

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

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

ON

H.R. 4783

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, 1989, AND
FOR OTHER PURPOSES

Part 4 (Pages 1-861)

Nondepartmental witnesses

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Senator HARKIN. Dr. Goldstein, thank you very much. Thank you for your support of the legislation. We hope we can get that through here this year.

There are roadblocks along the way but we have had those before. So I appreciate your being here. I appreciate your testimony. Thank you very much.

STATEMENT OF GERALDINE DIETZ FOX, CHAIRPERSON, GOVERNMENT RELATIONS COMMITTEE AND MEMBER OF THE BOARD OF DIRECTORS, DEAFNESS RESEARCH FOUNDATION

ACCOMPANIED BY:

LARRY BROWN, MEMBER, BOARD OF DIRECTORS, DEAFNESS RESEARCH FOUNDATION

RACHEL DUBIN, STUDENT, BALTIMORE, MD

LOUISE FLETCHER, MEMBER, BOARD OF DIRECTORS, DEAFNESS RESEARCH FOUNDATION

Senator HARKIN. Next I would like to call Geraldine Fox of the Deafness Research Foundation. I understand she will be accompanied by Larry Brown and Louise Fletcher. Please have a seat, and also, is this Rachel Dubin? I welcome you to the subcommittee.

Senator Specter wanted to be here to introduce you, but as you know he had a slight illness. He had an operation on his leg yesterday and is in the hospital. But I understand that he is OK.

I would like to introduce Geraldine Dietz Fox, member of the board of directors and chairperson of the Government Relations Committee of the Deafness Research Foundation.

The Deafness Research Foundation is a 30-year old private nonprofit organization dedicated to finding prevention, treatment, and cures of deafness and hearing disorders.

Ms. Fox has testified before this committee last year. She has lobbied on the Hill for several years and has increased public understanding of the needs of hearing-impaired individuals. The last year and a half she has been a strong proponent of the establishment of the separate National Institute on Deafness and Communication Disorders.

Also Larry Brown, who we have had here before, former member of Washington's favorite and only football team, the Redskins. He won the 1972 NFL player of year award. Mr. Brown is now the business community relations manager for the Xerox Corp.

Last year he testified with Ms. Fox before the House and Senate Appropriations Committees, and this year testified before Congressman Waxman's Health and Environment Subcommittee in favor of establishing the National Institute on Deafness and Communications Disorders. Mr. Brown is also a member of the board of directors of the Deafness Research Foundation.

I understand we also have Louise Fletcher, who as we know appeared in the movie, "One Flew Over the Cuckoo's Nest," which I remember very well. How many years ago was that?

Ms. FLETCHER. A few.

Senator HARKIN. Well, we do not want to talk about that.

Ms. FLETCHER. That is over 10 years ago.

Senator HARKIN. And do I understand that this is Rachel Dubin?

Ms. FLETCHER. Yes.

Senator HARKIN. This is Rachel Dubin from Baltimore, MD, 11 years, in the sixth grade at Park School in Baltimore.

This unusual young lady, in spite of a profound hearing impairment, manages in a regular classroom with an auditory trainer. This instrument is used with her hearing aid and helps her to hear the teacher's voice without any background noise.

Her teachers all write on the board, and from this she takes her own notes. Rachel is quite independent, studying long hours to constantly improve her speech and listening capacity.

I personally want to thank all of you for being here. You all know of my intense interest in this area. We welcome you here, and please proceed. I will try to give you each 3 minutes.

Ms. Fox. Thank you, Mr. Chairman and members of the subcommittee, 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 the Senate, guided by the strong leadership of Senators Chiles, Weicker, and Harkin, wrote that they considered research on hearing problems to be of great importance and recommended that activity in this field be significantly expanded.

Apparently, within the current structure, this has not been possible. However, the inequities might change at last.

On April 13, 1988, under Chairman Senator Edward Kennedy and ranking minority member Senator Orrin Hatch, the Senate Labor and Human Resources Committee approved the establishment of the National Institute on Deafness and Other Communication Disorders as part of the National Institutes of Health reauthorization bill. This important legislation was introduced by Senator Tom Harkin and Congressman Claude Pepper in the House.

