor, like Abraham Lincoln, and if it weren't for the honor," but I said, "my issue in health for Indian country, for Native American people is diabetes." And, he said, "Ambassador Blackwell, the President does not have an advisory council on diabetes." I said, "I accept the honor, and he should have."

And, I suppose that's my message today, I accept the honor for being here, and we should have an assistant secretary. I'm sorry that Mr. Pallone is not here to hear me voice my support and the support of Governor Anoatubby of my tribe, the 264 tribes who are members of the Self-Governance Coalition within Indian Health Service, but it's time that we have an advocate and a voice at the highest policymaking level to advocate for us on budget, on policy, on the issues that are significant. These are human issues to us.

On the Goshute Reservation in Nevada, I have been asked to help them, 82 percent of their tribal population on the reservation has diabetes. They are 250 miles from the closest medical facility, and Mr. Tauzin should know that fewer than 10 percent of the homes on the reservation have telephones. That's a formula for disaster, and it is disastrous, but that's only one throughout all of Indian country.

Thank you and I will appreciate expeditious attention and treatment, passage of H.R. 293. I appreciate Mr. Pallone's insight and support, and Mr. Nethercutt's, and others of you who have taken a particular and special interest in American Indian health issues.

We are not a disease, we are a people, to whom you have a very strong trust responsibility.

Thank you.

[The prepared statement of Charles Blackwell follows:]

PREPARED STATEMENT OF CHARLES W. BLACKWELL, CHICKASAW NATION, AMBASSADOR TO THE UNITED STATES OF AMERICA, DIRECTOR OF PUSHMATAHA HOUSE

Thank you Mister Chairman and members of the committee for the opportunity to appear before you today. My name is Charles W. Blackwell. I bring you the greetings of my Governor, Bill Anoatubby. I am the Chickasaw Nation Ambassador to the United States of America and the director of Pushmataha House on Capitol Hill. I appear before you today in my capacity, first, as the Chickasaw Nation Ambassador to the United States of America, second, as the director of Pushmataha House, and third, as a life-long consumer of PHS and IHS services.

As an enrolled Chickasaw who is also Choctaw, I have direct and personal knowledge of the Indian Health Service and of Indian health facilities throughout Indian Country. I was born in Concho Indian hospital; my oldest son was born in Fort Defiance Indian Hospital. Throughout my life, I have paid regular and emergency visits to Indian hospitals in Alaska, New Mexico, Arizona, California, and Oklahoma. Obviously I trust the system. Even now I go to my tribal home to avail myself of the services of Carl Albert Indian Health Facility in Ada, Oklahoma.

As I have toured Indian health facilities from Alaska to Florida, I have gained insight and formed definite opinions about the Indian Health Service. I know there is wide disparity in the services based on the allocations, for example. I have served four years on the President's Advisory Council on HIV/AIDS and I know there are health dangers left unaddressed. I am also currently building my storehouse of knowledge on diabetes in the American Indian community because too many of my people suffer with it. In all these capacities, but most especially in my capacity as an American Indian father and grandfather who has lived and worked in Washington, D.C. for nearly 20 years, I believe there is every compelling reason to establish the office of Assistant Secretary for Indian Health. The people, my brother and sister American Indians and Alaska natives, must be personalized in this process.

The establishment of the office of Assistant Secretary Indian Health will:

- Create input at the policy making level, providing an opportunity for direct representation and direct communication between the Indian Health Service, the Department of Health and Human Services, the Congress, and the White House.
- Assist a system that obviously needs attention in providing more effective and more sufficient health care to American Indians and Alaska natives.
- Fulfill the trust relationship and the government-to-government relationship between the federal government and Indian tribes by recognizing the federal obligation to provide health care for members of federally recognized tribes.

Because of its current posture, the Indian Health Service has not had the appropriate opportunity to represent itself at the policy-making level. Rockville is out of the loop. The gap in communication and representation between the Indian Health Service Director and the Secretary of the Department of Health and Human Services creates an inefficient communication process through which Indian health priorities are often lost. Consequently, the Indian Health Service has been constrained from fulfilling its obligation to providing effective health service to American Indians and Alaska Natives.

From the policy making level to the people at home on the reservations and in their villages, American Indians have health problems at rates disproportionate to other Americans. We have a genetic commonality in our predisposition to diabetes, for example. Life in my immediate family has served to remind me that the disease is something we all live with on a daily basis. Disparities in health care also exist in infant mortality, alcoholism, HIV/AIDS and other sexually transmitted diseases, suicide, accidents, abuse, and teen pregnancy. The current posture of the position of the Indian Health Service director is an impediment to having the Indian Health Service deal effectively with these disparities in health in Indian Country, effectively representing tribal concerns, and from securing adequate funds for programs, services, buildings, equipment, and updated technology.

The trust relationship and the government-to-government relationship between the federal government and Indian tribes establishes the foundation for the existence of the Indian Health Service as fulfillment of the federal obligation to provide health care for members of federally recognized tribes. Self-governance incentives have allowed tribes to administer Indian Health Service programs and services for

themselves, yet still the system fails to function at its full capability because of severe fiscal limitations. The establishment of an office of Assistant Secretary for Indian Health seems logically necessary for the Indian Health Service to streamline its service and purpose; to have a better opportunity for increasing funds; and to force itself to evolve into an agency capable of competent fulfillment of the federal government's commitment to the superior health care of Indian people.

The elevation of the position of Director of the Indian Health Service to the secretarial level should be used as an opportunity to alleviate the confusion between policies of self-determination and self-governance insofar as they impact Indian health. Section 1(b) should be carefully scrutinized to afford the maximum input in policy, budget, and service. In keeping with the subject of the hearing, we do not want to isolate or exclude Alaska Natives; perhaps it should be Assistant Secretary for Native American health. I would also like to suggest a series of oversight hearings and the Chickasaw Nation would volunteer to contribute in the examination of budget, policies, services, and true conditions of health for all of America's first citizens.

As surely as I, as a Chickasaw, do not accept ignorance, unemployment, poverty, depression, and cultural isolation as conditions for my People, no longer can all Native American People accept a second-rate policy posture which physically inhibits us from formulating the policies and priorities affecting our health. It is timely and appropriate for Congress to establish the Office of Assistant Secretary for Indian Health not just for the good of the bureaucracy; but for the good of the People. Thank you.

Mr. BILIRAKIS. Thank you, Mr. Blackwell, thank you very much.

Mr. David Gremillion, member of Board of Directors of Men's Health Network, please proceed, sir.

STATEMENT OF DAVID H. GREMILLION

Mr. GREMILLION. Good afternoon, Mr. Chairman and members of the committee. I'm David Gremillion, a Professor at the University of North Carolina School of Medicine, and a member of the Board of Directors of the Men's Health Network. I'm here today to support the Men's Health Act of 2001.

Before I assumed my current post at the University of North Carolina, I was a Colonel in the Air Force Medical Corps and President of the Society of Air Force Physicians, and in that capacity I began to observe that, in fact, men receiving good health screening and preventive behaviors had enhanced lifestyles. As I left the Air Force Medical Corps, I joined the Men's Health Network and began to promote healthy lifestyles among men.

In addition, I'm motivated by being the father of a 19 year old son, who I hope grows up in a world that values and promotes healthy behaviors and lifestyles for men.

Men's health is often narrowly defined as prostate cancer and erectile dysfunction, but focusing too narrowly on these two issues, as important as they are, unfortunately misses a key point for men's health. Men are notorious for their avoidance of health care. As a result, they lead in each of the ten categories, leading categories of death in America, and have an average life span of 5.7 years less than their female counterparts. Simply stated, males of America live sicker and die younger than their counterpart females. This dismal statistic applies across the life span and across the diagnostic spectrum. In fact, for African American males, the survival gap is 12 years.

The marked disparity in survival for American males is a relatively new phenomenon. In 1920, women lived on average 1 year longer than their male counterparts. By 1993, that survival gap had grown to a 7-year deficit. This results partly, partly, from improvement in maternal survival and increased health screening for

women in the current health care system, but cultural factors and other social factors underlie this deadly statistic as well. Men are socialized to ignore discomfort as a sign of weakness, and as a result signs of illness are ignored and presented at a later clinical and less manageable stage of their condition.

Thus, the social pressure that a young male feels when they are young to ignore the bruises and pains of life translate into decreased survival at middle age, when they begin to ignore early signs of significant disease, like chest pain. Men, thus, have an overall age-adjusted mortality of 1.6 times greater than that of their female counterparts.

The silent crisis in men's health and the well-being of American males is partly due to a lack of awareness or education and a paucity of male-specific health programs. While this crisis is of particular concern to men, it also is a concern for women, regarding their fathers, their husbands, their sons, and their brothers. Men's health is a concern for employers who pay the cost of medical care and lose productive employees. Men's health is a concern for Federal and State governments that absorb the enormous costs left behind by the premature death and disability, including the costs of caring for dependents left behind.

This year, 198,100 men will be diagnosed with prostate cancer, of which 31,500 will die. Prostate cancer increases sharply with age, and more than 75 percent of such cases are diagnosed in men age 65 and older. The incidence of prostate cancer and the resulting mortality among African American men is twice that among others. In spite of these dismal statistics, prostate cancer continues to receive limited funding for research, screening and interventions, compared to breast cancer. Prostate cancer makes up 37 percent of all cancer cases, and yet receives only 5 percent of research funding.

In 2000, cancer research expenditures for breast cancer were $424 million, for prostate cancer $190 million. The disparity in this funding level results, at least partly, from a lack of advocacy and focus at the national level. The Office of Women's Health was established in 1991 to serve as a focal point for women's health diseases and resulted in dramatic improvement in organization, research, and improved funding for breast cancer. Our current level of knowledge and concern about the health status of men has matured, so that we now believe it is timely to establish a similar focal point for men's health. There is an urgent need for the Office of Men's Health and improved prostate cancer funding.

Your act, the Men's Health Act of 2001, has now 74 committed co-sponsors, a number which will surely grow over the next few weeks. This support is a testimonial to the widespread recognition of the need for an increased awareness of issues, programs and investigations affecting men and the quality of their life. This is not just a bill for men, but a bill for those who employ them, those who depend on their productivity, and those who depend on their companionship, mentoring and their partnership in life.

It has been a pleasure to testify before this group, and I thank the committee for their focus on men's health issues. Thank you.

[The prepared statement of David H. Gremillion follows:]

PREPARED STATEMENT OF DAVID H. GREMILLION, DEPARTMENT OF INTERNAL MEDICINE, INFECTIOUS DISEASES, UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

Good Afternoon Mr. Chairman and members of the Committee. I am David H. Gremillion, MD, and a professor at The University of North Carolina School of Medicine at Chapel Hill. I am commenting today on behalf of HR 632, "Men's Health Act of 2001."

Before I assumed my current post at UNC Chapel Hill, I was Colonel, USAF Medical Corps and Consultant to the USAF Surgeon General for Infectious Diseases, and President, Society of Air Force Physicians. My current roles involve teaching and investigations in developmental therapeutics for bacterial infections and HIV disease. I also maintain an active clinical practice of Internal Medicine and Infectious Diseases. I am President Elect of the Wake County Medical Society, and vice-counselor 6th District, AMA. When I left active service with the USAF, I joined the Men's Health Network, and for the past 3 years, I have served as a member of the Board of Directors.

My interest in Men's Health derives partly from my earlier experience as a Military Medical officer with its structured health maintenance for personnel and the contrasting experience upon entering the civilian world. While in the military, I observed a medical system that promoted and even required health screening, maintenance and prompt clinical care among personnel. My experience in civilian medicine is quite the opposite, with few guidelines, incentives or even interest in health promotion among males. At a personal level I am motivated as the father of a 19-year-old son who wishes to see him grow up in a world that promotes health and healthy lifestyles in males.

Males Live Sicker And Die Younger

"Men's Health" is often narrowly defined as erectile dysfunction, prostate disease and prostate cancer. While these conditions are important, focusing on them exclusively diverts attention from the broader issue of the overall poor status of Men's health.

Men are notorious for their avoidance of health care. As a result they lead in each of the 10 leading causes of death in America and have a life span of 5.7 years shorter than their female counterparts.[1] Simply stated, *males live sicker and die younger* than females. This dismal statistic applies across the life span and for every ethnic group. The consequences for men and their quality of life as well as for families, dependent children, spouses and even the economy are substantial. When men do present to the healthcare system, it is often on an occasion of trauma, injury, or clinical crisis rather than routine health maintenance and screening. Consequently, their care is delayed, expensive, and less effective, and may leave them with a negative impression because of the urgency with which these crisis interventions are conducted.

Reduced Male Longevity

The marked disparity in longevity of men and women is a relatively recent phenomenon. Women have lived longer than men since death registration was started in 1900. In 1920 women lived on average 1 year longer than men. By 1993 the average longevity of white females was 78.8 years compared to 72.2 for males. By 1998 male longevity had improved to 74.5 years but still trailed females by 5.7 years. For African-American males, life expectancy at birth is 65 years, 12 years less than their white female counterparts. This disparity results partly from improved maternal survival and better access to routine and preventive care for women. But the issue is far more complex. Looking beyond the obvious we find that social and cultural factors as well as structural aspects of the health care system underlie this deadly statistic.

The "Silent Crisis" in Men's Health

Men are socialized to ignore discomfort as a "sign of weakness" and as a result early signs of clinical illness are ignored and present at a later and less manageable stage. Thus the social pressure males experience as a child to ignore the bruises and pain of life becomes life threatening at later stages of their life as they ignore chest pain or other early warning signs of disease. Consequently, men have an overall age-adjusted mortality 1.6 times greater than that of females. This applies across the diagnostic spectrum including heart disease, cancer, and chronic liver disease among others. Males carry a higher burden of chronic disease throughout their lives and not surprisingly have a higher death rate for each category. (See Table3). The

[1] Murphy, SL, Deaths: Final Data for 1998, Division of Vital Statistics, Centers for Disease Control, National Vital Statistics Report, Volume 48, Number 11 July 24, 2000

Commonwealth Fund[2] reported that men are "out of touch" with the health care system. Twenty-four percent of men did not see a physician during the prior year compared to only 8 % of women. Men frequently (33%) did not have a regular doctor compared to 19% of women. Men's irregular contact with doctors and their reluctance to seek health care place their health at risk. One in four men would wait "as long as possible" before seeking attention for a serious medical problem.

