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**RESEARCH ON NEUROLOGICAL AND
COMMUNICATION DISORDERS**

HEARING
BEFORE A
SUBCOMMITTEE OF THE
COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE
ONE HUNDRED FIFTH CONGRESS

FIRST SESSION

SPECIAL HEARING

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RESEARCH ON NEUROLOGICAL AND COMMUNICATION DISORDERS

THURSDAY, JUNE 5, 1997

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

The subcommittee met at 10:03 a.m., in room SD-192, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.
Present: Senators Specter, Craig, Faircloth, and Harkin.

NONDEPARTMENTAL WITNESSES

STATEMENT OF CHRISTOPHER REEVE, ACTOR ACCOMPANIED BY DANA REEVE

OPENING REMARKS OF SENATOR ARLEN SPECTER

Senator SPECTER. The hearing of the Appropriations Subcommittee on Labor, Health, Human Services and Education will now proceed. Today's hearing will focus on two special lines of NIH inquiry, on spinal cord injury and on deafness.

We are privileged to have with us today a distinguished American, Mr. Christopher Reeve, his wife Dana and his associates. Mr. Reeve is well known for his epic roles in "Superman" as well as other distinguished theatrical accomplishments and for a very tragic accident and injury where he sustained the severance of his spinal cord in a horseback riding incident.

Mr. Reeve has become a leading spokesperson for medical research generally and more particularly on the spinal cord issue.

Last week the subcommittee held a hearing that centered around the National Cancer Act, the 25th anniversary, in Los Angeles, and it has been our experience that when theatrical personalities speak out there is very considerable public attention to these issues. That happens to be a fact of life. When Hollywood speaks, the world listens. When Washington speaks the world frequently snoozes. And to get the kind of funding necessary to deal with these serious problems, it has become a practice for our hearings to call upon people who have had real life experiences, where there will be a tremendous amount of public interest.

There has been tremendous public interest and concern watching Mr. Reeve's recovery, which is very pronounced.

We had a hearing several months ago. We had many Senators join us in the Capitol. And Mr. Reeve was in town again today and

we thought we would utilize this opportunity to get an update on his condition and again to focus attention on the need for funding for spinal cord research and for other NIH research, specifically for the deaf.

This hearing is particularly timely because we are about to consider the NIH budget. We have those hearings scheduled next week. There has been great interest in increasing the NIH funding in the Congress, but a good bit of that interest has been more theoretical than real, I must tell you. We have that illustrated in the budget resolution 2 weeks ago, where a sense-of-the-Senate resolution was passed unanimously, 98 to nothing, to increase funding for NIH by \$2 billion.

The only problem with a resolution of that sort is it is simply an expression of the Senate's druthers and it does not mean a thing in terms of dollars. Druthers do not make dollars.

Senator Harkin and I then offered an amendment which would have added \$1.1 billion to NIH funding with a specific cut, and we proposed a four-tenths of 1 percent cut on nondefense discretionary spending, which could have been accommodated out of administrative costs and we think fairly easily done. That amendment was defeated 63 to 37.

We offered that amendment for a number of reasons. One was so that we would have real dollars to work with. The second reason was so that when various people came to see us who wanted to know where their share was of the \$2 billion, we could tell them that there was no \$2 billion. People have a hard time understanding Washington doublespeak: Sense-of-the-Senate resolution, \$2 billion—no money.

So that is why we are going to make a full-court press to turn the druthers into dollars. This subcommittee has set a target of a 7.5-percent increase, or \$952 million, this year. The target which has been suggested is to double NIH funding over 5 years. Well, that is about 20 percent a year and that would cost \$2.5 billion, which many of us would like to see. But the reality, candidly, is not present.

Now, that has led Senator Harkin and myself to introduce the National Fund for Health Research Act, which would require each health plan to contribute 1 percent of all health premiums received to the Federal Treasury, which would create an additional pool of some \$6 billion. This is tough because, it is a mandate or a tax that is hard to get done.

But it is my sense that this would be a good investment for the insurance industry because it would produce research which would save money on spinal cord injuries. There are 10,000 Americans who incur paralyzing, traumatic injury each year to their spinal cords, and there are about 200,000 Americans who live with the consequences of spinal cord injuries. Caring for these people costs \$5 billion annually.

There are many analyses and studies supporting the conclusion that it would be cost effective to have more money in research. We hope to persuade the insurance companies of the logic of our position or, in the absence of that, to persuade the Congress and the President that it is something that ought to be done as a matter of sound public policy.

I am pleased now to yield to my distinguished colleague, the ranking member, Senator Harkin.

OPENING REMARKS OF SENATOR TOM HARKIN

Senator HARKIN. Thank you, Chairman Specter. I do not know that I can add much to what you have just said, but to thank you for your leadership, to welcome our distinguished witnesses being here this morning.

Again, to Christopher Reeve, I just want to say thank you for serving as an eloquent advocate for improving people's lives by investing in medical research. Superman may have been science fiction, but the benefits from medical research are science fact. You are an eloquent spokesman for that.

Preventing strokes and slowing the progression of Alzheimer's, better and more effective treatments for spinal cord injuries, that is not Hollywood fantasy. It is some of the real life progress that is being made today in research institutes and laboratories and hospitals around the country.

I might also add that I too have a very personal interest in this. My nephew Kelly at the age of 19 years of age had an accident and he has been quadriplegic since, and that has been just about 20 years ago. As I have watched his progress and his difficulties, it has propelled me to do whatever I can to get more research into this area because I know there are breakthroughs there and I know there are things that can be done. We have seen them.

So again, we are on the brink of this, but we have got to invest in it.

Senator Specter just mentioned, the other day the Senate voted 98 to nothing to double funding for NIH. The next day Senator Specter offered an amendment to put the money where our mouths were and we lost it. Barely one-third of the Senate voted for it. One day we voted to double it—sense of the Senate, nice. The next day, to put the hard money there: I am sorry, we could not get that done.

So again, when we look at this—and I have often made the analogy, and I know, Christopher, I have talked to you about this and I know my colleagues have heard me say this many times—finding the cures and more cost effective treatments, it is like you have got 10 doors that are closed. Basic research, it is like you have got 10 doors that are closed, and you do not know behind which door may lie the answer. If you look behind one door, you have got a 10-percent chance of finding that answer.

Well, right now we fund about 25 percent of the peer-reviewed and accepted grant proposals at NIH. That means we can look behind door No. 1, but doors No. 2, No. 3, and No. 4 are closed. Maybe there is a cure for breast cancer behind door No. 2, or more effective treatments for Alzheimer's behind door No. 3, or better intervention for spinal injury and cures for spinal cord injury behind door No. 4. But we do not know, because we are not committing the resources to unlock those doors.

So I guess what I am saying, again, is that the budget agreement with the President makes it very clear, and I think the vote of the Senate the other day makes it very clear, that the only way we are going to devote the resources that we need and to keep from rob-

bing Peter to pay Paul is by going outside the regular spending process that we have.

As Senator Specter said, the budget resolution calls for \$24.2 billion in discretionary health spending in the year 2002. That includes all of NIH, all of the Center for Disease Control, all the community health centers, all the Older Americans Act programs, drug treatment, drug prevention, health professional training, maternal and child health care, and on and on. That adds up to \$24.2 billion.

If we doubled funding for NIH, as this body has voted to do, that would cost \$26 billion in 2002. In other words, that is \$2 billion more than our entire function is allotted under the budget. So even if you eliminated all the funding for breast cancer screening, Meals on Wheels for seniors, drug treatment, all of that, we still would be \$2 billion short of meeting the goal that the Senate wanted to have, to double NIH funding.

So the only way we are going to get it is to go outside. We need another mechanism and that is why, as Senator Specter said, we have supported the National Fund for Health Research Act, that both Senator Hatfield and I worked on for several years and now Senator Specter, who was a cosponsor of it in the past, has now taken up the lead on his side, as I have on my side.

One dollar. For every dollar that we spend on health care in this country, all we are asking for is just simply 1 penny, 1 penny. You spend a dollar on Blue Cross-Blue Shield or Aetna or Prudential or whatever your HMO may be, not 1 cent of that money goes for medical research, not 1 single penny. I think it is unconscionable and it borders on being criminal that we are spending \$700 billion a year this year in medical insurance payments and not even 1 penny is going for medical research. That is what we have to do.

If we can get that accomplished, we can meet these goals. If we can get that accomplished, we can open the doors No. 2, No. 3, and No. 4, and we can find the preventions and the cures that we need.

I hate to be so passionate about it, but I have had it up to here with everyone voting to double NIH funding in the abstract, but when it comes down to real money and we offer the amendment that Senator Specter did, everyone votes no. It is time that we have to look behind the normal resources that we have here.

Thank you very much, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Harkin.

Senator Craig, would you care to make an opening statement.

OPENING REMARKS OF SENATOR LARRY E. CRAIG

Senator CRAIG. Mr. Chairman, let me put my full statement in the record.

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

Senator CRAIG. Mr. Chairman, let me recognize and welcome Mr. Reeve before our committee. I think, Mr. Reeve, the world has watched you with compassion, but also with pride, since the time of your accident in Virginia forward to become a very loud and gallant spokesperson for spinal cord injury.

I suspect nearly all of us know someone or have someone in our family, as I do, who has experienced a situation that left them par-

alyzed and in a wheelchair, then to try to lead on with a life that they had expected to lead, and it becomes very, very difficult.

You have heard both our chairman and our ranking member talk of the difficulty of priorities here with limited dollars. We spend a great amount of money in medical research and it is never enough. Your ability to speak out as you have allows us to focus and to prioritize. There is a great amount of money being spent in a variety of areas. Maybe some of it ought to be relocated, instead of added to.