I want to especially recognize Senator Harkin and Senator Weicker of this committee for their foresight in approving and supporting legislation for a new Institute. Their faith in this endeavor has been a source of strength for all peoples afflicted with communication disorders.

Assuming that there would be an increase above the President's budget request of \$571 million for fiscal year 1989, this would increase the NINCDS appropriations to \$668 million.

Information that we have states that NINCDS recommends an operational budget of \$703 million for fiscal year 1989 in order to achieve a funding level of 50 percent for approved grant applications. NINCDS has also stated that it allocates 20 percent of the total funds for the Communicative Disorders Program.

Therefore, the funding for the Communicative Disorders Program for fiscal year 1989 for research and research training would total \$133.6 million. If the House takes similar action in approving the Institute in the next few weeks, and it creates the National Institute on Deafness and Other Communication Disorders, we would hope that at least the same amount of money will be provided by this committee for the new Institute, along with the necessary funds required for establishing administrative operations.

Please keep in mind that in the past the Senate has used strong language when recommending additional funds for deafness. But their words have gone unheeded.

Based on testimony over the past years, we critically need research centers and training programs. The Senate has given implicit directions to NINCDS while increasing their appropriations, but deafness and other communication disorders have not gotten their fair share of this increase.

To meet the critical present needs and to make up for past underfunding, please consider adding 10 percent more to this base figure of \$133.6 million. Then we can start to prevent the rapidly increasing cost to our society from deafness, which has now been estimated at \$30 billion annually.

We look forward to the day when deafness will no longer be the silent ignored disease, and Americans with hearing and other 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 concern, and in this way we are able to share important information with you.

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.

[The statement follows:]

STATEMENT OF GERALDINE DIETZ FOX

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 hearing disorders.

Last year, I appeared before you to testify for expanded deafness research funds within the National Institute of Neurological and Communicative Disorders and Stroke. Many of us were delighted and grateful, especially to Senators Chiles, Weicker and Harkin, not only for their previous leadership, and present guidance, but for their strong Report Language. On September 25, 1987, the full Senate Appropriations Report concluded:

....Concerns have been expressed that not enough funds are being channeled by the NINCDS into deafness research to discover the cause, prevention, treatment, and cure of hearing and balance disorders.

....The Committee considered 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 strongly recommends that activity in this field be significantly expanded.

....The Committee directs that a strong, sustained effort, targeted on hearing disorders, would enable scientists to pursue some of the more promising areas of investigation....

Apparently, within the current structure, this has not been possible. Hearing, speech and language, balance, and sense disorders (taste and smell) 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.

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

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 affect 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 \$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 deafness 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 the resources were not judiciously allocated. 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 must 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 Communicative 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 Chairman Senator Edward M. Kennedy and Ranking Minority Member Senator Orrin G. Hatch, the Senate Labor and Human Resources Committee approved the establishment of the National Institute on Deafness and Other Communication Disorders as part of the National Institutes of Health Reauthorization Bill. This important legislation was introduced by Senator Tom Harkin and Congressman Claude Pepper in the House.

I want particularly to recognize Senator Harkin and Senator Weicker, of this Committee, for their foresight in approving and supporting legislation for a new Institute. Their faith in this endeavor has been a source of strength for all peoples afflicted with deafness and other communication disorders.

Assuming that there would be an increase above the President's Budget Request of \$571 million for NINCDS for FY '89, this would increase the NINCDS Appropriations to \$668 million. (Information

that we have, states that NINCDS recommends an operational budget of \$703 million for FY '89. in order to achieve a funding level of 50% for approved grant applications.) NINCDS has also stated that it allocates 20% of the total NINCDS funds to the Communicative Disorders Program. Therefore, the funding to the Communicative Disorders Program for FY '89, for research and research training, would total \$133.6 million.

If the House takes similar action in approving the Institute in the next few weeks, and creates the National Institute on Deafness and Other Communication Disorders, we would hope that, at least, the same amount of money would be provided by this Committee for the new Institute, along with the necessary funds required for establishing administrative operations.

Please keep in mind that, in the past, the Senate has used strong language when recommending additional funds for Deafness and Other Communication Disorders, but their words have gone unheeded. Based on testimony over the past years, that we critically need Research, Centers, and Training Programs, the Senate has given implicit directions to NINCDS while increasing their Appropriations; but Deafness and Other Communication Disorders have not gotten their fair share of this increase.