The silent crisis in the health and well being of American men is partly due to a lack of awareness, poor health education, and a paucity of male-specific health programs. While this health crisis is of particular concern to men, it is also a concern for women regarding their fathers, husbands, sons, and brothers. Men's health is a concern for employers who pay the costs of medical care, and lose productive employees. Males are 12 times more likely to die from an injury at work than females.[3] For 1993 male death before age 65 resulted in a cumulative loss of 20,635 years of potential workplace productivity compared to 10,400 years for women.[4] Men's health is a concern to Federal and State governments that absorb the enormous costs of premature death and disability, including the costs of caring for dependents left behind.

Violence as a Cause of Morbidity and Mortality in Men

Men are risk takers and aggressive by nature so not surprisingly, violence is a major cause of mortality. Males have a 2.4 fold higher mortality due to accidents. Males account for the vast majority of murder victims. Suicide is 4 times more common in men and for those over age 85 men hold an 11:1 edge. For veterans and divorced men the risk is higher yet. Thoreau observed that "the mass of men lead lives of quiet desperation." Their sadness is "masked" and hidden by the same forces that would not allow them as young boys to acknowledge their physical pain for fear of appearing "unmanly".

Prostate Cancer as an Urgent Issue

This year 198,100 men will be newly diagnosed with prostate cancer of which 31,500 will die.[5] Prostate cancer rates increase sharply with age, and more than 75 percent of such cases are diagnosed in men age 65 and older. The incidence of prostate cancer and the resulting mortality rate in African American men is twice that in white men. In spite of these dismal statistics prostate cancer continues to receive limited funding for research, screening and interventions compared to breast cancer. Prostate Cancer makes up 37% of all cancer cases yet receives only 5% of research funding.[6]

Expenditures for Cancer Research by the National Cancer Institute in the Year 2000[7] Breast Cancer: $424,900,000; Prostate Cancer: $190,000,000
Expenditures for outreach and screening at CDC (2000): Breast and Cervical Cancer program: ±$185,000,000; Prostate Cancer program (no screening): ±$11,000,000

This disparity in funding results at least partly from a lack of advocacy and focus at the national level. The Office of Women's health was established in 1991 to improve awareness and funding for women's health issues with dramatic effect. This office and the Office of Research on Women's Health (ORWH) have helped to improve the quality of life for hundreds of thousands of women. Our level of knowledge and concern about the health status of men has matured so that we now believe that it is timely to establish a similar focal point for Men's Health. There is an urgent need for an Office on Men's Health to develop strategies, coordinate research activities, recommend public policies, engage in public-private partnerships, and take other actions that will encourage men to engage in healthy lifestyles, promote awareness of and early detection of diseases that adversely affect men, and search for answers to the perplexing problem of the deteriorating longevity and overall condition of men's health. A recent Institute of Medicine report,[8] Sex Affects Health, draws attention to the dramatic differences in biology, disease and treatment implication between the sexes and recommends more emphasis on these fundamental ob-

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[2] Sandman, D, Simantov, E, An, C; Out of Touch: American Men and the Health Care System. Commonwealth Fund Men's and Women's Health Survey Findings. March 2000. www.cmwf.org
[3] Murphy, SL, Deaths: Final Data for 1998, Division of Vital Statistics, Centers for Disease Control, National Vital Statistics Report, Volume 48, Number 11 July 24, 2000
[4] Centers for Disease Control and Prevention, National Center for Health Statistics
[5] CA Cancer J Clin 2001;51:23. American Cancer Society
[6] Source—National Prostate Cancer Coalition, (NPCC)
[7] Ibid.
[8] Exploring The Biological Contributions To Human Health: Does Sex Matter? Institute of Medicine Report. April 24, 2001.

servations in future investigations; further justification for an Office of Men's Health.

The Men's Health Act of 2001 now has 74 committed co-sponsors, a number which will surely grow in the weeks to come. This support is a testimonial to the widespread recognition of the need for an increased awareness of issues, programs and investigations affecting Men's health and their quality of life. This is not just a bill for men but for those who employ them, and those who depend on their productivity, companionship, mentoring and partnership in life.

The Office of Men's Health is urgently needed to slow the progressive deterioration in men's health and longevity. I urge this committee to pass HR632 and authorize the Men's Health Act of 2001 as expediently as possible.

It has been a pleasure to participate today with others concerned about the health status of American males. I would like to thank Representative Cunningham for his leadership on health issues and his concern about the health of men. I would also like to thank the Committee for creating this forum and for bringing us together to discuss these important issues. I would be pleased to answer any questions you might have. Thank you.

ADDENDUM: TABLES AND REFERENCES

Table 1. Life expectancy at birth [9]

Year	Women	Men
1940	65.2	60.8
1950	71.1	65.6
1960	73.1	66.6
1970	74.7	67.1
1971	75.0	67.4
1972	75.1	67.4
1973	75.3	67.6
1974	75.9	68.2
1975	76.6	68.8
1976	76.8	69.1
1977	77.2	69.5
1978	77.3	69.6
1979	77.8	70.0
1980	77.4	70.0
1981	77.8	70.4
1982	78.1	70.8
1983	78.1	71.0
1984	78.2	71.1
1985	78.2	71.1
1986	78.2	71.2
1987	78.3	71.4
1988	78.3	71.4
1989	78.5	71.7
1990	78.8	71.8
1991	78.9	72.0
1992	79.1	72.3
1993	78.8	72.2
1998	80.0	74.5

Between 1940 and 1970 the difference in life expectancy at birth between women and men increased from 4.4 to 7.6 years. After remaining stable in the 1970's the difference in life expectancy between women and men decreased. In 1993 life expectancy at birth was 78.8 years for women, 6.6 years longer than for men. As of 1998, preliminary figures suggest this gap has narrowed further to 5.7 years.

[9] National Center for Health Statistics Health, United States, 1995. Hyattsville, Maryland: Public Health Service. 1996. Library of Congress Catalog Number 76-641496 U.S. Government Printing Office, Washington, DC 20402

Table 2. Death Rates for selected ages and Causes of Death

Cause of death	Women	Men
Death rates for selected causes of death among persons 24-45 years		
Unintentional injuries	15.0	51.2
Heart disease	11.4	29.0
HIV/AIDS	9.1	57.0
Homicide	6.4	22.3
Death rates for selected causes of death among persons 45-64 years		
Cancer	240.1	298.7

Table 2. Death Rates for selected ages and Causes of Death—Continued

Cause of death	Women	Men
Heart disease	120.7	308.2
Stroke	26.2	33.3
Chronic obstructive Pulmonary disease	23.6	29.7
Diabetes	20.4	23.8
Death rates for selected causes of death among persons 65-74 years		
Cancer	688.4	1,113.3
Heart disease	589.3	1,175.3
Chronic obstructive Pulmonary disease	135.6	208.4
Stroke	118.7	157.4
Diabetes	76.6	85.1

Table 3. Chronic Diseases and Their Risk Factors: The Nation's Leading Causes of Death [10]

	US Totals		Male		Female	
	Number	Rate*	Number	Rate*	Number	Rate*
Ischemic Heart Disease	476,093	131.0	242,016	174.6	234,077	97.5
Cardiovascular Diseases	954,313	260.2	450,701	324.2	503,612	210.0
Stroke	159,931	42.0	62,471	44.4	97,460	39.9
All Cancers	539,508	167.2	281,883	206.9	257,625	139.6
Lung Cancer	151,902	48.8	91,554	68.1	60,348	34.3
Colorectal Cancer	56,754	16.9	27,989	20.5	28,765	14.2
Diabetes	61,766	18.5	27,646	20.1	34,120	17.2
No Health Care Coverage		16.8%		17.7%		16.0%

*Number per 100,000 population
Adapted from Centers for Disease Control and Prevention data
[10] U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, December 1999.

Mr. BILIRAKIS. Thank you, sir.

Doctor William J. Hall is President of the American College of Physicians, the American Society of Internal Medicine based here in Washington, DC. Please proceed, sir.

STATEMENT OF WILLIAM J. HALL

Mr. HALL. Thank you very much, Mr. Chairman.

Mr. BILIRAKIS. My son, by the way, is an internist. He was, at least, a member of your organization, I don't know whether he still is or not.

Mr. HALL. Well, we are going to intensively recruit him, Mr. Chairman, I can tell you that now. I also have a son who is an internist.

I'm an Internist and a Geriatrician, I practice in Rochester, New York. I'm here today representing the American College of Physicians, American Society of Internal Medicine. We are the Nation's largest physician specialty organization, we represent over 115,000 doctors of internal medicine. We provide the bulk of primary and specialty care for adults in this country, as we have for many, many generations.

I wanted to thank you, Mr. Chairman, for including the Flu Vaccine Availability Act, H.R. 943, in your agenda this afternoon. My organization, ACPSIM, strongly supports enactment of this bill to help ensure that the influence of vaccine shortages that many of you, or, perhaps, all of you, have heard about in this past flu season, doesn't occur again and continue to jeopardize the health of hundreds of thousands, if not millions, of Americans.

Simply stated, this bill would authorize funding under the Public Health Service Immunization Program, it would authorize distribution of influenza vaccine to qualified health providers throughout the country, including physicians. Enactment of this measure would go a long way to prevent a recurrence of the distribution problems that we had this past season, that I'll allude to in a few minutes. But just briefly, at that time we were faced, because of some technical problems, with a very limited vaccine supply. This, for a variety of reasons, was diverted from physicians, from hospitals, from health clinics, to non-professional distributors and the subsequent vaccine was distributed on a first-come, first-serve basis, regardless of risk, and, therefore, depriving the people who would benefit the most from this vaccination from getting the vaccination at all.

Internal medicine physicians, internists, take care of many people with chronic disease, and so we are very familiar with this problem on a day-to-day basis in our daily practices. For my own practice in geriatrics, it's something that I worry about almost continually, because I deal with the patient population that probably has the highest risk of having serious complications.

I'm very proud that I live in a community that historically has had the highest rate of immunization of any in the United States, in excess of 85 percent for high risk members of our population, generally, those over 65.

Last year, however, we were faced with a situation that our supply of vaccination that was available for these people, many of whom are uninsured and on limited incomes, was completely unavailable. We could not begin to even immunize people in our nursing homes.

Paradoxically, I was going to a meeting and changed planes in Chicago and there was a card table set up in one of the concourses where anybody walking by could get a flu shot for $15.00. This didn't seem to make any sense, and didn't seem to represent an equitable distribution and benefit from the health care dollars and the research dollars that had gone into this national program.

I'd like to concentrate really on two things. One is just a slight primer on influenza, and then to tell you a little bit about why the vaccination is such a cost effective measure for our country, and then a little bit about what this act does to make the distribution system a lot better.

Influenza is one of the great epidemics in history. It was responsible for some of the plagues. It's a worldwide disease, generally the wily virus is able to change its spots usually in Asia and over the centuries would then gradually spread to the western part of the world, through Europe and the United States. In an era of globalization, this spread can occur literally in about 6 to 7 hours, and, therefore, it is truly an epidemic problem of the greatest proportion.

I would venture to say that there's not a person in the room here who doesn't know what I mean when I say, got the flu, it's a ubiquitous disease, most of us just have a few very bad days, but some of us will not recover from the disease. We will actually die, as do 20,000 Americans every year.

While the rates of infection are highest in our kids, our young children, who also conveniently bring this disease home into our homes, but really the serious illnesses and the serious side effects occur in an older population of people, age 65. I don't have to remind you in the House here that the demographic imperative we are all facing is that the percentage of older adults in our population will be growing at an accelerated rate over the next 30 to 40 years, an unprecedented time in history. This is a very serious problem, if we have a preventative measure and it's not getting out to the people.

Just a word about the influenza vaccine. It's a very effective, perhaps, arguably one of the most cost-effective preventive measures that we have available to us in all of medicine. It works, it's relatively complication free, including local complications and more serious complications. It has been honed to a precise science in terms of formulating this precisely each year, and yet, what good does it do if people who really need it can't get it in their community, and yet anyone can get it at an airport concourse if you can pay enough money for it.

The various advisory committees on immunization practices throughout the country have set up prioritization, which has general agreement in the medical profession. People over age 65 are the very highest risk group because of complications. Individuals 50 to 64 would be the next highest, because of an elevated prevalence of the potential for complications, and then any of us who are around people with flu, health care workers for sure, but also family members, people who care for older people, also are at high risk.

Now, despite the fact that this is a very good product, it's cost effective, it has an enormous evidence-based scientific rationale for using it, current distribution has very, very major problems. During this last so-called winter season of flu, in 2000, vaccine distribution to retail outlets, to grocery stores and drug stores, was basically given equal priority with physician offices, health clinics, nursing home facilities.

Our own organization was alarmed by this unorganized distribution system, and our highest governing body, our Board of Regents, passed a resolution this March, basically, calling on manufacturers and government agencies to take this problem very seriously, and one of the response to that has been H.R. 943. We thought there needed to be a rationalization of the distribution system, so that the medicine gets to the right people at the right time, not an unreasonable request. But, we also began last year a very intensive program in virtually every State of the Union, among all of our 115,000 members, to make sure that our members were up to date on how to use influenza vaccine, how to recognize high-risk populations, and to get the job done. This is falling not on deaf ears, but it's falling on ears that can't turn to other ears to find out what they should do if they can't get the product.

