

**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION AND RE-  
LATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 1988**

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**HEARINGS**  
BEFORE A  
**SUBCOMMITTEE OF THE**  
**COMMITTEE ON APPROPRIATIONS**  
**UNITED STATES SENATE**  
**ONE HUNDREDTH CONGRESS**

FIRST SESSION

ON

**H.R. 3058**

AN ACT MAKING APPROPRIATIONS FOR THE DEPARTMENTS OF LABOR,  
HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED  
AGENCIES, FOR THE FISCAL YEAR ENDING SEPTEMBER 30, 1988, AND  
FOR OTHER PURPOSES

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**Part 3—(Pages 1-942)**

**Nondepartmental witnesses**

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STATEMENT OF GERALDINE FOX, DEAFNESS RESEARCH FOUNDATION  
ACCOMPANIED BY LARRY BROWN, DEAFNESS RESEARCH FOUNDATION

Mrs. Fox. Thank you, Senator Specter. I am really honored that you introduced me and I appreciate your taking the time from your busy schedule.

Mr. Chairman and members of the subcommittee, I appreciate the opportunity to testify today. I am here to encourage to expand new Federal moneys through NIH for deafness research in the field of deafness and other related hearing disabilities.

While some ear diseases can now be treated with either surgical or medical procedures, the vast majority of persons with hearing losses cannot at present be effectively treated because 80 percent of all hearing losses are caused by nerve deafness for which there is no cure.

Unfortunately, Mr. Chairman, there are still many unanswered questions. To close the gap on this invisible handicap will require a strong sustained effort, one that is targeted on deafness research. Such an effort would enable scientists to move ahead in the more promising areas of investigation.

Mr. Chairman, let me say to you and the members of your subcommittee that you have been true friends and we appreciate deeply the leadership that you have shown when it comes to deafness research. Your support in the past has meant so much to us and it has brought us closer to unraveling some of the deep medical mysteries that surround deafness. Given that 1 out of 10 Americans is afflicted with a hearing loss or some type of ear disease, it is clear that the level of research investment in this area lags far behind the need.

As a matter of fact, for the past 5 years deafness research has received only 10 percent of the funds appropriated to the National Institute of Communicative Disorders and Stroke. Moreover, in the President's budget, according to this NINCDS will be spending more than 8 percent less on deafness in fiscal year 1988 than it did in fiscal year 1987.

To put this in some perspective, next year NINCDS plans to spend \$41 million on a problem that cost society \$17 billion. Now with—

Senator SPECTER. \$17 billion.

Mrs. Fox. \$17 million.

Senator SPECTER. Billion.

Mrs. Fox. Did I say million? Thank you. That amounts to about \$2 per victim, or the cost of a cup of coffee and a donut, and that is for 22 million Americans alone who suffer partial or total hearing losses.

Considering the magnitude of the problem and the fact that there are so many talented and dedicated researchers who study hearing disorders, we believe that administrative mechanism such as a hearing research institute should be put in place for a stronger, more directed program in this area.

## PREPARED STATEMENT

In the meantime, our Foundation respectfully urges that no less than \$80 million be appropriated to deafness research in fiscal year 1988. Thank you, and I would like to give the platform to Mr. Brown who has a few things to say.

[The statement follows:]

## STATEMENT OF GERALDINE FOX

My name is Geraldine Dietz Fox and I am Chairperson of the Government Relations Committee of the Deafness Research Foundation. I appreciate the opportunity to testify today. I am here to encourage you to expand new federal monies through NIH for research in the field of deafness and other related hearing disabilities.

Accompanying me today are Mr. Lawrence Meli, the President of our Foundation, and Mr. Larry Brown, a distinguished member of our Board of Directors and a former member of the Washington Redskins.

Mr. Chairman, the Deafness Research Foundation is a national voluntary health organization that was established nearly thirty years ago. Its mission is to promote research to conquer deafness, an affliction that is more serious and widespread than is generally realized. Last year alone, we raised over two million dollars and awarded grants to 78 researchers in 35 states.

