DISABILITY AND REHABILITATION RESEARCH COALITION

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Outside Witness Testimony Submitted for the Record by the Disability and Rehabilitation Research Coalition before the United States Senate Committee on Appropriations for the full committee hearing entitled, "Driving Innovation through Federal Investments," to be held on Tuesday, April 29, 2014. *Submitted by Peter W. Thomas, J.D. (Peter.Thomas@ppsv.com; 202-872-6730) for the Disability and Rehabilitation Research Coalition on April 24, 2014.*

Chairwoman Mikulski, Ranking Member Shelby, and the Members of the Committee:

On behalf of 30 national organizations that comprise the Disability and Rehabilitation Research Coalition ("DRRC"), thank you for the opportunity to submit outside witness testimony for the record with respect to the full committee hearing entitled, "Driving Innovation through Federal Investments." The purpose of our testimony is to provide the committee with information specific to the value of investing in rehabilitation and disability research and the importance of elevating rehabilitation science at the National Institutes of Health (NIH). We believe that investment in rehabilitation and disability research will result in innovations that will significantly enhance the quality of life and independence of individuals with disabilities and chronic conditions.

My name is Peter Thomas and I am Counsel to the DRRC. I have personally experienced the benefits of rehabilitation and disability research throughout the course of my life as a bilateral leg amputee since the age of ten. The advancements in prosthetics alone over the past 40 years have been remarkable and many other areas of rehabilitation science have experienced the same progress. NIH supports approximately $300 million of rehabilitation research each year, with the "home" of rehabilitation science located at the National Center for Medical Rehabilitation Research ("NCMRR") within the Eunice Kennedy Shriver National Institute for Child Health and Human Development ("NICHD").

NCMRR was created by statute in 1990 after Congress debated whether to create an independent rehabilitation research Institute at NIH. Instead, a center was created and housed within NICHD under the theory that this Institute could nurture the center as it developed. For the first ten years of its existence, this concept proved successful. A comprehensive rehabilitation research plan was developed and published in 1993 and the budget grew with significant increases in funding throughout the 1990's and during the period of NIH's doubling of funding. Early investments in training grants have developed a significant cadre of senior rehabilitation researchers, and a diverse portfolio of research grants has been funded.

Rehabilitation and disability research is cross-cutting, multi-disciplinary, and focuses on restoring and improving functional capacity in individuals who have experienced an illness, injury, disability or chronic condition. This type of research also focuses on maintaining and preventing deterioration of functional skills and abilities in order to enhance quality of life and independent living. This is the kind of research that matters most to individuals when "cure" is no longer an option. Rehabilitation research crosses the lifespan and clinically focused research can rapidly translate into direct patient care in order to achieve maximal health care outcomes. Given the prevalence of disability in this country (approximately 13 to 14 percent) and the strong

correlation between disability and aging, greater investments in rehabilitation science have huge potential to guide better, more effective health and rehabilitative care in the future, and make the most of precious health care resources.

Rehabilitation research involves both basic and clinical science. To illustrate its value, consider the following research topics and the implications for people with these conditions:

- A variable geometry prosthetic socket that changes shape with the natural, volumetric changes in the residual limb during the course of a day's use of a prosthetic limb. This ensures proper fit and function of the prosthetic limb and decreases the risk of skin breakdowns and other secondary conditions.
- Seating systems that allow non-ambulatory individuals to rely on mobility devices (i.e., wheelchairs) to function throughout the day without developing decubitus ulcers or spinal mal-alignment due to long term wheelchair use.
- Determining the types and amounts of rehabilitation therapies and cognitive interventions needed to optimize recovery and rehabilitation in people with brain injuries due to trauma, stroke and other causes.
- Regeneration of nerve activity and function in people with spinal cord injury and other neuromuscular disorders.
- Sensory feedback technology that allows people with peripheral vascular disease and diabetes to better "feel" their insensate lower limbs to prevent ulcerations that often lead to amputation.

In recent years, the rehabilitation research program at NIH plateaued and has not thrived. As a result, Dr. Collins, NIH Director, and Dr. Alan Guttmacher, NICHD Director, empanelled a Blue Ribbon Panel on Medical Rehabilitation Research at the NIH ("BRP"). The panel produced a report and recommendations in December 2012 to the NICHD Director. Among the recommendations was a need to elevate the stature of rehabilitation research at NIH, greater coordination of rehabilitation science across NIH's Institutes and Centers ("ICs"), and a dedicated budget for NCMRR. In fact, in addition to a number of functional improvements to the NIH's rehabilitation research program, the BRP report recommended that NCMRR transition to an independent Institute or Center reporting directly to the NIH Director, or a new Office in the Office of the NIH Director. This was intended to elevate the stature and importance of rehabilitation science as a priority area of NIH research and lead to greater coordination of rehabilitation research being pursued by multiple ICs.

