

DEPARTMENTS OF LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES
APPROPRIATIONS FOR 1989

HEARINGS
BEFORE A
SUBCOMMITTEE OF THE
COMMITTEE ON APPROPRIATIONS
HOUSE OF REPRESENTATIVES
ONE HUNDREDTH CONGRESS
SECOND SESSION

SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND
HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

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PART 9

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER
INTERESTED INDIVIDUALS AND ORGANIZATIONS

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TUESDAY, MAY 3, 1988.

DEAFNESS RESEARCH**WITNESSES**

GERALDINE DIETZ FOX, CHAIRPERSON OF THE GOVERNMENTAL RELATIONS COMMITTEE OF THE DEAFNESS RESEARCH FOUNDATION

LARRY BROWN, FORMER WASHINGTON REDSKIN

RACHAEL DUBIN, SIXTH GRADE STUDENT, PARK SCHOOL IN BALTIMORE, MARYLAND

Mr. NATCHER. Mr. Hoyer?

Mr. HOYER. I am pleased to introduce to the committee Geraldine Fox. She is Chairperson of the Governmental Relations Committee of the Deafness Research Foundation. She has been a strong proponent for establishment of the National Institute of Deafness and Communications Disorders.

With her is somebody who needs no introduction he has been in Washington as long as I have, Larry Brown, one of the great football players of all time, and one of the great Redskins of all time, the 1971 player of the year.

And lastly, the delightful young lady to Ms. Fox's right is Rachael Dubin, a sixth grade student at the Park School in Baltimore. She studies long hours to improve her speech and listening capacity.

I think this is another demonstration of what we are here about. Thank you, Mr. Chairman.

Mr. NATCHER. We will be delighted to hear from each of you.

Before we proceed, Mr. Brown, I want to say this to you, you appeared before our committee last year. You have been good for sports, you have been good for this country. We are delighted to hear from you.

Mrs. Fox. Thank you, Chairman Natcher and Members of the committee. Thank you for the privilege of appearing before you today.

Last year when I testified for expanded deafness research funds within the National Institute of Neurological and Communicative Disorders and Stroke, I was extremely encouraged when you wrote a strong statement in the full House report about the importance of research on hearing problems and stated that it is your hope that activity in this field be significantly expanded.

Apparently, within the current structure, this has not been possible. In spite of the House's explicit directives, during this year's first trimester not only did we not receive an increase, it appears we did not receive as much as last year.

Hearing, speech and language, balance and sense disorders are collectively known as the communicative disorders. They comprise 60 percent of the disorders for which the entire neurology institute is responsible; yet in 1987, these disorders received less than 14 percent of the total NCDS budget. Only 200 of the 2,357 grants awarded by the neurology institute were for hearing and balance, while the total communicative disorders program received 320 grants.

I have attached to my testimony the comparison of the 1987 funding of some of the major diseases of neurology and communicative disorders.

In the intramural program and the neurology institute, there are 12 laboratories and nine branches involved in clinical and basic research. Only one of these 21 units is dedicated to hearing.

Our scientists have received high funding rates and priority scores that attest to the quality and maturity of our science, but there are good grants, good scientists and good laboratories that have been approved, but which have not been funded because of limited resources. This, coupled with the priorities of the neurology institute, has made it almost impossible to focus on the many problems that need solutions this year, though we have been encouraged that the inequities might change at last.

On April 13, 1988, under the leadership of Senators Ted Kennedy and Orrin Hatch, the Senate Labor and Human Resources Committee approved the establishment of the National Institute on Deafness and Communication Disorders as part of the National Institutes of Health reauthorization bill. This important legislation was spearheaded by Congressman Claude Pepper and cosponsored in the Senate by Senator Tom Harkin.

We have 95 cosponsors in the House. If the House takes similar action in the next few weeks and establishes the National Institute on Deafness and Communication Disorders, we would hope that at least the same amount of money that NINCDS designates for the communicative disorders program would be provided by this committee for the new institute, along with the necessary funds for administrative operations.