Deafness is often referred to as the invisible handicap. But I can assure you that for the 22 million Americans who are partially or totally deaf, the emotional or physical suffering they must endure is anything but invisible. For many, deafness may mean a life of confusion and withdrawal -- from families, loved ones, and society as a whole. And to the one million children who are afflicted, deafness can mean living a world apart from others throughout the most formative years of their lives. These children will never read beyond a sixth-grade level because their ability to learn language will be so compromised.

Tragically, hearing loss of any nature robs us of our full membership in the human community. But its implications go far beyond the individual. According to the latest estimates, deafness costs society more than \$17 billion annually when measured in terms of medical care, the added costs of special education programs, and loss in productivity.

Of course, there is no way to measure the cost of wasted lives caused by isolation, limited education (therefore limited jobs), and the very real and persistent social stigma that still haunts most deaf persons.

Let me say to you and to your colleagues on the Subcommittee that you have been true friends, and we appreciate deeply the leadership you have shown when it comes to deafness research. Your support in the past has brought us closer to unraveling some of the deep medical mysteries that surround deafness. In fact, progress has been rapid in certain areas.

Through research, for example, we have learned that some drugs used to treat cancer or bacterial infections can destroy hearing. This new-found knowledge has led us to avoid certain drugs or control their use by physicians.

We have also seen advances in hearing aid technology, and this has especially helped children and our increasing elderly population, which will double by the year 2006. Computers have yet to be used in the widespread development of hearing aids, yet computers and high technology were used in the development of more profitable items, such as the Sony Walkman.

It is interesting to note that much of what we have learned

through hearing research has had broader implications for society as a whole. Many of the technological advances in warning signals in industry, the military, and hospital intensive care units were the result of new knowledge gained through hearing research.

But while some ear diseases can now be treated with either medical or surgical procedures, the vast majority of persons with hearing loss cannot, at present, be effectively treated. This is because 80 percent of all hearing losses are caused by nerve deafness, for which there is no cure. Unfortunately Mr. Chairman, there are still many unanswered questions.

To close that gap will require a strong, sustained effort--one that is targeted on deafness research. Such an effort would enable scientists to move ahead on some of the more promising areas of investigation, including:

- \* developing a vaccine to combat ear infections in children;
- \* isolating genetic or hereditary factors which are believed to cause 50 percent of all hearing disorders;
- \* providing the profoundly deaf not only with hearing "sounds" which keep them environmentally safe (fire alarm, car horn, door closing) but with speech or language through a more sophisticated cochlear implant;
- \* perfecting drugs to control dizziness and Meniere's disease; and
- \* learning how we can prevent or treat tinnitus (inescapable ear noises).

Mr. Chairman, given that one out of ten Americans is afflicted with a hearing loss or some type of ear disease, it is clear that the level of research investment in this area lags far behind the need. As a matter of fact, for the past five years, hearing research has been allocated only about ten percent of the funds appropriated to the National Institute of Neurological and Communicative Disorders and Stroke. Moreover, according to the President's budget document, NINCDS estimates that it will be spending more than 8 percent less on hearing research in FY1988, compared to the FY1987 appropriation.

To put this in some perspective, next year NINCDS plans to spend only about \$41 million on a problem that costs society \$17 billion. That amounts to spending less than \$2 per victim or about the same as the cost of a cup of coffee and a doughnut!

Considering the magnitude of the problem and the fact that there are so many talented and dedicated researchers who study hearing disorders, we believe that administrative mechanisms, such as a hearing research institute, should be put in place to provide for a stronger, more directed research program in this area.

In the meantime, our Foundation respectfully urges that no less than \$80 million be allocated for deafness research in FY1988.

Although we can never recapture opportunities lost to the past, it is not too late to begin mounting a strong, sustained effort toward finding cures, preventions, and treatments for these serious problems.

Thank you, Mr. Chairman for kind attention and consideration.

Mr. BROWN. Mr. Chairman, members of the subcommittee, I am extremely pleased to have an opportunity to share with you a personal statement about my hearing impairment.

Fortunately for me, this hearing impairment did not impede my growth and development as a person, athlete, or businessman. There are two main reasons for this. First, the late Vince Lombardi encouraged me to reveal my hearing problem publicly, and gave me continued support.

Second, a local hearing aid specialist designed a hearing device for my football helmet. This enabled me to play better football and to be named the National Football League's Player of the Year in 1972.