To meet the critical present needs, and to make up for past underfunding, please consider adding 10% more to this base figure of \$133.6 million. Then we can start to prevent the rapidly increasing cost to our society from deafness, which has now been estimated at \$30 billion annually.

We look forward to the day when deafness will no longer be the silent, ignored disease, and 28 million Americans with hearing and other 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 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
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	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	\$33,707,000
Amyotrophic Lateral Sclerosis	14,000	35	

* 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

WHAT CAN WE FORESEE IN THE FUTURE? WHERE COULD DEAFNESS RESEARCH BE IN 10-20 YEARS WITH INCREASED FUNDING?

- A) Application of space-age technology promises better hearing aids to improve understanding of speech for the majority of those affected and...
- Surgically implantable hearing aids with sufficient clarity to assist those for whom prevention fails. Also,....
- Critical need to study the effects of cochlear implants in children.
- B) Identification of genes which cause deafness. This would address the question of why children are born deaf or why people experience sudden hearing loss.
- C) It is possible to grow the inner ear mechanism in tissue culture; what if such bold research could lead to the replacement of damaged inner ear sensory cells?
- D) Development of a vaccine for Otitis Media with accompanying clinical trials. Also, determining effectiveness of drugs to alleviate tinnitus, Meniere's Disease, noise induced hearing loss, and hearing in the aged, with accompanying clinical trials.
- E) Increased knowledge of how sound received by the ear is transmitted to the brain. Important for diagnosing and treating young children, who do not develop language, and elderly people who cannot understand the words that they hear.
- F) Development of reliable and valid measures of the hearing of children under two years of age because of the critical necessity for setting accurate levels on hearing aids for hearing-impaired youngsters.

By accelerating and facilitating research into the preventions, causes, diagnosis, treatments, and cures of all the communicative disorders, you can positively affect the quality of life for many of us here today.

Senator HARKIN. Thank you very much, Ms. Fox, for your continuing support and interest in this. You have provided a lot of information that we can use.

Let me get one thing clear. You are asking for funding for the communicative disorders program, \$133.6 million?

Ms. Fox. \$133.6 million is what they should receive in fiscal year 1989 from NINCDS.

Senator HARKIN. But in 1987 you said they received for deafness and communicative disorders about \$80 million which was spent on 320 grants.

Ms. Fox. Well, I am going by the figures that the last few years the Congress has increased the President's budget by 17 percent, plus the 20 percent of that budget that NINCDS gives to us.

Senator HARKIN. Thank you very much. Mr. Brown, welcome again to the subcommittee. Do I have a statement from you? Yes I do, I have a statement. Please proceed.

STATEMENT OF LARRY BROWN

Mr. BROWN. Thank you. Mr. Chairman, members of the appropriations subcommittee, I appreciate the opportunity to testify before you today.

Deafness has been called the invisible impairment. Like 28 million other Americans, my own deafness is not noticed until I fail to respond to a greeting, or miss the point of a joke.

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 protest this year 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.

In a world where power means getting heard, powerlessness has long been the status quo for the deaf. A separate Institute will provide us with a home of our own. We need to help control our destiny.

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.

PREPARED STATEMENT

This committee has already been generous with its vocal support. Now it is time to reinforce this support with the kind of funding that will make this dream a reality. Thank you very much.

[The statement follows:]

STATEMENT OF LARRY BROWN

Mr. Chairman, Members of the Appropriations Subcommittee. I appreciate the opportunity to testify before you today.

Deafness has been called "The Invisible Impairment." Like 28 million other Americans, my own deafness isn't noticed until I fail to respond to a greeting or miss the point of a joke, so sometimes you feel left out.

When I was growing up, it was obvious when a friend had a visual impairment - He wore glasses - But my deafness was never acknowledged until later, and often, I tried to hide it.

The protests this year over the selection of a President at Gallaudet University demonstrate that deaf people want to be heard and actively involved in decisions that affect their lives. In a world where power means getting heard, powerlessness has long been the status quo for the deaf.