At a time when our Nation speaks for a balanced budget and fiscal responsibility, it is our job here to establish those priorities, and I think when we talk of the will of the Senate or the Congress, it is in that context of striking that. So we respond to our publics, and when our publics are aware and understand the importance then we can get a good many things done.

PREPARED STATEMENT

You add to that awareness. And there is no question today that an understanding of and appreciation for the problems of spinal cord injury and therefore a refocusing of the public's interest is largely due to your effort. So you are to be congratulated. We are pleased you are with us and we look forward to your testimony.

Senator SPECTER. Thank you very much, Senator Craig.
[The statement follows:]

PREPARED STATEMENT OF SENATOR LARRY CRAIG

Mr. Chairman, I would like to thank you for holding this hearing today to spotlight medical research funding for neurological disorders and disabilities. I would also like to thank all of our witnesses here today for sharing their insights and personal experiences with us.

Communication is the essential element of interaction in our society. It greatly impacts our daily lives and profoundly affects our future. Funding for the National Institute on Deafness and Other Communication Disorders [NIDCD] is important because of the significant strides their research has already made. NIDCD represents 46 million Americans with diseases and disorders of human communication. In the last several years, NIDCD has made tremendous headway in the prevention and treatment of hearing and communication disorders. As a result of support for the NIDCD and new findings from their studies, a whole new field and strategy of research in the hearing sciences has been created. It is so very important that we continue this trend.

Funding for biomedical research, for all diseases, is necessary because medical research is the key to eradicating disease and improving the quality of life. The benefits from medical research are far-reaching. New discoveries return value to patients and their families, as they translate into better diagnosis, better treatment, and better prevention of disease. It is important that we focus on the need to advance the knowledge and practice of medicine through research while fostering the practical application of this knowledge to the care of patients.

In addition, the financial costs of disease are staggering, both to the individual and to society as a whole in medical costs and loss of productivity. The human costs of disease are incalculable. Recently Congress and the President negotiated a budget deal that will eventually lead us to a balanced budget. This will be a difficult challenge, making it more important than ever that we get our priorities straight. The testimony of our witnesses today will be very helpful in that process of priority-setting and goal setting for a shrinking budget.

Because of the advances that have been made in medical research thus far, we should be optimistic about our future. We should look at the progress that has been made in all areas of research and build on those successes. However, we should also be aware of the amount of work that is left to be done. The examples used here today on the progress the NIDCD has made with their research certainly sheds a promising light on the future of medical research.

Again, I would like to thank the chairman and our panel of witnesses here today. The insight you provide will be of great assistance to us as we focus our attention on the importance of medical research.

OPENING REMARKS OF SENATOR LAUCH FAIRCLOTH

Senator SPECTER. Senator Faircloth, would you care to make an opening statement?

Senator FAIRCLOTH. Yes; I have just a very, very brief statement, Senator Specter. Thank you, Mr. Chairman. I thank you for calling this hearing. I think it is a very good use of our time, and I thank Mr. Reeve for being here.

This type of thing can highlight the need that we have for research. As you mentioned, Mr. Chairman, we spend some \$5 billion a year for neurological treatment and the care of neurological injuries, including spinal, and money spent in research in this area could be well spent.

I had the opportunity of working with a very good friend who in fact was a father-in-law, and he gave, established a neurological center at Duke known as Brian Neurological Research Center, and they have made great headway on Alzheimer's and other neurological disorders. It was a pleasure to watch that come to fruition and what he did there.

I am not noted in the Congress as one of its advocates of big spending, but I think that this is an opportunity to really save money and money invested in this field, in this area, will down the road really amount to a major savings for the people of the country.

I thank you for being with us, Mr. Reeve, and I thank you, Mr. Chairman.

Senator SPECTER. Thank you, Senator Faircloth.

SUMMARY STATEMENT OF CHRISTOPHER REEVE

Well, again, Mr. Reeve, welcome, and we look forward to your testimony.

Mr. REEVE. Thank you very much. Thank you, Mr. Chairman and members of the committee, for inviting me to testify today. It is a great privilege.

About 57 years ago there was someone struck by a then-incurable disease and he spoke these prophetic words. He said:

We cannot be a strong nation unless we are a healthy nation. So we must recruit not only men, women, and materials, but also knowledge and science, in the service of national strength.

Well, those are the words of President Franklin Roosevelt taken from his address at the dedication of the National Institutes of Health back in October 1940. It is remarkable that, even as war was raging in Europe and as the United States stood on the brink of entering that conflict, President Roosevelt had the foresight to recognize the importance of our Nation's investment in medical research to its national security.

So the question today is whether our current President and our Congress have the vision and the wisdom to heed the words of Franklin Roosevelt and recognize the vital role played by medical research in the economic and health security of our Nation.

I firmly believe that medical research is the key to eliminating disease, reducing human suffering, and reducing health care costs.

Heart disease and cancer are the two leading causes of death among Americans and they constitute nearly one-fifth of America's health care bill. The cost of Alzheimer's disease, which devastates 4 million Americans, currently costs our Nation \$100 billion every year, and those costs are going to increase dramatically as the baby boomers age.

So the economic cost of disease, not to mention the human costs, are truly staggering. Parkinson's disease afflicts nearly half a million Americans and it costs our Nation at least \$6 billion a year. Nearly a quarter million Americans live with varying degrees of incapacity due to spinal cord injuries and we spend \$10 billion annually merely to maintain them.

A half a million Americans suffer strokes every year, which cost more than \$30 billion for medical treatment, for rehabilitation and long-term care as well as lost wages. Diabetes, which affects nearly 16 million Americans, costs our Nation between \$90 billion and \$140 billion annually. It is the leading cause of blindness, kidney disease, and limb amputations.

So how do we stop the economic and human costs of these diseases? The answer is research. When I met with the President in May 1996, he stated that the ratio of research to clinical results is greater in this country than anywhere else in the world. Money spent on research brings practical results that absolutely justify the investment. So let us just look at a couple of examples.

NIH-sponsored research has resulted in the identification of genetic mutations that cause osteoporosis, Lou Gehrig's disease, cystic fibrosis, and Huntington's disease. Effective treatment for acute lymphoblastic leukemia [ALL], has been developed, and today nearly 80 percent of children who are diagnosed with ALL are alive and disease-free after 5 years.

Because of research, the nature of medicine is changing. We are approaching disease at the cellular level. We are targeting problems earlier, more specifically, less intrusively, with greater success and fewer side effects. Advances in genetics will soon let us intervene in disease even before the symptoms appear.

Significant progress is being made in the battle against cancer, and as recently as 10 years ago AIDS was a virtual death sentence. Now, thanks to research, individuals with extremely low T-cell counts are often able to rebuild their immune systems because of new protocols developed at the NIH and NIH-funded laboratories. Scientists are now talking about the possibility of an AIDS vaccine, and just a few years ago that would have seemed like science fiction.

Now, in 1988 a great Swiss neuroscientist, Dr. Martin Schwab, discovered two proteins that inhibit growth in damaged mammalian spinal cords. That was a revolutionary finding. Until then it was believed that the cord's inability to regenerate was due to the absence of nerve growth factors. And 2 years later, in 1990, Schwab induced nerve regeneration in a rat spinal cord by blocking the inhibitory proteins with an antibody called IN-1, and with adequate funding he estimates that this antibody could be adapted for use in human beings within the next 1 to 2 years. That is how fast progress is moving.

Now, when we recall that 10 years ago a spinal cord injury was considered to be a hopeless condition, this progress is absolutely extraordinary. Similar progress is being made in the treatment of Parkinson's multiple sclerosis [MS], stroke, and other related diseases because research has led to a greater understanding of the complexities of the brain.

Now, we must not stop this progress because we are unwilling to commit enough money to get the job done. It is imperative that the public and, more importantly, our elected representatives, understand that research today is not speculative, it is not a waste of money. It is the only way to relieve suffering while helping to save the American economy at the same time.

Making this a reality demands an investment of real dollars, funds that just do not fit within the constraint of the budget amendment that was passed by Congress this week, which proposes in fact to reduce overall health spending by \$100 million next year and by more than \$2 billion over the next 5 years. That is why I support Senator Specter's and Harkin's proposal to establish a national fund for health research, to provide additional funds over and above the annual appropriations for the NIH.

This bill proposes to take 1 penny from each \$1 paid in insurance premiums, and that would result in as much as a \$6 billion increase a year for the NIH, which would be a 50-percent raise in the budget.

Now, some experts say that this bill will never pass because of the strength of the insurance lobby. Well, I think that recent experience has shown that even the most formidable lobbyists cannot derail legislation that has bipartisan and public support. Let us look at some examples. The NRA was not successful in repealing the ban on assault weapons and they are a very powerful lobby.

The American public watched in disbelief as a dozen tobacco company executives testified at a Senate hearing that nicotine is not addictive and they denied allegations that nicotine levels were being raised in cigarettes in order to increase addiction. Well, now we are witnessing the demise of the Marlboro Man and Joe Camel. There are lawsuits in virtually every State by individuals demanding punitive damages against the tobacco companies. And just this week thousands of Government workers petitioned the President to ban smoking in Government buildings. And I sincerely doubt that the tobacco lobby will be able to stop this initiative.

As you recall, the religious right, led by Pat Robertson, Pat Buchanan, the Christian Coalition, tried twice unsuccessfully, in 1992 and 1996, to hijack the Republican Party, and they failed in both attempts. Here again was a case where a supposedly powerful lobby did not succeed in promoting their agenda.

Now, I also know from personal experience as a lobbyist for the National Endowment for the Arts that, in spite of 5 years of arguing strenuously about the economic benefits of the arts in thousands of communities across the Nation and instead of mobilizing arts groups from around the country for Arts Advocacy Day, in spite of showing statistics that 61 percent of the American people believe more money should be spent on Federal spending on the arts, we watched in dismay as Congress turned a deaf ear and they

reduced the NEA budget from \$167 million a year to a hopelessly inadequate \$99 million.

