

FOR IMMEDIATE RELEASE

Nov 8, 2011: Recommendations for research presented at White House meeting

More than 100 individuals representing academic institutions, medical centers, federal agencies, industry, non-profit organizations, individuals with spinal cord injuries, and the U.S. Congress gathered on November 8 in the White House South Court Auditorium of the Eisenhower Executive Office Building to review and discuss a summary of recommendations arising from a state of the science (SOS) meeting held in Washington, June 5-7, 2011 on spinal cord injury (SCI) rehabilitation research. Welcomed by Kareem Dale, Special Assistant for Disabilities to President Obama, the program commenced with Dr. Alexa Posny, Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), followed by the recently appointed Director of the National Institute on Disability and Rehabilitation Research (NIDRR) and chair of the Interagency Committee on Disability Research (ICDR), Charlie Lakin. The meeting was sponsored by NIDRR and the ICDR and supported by the Steering Committee of the SOS conference.

Detailed presentations by the four conference track chairs were made by Dr. John Steeves, Vancouver, Dr. Michael Boninger, Pittsburgh, Dr. Suzanne Groah, Washington D.C., and Dr. Allen Heinemann, Chicago. Responses were given by Dr. Naomi Kleitman (National Institutes of Health), Ms. Ruth Brannon (NIDRR), Mr. Henry Claypool (Department of Health and Human Services), and by Mr. Andrew Imparato (Senate staff).

Recommendations were centered around the four main themes of the conference. A focus for functional and neurologic recovery was on improved measures of recovery and augmentation of recovery and limitation of secondary damage. Assistive technology discussions stressed access to technology and collaborative clinical and research endeavors. The focus for aging and secondary complications emphasized creative consideration of new research methods, identification of risk clusters and use of large and small datasets to improve our understanding of the aging process so that a more preventative and personalized approach to health care delivery can be constructed. Psychosocial, vocational, and quality of life outcomes sought to enhance individual skills, reduce barriers to employment, and examine community-based and peer programs.

Representing the White House, Mr. Jeff Crowley shared remarks to the group after an introduction by Ms. Sue Swenson, Deputy Assistant Secretary of OSERS.

The audience included representatives of the fourteen newly-funded SCI model systems programs, as well as the data center (home of the largest and longest-standing database on SCI), and the model systems knowledge translation center, charged with collating and disseminating information from the three model systems programs (traumatic brain injury and burn, in addition to SCI).

Other federal agencies represented included the National Institutes of Health, the Department of Veterans Affairs, Veterans Health Administration (the National Science Foundation and the Department of Defense. Several non-profit agencies devoted to SCI research were represented, as were several companies involved in SCI therapeutic interventions research.

State of the Science in Spinal Cord Injury Rehabilitation 2011:

Informing a New Research Agenda

In June 2011, a conference on the State of the Science in Spinal Cord Injury (SCI) Rehabilitation: Informing a New Research Agenda was held in Washington, DC to (a) identify priority research goals, (b) describe research approaches that are essential to progress, and (c) provide a vision for the achievements that will define SCI rehabilitation research over the next 10 years. Four themes that encompass the broad range of biopsychosocial issues in SCI rehabilitation, along with research recommendations were discussed:

Neurologic and Functional Recovery

1. Promote collaboration among scientists, clinicians, allied health professionals, caregivers, and people living with SCI.
2. Enhance active rehabilitation training as well as augmentation of functions that are preserved after SCI, such as pharmacological and electrical / electromagnetic stimulation of residual hand function.
3. Develop improved electrophysiological techniques, imaging technologies, and sensitive biomarkers to accurately detect and track neurological and functional changes after SCI.
4. Enable better characterization of functional outcome measures that are correlated with providing a clinically meaningful benefit.
5. Facilitate development of first generation neuroprotective / neural repair interventions – limiting secondary neural tissue damage through biochemical and pharmacological actions, Augmentation of functions that are preserved after SCI.
6. Develop telehealth and telerehabilitation interventions to facilitate rapid, cost-effective early detection of medical challenges, treatment without hospitalization, and long-term preservation of functional capacities.

Technology for Mobility and Function

1. Increase collaborative research activities to develop and test effectiveness of assistive technologies.
2. Evaluate and set priorities based on costs, benefits, consumer needs, and available technology.
3. Encourage a streamlined innovation pathway that supports technology development and transfer, which

is founded on a multidisciplinary approach and academic/industry partnerships.

4. Continue development of better outcome measures which will reliably detect the value of implemented technologies for people living with a disability.
5. Rationalize regulatory procedures for approval of assistive device inventions.
6. Increase access of consumers to evolving assistive technologies.

Aging and Secondary Conditions

1. Promote research designed to identify risk clusters and increase diagnostic capability and early detection of secondary conditions associated with SCI.
2. Continue to develop treatment guidelines aimed at functional recovery and prevention of complications and medical and social conditions likely to increase the burden of care and disability.
3. Investigate the value of a wide variety of approaches to human subjects research, including methods that use small sample sizes and quasi-experimental and observational designs.
4. Encourage development and use of large existing databases, specifically those from which longitudinal cohorts can be constructed.
5. Speed translation of discoveries through multidisciplinary aging-related translational research networks.
6. Explore options for self-management and research on self-management of health conditions associated with SCI.

Psychosocial, Vocational and Quality of Life Outcomes

1. Develop interventions to enhance individuals' skills, including self-efficacy and personal empowerment.
2. Examine and implement interventions to reduce environmental barriers to employment and community participation.
3. Design community and corporate programs that enhance employment and employment opportunities for people living with a spinal cord injury.
4. Identify unmet needs and promising interventions to improve family and social support.
5. Increase studies of dual trauma diagnoses to determine what alternative or combined rehabilitation services help maximize health, participation and employment outcomes.
6. Study the effectiveness of community-based rehabilitation programs.

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7. Evaluate benefits and limitations of peer mentoring programs.

For additional information

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