That's why the hearing impaired community was so pleased when Congressman Claude Pepper and Senator Tom Harkin introduced a Bill to establish a National Institute on Deafness and Communication Disorders. We were even more excited when the Senate (Labor and Human Resources) Committee approved the establishment of this separate Institute, as an amendment to the NIH Reauthorization 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.

Senator HARKIN. Mr. Brown, thank you very much for being here, and your continued support in this area. I appreciate it very much. I know the entire committee does also.

Ms. Fletcher, welcome to the subcommittee.

STATEMENT OF LOUISE FLETCHER

Ms. FLETCHER. Thank you very much, Mr. Chairman, members of the committee. Thank you for the privilege of speaking to you today.

I am the daughter of deaf parents, and a member of the board of the Deafness Research Foundation, and I have an enduring and passionate interest in all things affecting the deaf. And I try to do whatever I can to help out, and being here today is one of those things.

I do not have a prepared statement, but I would just like to relate something to you. The summer I was 10 years old I spent the entire summer climbing a tree, the tallest tree in our block.

I did not like climbing trees, but I thought that getting up to the top of this tree would put me closer to God, and maybe He could hear my prayer better than he heard my everyday ordinary bed-time prayers.

And my prayer was, please fix it so my mother and father can hear. You know, they need to hear the baby crying, they need to hear the doorbell and the telephone and the fire engine, and they needed to drive the car and they needed to talk to people and understand what they say when they are talking back to them.

They do not need a 10-year old to explain everything to them that is on the news, because I had an impossible time understanding the news, and I could not really explain it to them at 10.

So this came home to me when I was asked to come here and give my support for the establishment of this new Institute. And in the establishment of this new Institute, I believe that some of these prayers, like the one that I had when I was 10, would begin to be answered, about 28 million of them. And I thank you very much for letting me come today. That is my statement.

Senator HARKIN. Well, thank you very much. I can appreciate that story and am able to somewhat relate to it.

Ms. FLETCHER. I know.

Senator HARKIN. But you are very kind, and I am honored that you are here to support this.

Rachel Dubin is here. Now, I do not know, Rachel, can you hear me? Or do you understand sign language? Can you read my lips?

STATEMENT OF RACHEL DUBIN

Ms. DUBIN. Yes, Senator Harkin. Hello. My name is Rachel Dubin. I work very hard at speech, studying five times a week to learn to listen and get the most out of my hearing aid.

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 three times 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 better hearing aids and listening devices and determine why children lose their hearing without any reason, like I did.

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, Senator Harkin, for allowing me to speak to you today.

Senator HARKIN. Well, thank you very much, Rachel.

Ms. DUBIN. You are welcome.

Senator HARKIN. We are honored to have you here. Are your parents here? Oh, these are your parents.

Well, we are very proud of you also. Do you know who we had before my subcommittee about a month ago? We had the actress Marlee Matlin who, as you know, also recently won an Academy Award, and I just want you to know that I see a lot of the same traits in you that I see in her.

Regardless of what setbacks you have had because of your hearing impairment, I think you have a very bright future in front of you. I think you are going to be very successful.

Ms. DUBIN. Thank you very much, Senator Harkin.

Senator HARKIN. Well, thank you. Now, tell me, Rachel, how do you understand what your teachers are saying in school, when your teachers are at the blackboard? Because sometimes teachers do not speak directly to you, and if you cannot see their lips—

Ms. DUBIN. At first, they write on the board and then they start speaking. And also I use an auditory trainer. It is a machine that is removable, that attaches to my hearing aid. And my teacher has a microphone with battery packs. And it amplifies the teacher's voice and helps me to pay attention.

Senator HARKIN. Thank you all very much. Do you have any questions?

Mrs. DUBIN. We are hoping you will support our deafness research so that the things will improve in the future for our children communication-wise.

We think it is very important that she and other hearing impaired be very much a part of the hearing world society. Thank you for letting us speak today.

Senator HARKIN. Well, thank you all for being here. You are all wonderful. And I appreciate all of your continued interest and support of this effort. Thank you all.

Ms. DUBIN. Thank you.

Senator HARKIN. Next will be Raymond Connors, president, American Tuberos Sclerosis Association. I am learning a lot of things here today. Mr. Raymond Connors? Mr. Raymond Connors, going once, going twice.