S. HRG. 105-872

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1999

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED FIFTH CONGRESS

SECOND SESSION

ON

H.R. 4274/S. 2440

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, 1999, AND FOR OTHER PURPOSES

Department of Education
Department of Health and Human Services
Department of Labor
Nondepartmental witnesses

Printed for the use of the Committee on Appropriations

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1999

WEDNESDAY, APRIL 1, 1998

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 2:20 p.m., in room SD–192, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Cochran, Faircloth, Bumpers, and Kohl.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

STATEMENT OF HAROLD E. VARMUS, M.D., DIRECTOR

ACCOMPANIED BY:

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JACK WHITESCARVER, M.D., ACTING DIRECTOR, OFFICE OF AIDS RESEARCH

DENNIS P. WILLIAMS, DEPUTY ASSISTANT SECRETARY, BUDGET, DEPARTMENT OF HEALTH AND HUMAN SERVICES

OPENING REMARKS OF SENATOR SPECTER

Senator SPECTER. Good afternoon, ladies and gentlemen. The Subcommittee on Labor, Health and Human Services, and Education will now proceed.

I regret our late start. We had a vote scheduled for 2 o'clock, and if I am there to vote at 2 o'clock, I can get out at 2:01 and be here to have the minimal interruption with the hearing. But the 2 o'clock vote was postponed to 2:10, and then 2:15, and then 2:17. Then they decided to do that because they scheduled a vote right behind it. That 30 second explanation does not tell you about the proceedings in the Senate. I value your time very highly. I know this is an extraordinary assemblage of talent. As the saying goes, there is more talent in this room since President Kennedy dined alone—and I had better be careful of what I say here. [Laughter.]

The National Institutes of Health, as I so frequently say, in my opinion is the crown jewel of the Federal Government. Besides that, you are good. [Laughter.]

It may not take too much to be the crown jewel of the Federal Government, but the National Institutes of Health has set a mark in what you have accomplished and I am a total supporter.

We have a Federal budget of $1.7 trillion and if we set our priorities in order, there will be no problem in increasing your funding tremendously.

We give lip service to doubling the NIH budget over 5 years. It unanimously passed last year, 97 to 0. With Senator Harkin and I working together, crossing party lines—I learned a long time ago if you want anything done in Washington, you have to cross party lines and get bipartisan support—we tried to put the money into it by $1 billion plus budget amendment because the health account had been cut by $100 million, and it was defeated 63 to 27.

We have readied an amendment for $2 billion extra. We are talking about doubling, which would be more than $2.5 billion, but we are talking about a $2 billion addition.

past year. The first is a novel partnership with the Arthritis Foundation, the National Institute of Allergy and Infectious Diseases, and the Office of Research on Women's Health to support a national consortium of 12 research centers in the search for genes that determine susceptibility to rheumatoid arthritis. The Arthritis Foundation not only provides financial support, but plays an invaluable role in patient recruitment and in increasing awareness of this study, the largest such effort in the world. The NIAMS also has partnered with both the American Society for Bone and Mineral Research and the S.L.E. Foundation to co-fund grants. Such arrangements benefit both components—the voluntary and professional organizations benefit from the NIAMS' expertise in grant review, and the Institute is able to support more studies than would be possible without the co-funding. When we share common goals, as we do in the examples just cited, the partnerships are clearly beneficial—for the public, the voluntary groups, and the NIAMS.

The future: challenges and plans

What are the challenges to reaching the vision of the future that I described earlier and how do I plan to invest the budget to address those challenges? The increased budget will allow the NIAMS to support more research grants in key areas of opportunity and need, and we will expand our research portfolio in a number of priority areas. For example, we will explore specific opportunities to learn more about skeletal morphogenesis and growth, mechanisms of central nervous system damage and cardiovascular disease in systemic lupus erythematosus, hematopoietic (blood cell forming) and immune system effects on bone physiology, gene therapy for arthritis and skin disease, and structural biology of muscle membrane proteins. The NIAMS convened four working groups this year—in arthritis, bone, orthopaedics, and skin—to discuss clinical research needs and opportunities. There is a serious challenge in the field of clinical research, where problems include a shortage of people trained to do clinical research, and a shortage of people in the pipeline pursuing a career in clinical research. For example, our clinical panels expressed concern about the scarcity of individuals in NIAMS-related specialties, such as rheumatology, particularly pediatric rheumatology, as well as the dearth of physicians doing research in bone endocrinology, orthopaedic surgery, and dermatology. Our ability to derive maximum benefits from medical research will be seriously compromised if we do not address these shortfalls. Clinical researchers provide a vital bridge for translating bench research to bedside improvements, as well as translating bedside insights into bench opportunities. The new initiatives launched by the NIH in clinical research training and career development will help address important public health needs in NIAMS-mandated areas. I am confident that this aggressive and proactive approach will make a genuine difference in medical research in the future.