This has resulted in the loss of critical seed money to thousands of orchestras, dance companies, theaters, and museums. It is not only a serious setback to the quality of life in this country, but it is further proof that Congress can and does ignore a strong lobby with tremendous grassroots support when they so desire.

Now, I have spoken to executives at several insurance companies about this bill and I have been told that their profit margin is so small that the donation of 1 percent of income is an unreasonable hardship. Well, personally, I find this about as credible as the tobacco companies' claim that nicotine is not addictive. It is very hard to sympathize with insurance companies when you watch a mother in tears on a television program begging for a chair so her quadriplegic son can take a shower.

I know in my own case I have been denied coverage for any physical therapy below the level of my shoulders, in spite of the fact that leading researchers repeatedly stress the importance of cardiovascular conditioning and the prevention of osteoporosis and muscular atrophy in preparation for the functional recovery that spinal cord research will very likely achieve in the next few years.

I will give you another example. I am completely dependent on a ventilator to breathe. If this ventilator fails, I am in serious trouble. But my insurance company would not pay for a second ventilator. I had to pay for it, \$3,000, out of my own pocket. I am lucky; I can afford that. Many, many people cannot. And yet this kind of essential need is routinely denied.

Now, getting back to this piece of legislation, the insurance companies see it as a tax, though my question is: Why is that unreasonable when the insurance companies are going to save so much money in the long run? Research will keep the American people healthier and that will result in fewer insurance claims.

We tax oil companies. We use the money to build and maintain highways. In New York State, if you win the lottery you pay a significant tax which goes to a State fund for education. Now, most States have sales taxes which are a major source of revenue for a wide variety of programs and services that benefit the public.

Why should not insurance companies be asked to help, be asked to help to solve the health care crisis in this country?

Now, because of advances to date we can save millions of lives. Our challenge for the future is not just improving the quality of life of those we save, but finding the cures to prevent that suffering in the first place. Our scientists are on the threshold of major breakthroughs in almost every disease or condition that now cause so much hardship for people across the country and around the world.

PREPARED STATEMENT

The insurance companies owe it to our families and our society to make a small sacrifice which could do so much good. And I hope that this excellent piece of legislation, which already has tremendous grassroots support, will be enacted during this legislative session.

Thank you very much.
[The statement follows:]

PREPARED STATEMENT OF CHRISTOPHER REEVE

Fifty seven years ago, someone struck with a then incurable disease spoke these prophetic words: "We cannot be a strong nation unless we are a healthy nation. And so we must recruit not only men and women and materials but also knowledge and science in the service of national strength."

These are the words of President Franklin Roosevelt, taken from his address at the dedication of the National Institutes of Health in October 1940. It's remarkable that even as war was raging in Europe and as the United States stood on the brink of entering that conflict, President Roosevelt had the foresight to recognize the importance of our nation's investment in medical research to its national security.

The question today is whether our current President and the Congress have the vision and wisdom to heed the words of Franklin Roosevelt and recognize the vital role played by medical research in the economic and health security of our nation.

I firmly believe that medical research is key to eliminating disease, reducing human suffering, and reducing health care costs. Heart disease and cancer, the two leading causes of death among Americans, constitute nearly one-fifth of America's health care bill. The costs of Alzheimer's disease—which devastates four million Americans and currently costs our nation \$100 billion each year—are expected to increase dramatically as baby boomers age.

The economic costs of disease—not to mention the human costs—are truly staggering. Parkinson's disease afflicts nearly a half million Americans and costs our nation at least \$6 billion a year.

Nearly a quarter million Americans live with varying degrees of incapacity due to spinal cord injuries. We spend \$10 billion annually merely to maintain them.

A half million Americans suffer strokes each year, costing more than \$30 billion for medical treatment, rehabilitation and long-term care, as well as lost wages.

Diabetes, which afflicts nearly 16 million Americans, costs our nation between \$90 billion and \$140 billion annually and is the leading cause of blindness, kidney disease and limb amputations.

How do we stop the economic and human cost of these diseases? Research.

When I met with the President in May of 1996, he stated that the ratio of research to clinical results is greater in this country than anywhere else in the world. Money spent on research brings practical results that absolutely justify the investment. Let's look at a few examples.

NIH-sponsored research has resulted in the identification of genetic mutations that cause osteoporosis, Lou Gehrig's Disease, cystic fibrosis and Huntington's disease. Effective treatment for Acute Lymphoblastic Leukemia (ALL) has been developed and today nearly 80 percent of children diagnosed with ALL are alive and disease-free after 5 years.

Because of research, the nature of medicine is changing. We are approaching disease at the cellular level. We are targeting problems earlier, more specifically, less intrusively, with greater success and fewer side effects. Advances in genetics will soon let us intervene in disease before symptoms appear.

Significant progress is being made in the battle against cancer. As recently as 10 years ago AIDS was a virtual death sentence. Now, thanks to research, individuals with extremely low T-cell counts are often able to rebuild their immune systems because of new protocols developed at the NIH and NIH funded laboratories. Scientists are now talking about the possibility of an AIDS vaccine. Just a few years ago that would have seemed like science fiction.

In 1988 Swiss neuroscientist Martin Schwab discovered two proteins that inhibit growth in damaged mammalian spinal cords, a revolutionary finding. Until then, it was believed that the cord's inability to regenerate was due to the absence of nerve growth factors. In 1990 Schwab induced nerve regeneration in the rat spinal cord by blocking the inhibitory proteins with an antibody called IN-1. With adequate funding, it is estimated that Schwab's antibody could be adapted for use in humans within the next 1-2 years.

When we recall that 10 years ago a spinal cord injury was considered to be a hopeless condition, this progress is truly extraordinary. Similar progress is being made in the treatment of Parkinson's, MS, Stroke and other related diseases because research has led to a greater understanding of the complexities of the brain.

We must not stop this progress because we are unwilling to commit enough money to get the job done. It is imperative that the public—and more importantly our elected representatives understand that research today is not speculative. It is not a waste of money. It is the only way to relieve suffering while helping to save the American economy at the same time.

Making this a reality demands an investment of real dollars—funds that just don't fit within the constraints of the Budget Agreement passed by Congress this

week, which proposes to reduce overall health spending by \$100 million next year and by more than \$2 billion over the next 5 years.

That's why I support Senators Specter and Harkin's proposal to establish a National Fund for Health Research to provide additional funds over and above the annual appropriations for the National Institutes of Health. The Specter-Harkin bill proposes taking one penny from each dollar paid in insurance premiums, which would result in as much as a \$6 billion increase a year for the NIH.

Some experts say that this bill will never pass because of the strength of the insurance lobby. However recent experience has shown that even the most formidable lobbyists cannot derail legislation that has bipartisan and public support.

The NRA was not successful in repealing the ban on assault weapons.

The American public watched in disbelief as a dozen tobacco company executives testified at a Senate hearing that nicotine is not addictive and denied allegations that nicotine levels were being raised in cigarettes in order to increase addiction. Now we are witnessing the demise of the "Marlboro Man" and "Joe Camel". There are lawsuits in virtually every state by individuals demanding punitive damages against the tobacco companies. Just this week, thousands of government workers petitioned the President to ban smoking in government buildings. I sincerely doubt that the tobacco lobby will be able to stop this initiative.

The religious right led by Pat Robertson, Pat Buchanan and the Christian Coalition tried twice unsuccessfully (in 1992 and 1996) to hijack the Republican Party and failed in both attempts. Here again, was a case when a supposedly powerful lobby did not succeed in promoting their agenda.

I also know from personal experience as a lobbyist for the National Endowment of the Arts, that in spite of five years of arguing strenuously about the economic benefits of the arts in thousands of communities across the nation, in spite of mobilizing arts groups from around the country annually for "Arts Advocacy Day", in spite of showing statistics that 61 percent of the American people believe more money should be spent on Federal funding for the arts; we watched in dismay as Congress turned a deaf ear and reduced the NEA budget from \$167 million a year to a hopelessly inadequate \$99 million. This has resulted in the loss of critical seed money to thousands of orchestras, dance companies, theaters and museums. It is not only a serious setback to the quality of life in this country, but further proof that Congress can and does ignore a strong lobby with tremendous grassroots support, when they so desire.

I have spoken to executives at several insurance companies about this bill and have been told that their profit margin is so small that the donation of 1 percent of their income is an unreasonable hardship. Personally, I find this about as credible as the tobacco companies claim that nicotine is not addictive. It is hard to sympathize with insurance companies when you watch a mother in tears begging for a chair so that her quadriplegic son can take a shower. In my own case I have been denied coverage for any physical therapy below the level of my shoulders in spite of the fact that leading researchers repeatedly stress the importance of cardiovascular conditioning and the prevention of osteoporosis and muscular atrophy in preparation for the functional recovery that spinal cord research will very likely achieve within the next few years.

The insurance companies see this legislation as a tax. My question is: why is that unreasonable, particularly when the insurance companies would save so much money in the long run. Research will keep the American people healthier, resulting in fewer insurance claims. We tax oil companies and use the money to build and maintain highways. In New York state, if you win the lottery, you pay a significant tax which goes to a state fund for education. Most states have sales taxes which are a major source of revenue for a wide variety of programs and services that benefit the public. Why shouldn't insurance companies be asked to help solve the health care crisis in this country?

Because of the advances to date, we can save millions of lives. Our challenge for the future is not just improving the quality of life of those we save, but finding the cures to prevent that suffering in the first place.

Our scientists are on the threshold of major breakthroughs in almost every disease or condition that now cause so much hardship for people across the country and around the world. The insurance companies owe it to our families and our society to make a small sacrifice which can do so much good. I hope that this excellent piece of legislation which already has tremendous grassroots support will be enacted during this legislative session.