Mr. BILIRAKIS. Please try to summarize, Doctor.

Mr. HALL. So, in summary, we are very much in favor of the enactment of this legislation. It has a benefit to virtually everybody in the room here, and we thank you for your consideration.

[The prepared statement of Wiliam J. Hall follows:]

PREPARED STATEMENT OF WILLIAM J. HALL, PRESIDENT, AMERICAN COLLEGE OF PHYSICIANS—AMERICAN SOCIETY OF INTERNAL MEDICINE

The American College of Physicians—American Society of Internal Medicine (ACP—ASIM) is the largest medical specialty society and the second largest medical organization in the United States, representing 115,000 physicians who specialize in internal medicine and medical students.

ACP-ASIM supports the enactment of H.R. 943, the "Flu Vaccine Availability Act of 2001" to help ensure that influenza vaccine shortages do not jeopardize the health of thousands of Americans in future flu seasons. The bill would authorize funding under the Public Health Service immunization program for the distribution of influenza vaccine to qualifying health care providers including physicians. Enactment of this measure would help prevent a recurrence of the distribution problems that took place during the 2000 flu season. At that time, much of the limited vaccine supply was diverted from physicians and hospitals to non-professional distributors who distributed the vaccine on a first-come first-serve basis, regardless of risk, thereby depriving patients most in need from receiving the vaccine.

Many patients of internal medicine physicians qualify as high-risk for complications from influenza, due to either chronic health conditions or age. As a specialist in geriatrics, many of my patients are among those in the highest risk categories, yet I could not be assured of receiving adequate vaccine supplies last year. My colleagues across the country reported delays that lasted well past the beginning of flu season.

Without adequate and appropriate distribution of the influenza vaccine, we are putting patients at great risk.

Epidemics of influenza typically occur during the winter months and, according to the most recent report of the Advisory Committee on Immunization Practices (ACIP), are responsible for approximately 20,000 deaths per year in the United States. Rates of infection are highest among children, but rates of serious illness and death are highest among people over age 65 and persons of any age who have medical conditions that place them at increased risk for complications from influenza.

The ACIP has recommended that the following groups be targeted for annual vaccination:

a) groups that are at increased risk for influenza-related complications (e.g., persons aged 65 years and persons of any age with certain chronic medical conditions)
b) the group aged 50-64 years because this group has an elevated prevalence of certain chronic medical conditions
c) persons who live with or care for persons at high risk (e.g., health-care workers and household members who have frequent contact with persons at high risk and can transmit influenza infections to these persons at high risk).

Vaccination is a highly effective and cost-efficient means of preventing influenza. Research demonstrates that vaccinations reduce influenza-related respiratory illness and physician visits among all age groups, hospitalization and death among persons at high-risk, otitis media among children, and work absenteeism among adults.

Despite the demonstrated effectiveness of vaccination in particular risk groups, our national distribution system does not provide the vaccine to high-risk patients first. Current distribution is based on the date the vaccine was ordered rather than who needs it most. During the 2000 flu season, vaccine distribution to retail outlets, such as drugstores and grocery stores, was given the same priority as physician practices, nursing homes, and hospitals. In response to this unorganized distribution system, the ACP-ASIM Board of Regents adopted a resolution on March 31, 2001 to call upon the manufacturers of the influenza vaccine, non professional distributors of the vaccine, and appropriate government agencies to ensure that adequate supplies of the vaccine are made available to licensed health care providers prior to distribution to other parties.

In October 2000, ACP-ASIM also began a 30-month Adult Immunization Initiative to inspire, educate and assist our members to provide influenza and other adult immunizations, all with the underlying goal of improving adult immunization rates and preventing unnecessary illness. Our educational efforts include providing information on the recommended immunizations and immunization schedules, the risks associated with not vaccinating, how to identify high-risk patients within a typical patient population, and myths concerning immunization safety. This initiative will also provide ACP-ASIM members with practical tools to use in their offices.

The ACP-ASIM Adult Immunization Initiative has been supported by the Centers for Disease Control and other organizations that have the goal of improving overall adult immunization rates. Despite the efforts of ACP-ASIM and others, higher immunization rates can only be achieved if the vaccine is available to health care pro-

viders. If adequate supplies of the influenza vaccine are not available for physicians, the health of many high-risk Americans will remain in jeopardy. Therefore, we urge you to pass this important legislation needed to improve the supply and distribution of influenza vaccine in future years.

Mr. BILIRAKIS. Thank you very much, Doctor.

Ms. Debra Lundquist is Administrative Director for the American Society for Reflex Sympathetic Dystrophy (RSD) and Complex Regional Pain Syndrome (CPRS). Ms. Lundquist, please proceed.

STATEMENT OF DEBRA LUNDQUIST

Ms. LUNDQUIST. Thank you for giving me this opportunity to speak for nearly 5 to 7 million Americans who live with Reflex Sympathetic Dystrophy, a destructive and debilitatingly painful neurological disease. We live with this constantly, although the intensity of the pain varies, depending on the time of day, stress, lack of sleep, weather. The list is endless.

The pain is the one common denominator for RSD patients. The McGill Pain Index is used as a way to gauge the intensity of the pain. It places the worst cancer at 27, and unexpected amputation of a limb at 40, and RSD at 42, with nothing higher. However, RSD is not just pain, it affects the nerves, the skin, blood vessels, the muscles, bones and more. It is air movement on the skin that brings you to your knees, hence the gloves. It is a sympathetic nervous system gone amuck, that for some unknown reason will not turn off, and RSD can be fatal.

Because our immune system is destroyed, we will most likely end up with other diseases. Other secondary effects of RSD are things that can affect our hearts, lungs, teeth, eyes, to name a few. The highest cause of death for an RSD patient is suicide.

Congressional support for an RSD Awareness Month would give us a stepping stone to begin a massive educational program. We need to educate all individuals on all aspects of this disease. They need to be informed that a person can get RSD from anything, literally. Such things as a paper cut, an infection, a stroke, child birth, surgery, or any injury can cause it. RSD does not discriminate, it can affect anyone. However, it does appear that there is a higher incidence in women, and the cases of children contracting it is increasing. Individuals need to be informed on treatments for the disease and the purpose for those treatments. There is no cure, but there could be a remission of the pain. However, the treatments are barbaric at best and have not changed much in the last 20 years or longer.

Education needs to start in our communities, and it needs to be at all levels, and it needs to be in place prior to someone contracting this disease to aid in the emotional support for the patient, their family and care givers, to prevent families from being destroyed through divorce and desertion, to prevent the RSD family from losing everything they have worked so hard for, and having to claim bankruptcy. Education needs to be in the school systems, because children with RSD are basically abused when at school by unknowing teachers and classmates. Education is needed with Social Security, so that disability is not so difficult to get for the RSD patient. Without Social Security, one cannot get Medicare, without Medicare some are completely denied any treatment whatsoever.

Workmen's Compensation and private insurance refuse patients, doctor's appointments, tests and treatments. What is so sad about this is that if patients were diagnosed within the first 3 to 6 months and treated correctly, that individual may be placed in remission and may be able to get back on the roles of the working, instead of being on the roles of the disabled.

Congressional support for our RSD Awareness Month would give us a head start in educating and would help us to do so on a much broader level than we can right now. The medical community is even uninformed when it comes to this disease. An unbelievable number of professionals in the medical field know absolutely nothing about RSD, including neurologists.

Another problem that we have is that RSD is known by several other names, which causes problems in the proper diagnosis and the proper treatment, and it all stems from a lack of education, and we need research.

NIH has given us a budget line, however, there is very little research being done. Information that we have been given on RSD has come to us mostly as backwash from other research on other diseases, and from the human guinea pigs we RSD patients have become.

We need congressional support for our awareness month desperately. We need it for education and for awakening the medical community. We need this all for the reasons previously stated and so that the proper diagnosis and treatment are given in time.

Do you remember the last time you hit your crazy bone? Do you remember the stinging and the burning feeling it gave you? Imagine that ten times worse and living with it constantly. This is close to RSD pain.

Please help us by putting your signature on the bottom of this resolution. You will be helping 7 million Americans and may also be helping someone in your family, if not yourselves.

Thank you for allowing me to speak on this issue.

[The prepared statement of Debra Lundquist follows:]

PREPARED STATEMENT OF DEBRA LUNDQUIST, ADMINISTRATIVE DIRECTOR, AMERICAN SOCIETY FOR REFLEX SYMPATHETIC DYSTROPHY/COMPLEX REGIONAL PLAN SYNDROME

My name is Debra Lundquist and I have had RSD for more than two years. Mine was caused from a car accident and is now full-body. Thank you for giving me this opportunity to speak for nearly seven million Americans who live with Reflex Sympathetic Dystrophy, a destructive and debilitatingly painful neurological disease. We live with this constantly, although the intensity of the pain varies depending on the time of day, stress, lack of sleep, weather . . . the list is endless. The pain is the one common denominator for RSD patients.

The McGill Pain Index is used as a way to gauge the intensity of pain. It places the worst cancer as 27, an unexpected amputation is 40, and RSD is a 42 with nothing above it.

However, RSD is not just pain. It affects the nerves, skin, blood vessels, muscles, and bones. It is a sympathetic nervous system gone amuck that for some unknown reason will not turn off. The list of the effects of RSD is too long to mention here, but are included in the materials that you have been given.

And RSD can be fatal. Because our immune system is destroyed we will most likely end up with osteoporosis, arthritis, and other illnesses such as lupus. Other secondary effects of RSD can affect our hearts, lungs, teeth, eyes, to name a few. The highest cause of death for the RSD patient is suicide.

This RSD awareness month is absolutely vital to our well being. Although RSD was first labeled during the Civil War, there has been little research done on it. Amazing considering that RSD affects between 5-7 million Americans. Interestingly, most people have never even heard of it. I know I hadn't.

An RSD awareness month would give us a stepping stone to begin a massive educational program. We need to educate all individuals on all aspects of this disease. They need to be informed that a person can get RSD from anything, literally. Such things as a paper cut, an infection, a stroke, childbirth, surgery, or any injury can cause it. RSD does not discriminate. It can affect anyone. However, it appears that there is a higher incidence in women and the cases of children contracting it is increasing.

Individuals need to be informed on treatments for the disease and the purpose for those treatments. There is no cure, there could be remission of the pain. However, the treatments are barbaric at best and have not changed much in the last 20 years or longer.

The education needs to start in our communities. It needs to be statewide as well as at the Federal level. It needs to be in place prior to someone contracting this disease to aid in the emotional support for the patient, their family, and care givers; to prevent families from being destroyed through divorce and desertion; to prevent the RSD family from losing everything they have worked so hard for and having to claim bankruptcy.

Education needs to be in the school systems because children with RSD are basically abused when at school by unknowing teachers and classmates. Parents are being charged with truancy because their children are out of school for such long periods of time.

Education is needed with social security so that disability is not so difficult to get for the RSD patient. Without social security, one cannot get medicare. Without medicare, some are completely denied any treatment whatsoever.

Workman's Compensation refuses patient's doctor's appointments, tests, and treatments. What is so sad about this is that if the patient were diagnosed within the first 3-6 months and treated correctly, that individual may be placed in remission and may be able to get back on the roles of the working instead of the roles of the disabled. Private insurance is much the same way for some patients.

The awareness resolution, would give us a head start in educating and would help us to do so on a much broader level then we can right now. The medical community is even uninformed when it comes to this disease. An unbelievable number of professionals in the medical field know absolutely nothing about RSD, including neurologists. When someone with RSD has to make an Emergency Room visit, that individual has to be sure that the doctors and nursing staff understand RSD.

Another problem that we have is that RSD is known by several other names. The multitude of names for this disease causes problems in the proper diagnosis and proper treatment. And it all stems from a lack of education.

And we need Research. NIH has given us a budget line. However, there is very little research being done. The researchers have yet to prove the hypothesis of what it is and how it works. Information that we have been given on RSD has come to us mostly as backwash from research on other diseases and from the human guinea pigs that we as RSD patients have become.

We need this RSD awareness month desperately. We need it for education and for awakening the medical community to the horrors perpetuated on us by the lack of this education. We need this month to help educate the insurance companies, including workman's compensation, so that the proper diagnosis and treatment are given in time to place the majority of individuals into remission.

Please help us by putting your signature on the bottom of this resolution. You will be helping seven million Americans and may also be helping someone in your family, if not yourself. Thank you for allowing me to speak on this issue.

RSD Patients by State

State	No.	State	No.	State	No.	State	No.
AK	15,594	IL	308,914	MT	22,441	RI	26,076
AL	110,616	IN	151,244	NE	42,565	SC	102,032
AR	66,497	IA	72,788	NV	49,704	SD	18,776
AZ	127,718	KS	66,871	NH	30,738	TN	146,488
CA	842,513	KY	100,534	NJ	209,296	TX	518,662
CO	106,988	LA	111,160	NM	45,246	UT	55,547
CT	84,734	MA	157,925	NY	472,014	VT	15,144
DC	14,229	ME	31,712	NC	200,216	VA	176,069
DE	19,491	MD	131,743	ND	13,486	WA	146,608
FL	397,541	MI	247,206	OH	282,394	WV	44,980
GA	203,602	MN	122,366	OK	85,830	WI	133,414
HI	30,135	MS	70,762	OR	85,103	WY	12,282

RSD Patients by State—Continued

State	No.	State	No.	State	No.	State	No.
ID	32,185	MO	139,174	PA	305,475		

Updated January, 2001

STAGES

The symptoms for RSD/CRPS have been divided into 3 or 4 different stages, depending on the literature that one reads. The 4th stage is possible but has not been agreed upon by all doctors. Individuals will move through these stages at their own pace. Some patients may have symptoms for less than the 3 month period stated throughout this literature, while others will have symptoms for years if not the rest of their lives. Some patients may stay at one stage for years and never progress to the next stage, some may rapidly move through the stages, some may move back and forth between stages, and yet others will have some symptoms in all stages, but not all symptoms in any one stage. The stages are used as a benchmark for the severity of the RSD/CRPS that a patient may be experiencing and the amount of time usually spent in a single stage will vary. This cannot be stressed enough. However, in other literature one sees these time frames listed and therefore we felt a need to reference them strictly for informational purposes. Please do not use these stages or time frames as a yardstick for each person with RSD/CRPS, but more as a tool for how it may possibly progress.