Congress has a very unique opportunity to respond to the needs of the 28 million deaf and communicatively impaired Americans and to prevent clear, increasing costs to our society. These costs, now estimated at \$29,930,000,000 annually, are growing rapidly with our elderly population explosion. We look forward to the day when deafness will no longer be the silent, ignored disease and millions of Americans with hearing and communication disorders will be productive, participating citizens again.

Mr. Chairman and Members of the subcommittee, each year we are allowed to come and inform you of the changes and needs of our concerns, and in this way, we are able to share important information with you. We are deeply grateful to you and to your fine legislative staff Rob Bradner, Jim Hazzard, Dave Mengebier, Larry Wine and Gregory Gill, Peter Gossens was here, Mike Stevens, and we appreciate their constant input and helping guide us.

Thank you for allowing me to express my thoughts to you.

[The information follows:]

STATEMENT OF THE
DEAFNESS RESEARCH FOUNDATION
TO THE
HOUSE APPROPRIATIONS SUBCOMMITTEE
ON
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION

RELATIVE TO
FISCAL YEAR 1989 APPROPRIATIONS
FOR THE
NATIONAL INSTITUTES OF HEALTH

SUBMITTED BY

Mrs. Geraldine Dietz Fox
Chairperson, Government Relations Committee
Member, Board of Directors
Deafness Research Foundation
Larry Brown
Member, Board of Directors
Deafness Research Foundation
and
Rachel Dubin
Student
Baltimore, Maryland

MAY 3, 1988

Thank you Chairman Natcher, and Members of the Committee, for the privilege of appearing before you today.

I am Geraldine Dietz Fox, Chairperson of the Government Relations Committee of the Deafness Research Foundation, a 30-year-old, non-profit, volunteer organization dedicated to finding preventions, treatments, and cures of deafness and hearing disabilities.

Last year I appeared before you to testify for expanded deafness research funds within the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS). Many of us were delighted when, on July 30, 1987, in the full House Report from the Committee on Appropriations, you concluded:

...The Committee considers research on hearing problems to be of great importance because of the large number of older Americans who suffer various degrees of hearing loss. With the increased resources made available and within the limits of the science opportunities currently available, the Committee is hopeful that activity in this field can be significantly expanded.

Apparently, within the current structure, this has not been possible.

In spite of the House's explicit directives, during this year's first trimester, not only did we not receive an increase, it appears we did not receive as much as last year.

Hearing, speech and language, balance, and sense disorders are collectively known as Communicative Disorders. They comprise 60 percent of the disorders for which the entire Neurology Institute is responsible, yet, in 1987, these disorders received less than 14 percent of the total NINCDS budget. Only 200 of the 2,357 grants awarded by the Neurology Institute were for hearing and balance, while the total Communicative Disorders Program received 320 grants.

The Neurology Institute tends to lump all Communicative Disorders together as one disease, instead of looking at each one separately, as they do the neurology disorders. For instance:

Let's compare the 1987 funding of some of the major diseases of both the Neurology and Communicative Disorders Program ¹:

1. Alzheimer's Disease and Presbycusis (hearing in the aged) both have profound effects on the older citizen, causing withdrawal, isolation, and great reliance on social services. Alzheimer's Disease and related dementias affects 3 million Americans and received 39 grants for \$17,776,000. Presbycusis, the third most chronic condition in persons 65 years and older, affects 4 million senior citizens now, and will affect 10 million by the year 2025. It received 4 full grants and 5 partial grants for \$1,278,080.
2. Parkinson and Huntington Diseases, along with other movement disorders affect 500,000 people and received 58 grants for

¹ NINCDS Profiles: November 1987.

\$15,625,000. Let's combine Congenital Deafness, which affects 1 in every 1,000 babies, and Otitis Media, a middle ear infection which can cause hearing loss and learning disabilities in the young child and affects 20 million children under the age of 3. Combined, they received 14 grants for \$5,398,198.

3. May I point out that in 1987, the \$34 million funding for Epilepsy, which affects only 2 million people, was equivalent to almost the entire amount of funding for Hearing and Vestibular Disorders, which affects 14 million people.

Another important part of the National Institutes of Health (NIH) is its Intramural Program. In the Neurology Institute, there are 12 Laboratories and 9 branches involved in clinical and basic research. Only one of these 21 units is dedicated to Hearing.