The activities of the NIAMS are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

In closing, I want to express my gratitude to the members of this subcommittee for their strong and unwavering support of medical research. I hope that ten years from now we will be able to speak about the benefits that medical research has enabled—that we will be able to enjoy progress in all aspects of the lives of the American people. I am focused on that goal—the research we are supporting, conducting, and planning is aimed at achieving that goal. I am optimistic that we are on the way to achieving that goal.

My colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF JAMES F. BATTEY, JR.

Mr. Chairman and Members of the Committee: I am honored to appear before you as the newly appointed Director of the National Institute on Deafness and Other Communication Disorders (NIDCD). Several members of Congress were actively involved in the creation of the NIDCD nearly ten years ago. As you envisioned, NIDCD has become the focal point of research in human communication supported and conducted by the Federal government in the fifty states. In the last several years, in my role as the NIDCD's Scientific Director, I was part of the Institute's growth and development, whose goal is to advance knowledge about the mechanisms

and processes of human communication, and revolutionizing prevention and treatment of disease and disorder. The President in his 1999 budget has proposed that the National Institute on Deafness and Other Communication Disorders receive $213.8 million, an increase of $14.9 million over the non-AIDS portion of the fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NIDCD is $215.7 million, an increase of $15 million over the fiscal year 1998 appropriation. Funds for NIDCD efforts in AIDS research are included within the Office of AIDS Research budget request.

COMMUNICATION SKILLS AT THE CENTER OF SUCCESSFUL LIFE IN THE NEW CENTURY

Communication skills will be central to a successful life in the new century for all Americans. For the 46 million Americans with communication disabilities, however, getting up and facing each day is a challenge. The simple acts of speaking, listening, of making their wants and their needs understood, are often impossible. For the individual who has vertigo, or the person who finds himself or herself suddenly unable to hear, the days are challenging. For those who cannot speak without stuttering or for those who are unable to express ideas clearly after suffering a stroke, for those who cannot use their voices to talk with a friend on the phone due to the devastation of throat cancer—each day is challenging. The days are challenging for the child who has autism. They are also a challenge for the individual who cannot participate in activities because his or her tinnitus has become overwhelming. For an older person a loss of balance can result in falls and fractured bones, and a loss of hearing results in isolation. For the young child who begins a struggle with language, that if not for intervention, will be a lifelong struggle—communication disabilities pose a constant challenge. NIDCD made important progress in the disorders of human communication this year and has identified new targets, new tools and new teams for accelerating discovery in fiscal year 1999.

NEW TOOLS: SENSORY IMAGING

In reviewing the progress of the past year, the advances made in human communication research are frequently based upon new tools, new targets and new teams of scientists looking at research in novel ways. For example, we now have the ability to see the brain at work during human communication through the use of powerful imaging tools. Much of the human brain is used for hearing, balance, voice, speech and the manipulation and production of language, as well as the ability to smell and to taste.

IMAGING PROVIDES FIRST OBJECTIVE VIEW OF TINNITUS

Having the ability to image brain activity patterns during various communication events involving stuttering, aphasia, tinnitus, and American Sign Language is revolutionizing our understanding of normal and disordered processes of human communication. In one of many remarkable advances this year, NIDCD scientists are able to visualize brain activity occurring with tinnitus, or ringing in the ears. Tinnitus has been extremely difficult to study without an objective model as it is associated with virtually every kind of hearing loss. These studies provide ground-breaking information about the nature of tinnitus, which will hopefully lead to improved strategies for diagnosis and treatment for the millions of Americans challenged with the incessant or intermittent audiotory sensation that is tinnitus.

SENSORY HAIR CELL REGENERATION PROGRESS

NIDCD-supported scientists are determining the properties of unique sensory cells of the inner ear called "hair cells." [Exhibit 1: Sensory Hair Cells] These cells are critical for converting mechanical energy from sound or motion into electrochemical signals sent to the brain. Loss of hair cells is frequently the cause of hearing impairment and balance disorders. NIDCD-supported scientists are studying the molecular mechanisms underlying hair cell regeneration in animal model systems with the ultimate goal of using this information to restore hair cells in individuals with hearing impairment and balance disorders.

