

February 27, 2006

Elias A. Zerhouni, M.D.  
Director  
National Institutes of Health  
9000 Rockville Pike  
Building 1, Mail Stop 0148  
Bethesda, MD 20892

**Re: Follow Up from Meeting on Rehabilitation and Disability Research at NIH**

Dear Dr. Zerhouni:

This letter is sent to follow up from our December 8, 2005 meeting with you and your senior staff, including Dr. Duane Alexander, Director of the NICHD. Thank you for taking the time to meet with us and discuss the important issue of rehabilitation and disability research at NIH and the progress and promise it holds for people with disabilities and chronic health conditions of all ages.

During the course of our meeting with you, we explored a range of both programmatic and structural issues that we, as a coalition of organizations interested in rehabilitation research, believe require and deserve greater attention at NIH. We continue to believe that many of the challenges and shortcomings we identified in the presentation could be effectively addressed through a structural change in the status of the National Center for Medical Rehabilitation Research. But we also recognize that many of the broader initiatives that you are promoting create opportunities to advance the state of rehabilitation science at NIH. It is in this spirit that we restate below some of the areas on which we would like to continue working with you and Dr. Alexander:

1. ***Rehabilitation Science as a Trans-NIH Initiative:*** We believe that rehabilitation research is best pursued by many disciplines in a variety of settings. The breadth of the diagnostic conditions, functional levels, and ages at issue with this patient population render rehabilitation science ripe for treatment as a trans-NIH initiative that includes community based research for carrying new findings to people with disabilities and chronic health conditions. The Office of Portfolio Analysis and Strategic Initiatives (OPASI) should analyze NCMRR's 15-year track record, the record of rehabilitation research across all NIH institutes (across the domains of research, from basic science to clinical application), and assess how well NIH has done in meeting the needs of people with disabilities. This information could form the basis of an OPASI-led initiative that coordinates with NCMRR and collaborates with other NIH institutes and centers to address rehabilitation and disability research across NIH as a whole in the coming years. We believe that rehabilitation science is a prime example of the type of research that you envision in the NIH Roadmap as well as the OPASI initiative and we commend you for your leadership in moving these forward. We look forward to working with you to build new initiatives in rehabilitation research that cut across traditional boundaries at NIH.

2. ***Greater Balance in Rehabilitation Research Agenda-Setting:*** With NIH resources being limited by Congress, and with more than two thirds of rehabilitation and disability research being funded by Institutes other than NICHD, we believe that NCMRR should play a greater leadership role in defining the gaps in current research and plotting a course for the achievement of research outcomes that have the maximum impact on the lives of people with disabilities. In addition to relying on investigator-initiated research with the highest scores, NCMRR should take a more balanced approach to setting the research agenda by issuing RFAs, funding program project grants that grow into rehabilitation research centers, and convening conferences (such as the recent musculoskeletal research gap conference) to identify promising research areas.
3. ***Raising the Profile of Rehabilitation and Disability Research:*** Given the severity of the problem of disability in America, and considering the expected demographic impacts in the coming years, NIH (NICHD and NCMRR) should take a lead role in raising the public profile of rehabilitation and disability research. NIH should utilize techniques at its disposal to marshal resources, build awareness, and create a mission that will stimulate interest in the importance of prioritizing this area of research. We believe creative thinking is in order to affix a moniker on rehabilitation and disability research that will become a widely known initiative of the government.
4. ***Efficacy Research is in Need of Greater Attention:*** NCMRR should place far greater emphasis on one of the seven domains of research that its original research plan highlighted: developing evidence of the efficacy of rehabilitation care. As more rehabilitation therapies, techniques and devices are provided in the coming years, it will be imperative to know what produces optimal outcomes and what is not effective. The infrastructure to conduct this type of research is simply not present in the rehabilitation field today and is greatly needed.
5. ***Development of Rehabilitation Research Processes:*** Part of the challenge of developing efficacy research is the fact that rehabilitation science is in need of improvements in a series of processes that tend to be more developed in other areas of medical research. For instance, NIH should take the lead in assisting with the development of:
  - a. better standardized rehabilitation and disability research cataloguing techniques;
  - b. more consistent measures for functional outcomes and quality of life;
  - c. consensus approaches to research designs that are appropriate at different phases of advancing rehabilitation and disability research; and
  - d. testable models of important human functions across the domains of rehabilitation and disability research
6. ***Improving Peer Review:*** Because the NIH system of peer review has a profound impact on the type of research that is funded, NIH should assess the adequacy of peer review for rehabilitation and disability research grants and, where appropriate, improve the mechanism for evaluating medical rehabilitation and disability research proposals. This clinically important field poses unique methodological problems for research, which are often not understood by experts in other areas. Compounding the