Thank you very much.

PROGNOSIS FOR THE FUTURE

Senator SPECTER. Thank you very much, Mr. Reeve.

We will now proceed with a 5-minute round on the panel.

Mr. Reeve, we are delighted to see you progressing and doing so well. Could you give us a short summary of the progress which you have made up to date and what your doctors' prognosis is for the future, please?

Mr. REEVE. Well, the prognosis for the future is going to be very dependent, again, on how research progresses. But I in the last few months have achieved sensation all the way down the spinal cord. This is a very encouraging sign because it means that the injury is incomplete and it had previously been thought to be complete, and that is a very significant piece of news for me and for my family.

Senator SPECTER. You have made a reference to the nerve regeneration in rats, and it is your hope, expectation, that that can be duplicated in humans, that that could pose a cure for your paralysis?

Mr. REEVE. Yes; you see, the most encouraging thing is that not only did Dr. Schwab achieve regeneration in rats in his laboratory in Zurich, but Dr. Weiss Young at the NYU Medical Center in New York has achieved the same thing. So two scientists working in different parts of the world.

Senator SPECTER. Do you have a sense for how far away the science may be in the nerve regeneration in humans if there is adequate funding?

Mr. REEVE. With adequate funding, within 1 to 2 years, and that is absolutely staggering progress. Recently I watched a video of the rats in Dr. Young's laboratory, and they were placed in a fairly large dish—

Senator SPECTER. So with adequate funding you think that there could be regeneration of the nerves in humans which would solve your spinal cord injury and your paralysis?

Mr. REEVE. That would be the beginning of clinical trials in humans, and what would happen is that—you see, the antibody that works in rats has to be modified to work in a human model, and that will take another year or so in order to accomplish. We have to be careful that there are not excessive levels of toxicity and those kinds of things.

Senator SPECTER. On the best case scenario, how long do you think it might be where you could walk again and resume your Superman career?

Mr. REEVE. Well, let us walk before we fly. But I would say that with adequate funding, with bringing new people into the field, continuing their clinical trials that they are on the brink of doing now, that we are looking at probably 4 to 5 years I could be up on my feet again, and so could millions of Americans.

Senator SPECTER. Mr. Reeve, I ask that question because many people have followed your career. They watched you fly, they watched you fall, and they would like to see you walk again as a preliminary to flying again. And I ask you on the best case scenario because people will see what Christopher Reeve does and will say, I can do that too if the opportunity is present.

That is the great value of a role model, and it will also have an impact on our colleagues in the Congress to provide the kind of funding which would enable scientific research to enable you to walk first and then to fly. So that is why I ask you about the best case scenario, because your words will be heard by millions of people who have similar problems.

Mr. REEVE. The main thing to remember is that these breakthroughs that Dr. Young and Dr. Schwab and others have done is really defying millions of years of evolution, because evolution provided that the spinal cord could not regenerate and that was always the common wisdom, that the peripheral nerves can regenerate but not the nerves in the spinal cord. And the identification of this antibody, the identification of this protein, is an incredible breakthrough.

What can happen is, as the antibody is developed the protein will be effectively knocked out and then regeneration will occur. The question is now will the nerves know where to go. And the evidence seems to be that they have a sense of where they belong. So we are talking about building a relatively small bridge and then, provided you keep your body in shape, you should be able to regain significant functional recovery within a short period of time.

Senator SPECTER. Well, one more bridge for the future.

Mr. REEVE. That is right.

Senator SPECTER. One more bridge for the future, and if we can succeed on spinal cord injury and if Superman can fly again, that translates into hope for cancer victims, for those who suffer from heart ailments, for those who suffer from Alzheimer's, cystic fibrosis, hearing disability, and many other lines.

So we salute you for your good work and, Mr. Reeve, we thank you for being here, and we will work with you.

Senator Harkin.

Senator HARKIN. Thank you very much, Mr. Chairman.

Again, Mr. Reeve, thank you very much again for a very eloquent statement, and thank you for speaking truth to power, as they say. The insurance companies need to hear this, and they are very powerful. The people that you are speaking to here are also very powerful and they need to hear that truth. The truth is, is that we are not investing in medical research.

I know it sounds like a lot of money when we say we are putting about \$13 billion this year into medical research with NIH, but I always point out to my friends, my friends and foes alike, that in the last 5 years we have spent more on military research and development in 5 years than we have on all biomedical research since the turn of the century. We have smart missiles and we have smart bombs, and thank God they help defend our country. But it is research that got us here.

The Defense Department right now is spending about 15 percent of every \$1 on research. In medicine we do not even spend 1 penny out of every \$1 on research, and that is why I think it is criminal and that is why I appreciate what you are doing.

We have been on this for some time. There is broad-based support for the concept that Senator Specter and I are trying to get through. Almost every disease-related group in America, research institutions, the private sector, private corporations, but we cannot

seem to get the breakthrough. I do not know if maybe we are not communicating it well.

If you have any thoughts on what message would resonate with Americans, how do we get the American public to help us in this effort. We have got to get that grassroots out there demanding this. And as you say, if they demand it, I do not care how powerful the insurance companies are, we will roll over them. But we have got to get the public to understand what we are talking about.

Quite frankly, I think I have failed in that regard. I just do not think I have been able to communicate that adequately to the public. If you have any advice for me, I am looking for it.

Mr. REEVE. In my opinion what makes the greatest difference is when the American people realize that these diseases and afflictions affect the entire American family, rather than just a small segment. If you take the case of AIDS, for example, back in the early eighties it was considered to be a disease that afflicted a very small segment of the population, and then gradually, when a young woman contracted the AIDS virus from a dentist, when children began to die of AIDS, when Rock Hudson and Elizabeth Glazer, public figures, when it began to resonate across the country that this is something that is robbing many, many Americans, then people take notice, and they said: Wait a minute, it is about us; it is not about them; it is about the entire American family.

And what is happening now is these diseases of the brain, which I call inner space—there is only one degree of separation. Any of us in this room can talk about a relative or a close friend who has one of these conditions. And as we live longer and as the baby boomers age, it is going to get worse and worse.

But the hopeful sign is that as people realize that people close to them are suffering, then they become more motivated to do something about it. People tend to respond when there is an emotional and psychological connection to a condition, and then they are willing to speak up and put pressure on Capitol Hill and put pressure on various companies and on the private sector to do something about it.

So what I would say is we have to remind people that it is not about others; it is about ourselves and the entire American family. That word is beginning to get out as people recognize that the suffering is so widespread and it is a huge human cost as well as a huge economic cost to the country. By reinforcing that message, I think you are going to get more of a demand for action, more of a demand for a response, and that will lead to more dollars being pointed in the right direction.

Senator HARKIN. Well, I appreciate that. And again, I cannot tell you how much we are thankful for your help and your leadership in this area.

I might also add that your influence has extended widely throughout the country on this issue. As I mentioned in my opening statement, my nephew Kelly McQuaid has been quadriplegic, as I said, now for almost 20 years as a result of a tragic accident, as you had. In my last communication with him he wanted to know—I told him that you were going to be testifying here and he wanted to know if you had any new information, because he also

knows that you have been leading this, and he wanted to know if you had any new information on breakthroughs.

What you have just said here about the new protein, I did not know about. If I could get some of that information from you, I would love to be able to send that on to my nephew.

Mr. REEVE. Absolutely.

Senator HARKIN. Because he has been fighting for 20 years on this, and he has never given up. He has never given up hope, and you have given him new hope, and I appreciate that.

Mr. REEVE. On my left here is Susan Howley, who is the research director of the American Paralysis Association, and she can provide you with all of that information. What we are doing at the American Paralysis Association is bringing scientists together from all over the world and getting them to work together, and that is going to make all the difference.

Senator HARKIN. Thank you again very much.

Senator SPECTER. Thank you, Senator Harkin.

Senator Craig.

Senator CRAIG. Mr. Chairman, thank you.

Christopher, your eloquence and your passion will advance the cause of research in neurological disorders, spinal cord injury, more than anything that can be done. And I say that because, while lobbyists and lobbies are a powerful force in this city, they are not as powerful as the American people when that body makes up its mind.

You referenced the National Endowment for the Arts and the decision on the part of Congress. That was, as you know, a hard-fought decision. I voted to cut funding and the reason I did was because public dollars are precious dollars and they were spending money in categories that were not generally believed to be acceptable by the public. When they decided they would change, I once again began to support it and I voted for the National Endowment last year again and the year before.

What I am suggesting is that when the public is well informed they can also cause the Congress to do things, and they felt they were informed. At least my public reacted, and then my public, once we had changed or the National Endowment agreed to change, my public accepted my vote again in support, because many of the communities in my State—as you reflected, communities across the country—were the beneficiaries of those kinds of dollars.

So I encourage you to continue and I am sure you will, because this particular illness or injury that a good many Americans experience now has a marvelous spokesperson. I do not believe it had that before, and that can go a great long ways in causing us to do and causing the public to react in ways that will cause us to move in the appropriate directions.

Thank you.

Senator SPECTER. Thank you very much, Senator Craig.

We are very appreciative of your appearance here, Mr. Reeve, and we will work with you, and we appreciate your helping us with the other Members of Congress and with the insurance industry.

Senator HARKIN. Might I ask one followup question?

Senator SPECTER. Senator Harkin has one quick question.

Senator HARKIN. One quick question. I do not want to put anyone on the spot, but I always believe in dealing openly and honestly with people. Were there any promises or overtures, promises, commitments, made to you by the President to increase funding for spinal cord research last year?

Mr. REEVE. Yes; when we met in May 1996 he told me that he would commit an additional \$10 million in fiscal 1996-97 specifically for spinal cord research, and I spoke recently with Dr. Varmas at NIH and that money already is being spent.

