Coalition Update

International Polio Network is still collecting information from individuals who are interested in receiving updated information about the National Polio Research Coalition's (NPRC) efforts to encourage post-polio research at the National Institutes of Health. If you have not already done so, please send your name to NPRC, 5100 Oakland Ave., #206, St. Louis, MO 63110.

Lauro S. Halstead, MD, testified before the House Appropriations Committee on April 30, 1992. His comments are printed below. He also testified before the Senate Appropriations Committee on July 23, 1992. The key congressional individuals in the Senate are listed. If your senator is listed, please consider a personal contact either by mail or by phone in support of funds for post-polio research.


Good morning Mr. Chairman. My name is Lauro Halstead. I am a physician and Director of the Post-Polio Program at the National Rehabilitation Hospital here in Washington, DC. I also serve on the Board of Directors of the Washington based Polio Society, and am a polio survivor myself.

I want to thank you and the rest of the subcommittee for including language last year in your report and the Conference Report urging the National Institute of Neurological Disorders and Stroke (NINDS) to enhance its research efforts of Post Polio Syndrome (PPS). I am sorry to report, however, that little, if anything, has been done to research the cause or treatments of post-polio syndrome since last year. We are aware that NINDS has reported to you that they have spent $884,000 on Post-Polio Syndrome research and that a program announcement was made in February 1992. From what we know the research funded by NINDS while important, was not entirely related to Post-Polio Syndrome and it predated the requests by Congress to increase funding for Post-Polio Syndrome. The program announcement earlier this year by NINDS was the least it could do to react to the Congressional mandate to address the need for research. Specific requests for applications (RFAs) with specific funding attached are desperately needed to get research underway.

This is my third opportunity to testify before you. What has happened over the past two years? Not nearly enough. We are seeing more cases in our clinics. There is greater uncertainty. Persons who had paralytic polio in the past, even those with mild cases, are now wondering what will happen to them over the next few years. Will they suffer new weakness — will they have to go back to using braces, crutches or a wheelchair — how will it effect their ability to work — should they restrict their activity even though they have no symptoms? We don't have the answers because we haven't done the research.

Polio has usually been considered a stable, chronic disease. Once a person recovered from the acute phase, the condition stabilized, or so it was thought. According to a 1987 survey by the National Center for Health Statistics, there are estimated to be 640,000 persons in the United States who contracted paralytic polio and are still alive. As many as two thirds of these persons have begun to experience new health problems which seem to be related to polio — a disease they thought had stabilized many years before.

The new health problems are called the late effects of polio, or Post-Polio Syndrome (PPS). There are many symptoms and their exact relationship to the original disease is not fully understood. But the evidence is unmistakable. Persons who had polio during the 1940s and 1950s are now experiencing new problems such as intense fatigue, muscle weakness, muscle atrophy, loss of function, joint and muscle pain, and respiratory problems at a much higher rate than the rest of the population. Many of these persons have been so seriously affected they have been forced to start using braces or wheelchairs; others have had to take early retirement, and others have died from complications.

RESEARCH NEEDS

There are basically two areas of research needs:

1) Investigation of the causes of Post-Polio Syndrome; and

2) Investigation of the most effective treatments of Post-Polio Syndrome.

Causes: The cause(s) of PPS is unknown. A number of hypotheses have been proposed. Both intramural and extramural NIH funded research should be directed through the new National Center for Medical Rehabilitation Research (NCMRR). Research should be directed at the most likely causes of PPS which include the following:

1) neuromuscular overuse;
2) neuromuscular transmission defects;
3) muscle cell breakdown;
4) normal and/or premature aging;
5) an immune response;
6) a reactivation or re-exposure to the polio virus; and
7) a hormonal imbalance or deficit.
Treatments: The only available treatments to date are supportive. There is no cure.

