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AMYOTROPHIC LATERAL SCLEROSIS

HEARING

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED SIXTH CONGRESS

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SPECIAL HEARING

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AMYOTROPHIC LATERAL SCLEROSIS

THURSDAY, MAY 18, 2000

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

The subcommittee met at 9:35 a.m., in room SH–216, Hart Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter and Reid.

Also present: Representative Capps.

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning, ladies and gentlemen. The appropriations Subcommittee on Labor, Health and Human Services, and Education will now proceed with our special hearing on amyotrophic lateral sclerosis.

We thank you all for coming. We have a very distinguished witness list, and we have a very distinguished guest list of all those who are in attendance today to proceed with the hearing to hear what is being done, what can be done for the dreaded ailment of amyotrophic lateral sclerosis. This is an ailment which affects some 15,000 to 20,000 Americans, with about 5,000 new cases each year. Some 90 percent of amyotrophic lateral sclerosis patients die within 5 years of being diagnosed and only 10 percent live longer than 5 years.

At the present time, there is no known cure for amyotrophic lateral sclerosis. I have inquired of Dr. Fischbach earlier today specifically on ALS as to whether the new developments on stem cells might have some potential for treatment or for prevention. Stem cells, as you may know, are those substances derived from embryos where they have shown great promise on a number of ailments, Parkinson's and heart disease. They are a veritable fountain of youth with these stem cells being extracted and then being put into the human body to replace defective cells.

That issue is soon to come before the Senate on a bill to eliminate the current prohibition against Federal funding to extract stems cells from embryos. Controversy arises—and we have had a series of five hearings on that subject, but it is relevant to amyotrophic lateral sclerosis perhaps. We will hear Dr. Fischbach's testimony on that. But it is irrelevant because at the present time there is a Federal law which prohibits the National Institutes of Health from using Federal funding to extract stem cells from embryos.

These embryos have been created for in vitro fertilization and they are discarded. They are not to be used. If there were any possibility that they could produce life, I would be totally against their utilization. But in the situation where they are going to be discarded and not used for anything and not produce human life, then it is my view that we ought to try to save lives with the use of these stem cells.

But that is an issue which will be debated on the Senate floor in the course of the next several weeks, but I call it to your attention because these are matters where Members of the Senate ought to know what the views of their constituents are. So, if you have a view, you may want to consider presenting it to your United States Senator.

I am pleased to report that we are moving ahead with increased funding for the National Institutes of Health. I frequently say that the National Institutes of Health is the crown jewel of the Federal Government. I think it may be the only jewel of the Federal Government.

Senator Tom Harkin, a Democrat of Iowa, and I have worked collaboratively with this subcommittee and the full committee on a bipartisan basis to make enormous increases in funding for NIH. I learned a long time ago if you want to get something done in Washington, you have to be willing to cross party lines. And we have increased the funding in the last 3 years by more than $5 billion so that NIH is now funded at almost $18 billion, and we have put $2.7 billion in this year. Candidly it is going to be a tough battle to keep it in the budget, but we are going to try to do that to bring the total funding to approximately $20.5 billion.

As we have increased funding for NIH generally, we have increased funding very significantly for amyotrophic lateral sclerosis, with a funding over the decade from 1990 of $5.8 million to this year to $19.2 million, three to four times as much as it had been in the past.

I had an inquiry yesterday from national television about why all the celebrities. And my response is that when people appear, whom the public associated with, they understand it. When Michael J. Fox came in to testify about Parkinson's and how he was leaving the television show, people relate to that. When Christopher Reeve comes in to testify about the accident he had, being thrown from a horse, and his paralysis and severed spinal cord, people say if it can happen to Superman, it can happen to anyone. And the public attention does help focus on the Congress the need for increased funding and other constituent interests such as stem cell research.

With that brief introduction, let me turn to the distinguished Senator from Nevada, Senator Reid, who was next to arrive here.

OPENING STATEMENT OF SENATOR HARRY REID

Senator REID. Senator Specter, first of all, let me say there are more jewels in the Federal Government than NIH.

But one of those jewels is this subcommittee. I think this subcommittee has done remarkably good work, and I want to make sure everyone within the sound of our voices understands that you talked about not a $5 million increase, but a $5 billion increase. That is significant, especially when we have been cutting back and

holding—so, I do believe this subcommittee is one of the jewels of the Federal Government. You and Tom Harkin have set an example of bipartisanship that most everyone else in the Congress could take a lesson from.

Many of us know that ALS is the disease that took the life of the famed Yankee first baseman, Lou Gehrig. Yet, few of us are aware of the prevalence of this disease and the devastating effect it has on its victims. We know at least 30,000 Americans suffer from this diseases, perhaps many more. In Nevada, a resident is diagnosed every week with this disease. In Las Vegas, the average age of the ALS is patient is 45, and the average survival rate is 18 months.

Today we are joined by a distinguished Nevadan, Steve Rigazio who, like many people who are stricken with this disease, was at the top of his game, so to speak, when he was diagnosed with this disease. He was one of our more prominent business people in Nevada and his story is part of the many stories that we have told here today. I am glad that the chairman allowed Mr. Rigazio to be here today.

In the years since Gehrig's death in 1941, very little progress has been made, and the cause of the disease that bears his name still remains a mystery. Just last week, this committee approved $2.7 billion increase for the National Institutes of Health for this year. I hope that the National Institute of Neurological Disorders and Stroke will give scientists the tools and the necessary resources to identify a breakthrough that will lead to a cure for this devastating disease. Until research identifies a cure, we must do everything possible to encourage the development of effective drugs to treat and improve the quality of life of these patients.

I have serious concerns—and it will come up during this hearing—of FDA's handling of one such drug, Myotrophin, and the fear that this has set a damaging precedent that could discourage other drug companies from participating in ALS research.

We also need to fix a flaw in the Medicare program that requires ALS patients to endure a 2-year waiting period—remember, I have already established in that in Nevada there is an average life expectancy of 18 months—to wait until the final months of their illness to be able to receive Medicare services. It defies common sense and even human decency.

I am 1 of approximately 20 Senators who support S. 1074 that would correct this problem. I am pleased that the House companion measure—we have Representative Capps here—has the support of 230 House Members.

Finally, we cannot ignore the families of ALS patients. Family caregivers must be recognized for their efforts in this field and others, and I hope that Congress will pass legislation that will give a tax credit to family caregivers.

ALS is a disease that strikes at every community with the potential for striking every American. As my friend Steve recently learned, no one is immune. Everyone is vulnerable. I hope that this hearing will help focus important research efforts on this tragic illness. We must act today because ALS patients and their families do not have the luxury of time.

I say, Mr. Chairman, I hope that you will excuse me off and on during this hearing. I just got a beep and I have to go return to the floor. Thank you.

Senator SPECTER. Thank you very much, Senator Reid.

You make a pretty good case that there may be some other jewels in the Federal Government. I am going to reserve judgment on that about the subcommittee. I still think NIH is the crown jewel.

STATEMENT OF REPRESENTATIVE LOIS CAPPS

Senator SPECTER. We have invited to join us today the Honorable Lois Capps, Congresswoman from California, who has introduced legislation on amyotrophic lateral sclerosis. She won election in a special election to succeed her late husband, Congressman Walter Capps. She serves on the Commerce Committee and she has this legislative proposal which I thought merited consideration, and we have decided not to have her as a witness, but have her join us on the panel, and we are glad to yield a few minutes to you, Congresswoman Capps.

Ms. CAPPS. Thank you. Mr. Chairman, I so much appreciate the opportunity to join you at this important hearing. I have enormous respect for you, Senator Specter, and also your colleague, Senator Reid, for your leadership in this area. I want to congratulate you for your leadership in general in the area of medical research, as you have both alluded to these jewels. We would like to increase either their size or their number, and I think that is a joint effort, bipartisan effort, in the House as well as in the Senate. And it speaks well for our Government to be focused in this way.

This hearing is yet another testament to the leading role that you have played in highlighting the needs in this area. As a former public health nurse, I want to thank you for those efforts on behalf of people across the country represented by those in the audience today.

Most of us know of the famed baseball star for which amyotrophic lateral sclerosis is named. Many of us are unaware of the tragic consequences of Lou Gehrig's disease. First diagnosed over 130 years ago, ALS is a progressive, fatal, neuromuscular disease afflicting 25,000 to 30,000 individuals in the United States today. Approximately 5,000 new cases are reported each year.

This hearing on research efforts into the causes, the treatments, and the cures for ALS is so very timely. Today we are on the cusp of medical breakthroughs that will change the lives of millions of Americans who suffer from diseases such as ALS and Parkinson's and others. I am so excited about the ALS Association's new research initiative which is going to be announced today. I am very interested in hearing from Dr. Fischbach on advances in research at NINDS and his views on what we in Congress can do to support this kind of work. We here in the Senate and the House certainly need to ensure that the Federal Government meets its responsibilities in NIH funding and in other areas.

As was mentioned, I am trying to address some of those needs through legislation I sponsored, the ALS Treatment and Assistance Act, which is House resolution 353. My bill will waive the 24-month waiting period for Medicare coverage for ALS patients. It is only reasonable since the life expectancy for persons with ALS is,

tragically, often shorter than this waiting period itself, and ALS patients have usually paid into the Social Security and Medicare systems for years prior to their diagnosis.

My bill will also provide Medicare coverage for outpatient drugs and therapies for ALS. This coverage will help ALS patients and also help spur the development of new treatments for this disease.

Currently, as was mentioned, more than 230 House Members are cosponsors of this bill, and I hope that we can enact it into law this session. I know that Senator Torricelli has introduced companion legislation here in the Senate, Senate bill 1074, and I would like to thank him for his leadership on this issue.

But the biggest thanks of all goes to many people across this country, PALS. You are in this room. Persons with ALS and your families. You are the ones who have caused the momentum to build in the House for those 230 cosigners. I have to tell you this ALS Day on the Hill that now I have experienced for three times is one of the most inspiring days for this Member of Congress, to see you here, tirelessly going from office to office, personally asking your Representatives. That is democracy in action. And it has proven to be effective.

Now, this hearing will help build the momentum even further, and we can expect, hopefully, legislation this year.

Members of Congress and Senators have been educated regarding the debilitating aspects of this disease and the critical need for more research. Many times making this personal connection makes all the difference.

I have a personal connection as well that I just want to mention briefly. The inspiration for this legislation comes from just that personal connection. My late husband Walter was in rehabilitation after a terrible car accident in 1996, and he struck up a friendship with a Santa Barbara resident, Tom Rogers, who suffers from ALS. Tom was a compelling and able legislator, a county supervisor, on a fast track toward great political success when he was struck down with this disease. He is a leader still in the environmental movement in Santa Barbara County in California. His struggle with this disease has been and still is heroic and an inspiration to all who know him.

During my husband Walter's campaign for Congress, Tom gave him his running shoes. He said he could no longer use them himself due to the toll that ALS was taking on his life. Walter wore those shoes throughout the months leading up to his election to the House. It was this gesture of friendship and support that drew Walter and later me into looking at the costs that ALS exacts and the desperate need for more research into this disease.

So, I really do want to thank you, Mr. Chairman, both personally on behalf of all of these people here for holding this hearing on an issue we all know is so important. I thank our witnesses for coming today and I do look forward to hearing from them. Thank you for the time.

Senator SPECTER. Thank you very much, Congresswoman Capps.

The subcommittee had invited Senator Torricelli to appear as well. He is the principal cosponsor of the Senate companion bill. I am pleased to be a cosponsor. It seems to me that given the problems of amyotrophic lateral sclerosis and the fatality and the short

life span, that it is too much to have the regular 24-month waiting period apply. So, that is a reasonable, even if somewhat costly, provision. So, we will push hard to see if we can get the bill enacted.

STATEMENT OF GERALD D. FISCHBACH, M.D., DIRECTOR, NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE, NATIONAL INSTITUTES OF HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Senator SPECTER. We now turn to our first witness, Dr. Gerald Fischbach, Director of the National Institute of Neurological Disorders and Stroke at NIH since July of 1998. Dr. Fischbach had been Chairman of the Neurobiology Department at Washington University, Harvard Medical School, and Massachusetts General. He is a past President of the Society of Neuroscience, a member of the National Academy of Sciences.

Welcome, Dr. Fischbach, and we look forward to your testimony.

Dr. FISCHBACH. Thank you, Mr. Chairman. Thank you for having this very, very important hearing. I want to add my thanks to you and this committee for its wonderful and remarkable support for biomedical science over the years. My view is NIH is a jewel. My perspective is that it is the jewel of world biomedical science. This is because we now are on course for funding that will allow NIH supported investigators to spread their wings and take advantage of every scientific opportunity that comes our way.

The subject today is amyotrophic lateral sclerosis, and I thought I would spend a few minutes defining the disease, say what we understand about it now, and then say a few words about hopes for the future and what we may think about in the future in terms of new therapeutics.

Amyotrophic lateral sclerosis is a difficult name to say. Amyotrophic because muscles atrophy and waste. The nervous system can no longer support the development and the health and the strength of the muscles so essential for movement. Lateral because the nerve cells that control the muscles are lateral in the nervous system. They are not in the midline. And sclerosis because as the nerve cells die, a scar of sorts forms to replace the disappearing cells. So, ALS is well understood. It has been studied for 130 years in terms of its pathology, and we are learning more and more about its causes. That knowledge will teach us new therapeutic interventions.

The nerve cells that control muscle are very unusual nerve cells. They are lodged in the spinal cord but they send long processes that reach out to touch the muscles and control their contraction and ultimately to support their health. They are extremely vulnerable cells. One wonders why motor neurons are affected in this disease. To give you some idea of the burden that a motor neuron bears and the size of this long extension that reaches out to muscles, if one nerve cell were the size of my head, its extension, called its axon, reaching out to muscles would wrap around this room 20 times. The cell body has to support that large extension. It has an enormous metabolic burden to keep it intact and to signal the muscles to contract in a normal, healthy movement.

The disease does affect about 25,000 to 30,000 people in this country, but it seems to me and to many people that it is more prevalent than that. We all know people with ALS and the pres-

ence of the advocates in this room makes one realize that this has implications far beyond the number of people we now know are affected by the disorder.

There is a terrible and inexorable march of the disease in that we do not know how to reverse it. The predictions are correct of about a 3- to 5-year life span after diagnosis. It affects men a little more frequently than women, and there are various clues to what causes the disorder. There are genetic causes. There are environmental causes and there are some hints about infectious agents that might be possible inciting causes.

I think there is reason for hope in ALS despite the terrible current prognosis. The reasons I have for hope are: First we have learned a tremendous amount in the last 7 years about the genetics of ALS; second, we know a lot now about how cells actually degenerate, and everything we learn about that process offers new opportunities for therapeutic intervention; third, there are new therapeutics on the horizon. One was mentioned, a neurotrophic factor. But there are also new methods for screening for new therapeutics called high throughput assays, which offer new opportunities for collaboration between Government and industry; fourth, there is very promising discussion and early animal experiments on stem cell replacement therapy and gene therapy. The more we learn about the defective genes, the more we can attempt to replace them.