Senator HARKIN. An additional \$10 million?

Mr. REEVE. An additional \$10 million, above the \$40 million which is normally spent. So that additional \$10 million is being used now for additional grants and symposiums on spinal cord injury, but mostly on funding for more grants. What we really need to do is bring new graduates of our medical schools, new M.D.-Ph.D.'s, into the field, and the way we do it is by making enough money available so that the research can continue and they will want to be part of it.

Research is a tough life for someone who is coming out of medical school. They have got to repay their loans, they have got to make a living. But if we really show them that they can participate in breakthroughs of major proportions and that they will be able to make a living doing it, then we are going to have new intelligence, new talent, brought to the field, and that is what we really need to continue the progress.

So not only will this money fund existing scientists, but it will open the field to new researchers, and that will make a tremendous difference.

Senator SPECTER. Before we proceed to our next panel, we are going to take a 2-minute recess.

Thank you very much, Mr. Reeve.

Mr. REEVE. Thank you.

[A brief recess was taken.]

STATEMENT OF GERALDINE DIETZ FOX, PRESIDENT, NATIONAL ORGANIZATION FOR HEARING RESEARCH

Senator SPECTER. May we now call our next witnesses: Ms. Geraldine Fox, Dr. Josef Miller, and Ms. Caitlin Parton. Ms. Geraldine Fox, president of the National Organization for Hearing Research, former chairman of the National Institute on Deafness and Other Communication Disorders, former member of the Deafness Research Foundation Board of Directors, and a long-time advocate for increased funding for deafness research, she really has been responsible for the establishment of the National Institute on Deafness and Other Communication Disorders.

She has received numerous awards and citations recognizing her work and commitment to this cause and has been my personal friend for some three decades.

Ms. Fox, welcome and we look forward to your testimony.

Ms. FOX. Thank you very much, Mr. Chairman Specter and Senator Harkin, for the opportunity to appear before you and the members of this subcommittee today on behalf of expanded funding for research and training at the National Institute on Deafness and

Other Communication Disorders. It is a privilege to be able to thank you for your continuing attention to these issues.

Dr. Joe Miller in a few minutes will tell you of the tremendous progress that has been made in the years since the establishment of NIDCD. I believe this is because the legislators have consistently shown their understanding that research not only enables people with communication disorders to lead more meaningful lives, but also it saves the Government money. The generosity of the Congress has fueled the Institute's growth and expansion since its inception and has thus been a loyal friend to the communicatively impaired. We are extremely grateful for your dedication to improving the quality of life for this segment of society.

I am entering into the testimony a letter from Actress Nanette Fabray, who has long been a supporter of research. Miss Fabray experienced the difficulties and hardship of hearing impairment firsthand before surgery cured her otosclerosis. Nanette wanted to be with us today, but she is appearing in a play in New York.

Many other famous people have been candid about their own or someone in their family's communication disorder, people such as Louise Fletcher, the Academy Award-winning actress whose parents were deaf; rock performers, Pete Townsend of the "Who and Lars Ulrich of Metallica," who both suffer because of their own loud music and now wear hearing protectors when they play; deaf actress Marlee Matlin; the golfer Arnold Palmer; dress designer Gianni Versace, who mentioned his cancerous ear tumor operation in a recent issue of Vanity Fair magazine; singer-actress Barbara Streisand, who revealed her problem with tinnitus in Vanity Fair magazine; deaf Miss America Heather Whitestone; Detroit Tigers baseball player Curtis Pride; our own Pennsylvania Governor Tom Ridge; Marilyn Quayle, wife of the former Vice President, has a deaf sister; Senator Harris Wofford, now head of the Corporation of National Service, grandmother was deaf and grandfather was educated as a tutor for the deaf; and Beverly Sills, whose daughter was hearing impaired.

Lionel Hampton, who suffers from tinnitus, has established the Lionel Hampton Ear Research Foundation. And Ray Charles, who because of blindness strongly depends upon his hearing to connect him to the world, he has established his own Robinson Hearing Foundation Research Center.

This short list of recognizable names suggests how basic communication disorders are in our society. In fact, according to the NIDCD, communication disorders affect more than 46 million Americans of all ages, races, gender, and socioeconomic levels. As the American population ages and as the survival rate of low birth-weight babies improves, the number of individuals afflicted with or experiencing communication disorders is expected to increase.

These disorders can impose a serious toll on the afflicted. Depending on the age at which a person is stricken, they can negatively impact a person's emotional, social, economic, educational, and cognitive development. The cost of these disorders in suffering, unfilled potential, and economic factors is incalculable.

Additional and increased Federal support is required, not just to maintain the level of progress, but to strive for even more substantial achievements in this field. I would like to urge the committee

that enlarging NIH funding will not only increase NIDCD's funding for research and training, but it is also truly justifiable and in the best interests of the country.

I was fascinated to read in a May 15 New York Times editorial concerning a National Science Foundation study that—

Research funded by Government and nonprofit agencies accounts for over 70 percent of the scientific papers in the study sample of recent patentholders. Spending by the Government on research and development contributes perhaps half of the growth in American living standards. Each dollar spent on basic research permanently adds 50 cents or more each year to the national output, an impact that is many times larger than the permanent gains from increases in ordinary business investments. This latest study suggests that Government and university-based research packed the biggest wallop.

PREPARED STATEMENT

I see a red light, but I do want to tell you that we at NIDCD will uphold our tradition and mandate to fund only the finest quality science, and we remain deeply grateful that you, this committee, grasp the importance of granting our esteemed researchers the opportunities to enable people to participate to the fullest in a society that grows more communications-oriented every day.

Thank you very much.

Senator SPECTER. Thank you very much, Geraldine, Gerry, for your testimony and, more importantly, for your leadership on this very important cause.

Ms. FOX. Thank you.

[The statement follows:]

PREPARED STATEMENT OF GERALDINE DIETZ FOX

Thank you, Chairman Specter and Senator Harkin for the opportunity to appear before you and the members of the Senate Appropriations Labor, Health and Human Services, Education and Related Agencies Subcommittee today on behalf of expanded funding for research and training at the National Institute on Deafness and Other Communication Disorders. It is a privilege to be able to thank you for your continuing attention to issues related to communication disorders.

My name is Geraldine Dietz Fox, and I became hearing-impaired after contracting the mumps at age 27. I last appeared before you in 1993 when I had completed my term of four years as Chairperson of the Advisory Board of the National Institute on Deafness and Other Communication Disorders. I am now the President of the National Organization for Hearing Research, a private charitable foundation which gives grants to auditory scientists to explore the preventions, causes, cures and treatments of deafness and hearing impairments.

In a moment, the program areas and progress of the National Institute on Deafness and Other Communication Disorders will be highlighted by one of our field's most eminent scientists, Dr. Josef Miller. Dr. Miller is Director of the Kresge Hearing Research Institute and the Lynn and Ruth Townsend Professor for Communicative Disorders at the University of Michigan.

Tremendous progress has been made in the years since the establishment of the Institute. I believe this is because the legislators have repeatedly shown their understanding that research not only enables people with communication disorders to lead more meaningful and productive lives, but also saves the government money. Through its generosity, Congress has fueled the Institute's growth and expansion since its inception, and has thus been a loyal friend to the communicatively disordered. We are extremely grateful for your dedication to improving the quality of life for this segment of society.

I am entering into the testimony a letter from actress Nanette Fabray, who has long been a supporter of communication disorders research. Miss Fabray experienced the difficulties and hardships of hearing impairment first-hand before surgery cured her otosclerosis. Nanette wanted to be with us today, but she is appearing in a play on Broadway.

Many other famous people have been candid about their own or someone in their family's communication disorder, people such as Louise Fletcher, whose parents were deaf; rock performers Pete Townsend of The Who and Lars Ulrich of Metallica, who both suffer because of their own loud music and now wear hearing protectors when they play; actress Marlee Matlin; golfer Arnold Palmer; dress designer Gianni Versace (who mentioned his cancerous ear-tumor operation in a recent issue of *Vanity Fair* magazine); singer-actress Barbra Streisand (who revealed her problem with tinnitus in *Vanity Fair* magazine); Gil McDougald, a New York Yankees baseball player in the 1950's; actor Richard Dysart; NBC medical correspondent Art Ulene; the first deaf Miss America Heather Whitestone; actor William Shatner (who has testified before you for increased funds for tinnitus); actress Florence Henderson (who was cured of otosclerosis through surgery); Detroit Tigers baseball player Curtis Pride; Pennsylvania Governor Tom Ridge; Marilyn Quayle, wife of the former Vice President, has a deaf sister; former Senator Harris Wofford, now head of the Corporation for National Service (whose grandmother was deaf and whose grandfather was educated as a tutor for the deaf); Beverly Sills (whose daughter is hearing impaired); singer Stephen Sills (of Crosby, Sills, and Nash); Kathy Buckley, the deaf comedienne; actor Richard Thomas; and former NFL Player of the Year Larry Brown (who testified with me several times). Lionel Hampton, who suffers from tinnitus, has established the Lionel Hampton Ear Research Foundation; and Ray Charles who, because of blindness, strongly depends upon his hearing to connect him to the world, has established the Robinson Hearing Research Foundation. These are but a few names that come to mind of people who have shared their stories with other people and are concerned about the distressing effects of a communication disorder.

This short list suggests how pervasive communication disorders are in our society. In fact, according to the NIDCD, communication disorders affect more than 46 million Americans of all ages, races, gender and socio-economic levels. As the American population ages, and as the survival rate of low-birth weight babies improves, the number of individuals afflicted with or experiencing communication disorders is expected to increase. These disorders can impose a serious toll on the afflicted. Depending on the age at which a person is stricken, they can negatively impact a person's emotional, social, educational and cognitive development. The cost of these disorders in suffering, unfulfilled potential and economic factors is incalculable.