Stage 1

This stage is listed as the acute stage and it is suggested that it may last from one to three months. A mild case of this disease lasts a few weeks, then subsides spontaneously or responds rapidly to treatment. Characteristics of this stage may include the intense pain we discussed earlier including the burning sensation, deep aching, throbbing, tingling, or a sharp stabbing feeling; hypersensitivity to touch at and near the injury site; swelling, temperature changes, sweating, and hair and nail growth may occur in the affected area. Many may notice stiffness of joints and limited mobility developing. Any stimulation, be it physical or emotional upset, will increase the symptoms at this stage. Around 3 months into the disease, bone changes may be visible on x-rays and layered bone scans may show hot spots where the RSD/CRPS is located. At this stage there is decreased sympathetic activity.

Stage 2

Stage 2 is acknowledged as the Dystrophic Stage and it may last from three to six months. Characteristics at this stage may include: pain as listed in Stage 1, but now it is a more chronic pain, meaning it is more constant; one might notice that the skin has a different almost bluish- cyan color to it or it becomes mottled with different colors, brown, red, purple. RSD/CRPS is a very colorful disease. Temperature changes will persist and become more noticeable, as well as swelling and sweating. One may start noticing hair loss in the affected area, nails may become brittle and ridged. One may also notice an increase in the thickness of the joints; muscle wasting may become noticeable and x-rays may reveal signs of osteoporosis. The skin may develop a shiny appearance in the affected area. The patient may start having short-term memory losses and they may start repeating themselves. The senses, especially hearing and touch, may become extra-sensitive. At this stage there is increased sympathetic activity.

Stage 3

Stage 3 is acknowledged as the Atrophic Stage and it may last an undefined period of time. Characteristics at this stage may include: pain as listed in Stage 1, but the pain may decrease or increase depending on the situation or it may start spreading to involve the entire extremity or even to other parts of the body. As stated earlier, RSD/CRPS has its own personality and can spread in whichever direction it so chooses. If one starts with left arm involvement, it may decide to go to the right arm, or maybe the right leg, or possibly the shoulder and neck. At this stage, the skin may become cool, thin, and shiny. Contraction of the affected areas may be seen as well as atrophy of the extremity or decreased joint movement; x-rays may show marked demineralization and increased osteoporosis. Outwardly, there may be skin atrophy or wasting away and irreversible damage may occur with affected tissues.

Stage 4

As stated in the beginning, stage 4 is still controversial to the medical and research communities. However, since one sees it listed in some publications, we are showing it here. It is suggested that at this point, which could be two years or more from the onset of the injury/disease, the RSD/CRPS is probably not going to be helped with nerve blocks because it has now changed "directors". The brain, from this point on, originates the pain signals and distributes them throughout the body instead of receiving the signals from the affected areas. The brain, one might say, has effectively been "reprogrammed" and is now "directing" the pain.

One more issue to note is that it is unknown what percentage of patients actually have their RSD/CRPS spread through their entire body or become what is known as "full body". At this juncture, it becomes what is known as "systemic".

Mr. BILIRAKIS. Thank you very much.

Mr. Larry Balthazar. I probably mispronounced it.

Mr. BALTHAZAR. That's correct.

Mr. BILIRAKIS. Is that correct? Good, of Houston, Texas. Sir, please proceed.

STATEMENT OF LARRY BALTHAZAR

Mr. BALTHAZAR. Thank you.

Good afternoon. I would like to thank Chairman Bilirakis, Representative Gene Green, and the distinguished members of this subcommittee, for the opportunity to appear before you.

It's an honor and a great privilege to speak to day about our life with diabetes. We are grateful that you are concerned about how juvenile diabetes has dominated our lives for the last 3½ years. Over 16 million Americans are afflicted with diabetes, including hundreds of thousands of children.

My emotions must dictate my story today. Our life with our son, Larry, Jr., who suffers from juvenile diabetes, is frighteningly difficult, fearful, painful and unpredictable. We are doing everything we know how just to survive. All our energies are spent on an impossible balancing act that has robbed my son of the carefree childhood every young person deserves. I pray that you will never have to experience diabetes first hand, and witness the responsibility and discipline forced on these innocent children just to keep them alive.

I wish I could take my son's pain away. I wish I was the one who had to endure these painful injections, prick my fingers many times a day to test my blood glucose, and be the one to worry about losing my eyesight, kidney function, and many other life-threatening complications, but I don't have that option. So for now, I must do all I can to assure Larry, Jr., that I am doing all I can to help him. This is why I am here today.

On October 1, 1997, at 10:50 a.m., my office telephone rang. I answered it and heard my wife's voice. I do not remember her words, but I do remember the hurt and sadness in her voice. She had taken our then 2 year old son in to his pediatrician for an examination. He was experiencing excessive bed wetting, an insatiable appetite for liquids, and often times seemed very lethargic for a 2-year old. The news was he had juvenile diabetes. We were in shock. I was not sure what it was, but I knew I did not want it for my son. My wife said to meet her at Children's Hospital immediately. I told Judy, my assistant, about his diagnosis, and she sprang from her desk and gave me a big hug. With tears already flowing from her eyes, she said, "Little Larry will be all right, take your time

and drive carefully to the hospital. Wait until you get all the facts and don't worry about your desk, just take care of your family and little Larry." She had never hugged me before, nor had I seen her cry. Her father had diabetes.

Two hours after arriving at the hospital, my wife and I were injecting ourselves in the upper thigh with a saline solution in order to experience first hand what our son would be required to receive for the rest of his life. We soon learned that insulin is not a cure, merely life support to stay alive. He was 2½ years old. We were fortunate to have a great diabetes team to educate and coach us as we trained little Larry, and we became his doctor and nurse in addition to being his parents. The carefree days end for parents, too.

As I watched the diabetes team's compassionate strategy to comfort us, it made the diagnosis even more frightening. Jill was one of two nurses assisting us. I watched her as she fought back tears while trying to convince us that he could live a normal life. She had only been a diabetes nurse for a short time, and she resigned shortly thereafter, because of the emotional toll it had on her and the experience she had of sharing this news to children and parents. She's still in our life, and offers emotional support.

We quickly decided that if we continued with our current lifestyle, our careers, our church involvement, our social calendar, there may be a chance that at the age of 20 Larry could have a leg amputated, suffer kidney failures, lose his eyesight, or even die as a result of his diabetes. Major changes were inevitable. What could we possibly gain that would be sufficient to forgive our conscience and ease his hurt and disappointment in his daddy and mommy? Nothing, our best efforts are not a guarantee against the complications, however, we hope our efforts will confirm to us that we did everything we could to make managing Larry's diabetes our family priority.

Larry is our son. We are not naive enough to believe we care anymore, work any harder, or suffer more deeply than the other 1 million affected by Type I Juvenile Diabetes. However, the millions that are suffering in silence, fear and embarrassment saddens us. Our opportunity for a cure is too great, and the long-term complications are too devastating to be silent in our children's time of need.

The resolution being considered by this subcommittee urges Congress to abide by funding recommendations set forth in a congressionally mandated Diabetes Research Working Group report. Congress mandated the report to investigate scientific opportunity and the need for the National Institutes of Health, and I urge you to take these expert recommendations seriously. Research in islet transplantation has allowed 20 adults around the world to throw away their syringes and vials of insulin for good. I want my son, Larry, Jr., to experience the same.

As I conclude, Larry, Jr., has shown tremendous courage to help us help him. Ten days after he was diagnosed, my wife and I were agonizing over having to prick his tiny little fingers for the fifth time, and it was only mid-afternoon. We began to cry and comfort each other in prayer, seeking the energy and discipline to keep him alive and healthy. Unaware of his presence as we sobbed uncontrollably, he began to unzip his diabetes supply kit, removed his

glucometer and attempted to insert a test strip into the meter for testing his blood sugar. Of course, he was unsuccessful, but he recognized we needed him to help us help him. Unfortunately, we cannot rely on great acts of courage from our child to win this battle. We need great acts of courage from the men and women of the U.S. Congress to recognize the almost unimaginable requirements associated with living with diabetes.

I ask that you take a moment to think about your own loved ones and how you would stop at nothing if your child were in pain. Research is our only hope. Please support the funding recommendations provided by the Diabetes Research Working Group in House concurrent resolution 36, and give my son the same chance you would want to give your own.

I thank you for this opportunity, and I thank you for your noble work in public service. I would be happy to answer any questions.

[The prepared statement of Larry Balthazar follows:]

PREPARED STATEMENT OF LARRY BALTHAZAR

Good afternoon. I would like to thank Chairman Bilirakis, Representative Gene Green and the distinguished members of this subcommittee for the opportunity to appear before you. It is an honor and a great privilege to speak today about our life with diabetes. We are grateful that you are concerned about how juvenile diabetes has dominated our lives for the last three and a half years. Over 16 million Americans are afflicted with diabetes including hundreds of thousands of children.

My emotions must dictate my story today. Our life with our son Larry Jr. who suffers from juvenile diabetes is frighteningly difficult, fearful, painful and unpredictable. We are doing everything we know how to just to survive. All of our energies are spent on an impossible balancing act that has robbed my son of the carefree childhood every young person deserves. I pray that you will never have to experience diabetes first hand and witness the responsibility and discipline forced on these innocent children just to keep them alive. I wish I could take my son's pain away. I wish I were the one who has to take painful multiple injections, prick my finger many times a day to test my blood glucose and be the one to worry about losing my eyesight, kidney function and many other life threatening complications, but I don't have that option. So, for now, I must do all I can to assure Larry Jr. that I am doing all I can to help. This is why I am here today.

Oct. 1, 1997 at 10:50am, my office telephone rang. I answered and heard my wife's voice. I do not remember her words, but I do remember the hurt and sadness and fear in her voice. She had taken our then 2-year-old son in to the pediatrician for an examination. He was experiencing excessive bed wetting, insatiable appetite for water and juice and often times seemed very lethargic for a two-year-old. The news that he had been diagnosed with juvenile diabetes. We were in shock. I was not sure what it was, but I knew I did not want it for my son. My wife said to meet her at the children's hospital immediately. I told Judy, my assistant, about his diagnosis and she sprang from her desk and gave me a big hug. With tears already flowing from her eyes, she said, "Little Larry will be all right. Take your time and drive carefully to the hospital. Wait until you get all the facts. Don't worry about your desk, just take care of your family." She had never hugged me nor had I seen her cry before. He father had diabetes.

Two hours after arriving at the hospital, my wife and I were injecting ourselves in the upper thigh with a saline solution in order to experience first hand what our son would be required to receive (insulin) for the rest of his life. We soon learned that insulin is not a cure; merely life support to stay alive. He was two and a half years old. We were fortunate to have a great diabetes team to educate and coach us as we trained to become Larry's doctor and nurse in addition to being his parents. The carefree days end for the parents, too.

As I watched the diabetes team's compassionate strategy to comfort us, it made the diagnosis even more frightening. Jill was one of two nurses assisting us. I watched her as she fought back tears while trying to convince us he could live a healthy normal life. She had only been a diabetes nurse for a short time, and she resigned shortly after because of the emotional toll she experienced with sharing this news with parents and children. She is still in our life and offers much emotional support.

We quickly decided that if we continued with our current lifestyle, our careers, church involvement, social calendar, etc, there may be a chance that at the age of twenty, Larry could have a leg amputated, suffer kidney failures, lose his eye sight or even die as a result of his diabetes. Major changes were inevitable. What could we possibly gain that would be sufficient to forgive our conscience and ease his hurt and disappointment in his daddy and mommy. Nothing. Our best efforts are not a guarantee against the complications, however we hope our efforts will confirm to us that we did everything we could to make managing Larry's diabetes our family's priority.

Larry is our son. We are not naïve enough to believe we care any more, work any harder or suffer more deeply than the other 1 million plus affected by Type 1 or "juvenile" diabetes. However, the millions that are suffering in silence, fear and embarrassment sadden us. Our opportunity for a cure is too great and the long-term complications are too devastating to be silent in our children's time of need. The resolution being considered by this subcommittee urges Congress to abide by funding recommendations set forth in the Congressionally mandated Diabetes Research Working Group report. Congress mandated the report to investigate scientific opportunity and need at the National Institues of Health and I urge you to take these expert recommendations seriously. Research in islet transplantation has allowed twenty adult patients around the world to throw away their syringes and vials of insulin for good. I want the same for Larry Jr.

Larry Jr. has shown tremendous courage to help us help him. Ten days after he was diagnosed my wife and I were agonizing over having to prick his tiny two year old fingers for the fifth time and it was only mid afternoon. We began to cry and comfort each other in prayer, seeking the energy and discipline to keep him alive and healthy. Unaware of Larry's presence, as we sobbed uncontrollably, he began to unzip his diabetes supply kit, removed his glucometer and attempted to insert a test strip into the meter for testing his blood. Of course, he was unsuccessful, but he recognized we needed him to help us help him.

Unfortunately, we can not rely on great acts of courage from our child to win this battle. We need great acts of courage from the men and women of the US Congress to recognize the almost unimaginable requirements associated with living with diabetes. I ask that you take a moment to think about your own loved ones and how you would stop at nothing if your child were in pain. Research is our only hope. Please support the funding recommendations provided by the Diabetes Research Working Group in House Concurrent Resolution 36 and give my son the same chance you would want to give your own. I thank you for this opportunity and I thank you for your noble work in public service. I would be happy to answer any questions from the subcommittee.