A very small percentage of patients with ALS have inherited this disorder, passed on in families, but the sporadic cases, that is, the cases that arise seemingly de novo in the population are very similar to the cases that are inherited and passed on in families. So, discovery of a gene that is defective in the familial form of ALS has enormous implications for everyone because it may teach us how all cases of ALS progress.

So, the discovery of a gene that encodes an important enzyme, superoxide dismutase, 7 years ago, opened enormous avenues of investigation. This enzyme is responsible for removing destructive chemicals that build up within cells, and it offered several insights into possible mechanisms that may be responsible for nerve cell death, and those investigations are underway today.

We know how these cells die. We know that there are amino acids that are toxic in the nervous system and current therapeutics are attempting to reduce the effect of these amino acids.

Senator SPECTER. Dr. Fischbach, we have a very long list of witnesses and the red light has been on a while. Would you sum up please?

PREPARED STATEMENT

Dr. FISCHBACH. Beyond these, the new therapeutics are promising, and as I mentioned, the animal experimentation suggests that cell replacement therapy with embryonic stem cells may very well have a very important function in treatment in the near future of ALS.

[The statement follows:]

PREPARED STATEMENT OF GERALD D. FISCHBACH

Amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease, is a devastating neurological disorder that robs people of their ability to move, eventually causing death. The progression of weakness and muscle wasting can follow several different patterns. It may begin, for example, with difficulty of fine finger movements, such as handling keys or buttons, and progress to affect muscles of the hand, arm, shoulder, and legs. Later, muscles that control swallowing and respiration become involved. Regardless of how it begins, ALS is relentless in its progression. About 5,000 people in the United States develop ALS each year, and about 90 percent of them die within 5 years of when symptoms are first detected.

The symptoms of ALS reflect the death of motor neurons, nerve cells in the brain and spinal cord that innervate muscles and cause them to contract, making movement possible. Motor neurons are remarkable machines. Their cell bodies, which hold the genetic blueprints and manufacture most cell components, lie in the brain and spinal cord, but each one extends a long thin fiber called an axon that projects far to connect precisely to muscle cells. Although the axons are microscopic in diameter, the total volume of a motor neuron can be 5000 times that of a typical cell because the axons are so long. The large size of motor neurons, their high energy requirements, and the extent of axons out of the protected environment of the brain and spinal cord contribute to the vulnerability of these cells.

In addition to the spinal cord motor neurons themselves, the so called "upper motor neurons" also die in ALS. These are nerve cells in the cerebral cortex that activate the motor neurons. The cerebral cortex helps coordinate the planning and initiation of voluntary movement. Upper motor neurons, like motor neurons, must support very long axons, extending as far as from the head to the lower spinal cord, and this may contribute to their vulnerability.

Although motor neurons are the best studied of all nerve cells, we don't know why cells die in ALS, why the disease selectively affects motor neurons and spares other cells, and whether a defect in the motor neurons themselves, or some other factor, triggers the disease. Most importantly, we do not yet know how to stop the progress of ALS.

HOW NERVE CELLS DIE IN ALS/WHAT CAUSES ALS

There are many disorders in which nerve cells die. The particular diseases that result depend on which parts of the nervous system are affected. Recent research has shown that the final steps leading to nerve cell death may be the same in many disorders including ALS, Parkinson's, Alzheimer's and Huntington's disease, and in trauma and stroke. The discovery that common themes play out in each disease offers hope because progress against one disorder will very likely help in the fight against others.

Apoptosis, or "cell suicide," is one unifying theme in neurodegeneration that has come to prominence in ALS research. Studies of the development of the nervous system, particularly in simple organisms such as nematode worms, revealed that many nerve cells take an active role in their own death. Cells invoke a step-by-step disassembly process called apoptosis. During apoptosis a cascade of enzymes takes place, in which one activates the next like the steps in a computer program, ultimately leading to the destruction of the cell. Despite the fact that apoptosis is a late step in the progression of disease, there are now tantalizing suggestions in animal models that interrupting apoptosis may slow the progress of ALS. Each step in the cascade offers targets for the development of drugs or other interventions.

In addition to the cell death cascade itself, a great deal of research is directed at insults that set it off. Cells enter apoptosis when they are damaged. Free radicals are among the leading culprits suspected of causing damage in neurodegenerative disorders including ALS. Free radicals are highly reactive chemicals that are a byproduct of normal energy metabolism. If produced in excess or insufficiently controlled, these chemicals damage critical components of nerve cells. Because nerve cells, and especially motor neurons, require so much energy to carry out their electrical and metabolic activities, they are especially vulnerable to free radical damage.

Molecular genetics is contributing greatly to our understanding of ALS, and has reinforced the suspicions about a role for free radicals in the disease process. Although only about ten percent of people with ALS inherit the disease, studying those familial cases is helping scientists to understand ALS because genetics can identify the first step in the disease—a mutant gene—in these cases. Mutations in the gene for the enzyme superoxide dismutase (SOD) cause some cases of inherited ALS. SOD normally acts to safely remove free radicals. However, it appears that the mutation may lead to ALS not because the enzyme fails to do its job, but because it creates excess free radicals. This surprising result is an excellent illustra-

tion of the power of genetics to focus attention and generate new hypotheses. Inherited ALS is clinically similar to the more common forms of the disease, and scientists are actively investigating the extent to which the underlying mechanisms of inherited and sporadic ALS are also alike. Meanwhile, geneticists are searching for other mutations that can cause this disease and provide additional clues.

The discovery of SOD mutations led to another crucial advance in ALS research. Scientists leveraged this gene finding by engineering mice that develop a disease that mimics ALS. These mice are now critical tools for studying ALS and testing treatments. Several therapeutic strategies have already shown promise in these animals. For example, the nutritional supplement creatine, a natural component of energy metabolism, extended the lives of ALS mice and is now being tested in people with ALS.

Other processes that damage nerve cells in other neurological disorders have been implicated in ALS. "Excitotoxicity" occurs when nerve cells are overstimulated by the neurotransmitter glutamate, a normal chemical signal by which nerve cells electrically activate one another. In ALS there may be a failure to clear glutamate adequately, allowing too much to accumulate. Too much glutamate can lead to abnormal accumulation of calcium within cells and this disrupts many critical cellular functions. Excitotoxicity and excess calcium can harm mitochondria, the energy factories of the cell, causing excess production of free radicals, triggering apoptosis. Free radicals can damage many parts of cells including neurofilaments, an essential component of the internal "skeleton" of nerve cells that is especially important in the long axons of motor neurons. Abnormal aggregation of proteins, including neurofilament proteins, is another recurring theme in neurodegenerative diseases that has been a focus of attention in ALS. The role of the immune system in ALS has also been a target of investigation, with some studies indicating an autoimmune attack on calcium channels in ALS. (However, a variety of immune based therapies have been tried and failed to slow the disease.) Similarly, there have recently—and in the past—been suggestions that a virus may be associated with the disease in some way, but further investigations will need to determine whether a virus can actually cause the disease. Understanding how these processes come together to cause ALS, and what triggers the harmful interactions to begin, is a complicated puzzle that must be solved to defeat ALS.

HOW NERVE CELLS LIVE

Despite the accumulating information about what causes nerve cells to die, we still don't know why neurodegeneration begins in ALS. It is also a mystery why nerve cell death proceeds so quickly, compared with disorders like Parkinson's and Alzheimer's. The rapid progression of ALS may reflect a downward spiral of effects, each one triggering the next. In addition to processes that damage nerve cells, the disruption of factors that normally sustain cells may be critical. In other words, to understand ALS we must attend not only to how nerve cells die, but also to how nerve cells live.

Nerve cells do not live in isolation, but continually engage in conversations with other nerve cells, with supporting cells called glia that greatly outnumber nerve cells, and with target cells, such as muscles, to which motor neurons connect. Glia, for example, are largely responsible for clearing excess glutamate to prevent excitotoxicity, and a deficiency in glutamate clearance has been implicated in ALS. So, although motor neurons have been the obvious focus of research in ALS, other cells may also play a crucial role in this disease. Understanding these complex interrelationships is critical for understanding what triggers ALS and why it proceeds so rapidly.

The neuromuscular junction illustrates the intricacy of communication between cells, which includes not only rapid messages that evoke muscle contraction but also more slowly acting factors that influence cell growth, survival and specialization. The neuromuscular junction is the functional connection, or synapse, between the axons of motor neurons and muscle cells. The motor neuron axon and the muscle cell each form highly specialized, precisely aligned structures that together make up the neuromuscular junction. The result allows rapid and reliable activation of muscles by neurotransmitters released by the axon. During the development of the neuromuscular junction, the motor neuron axon and the muscle cell intimately exchange signals that guides each to form its part of the junction. Likewise, even in the adult, there is a continual remodeling of the junction with an ongoing interaction between nerve, muscle and glial cells.

Natural growth and survival molecules called neurotrophic factors are one token of the slower, nutritive communication between cells. The receptiveness of cells to these molecules depends on how electrically active cells are. So, as motor neurons

are damaged, for whatever reason, their interaction with other nerve cells, glial cells, and muscle may be affected, leading to further problems. Experiments using neurotrophic factors as therapy have produced some promising results in animal models of ALS and other neurodegenerative disorders. So far, success has not followed in people with these diseases, although trials are continuing. The lack of early success is not surprising, and should not be discouraging, given how difficult it is to get neurotrophic factors into the brain and spinal cord where they are needed and how little we understand about which molecules, perhaps in combination, are most appropriate.

Other areas of fundamental neuroscience are also likely to have a bearing on ALS research in the future, and ALS has attracted the interest of some of the best scientists from many areas of research. There has been astonishing progress in understanding the steps by which a primitive embryonic cell becomes a highly specialized motor neuron. Within cells chemical messengers called transcription factors bind to specific regions of DNA and turn on and off particular genes, thereby regulating the fate of the developing cells. Which genes are active in a cell determines what kind of cell that cell will be. The transcription factors, in turn, are regulated by chemical signals from neighboring cells. Insights about how motor neurons specialize to differ from other nerve cells provide essential clues for understanding why these cells are selectively lost in ALS. Strategies, such as gene therapy, might also exploit the gene control elements to target potential therapeutic genes to motor neurons. Perhaps in the not too distant future, the developmental pathways might also be invoked to generate replacement motor neurons from stem cells.

DEVELOPING THERAPIES

The more we understand what causes cells to die in ALS and what nerve cells need to live, the more rationally we can develop therapies. Drugs might plausibly target any of the processes implicated in ALS—free radical damage, excitotoxicity, calcium concentration, apoptosis, and so on—or therapeutic interventions might supplement sustaining factors like neurotrophic factors and electrical activity, try to replace or repair defective proteins such as SOD or even aim to replace lost cells. A combination of approaches may well be the best strategy.

Pharmaceutical companies use a technology called high throughput screening to accelerate the development of new drugs. Using robotics, this approach screens hundreds of thousands of chemicals in a short time to identify lead compounds for drug development. Although industry invests heavily in high throughput screening, private companies are less likely to focus on relatively uncommon disorders such as ALS. NINDS is trying to find the best ways to put this technology in the hands of researchers who are focusing on ALS and other neurological disorders. An important part of the high throughput strategy is the requirement for simple, repeatable assays, or tests, for the effectiveness of a potential drug. On April 10–11 NINDS, working closely with private ALS and SMA groups, held a workshop on "Assays for High-Throughput Screening of Drug Candidates for Amyotrophic Lateral Sclerosis and Spinal Muscular Atrophy" to help guide that effort. The meeting brought together experts from academia, large pharmaceutical companies, small biotechnology organizations, government and private advocacy groups. NIH will follow up with specific programs to foster the development of assays and to make the robotics, chemical libraries, and other requirements for high throughput drug screening technology accessible to academic investigators.

Several other new therapeutic strategies now on the horizon may also apply to ALS. NIH is very interested in the development of safe and effective stem cell and gene transfer therapies, to name two areas of medicine that have properly captured the public's attention. Stem cells are developmentally primitive cells that can be coaxed to multiply and to specialize to form particular cell types, such as motor neurons. Stem cells might ultimately provide replacements for lost cells, but these versatile cells can be used for therapy in other ways. Stem cells, perhaps altered by genetic engineering, might augment the tissue's ability to clear glutamate or provide neurotrophic factors. Gene transfer therapy likewise might be employed in several different strategies, beyond replacing defective genes, for both inherited and non-inherited forms of disease. Providing neurotrophic factors via gene transfer therapy is one strategy that has shown promise in animals for ALS and other neurological disorders. While stem cells and gene transfer therapy have great potential, each also presents difficulties that must be resolved before their application in people with ALS, and both require substantial investments to build a foundation of basic biological understanding.

Developing better means to deliver therapeutic agents—drugs, cells, and genes—to where they are needed in the brain and spinal cord is another focus of attention

with implications for ALS and many other diseases. The blood-brain barrier (and blood-spinal cord barrier) normally exclude many potentially helpful drugs. Surgical access to the brain is itself not a trivial matter, even with the dramatic advances in brain imaging to guide surgeons, and better methods for physically introducing therapeutics to specific regions of the brain are needed. Likewise, the ongoing efforts to develop drugs that target free radical damage, excitotoxicity, and apoptosis may have a broad range of applications. Just as common mechanisms of damage in many neurological disorders provide synergies for progress, the shared obstacles to therapy for many diseases can also have a positive effect as insights gleaned from each may apply to others.

Although investigator initiated research proposals are at the heart of NIH strategy, we actively stimulate research in particular disorders when emerging scientific opportunities or public impact of a disease warrant such intervention. On both counts we certainly believe ALS merits special attention. The NINDS extramural program has been reorganized with creation of a Neurodegeneration Cluster that reflects the common themes driving neurodegeneration research. We are working to enhance research on ALS in a number of ways, including grant solicitations, workshops, and informal discussions with the research community, and are working closely with ALS advocacy groups in many of these efforts. In March 2000, NINDS released a request for applications (RFA NS–01–004) "Spinal Muscular Atrophy, Amyotrophic Lateral Sclerosis, and Other Motor Neuron Disorders." This RFA sets aside $3 million to fund novel approaches to understanding and treating ALS, spinal muscular atrophy, and other disorders whose cardinal feature is a loss of motor neurons. Given the time required for investigators to write applications and for staff to review and fund new grants, successful proposals are expected to begin in fiscal year 2001. In March NINDS also released an RFA (RFA NS–01–003) entitled "Mitochondrial Function in Neurodegeneration." There is compelling evidence that mitochondria, the energy factories of the cell, play an important role in the generation of free radicals and in apoptosis in ALS and other neurodegenerative disorders. Several of the broad NIH efforts to provide access to emerging technologies, such as gene arrays and transgenic mice, will also be important for ALS research.