You will hear in detail from Dr. Miller how the legislators' past concern and commitment has resulted in new initiatives, new investigations new discoveries and new therapies. But additional and increased Federal support is required not just to maintain the level of progress but to strive for even more substantial achievements in this field. I would like to urge the Committee that enlarging NIH's funding will not only increase NIDCD's funding for research and training, but it is also truly justifiable and in the best interests of the country.

I was fascinated to read in a May 15, 1997 New York Times editorial concerning a National Science Foundation study that, "Research funded by government and nonprofit agencies accounts for over 70 percent of the scientific papers cited in the study's sample of recent patent holders." The editorial continues, "Spending (by the government) on research and development contributes perhaps half of the growth in American living standards. Each dollar spent on basic research permanently adds 50 cents or more each year to the national output—an impact that is many times larger than the permanent gains from increases in ordinary business investment. This latest [National Science Foundation] study suggests that government and university-based research pack the biggest wallop."

In the case of this Committee's appropriation to the National Institute on Deafness and Other Communication Disorders, increased funds will support research that has far-reaching results. Discoveries resulting from government-supported research may not only relieve communicatively-impaired Americans of a burdensome, confining disability. They may also free them from or mitigate the constraints limiting their ability to fulfill their potential to contribute to our communications-oriented society. The benefits of knowledge produced by scientific research thus radiate outward from the individual, to the family, to the school, to the workplace, to the community, to the nation as a whole.

We applaud the accomplishments of the National Institute on Deafness and Other Communication Disorders as it enters its ninth year confident that the upcoming year will be filled with excitement and vitality. We thank Congress for their astuteness and belief in our mission and goals. We uphold our tradition and mandate to fund only the finest quality science and we remain deeply grateful that you grasp the importance of granting our esteemed researchers the opportunities to enable people to participate to the fullest in a society that grows more communications-oriented every day.

STATEMENT OF DR. JOSEPH MILLER, DIRECTOR, KRESGE HEARING RESEARCH INSTITUTE, UNIVERSITY OF MICHIGAN, PROFESSOR OF COMMUNICATIONS DISORDERS, PROFESSOR OF OTOLARYNGOLOGY

Senator SPECTER. We now turn to Dr. Joseph Miller, director of the Kresge Hearing Research Institute at the University of Michigan, professor of communications disorders and professor of otolaryngology. He has done research on middle ear function, noise exposure, and the development of cochlear implants, been a member of the research advisory committee for Gallaudet College here in Washington, and is a director of the board of the International Hearing Foundation.

Thank you for coming today, Dr. Miller, and we look forward to your testimony.

Dr. MILLER. Thank you very much. Senator Specter, Senator Harkin, members of the subcommittee: I am here before you on behalf of the Friends of the NIDCD, which represents the health care professionals and research scientists concerned with the National Institutes of Deafness and Other Communication Disorders and the 46 million Americans with diseases and disorders of human communication that it represents.

First let me say thank you very much for the very important and effective efforts to increase funding of the NIH last year and your efforts to increase its funding for this and coming years. The NIDCD is the principal resource for new knowledge for the prevention and treatment of diseases and disorders of hearing and communication, which affects more than one in every six Americans. This agency is the single most important source of support and hope for our citizens with hearing impairment, the Nation's No. 1 disability.

As a result of the NIDCD support this year, we have identified new genes that cause hearing loss and how they work, and we will learn how to prevent genetic hearing loss. NIDCD research has made major inroads in the prevention of acquired deafness. Intense noise is the leading cause of acquired deafness in the industrialized world. We have discovered that treatment with certain hormones and growth factors can greatly reduce or prevent noise damage to the delicate sensory cells of the inner ear and prevent deafness. This treatment can also reduce or prevent deafness from drugs that cause hearing loss.

At the present time, however, genetic and acquired deafness is still a major problem. But NIDCD-sponsored research has made great progress in the treatment of deafness. The cochlear prosthesis or bionic ear continues to be a major success, and now prototypes of the next generation of prostheses have been developed with solid state technology that make them more effective, more reliable, less expensive, and more available.

Molecular treatments of the deaf auditory system is being developed to restore hearing. Treatments with chemical survival factors, neurotrophins, can prevent nerves from dying and induce regrowth of nerve endings, as we heard in the last testimony by Christopher Reeve. Eventually, we hope it will yield hair cell regeneration. This new area of medicine is termed tissue engineering and molecular medicine. Newly identified molecules, drugs, and other factors are

introduced directly into the inner ear to enhance resistance to environmental stress factors, prevent cell death, hasten repair, and eventually cause regeneration.

As a part of this approach, cochlear prostheses will soon include channels for delivery of drugs and be covered with biopolymers that will act as matrix carriers for genetically transformed cells to function as tiny chemical factories to deliver other agents to the ear. These drugs, coupled with the implant, will stimulate nerve contact with the prosthesis, provide additional channels of auditory information to the brain, and increase speech recognition and comprehension.

Testing of these new devices is just beginning under NIDCD support. These are just a few of the exciting new findings and developments from individual NIDCD-sponsored research activities. We should add the initiation by NIDCD of clinical trials of a vaccine for titus media in children, treatments of sudden hearing loss, swallowing disorders, and deafness.

My examples have been drawn from the area of hearing sciences and deafness. Similar exciting advances in the areas of balance, taste, smell, voice, speech, and language that make up the responsibilities of the NIDCD could have equally been drawn. We have an ever-increasing ability to prevent and treat communication disorders. The laboratories are in place. The basic and clinical researchers are more devoted and dedicated and willing than ever. It is a wonderful time and the opportunities are great.

However, the challenges are also great. Of the 5 million children receiving special education, more than 80 percent require training because of a hearing loss. Communication disorders are a factor in school performance and the occupational choices of our youth. Currently, deafness and communication disorders cost our country more than \$30 billion each year. Communication underlies our service-based economy and communication disorders will compromise the success and standards of our country's progress into the next generation.

PREPARED STATEMENT

It is the professional judgment of the officers of the NIDCD that the appropriations and funding of this Institute be increased by 50 percent. We know that is impossible. We request that every effort be made to increase the funding of the NIDCD by 12 percent. That is \$22,300,000.

Senator Specter, I am grateful to you for providing this opportunity to present this information and would be pleased to answer any questions you may have.

[The statement follows:]

PREPARED STATEMENT OF DR. JOSEF MILLER

Senator Specter, members of the subcommittee, ladies and gentlemen, I am Dr. Josef Miller, Professor and Director of the Kresge Hearing Institute, Department of Otolaryngology, University of Michigan. I am here before you on behalf of the Friends of the NIDCD, which represents the professional organizations of Otolaryngologists, Audiologists, Speech and Language Therapists, and associated clinical and basic research scientists. We all share a concern for the National Institute on Deafness and Other Communication Disorders and the 46 million Americans with diseases and disorders of human communication that it represents.

First, on behalf of all the biomedical researchers and health care providers of this country, thank you for your funding of the NIH last year. The 5.7 percent increase you provided is having a remarkable effect on the efforts and new discoveries that drive the effectiveness of our health care enterprise. And thank you for your proposed 7 percent increase for the NIH for this and coming years.

The NIDCD is the principal resource for developing new knowledge for the prevention and treatment of diseases and disorders of hearing and communication. These diseases and disorders affect 46 million Americans, more than one in every six people. This agency is the single most important source of support and hope for our citizens with hearing impairment, this Nation's No. 1 disability. As a result of NIDCD support this year, we have identified new genes that cause hearing loss, the way they cause hearing loss, and we will learn how to prevent these effects. We have also made major inroads in the prevention of acquired hearing loss. We have discovered that certain hormones and growth factors may prevent damage to the delicate sensory cells of the inner ear by intense noise, the leading cause of acquired deafness in the industrialized world. We have begun the development of novel delivery systems for new drugs and molecules directly to the inner ear, to prevent and treat hearing loss. Basic research has demonstrated this past year that it is possible to use viral vectors and genetically transformed cells to introduce genes and proteins into the inner ear—that will one day allow us a wholly new strategy for the prevention and treatment of hearing loss. We have demonstrated that we can prevent the death of auditory nerves and initiate regrowth of nerve endings. With continued success and luck we may learn how to make sensory cells regenerate with these and other strategies.

During this last year the first of a new generation of cochlear prostheses, or bionic ears, have been produced. These new devices are based on solid-state technology and are now being tested in animals, with NIDCD support. This technology not only promises to provide a much more effective and reliable implant, for bypassing the deaf ear to directly stimulate the nerves to the brain, but should reduce by half, the costs of these devices. And, during this past year, we have initiated or continued clinical trials of a vaccine for otitis media in children, prevention of antibiotic-induced hearing loss, treatments of sudden hearing loss, swallowing disorders, and the very important problem of detection of deafness in infants so treatments can begin early in the life of the child.

As a result of NIDCD support and new findings from studies at the interface of molecular and systems research, we have created a whole new field and strategy of research in the hearing sciences: the field of "tissue engineering" of the inner ear. This research is aimed at the identification of new molecules, drugs, and proteins that may be directly introduced into the inner ear to enhance its resistance to environmental stress factors, to prevent cell death and stimulate growth, and to hasten repair and cause regeneration. A wonderful example of the application of this strategy, but only one of many, is our next generation of cochlear implants. These new solid state electrodes will be coated with biological materials that will themselves deliver drugs and also act as a carrier for genetically transformed cells that will function as cellular chemical factories to deliver other agents to the ear. These drugs, coupled to the implant, will stimulate a growth of the hearing nerves to make intimate contact with the electrodes of the prosthesis, allowing much finer and a wider range of control of nerve activation. This will allow us to create additional channels of information to the brain and far greater benefits in speech recognition and comprehension.