Mr. BILIRAKIS. Thank you very much, sir. I know it was awfully tough on you.

Michael Coburn is President and CEO of the Tuberous Sclerosis Alliance. Mr. Coburn, please proceed.

STATEMENT OF MICHAEL COBURN

Mr. COBURN. Thank you, Mr. Chairman. It's a pleasure to join you today.

I represent the Tuberous Sclerosis Alliance, which is the only national voluntary health organization dedicated to finding a cure while improving the quality of life for those affected with tuberous sclerosis. Tuberous Sclerosis Complex is a genetic disorder characterized by seizures and tumor growth in organs such as the brain, heart, kidneys, lungs and skin. Individuals with tuberous sclerosis commonly begin having seizures in the first year of life, and conventional epilepsy therapies often do not control this seizure activity.

Seizures, as well as brain tumors, contribute to cognitive impairment, and as a result the majority of those afflicted with tuberous sclerosis experience some form of learning disability, behavioral problem, autism or mental retardation. Tumors in individuals with tuberous sclerosis are benign but compromise the function of a

number of organs. Kidney tumors, for instance, may lead to significant difficulties, and even death, if not properly diagnosed and treated. Skin tumors and lesions can be disfiguring and cause medical complications and social stigma in the life of those living with tuberous sclerosis.

The toll on the family of a person with tuberous sclerosis is enormous. Care for individuals with tuberous sclerosis often requires ongoing treatment that involves five or more medical specialists, speech, occupational and other therapists, as well as those skilled in the care and educational, as well as emotional, development of any medically and mentally disabled individual. Many families face significant financial, emotional and social hardships, and sadly, more than 60 percent of those living with tuberous sclerosis will never live an independent life or lead the quality of life that we would hope for every man, woman and child.

There are an estimated 50,000 Americans and 1 million people worldwide affected by tuberous sclerosis. One in every 6,000 infants is born with this disease. Unfortunately and however, this disease has a relatively low profile. To date, there have been no known prominent individuals or high-profile individuals affected by tuberous sclerosis whose personal story would likely raise the public profile of this disease. What is even more notable and disturbing, however, is that the medical community lacks awareness of tuberous sclerosis, and many cases go either undiagnosed or misdiagnosed. Yet, tuberous sclerosis is more prevalent than a number of diseases or medical conditions that have become well known by name in the general population.

Tuberous sclerosis is caused by a genetic mutation, either inherited or spontaneous. Research initiated for and funded by the Tuberous Sclerosis Alliance has helped identify genes associated with the disease. Continuing molecular research supported by the Tuberous Sclerosis Alliance and others continues to shed light on the interactions between the proteins in these genes with significant implications and links to other major diseases and disorders. This research is critical in developing effective remedies, therapies and treatments for tuberous sclerosis, but also this research using this known genetic disease model may provide answers to a host of questions about cancer, renal disease, or a number of neurological disorders, including autism and epilepsy.

The Tuberous Sclerosis Alliance funds a modest, yet successful, basic science program, and most recently awarded $1.7 million in multi-year grants. These funds raised by the Alliance come largely from the families and friends of those challenged by the disease. This program funds a major portion of all direct research on tuberous sclerosis. There is a huge disparity in the research that a relatively small group of families and individuals are able to fund as compared to the research necessary for a population of individuals with tuberous sclerosis that compares to, for instance, the entire population of the city of Harrisburg, Pennsylvania, or a similar-sized city.

The Tuberous Sclerosis Alliance is seeking the help of Congress to raise awareness and cause dedicated research on tuberous sclerosis. The outstanding talent and resources of the Federal Government's health system, through a coordinated effort, can accelerate

the understanding of the biological mechanisms causing tuberous sclerosis.

Awareness caused by the appropriate health institutions within the Federal system can help lead to accurate and early diagnosis. Early and aggressive diagnosis and interventions can dramatically improve the chances for a higher quality of life for those born with tuberous sclerosis. Increased scientific and clinical research is needed now to develop therapeutics or interventions to control epilepsy and tumor growth. Behavioral research is needed to identify the causes of autism or other cognitive impairment and mental illness in tuberous sclerosis.

Genetic medicine, with the increased knowledge of the human genome, needs to be explored. In fact, there are more than a dozen institutes or centers within the National Institutes of Health that can play a significant role in tuberous sclerosis scientific and clinical research. We ask for the help of Congress to request through the NIH Director that cross-institute resources be identified and engaged to develop a comprehensive research plan to cure tuberous sclerosis and that increased funding be earmarked to support this effort. We ask for the help of Congress, and through the appropriate medical and scientific agencies, to help increase the awareness of tuberous sclerosis within the Nation's health system.

Finally, we are thankful for the support of Representative Sue Kelly, for sponsoring House concurrent resolution 25, for her personal interest in tuberous sclerosis. We also thank the many members who have joined Representative Kelly in sponsorship of H. Con. Res. 25, and look forward to working with the leadership of Congress and the NIH to find a cure for tuberous sclerosis and improve the quality of life for those who are affected with this disorder.

Thank you very much, Mr. Chairman.

[The prepared statement of Michael Coburn follows:]

PREPARED STATEMENT OF MICHAEL COBURN, PRESIDENT AND CHIEF EXECUTIVE OFFICER, TUBEROUS SCLEROSIS ALLIANCE

Good afternoon. My name is Michael Coburn and I am president and chief executive officer of the Tuberous Sclerosis Alliance, the only national voluntary health agency dedicated to finding a cure for tuberous sclerosis while improving the quality of life of those affected by this disease.

Tuberous sclerosis complex (TSC) is a genetic disorder characterized by seizures and tumor growth in vital organs such as the brain, heart, kidneys, lungs and skin. Individuals with tuberous sclerosis commonly begin having seizures during the first year of life, and conventional epilepsy therapies often do not control the seizure activity in infants, children or adults. Seizures, as well as brain tumors, contribute to cognitive impairment. As a result, a majority of those afflicted with tuberous sclerosis experience some form of learning disability, behavioral problem, attention deficit hyperactivity disorder, autism or mental retardation.

Tumors in individuals with tuberous sclerosis are benign but compromise the function of a number of major organs. Kidney tumors may lead to significant difficulties and even death if not properly diagnosed and treated. Skin tumors and lesions can be disfiguring and cause medical complications and social stigma in the life of an individual living with tuberous sclerosis.

The toll on the family of a person with tuberous sclerosis is enormous. Care for a tuberous sclerosis patient often requires ongoing treatment that involves five or more medical specialists, speech, occupational and other therapists, as well as those skilled in the proper care and educational and emotional development of a medically and mentally disabled individual.

Many families face significant financial, emotional and social hardships. Sadly, more than 60 percent of those living with tuberous sclerosis will never be able to

live independently or experience the quality of life we would hope and wish for every child, woman or man.

There are an estimated 50,000 Americans and 1 million people worldwide affected by tuberous sclerosis. One in 6,000 infants are born with TSC. Unfortunately, however, this disease has a relatively low profile.

To date, there are no known prominent or high profile individuals affected by tuberous sclerosis whose personal story would likely help raise the public profile of this disease. What is even more notable and disturbing is the lack of knowledge about TSC within the medical community, and as a result, countless cases either go undiagnosed or misdiagnosed. Yet, tuberous sclerosis is more prevalent than a number of diseases or medical conditions that have become well known by name in the general population.

Tuberous sclerosis is caused by a genetic mutation, either inherited or spontaneous. Research initiated or funded by the Tuberous Sclerosis Alliance has helped identify the genes associated with the disease, TSC1 and TSC2. Continuing molecular research supported by the Tuberous Sclerosis Alliance and others continues to shed light on interactions between the proteins in the TSC1 and TSC2 genes with significant implications and links to several other major diseases or disorders. This research is critical in developing effective remedies, therapies and treatments for tuberous sclerosis, but also, research using this known genetic disease model may provide answers to a host of questions about cancer, renal disease, or a number of neurological disorders, including epilepsy and autism.

The Tuberous Sclerosis Alliance funds a modest yet successful basic science research program and most recently awarded $1.7 million dollars in multi-year research grants focused on building the scientific knowledge of tuberous sclerosis to help identify treatments and cures for all aspects of TSC.

These funds, raised by the Alliance, come largely from families and friends of those challenged by this disease. This research program funds a major portion of all research conducted directly on TSC. There is a huge disparity in the research that a relatively small group families and individuals are able to fund as compared to the research necessary for a population of TS-affected individuals that compares to, for instance, the population of the city of Harrisburg, Pennsylvania, or similar cities.

The Tuberous Sclerosis Alliance is seeking the help of Congress to raise awareness and to cause dedicated research on tuberous sclerosis. The outstanding talent and resources of the federal government's health and research institutes, through a coordinated effort, can accelerate the understanding of the biological mechanisms causing tuberous sclerosis. Working in partnership with other research initiatives, the government can help lessen the long-term impact of this devastating disease.

Awareness caused by the appropriate health institutions within the federal system can help lead to accurate and early diagnosis. Early and aggressive interventions can help dramatically improve the chances for a higher quality of life for those born with tuberous sclerosis.

Increased scientific and clinical research is needed now to develop therapeutics or other interventions to control the epilepsy and tumor growth in the brain. Behavioral research is needed to identify causes of autism, or other cognitive impairment and mental illness caused by tuberous sclerosis. Genetic medicine, with the increased knowledge of the human genome, needs to be explored. In fact, there are more than a dozen institutes or centers within the National Institutes of Health that can play a significant role in tuberous sclerosis scientific and clinical research.

We ask for the help of Congress to request, through the NIH director, that cross-institute resources be identified and engaged to develop a comprehensive research plan to cure tuberous sclerosis and that increased funding be earmarked to support this research.

We ask for the help of Congress to request that the appropriate federal medical and scientific agencies help increase the awareness of tuberous sclerosis within the nation's health system to provide the earliest possible detection and treatment for a disease that can have such severe life-long consequences. We greatly appreciate the increased level of funding for the National Institutes of Health and applaud the leadership of Congress to advance research toward optimizing the health of our citizens. We look forward to better serving the population affected by tuberous sclerosis by including this disease among the priorities established to advance the health of the American people.

The Tuberous Sclerosis Alliance thanks Representative Sue Kelly for sponsoring House Concurrent Resolution 25 and for her personal interest in tuberous sclerosis. We thank the many Members who have joined Rep. Kelly as co-sponsors of H. CON. RES. 25. We look forward to working with Members of Congress and leadership of the National Institutes of Health in doing all that is possible to find a cure for tu-

berous sclerosis while improving the quality of life for every person born with this disease.

Thank you very much for this opportunity to address the Subcommittee.

Mr. BILIRAKIS. Thank you very much, Mr. Coburn, and I will tell you that having Ms. Kelly as the proponent is good, because she's very vocal, and she's approached me many times as recently as just yesterday on pieces of legislation.

Ms. Judy Cushing is the Immediate Past President of the National Family Partnership. Ms. Cushing, please proceed.

STATEMENT OF JUDY CUSHING

Ms. CUSHING. Thank you, Mr. Chairman. Thank you, Chairman Bilirakis, and Ranking Member Sherrod Brown, and members of the subcommittee for inviting me to speak to you today on an important topic of substance abuse awareness and prevention.

I am going to make my remarks very brief, and stray from my written testimony to say that I've been moved in what I've just heard in the last half hour in the testimony about the debilitating diseases affecting young people and adults in this country, very serious diseases, and I wouldn't trade places with you for the world as you make decisions regarding research and support for those important efforts.

I'm here to talk to you about another very serious health issue facing young people in this country, and that's alcohol and drug abuse. Alcohol-related accidents are the No. 1 killer of America's teens, from automobile crashes, to homicides, to suicides, and other related accidents. Alcohol use in this country is now affecting our youngsters. The average age of first use of alcohol today for boys is 11, for girls it's 12.8 years.

The research is telling us now that if young people begin using alcohol and drugs before the age of 15 they are four times more likely to become addicted. We will have an epidemic in this country in the next decade unless we stand up on this issue. This is an issue that society doesn't really want to address. It's an issue that's shoved under the table a lot of the times.

In 1980, an organization was formed, the National Federation of Parents for Drug Free Youth, now called the National Family Partnership, by parents who were concerned about the issues facing kids then. A lot of it had to do with the rising drug use across the country. Parents armed themselves with information and they mobilized around kitchen tables and school libraries and said we're going to do something about this. The National Family Partnership and other groups formed a parent movement that from 1979 to 1992 reduced drug abuse in this country by 50 percent.

During that time, an occurrence that changed our field happened with the death of "Kiki" Camarena, a DEA agent who was brutally tortured and murdered in Guadalajara, Mexico. Mr. Camarena represented the efforts, not only by law enforcement, but by communities, in trying to create awareness and do something about reducing drug abuse among youth.

Following the death of Kiki Camarena in 1985, the youth and citizens of Calexico, California, his hometown, banded together and said we are going to do something about this problem, something that our young here and father of two stood for, and that was com-

bating drug abuse among youth in the country. They began wearing red ribbons, and soon California began wearing red ribbons, and the National Federation of Parents for Drug Free Youth picked up the banner and the red ribbon celebration began. The red ribbon has become the national symbol for drug prevention in our country. Every year more than 81 million people, young people, their families and their schools and communities, gather around to raise awareness about the issues facing communities, and it is communities that will make a difference on this issue.

I want to thank Representative Baca for bringing House Resolution 84 before you, concurrent House resolution, to support the National Red Ribbon Celebration. I want to thank you for your understanding of the fact that drug abuse and drug prevention can occur only in communities and families where it begins. I thank you for your willingness to stand up and be counted, and to recognize the National Family Partnership and our partners across the country.