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problem of adequate review of rehabilitation science is the basic premise of the field: multidisciplinary research in a variety of settings. When a rehabilitation science grant application is assigned to a study section, the study section may have very few members with expertise in the areas of science presented in the grant application. To help limit the negative impact of this phenomenon, we suggest that Requests for Applications be used by the NCMRR and others at the NIH to have initial reviews made by Institute managed study sections. This has several benefits. The review group can be selected based on the multidisciplinary nature of the rehabilitation science application. This will provide a relevant, quality review of the proposal. Those who perform the reviews will learn the art of review. These individuals will then be a resource for study sections under the Center for Scientific Review. Using the RFA approach will allow the NCMRR to shape the future of rehabilitation and disability research by directing funding to areas that need development.

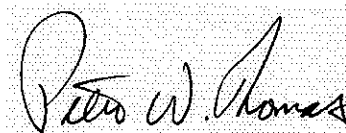
7. **Greater Consumer Involvement in Research Agenda-Setting:** The NCMRR Advisory Board was a unique body back in 1992 when it first met and assisted in producing the 1993 NCMRR Research Plan. With six members of the 18-member advisory board representing people with disabilities, the structure continues to exist for NCMRR to obtain robust consumer input in the research agenda setting process. This advisory board should be given greater authority and should be routinely consulted by NCMRR staff for subject matter expertise in the research agenda setting exercise. NIH and NICHD should examine other ways to strengthen the input it receives from the rehabilitation and disability constituencies.
8. **The Need to Increase Rehabilitation Research Funding:** The need to increase funding is a common refrain from many fields of research supported by NIH, especially in recent years. But compared to the enormity of the research challenges in the field of rehabilitation and the potential improvements in the functional capacity and quality of life of people for whom "cure" is no longer relevant, the current federal investment in rehabilitation research is simply inadequate. We look forward to working with you to identify ways to make the need for increased funding more compelling.

Thank you again for taking the time to meet with us to discuss this important set of issues. We will be following up with Dr. Alexander and his colleagues and look forward to continuing this dialogue with you and your office as well.

Sincerely,



Michael Manganiello  
Christopher Reeve Foundation  
On behalf of the NCMRR Coalition



Peter W. Thomas, Esq.  
Powers Pyles Sutter & Verville, P.C.  
On behalf of the NCMRR Coalition

Cc: Duane F. Alexander, M.D.

Attachment: List of Coalition Member Organizations

## **NCMRR Coalition Members**

American Academy of Neurology  
American Academy of Orthotists and Prosthetists  
American Academy of Physical Medicine & Rehabilitation  
American Association of Spinal Cord Injury Psychologists and Social Workers  
American Congress of Rehabilitation Medicine  
American Hospital Association  
American Medical Rehabilitation Providers Association  
American Occupational Therapy Association  
American Physical Therapy Association  
American Society of Neurorehabilitation  
American Therapeutic Recreation Association  
Amputee Coalition of America  
Arthritis Foundation  
Association of Academic Physiatrists  
Association of Rehabilitation Nurses  
Brain Injury Association of America  
Christopher Reeve Foundation  
Division of Rehabilitation Psychology - American Psychological Association  
Federation of American Hospitals  
International Neuropsychological Society  
National Association for the Advancement of Orthotics & Prosthetics  
National Council on Independent Living  
National Spinal Cord Injury Association  
Paralyzed Veterans of America  
United Spinal Association