Within the last 10 years, the Communicative Disorders field has grown dramatically in its strength and maturity. The number and quality of researchers have increased in competency. The high funding rates and priority scores that our scientists have received attests to both the quality and maturity of our science.

But there are good grants, good scientists, and good laboratories that have been approved, but which have not been funded because of the limited resources. This, coupled with the priorities of the Neurology Institute, has made it almost impossible to focus on the many problems that need solutions.

While this is especially acute in the Communicative Disorders field because of its historic lack of support, it is not unique. More funds for Basic Bio-medical Research should be a priority for this nation.

We can only hope that, soon, interest and research in hearing and communicative disorders will become as important as another sensory disorder, the eye.

A booklet from the Eye Institute shows 17 clinical trials are now in progress on such important projects as laser therapy for diabetic eye diseases and glaucoma. The Communication Disorders Program can only point to 3 similar types of studies: one on Cochlear Implants; and two dealing with Otitis Media, the most common disorder in young children for which medical attention is sought. There is no reason to believe that we cannot make as great strides in the treatment of ear diseases as eye researchers have made in solving vision problems. We simply need the opportunity to do so.

In 1987, \$80,000,000 was spent on 320 grants for the total Communicative Disorders Program serving 28 million people; while the Eye Disorders Program spent \$216,528,000 on 1,317 grants which serve 1.7 million visually impaired persons and 500,000 legally blind persons.

This year, though, we have been encouraged that the inequities might change at last. On April 13, 1988, under the leadership of Sen. Edward M. Kennedy and Sen. Orrin G. Hatch, the Senate Labor and Human Resources Committee approved the

establishment of the National Institute on Deafness and Communication Disorders, as part of the National Institutes of Health Reauthorization bill. This important legislation was introduced by Rep. Claude Pepper and Sen. Tom Harkin. We hope that the bill in the House brings positive results in the near future.

If the House does take similar action and establishes the National Institute on Deafness and Communication Disorders, we would hope that at least the same amount of money that NINCDS designates for the Communicative Disorders Program, would be provided by this Committee for the new Institute, along with the necessary funds for administrative operations.

Congress has a very unique opportunity to respond to the needs of the 28 million deaf and communicatively impaired Americans and to prevent clear, increasing costs to our society. These costs, now estimated at \$29.93 billion annually, are growing rapidly with our elderly population explosion. We look forward to the day when deafness will no longer be the silent, ignored disease and millions of Americans with hearing and communication disorders will be productive, participating citizens again.

Mr. Chairman and members of the Subcommittee, each year we are allowed to come and inform you of the changes and needs of our concerns, and in this way, we are able to share important information with you.

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We are deeply grateful to you and your fine legislative staff for your valuable time, interest and consideration.

Thank you for allowing me to express my thoughts to you.

NINCDS GRANT ALLOCATIONS
for some of the Communicative Disorders

1987 ALLOCATIONS *

<u>Disorder</u>	<u>#People</u>	<u># Grants**</u>	<u>\$ Allocation</u>
Otitis Media with Effusion in Children	15-20% of all Children		
Active Chronic Otitis Media	4-6 Million		
Healed Otitis Media with Sequellae	20 Million		
		10**	\$ 5,076,953
Tinnitus	17% of the Population (@ 34 Million) with Mild Disturbance		
	1% of the Population (@ 2 Million) Suffer Severe Problems		
	1/2% of the Population (1 Million) are Unable to Lead Normal Lives		
		3	\$ 240,354

** Whole and Partial Grants

NINCDS Grants Allocations for some of the Communicative Disorders (con'd):

Sudden Deafness	20,000 New Cases per year	2	\$ 316,470
Stuttering	0.46% of the Population (@920,000)	No Single Grant, but 10% of ea. of 3 grts.	\$ 194,345
Congenital Deafness	1 in every 1,000 Babies	4	\$ 321,245
Presbycusis	3rd most common Chronic Cond. in persons 65 yrs. or older (@ 284 per 1,000 persons)	10**	\$1,278,080