CONCLUSION

The best strategy to find a cure for ALS is to support a broad research program, including research focused on ALS, on common themes in neurodegeneration, and on fundamental neuroscience, with an emphasis on funding the best quality science. It would be a disservice to patients and families to make promises about when this disease will be cured. The problems ALS presents are complex and medical progress is notoriously difficult to predict. However, most researchers, energized by progress in fundamental neuroscience, about neurodegeneration in general, and on ALS in particular, feel a cautious optimism that stopping ALS and other neurological disorders is a realistic goal. We share that belief, and will continue our efforts to speed the day when we can better treat, cure, and ultimately prevent ALS.

Senator SPECTER. Dr. Fischbach, thank you very much.

STATEMENT OF TOM MANIATIS, Ph.D., CHAIRMAN, CURE ADVISORY COMMITTEE, AMYOTROPHIC LATERAL SCLEROSIS ASSOCIATION

Senator SPECTER. We are going to call our second witness—we would like you to remain at the panel—before we go to a round of questioning. Our second witness is Dr. Tom Maniatis, Chairman of the ALS Association's Cure Advisory Committee, and Professor of Molecular and Cellular Biology at Harvard. He received his Ph.D. from Vanderbilt, his B.A. from the University of Colorado. He has had within his own family the tragedy of a sister who succumbed to ALS. Thank you very much for joining us, Dr. Maniatis.

Dr. MANIATIS. Thank you, Mr. Chairman. I would like to thank the committee for all their support of NIH which I agree with everything you have said about the importance of the work that is being done there.

My name is Tom Maniatis. I am a Professor of Molecular and Cellular Biology at Harvard University. I teach and direct an NIH-funded research program in the field of gene regulation. My lab pi-

oneered the development of gene cloning methods and has used these methods to study how the readout of genetic information is regulated. Our work has had a significant impact on the human genome project and has led to important insights into human genetic diseases and inflammatory diseases such as arthritis and asthma.

Recently I have been involved in an effort to identify and initiate new directions in ALS research. My interest in this cause was initiated by the recent death of my sister Carol from ALS. A little over 2 years ago, Carol was an executive secretary for a computer company in Denver, and at the age of 57 was active, energetic, and full of life. After working and raising four children, she was at a stage in her life where she had time to enjoy her grandchildren, spend weekends in the mountains, and travel.

Suddenly, however, she began to experience the weakness in her legs and would stumble and fall at work. A series of medical tests led to the devastating conclusion that she had ALS. Her next and final 2 years were an unimaginable nightmare for everyone close to her. Step by step her freedom was taken away. First, she had to leave the job she loved. This was followed by a period when she was unable to walk at all, but could move around controlling the wheelchair with a toggle switch. However, even that was lost as the muscles in her arms and legs degenerated. Then she was unable to talk. Her once articulate and happy voice was gone, replaced by a barely intelligible noises. Then she could not eat. This necessitated the insertion of a tube in her stomach. Then she would choke because she could not swallow. She was ultimately reduced to a limp and lifeless body with a perfectly good mind inside.

Although her basic needs could be conveyed at first with the computer and later with her eyes, she was unable to express the complicated emotions one must feel while the most fundamental human activities are relentlessly taken from you day by day. At least with most other diseases, it is possible to express the feeling of sadness and the fear of dying and to be comforted in a meaningful way.

A year ago, 2 weeks after her 60th birthday, Carol died of asphyxiation, leaving emotionally exhausted and deeply saddened friends and family behind.

I am not a neurologist or even a neurobiologist, but I have a very broad understanding of biology. I can recognize good science, and I am familiar with the latest technical advances that could be applied to the understanding of ALS. I have, therefore, been involved in establishing a new cure-directed research initiative for the ALS Association called The Lou Gehrig Challenge: Cure ALS Initiative. Our mission is to identify promising new directions in ALS research and to develop new therapies. Our strategy is to recruit outstanding investigators and exploit the latest technological advances in biology and drug development, with a commitment to understand the disease and find a truly effective treatment for ALS.

The Lou Gehrig Challenge: Cure ALS Initiative is funding a number of research initiatives, including the establishment of better animal models for the disease in collaboration with Jackson Labs, and the development of cell based assays for high throughput drug screening.

Efforts have also been initiated to identify new genes in mice and humans that are involved in the familial form of ALS, and as Dr. Fischbach mentioned, this could lead to major insights into the mechanisms of the disease.

In addition, we have organized and are funding an investigation of a recent report which claims an association between a polio-like virus and the sporadic form of ALS.

Soon the DNA-sequence of the human genome will be completed, providing exciting new approaches to understanding ALS. This sequence information will dramatically facilitate genetic studies and will make it possible to detect small differences between normal and ALS motor neurons.

Another exciting new direction, which this committee has discussed extensively, is stem cell research, as Dr. Fischbach has mentioned. Preliminary experiments suggest that this technology could provide new therapeutic approaches, but a great deal of fundamental research is required to assess the feasibility and the safety of this approach.

The cost of the Lou Gehrig Challenge: Cure ALS Initiative is provided by a special fund established by the ALS Association. However, we view this fund as seed capital hoping that it will lead to exciting breakthroughs that will attract the interest of the NIH to fund more work on ALS and the interest of drug companies to increase their efforts to develop drugs.

I would like to emphasize, however, that we know relatively little about the disease. So much more basic research is required. However, it is important to point out the fundamental understanding of motor neurons gained in the study of ALS research will be cost effective because of the applicability of this understanding to other neurodegenerative disorders.

PREPARED STATEMENT

I would like to thank the chairman of the committee for giving me the opportunity to speak and urge them to enthusiastically support the funding of efforts to understand and find a cure for ALS.

[The statement follows:]

PREPARED STATEMENT OF TOM MANIATIS

My name is Tom Maniatis, and I am a professor of Molecular and Cellular Biology at Harvard University. I teach and direct a NIH-funded research program in the field of gene regulation. My lab pioneered the development of gene cloning methods, and has used these methods to study how the readout of genetic information in the cell is regulated during embryonic development and in response to infection by pathogenic microorganisms.

Recently, I have been involved in an effort to identify and initiate new directions in ALS research. My interest in this cause was initiated by the recent death of my sister Carol from ALS. A little over two years ago Carol was an executive secretary for a computer company in Denver Colorado, and at the age of 57 was active, energetic and full of life. After working, and raising four children she was at a stage in her life where she had time to enjoy her grandchildren, spend weekends in the mountains and travel.

Suddenly, however, she began to experience weakness in her legs and would stumble and fall at work. A series of medical tests led to the devastating conclusion that she had ALS. Her next, and final two years were an unimaginable nightmare for her and everyone close to her. Step by step her freedom, and her dignity were taken away. First, she had to leave the job she loved. Then, she could no longer drive her car. This was followed by a period when she was unable to walk at all, but could move around by controlling the toggle switch on her electric wheel chair.

However, even that was lost as the muscles in her arms and hands degenerated. Then she was unable to talk—her once articulate and happy voice was gone, replaced by barely intelligible noises. Then she could not eat—this necessitated the insertion of a tube in her stomach, liquid feeding and the loss of the joy of tasting food. Then she would chock because she could not swallow—thus, a tube was inserted into her throat so she could breath. Carol was ultimately reduced to a limp lifeless body of skin and bones with a perfectly good mind inside. Perhaps the most tragic aspect of this disease is the inability to communicate. Although many of her basic needs could be conveyed, at first with a computer and later with her eyes, she was unable to express the complicated emotions one must feel while the most fundamental human activities are relentlessly taken from you day by day. At least with most other diseases it is possible to express the feeling of sadness and fear of dying, and to be comforted in a meaningful way. A year ago, two weeks after her 60th birthday Carol died of asphyxiation, leaving emotionally exhausted and deeply saddened friends and family behind.

I am not a neurologist or even a neurobiologist, but I have a broad understanding of biology, I can recognize good research, and am familiar with the latest technical advances that could be applied to the understanding and cure of ALS. I have therefore been involved in establishing a new cure-directed research initiative for the ALS Association. Our mission is to identify promising new directions in ALS research and to develop new therapies. Our strategy is to recruit outstanding investigators and to exploit the latest technological advances in biology and drug development, with a commitment to understand the disease and find a truly effective treatments of ALS.

We are currently supporting a number of new research initiatives, including the establishment of better animal models for the disease, and the development of cell based assays for high throughput drug screening. Efforts have also been initiated to identify new genes in mice and humans that are involved in the familial form of ALS. In addition, we have organized and are funded an investigation of a recent report which claims an association between a polio-like virus and the sporadic form of ALS.

Soon, the DNA sequence of the human genome will be completed, providing exciting new approaches to understanding ALS. This sequence information will dramatically facilitate genetic studies, and make it possible to detect small differences between normal and ALS motor neurons.

Another exciting direction is stem cell research. Preliminary experiments in a mouse model of ALS suggest that this technology may provide new therapeutic approaches, but a great deal of fundamental research will be required to asses the feasibility and safety of this approach.

The expense of our new research initiatives is covered by a special fund established by the ALS association. However, we view this fund as seed capital, hoping that it will lead to exciting breakthroughs that will attract the interest of NIH to fund more work on ALS, and the interest of drug companies to increase their efforts to develop drugs.

I would like to thank the committee for supporting the recent congressional appropriations to NIH, which have made it possible for Dr. Gerry Fischbach the director of the NINDS to consider new research initiatives in neuromuscular diseases. For example, in collaboration with the NINDS the ALS association recently held a meeting at NIH to discuss the development of cell based assays for neuromuscular diseases. These assays would then be used in conjuction with the latest advances in combinatorial chemistry and high throughput screening technology, to search for new drugs for the treatment of ALS. The meeting ended with two important objectives. First, to promote the further devolopment of a data base of small molecules (called chembank) and explore ways of funding the acquisition and distribution of small molecules for drug screening in an medical/academic setting. Second, to formulate a contract for the establishment of one or more regional high throughput screening centers that would make it possible to search for potential drugs in an academic setting.

Support of ALS research is cost-effective because of applicability to other neurodegenerative disorders.

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

Dr. Fischbach, in the brief period of time we have for questioning, I would like to focus on the possibilities of finding a cure for amyotrophic lateral sclerosis. We have talked a little bit about stem cell research. We have talked about the genome identification. In this week's edition of the New England Journal of Medicine, the

report was that there has been a mapping of chromosome 21, which is associated with amyotrophic lateral sclerosis and some other ailments.

Starting with the issue of stem cells and their extraction from embryos, what do you see as a possibility if the full research potential of the National Institutes of Health was unleashed so that we eliminated the current law which prohibits Federal funding for embryo stem cell research to really go at this in a very concerted way? What are the possibilities? I know you cannot speak with certainty, but what are the possibilities for stem cell research offering a cure for ALS?

Dr. FISCHBACH. Certainly the possibilities are much, much greater than they were just 2 or 3 years ago because we have learned so much more about human embryonic stem cells. I cannot put a number on it. It is a very difficult disorder.

Senator SPECTER. Explain just a bit in lay terms for people here and people watching on C-SPAN just what the stem cell does, how it replaces deficient cells and is characterized accurately as a veritable fountain of youth.

Dr. FISCHBACH. Well, the stem cell is a cell that can give rise to many different types of daughter cells, at the same time renewing itself. So, it is not depleted in principle. The key is, how many different types of cells can a stem cell give rise to and how can it reproduce itself and for how long. In both those categories, it appears that embryonic stem cells are different from other types of stem cells and have more potential for a greater diversity of cell types and for creating large populations of stem cells, which will be needed for useful therapeutics.

Senator SPECTER. So, the embryos are necessary in order to effectively carry out stem cell research?

Dr. FISCHBACH. Well, "effectively" is the key word. In my view, human embryonic stem cell research is the most promising avenue of stem cell research today.

Senator SPECTER. Dealing with the objections which have been raised from using embryos, is it not true that the only ones used are those which have been discarded so that if there is any possibility of the embryo creating a life, there is absolutely no use of that embryo, but only the ones which have been discarded?

Dr. FISCHBACH. To my understanding, that is correct.

Senator SPECTER. Is this analogous to the controversy which we had on the use of fetal tissue where many had objected to the use of fetal tissue on the ground that it would encourage abortions? And then it was made plain and the procedure was established to use only discarded fetal tissue so that it was not a matter of encouraging abortions, but it was a matter of using discarded fetal tissue where abortions had already taken place.

Dr. FISCHBACH. I think the current regulation is that fetal tissue cannot be obtained for the purpose of research, but that discarded fetal tissue is available.

Senator SPECTER. My yellow light is on, so I am going to conclude with just one more question with respect to the identification of the gene and chromosome 21. Explain in lay language just what that means and what the potential is for the possibility of curing ALS.

Dr. FISCHBACH. Every gene that is discovered that is mutant in this disorder offers hope that we will understand the mechanism of the disease. And once we understand the mechanism of the disease, we will have a much clearer view of therapeutics. So, I think discovery of the gene is tremendously important.

There is one additional tremendous advantage of discovering a gene, and that is creating an animal model for the disease.

Senator SPECTER. How do you spell that? Repeat that.

Dr. FISCHBACH. A second great advantage of discovering the gene beyond understanding the disease process is the gene can be used to modify the genome of an animal to create a model for the disease. And now there is a very effective model for ALS in mice, and new therapeutics will be screened in the mice. I think that is a tremendous advance.

Senator SPECTER. My red light is on, so I will turn now to Senator Reid.

Senator REID. Mr. Chairman, I am concerned about this drug that we have talked about, Myotrophin. It seems the evidence is clear that it has helped a significant number of patients, and now we are told that because the FDA did not approve this under their fast approval track that they are allowed by law, that the manufacturer is no longer going to make the drug and notified patients they will no longer be able to get this product.

Do you have any ideas of what we can do to help this situation?

Dr. FISCHBACH. Tom, you should jump in whenever you want, if you would like.

I am not familiar firsthand with the decision not to produce the drug any longer. It is a peptide.

Senator REID. It is a what?

Dr. FISCHBACH. It is a small protein that is being used as a medicine. It is not the usual small molecule drug that we ordinarily take as a pill by mouth.

But the FDA decision does have an effect on industry, and I think that is all the more reason to support the basic science labs, to keep modifying this drug, this peptide, and to encourage further clinical trials so that it will pass FDA inspection and regulation.

Senator REID. We have written to the FDA. I wrote to them in February and got an answer back several months later. During the months, of course—we do not have a lot of time to wait around. I am just very disappointed in FDA.

I think that we have to come up with some way to have this manufacturer and others continue to work on this. I would hope through your good offices, the National Institutes of Health, you would reach out to some of these pharmaceutical companies and individuals who are interested in these experimental drugs. That is what they are. We know this one has given relief to people. I have talked to people it helps. Until we find a cure, we have to look for these kinds of things to relieve pain and prolong life.

I would hope that you, as a researcher, doctor at Harvard, and you having this prominent position in the National Institutes of Health would gather your colleagues and try to give some ray of hope to the manufacturer. The reason they stopped, it is a small number of people that it helps, because we have established that there is at most at this time 30,000 patients.