[The prepared statement of Judy Cushing follows:]

PREPARED STATEMENT OF JUDY CUSHING, PRESIDENT/CEO, OREGON PARTNERSHIP

My name is Judy Cushing. I am President and CEO of the Oregon Partnership, a statewide non-profit organization dedicated to substance abuse prevention education and treatment referral. I am immediate past-President of National Family Partnership (NFP), a network of parents and parent groups, and the national sponsor of the Red Ribbon Celebration. Before I begin my prepared remarks, I wish to thank you, Chairman Bilirakis, and Ranking Member, Representative Sherrod Brown, and the members of the Subcommittee on Health for inviting me to speak to you today on the important topic of substance abuse awareness and prevention.

The National Family Partnership (formerly the National Federation of Parents for Drug Free Youth) was formed in 1980 by parents across America in response to the rising level of youth drug use. The mission of the National Family Partnership is "to lead and support our nation's families and communities to nurture the full potential of healthy, drug-free youth." The National Family Partnership works to accomplish its mission through the distribution of educational materials, parent networking and a membership of concerned individuals and affiliated groups nationwide. Peggy B. Sapp of Miami, Florida, currently serves as President of National Family Partnership.

Oregon Partnership is a state affiliate of the National Family Partnership. Through my work with NFP and Oregon Partnership, I know the value and importance of the public awareness NFP brings to bear on prevention issues, most notably through coordination of the national Red Ribbon Celebration.

Red Ribbon Week began in 1985 following the death of Enrique "Kiki" Camarena, a Drug Enforcement Agent who was close to uncovering the identities of key members of a Mexican drug cartel. Saddened by his death and concerned by the destruction caused by drugs in America, his friends, and family and young people, in his hometown of Calexico, California began wearing Red Ribbons in his honor to raise the consciousness of communities throughout the Imperial Valley. "Camarena Clubs" sprouted throughout the little border town and the rest of the Valley, led by the efforts of Congressman Duncan Hunter, his wife, Lynn Hunter, and a former schoolmate of Kiki's, Henry Lozano. At that time, Mr. Lozano was Executive Director of Teen Challenge. Inspired by Kiki's commitment to drug-free kids, Henry traveled across the Imperial Valley establishing Camarena Clubs and sparking public awareness about the importance of drug prevention.

Through his local and statewide prevention efforts, Henry Lozano invited Carol Stein, President of Californians for Drug Free Youth—a state affiliate of the National Family Partnership—to be part of Red Ribbon activities. The National Family Partnership and its affiliated organizations started a grassroots movement using the Red Ribbon as a symbol of their commitment to drug free youth. By the early 1990's, National Family Partnership had taken Red Ribbon Week nationwide, and today the Red Ribbon has become the national symbol for drug prevention across America.

This year's Red Ribbon Celebration theme is "Plant the Promise to Keep Kids Drug Free." On Tuesday, October 23, 2001, National Plant the Promise Day, parents and students across America will plant bulbs that bloom into vibrant red tulips in

the Spring to serve as a constant reminder of the importance of remaining drug free. The National Family Partnership is honored that President George W. Bush and First Lady, Laura Bush are Honorary Chairpersons of the National Red Ribbon Celebration for 2001.

Since it's inception in 1985, Red Ribbon Week has left a long list of accomplishments. Among them:

- Red Ribbon Week activities engage over 80 million participants annually. From schools and businesses, to neighborhoods, youth, and families—Red Ribbon Week is a catalyst for action.
- Red Ribbon awareness extends well beyond October, with teachers utilizing lesson plans and resources from National Family Partnership and its affiliate members in thousands of schools and communities year-round.
- In Oregon, Red Ribbon is a springboard to raising public awareness. For example, Oregon Partnership launches a Red Ribbon public awareness campaign in tandem with local businesses each year.
- The Oregon Youth Soccer Association partners with Oregon Partnership to distribute substance abuse prevention information and materials to 50,000 youth and parents throughout Oregon.
- Last year, in Connecticut, a local ice cream chain offered special discounts and free ice cream to Red Ribbon Week participants—and they distributed awareness materials throughout their communities.

These are just a few concrete examples of how the National Family Partnership and Red Ribbon Week activities make a positive impact in communities nationwide. It is fair to say that although our motto at Oregon Partnership is "Preventing Substance Abuse . . . Changing Lives," Red Ribbon is a major catalyst to helping us to meet that goal—not just in Oregon, but also throughout America.

Additionally, this year the National Family Partnership hopes to collaborate with Congress through an initiative to engage parents across America. National Family Partnership's "Parent College" will recruit and train parents in prevention education for their children's critical early years. The program focuses on identifying resources for parents and collaborating with community stakeholders to provide primary prevention and education to strengthen healthy families. This effort will result in measurable, qualitative outcomes.

Thank you all for the opportunity to share this information with you today. I would like to reiterate my thanks to the Chairman for inviting my comments. I would also like to thank the National Family Partnership and Peggy Sapp for the opportunity to testify on their behalf, and to Henry Lozano for his tireless work on behalf of prevention advocates everywhere. Red Ribbon Week prevention activities are a critical tool through which local communities learn, educate, and act to ensure a healthier future for our children. I do hope the committee will look favorably on, and indeed pass, the proposed resolution for which this hearing has been called.

Mr. BILIRAKIS. Thank you, Ms. Cushing.

You made the comment of, and I could see it on the expression on your face, while the testimony was taking place, of the sadness you feel hearing these stories. It hits me that Larry's son did not do anything to acquire Type I Juvenile Diabetes, and the story of Mr. Coburn, and so many others, Mr. McMahon, Ms. Furlong, their lives are hurt or shattered, and not by virtue of anything that they did. Yet there are so many people out there who shatter their own lives as a result of taking drugs and liquor. It's terrible.

I talk about the horrible story of autism, and other diseases, and I was telling Mr. McMahon last night that a kind of the sadness comes with this job of learning about diseases, some that you didn't even know existed. You could hear a pin drop in here while the witnesses were testifying, and I can dare say there aren't many committees in the Congress that can say that.

One thing too about health, it's like I say about flying, it kind of makes me wonder why the airlines are not more aware of the problems, and the late schedules, and the cancellations, sometimes without any good reason and they should realize that every Member of Congress flies, and we experience those problems, and I dare say if somebody had the courage to bring up a re-regulation bill,

it might be a result of our personal experiences. So, when it comes to health, all members of our family, my wife has diabetes, and her mother passed away with diabetes, and other members of the family. My youngest brother passed away with Parkinson's, Parkinson's related, so we've all experienced, and even though we are in an ivory tower we have to make decisions on so many pieces of legislation, many of them we've never really experienced. We do the best that we can based on testimony, based on debates, based on what our staffs recommend to us, and based sometimes on what your heart tells us, but when it comes to health we've experienced it, and we experience it all the time.

We can go into a lot of questions here. I would ask you, Mr. Merenstein, I am sorry I wasn't in the room when you testified, you mentioned the BRAVO bill, talked about it, I'm not sure if Mr. Brown was even here at that time, but—he was, that's great, because he's my partner on that legislation. A Member of Congress asked me to go out and talk to him and a member of one of his constituents regarding a Food and Drug Administration problem. We have all that too in this committee, and that's why I went outside here and spoke with him so I couldn't hear you testify.

If we could get your help on the BRAVO Act, or something like it. There's no pride in authorship here, something like it, so that people who have an opportunity to get an income tax refund can decide if a certain portion of it, check off a certain portion of that would go to NIH for funding, I think it would just be fantastic. And, the legislation specifically says this is not to be offset by the regular appropriation on the part of the Congress. We would be very careful with that.

So, you can help your cause, and it's not your cause, your cause is people, by really getting vocal in that regard and helping us to gain some co-sponsors. The problem that we're having there, I don't mind telling you, as I understand it from my staffs over the years, is that Ways and Means feels they are going to be creating another precedent for a check off on the tax return and where do you stop. I don't think that's a good enough reason to not do it, and if it is a precedent it's a darn good one, I think.

Having said all that, I'm just going to yield to Mr. Brown at this point.

Mr. Brown.

Mr. BROWN. Thank you, Mr. Chairman. Thank you for your comments.

One, I would like to enter this article, Ms. Eshoo would like to, the New York Times article today about stem cell research.

Mr. BILIRAKIS. Without objection, that will be the case.

[The New York Times article follows:]

[Wednesday, June 27, 2001—The New York Times]

U.S. STUDY HAILS STEM CELLS' PROMISE

By Robert Pear

A new report from the National Institutes of Health says research on stem cells derived from both human embryos and adult tissue promises "a dazzling array" of treatments for various diseases, but for some purposes, it says, the embryonic cells are clearly superior.

The confidential study was prepared as part of the Bush administration's review of federal policy on embryonic stem cells. Officials within the administration are

split over whether to prohibit federal spending on experiments using such cells, which have the ability to develop into almost any cells or tissues in the human body and thus may be useful in replacing or repairing failed tissues and organs.

The report, while emphasizing the limitless potential of embryonic stem cells, also suggests that the government should support research on adult stem cells. The adult cells "are capable of developing into more kinds of cells than previously imagined," it says, noting how blood stem cells can develop into brain cells, liver cells and heart muscle cells.

"All avenues of research should be exhaustively investigated, including both adult and embryonic sources of tissue," the report says.

The report, based in part on an exhaustive survey of scientific journals, affirms the scientific consensus, with an immense amount of detail obtained from interviews with researchers around the world. But it does not analyze ethical, legal or social issues of stem cell research.

While advocates of federal spending for such research point to the promise of new treatments or cures for ills like Parkinson's disease and diabetes, anti-abortion groups, conservatives and the Roman Catholic Church object on moral grounds to using stem cells extracted from embryos, even those at fertility clinics that might otherwise be discarded.

Some Bush advisers, led by Karl Rove, fear that federal support for the research will alienate these groups at a time when President Bush seeks to solidify his support among conservatives and Catholic voters.

Mr. Bush has said he opposes federal spending on stem cell research that involves the destruction of living human embryos. But he says he supports "promising research on stem cells from adult tissue."

The embryonic stem cells are typically derived from five-day-old embryos consisting of 200 to 250 cells, says the report, titled, "Stem Cells: Scientific Progress and Future Research Directions."

The report notes some of the limitations of research with adult cells.

"Adult stem cells are rare," the report says. "One of the advantages of using embryonic stem cells as compared with adult stem cells is that the embryonic cells have an unlimited ability to proliferate" in the laboratory.

But for this very reason, the report says, the embryonic cells carry a special risk: their ability to proliferate means that they are more likely to induce the formation of tumors, particularly benign tumors.

White House officials said they were not familiar with the institutes' study, which was requested by the secretary of health and human services, Tommy G. Thompson. Mr. Thompson was evidently planning to share the study with the White House, but an aide to Mr. Bush asked the department for details today after The New York Times obtained a copy of the document and asked the administration for comment.

Lawyers at the Department of Health and Human Services are studying whether the government can pay for experiments with embryonic stem cells in view of a law that says no federal money can be used for "the creation of a human embryo or embryos for research purposes."

Under guidelines issued by the Clinton administration last August, scientists can use federal money to conduct research with embryonic stem cells created in the course of fertility treatments. But scientists cannot use federal money to extract the stem cells from human embryos.

The National Conference of Catholic Bishops and other critics denounce this distinction as sophistry. In the process of obtaining embryonic stem cells, they say, scientists destroy the embryos, thus killing human life.

The study describes the potential uses of stem cells in treating Alzheimer's disease, Parkinson's disease, heart disease and diabetes, among other illnesses. It may soon be possible, the report says, to coax human embryonic stem cells into forming pancreatic cells that produce insulin and reverse the symptoms of diabetes.

Likewise, the report said, scientists have developed a technique to induce stem cells from mouse embryos to develop into nerve cell precursors that secrete a chemical messenger known as dopamine, and unpublished research suggests that these nerve cells may be able to eliminate symptoms of Parkinson's disease in rats.

Dopamine helps the nervous system control muscle activity. In patients with Parkinson's disease, dopamine-producing nerve cells degenerate for unknown reasons.

With heart disease, the report says, both embryonic and adult stem cells may be able to replace damaged heart muscle, and to develop new blood vessels that supply the heart muscle. Adult stem cells are "viable candidates for heart repair" work, the study said, but the embryonic cells have an advantage because they produce a larger supply of cells for transplants.

The report also cites evidence that embryonic stem cells can restore nerves and mobility in rats paralyzed with a condition similar to Lou Gehrig's disease.

Within three months of receiving injections of cells derived from embryonic stem-cells, it said,"many of the treated rats were able to move their hind limbs and walk, albeit clumsily, while rats that did not receive cell injections remained paralyzed."

The study also examined possible treatments for heart disease. The repair of a damaged human heart, it said, would probably require millions of heart muscle cells. The capacity of embryonic stem cells to replicate in the laboratory "may give them an advantage over adult stem cells by providing large numbers of replacement cells in tissue culture for transplantation purposes," the report said. But it is unclear how adult stem cells could generate sufficient heart muscle to meet patients' demand, the study said.

Mr. BROWN. Ms. Furlong, thank you for joining us, a fellow Ohioan, and Ms. Furlong, I know everyone listened to her today, I unfortunately had another committee I had to run and came back in the middle of your testimony, but she and her daughter were in Washington several months ago, and I heard her, the first time I met her and heard her speak about her family and heard her speak so passionately, not just about the most important thing in her life, her family, but also what she was doing to help others.

And, she and her daughter both, in many ways, have put their life on hold to help others, and to suffer from this terrible disease, and everyone here should know that, and all of us should be grateful for what you do, and the courage you've shown, and the compassion you've shown, so thank you for that.

Ms. FURLONG. Thank you.