COCHLEAR IMPLANTS RESTORE HEARING

In a different way, NIDCD scientists are trying to restore hearing through support of the development of the cochlear implant. The cochlear implant is a sensory neural auditory prosthesis that improves economic and social outcomes for post-lingual hearing impaired individuals. [Exhibit 2: Cochlear Implant and Figure A: Inner ear and cochlear implant] Here is a modern cochlear implant. Let me show you how it works. Part of it is surgically implanted within and behind the ear and the other

components are worn. The implant bypasses the nonfunctioning hair cells in the cochlea and stimulates the auditory neural pathway. The prosthesis also includes a voice processor that has been designed to sample and convert sound at high speed and through a brilliant speech processing strategy. As an indication of how well this implantable prosthesis works, many who become suddenly deaf in mid-career are now able to remain in their jobs. These individuals are able to use the telephone again after learning to use the implant through rehabilitation training.

EARLY IDENTIFICATION OF DEAF AND HARD OF HEARING INFANTS AND DEVELOPMENT OF LANGUAGE

NIDCD has continued to investigate the development of language, signed or spoken, in children who are deaf or hard of hearing. NIDCD-supported scientists have shown that the first six months of life represent a crucial period for subsequent development of language either spoken or signed. A number of states are implementing universal newborn hearing screening which begins with a test for auditory function very soon after birth. In 1998, NIDCD-supported scientists will complete a five-year study showing that two screening methods, measurement of otoacoustic emissions and auditory brainstem responses, can be used to accurately identify these deaf and hearing-impaired newborns. These research results will provide much needed guidance for implementing universal newborn hearing screening.

PROGRESS IN UNDERSTANDING OLFACTORY RECEPTION

The olfactory receptor gene family has about 1,000 members. More than five years ago, scientists discovered this large, multi-gene family, but had difficulty proving that these receptors responded to an odorant. An NIDCD-supported laboratory has shown that a member of the multi-gene family first identified as encoding a putative odorant receptor does indeed code for a protein that is capable of specific odor binding leading to a physiological response. Using a recombinant adenovirus, scientists were able to direct expression of a particular receptor gene in an increased number of rat olfactory neurons. Electrophysiological recording showed that increased expression of a single olfactory receptor gene increases odor and sensitivity to a small subset of odorants. These studies provide the basis for additional research that will correlate olfactory receptor structure with odorant responses.

NEW APPROACH FOR CHILDREN WITH SPECIFIC LANGUAGE IMPAIRMENT

NIDCD has also made progress in studying specific language impairment (SLI) in hearing children. Specific language impairment, or SLI, is a deficit in language acquisition found in the absence of other cognitive impairment, and is present in about 8 percent of American school age children. SLI is a common cause of poor academic performance and frustration with learning. For a long time the focus of research was upon language and language strategies. Within the last few years, however, NIDCD-supported scientists have determined that SLI is often caused by a specific inability to process rapidly changing auditory information, such as occurs in some normal human speech. These findings will allow a more precise diagnosis of SLI, and suggests new intervention strategies to help children with SLI.

MOLECULAR GENETICS COLLABORATION PROVIDES KEY TO FORM OF HEARING IMPAIRMENT

Molecular genetics is revealing genes involved in many disorders of human communication. The search for hearing impairment genes is greatly facilitated by the timely, collaborative information exchange among different NIH Institutes working with a common purpose. For example, when a gene for a syndrome consisting of hearing impairment coupled with thyroid abnormalities was identified by a National Human Genome Research Institute scientist, this information was shared with NIDCD intramural investigators. The NIDCD scientists used the information to show that different mutations in the same gene also causes recessive non-syndromic hereditary hearing impairment in some families.

IMPROVED UNDERSTANDING OF THE CAUSE OF RECURRENT OTITIS MEDIA

As every parent knows, otitis media or middle ear infection, is the most frequent reason that a sick child visits either emergency rooms or physicians' offices, and the estimated cost of treating otitis media is $5 billion a year. Otitis media appears to be increasingly resistant to conventional antibiotic therapy. One of the most difficult aspects of treating otitis media is that relapses often occur within several weeks of antibiotic treatment. This clinical problem was difficult to explain, since most middle ear effusions showed no evidence of bacterial infection when cultured. Using a