Without repeating myself, we really need to come up with a plan. As a legislator, I am having a difficult time doing that, and I would hope that the research community would give us some assistance.

Dr. FISCHBACH. Senator Reid, I would like to respond to you in writing after we have a chance to make further inquiries and try and understand what we can actually do right now to make sure that research does not disappear.

Dr. MANIATIS. I would agree with that. I am not fully familiar with the details of the clinical trials, but I think it is really important to look at those very carefully, as Dr. Fischbach says. If improvements could be made that would increase the efficacy, every effort should be made to do that and support the companies who are trying to develop the drug.

Senator REID. Thank you.

Senator SPECTER. Congresswoman Capps, would you care to question?

Ms. CAPPS. I would appreciate the opportunity. Thank you.

I want to start out by congratulating the ALS Association and Dr. Maniatis for your leadership in this new cure-directed research effort of the association and commend you for focusing in the way that you have on this targeted kind of response. Hopefully there might be time to hear a little bit more about how you are doing that.

As a segue, I use that to ask Dr. Fischbach if NIH is focused in the same way. I applaud all of the efforts that have been expressed here and fuller funding for it in general, the genome study, all of these interrelated areas that are benefitted by the research in gene efforts and stem cell and all of it because it does not just affect ALS. It affects a broad range of neurological disorders at least, others as well.

Could you comment please on whether you believe the NIH is targeting ALS sufficiently and are there ways that we could help in that arena?

Dr. FISCHBACH. First, Representative Capps, let me join you in the sentiment that it is wonderful to see the ALS Association bring scientists from other fields, prominent scientists, wonderful scientists like Dr. Maniatis, and a group that is now working with them. One of the greatest challenges is to bring people from other fields to think about this problem in fresh and new ways, and that is happening. We are hopefully part of it at the NIH.

The NINDS is focusing on ALS. You have put it very well, that we are focusing on it because it is an example of a neurodegenerative disorder that has enormous implications for all neurodegenerative disorders, Huntington's disease, Parkinson's disease, even Alzheimer's disease. Similar processes may be at work here.

But we are focusing on ALS specifically, and we have recently released an RFA, a request for applications, dealing with motor neuron diseases and ALS in particular. And we sponsored a conference with the ALS Association that Dr. Maniatis chaired on looking for new therapeutics. I believe that our group within the Institute interested in neurorepair and regeneration and interested in neurodegeneration spend a great deal of their day thinking about ALS and stimulating research in this area.

Dr. MANIATIS. I would like to comment that we have been working with NINDS. In particular, I think one of the really exciting initiatives is an RFA on high throughput mutagenesis screening at Jackson Labs to look for new mutations that affect motor neurons. This could really be an extremely exciting approach that would identify a pathway leading to the disease.

In addition, this conference that Dr. Fischbach mentioned involved bringing people together from industry, from academic science, and from medicine to begin to look at how one could begin to establish new assays for detecting ALS in vitro in a cell-based assay, and then to employ the high throughput screening methods that drug companies have used in an academic setting which would interface the medicine, the science, and the drug screening. That was a very exciting conference. I think it led to a number of proposals that are now being followed up on.

So, from my perspective, this is an extremely exciting time in biology, and this technology and these ideas have not been applied to ALS, and that is what we are trying to do, to bring together people who are experts in these new areas and focus them on the disease.

Ms. CAPPS. The yellow light is on. I just want to commend you for that kind of fresh insight, and I think that is, as you said, Dr. Fischbach, a model for all of us. Thank you.

Senator SPECTER. Thank you very much, Congresswoman Capps. Thank you very much, Dr. Fischbach and Dr. Maniatis. We are going to continue to support you through the NIH funding, but we are going to look for results.

Dr. FISCHBACH. That is fair.

STATEMENT OF STEVE BEUERLEIN, QUARTERBACK, CAROLINA PANTHERS

Senator SPECTER. I would like to call our next panel, Mr. Steve Beuerlein, Mr. Steve Garvey, and Mr. Dick Schaap. Would you gentlemen step forward please?

This distinguished panel of sports personalities will be adding to our knowledge base on amyotrophic lateral sclerosis. We are going to lead off with Steve Beuerlein, starting quarterback for the NFL's Carolina Panthers. His season this year was highlighted with a Pro Bowl appearance. Before starting his professional career, Mr. Beuerlein was a 4-year starter at Notre Dame, where he set numerous records for passing and total offense.

Mr. Beuerlein's high school friend, Jeff Sherer, age 34—Mr. Sherer is seated in the front row—talk just a bit about another medical problem facing quarterbacks, and that is the excessive punishment in the National Football League. And I asked for Mr. Beuerlein's expert opinion, as we asked not too long ago for Troy Aikman's expert opinion, on the approach that there are too many late hits and too many pounding into the ground after it was plain that the ball has gone. If we have any time after ALS, Mr. Beuerlein, we may ask for your expert opinion on that.

Mr. BEUERLEIN. Let the record show that I agree with you 100 percent.

Senator SPECTER. In the anteroom before we started, Mr. Beuerlein suggested legislation which I think would have fit in with our jurisdiction over the Commerce Clause.

Thank you for joining us, Mr. Beuerlein, and the floor is yours.

Mr. BEUERLEIN. Thank you, Mr. Chairman, distinguished members of the subcommittee. It is truly an honor to be here testifying on behalf of ALS today.

I would also like to say before I get going, that my reception here in Washington, D.C. has been a little different than it normally is as an opposing quarterback coming into these parts. Generally speaking, it is not a very warm reception, but I have been treated well in the 24 hours or so that I have been here. I am not naive enough to think, though, that on September 3rd, when we come here to open our season against the Washington Redskins, that the reception will be quite as warm. In fact, there are probably several people sitting here today that will be getting pretty excited every time I get knocked to the turf in that game. But I can handle that and deal with that. That is part of my job.

My reason for being here today is very straightforward. I am here on behalf of my friend, Jeff Sherer, who has ALS, one of my best friends from high school. I am here to encourage this subcommittee and all the relevant Federal agencies, as well as the researchers who testified earlier today, and the ALS Association to pursue all avenues possible to find a cure for this dreadful disease. I know, Mr. Chairman, that you and the other members of the subcommittee share this objective, and I respect you tremendously for that.

I met Jeff back in 1979 on a football field in southern California at Servite High School. Over the 4 years that we played together, we developed a very close relationship. We won a State championship my senior year, had a tremendous year. And I have got three more of my teammates sitting over here that came out to support this cause today as well.

But during the course of that season, I was very fortunate to not get hit very often by anybody from the other team, and one of the main reasons, in fact the biggest reason for that, was my right tackle, Jeff Sherer. He was 6 foot 2 and 300 pounds, conservatively as a freshman in high school.

As he caught up with his body, he became a tremendous football player. I never worried about the right side of my offensive line because I knew that Jeff had it taken care of. He played with tremendous heart. Every time I knew that I could count on him no matter what the situation was, and he today he plays with tremendous heart every time he wakes up in the morning and fights this terrible disease.

Away from the football field, Jeff always lived his life with tremendous passion, and he still does. He loves to smile, loves to make other people smile. If I could give just one example. I always remember every time we got together as a group, all the ladies would always fight to find a way to get close to Jeff, and I never could figure out why. But the reason was because they knew if they were close to Jeff, they probably had the first chance of getting that famous Jeff Sherer back rub.

I used to find myself scooting in there once in a while as well.

But the point of the matter there is that Jeff has always been a tremendous friend, always thinking about other people. He had dreams like all of us, big dreams, and when he met his wife and married her, Marya—she is here today as well—he started to live out a lot of those dreams. She is an unbelievable woman. She is a rock, and I have no idea where Jeff would be without her today. But they have three kids: a 4-year old, a 22-month old, and a 5-month old.

When Jeff was diagnosed with ALS 2½ years ago, a lot of those dreams were put on hold for obvious reasons. As you know, Mr. Chairman, this horrible disease is incurable and it is relentless. I believe that Jeff knows, as well as anybody, that he is fighting for his life. He is battling for his life against a disease that in its most tragic sense has never been defeated.

At the age of 34 today, this once tremendous athlete, Jeff no longer has the use of his arms or his legs. His 5-month-old son he has never been able to pick up and hold and tell him that he loves him. Imagine the frustration and the pain that goes along with that.

What can we do? Well, every night my wife and I say our prayers and we think about Jeff and his family. We pray that the Lord will guide them through this difficult disease, this difficult time. But while we hope for a miracle from heaven, it is up to us to use all of our resources possible to find a cure here on earth for this disease.

In conclusion, I would like to say, Mr. Chairman, that I am here for my friend Jeff Sherer. I am also here for all those people living with ALS in this country and their families and those who care about them, and I am here for the 14 Americans that today will find out that they too have ALS.

My testimony today began with a little bit of football humor. My relationship with Jeff Sherer began on a football field back in 1979, and I would like to submit to this committee that we take an aggressive football-style attacking approach to finding a cure for this disease. We need to pursue the cure. We need to hunt the disease down and stop it cold in its tracks.

PREPARED STATEMENT

Senator Specter, from what I have seen today and from what I have read and observed about you and your past, your aggressive style of leadership, I have no doubt that you are the right man to be sitting in this chair and leading and orchestrating this effort. On behalf of all the people that are affected with ALS and those that care about them and their families, this is a desperate situation. In football terms, we could say it is fourth in goal, the clock is running, we have got our backs up against the wall. Just ask Jeff Sherer or any of the other ALS patients that are here today.

Thank you and God bless you.

[The statement follows:]

PREPARED STATEMENT OF STEVE BEUERLEIN

Thank you, Mr. Chairman, and the other distinguished members of the Subcommittee, I am both humbled and honored to testify before you this morning.

I appear before you today for a reason that is both straightforward and profound. My best friend—or one of my best friends from childhood—Jeff Sherer, has ALS. I

am here to do my small part to encourage this Subcommittee, all of the relevant federal agencies, the researchers who testified earlier, and the ALS Association to join forces to find a cure for ALS. And, Mr. Chairman, let me say up front that I know you have the same objective because it is only through your leadership that we are here this morning,

Let me talk for a few moments about my friend, Jeff.

He and I played football together in high school. Jeff was the starting offensive right tackle on a team that won the California state championship.

Jeff was 6-foot-3, 280 pounds. He was so large that we affectionately nicknamed him, "the Coke Machine." When he blocked someone, the other guy would basically disappear . . . Jeff would just kind of engulf him.

I never worried about Jeff as my right tackle, He was so big and so powerful and so smart, he always came through.

Jeff went on to college . . . began his career . . . got married to a wonderful woman, and began to raise a family. Today, Jeff and his wife, Marya, have three small, children—a daughter, Madison, and two sons, Jeff, who is 22 months old, and A.J., the baby who is just 12 weeks old.

Jeff had big dreams, just like all of us have dreams for our lives. Jeff had begun to live his dreams.

And then he was diagnosed with this horrible, incurable disease known as amyotrophic lateral scleroses, or ALS. Today, all of Jeff's dreams have been put on hold. He is, quite literally, battling for his life against an opponent that is relentless. Jeff is up against a disease that, in the most horrible and tragic sense, is undefeated.

As you know, Mr. Chairman, there is no known cause, prevention or cure for ALS.

And so, my best friend and former teammate, Jeff Sherer, at age 34 is confined to a wheelchair, This once strapping athlete is now unable to move his arms or his legs. This father of three young children breathes with the aid of a machine at night to help him sleep. Jeff now even has trouble speaking.

I pray for Jeff and his family every night. I pray for the Lord to guide and comfort, all of them through this terrible disease.

But I also know that while we must pray for a miracle from heaven, we must work together on Earth for a cure. That's why I am encouraged by the testimony I have heard from Dr. Fischbach and Dr. Maniatis, and by the discussions I have had with the leadership of the ALS Association,

I am here for Jeff Sherer. But I am also here for all of the ALS patients, family members, and other ALS activists who have filled this hearing room. I am here for the Americans who already are living with ALS. And I am here for the 14 Americans who will be called into a doctor's office today and be told that they have been diagnosed with ALS.

Mr, Chairman, I began my testimony today by talking briefly about football. After all, my friendship with Jeff Sherer began on the football field. It has been said that the perfect middle linebacker must be "AGILE, HOSTILE and MOBILE"—pronounce each with a long "I" so the words rhyme.

Mr. Chairman, I would submit to you that we need the same approach to find a cure for ALS. We need an approach that is AGILE, HOSTILE, and MOBILE. We need to pursue a cure for ALS, hunt this disease down, and stop it in its tracks. Senator Specter, from what I have seen and heard today . . . from what I have read and observed about your style of aggressive leadership, I know that you are the right Senator to be sitting in that chair to help lead and orchestrate this effort.

Thank you, and God bless you.

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

The subcommittee is going to have to take a very brief recess because there is a simultaneous Judiciary Committee executive session down the hall taking up the issue of subpoenas on a subcommittee which I chair. The recess is going to be very brief, and I will return in just a moment or two to pick up with the testimony of Mr. Garvey and Mr. Schaap. So, the committee stands in brief recess.

The appropriations Subcommittee on Labor, Health and Human Services, and Education will now resume. That may set the record for the briefest recess of a Senate subcommittee.

When I walked back in and saw all of the photo taking and all the autographs and all the handshaking, the thought crossed my

mind that that was probably the best part of the hearing, to have the recess and give you a chance to get the Schaap, Garvey, Beuerlein autograph session and the photographs.

STATEMENT OF STEVE GARVEY, FORMER FIRST BASEMAN, LOS ANGELES DODGERS

Senator SPECTER. We now turn to one of baseball's great sports personalities, Mr. Steve Garvey, 19 years as first baseman for the Los Angeles Dodgers and San Diego Padres, 5 World Series, 4 Gold Glove Awards, nationally MVP, most valuable player, in 1974 and the most valuable player in the 1978 and 1984 National League Championship Series.

He retired from baseball in 1987, ending a streak of 1,207 consecutive games. That is quite a record, quite a streak, not quite up to Lou Gehrig's 2,130, but phenomenal.

The biographical material I have also lists Mr. Garvey having played in 10 All Star games. I think that probably omits the Softball All Star game which was played in Philadelphia in 1995 before the regular All Star game after you had retired. That was a Softball All Star game of particular moment to me because, as a Philadelphian, I was on the team. Based on having played second base for the Russell, Kansas Junior American Legion baseball team when I was 15, which got to the semi-finals, I felt a little bit at home at second base until the ground balls started coming my way. And Keith Hernandez was playing first—I am taking more time than I should, but this was quite a day for me. There was a sharp grounder hit at me. I did not know quite what to do until Keith Hernandez came over from first base and scooped it up and got the player out.

You may not remember this, Mr. Garvey, but you got the base winning hit. You hit one to my right and Hernandez could not quite handle it.

But that was an exciting All Star game for me.