The NIH has responded to date by dedicating a definable portion of the NICHD extramural research budget to NCMRR research. This has created a stable floor of NCMRR research funding that we hope will grow in future years. New leadership for the Center is underway as a search committee seeks a new Director to lead the Center. And the rehabilitation research plan that was published in 1993 is expected to be updated in the near future to address current gaps in rehabilitation science and address contemporary priorities in the field. These are very positive developments that the DRRC supports. However, there are two major issues of concern that remain unresolved.

1. Co-Funding of Rehabilitation Research: DRRC believes, and NIH recognizes, that

coordination in rehabilitation science across the NIH Institutes and Centers is in need of significant attention. NIH has chosen to address this concern of the Blue Ribbon Panel through a co-funding model that seeks to transition NCMRR into a co-funder of rehabilitation research grants that are primarily housed in other ICs, with these other ICs taking the lead in selection and management of these grants. This differs markedly from the way NCMRR currently operates and, arguably, alters NCMRR's statutory mission of "conducting and supporting" rehabilitation research. While NIH's intention is to permit NCMRR to continue to fund completely on its own a small number of high priority grants, the majority of the research portfolio will be directed outside of NCMRR in other NIH ICs. NIH argues that this will stimulate investment by other ICs in rehabilitation science and lead to greater coordination of rehabilitation research. But there is a significant risk that this co-funding model will lead to a dilution of priority items on the rehabilitation research agenda and undermine NCMRR as the "home" for rehabilitation science at NIH. There is also a risk of diluting the intellectual capacity currently residing in NCMRR staff to continue to assist rehabilitation scientists through the application and implementation of rehabilitation research grants. DRRC, therefore, requests Congress to examine this issue and work with NIH officials and DRRC organizations to minimize the risks described above and establish benchmarks to measure success or failure of this co-funding model as it is being implemented.

2. Elevation in the Stature of Rehabilitation Science at NIH: The only major recommendation of the Blue Ribbon Panel report to remain unaddressed by NIH is the structural recommendation to elevate the NCMRR to an independent Institute or Center reporting directly to the NIH Director, or to establish a new Office of Rehabilitation Research within the Office of the NIH Director. Implementation of this structural recommendation would require a statutory change and the NIH did not materially address this major recommendation in its responses to the BRP report. Elevation of NCMRR has been viewed from the start as a critical step in achieving sufficient critical mass to coordinate rehabilitation science across all the ICs at NIH that conduct and support research directly addressing—or related to—rehabilitation science. While NICHD has nurtured the Center in its first two decades of existence, the NCMRR's current placement, a Center within the Child Health Institute, does not easily allow for successful implementation of a coordinating committee that—by statute—the NCMRR Director chairs. In addition, its location within NIH does not result in sufficient focus and priority among the ICs conducting rehabilitation research that benefits people with myriad conditions and disabilities across the lifespan. This is why it is so important for NIH to materially address this recommendation of the Blue Ribbon Panel and offer guidance to Congress as to how NIH would implement it in the most appropriate manner possible, whether or not the recommendation is adopted at this time.

Rehabilitation and disability research offers such incredible promise for improving the lives of people with injuries, illnesses, disabilities and chronic conditions. It stands to dramatically improve our health care delivery system while targeting precious health care resources where they can make the greatest impact. DRRC strongly urges Congress to further explore the recommendations of the Blue Ribbon Panel on Medical Rehabilitation Research and work with NIH officials and DRRC organizations to maximize the federal investment in this important research area of priority.

Thank you for the opportunity to submit this statement for the written record.

DRRC Member Organizations

American Academy of Neurology
American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine & Rehabilitation
American Association of People with Disabilities
American Association of Spinal Cord Injury Psychologists and Social Workers
American Association on Health and Disability
American Congress of Rehabilitation Medicine
American Hospital Association
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Amputee Coalition of America
Arthritis Foundation
Association of Academic Physiatrists
Association of Rehabilitation Nurses
Brain Injury Association of America
Child Neurology Foundation
Child Neurology Society
Christopher and Dana Reeve Foundation
Disability Rights Education and Defense Fund
Federation for American Hospitals
March of Dimes
National Association for the Advancement Orthotics & Prosthetics
National Association of Rehabilitation Research Training Centers
National Association of State Head Injury Administrators
National Association of Veterans' Research and Education Foundations
National Council on Independent Living
National Multiple Sclerosis Society
North American Brain Injury Society
Paralyzed Veterans of America
RESNA
United Spinal Association