Mr. BROWN. You know, we've known about the gene that causes Duchenne since 1987. Tell us, if you would, the most significant muscle-related research success stories over the last 5 years or so, if you would, just to give us an understanding of what we can and should do if we pursue the sort of research on this disease, and for that matter with Mr. Balthazar on diabetes, and so many others, but if you can give us sort of where we've come in the last 5 years and developed.

Ms. FURLONG. I think we have a number of emerging strategies that could be significant, and certainly we hope in the near term could be translated to these children. One of them that would be specific for a subset of the population would be gentomyocin. This is an antibiotic that is currently available, FDA approved and so on, that's been found to read through one of the particular mutations called a premature stop code. Essentially, what we are looking at is some of the children, a subset of the children, have sort of a period in their DNA code, and this period says to stop reading through, and, therefore, they don't have dystrophin. If we can get the gentomyocin to work and read through there are some sort of problems in terms of the isomers and the chemical configuration of the aminoglycaside gentomyocin, but that would certainly, and could promote the health of a certain subset of the population.

The scientists have been capable on another feat of reducing the size of the dystrophin gene. This is one of the largest genes identified. It's 2.5 million base pairs, which makes it a considerable size to sort of smoosh into a vector and then deliver to the cells. So, they have been significantly successful at reducing and using the most important points and getting a mini gene, if you will, or a small version of that gene, and as maybe, perhaps, some of you know, the Adeno-Associated Virus has been relatively successful in the hemophilia trials and, in fact, if mini gene does fit into the AAV or the Adeno-Associated Virus.

So, there are also strategies to repair the gene that are emerging, it's called chimeraplasty, and a number of other approaches to look at the specific mutation of each individual child or subset of children and try to repair the genetic error.

There's one other strategy that is certainly useful and promising, and that is the up-regulation of an associated protein called eutrophin, and certainly that eutrophin has been found to be and able to substitute for dystrophin, so those are the emerging strategies that certainly could have an effect on these boys.

Mr. BROWN. Thank you.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. You know your subject, and I apologize, I messed up your name a moment ago I think.

Ms. FURLONG. That's okay.

Mr. BILIRAKIS. Mr. Pitts, and we appreciate your staying here all of this time, sir.

Mr. PITTS. Thank you, Mr. Chairman, and thank you for convening this hearing, inviting this distinguished panel of witnesses, and for having the privilege of hearing such moving testimony.

First of all, I'd like to associate myself with the comments of my colleague from Pennsylvania, Mr. Greenwood, who earlier stressed the need for legislation for Lyme disease, since there's an epidemic of Lyme disease in my district. I look forward to working with you and Mr. Greenwood to address this disease, and I am hopeful that we can move some legislation regarding Lyme disease through this subcommittee.

Mr. McMahon, I'm told you've been working with the Muscular Dystrophy Association for over 30 years. What changes have you seen in this period that give you cause for optimism? In your written statement, you say, "Until recently MDA managed to fund all the research into muscular dystrophy that was scientifically justified. That's no longer the case." What has changed?

Mr. MCMAHON. Well, we still have all the obligations of using the money for AIDS. You know, money goes to braces, and wheelchairs, and elevator lifts on the side of vans, things of that nature. So about, I would guess it's maybe a two third to one third ratio. Last year, for example, $30 million went into research.

Now, what has changed over the years is that we have started to find some breakthroughs to identify where all these gene defections are, so what we are asking here today is to have this CARE Act 805, where there will be centers where this can be pursued on a government basis, nothing to do with our organization, we'll continue to do what we've been doing over the last 50 years, but we would also ask the government to step in and assume some of that very expensive focusing treatment in the future.

Mr. PITTS. Thank you.

Ambassador Blackwell, I'm new to the committee, and maybe you can educate me on this. Why have we established a separate health care system in Indian Health Service solely for a given racial or ethnic group? Do IHS clinics or hospitals serve anyone who is not listed on the roles of a tribe?

Mr. BLACKWELL. The trust responsibility arises out of the Commerce Clause of the Constitution, and through a recognition of American Indian tribes as domestic sovereign nations. Congress

has been given the plenary power and the responsibility to oversee that relationship, commonly called the "trust relationship."

The matter of health care for American Indian people is one that has arisen along with that of education and subsistence living, placement on reservations, removal from the south to Indian territory in Oklahoma, what is now Oklahoma, and the various policies.

From the time of first European contact until Richard Nixon was President, there was little glimmer of hope, and that glimmer was called Indian Self-Determination, the Indian Self-Determination and Education Assistance Act.

To precisely answer your question, whenever the Federal Government—I suppose it's an embodiment in international law, when a conqueror conquers a people, they become responsible for the general welfare and benefit of those people, and we saw that happen in World War II with Japan, and that seems to be part of the American spirit that is embodied in the European American spirit, that's embodied in the Constitution.

Mr. PITTS. Do the IHS clinics treat anyone who is not on the roles of the Indian tribes?

Mr. BLACKWELL. The amount of money that is set aside for the Indian Health Service is based on a service population. There are those who are much better informed on this than I am, but the service population is restricted to those people who are members of federally recognized American Indian tribes.

Insofar as I know, in isolated instances where the Indian Health Service facility is the only one that's available. With your permission, I'll research that and respond to you in writing. The limitations I would see would be the restriction—the budget restrictions and passage of H.R. 293 would help relieve those limitations, and I would assume in the spirit of the new self-determination encourage alliances and business relationships between private health care organizations, and Indian tribes, and the Federal Government, thereby enabling in isolated and necessary situations.

But, as a general rule, no.

Mr. BILIRAKIS. The gentleman's time is expired, but I think you indicated, sir, you'd like to research that and maybe you might advise Mr. Pitts and the committee, since it is an outstanding question, outstanding in the sense that it's not completely answered.

Mr. BLACKWELL. Thank you, and I will.

Mr. BILIRAKIS. Mr. Green.

Mr. GREEN. Thank you, Mr. Chairman, and I want to apologize to the panel because so many of us had other things. In fact, I was actually on the floor, I have a district in Houston, and we have the Energy and Water Bill on the floor of the House, and trying to make sure we have a Corps of Engineers project to make sure we don't flood again like we did 2 weeks ago. But, I appreciate the panel for being here, particularly, Larry Balthazar, and like I said, I've gotten to know the family, I guess, 3 years ago, and heard their testimony before, and I know it's always moving.

Let me ask Mr. Balthazar, I want to thank you again for coming and being willing to share, not only your wife and your family's effort with this, and your son. You mentioned in your testimony that the islet transplantation has allowed 20 people with diabetes to stop using insulin. Can you tell us a little bit more about this

breakthrough, and it sounds like this could be the cure, but then with a lot of diseases what may work we find out later, but can you share with the committee some more information about that?

Mr. BALTHAZAR. There's one particular test that's going on, it's called the Edmonton Protocol, and out of that we've been able to, or scientists and researchers have been able to isolate the beta cells within the pancreas, and transplant them in diabetics, and allow them to live without insulin injections. Obviously, that's a very demanding and intense process that can only satisfy the needs of a very, very few people, and they've been able to survive without insulin injections for the last several years.

We can get a little more information for you in particular, I need to be very careful with the details of that.

Mr. GREEN. If there's anything else on any other suggestions. Of course, our problem often times is that we can't keep up with some of the successes, except if we happen to read it in the paper, whether it's juvenile diabetes, or anything else, and so any information that you can share, any of you can share.

Again, I appreciate you and your family for bringing this up, and I know we can't find the cures without the resources, and that's part of our job here, to be able to do that.

Doctor Gremillion, I noticed in your testimony on your table, Table 3, where actually the male rate for lung cancer was almost double. Can you tell me, in your experience, is there a reason for that? Is it tobacco use, or is there something else?

Mr. GREMILLION. Well, recall that I'm a Tar Heel, University of North Carolina.

Mr. GREEN. I understand where you are from.

Mr. GREMILLION. The gap in smoking between men and women was substantial until the 1950's, when women began to smoke at a higher rate. Now, what we are anticipating is, as the lag between the cigarette smoking provocation of lung cancer catches up women will, in fact, increase their lung cancer rate very substantially, probably over the next 10 years.

Mr. GREEN. That's not—I was hoping we would see it going down for both of them instead of our females going up, but you attribute it to mainly tobacco use, or is it some other environmental factor? I know in your testimony you talk about males typically are risk takers and things like that, is there anything else other than tobacco use you can attribute that to?

Mr. GREMILLION. There are some other very minor potential causes, like radon exposure, et cetera. However, without question, tobacco use is the provocative agent in lung cancer.

Mr. GREEN. Okay.

Mr. Blackwell, in your testimony or your statement, you reference that you hope to learn more about diabetes since it has such a disproportionate effect on certain Native American tribes. I know that almost one in two Pima Indians in the southwest suffer from diabetes. I also have a district that's substantially Hispanic, and we see increased numbers for diabetes with our Hispanic Americans. How would elevating the Director of the Indian Health Service aid the Agency in managing the burden of diabetes on the Native American population?

Mr. BLACKWELL. It would put at least this issue among others that are significantly important in Indian country at the secretarial level for consideration, and policy, and budget, and procedures, which would result in, we would hope result, in an elevated level of care for individual Indian people.

And, it's my observation that diabetes, that you are absolutely correct, it's for many, many people of color, particularly people of African descent and American Indian, but the research that this committee controls, we would support it totally. There's not a tribal chairman, and I feel comfortable saying this, and I wouldn't say it very often in very many places, but there's not a tribal—sitting tribal chairman of any of the 352 tribes who wouldn't support more increased funds for research on diabetes.

Mr. GREEN. Thank you, Mr. Chairman. I know my time has expired, but again, I want to thank you for calling this panel today. Obviously, it's a very broad cross section of illnesses and diseases. I appreciate it.

Mr. BILIRAKIS. I thank the gentleman.

We customarily request that you respond to written questions that have not been asked here today, and I would ask you to respond to those questions in a timely fashion, because it's always going to be helpful.

I would also suggest to you that the reasons why you are here, and the reasons why we held this hearing with respect to these specific disease issues, is because we intend to move every one of these pieces of legislation. This does not mean that there won't be possibly some reforming of some areas.

The funding, for the Congress to, and this is maybe not the very popular statement to make, but for the Congress it's been decided quite some time ago that we don't have knowledge to be able to tell NIH, to spend X amount of dollars regarding research on this disease, as against that disease, et cetera. We made the decision a long time ago to try to do everything we can to increase, to double the funding. But, we have sent letters, I have sent letters, and we've had legislation which, like in the case of diabetes, we would say to NIH, I consider increased funding for diabetes research, rather than to say to them, specifically. I just wanted you to know that.

We've had a lot of people in here, pretty powerful people, who wanted us to increase funding for certain diseases, Muhammad Ali for instance on Parkinson's, but are we in a position where we should be able to tell? They know where the close breakthroughs are. Plus, we, of course, are subject to politics, and, yes, there must be politics, they are everywhere, and NIH has their share of politics, but, I think for the most part they know what they are doing in terms of funding that should be appropriated or allocated, for a particular disease. I just wanted you to know that.

Every one of these pieces of legislation is on the path to coming up for a mark-up in this committee and on the floor of the House.

Having said that, if there isn't anything further, Mr. Brown?

Mr. BROWN. No, only that we will bipartisanly move these bills through the Congress.

Mr. BILIRAKIS. Yes, and we scheduled this hearing on a very good bipartisan basis. I know that we are all grateful to all of our staffs for working so hard.

You can imagine how much help you've been to us here. It's just been wonderful. We appreciate particularly the volunteers, people like Mr. McMahon, and so many others who are volunteers. Mr. Balthazar, you are here of your own accord, and we appreciate that story, even though it's a pretty sad one. We are going to do the best we can.

God bless you. Thank you.

The hearing is adjourned.

[The hearing was adjourned at 3:43 p.m.]

[Additional material submitted for the record follows:]

PREPARED STATEMENT OF HON. RANDY "DUKE" CUNNINGHAM, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Chairman Bilirakis, Ranking Member Brown, and Members of the Committee, I would like to thank you for holding this hearing today to consider the various health needs of the American public. In particular, I would like to thank you for focusing on the need to raise awareness about men's health.

On May 10, 1972 I flew my 300th mission over North Vietnam. I shot down three MIGs that day to become the first Ace of the Vietnam War. Shortly after my third kill, I was hit by enemy fire and forced to eject along with my backseat, Willie Driscoll. As we parachuted down into enemy territory, I did not know whether I was going to live, die, or possibly be taken as a prisoner of war. It was indeed the scariest moment in my life—until the day my doctor looked me in the eye and told me that I had cancer.

I am one of thousands of men who was diagnosed following a simple prostate-specific antigen (PSA) test. During my annual examination in the summer of 1998, my doctor noted a slight elevation in my PSA test. He followed up with a sonogram and an MRI, neither of which revealed the disease. It was only after a prostate biopsy that it was determined that I had cancer. Following the diagnosis, in consultation with my family, I decided to pursue surgery as my treatment option. I am fortunate—early detection saved my life. My doctor was familiar with PSA results, and I had healthcare coverage for my treatments. Early detection and treatment meant the difference between life and death.

This year, 198,100 men will be diagnosed with prostate cancer and 31,500 will die from this terrible disease. But prostate cancer is only a small component of the men's health crisis: men have a higher death rate than women do for every single one of the ten leading causes of death in this country. Life expectancy has been longer for women than for men for several decades.

Sadly, the largest part of the problem is that men do not take particularly good care of themselves. Only one-half of all men have received preventative health care services in the past year. Overall, men are three times less likely to have visited a physician in the past year—and that's even factoring out women's prenatal visits. Men's health needs special attention, and men need better education about the health risks that affect them.

What can we do about this? First, we can make men's health a priority. Just as we support public service announcements to urge women to get regular mammograms and perform routine self exams, we must encourage men to get regular health checkups and perform routine self exams. Testicular cancer, which is the most common cancer in men under 35, is almost always curable if caught early enough.