I know there is a lot of excitement in having you here and the others to talk about amyotrophic lateral sclerosis. So, thank you for joining us and the floor is yours.

Mr. GARVEY. Mr. Chairman, you still maintain your quickness with that brief break, as we noticed back in 1995. It is nice to be with you again, members of the subcommittee. Steve, Mr. Schaap, and I now realize that we are a little too close to you. A Panther in Redskin country is a little perilous here. Your presentation was wonderful.

I am Steve Garvey, former first baseman with the Los Angeles Dodgers and San Diego Padres, and part of Lou's team. Dick and I and Steve a number of other committed people are part of Lou's team, along with this wonderful group of men and women behind us. We are here simply as foot soldiers. The two committed doctors who made presentations to you are at the front line in fighting this disease.

It is ironic that such a crippling disease as ALS would hit another first baseman, one whose incredible strength, stamina and consistency earned him the name "The Ironman." I am speaking, of course, about Lou Gehrig, whose name will forever be linked

with this disease. ALS struck Lou Gehrig at age 36, and he expired 2 years later.

I have been blessed that no one in my family has been affected by ALS. However, I do know that ALS has been a death sentence. It affects the nerves and muscles, making them unusable. One day you find yourself tripping over your own feet. Then you seem to have trouble lifting small objects. Your speech starts to slur. You cannot swallow. Eventually your body becomes paralyzed while your mind stays alert. You and your family prepare for the inevitable. Essentially you become a prisoner in your own body.

The life expectancy of an ALS patient averages 2 to 5 years from time of diagnosis. A simple example was the time that we have sent our children to college for a 4 or 5 year span.

ALS can strike anyone. It knows no ethnic or racial boundaries, although men are 20 percent more likely than women to get ALS. You are probably aware of numerous celebrities have died from ALS like actor Robert Niven, Michael Zaslow, Sesame Street creator Jon Stone, fellow major leaguer Catfish Hunter, and someone who was special to Congress, Jacob Javits.

But ordinary people, those close to your heart, could be ALS' next victim. It might be your grandmother, your daughter, your son, or your wife. No one is immune. And the devastation of watching a loved one die is coupled with the fact that the medical costs for treating ALS can reach $200,000 a year.

The ALS Association's ultimate goal is to find a cure for ALS. But until then, we want to improve the quality of life for those who have been diagnosed with ALS. Currently the ALS Association is funding 80 live research projects.

A woman like Shelbie Oppenheimer, an ALS patient, who will speak to you today. ALS patients like Corinne Werdel. Let me tell you just briefly about Corinne. She has a pacemaker, a feeding tube, and has been on a ventilator for more than 2 years. She has lost all movement except for the muscles in her face which she uses to work a computer. Corinne has the courage to continue her life. She is a true heroine.

PREPARED STATEMENT

We are with you today because we believe in you. Using baseball terms, we have stepped up to the plate, we have made our pitch, even for an old first baseman, and it may only be 80 miles per hour, but we are asking you, the committee, to hit a home run for us. We stand on guard for you. We are your foot soldiers. We are here to support you.

May God bless you and as the Apostle said, "We shall run the good race, fight the good fight, do good deeds from a good heart, be kind and just, fair in principle, and in the end we shall succeed." Thank you.

[The statement follows:]

PREPARED STATEMENT OF STEVE GARVEY

Mr. Chairman and Members of the Subcommittee, thank you for providing me with the opportunity to testify. I am Steve Garvey and I am a former first baseman with the Los Angeles Dodgers and the San Diego Padres.

It's ironic that such a crippling disease as ALS would hit another first baseman, one whose incredible strength, stamina, and consistency earned him the nickname,

"The Ironman." I am speaking, of course, about Lou Gehrig, whose name will forever be linked with the disease. ALS struck Lou Gehrig at age 36. He was dead two years later.

I have been blessed that no one in my family has been affected with ALS. However, I do know that ALS has been a death sentence. It affects the nerves and muscles, making them unusable. One day, you find yourself tripping over your own feet. Then, you seem to have trouble lifting the smallest objects. Your speech starts to slur. You can't swallow. Eventually, your body becomes paralyzed, while your mind stays alert. You and your family prepare for the inevitable.

The life expectancy of an ALS patient averages two to five years from the time of diagnosis. Think of it this way: In the time it took for you to go through college, that would be how long you'd likely have left to live after being diagnosed.

ALS can strike anyone. It knows no ethnic or racial boundaries, although men are 20 percent more likely to get ALS than women. You are probably aware of numerous celebrities who have died from ALS like actor Robert Niven, Sesame Street creator Jon Stone and fellow major leaguer Jim "Catfish" Hunter. These celebrities' tragic deaths helped to bring ALS into the spotlight. But ordinary people—those close to your heart—could be ALS's next victims. It might be your grandmother . . . your daughter . . . your wife. No one is immune. And the devastation of watching a loved one die is coupled with the fact that the medical costs for treating ALS can reach $200,000 a year.

The ALS Association's ultimate goal is to find a cure for ALS. But, until we can find a cure, there should be ways to improve the quality of life for those who have been diagnosed with ALS. Currently, the ALS Association is funding 80 "live" research projects.

Because of what was learned from such research, Rilutek, a drug approved by the FDA, was developed and was found to modestly slow down the progression of ALS. Rilutek enables ALS patients to live a few months more.

You may think, what are a few more months of life if you are inflicted with this disabling disease? Ask that question to Shelbie Oppenheimer, an ALS patient who will speak to you today. Ask one of the thousands of ALS patients like Corinne Werdel. Currently, Corinne has a pace-maker, a feeding tube, and has been on a ventilator for more than two years. She has lost all movement except for the muscles in her face, which she uses to work a computer. Corrine has the courage to continue her life.

With the Lou Gehrig Challenge/Cure ALS research initiative—the largest research effort ever undertaken to cure ALS—there is more that can be accomplished. Funded by ALSA's $25 million, five-year research initiative, scientists, using powerful computers, will be able to test thousands of new chemical combinations simultaneously and assess their potential as a treatment or as a cure for ALS.

With the Lou Gehrig Challenge, the ALS Association and a selected committee of researchers will actually take the initiative themselves to determine what questions need to be answered to find a cure for the disease. Then, the Committee will decide who are the best researchers and institutions to conduct particular research projects.

With increased government interest in ALS, including the king of partnering the National Institute of Neurological Disorders and Stroke has already undertaken in the ALS Association's research—for which we are most grateful—and advanced technologies available to research, a cure could be found for ALS in this decade.

That is why I traveled here to Capitol Hill and volunteered my time to speak for just five minutes. Although ALS has not affected my life directly—it could. There are 14 new cases of ALS each day. That's a new case every one hundred minutes. We need to find out why ALS happens. And, of course, we need to find the cure. That's why I am here.

That's why these ALS patients, their family members, and other ALS activists have packed this hearing room.

Of course, Mr. Chairman, none of us would have had this opportunity without your great leadership of this Subcommittee. We respect you, the other members of the Subcommittee, and the fine work of your staff led by Betti Lou Taylor.

Thank you for the opportunity to add my voice of support to everyone who is working so hard to find a cure for ALS.

Senator SPECTER. Thank you very much, Steve Garvey, for those inspirational words.

STATEMENT OF DICK SCHAAP, HOST, ESPN'S THE SPORTS REPORTERS

Senator SPECTER. We now turn to Mr. Dick Schaap, host of ESPN's The Sports Reporters. Mr. Schaap began his broadcasting career in 1969 and is cohost of the Joe Namath Show. Perhaps he will tell us who the other cohost was. During his distinguished career, he has reported on sports and non-sporting events with many features on 20/20 and on ABC's World News Tonight, received numerous Emmy Awards for his reports on AIDS, the Olympics, cultural events, authored 31 books. A Brooklyn native. He is a graduate of Cornell University and the Columbia University Graduate School of Journalism.

Thank you for joining us, Mr. Schaap and the floor is yours.

Mr. SCHAAP. Thank you, Mr. Chairman, for this opportunity to share my thoughts at this critical ALS hearing.

First of all, my cohost was from Pennsylvania, from western Pennsylvania, Mr. Namath.

Was that the year the Jets won the championship?

Mr. SCHAAP. Yes, it was. I was a front runner and I hope I am here too.

Second, if all the athletes I covered were as articulate as Steve Beuerlein and Steve Garvey, I would have a very easy job.

I am a journalist. I cover mostly sports, but I have written books about murderers, drug addicts, comedians, and even politicians.

I am fortunate that no one in my own family has been directly affected by amyotrophic lateral sclerosis. But as a sports writer I know how devastating the disease can be, how it can strike people as sturdy as Lou Gehrig and Jim Catfish Hunter, each of whom was an Ironman in his own way. I have worked for several years, side by side, with Mitch Albin, whose eloquent and moving account of his college mentor living and dying with ALS, his professor, Morrie Schwartz, who set a noble example for all of us. One quote from Morrie that Mitch used was he was intent on proving that the word dying was not synonymous with useless, and I think the people here today prove that eloquently.

For the past 5 years, I have been the master of ceremonies at the Lou Gehrig's sports banquet, the Nation's largest fund raising event for the ALS Association. There I have met so many wonderful and brave men and women at this banquet. The following year I have come back and seen their husbands or their wives alone, and I have known, without asking, that those people have died of ALS, as so many people do each year.

I could reiterate some of the things that the doctors said, but they are far more expert on that than I am. My field is people and I worry about people who suffer from all illnesses, and particularly from this dreaded illness. I hope that you and your subcommittee, with your help and with your leadership, through you people, that some day when I emcee one of these Lou Gehrig dinners, I will inquire into a wife or a husband and I will be told he or she has recovered. When that happens, I will consider myself one of the luckiest men on the face of the earth.

Thank you.

[The statement follows:]

PREPARED STATEMENT OF DICK SCHAAP

Thank you, Mr. Chairman. I appreciate the opportunity to appear with these other panelists at this important hearing on ALS.

As you may know, I am a reporter. Although I have covered a variety of news stories over the years, I am probably best known as a sports reporter.

ALS has not directly affected my family. But as a journalist for the past five decades, I have covered the careers of such athletes as George Brett, Kent Hrbek, Terry Steinback, and Jim "Catfish" Hunter.

George Brett lost his best friend to ALS . . . both Kent and Terry lost their fathers to ALS . . . and, of course, Catfish Hunter died of ALS last year.

Mr. Chairman, I believe in the words of the poet, John Dunne, who wrote: "No man is an island, entire of itself . . . any man's death diminishes me, because I am involved in mankind."

The death of those men diminishes me . . . they diminish all of us. That's in part, why, for the past five years, I have served as the Master of Ceremonies at the Lou Gehrig Sports Banquet in New York City. It is the nation's largest annual fund raiser for the ALS Association. During the past five years, we have raised a total of more than $5 million.

I support the ALS Association because it is the only national, non-profit voluntary health organization dedicated exclusively to the fight against ALS. ALSA aggressively encourages the identification and funding of research into the cause, means or prevention, and cure of ALS. ALSA helps patients and families cope with the day-to-day challenges of living with ALS. Some of these patients and families have traveled to be here today.

As some of the other panelists have stated, these men and women are extremely courageous. They deserve our commitment in the fight against ALS.

Mr. Chairman, I began by alluding to my career as a journalist. I am trained to report the facts. In closing, I would like to share a few important facts for your Subcommittee to consider as you work through the appropriations process this year.

Fact Number One: ALS and other neurodegenerative disorders already present a major public health challenge. That challenge will grow in the years to come. Within the next generation, neurodegenerative disorders will rival heart disease as the leading cause of disability and death in this country.

Fact Number Two: Current research indicates that a seemingly diverse group of syndromes, from epilepsy to depression, share key features and mechanisms. Research into ALS will yield benefits for all neurodegenerative disorders. Likewise, advancements in our understanding of neurodegeneration will benefit Americans with ALS.

Fact Number Three: There are now new opportunities for study, and much shorter time frames for converting research findings into clinical applications. It's clear from the testimony today that if NIH, NINDS, CDC, and other relevant federal agencies continue to join forces with private organizations such as the ALS Association, we will find better treatments and, ultimately, a cure for ALS.

Mr. Chairman, your Subcommittee is in a position to be the catalyst for quantum leaps forward. Thank you for your continued leadership in this area.

Senator SPECTER. Well, thank you, Mr. Schaap, for those profound comments.

This subcommittee is determined to do the maximum for funding for biomedical research. We have undertaken the cause because we now know that out of every 100 applications which are filed for research grants, only 30 are accepted, and it is impossible to know what is behind those other 70 doors out of the 100 which might be produced.

We are a very wealthy Nation. Our budget this year for the Federal Government is $1,850,000,000,000. Do you know how much money that is? I do not think anybody else does either.

They say if you had an enormous auditorium like this one, there is insufficient space to stuff $10,000 bills, not enough room. Now, that is the Federal budget, and we have an economy which is in the $7 trillion to $8 trillion. That means we have the potential to do what we choose once we establish priorities. The National Insti-

tutes of Health have had remarkable results on what they have done.

These are a line of ailments which affect everybody. When you talk about cancer, if you live long enough, they say you are bound to get it, and the problem is breast cancer in young women or middle-age women or even old women or prostate cancer, or heart ailments or Parkinson's disease or Alzheimer's.

And it is a real battle, as we find that there are opportunities, like on stem cells, to get the full medical use. They have already shown the effectiveness on Parkinson's, and the question is about amyotrophic lateral sclerosis. That is why we focused on that and the identification of the genomes, all the genes in the body. So, those doors can be opened.

Senator Harkin and I and this subcommittee have had a tough job on getting the funding. This year was the first time we got a majority of Senators to approve our resolution for increased NIH funding, 54 to 46. 3 years ago, we lost 63 to 37, and then we lost 59 to 41, and then about 55 to 45. And for the first time, this year we got a majority of the votes because we have been talking in this hearing room, which is carried on C-SPAN and some of the national networks, about what it can mean, and people are motivated to call their Senators and call their Congressmen, tell them how important they think it is because it touches everyone and it is a matter of priorities. There is nothing we cannot do on this subject if we make up our minds to do it and set the priorities.

So, let me ask you three men, with some experience that you have had as celebrities in attracting attention. Sometimes these hearings are criticized. Why are you bringing in celebrities? What is the point? And I was interviewed yesterday by ABC. Why are you bringing in celebrities?

And I make a very simple point, and it is the point that when Michael J. Fox comes in and testifies about his own problem with Parkinson's, people see some of the incipient symptoms, and they know he is leaving his television show, and they associate with him. He is the guy next door. They say, hey, that is serious. If we can cure Parkinson's, let us do it. Let us put our money there instead of somewhere else. There are a lot of priorities, but this ought to be elevated.

Or as I said before, Christopher Reeve comes in, and we all see Christopher Reeve on his high flyer in his Superman uniform. And he comes in and he is in the wheelchair, as so many men and women who are here today with ALS, and his neck is in a very rigid position because his spinal column was severed. So, if it happened to Superman, it can happen to anybody.