The cochlear implant is the success story of the NIDCD. It is the model for neuroprostheses and may lead to effective visual and motor prostheses. The technology we are developing in this area, particularly in relation to signal processing, is providing new directions for conventional hearing aid development. Studies of the cochlear prosthesis have provided a unique opportunity to learn more of how the nervous system processes information and the neural basis for perception. These implants will continue to improve. However, with new findings based on these novel and powerful strategies, we will soon discover how to use neurotrophins or mitogens to reengineer the ear tissues so they will repair and regenerate themselves. We will connect new sensory cells to regrown nerve fibers. This will be a treatment applicable to millions of children and the elderly who suffer from inner ear hearing loss.

These new findings and developments are generated through individual research activities in laboratories and clinics throughout the country. They are generated through collaborative programs across agencies of the federal and state governments, and through collaborations between universities and industry, and they are generated across the globe. This combined approach is drawing effectively upon a much broader base of resources than ever before, increasing the efficiency of the field and integrating our new findings more effectively into the larger data base of

biomedical research. We are benefiting more than ever from a diversity of research activities across a broader range of behavioral, biomedical and bioengineering disciplines. With these new research strategies and findings we are creating wonderful opportunities and excitement. These opportunities lie at a basic cellular and molecular level, but they also lie at the level of transnational research. New devices, new preventions and new treatments are at hand.

My examples have been drawn from the area of hearing sciences and deafness. They could as easily and richly been selected from studies of balance, taste, smell, voice, speech, and language, the research areas that comprise the responsibilities of the NIDCD. We have an ever increasing ability to prevent and treat communication disorders, the laboratories are in place, the basic and clinical researchers are more devoted dedicated and willing than ever in our history. It is a wonderful time and we have great opportunities, however the challenges are also great.

Of the 5 million children receiving special education, more than 80 percent require such training because of a hearing loss. Communication disorders are a factor in school performance and the occupational choices open to our youth. Communication underlies our service-based economy and communication disorders will compromise the success and standard of our country's progress in the next millennium. Currently deafness and communication disorders affect 46 million citizens and is estimated to cost our country \$30 billion each year. Communication is an essential element in the fabric of our society and the structure upon which our bridges to and through the next century will be built. The payoff in terms of attacking a problem that must underlie the personal and economic success of a large portion of our society for the next century is enormous. It is the professional judgment of the officers of the Friends of the NIDCD that it would be appropriate to increase the funding of this institute by 50 percent. We know that is not possible. We request that every effort be made to provide a 12 percent increase to the National Institute of Deafness and Other Communication Disorders to address the challenges presented to the lives of the large percentage of Americans with diseases and disorders affecting human communication.

Senator Specter, I am grateful to you for providing the opportunity to present this information about this important part of the biomedical and behavioral sciences. I would be pleased to answer any questions you may have.

**STATEMENT OF CAITLIN PARTON, STUDENT, TREVOR DAY SCHOOL,
NEW YORK, NY**

Senator SPECTER. Thank you very much, Dr. Miller. We will have a question or two.

We now turn to the third member of the panel, Miss Caitlin Parton, student, Trevor Day School, where she is active in many extracurricular activities: music, performing arts, gymnastics. She has testified before the FDA regarding the approval of cochlear implants for the use of children and she has also appeared on the CBS news show "60 Minutes" and the subject of many articles.

We welcome you here, Miss Parton, and look forward to your testimony.

Miss PARTON. Good morning. My name is Caitlin Parton. I would like to thank Senator Specter and members of the subcommittee for this opportunity to support the funding of medical research and to testify how that research has helped people like me.

Hello, Senator Harkin. The last time I was here before this committee I was 5 years old.

I am profoundly deaf. I got meningitis and almost died when I was a baby. After my illness I could not hear anything. A few months later I became a candidate for a cochlear implant. My parents made a very hard decision. The cochlear implant was still in investigative status with the FDA and there were not any other little kids to watch and see how the device helped.

All that has changed. Today there are thousands of children using and benefiting from cochlear implants. But in January 1988

I was the youngest child in the United States to have the implant surgery.

I have been using the nucleus 22-channel device for 9½ years, and I love it. It is helping me a lot. The device delivers sound to my brain much the way the ear does. It consists of a microphone up here behind my ear. It picks up sounds and sends signals to a processor, this little computer box I wear in a pouch. The computer relays those signals to this magnet. That transmits the signals to a receiver under my skin and then to a string of electrodes which has been surgically implanted in my cochlea. The electrodes stimulate my auditory nerve. My brain interprets those signals and I hear. It is really amazing.

I do not remember much about the operation or having to go to therapy at the League for the Hard of Hearing instead of doing other things. I worked hard to learn to listen and speak. These are things most people take for granted.

I am very glad the implant was invented. I think it is important to have the implant as a choice for people who are born deaf or lose their hearing. It is a tool that brings you into the hearing world, the world of sound.

I wear this miracle of modern science and I am a little different. I am a lot like everyone else, too. I do not wear the implant when I sleep, so in the morning when I wake up it is a shock to put the magnet on. At first it is a blur of sound, and then my brain filters out what the different sounds are: the radio, dad cooking breakfast, things dropping, the traffic outdoors, my parents asking if I remember this or that, or all of us going over the plans for the day.

Sounds are really important to me. They give me something exciting to experience every day. Some of the sounds I enjoy most are my parents' and friends' voices, and me talking to everybody.

I love music. I play the piano and I just started the flute. I like hearing what I play. I hate hearing my mistakes. I have a boom box and I love listening to my CD's and tapes.

I am finishing the sixth grade. English, art, social studies, and French are my favorite subjects. I just finished an oral report on Franklin Delano Roosevelt. I sing in the chorus and was in our school musical. I had a great time. I think it is fun to learn. When I grow up I want to be an author and illustrator of children's books.

I am also a member of the National Dance Institute. Over 1,000 kids from all over New York's public and private schools dance together. My implant helps me hear the music, the director, and the beat that I have to dance to.

Like most kids my age, I like talking on the phone. It helps me get homework assignments and make plans with my friends. I like being able to talk with my grandparents.

This spring I started to travel home from school on the public bus by myself. I can call and tell my parents where I am and they do not worry, as much.

Sometimes my parents let me go to the store by myself. I like being able to hear the cars and sirens. I feel safer. I like being able to ask the store clerk where something is. I like hearing the specials at a restaurant and ordering for myself.

I love reading out loud to my little cousins. I love traveling and listening to different languages. I love the sound of waves crashing

on the beach, thunder, wind in the trees, and all the summer picnic sounds. I like the sounds of the school cafeteria. It is noisy, but it sounds like a party to me.

Practically the only sounds I do not like are my parents' words: It is time for bed.

I do not wear the implant when I swim or play around water. That is when lip-reading comes in handy. I hope some day there will be a waterproof implant. I have also heard that very soon they will have one without a wire. I am looking forward to that, too.

This technology is not perfect. I do not hear everything. Some situations are hard for me. I have to ask people to help or repeat things. But I think with research the implant will keep getting better, and the fact that new kinds of implants are being developed will help all of us.

I have hearing and deaf friends. I go to A.G. Bell and Cochlear Implant Club conventions and have made friends from around the world. Most of the time I like being deaf. I feel special.

I have worked hard and I am proud of what I have done. I have read some articles against the implant. I know some people say that kids like me will grow up and not really belong to the deaf culture world and we will not belong to the hearing world either. They say implanted deaf kids will not fit in anywhere.

Instead of separating us into little groups or cliques, we need to learn to respect our differences, because deep down we are all the same. I think we need to remember we have something in common. We are all part of one community.

The cochlear implant has given me choices and opened up the world for me. I know without the funding for research this device would never have been developed or improved. I would like to thank you for all the children like me and ask you to continue supporting this important work for our future.

Senator SPECTER. Thank you very much, Caitlin, for your role model here, your leadership.

With the device that you have, are you able to hear fully and completely?

Miss PARTON. I can hear almost all sounds. But of course, no one hears everything.

Senator SPECTER. You find out you do not know what you do not know. But it brings you up to what the doctors tell you is normal hearing? Do the doctors say that the device which you have gives you normal hearing?

Miss PARTON. It is not exactly normal hearing. It gives you the benefit of getting as much sound as you can. It gives you more sound than normal hearing aids.

Senator SPECTER. How expensive is it, if you know?

Miss PARTON. What?

Senator SPECTER. How expensive is it, how costly?

Miss PARTON. I am not sure.

Senator SPECTER. Well, thank you for your good work.

Ms. Fox, when the request is made for an increase in funding, what achievements do you anticipate if there is a significant increase in funding?

Ms. FOX. Well, I believe in the next 5 to 10 years we definitely will be able to hair cells. I think there will be genetic replacements

for deaf people. I really believe that we will be able to prevent damage from noise in some people. I am not sure; I think that some people are more susceptible to it. But I think that there is going to be a way that we will be able to prevent that loud sounds cause so much damage.

Probably Dr. Miller could answer this more fully than I am answering it. But those are the three things that I see that are the most important.

Senator SPECTER. Dr. Miller, do you think you are in a better position to answer that question than Ms. Fox?

Dr. MILLER. Well, I am not sure better, but I can add to it.

Senator SPECTER. I think her expertise in this line is unparalleled.

Dr. MILLER. It is remarkable, I absolutely agree.

Senator SPECTER. When you ask for an increase of 12 percent, Dr. Miller, do you have any special reason for asking for that precise amount?

Dr. MILLER. Yes; as I think about the comments of Senator Harkin, the number of excellent, outstanding, not very good but the excellent, grants that currently come before the council of the NIDCD, and I know the number of them that include breakthrough findings potentially that we have to put behind a closed door, to use your analogy, that we cannot get out.