Research funded through NCMRR should include:
1) intervention trials of nonsteroidal drugs;
2) trials of various exercise regimens;
3) evaluation of the effect of lifestyle modifications including the use of orthotics and new assistive device technologies;
4) prospective studies on asymptomatic polio survivors at risk for developing PPS to identify the most effective strategies to avoid or minimize the onset of PPS;
5) studies of symptomatic and asymptomatic polio survivors to learn more about the effects of aging with a chronic neuromuscular disability and how to minimize those effects; and
6) new outcome measures to be used in the ambulatory setting need to be developed, tested, and validated which are appropriate for the type and degree of functional changes experienced by persons with PPS and other chronic neuromuscular disorders.

CONCLUSION

PPS has been a neglected area of research and it has not been listed as a priority by NIH. Investigators will not submit competitive proposals until funding agencies specifically solicit this type of research. This is the same problem with any new area of research. We commend the NCMRR for the interest they have already shown in Post-Polio Syndrome. We request language with the appropriations that require National Center for Medical Rehabilitation Research to initiate Requests for Applications (RFAs) for the cause(s) of PPS and to fund research for the treatment of PPS in the amount of $3 million. We also support the request of other disability related organizations to fund NCMRR at $20 million for FY 1993.

We thank the National Institute of Neurological Disorders and Stroke for their program announcement and encourage them to continue and expand their efforts on Post-Polio Syndrome. Specifically, we ask that this subcommittee require NINDS to issue RFAs for $2 million. Our recommendation to fund additional research at the NCMRR is predicated on the Center receiving a substantial increase in funding.

The post-polio problem offers a unique scientific opportunity to study the effects of aging on the nervous system. Lessons learned from studying polio may be important in understanding other neurological diseases, and there is a moral obligation to the 640,000 polio survivors who have led the fight for disability rights and the Americans with Disabilities Act (ADA), and struggled hard to overcome adversity in their own lives.

I thank you for your support in the past and this opportunity to speak to you again today.

Key Congressional Committees for Post-Polio Issues

U.S. Senate

Appropriations Committee: Subcommittee for Departments of Labor, HHS, and Education

Tom Harkin (D-IA), Chair
Robert Byrd (D-WV) staff: Joan Drummond
Ernest Hollings (D-SC) staff: Eddie Moore
Quinnin Burdick (D-ND) staff: Mary Wakefield
Daniel Inouye (D-HI) staff: Patrick DeLeon
Dale Bumpers (D-AR) staff: Elizabeth Goss
Harry Reid (D-NV) staff: Karen Judge
Brock Adams (D-WA) staff: Tom Keefe

Arlen Specter (R-PA) Ranking Minority Member staff: Douglas Loon
Mark Hatfield (R-OR) staff: Betty Lou Taylor
Ted Stevens (R-AK) staff: Jane Rosenquist
Warren Rudman (R-NH) staff: Christine Ciccone
Thad Cochran (R-MS) staff: Forest Thigpen
Phil Gramm (R-TX) staff: John Cerisano

Subcommittee Staff

Michael Hall, Staff Director
186 Dirksen Senate Office Building
Phone: 202/224-7283

Phone Calls: All phone calls can be made through the Capitol Switchboard 202/224-3121. Ask for the office you are calling, i.e., the Member's office or the committee or subcommittee office. With the exception of the chair and ranking minority of each sub-committee, staff will be in the office of their member.

Letters: Room numbers are not necessary to write a Member of Congress; all mail goes through the Post Office at the Capitol. Letters to Senators should be addressed: The Honorable (name of Senator) United States Senate Washington, DC 20510

In the Spring 1992, Polio Network News (Vol 8., No 2) we incorrectly printed a P.O. Box number for Nancy Baldwin Carter's book of essays entitled Of Myths and Chicken Feet: A Polio Survivor Looks at Survival. It is available from Nebraska Polio Survivors Association, P.O. Box 37139, Omaha, NE 68137 USA for $6.95 plus $2.00 shipping and handling.