And Elizabeth Taylor comes in to testify about AIDS, and that is sort of a tough item. It is of epidemic proportion, but there is just a little bit of public resistance to funding for AIDS. But if Elizabeth Taylor says something is worthwhile, a lot of people give it a little extra consideration.

Now, maybe it should not be that way. Maybe if Betty Brown came in, they ought to pay as much attention, or if Steve Mills came in, they ought to pay as much attention as Steve Garvey or Steve Beuerlein. But they do not.

So, let me start with you, Mr. Schaap. You are the author of 31 books. You corralled Joe Namath to cohost his show. ABC may run you tonight. They will not run my question of you, but they may run you tonight on why Dick Schaap is an effective witness to get funding for amyotrophic lateral sclerosis. How about it?

Mr. SCHAAP. Well, I think all three of us up here have been associated with many different causes and with many diseases that need help from your committee and from the medical community. This is one disease that is particularly close to us because of its roots in the sports community, because of the fact that it is named after an athlete. It is commonly called Lou Gehrig's disease. And because all of us have seen Steve Beuerlein up close with a friend and me with people who I just meet casually and people Steve knows. How devastating this disease can be. To me it is frightening if there is any disease in this day and age for which there is no known cure, no known cause, and no real treatment.

With the state of science today, I almost feel there is no excuse for that, and the only excuse is the one, of course, you mentioned, the shortage of available funds. I think this is a disease that can be defeated and it is a disease that, in defeating it, will also help defeat other diseases.

Senator SPECTER. Well, Mr. Schaap, why will people listen to Dick Schaap more so than Dick Smith or Dick Brown?

Mr. SCHAAP. They probably should not, as you pointed out, but over the years I have developed a certain amount of credibility, and I would think that is probably rare among journalists these days.

Senator SPECTER. How do journalists rate with elected officials on the unpopularity scale?

Mr. SCHAAP. When I was covering politics, Senator Robert Kennedy once asked me if I missed covering sports, and I said, not really, it was a lot like covering politics, except that the athletes were not smart enough to lie.

But his response to me was everybody in your profession lies too.

Senator SPECTER. We may have some athletes who will challenge you, at least on the smart point.

Mr. SCHAAP. Some have become Senators.

Senator SPECTER. And some Senators have become athletes.

The athletes here may challenge you on the issue of how smart they are. They will not challenge you on that lie issue. They will agree that athletes do not lie.

Mr. SCHAAP. Since we have built up a certain following, if we say what we believe, some people are going to pay attention. Even if it is only a few people, even if it is people who have misplaced faith in my credibility, still it will help. Television is a tremendously powerful medium. People believe what they see on television. When I was working on a book with Peter Falk and he was playing a lawyer at the time on television, we had people turn themselves into him while we were on the streets. People believe, maybe not as much now as they did 20 years ago, but there is a great deal of trust and credibility that goes back and forth. I hope that can be used for causes that deserve it, such as this.

Senator SPECTER. Well, I think you put your finger on the point of credibility. People think they know Dick Schaap, and people

trust Dick Schaap. So, when Dick Schaap says something, it has some resonance.

Steve Beuerlein, is it possible to bring Jeff Sherer up to the table into the camera range? I think people would be interested in your talking a little bit more about Jeff Sherer. Welcome, Mr. Sherer.

I see from your prepared statement, Mr. Beuerlein, that you say that Jeff Sherer was so large that he was affectionately known as the Coke Machine.

Mr. BEUERLEIN. Yes.

Senator SPECTER. And when he blocked someone, you said here the other guy would basically disappear. Jeff would just kind of engulf him.

Jeff, are you in a position to confirm or deny that?

Mr. BEUERLEIN. I think he is agreeing that he was a very large man.

Senator SPECTER. Just nod yes if you agree.

So, how about it, Steve? What did he do to those opposing players? And this was high school?

Mr. BEUERLEIN. High school, and he went on to play college football as well at Long Beach State in southern California. He became a very good football player. But he was a large man. He used his strength very well. He would literally swallow up a defensive lineman a lot of times. If he had a chance to get a guy down, he did not hesitate to throw that big body on top of him either.

Senator SPECTER. Is that Mrs. Sherer? Would you step forward please? Mrs. Sherer, why do you not have a chair next to Mr. Beuerlein and sit down and relax.

Tell us a little bit about Jeff. First of all, how long have you two been married?

Ms. SHERER. 6 years this April.

Senator SPECTER. And Steve referred to a son.

Ms. SHERER. We actually have two sons and a daughter.

Senator SPECTER. And when did Jeff first know he had ALS?

Ms. SHERER. Jeff started showing symptoms in April of 1997. He had slurred speech. He has what they call the bulbar onset. Actually it was quite humorous because we would go places and people would think that he had been drinking. So, they would threaten to cut him off, but it was just because he had this slur.

After about 6 months, after a lot of doctors' visits, it was finally diagnosed in January of 1998.

Senator SPECTER. Of 1998. So, the diagnosis was just 2½ years ago, and the onset was just 3 years ago.

Ms. SHERER. Correct.

Senator SPECTER. Tell us a little bit about what happened to Jeff during the course of the last 2½ years physically.

Ms. SHERER. Well, as we found out through our experience with other members of the ALS Association, it really affects everybody differently. So, Jeff lost his speech first. It then moved into his hands and then down to his legs. So, he currently has no use of his arms. He speaks mostly through me. A lot of his close friends can understand him with a little interpretation. He basically has no use of his legs either. Right now he is starting to have respiratory problems. So, he has moved into that stage, which is a pretty serious stage.

Senator SPECTER. Well, he is a real fighter though. He is still in there battling, and you are at his side.

Are your children here today?

Ms. SHERER. Our children are not here today. We chose to make the trip without them, but we do bring pictures, though. If you would like to see them, I would be more than happy to show them to you.

We definitely brought many family members and friends, a lot of our teammates.

Senator SPECTER. Do you still live in California?

Ms. SHERER. Still live in California, yes.

Senator SPECTER. Well, we appreciate your being here because when people see Jeff Sherer and hear Steve Beuerlein talk about his decimating opposing lineman and see the situation today, it produces an inevitable reaction that we ought to be doing something about it, if it is humanly possible to do it.

Ms. SHERER. Thank you very much for the opportunity to let us be here.

Senator SPECTER. If it is possible to prevent people from getting ALS in the future, we ought to be doing it.

Mr. Garvey, let me come back to you with thoughts you might have. I know you have been associated with many causes. You have had a phenomenal career and people look up to you in all walks of life. What is your recommendation about how to develop more public understanding and support for medical research to try to cure ailments like ALS?

Mr. GARVEY. Mr. Chairman, just a brief footnote. There was I think one time back in the 1970's or early 1980's where seven athletes ran for office and seven journalists ran for office. With due respect to Mr. Schaap, the seven athletes won.

We can draw our own conclusion. If Mr. Schaap would have won——

Mr. SCHAAP. I draw my conclusion from that.

Mr. GARVEY. Quite simply, my wife Candace, our children, and myself have a simple family philosophy, and that is life is God's gift to us. What we do with it is our gift to God. For those of us who have been blessed with strong minds and strong bodies, whether it is the ability to write, the ability to lead, the ability to play a sport, to be a business leader or religious leader and then to be able to take the recognition from that and stand in front or sit in front of a subcommittee or thousands of people in front of television cameras and be able to speak what you truly believe in with your heart and your soul and to be able to introduce people like Jeff and his wife and the other patients here today, it is a wonderful opportunity to give back. We do not always have that opportunity. Your words today have reinforced to us your commitment and your dedication and your influence on helping us find a cure for ALS.

When we talk to our children, we always say either they get it or they do not get it. For those in the media that question why people like Dick and myself and Steve and Blair and anyone else would take the time to advocate and stand up for something we believe in, I challenge them to take their name and their visibility and their opportunity to reach millions of people and join Lou's

team or stand up for another cause they believe in because it is very easy to criticize. Critics are many. It is those people that actually stand up, that look beyond the critic, and see the end in sight are the ones that my family and everyone here applaud. That is our philosophy.

Senator SPECTER. Well, thank you very much, Mr. Garvey.

I have just one final question for you. Who was the toughest pitcher you ever faced?

Mr. GARVEY. I have had the opportunity to face many Hall of Famers, but I always found Phil Niekro the thoughest because he threw the knuckle ball. He did not know where it was going. The catcher did not know where it was going. So, it was extremely difficult to hit, very tough.

Just one final question for you, Steve Beuerlein. Who was on the other end of the toughest sack or knockdown you ever sustained?

Mr. BEUERLEIN. The toughest one. There have been so many. We were talking earlier in the chambers in the back about Troy Aiken having four known concussions, and I made the point that those are the only ones that he knows about. He probably had several more. I have not had any documented in the NFL, but a lot of hits I do not even remember. So, it would be hard for me to put my finger on it.

If I had to put my finger on one, it goes back to when I was playing at Notre Dame. A man named Cornelius Bennett was playing for the University of Alabama, and I was running the naked bootleg where I was faking the run one way and trying to sell——

Senator SPECTER. We all know what a naked bootleg is.

Mr. BEUERLEIN. I know you do, but I came out of there. And then Cornelius Bennett did not bite on the fake, and he met me in the back field, put his on my chin and drove my head into the artificial turf which is like playing on this carpet right here. So, it did not feel very good.

Senator SPECTER. Well, you made a mistake. You should have Jeff Sherer as your offensive linebacker.

Mr. BEUERLEIN. I would have loved to have had that opportunity.

Senator SPECTER. Well, thank you very much, Mrs. Sherer, Mr. Jeff Sherer, Steve Beuerlein, Steve Garvey, and Dick Schaap.

Those who may be watching on C-SPAN, which is carrying this, we would ask you if you think more money ought to be directed to ALS, call up or write to your Senators or to me. We will tabulate them and we will put them up on the big board.

Thank you all very much.

We now call our final panel: Mr. Blair Underwood, who stars as Dr. Ben Turner; Ms. Shelbie Oppenheimer, and Mr. Steve Rigazio. If you would come forward.

Mr. HICKOCK. Excuse me, sir. Excuse me. I have ALS. I know I am out of order. I am very sorry. You need to hear from somebody who has got ALS who has a mouth and can speak.

Senator SPECTER. We would be pleased to hear from you. Will you identify yourself?

STATEMENT OF GREG HICKOCK, ALS PATIENT, JACKSON, MI

Mr. HICKOCK. My name is Greg Hickock. I am from Jackson, MI.

I want to fire you up so hard that you lose weight, you got 5 hours of a sleep of night, whatever you need to do. We do not need you to take action before you need to or whatever, but we need to get it through there. We need to have people aware of what is going on.

You talk about stem cells. I come across the country in my wheelchair. I heard at Johns Hopkins University from a researcher who is working with stem cells. It would cover a whole lot of areas. It would cover Alzheimer's, Parkinson's. It would cover the nerves. The stem cells—the research shows that they can grow new organs with it. It would cover a whole lot.

Senator SPECTER. So, Mr. Hickock, you are in favor of stem cell research.

Mr. HICKOCK. I am in very favor of it.

Senator SPECTER. Tell us a little about yourself, about your own background. First of all, where do you live?

Mr. HICKOCK. I am sorry. I might appear as a scum bag. I am sorry.

I am from Jackson, MI. We live northwest of Jackson, MI.

Senator SPECTER. OK, Mr. Hickock, you look to me like a citizen and a taxpayer.

Mr. HICKOCK. I am a citizen and a taxpayer.

Senator SPECTER. We have got time to hear you.

Mr. HICKOCK. Thank you.

Senator SPECTER. Tell us when you developed ALS?

Mr. HICKOCK. It was diagnosed in November of 1995. Symptoms before that—I do not know for sure when it started.

Senator SPECTER. In 1995.

Mr. HICKOCK. Yes, sir. In 1995 I was working as a field engineer at the time. I was working as a field engineer and they told me I needed to quit because I was working with high voltage and they did not need the liability. I do not want them to have the liability.

Senator SPECTER. What were the first symptoms that you felt?

Mr. HICKOCK. The first symptoms that I felt was I felt myself not being able to walk any farther. I had to stop in the middle of a parking lot and rest.

Senator SPECTER. And what happened after that?

Mr. HICKOCK. It was very cold. I figured if I was going to live, if I was going to survive, I needed to pick my suitcases up and get to my car.

Senator SPECTER. And go someplace else to live do you mean?

Mr. HICKOCK. No. I was on a business trip at the time. I needed to get back to the apartment where I was staying. I just started a new job.

Senator SPECTER. Mr. Hickock, how long have you been in a wheelchair?

Mr. HICKOCK. I have been in a wheelchair since the first part of 1997. I used my engineering background. I had a computer program I could help design my house, so I am one of the fortunate ones. Believe me, I am fortunate to be here. I am fortunate to talk to you.

But I designed my house so that I could make my bathroom big enough to get my wheelchair in. I designed ramps so I could get around my house. I designed a ramp so I could get out my door.

Senator SPECTER. How are you feeling at the present time?

Mr. HICKOCK. Very nervous.

Senator SPECTER. So am I, but how are you feeling?

Mr. HICKOCK. I am very sorry. I do not mean to put you on the spot.

Senator SPECTER. You have already done that, but that is OK.

Mr. HICKOCK. I do not mean to put any of these other guys out.

Senator SPECTER. That is within my pay grade.

Mr. HICKOCK. I am very sorry.

Senator SPECTER. Well, that is OK.

What I would like you to tell us about, what your symptoms are, how you are feeling, whether the situation is getting worse, whether it is staying about the same. I understand it does not get better.

Mr. HICKOCK. It is definitely getting worse. No, it does not get better.

Senator SPECTER. How much deterioration or getting worse do you actually feel?

Mr. HICKOCK. Well, I would like to tell about something else first, if I could. I am sorry. But the stem cell. They are talking about even possibly reversing the effects of ALS. They do not know for sure, but looking at the research data that was presented to us, it is about six or eight times more effective than anything they have got right now. We need to fund that research.

I tell you what. You talk about spending money. I understand. Trillions. That has got too many zeroes in it for my mind even to conceive. But what is being spent on ALS and ALS research is about a one-hundredth of what is being spent on other things. I could name names, but I do not want to name names. I do not want to do that. I do not want to drive that in the ground. I just want to increase ALS spending.

Senator SPECTER. Mr. Hickock, you can name names if you want to. We will listen to whatever you want to say.

But I would like to know about your condition.

Mr. HICKOCK. My condition is getting worse.

Senator SPECTER. I would like to know how it is getting worse and how you are feeling, so people can have some idea as to what it is like to have ALS.

Mr. HICKOCK. Thank you. I appreciate it.

To have ALS, I notice myself my hands getting weaker, my legs getting weaker, my breathing getting weaker. I notice myself choking more. I notice myself not being able to do the things that I like to. I am mechanical. I really like to be able to fix things.

Senator SPECTER. Do you have family?