Life is precious, and we want men to live as long as they can. Because they live longer, women are in the unenviable position of seeing their husbands, fathers, and even their sons suffer and die prematurely. If an educational and research emphasis geared toward the different nature of men were put in place there is no doubt that men could also raise their life expectancy. Which of course is good news for their wives, children and society.

We need a plan to help men make better healthcare choices, and to give men the support, encouragement and resources they need to live longer and healthier lives. Congress is taking notice—In 1994, Congress established the week leading up to and including Father's Day as National Men's Health Week. Here on the Hill, we celebrate Men's Health Week by offering health screenings to Members of Congress

and their staff. While Men's Health Week was an important first step, there is still much to be done to improve the health of American men. Over 70 members of Congress have joined with me this year to cosponsor the Men's Health Act (H.R. 632).

The Men's Health Act will establish an Office of Men's Health—a crucial step in the concerted effort to combat the problems facing men's health. This office would be responsible for monitoring, coordinating, and improving men's health in America, and would provide resources to organizations providing outreach and education services. An Office of Men's Health is needed to coordinate the fragments of men's health awareness, prevention, and research efforts now being conducted by federal and state governments.

The Office of Men's Health, styled after the Office of Women's Health, will be well placed to coordinate outreach and awareness efforts on the federal and state levels, promote preventative health behaviors and provide a vehicle whereby researchers on men's health can network and share information and findings. The Office of Women's Health has done a wonderful job in recent years coordinating this type of outreach and supporting positive women's health policies. It is my hope that these two offices could work together, and jointly conduct gender based efforts to eliminate the health disparities between men and women.

Getting shot down over Vietnam was a frightening and life-changing experience, but it does not compare to the fear that struck me when a doctor looked me in the eye and said "Duke Cunningham, you have cancer." Early detection saved my life. The Office of Men's Health will offer men support and resources to help them take control of their health concerns and maybe even save their lives.

PREPARED STATEMENT OF HON. GARY A. CONDIT, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

I'd like to thank Chairman Bilirakis and the committee for convening this hearing on "Advancing the Health of the American People: Addressing Various Public Health Needs."

Last years flu vaccine crisis displayed just how unreliable the private distribution network for flu vaccines can be. Newspapers across the country gave accounts of chain grocery stores selling flu vaccines on a first come-first serve basis, while public health agencies, doctors, hospitals, and nursing homes were placed on hold. My home state of California, for example, waited over three months before it's shipment of flu vaccines was completely filled. This should not happen.

While there are many explanations of what caused delays in last years flu vaccine shipments, one thing is abundantly clear: flu vaccine distributors put profit ahead of the health and well being of the American people. Regardless of how smoothly this private distribution has worked in the past, last year we caught a glimpse of what occurs when there is a bump in the road.

For these reasons, I have introduced HR 943—the Flu Vaccine Availability Act of 2001. This bill is designed to give the Centers for Disease Control and Prevention the needed funds and direction to improve the flu vaccine distribution infrastructure and ensure distribution is equitable. This bill would direct the CDC to provide flu vaccines to physicians and qualifying health care providers at no charge. These vaccines would not be distributed in a haphazard manner, and would only be available if used per CDC guidelines. These guidelines currently target the underinsured and highest at risk populations. Additionally, these guidelines do not permit one to charge for CDC provided vaccine.

I am convinced, as is the American Medical Association, California Medical Association, and American College of Physicians—American Society of Internal Medicine that this legislation is a great step forward to ensure flu vaccines reach those who need them most.

PREPARED STATEMENT OF HON. J.D. HAYWORTH, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ARIZONA

Mr. Chairman, I commend you and your distinguished committee members for holding today's hearing on several bills relating to various public health issues. I truly appreciate your strong leadership in this area and look forward to working with you as we strive to advance the health of all Americans, including Native Americans.

As co-chairman the of the Congressional Native-American Caucus, I strongly support the efforts of our colleague George Nethercutt who I have been honored to collaborate with on several Native American health issues. I am pleased to support his

legislation H.R. 263, which would elevate the position of Director of the Indian Health Service (IHS) to Assistant Secretary of Health and Human Services.

IHS is the lead agency in providing health care to the 557 federally recognized tribes in the United States. Services ranging from facility construction to pediatrics assist approximately 1.5 million Native American and Alaska Natives each year. The IHS currently falls under the authority of the Public Health Service within the Department of Health and Human Services (HHS). Today, the IHS Director is the top administration official charged with carrying out the federal trust responsibility for IHS, but he does not report to the HHS Secretary.

Designating the IHS Director as an Assistant Secretary of Indian Health would afford IHS a stronger advocacy function within HHS, and allow for increased representation during the budget process. Currently the ability of the IHS to affect budgetary policy is limited, in part, by the Director's inability to directly participate in budget negotiations.

It is important to note that the Congressional Budget Office has estimated that this proposal would have no significant effect on the federal budget.

I look forward to working with the Chairman on this legislation and other issues that fulfill Congress' special trust responsibility to assure the highest possible health status for Native Americans.

PREPARED STATEMENT OF HON. JIM MCDERMOTT, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF WASHINGTON

Mr. Chairman, I am very pleased to have the opportunity to share my views with the Energy and Commerce Subcommittee of Health regarding the Men's Health Act of 2001 as part of the hearing on Advancing the Health of the American People: Addressing Various Public Health Needs.

The gender gap in life expectancy began about 80 years ago. Today, men live on average six years less than do women. The magnitude of this difference has existed for several decades.

There are racial differences as well. While mortality rates are higher in general for black than white individuals, the gender gap exists within the black race as well. That is, life expectancy is also shorter for black men than black women.

Clearly, this is a problem. It is a problem for men, and it is a problem for the families that they leave behind.

We don't know why or what accounts for these discrepancies. We don't know if the same reasons are afflicting all men among all races. We do know that men do not live as long and this problem has persisted for decades. We do know that men are less likely than women to visit a doctor. That is why we must establish an *Office of Mens Health.* This office will do the research and find out why men are not living as long.

Since 1990, the Office of Research on Women's Health, which I fully supported has greatly improved the health of women throughout the United States through the coordination of research, health care services, and education. It is vitally important that we create a similar office of men's health to raise awareness and promote education about the need for screening and prevention.

Men's health needs special attention. American men need better education about health risks that affect them. The establishment of this office could positively change the lives of American men through raising awareness and promoting education.

PREPARED STATEMENT OF HON. COLLIN C. PETERSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MINNESOTA

Good morning. I am Collin Peterson and I represent the 7th District of Minnesota. I'd like to thank Chairman Bilirakas and the subcommittee for inviting me to testify today.

Representative Wicker and I introduced legislation, the Duchenne Muscular Dystrophy (DMD) Care Act, H.R. 717. This bill is designed to fight childhood muscular dystrophy by boosting research funding and raising public awareness. I urge you to pass this bill on behalf of my constituents in particular an extraordinary 9-year-old boy who has DMD. Without your help today this boy will not live to see his early 20s.

Like many children that have DMD, his life expectancy is only into the late teens or early 20s. Children with DMD are typically diagnosed between the ages of 3 & 5 years when they start to show signs of slow development of motor skills, and their legs begin to collapse without any warning, even to themselves. There after, the dis-

ease is characterized by progressive weakness, with a gradual deterioration of muscle capacity, first in the legs, then in the arms, back, lungs, and heart. Currently, the boy I know uses a motorized scooter to get around but soon he will need a ventilator to breathe. He is the inspiration for H.R. 717, the DMD Care Act, but I expect that members of the Subcommittee would be inspired by the courage of any child who suffers from this, terrible condition.

DMD is the world's most common and catastrophic form of genetic childhood disease. Although the dystrophin gene that causes DMD was successfully identified and isolated by medical researchers in 1987, federal research devoted to potential treatment options or a cure since this discovery has been minimal. Many family physicians and health care professionals lack the knowledge and resources to detect and properly diagnose the disease as early as possible, thus exacerbating the progression of symptoms in cases that go undetected or misdiagnosed.

One of the barriers to progress has been the lack of federal support committed to research efforts on muscular dystrophy. Less than 1/2000 of the NIH budget is focused on research linked to muscular dystrophy.Our legislation will:

- Authorize three centers of excellence for DMD Research at the National Institutes of Health
- Authorize three centers of excellence for DMD Epidemiology, data collection, and surveillance at the Centers for Disease Control and Prevention
- Expand collaboration activities and encourages coordination among the National Institute of Arthritis and Musceoskeletal and Skin Diseases, National Institute of Neurological Disorders and Stroke, and National Institute of Childhood Diseases at NIH on DMD research initiatives.

There is no treatment for DMD even though the dystrophin gene was first identified over 14 years ago. The life expectancy of a child with DMD has not changed since 1859 when it was first identified. It is time for us to focus our efforts and target funds to DMD research at NIH and CDC. Time is running out. Without your help thousands of children will lose the battle against DMD.

I asked my young constituent, if he could trade places with anyone in the world who would he be; I expected him to say a famous athlete or movie star, but he simply answered his older brother, so he can play football with his friends. You see his biggest wish is to be a regular boy. Today lets do what we can to help this little boy grow up to play football with his friends.

Mr. Chairman, members of the Subcommittee, thank you again for inviting me to testify today on this important legislation.

PREPARED STATEMENT OF ROBERT HALL, PRESIDENT, NATIONAL COUNCIL OF URBAN INDIAN HEALTH

Honorable Chairman and Committee Members, my name is Robert Hall. I am the president of the National Council of Urban Indian Health (NCUIH). I am a member of the three affiliated tribes of North Dakota: Grosventre, Mandan and Hidatsi. I am also the Executive Director of the South Dakota Urban Indian Health Clinic. On behalf of NCUIH, I would like to express our appreciation for this opportunity to address to the Committee on the importance for the urban Indian population and communities of elevating the position of Director of the Indian Health Service to the status of Assistant Secretary for Indian Health.

Founded in 1998, NCUIH is the only membership organization representing urban Indian health programs. Our programs provide a wide range of health care and referral services in 34 cities to a population of approximately 332,000 urban Indians.

According to the 1990 census, 58% of American Indians live in urban areas. We expect that the 2000 census will show that over 60% of American Indians now live in urban areas. Like their reservation counterparts, urban Indians historically suffer from poor health and substandard health care services.

In 1976, Congress passed the Indian Health Care Improvement Act. The original purpose of this act, as set forth in a contemporaneous House report, was "to raise the status of health care for American Indians and Alaska Natives, *over a seven-year period*, to a level equal to that enjoyed by other American citizens." House Report No. 94-1026, Part I, p.13 (emphasis added).

It has been twenty-five years since that commitment was made, and eighteen years since the deadline for achieving it has passed. And yet, Indians, whether reservation or urban, continue to occupy the lowest rung on the health care ladder, with the poorest access to America's vaunted health care system.

What will make a difference? First, and foremost, Indian people need a stronger voice in the health care debate. Too often our voices are literally drowned out by

the cacophony of other health care interests. Elevating the position of Director of Indian Health Service to that of Assistant Secretary for Indian Health will greatly strengthen the voice of Indian country, whether in the halls of the HHS, the corridors of U.S. policymaking Congress, or wherever the health care debate occurs and policy decisions are made.

When we hear that the Director of IHS cannot attend certain meetings because of his lesser position, by formality of political protocol, it is time for a change. Protocol should never come at the price of common sense and the health needs of Americans. The elevation of the status of the Director of IHS will go a long way to addressing these very real concerns.

I would like to take this opportunity to emphasize that the entire Indian population, both reservation and urban, is deserving, both morally and legally, of support from the Federal government in achieving the highest possible health status. One of the fundamental principles of Federal Indian law is the Federal government's trust obligation to protect American Indians. NCUIH does not believe that this obligation stops at the reservation boundary. As much as their reservation counterparts, urban Indians have been affected by Federal programs and policies. Indeed, the formation of the urban Indian community is a direct result of a number of such programs and policies, including:

(1) the BIA relocation program, which relocated 160,000 Indians to cities between 1953 and 1962. Today, the children, grandchildren and great-grandchildren of these Indians are still in the cities;
(2) the failure of Federal economic policies on reservations which has forced many Indians to become economic refugees in the cities;
(3) the Federal policy of "terminating" tribes in the 1950s and 1960s, many of which have not yet been restored to recognition;
(4) The marginalization of tribal communities, such that they exist, but are not federally recognized;
(5) Indian service in the U.S. military, which brought Indians into the urban environment;
(6) the General Allotment Act, which resulted in many Indians losing there lands and having to move to nearby cities and towns;
(7) court-sanctioned adoption of Indian children by non-Indian families; and,
(8) Federal boarding schools for Indians.

Some of these federal policies were designed to force assimilation and to breakdown tribal governments; others may have been intended, at some misguided level, to benefit Indians, but most failed miserably. One of the main effects of this "course of dealing," however, is the same: the creation of an urban Indian community. In the same 1976 report, the House noted that the Congress has "... a responsibility to assist..." urban Indians in achieving "... a life of decency and self-sufficiency..." and has acknowledged that "... [i]t is, in part, because of the failure of former Federal Indian policies and programs on the reservations that thousands of Indians have sought a better way of life in the cities..." House Report No. 94-1026 on Pub. Law 94-437, p. 116.

America is nowhere near the lofty goal set by the U.S. Congress in 1976, of achieving equal health care for American Indians, whether reservation or urban. I challenge this Committee to think in terms of that goal as it considers unquestioned need to elevate the status of the Director of the Indian Health Service to that of Assistant Secretary for Indian Health and, just as importantly, as it implements its trust responsibility to American Indians.

NCUIH thanks this Committee for this opportunity to provide testimony on the elevation of the Director of the Indian Health Service to the status of Assistant Secretary for Indian Health.

We strongly request your support on this matter.