* Information provided by Legislative Analysis Branch

** Whole and Partial Grants

NINCDS GRANT ALLOCATIONS
for some of the Neurological Diseases

1987 ALLOCATIONS *

<u>Disorder</u>	<u># People</u>	<u># Grants</u>	<u>\$ Allocation</u>
Stroke	1,900,000	121	\$32,909,000
Epilepsy	2,000,000	162	\$33,663,000
Alzheimer Disease & related dementia ¹	3,000,000	39	\$17,776,000
Parkinson Disease, Huntington Disease, & other Movement Disorders	500,000	43 15	\$15,625,000
Multiple Sclerosis	131,000	138	
Amyotrophic Lateral Sclerosis	14,000	35	\$33,707,000

* Information provided by: Legislative Analysis Branch

ANNUAL COSTS TO SOCIETY
OF
HEARING, SPEECH, AND LANGUAGE DISORDERS *

1987

<u>Disorder</u>	<u>Cost to Society **</u>
Deafness	\$ 1.8 Billion
Partial Deafness	\$11.6 Billion
Speech	\$ 9.00 Billion
Language	\$ 7.53 Billion

TOTAL	\$29.93 BILLION

* NINCDS: PROFILE; November 1987

** Cost of Health Care, the added Cost of Special Education Programs, and Loss of Income due to illness

Mr. HOYER. The staff are very impressed. I know that.

Mr. EARLY. We are going to recess, go vote and come right back. Otherwise, the time is going to run and we are going to have to get up and leave, so we are going to recess now.

[Recess.]

Mr. NATCHER. All right. Who is next?

Mr. Brown, we will be pleased to hear from you at this time.

Mr. BROWN. Thank you.

Mr. Chairman, members of the Appropriations Committee, I appreciate the opportunity to testify before you today. In a world where power means getting heard, powerlessness has long been the status quo for the deaf. As one of the 28 million Americans afflicted with a hearing disorder, I believe I may be helpful in offering first-hand testimony about the critical need to establish more funds for deafness research.

Deafness has been called "the invisible impairment." My own deafness isn't noticed until I fail to respond to a greeting or miss the point of a joke, so sometimes I feel left out.

When I was growing up, it was obvious when a friend had a visual impairment—he or she wore glasses—but my deafness was never acknowledged until later, and often I tried to hide it.

The recent protests over the selection of a President at Gallaudet University demonstrates that deaf people want to be heard and actively involved in decisions that affect their lives.

That is why the hearing impaired community was so excited when the Senate Labor Human Relations Committee introduced a bill for the National Institute on Deafness and Communication Disorders as an amendment to the bill.

Just as the right blend of talent, resources and management makes a football team or a corporation powerful and successful, the same principle is true if you bring doctors, scientists and technicians together to find solutions to our country's most chronic impairment.

Thank you for the opportunity to appear before you and share with you my thoughts and feelings about a problem for which I have great concern.

Mr. NATCHER. Thank you very much, Mr. Brown.

Now we will hear from Rachael Dubin. We will be pleased to hear from you, Rachael.

Ms. DUBIN. My name is Rachael Dubin. I work very hard at speech. I study speech twice a week along with auditory training. That is, I learn to listen and get the most out of my hearing aid. I also see my itinerant teacher for the hearing impaired three times a week. We discuss school, school work, and I keep her up to date on the latest that is happening in my classes.

I do not sign, but I am able to understand with the use of my hearing aid and lip reading.

The hardest parts of being hearing impaired are paying attention, not being able to hear what my friends are saying, and not hearing over the phone. Sometimes my friends get frustrated when I ask them to repeat what they said. Often they just give up trying to communicate with me and say, "Never mind."

I think that if the government gave more money for deafness research, they could develop hearing aids and listening devices and

determine why children lose their hearing without any reason, like I did. I was never seriously ill, and there was no deafness on either side of my parents' families. I lost my residual hearing suddenly at five years of age, leaving me profoundly deaf.

Mr. Chairman, when I was little I used to ask my parents questions like: "When will I hear like other kids?" and "What does a bird sound like?"

Now I ask more serious questions: "Do you think I will ever be able to hear my friends' voices on the telephone?" and "Will my children be hearing impaired?"