Mr. HICKOCK. Yes.

Senator SPECTER. Children?

Mr. HICKOCK. I have got four boys, 13, 16, 18, and 20. Perry is with me today here, my youngest one. He is 13. My oldest one had a—I have got a granddaughter. I am one of the fortunate ones.

Senator SPECTER. And tell us a little bit about the impact on the family. We can well understand how tough it is on the family, but let us hear it from you.

Mr. HICKOCK. We really put them through heck.

Believe me, there is a guy that came from New York to Washington in his wheelchair to be here today. I see a lot of people doing

super things, just unbelievable things. You would not believe the jurisdictions that you got to go through, the logistics, and all of that. Just getting here this morning, we had a guy that parked right in front of one of the—we were late today because this guy parked right in front of one of the wheelchair access to get down off the curb, even in front of the old Capitol Building. We were going to call President Clinton and see if he would come down and lay down before us so we could get down off the curb.

Senator SPECTER. Did you get a busy signal when you called?

Mr. HICKOCK. We did not get a hold of him, no. He would not answer his phone.

Senator SPECTER. Did you call him?

Mr. HICKOCK. I did not even know where to start.

Senator SPECTER. His number is 456–1414.

Mr. HICKOCK. Just a minute. Let me get a piece of paper and a pencil. Somebody will write it down, I am sure.

Senator SPECTER. Well, Mr. Hickock, we gave you the full time. The red light has been on a little bit. We appreciate your coming. We know how difficult it is. We thank all the people who have come under very adverse circumstances for the ALS Awareness Month March, which is in May of this year, and that is why you are here and we scheduled this hearing specially to focus attention on ALS because we knew you would all be in town. When you step forward and wanted to be heard, we are glad to hear you. We are glad that although some of your faculties may be a little skittish, that you still have got a lot of guts, a lot of courage, and you have stepped forward and you speak your piece.

Mr. HICKOCK. I did. Thank you.

Senator SPECTER. I admire and respect that.

Mr. HICKOCK. Thank you.

Senator SPECTER. It is just a little late for you to file for the Senate race in Michigan, but there is another election coming up in a year or 2.

Mr. HICKOCK. I cannot guarantee I will be here in year or 2.

Senator SPECTER. Well, if you are, fine.

Mr. HICKOCK. I would love to meet you then. Maybe I will.

Senator SPECTER. I am not up for a while yet. You do not live in Pennsylvania or I would not have been so generous with all this committee time.

Just kidding. We have been glad to hear from you under any circumstance.

I will tell you a short story. Paul Tsongas, Senator Tsongas, in 1984 was up for reelection and he had lymphoma. Paul decided he did not want to run because he might not live out his term. In my own background, I have had some diagnoses which were stark. 7 years ago I was given 3 to 6 weeks. I said to Tsongas back in 1984, when I had also had the problem before that, you owe duty to tell the people your condition. You ought not to keep it a secret if you are running for reelection, but you do not owe them a duty to serve out your term if they elect you and lymphoma takes you. He disagreed with me and did not run.

He lived out past 1990, ran for President in 1992. If he had run for the Senate in 1984, and then had run for the presidency in 1992, and you wanted to call up the President today, you might

have been calling somebody else. He might have been elected in 1992. So, stay tuned. If you feel good, run.

STATEMENT OF BLAIR UNDERWOOD, ACTOR

Senator SPECTER. Let us go back to our regular witness list. Our first witness is Mr. Blair Underwood, who stars as Dr. Ben Turner in the new TV hit drama, City of Angels. He is also currently starring in the box office hit, Rules of Engagement, which I saw and liked very much. He made his professional debut in the Cosby Show and since that time has played many leading roles. Received the NAACP Image Award for the outstanding actor in a drama series in 1994. A graduate of Carnegie Mellon University, Pennsylvania. His grandmother died of ALS.

Thank you for joining us, Dr. Turner, Mr. Underwood. The floor is yours.

Mr. UNDERWOOD. Thank you, Mr. Chairman. I am pleased and honored to be here this morning, and I thank you for your leadership on this subcommittee.

And, Mr. Hickock, thank you for your initiative. I very much appreciate it.

I also, Mr. Chairman, wanted to thank you for defending your right to invite celebrities to this hearing because before we are so-called celebrities, we are sons and daughters and fathers and grandsons. As you alluded to, my grandmother died from ALS in 1978. Out of all the roles I have been blessed to play in my career, the one that affected me the most, of course, was that role of caretaker to my grandmother. Her name was Betsy Scales from Buffalo, New York. She was a sweet, hardworking, loving woman, a single mother in the 1930's. She raised my mother who was born in 1932 by herself. So, she was a very strong woman. So, you can understand how and why we were awestruck when she was diagnosed with ALS.

The experience of living with someone with ALS is like Mr. Hickock said. It puts the family through heck, but that is absolutely nothing compared to what the patients are going through, like Mr. Hickock. She was very able to use her vocal cords, and it was her body that was ravaged initially. Her right hand atrophied first, and then her left arm and hand was completely limp. The best analogy or metaphor I can give you to watch this happen to a loved one is if you think of a strong ice sculpture, it is akin to watching that ice sculpture melt away. And it is devastating to watch.

In a sense, though, I am preaching to the converted because you are leading the charge, and I thank you for that.

Amyotrophic lateral sclerosis was a word I learned when I was 14 years old. It is a word and a medical term that no 14-year-old or 4-year-old or 40-year-old should ever have to know or learn unless it is in a history book of something that used to be.

My mother, Betsy Scales' daughter, Marilyn Scales, later to be Marilyn Underwood, now has multiple sclerosis. So, this neurodegenerative disease process runs in the family. So, coming here today is very personal to me and to hear the testimonies has been very moving to me as well.

PREPARED STATEMENT

So, I will not belabor the point or be redundant, but I encourage you and the members of the subcommittee and the viewers, of course, on ESPN watching this all over the world to take note of the testimonies and the faces and the experiences in front of us and take effort to give us more funding for research because we must find a cure. As Mr. Schaap said, it is almost embarrassing in this day and age, in this climate of medical research, to not have a cure, to have no known cause, not have a cure, or not have any real, viable treatment.

So, again, thank you for your leadership.

[The statement follows:]

PREPARED STATEMENT OF BLAIR UNDERWOOD

Mr. Chairman, thank you. I have great respect for the medical researchers who have testified before me today. I may play a medical doctor on TV, but Dr. Fischbach and Dr. Maniatis are the real McCoy, and I applaud their work.

I grew up as an "Army brat" so my family moved all over the world, but I call Virginia home. It's good to be just across the river today, here in the District. I began acting as a way to deal with my family's transient lifestyle and I have been studying acting, directing and producing ever since.

During my career, I have portrayed a U.S. Marine captain, a psychotic stalker, a space shuttle navigator, a death row inmate, a geneticist, a corporate banker, a lawyer, a police officer, a social worker, and a newspaper reporter, among others. I have portrayed Jackie Robinson, I am right now preparing for a movie role as the heavyweight boxing champion Floyd Patterson, and I once even played Jesus Christ in the movie "Second Coming."

But I am not here to tell you about my acting career. In fact, the most difficult role I was ever given to play did not involve a movie script. It was not make believe. My most difficult role was all too real. I was a caregiver to my wonderful grandmother who died of ALS.

My mom's mom was diagnosed with ALS when I was 14 years old. I remember that her left hand was crippled with arthritis, and her right arm was completely limp due to the ALS. My grandmother passed away while I was in high school. Because I loved her so much, it was ironic that she died on Valentine's Day. I was rehearsing a play at school when I got the news that she had died. She had been diagnosed with ALS less than a year before. After she was diagnosed, she just gradually slowed down, her muscles wasting away. It was like seeing a beautiful ice sculpture melting away before my eyes.

Now, my mother has multiple sclerosis, or MS. Mr. Chairman, I understand that you and your Subcommittee already have held hearings this year on MS and other degenerative disorders. Thank you for that. My mother's diagnosis with MS, combined with my grandmother having died of ALS, means that coming to Capitol Hill to speak out about ALS is very important to me. It is my chance to do something to stop this disease once and for all. This cause is very personal to me. The genetic lineage of my grandmother to my mother means that this could affect my children or in the future, their children.

Of course, ALS could affect me directly.

Naturally, I question whether my mother having MS and my grandmother having ALS is somehow related. One thing you come to learn when portraying a doctor in a television series is that doctors can't solve every medical problem. There is only so much funding for research for diseases. We need more funding if we are going to fight a disease like ALS and other neurodegenerative disorders.

Mr. Chairman, the tremendous efforts of this Subcommittee, and the work of such distinguished scientists as Dr. Maniatis and Dr. Fischbach, is too late for my grandmother. However, my strong sense is that we are on the threshold of great progress in the treatment of ALS. All of the encouraging testimony that I have heard today confirms this belief

As Dr. Maniatis testified, the ALS Association is formally announcing today its largest and most aggressive research initiative. The Lou Gehrig Challenge will get to the heart of the matter. It will answer those questions that need to be answered now so that effective and viable treatments for ALS can be developed more rapidly.

But what I find most encouraging is that the ALS Association is not alone. Several federal agencies are rallying to fight ALS as well.

Just weeks ago, the Department of Veterans Affairs and the Department of Defense launched a nationwide study to determine the rate of ALS among military veterans who were on active duty during the Gulf War.

Dr. Fischbach's agency, the National Institute of Neurological Disorders and Stroke, also has joined with the ALS Association to search for new therapies for motor neuron diseases such as the purchase or creation of chemical libraries, and the funding of highthroughput screening facilities.

These research partnerships will accelerate the discovery of clinical treatments and drug development. These discoveries will, ultimately, lead to a cure for ALS and other neurodegenerative disorders.

Mr. Chairman, the future is now. We've entered a new millennium. Let's enter a new era of prevention, treatment, and cure.

Thank you, Mr. Chairman. My hopes and prayers will be with you, your staff, the researchers, the ALS patients, and their families. Thank you.

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

STATEMENT OF SHELBIE OPPENHEIMER, ALS PATIENT, NEW HOPE, PA

Senator SPECTER. We turn now to Ms. Shelbie Oppenheimer, who was diagnosed with ALS at the age of 21. Since that diagnosis, she has become an ALS advocate working with local groups, particularly in the greater Philadelphia area. She is the mother of a 2-year-old daughter, Isabel, resides in New Hope, Pennsylvania.

Thank you for joining us, Ms. Oppenheimer, and we look forward to your testimony.

Ms. OPPENHEIMER. Thank you, Senator Specter, and it is good to see you again. I was present when you received the first Jacob Javits Award 3 years ago, and I would like to thank you for sticking with our fight.

This gathering today is a step forward in our journey toward a cure for Lou Gehrig's disease. I thank you all for making this happen and I am honored to be here today to tell you how ALS has affected my life.

My name is Shelbie Oppenheimer, and for so long my life had been a fairy tale. As the daughter of Gloria and Jerry Wasserman and the sister of Brian Wasserman, I grew up in a loving and nurturing family, the kind of family that laughs together over supper. I have also been fortunate enough to have the same best friend since I was 3, and I married my soul mate and the love of my life, Jeff Oppenheimer.

We soon, after we got married, relocated to Bucks County, Pennsylvania. The plan was to buy a house in the suburbs and start a family, but as we were to about to embark on this beautiful and fulfilling life's mission, an old Yiddish expression became relevant to my story: A mench tracht and Gott lacht. We plan and God laughs.

On the same day we discovered and put a deposit on our dream home, in the call that we made to my parents to share this exciting news, we learned that my mother had been diagnosed with stage IV cancer. As I sat at her bedside for weeks, while she fought and lost this brief and brutal bout with lung cancer, I thought nothing could be worse. Only now can I appreciate that through this horrible struggle, she knew that thousands of researchers and billions of dollars had beaten forms of her disease, were making progress on others, and because of this, she had hope that maybe, just

maybe, she would be the beneficiary of all this research. Sadly, that did not happen for her, but that hope gave her comfort and kept her strong.

When I began to feel strong enough mentally, my husband and I had decided to start a family, but I was not quite ready after the shock of losing my mom. But when I began to feel better mentally, there was a matter of some weakness and twitching in my left arm that my family physician had recommended I see a specialist about.

Little did I know that from this innocent-enough consultation with our family physician that the terrifying, surreal process of elimination had begun. I had noticed twitching and weakness in my left arm. Since I was a healthy, active 28-year-old, my doctor assumed it was a pinched nerve and sent me to a neurologist.

Well, it was not that simple. After numerous x-rays, MRI's, EMG's, it was determined that this definitely was not a pinched nerve. I was told that it most likely was amyotrophic lateral sclerosis. My neurologist also told me that they were testing for other possibilities and urged me not to read anything about ALS until they were sure.

The next day at the bookstore, I looked up ALS in a medical encyclopedia, and that is when I learned that ALS is Lou Gehrig's disease. The book said that this is a degenerative nerve disorder that causes nerves to die, muscles to atrophy, and eventually leads to the inability to breath and imminent death. As I read on, I learned that this usually happens within 2 to 5 years after diagnosis, and all the while the patient is mentally alert and aware. I read that it affects 30,000 Americans and there is no cure. I read on and I cried right there in the store.

It was several months later at Johns Hopkins University it was confirmed that, yes, I have ALS. At age 28, I was diagnosed with a terminal illness.

Every good fairy tale has its moment of dark, impending tragedy. For me the tragedy was not just that my life would be cut short, but that I may never hear the words, "Mommy, I love you." I am happy to share with you today that I hear these words every day. It has been 2 years since my husband and I adopted Isabel from Guatemala. Although I devote myself every day to caring for, loving, and nurturing my daughter and not wasting them away consumed by what may be, sometimes I cannot help but worry which muscle will fail me next and how will that effect my ability to care for her. When will my physical limitations become too big to hide from her? Will she need to feed me as I once fed her?

Instead of weekend plans, what to serve for dinner, which preschool for Isabel, I cannot help but be angry that I must think about slowly fading away physically and being completely aware of it mentally. I cry at the thought of not being able to tell my husband and daughter that I love them, and I weep at the thought of my father burying another child.

PREPARED STATEMENT

I am tougher than I look and I am going to do what it takes to beat this. And I am asking you to do the same. With your commitment of support, someday, somewhere a young woman still not yet

diagnosed, will look up ALS in the medical encyclopedia, much like I did. Her heart will pound as she reads about its devastating effects on her body. But her spirits will soar as she reads on. There in black and white she will read about a research breakthrough that you, by being here today, helped to make happen. And I will be damned if I am not browsing a couple of aisles over.

Thank you.

[The statement follows:]

PREPARED STATEMENT OF SHELBIE OPPENHEIMER

Thank you, Chairman and distinguished Subcommittee members: This gathering today is a step forward in our journey toward a cure for Lou Gehrig's disease. I thank all of you for making this happen. I am honored to be here today to tell you how ALS has effected my life.