Some 7 years ago, for better or for worse, you created a new Institute and with that the success has been remarkable. The field has been energized. The number of investigators, the new programs that have been developed offer opportunities now that are remarkable. We will be able to have air cell regeneration so the ear cures itself. We will take nerves of the deaf child and have them regrow to grow out to that next generation of implants.

Senator SPECTER. Is any of that available at the present time?

Dr. MILLER. Pardon me?

Senator SPECTER. Is any of that regeneration available at the present time?

Dr. MILLER. Right now we know how to cause regeneration under special conditions in nonmammals, in birds, which we did not know a year ago. It could only occur with damage. Now we can initiate it with new stimulants, new kinds of chemicals. We are going to be testing those now in mammals to see whether it will work.

We have discovered that certain cells that are not available in mammals, but are available in birds, that underlie the generation of the new hair cells.

Senator SPECTER. Regeneration is not available as of this moment?

Dr. MILLER. No; it is not available as of this moment. We have other steps that we do.

Senator SPECTER. What is the availability of detecting hearing loss at an early age so that we do not have children who have hearing loss which is not known?

Dr. MILLER. We have two or three excellent technologies for being able to do that. They are undergoing clinical trials now to be able to determine which is the very best. We should be able to bring the detection of hearing loss in this country down from an av-

erage of where it is now with 3 years down to the order of 7 months.

That will be key for being able to introduce rehabilitation at a time when the brain is really available and open to this new education.

Senator SPECTER. Well, I would urge you to help us make the opportunities in your field known, because the sky is the limit. Senator Harkin puts it very well on the closed doors. Nobody knows what is behind them. But we have our work cut out for us.

Senator Harkin.

Senator HARKIN. We sure do. Thank you, Mr. Chairman, and thank you all for being here.

Caitlin, I hope you will forgive me if I do not remember your face. You have changed a lot. I remember the name. That is why I could not quite put the two together. You have grown up a lot since I last saw you. When you said that, I looked at Gerry Fox. I remembered that you were here a long time ago.

How many years ago were you here?

Miss PARTON. About 6 years ago.

Senator HARKIN. About 6 years ago. Well, it seems like you have really worked well with the implant?

Miss PARTON. Yes; it has really helped.

Senator HARKIN. What year are you in school now?

Miss PARTON. I go to the Trevor Day School.

Senator HARKIN. What year are you in school, what class?

Miss PARTON. I am going into seventh next year.

Senator HARKIN. Good for you. Good luck. Keep up your studies. That is great.

Dr. Miller, Caitlin had meningitis. My brother, who is probably about 60 years older than you, also had meningitis, a long time ago. So many people have become deaf as the result of having had meningitis. I have asked this many times before, and I just wonder if there has been any new research as to why 50 years ago—well, let us see—in my brother's case almost 60 years ago, when he had meningitis, he became deaf as a young man, and here we are 60 years later, people still getting meningitis, becoming deaf.

You would think that we would have done some research to find out, why does meningitis so often cause deafness?

Dr. MILLER. We know that meningitis can attack the nerves of the inner ear that go to the brain. Now we have developed certain vaccines that are beginning to be tested—

Senator HARKIN. I am sorry, Joe. I cannot hear you.

Dr. MILLER. We have developed certain vaccines that are being tested to prevent this. So there have been advances that have been made. But we have a ways to go. We still have to get those antibodies that we are using in the vaccines to target exactly the right antibody. We need more research. But there has been progress and we are making progress in that area, and we are reducing it.

Senator HARKIN. Is there any corollary research being done at the National Institute on Neurological, dah, dah, dah, dah, dah, on meningitis and its—

Dr. MILLER. I am sure there is. I unfortunately cannot answer that question as to what is going on in that area.

Senator HARKIN. Well, I guess I am going to have to find out more. I have asked this question over the last several years and I just cannot seem to quite get my hands on focusing on meningitis itself, because of all of the causes of profound deafness in young people it seems to me meningitis always sticks out to me as being the No. 1 cause of profound deafness in young people.

Dr. MILLER. Importantly, some of the causes of meningitis are similar to those that cause middle ear disease. And trials on middle ear disease, the principal cause of children going to a physician under the age of 7, are under way now at the NIDCD, and we are hoping for remarkable reductions in that very costly disease in children. That I can tell you on the part of the NIDCD. The Neurology Institute, I—

Senator HARKIN. Well, I am just wondering. You know, meningitis goes into other areas.

Dr. MILLER. Yes.

Senator HARKIN. Disease and that type of thing, and I was just wondering if other institutes. Maybe I will just ask for a report from Dr. Varmas on that and find out just what is being done to look at meningitis itself as an illness and why it is affecting so much hearing loss in young people.

It just seems like, after all these years, you would think that we would have found some blockage, something to not only prevent meningitis, but to prevent the lasting effects of meningitis.

I am familiar, as you know, Gerry—and I appreciate all the work that you have done on this—with some of the advances that have been done in nerve cell regeneration. I must admit for the last year I have not perhaps kept up over the last year as much as I should have. But have we continued to make really good progress in the hair—what do you call it?

Dr. MILLER. The hair cells in the inner ear?

Senator HARKIN. Yes; the hair cells, regrowth and regeneration. You mentioned it briefly, both of you, I think a little bit. But you feel we are really making some good progress?

Ms. FOX. I believe so, because we have more young people that are now interested in doing this type of work and sending—trying new things and sending their applications off to the NIDCD and also to the private foundations such as mine. We found very innovative, creative science, so that we get kind of off the wall ideas that, if they are successful, they will really change the field.

But what we are seeing is that, as our field grows, we have more and more young physicians and doctors becoming—I said physicians and doctors; I meant researchers—becoming very interested and applying to the field, which is why we get so many wonderful, wonderful applications at NIDCD that cannot be funded, which is why we are here asking for more money.

It is very sad. In fact, I read something in the paper, thinking about your proposal with the health care institutes. I read something in the paper someone sent me from a New Jersey paper where several years ago they had made a proposal that in the gambling houses in New Jersey that they would give a percentage toward research. So I am hoping that they will do that. That would be wonderful, and then we would have more researchers being able to try out their ideas.

Senator HARKIN. Sure.

Dr. MILLER. Senator Harkin, may I add to your question, to Gerry's answer? There is excellent research going on in regeneration. It is also important not to lose sight that there have been new recent exciting discoveries to prevent loss of the cells to begin with, to prevent loss from noise-induced injury, which really is the primary cause of hearing loss, of acquired hearing loss, and from drug-induced hearing loss, which causes thousands of cases of deafness in our country every year.

It looks as though this year we have discovered factors. They are the same factors that Christopher Reeve mentioned. They are factors related to these neurotrophins that cause nerve growth, that we can use to protect these cells and increase their resistance to environmental stress. That could have an enormous impact, not only on our youth, but also in the elderly, in years to come. That is very exciting to us at this time.

Senator HARKIN. One last thing, I also suffer from hearing loss. I go back to my days flying airplanes and I trace it to that, although my hearing loss is not as profound as my wife says it is, I can assure you.

But I have suffered, as you know, Gerry, for years from tinnitus. It varies. Sometimes it gets worse than others, but sometimes it is pretty bad. And as you know, I have tried everything to solve it. I have talked to Dr. Snow many times about the research into that.

Are you confident that we are making any headway at all in finding out, tinnitus, what causes it? No one even knows what causes it?

Dr. MILLER. I know. It has been an enormously difficult problem because it is so subjective, so to be able to take it and put it into an animal model and study the basic mechanisms has been a very difficult hurdle to overcome. We seem to be able—we seem to be beginning to do that. It is just at its initial stage, but we may have some models now that are beginning to work. We may have some new imaging techniques that are perhaps telling us objectively when tinnitus is present in the brain. That will give us a measure then that we can more precisely evaluate treatments. It is beginning. It is promising.

Senator HARKIN. Gerry, again let me thank you very much for all of your efforts in the past, your work to help get the Institute set up. It already seems it has been—how many years now, 8, 9?

Ms. FOX. Pardon?

Senator HARKIN. How many years have we had the Institute now?

Ms. FOX. Nine.

Senator HARKIN. Nine years?

Ms. FOX. Yes; and I want to thank you for your instrumental help with Congressman Claude Pepper, because without the two of you we would not have had an Institute.

Senator HARKIN. Well, keep pushing for the 12 percent. I do not know that we are going to be able to do it unless my friend here can come up with it here.

Senator SPECTER. I join my colleague in expressing appreciation from the subcommittee, the committee, and the whole Congress for your work. And we thank you, Dr. Miller, and you, Caitlin.

Ms. FOX. Thank you very much.

Senator SPECTER. What we need is some help on the lobbying effort. There is nobody better in America than Geraldine Fox.

Senator HARKIN. What we need—one thing I want to do with this. You have heard me preach this so many times, Gerry, about this fund for research. You have heard me talk about the 1 penny from the dollar to set up this trust fund. See, there are a lot of, I think, Institutes and illnesses, diseases, that are being underfunded in terms of research in this country.

If you looked at the number of people affected, the amount of dollars being spent, some are getting thousands of dollars per person affected. Others are getting tens of dollars per person affected. Hopefully, if we ever get this trust fund established, we can begin to correct that imbalance a little bit.

Of course, this is one of the areas that is drastically underfunded. In terms of the number of people affected and the amount of money we put into research, I think it is like——

Ms. FOX. About 46 million communicatively impaired people.

Senator HARKIN. I think it is around, if I am not mistaken, it is less than \$20 per person.

Ms. FOX. And worldwide, hearing impairments just alone worldwide, 120 million.

Senator HARKIN. Was it \$2? Oh, it is \$2 per person. Thank you.

CONCLUSION OF HEARING

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

Senator HARKIN. Thank you.

[Whereupon, at 11:32 a.m., Thursday, June 5, the hearing was concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]