I was one of the fortunate ones. How many Vince Lombardis are there in the world? He found a way to help me hear better. We are here today to ask you to help 22 million people hear better, and to give them an opportunity to become active members of America's team, and to be recognized for their contributions to our society. What happens to these people without your continuous and increased support? Your role is vitally important to the growth and the development of this enormous segment of our population, and you could be their Vince Lombardi. Thank you.

Senator HARKIN. Thank you very much, Mr. Brown. Senator Specter, do you have any questions?

Senator SPECTER. I would like to thank both of you for coming in today. I would like to thank all the witnesses who are here. Your messages are very important beyond any question. Gerry Fox's experience as a teacher doing public service and contracting mumps and losing the hearing capacity in her left ear, and your experience, Mr. Brown, as a professional football player.

I expected you to be a lot bigger from recollection of watching you play.

Senator HARKIN. He sure looked big in those days. When you watched him on television he filled the whole screen.

Senator SPECTER. You looked big when you played against the Philadelphia Eagles.

You are great examples. Your experience as a professional football player and your success notwithstanding the impediment is a great example for people with all sorts of disabilities, not only hearing.

Senator Harkin and I on the subcommittee and the whole Senate and Congress have a very tough job in allocating funds. We will weigh very carefully what you said. We heard you.

Senator HARKIN. Thank you. I want you both to know that also I have a longstanding interest in hearing research because I have a brother who is deaf. My brother has been deaf since he was 10 years old. So I have been through all of that all of my life with him and all of his problems in going through the school for the deaf and his employment problems and everything else that has followed him all through his life.

When you talk about the problems of the deaf, I know what you are talking about. I want you to know there are a lot of people, not just myself, Senator Specter also is very supportive of our efforts in addressing the problems of the deaf, that are very much on your side on this. Thank you.

**STATEMENT OF LAWRENCE S. HOFFHEIMER, NATIONAL COMMITTEE FOR RESEARCH IN NEUROLOGICAL AND COMMUNICATIVE DISORDERS  
ACCOMPANIED BY BOBBY R. ALFORD, M.D., NATIONAL COMMITTEE FOR RESEARCH IN NEUROLOGICAL AND COMMUNICATIVE DISORDERS**

Senator HARKIN. Next we will turn to Lawrence S. Hoffheimer, National Committee for Research in Neurological and Communicative Disorders.

Mr. HOFFHEIMER. Thank you, Mr. Chairman.

Senator HARKIN. Welcome to the committee. Please proceed.

Mr. HOFFHEIMER. It is my pleasure to be here today. Thank you for the opportunity to present Dr. Bobby Alford who is chairman of the National Committee for Research and Neurological and Communicative Disorders, which is a coalition of more than 60 organizations who are interested in communicative and neurological research.

Dr. Alford is vice president and dean of academic and clinic affairs at Baylor College of Medicine. It is my pleasure to introduce him to deliver the testimony to this committee today.

Dr. ALFORD. Mr. Chairman, thank you for the privilege of appearing before you today. These 62 voluntary and professional health organizations that are in a coalition are dedicated solely to increasing support for research in neurological and communicative disorders.

My message today is very simple, Mr. Chairman. There are four points that I wish to make. The first point is that in the NIH, NINCDS is this country's leading research organization which is striving to prevent, correct, cure, or ameliorate some 600 neurological and communicative disorders. These disorders cost society \$114 million annually for treatment. Yet, at the NINCDS we spend \$399 million, or only 0.0035 percent of that cost to society and federally supported research on the causes, prevention and cure of these disorders.

Point two is the scientific research momentum created by NINCDS is accelerating. There are many new opportunities for greater understanding in this field. Most recently you have probably seen articles about the genetic link to Alzheimer's disease and Down's Syndrome, and the exciting work with the transplant to help Parkinson's patients.

Because I am an otorhinolaryngologist, head and neck surgeon, I am interested in hearing and we have been excited about the work cochlear implants. This has led to improvements in designs of hearing aids. We are also excited about the results of some clinical trials in secretoritis median. It has led us to the most effective treatment of that problem which is so rampant in small children.

Point three is that over 60 percent of grants go unfunded. These are approved grants, approved through the NINCDS mechanism and they