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Three years after Jeff and I were married, the company he and a friend had started in the basement was now large enough to attract the attention of a much larger competitor. After his company was purchased, we relocated to Bucks County, Pennsylvania.

Our plan was to buy a house in the suburbs and start a family. But, as we were about to embark on this beautiful and fulfilling life's mission, an old Yiddish expression unfortunately became relevant to my story: A mench tracht und Gott lacht . . . We plan, and God laughs.

On the day we discovered and put a deposit on our dream home, we made a call to my parents to share this exciting news. What was to be happy conversation turned tragic. We learned that my mother had been diagnosed with stage four Cancer. I sat at her bedside for weeks while she fought a brief and brutal bout with lung cancer.

As I watched my mother die, I thought nothing could be worse. Only now can I appreciate that through this horrible struggle, my mother knew that thousands of researchers and billions of dollars had beaten forms of her disease, were making progress on others and that maybe, just maybe, she would be the beneficiary of all these resources. Sadly, that didn't happen for her. But that hope gave her comfort and kept her strong.

Since then, I've learned that daughters don't ever fully recover from losing their mothers. I did not feel emotionally up to carrying and caring for a child just then, but soon, very soon. And when I began to feel strong enough mentally, there was a matter of this pinched nerve that my family doctor had recommended I see a specialist about once we settled into our new area.

Little did I know that from this innocent-enough consultation with our family physician that the terrifying, surreal process of elimination had begun.

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I'm tougher then I look and I will do what it takes to win this. I'm asking you to do the same. With your commitment of support, someday, somewhere a young woman still not yet diagnosed, will look up ALS in a medical encyclopedia much like I did. Her-heart will pound as she reads about its effects. But her spirits will then sore, as she reads on. There, in black and white, she will read about a research breakthrough that you, by being here, helped to make happen. And I'll be damned if I'm not browsing the bookshelves a couple of aisles away.

Senator SPECTER. Thank you very much, Mrs. Oppenheimer, for those very moving statements. We will come back to you for some questions in a moment or two.

STATEMENT OF STEVE RIGAZIO, ALS PATIENT, LAS VEGAS, NV

Senator SPECTER. I would like now to turn to our final witness, Mr. Steve Rigazio, diagnosed with ALS just last year at the age of 44. Senior Vice President of Energy Delivery of the Nevada Power Company. Holds a master's from the University of Nevada at Reno, and a bachelor's degree from Eureka College, Illinois.

Thank you for joining us, Mr. Rigazio, and we look forward to your testimony.

Mr. RIGAZIO. Thank you very much. My name is Steve Rigazio, and I am a family man and businessman from Las Vegas, Nevada, constituent of Senator Reid. And I appreciate his comments this morning, very kind comments, and I appreciate very much his office and staff and Senator Reid. Since I have been diagnosed, he has been there every minute for me, and I appreciate it very much.

I am 45 years old. I have been married for 22 years to my wife Annette and have two children, Bethanie who is 16, a junior in high school, and my son David is 13. Like any concerned parent, we are afraid to take the kids out of school for 3 days, so Annette and the kids are back in Las Vegas attending school. 16-year-old girls have a tendency to—at this stage, you have to watch them a little and make sure they do attend school.

But I do have my brother here today, Mark, and my brother-in-law Pete and my sister Mary and their 9-year-old daughter Elizabeth, my niece, who is out here today. I appreciate them being here.

I actually started out in the electric utility industry as an iron worker and began iron work in a power plant for 2 years, went back to school, saved enough money, earned money and went on for my master's degree at the University of Nevada, came back to the industry as an analyst. I was very fortunate, worked my way up the corporate ladder, and last year, upon a merger of two power companies, I was named Senior Vice President of Operations of both companies.

I am very active in the Las Vegas community. I am on a number of boards. I am on the Board of Regents of Bishop Gorman High

School, the only Catholic high school in Las Vegas, Salvation Army, Sunrise Children's Hospital, Channel 10 public broadcasting, New Horizons Academy, which is a school for children with learning disabilities where my son attends.

I have always been physically active and athletic. As a child growing up in a small town of Oglesby, Illinois, my brother Mark and I played baseball morning till night as my mom called us in for dinner. In the wintertime, I played ice hockey and played competitively. 12 months ago, May of last year, I was on the ice getting banged around by a bunch of big guys and enjoying every minute of it. Today I cannot even put on my coat.

All that changed for me on August 25th, 1999. I was diagnosed with ALS, at the Baylor College of Medicine. It obviously shattered me, my wife, and kids and our dreams. The most disappointing thing to me, after receiving the news, was to find that there is no cure and very few medications that can even slow the disease down. Myotrophin, one of those, was pulled off the market 4 months after I was diagnosed. I never had that opportunity to even try it.

When you have something like this, you are grasping for straws. Basically I enjoy life. I have a deep faith and family values. I just want to be with my family and friends in my community of Las Vegas and live life to its fullest for a long time.

I really want to see my daughter go on to college and graduate from college. I want to see my son get through grade school and high school. I want to come back here in 9 years and see Lizzy graduate from high school, if I can.

PREPARED STATEMENT

When you have this, you can take different attitudes. I have chosen to try to put a positive spin on this as best I can, and shortly after diagnosis and the initial trauma, some friends of mine in Nevada started a foundation called Nevadans for the Prevention of ALS, and we are trying to raise money for awareness, research, and provide money to the local ALS chapter for patient care. We had our first fund raiser last week, a dinner. Senator Reid's staff was there. We raised over $100,000. In some small way, maybe this will lead to a cure and a new life for those afflicted with this horrible disease.

Thank you very much.

[The statement follows:]

PREPARED STATEMENT OF STEVE RIGAZIO

My name is Steve Rigazio. I am 45 years old. I have been married for 22 years to my wife, Annette and we have two children. Bethanie is 16 years old and David is 13 years of age.

I am currently a Senior Vice President for Nevada Power Company, an electric utility company in Las Vegas, Nevada.

I am very active in the Las Vegas Community. I am on a number of boards including Bishop Gorman Regents, a local catholic high school, the Salvation Army, the Sunrise Children's Hospital, a local public broadcasting TV station, the Nevada Taxpayers Association, New Horizons Academy. a school for children with learning disabilities and the Chamber of Commerce Board of Advisors.

I was always physically active and athletic. As a child growing up I played baseball and ice hockey and continued doing so as an adult.

On August 25, 1999, 1 was diagnosed with Amyotrophic Lateral Sclerosis (ALS—Lou Gehrig's disease). Obviously, that shattered me, my wife and kids and our

dreams. The most disappointing thing to me is after receiving the news, was to find there is no cure and few medications that slow the disease down. One of these is Myotrophin which was pulled off the market shortly after my diagnosis. When you have something like this, you are grasping for straws. Basically, I enjoy life. I have a deep faith and family values. I just want to be with my family and friends in my community of Las Vegas, and live life to its fullest for a long time.

Finally, shortly after diagnosis and after the initial trauma, a group of friends and prominent Nevadans approached me about starting a foundation in order to help in some way. We formed Nevadans for the Prevention of ALS (NPALS). Our goal is to raise funds for awareness of ALS, patient care, and research. Last week in Las Vegas we had our first fundraiser, a dinner that raised $110,000. In some small way, maybe this will lead to a cure and new life for those afflicted with this horrible disease.

In closing, I would like to thank this committee, in particular Senator Harry Reid from Nevada, for his support, and you for the opportunity to speak before the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education.

Senator SPECTER. Thank you very much, Mr. Rigazio, for sharing those personal feelings, experiences with us.

Mrs. Oppenheimer, I was interested in your quotation of "A mench tracht, Gott lacht." My grandmother taught me that one as well, but your written statement has the translation as "we plan and God laughs." I was taught the translation was, "People plan and God laughs." It is about the same. Somehow it has a lot more pizazz and oomph in Yiddish, "A mench tracht, Gott lacht," than it does in the translation.

Ms. OPPENHEIMER. Everything does.

Senator SPECTER. Tell us a little bit about what happened to you at the onset of ALS. You were 28. We are going to have ask you how long ago that was. I do not like to ask a woman her age.

Ms. OPPENHEIMER. Well, my symptoms of ALS started 4 years ago, so I am very fortunate that the progression in my case is considered slow.

Senator SPECTER. What were the first symptoms?

Ms. OPPENHEIMER. The first symptoms were weakness in my left arm and twitching, the inability to do little things like buttoning. It just became more difficult.

Senator SPECTER. And what happened next?

Ms. OPPENHEIMER. I was seen by several neurologists. I think when you are 28, that is not something that comes to mind right away when they are looking at you. So, lots of tests, EMG's, MRI's, blood tests. There is not one specific test for ALS, so they rule out a lot of other things.

Senator SPECTER. This is somewhat personal, but perhaps all of it is. You adopted a daughter. You had testified about your plans to have a family, move to the suburbs, have a family. You decided not to do it but go the adoption route?

Ms. OPPENHEIMER. No. Well, at the time I was diagnosed, we did not realize that I was slow progressing, and we really did not want to waste a lot of time. So, we opted to go the adoption route just for certainty purposes.

Senator SPECTER. And how are you feeling now?

Ms. OPPENHEIMER. On a day-to-day basis, I feel pretty good. But the disease progresses. Even though it is slow in me, it is always progressing, so everyday there are new challenges.

Senator SPECTER. To what extent has ALS disrupted your normal living activities?

Ms. OPPENHEIMER. Well, because of my weakness and fatigue, I can no longer work. So, I am a stay-at-home mom, but I am not even a full-time stay-at-home mom because I cannot care for her by myself all the time. So, my daughter goes to day care for 2 days a week so that I can rest and do heavy chores that I cannot do while she is around.

Senator SPECTER. Mr. Rigazio, you felt the symptoms just in the course of the past year, and what kind of progression have you felt?

Mr. RIGAZIO. Very similar to Ms. Oppenheimer. I started in my right arm and hand, twitching in muscles, about January of 1999, and went through about a 6-month period thinking I had a pinched nerve, a weakness in my arms and hands. After the whole battery of tests in August of last year, everything else was ruled out, and it was ALS. My case is progressing also, hopefully slow, but every day I can feel the difference, and weakness in my hands and arms and shoulders.

Senator SPECTER. To what extent has it interfered with your work?

Mr. RIGAZIO. Quite a bit. It is interesting. I got the promotion to Senior Vice President of the company 25 days before this diagnosis. I still go to work every day. However, I am unable to drive a car anymore, so I need assistance in getting to and from work and need assistance at work. Particularly I need assistance dressing, which my wonderful wife Annette and my children help out, and assistance eating. I am unable to cut steak with a knife, things such as that.

Senator SPECTER. Who is that, Mrs. Oppenheimer?

Ms. OPPENHEIMER. This is my daughter, Isabel.

Senator SPECTER. OK, Isabel. Be careful. You are on camera now.

How old is she, Mrs. Oppenheimer?

Ms. OPPENHEIMER. She is 2.

Senator SPECTER. At 2, I do not suppose she has much awareness of what you are going through.

Ms. OPPENHEIMER. No. She is the only person that does not see me as having any physical limitations.

Senator SPECTER. Well, she just ran right up and jumped on your lap.

Tell us, Mr. Rigazio, about the impact on your family. How has that been?

Mr. RIGAZIO. I am a very lucky person. I have a wonderful family. My parents are married I think 46 years. My in-laws have been married 48 years. I come from a large family. We had a lot of fun growing up. I married a wonderful lady. For 22 years we have been married. Two kids.

It changed a lot of things. I was looking forward to retiring in 10 years at age 55. All that is going to change. Annette and I were looking forward to our 25th wedding anniversary and taking an Alaskan cruise. We decided to change that and make it about 2 months from now on our 22nd anniversary.

Around the house I am unable to do the things I used to do, but I still have the love of my wife and my children and my family. So, I am a very fortunate person from that standpoint.

Senator SPECTER. Mr. Underwood, you talked about ALS striking your grandmother. Can you tell us what you observed, how her situation was, what deterioration, if any?

Mr. UNDERWOOD. Well, Mr. Chairman, her situation started very much like Mr. Rigazio and Mrs. Oppenheimer, in her hands, twitching in her left finger. And then it progressed to the point where, as I said, her right hand had atrophied and the left became very limp. She was still able to walk and she was still able to speak when she expired in her sleep.

Senator SPECTER. She died in her sleep?

Mr. UNDERWOOD. Yes, she did.

Senator SPECTER. And how old was she?

Mr. UNDERWOOD. She was 68 years old at that time.

Senator SPECTER. Tell us about the impact on the family. You were 14 at the time?

Mr. UNDERWOOD. I was 14 at the time, and the impact was just a tremendous sense of helplessness. You feel like an innocent, helpless bystander. There is nothing you can do but give support and love and encouragement and be there.

Another aspect of this disease is sometimes the mental pressure and sometimes depression which may mean therapy and medication, but that is another side of this that has not been brought up today. So, that support of family is vital.

Senator SPECTER. Ms. Oppenheimer, I think I know the answer to this question, but tell us your views with respect to hope, faith that we will find a cure for ALS to save your situation.

Ms. OPPENHEIMER. Well, I am much more hopeful than I was when I was first diagnosed 4 years ago because there has really been an explosion in research. Just some of the most brilliant minds in medical research are working on ALS, but unfortunately, as you know, it just all requires money. I guess as long as they are properly funded, I think that there is definite hope for patients with ALS.

Senator SPECTER. Mr. Rigazio has been diagnosed for just a little less than a year. What is your sense of hope with respect to the possibility of curing your disease in time?

Mr. RIGAZIO. I have tremendous hope and I believe a lot of the reason for that is the awareness brought to this disease over the last several years, which is significantly more than it has ever been. And events like today with the people that are here today telling their stories from all walks of life, I have a great deal of hope, a great amount of faith. I am thoroughly convinced that the cure will be found and I am going to be cured. I really believe that.

Senator SPECTER. Well, Mr. Underwood, we will give you the last word. You are a doctor in the TV drama, City of Angels, but you are a surgeon. You are not a neurologist.

Mr. UNDERWOOD. That is correct.

Senator SPECTER. I do not know what weight we should give to the surgeon's views. But how do you evaluate the situation? What can people like you do to bring public attention to focus the Congress on providing enough money to get a breakthrough?

Mr. UNDERWOOD. Well, Mr. Chairman, I think Steve Garvey said it so eloquently, that we are blessed to do what we enjoy doing and to use our God-given abilities, and if that brings you some sense

of awareness from people and for whatever reason, right or wrong, earned or unearned, people will listen to what you have to say, then so be it. That is why I wanted to be here today.

But you are doing it, Senator, and this subcommittee is doing the work and the testimonies of people coming here today.

Senator SPECTER. Well, thank you, Mr. Underwood. Thank you, Mr. Rigazio. Thank you, Mrs. Oppenheimer, and Miss Isabel Oppenheimer.

Ms. OPPENHEIMER. 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.

[Whereupon, at 11:40 a.m., Thursday, May 18, the hearing was concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]

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