Please help me and other hearing impaired kids look forward to a better and brighter future.

Thank you, Congressman Natcher, for allowing me to speak to you today.

Mr. NATCHER. Thank you very much. Rachael, you have made an excellent statement. We appreciate it. Mr. Hoyer, I yield to you.

Mr. HOYER. Rachael's Congressman has now joined us. She has shown a great deal of ability, and one of the most able members personally, I think of the United States is her Congressman, Congressman Cardin. He has joined us here today.

Mr. NATCHER. We are delighted to have you. I will be happy to yield to you.

Mr. CARDIN. I am very proud Rachael is here today to testify before your committee, and I thank you for the courtesy extended to her, and I am very pleased to see you here today. Congratulations.

Mr. NATCHER. Rachael, walk around this way. I want to shake hands with you. Come on around here.

Thank you very much, Rachael. Mrs. Fox and Mr. Brown, we want you to know you have made good statements, and we appreciate it.

Mr. CONTE. Mr. Chairman, I want to join with you in commending Larry Brown. My wife and I watched every one of your games here in Washington, and I want to join the chairman in saying you certainly have been a credit to the sport of football, a gentleman on and off the field, a great American, and we are really proud of you, Larry. Your picture is all over the walls of my play room in my house.

Mr. BROWN. Thank you very much.

Mr. EARLY. Mr. Chairman?

Mr. NATCHER. Mr. Early.

Mr. EARLY. When you were playing, as Mr. Conte said, it was mentioned that you had some hearing problems. I think, if there was anything that really threw out the signal to people in my area with hearing problems, was that you could participate at that level with that problem.

We had some outstanding testimony this morning with regard to deafness. And we had an incident in Massachusetts come to light last Friday where a young child sat in a class for two years in a public school, a five-year-old, before it was discovered that she was deaf. So when you take some time to come up, I really think you don't know how much of a contribution you make.

In this committee, when we have mark up, there are two people we have to move, and that is Mr. Conte and Mr. Natcher. Believe

me, you know Mr. Hoyer didn't joke. That is where it is. We really do appreciate your coming up to testify.

Mr. BROWN. Thank you. I look forward to visiting you in the future.

Mr. NATCHER. Thank you very much.

Mr. HOYER. What he means if they write the songs, and we just say "amen".

TUESDAY, MAY 3, 1988.

**NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND
KIDNEY DISEASES**

WITNESS

STUART A. KLEIT, CHAIRMAN, NATIONAL KIDNEY AND UROLOGIC DISEASES ADVISORY BOARD

Mr. NATCHER. Our next witness is Dr. Stuart A. Kleit. Come around, Doctor. Dr. Kleit, we will be pleased to hear from you at this time.

Dr. KLEIT. Thank you, Mr. Chairman.

I am Dr. Stuart A. Kleit, Chief of the Renal Section, as well as Associate Dean for Clinical Affairs at Indiana University School of Medicine and chairman of the National Kidney and Urologic Disease Advisory Board. I am honored to have this opportunity to testify on behalf of the Board to this Committee.

I would like to request that my written testimony be entered into the record.

The Board was established in Public Law 92-463 and held its first meeting in June of 1987. Its function as outlined in its charter is to develop a long-range plan to combat kidney and urologic diseases providing specific recommendations for the utilization and organization of national resources in this struggle. The Secretary of the Department of Health and Human Services appointed the Board in May, 1987, and the Board held its first meeting in June, 1987.

The Board has spent the last 10 months organizing to accomplish its task, setting work schedules and goals, and initiating the collection of data. The Board has divided into four basic committees and added expert consultants to the committees to provide a board base of input into its recommendations. I might say we have over 400 people involved in the Board at this time.

The Data Committee is searching the medical literature and existing Federal and other data banks for information on the extent, types and costs associated with kidney and urologic diseases. While the extent of ESRD and its \$3,000,000,000 cost are evident, the true costs, incidence and problems associated with more common kidney and urologic diseases are more difficult to obtain.

The Research Committee is analyzing current and past research efforts and seeking clues to future areas that hold prospects for prevention and cure. It is devoting major efforts to determining the number and training needs of M.D.'s and Ph.D.'s. It has major con-