May 2015 MSKTC Headlines

MSKTC Releases Infographics Tool

The MSKTC released the new tool, *Presenting Data Using Infographics*. Infographics are visual representations of information, data, or knowledge that can provide a great amount of complex information succinctly. The tool provides five of the most common types of infographics and tips for how they can be used. View the tool here.

======Spinal Cord Injury (SCI)======

Resource Highlight: SCI Model System Releases a Toolkit

The New England Regional Spinal Cord Injury Center Model System (NERSCIC) has completed the development of the New England Spinal Cord Injury Toolkit. The goal of the Toolkit is to improve care by providing SCI-specific resources and clinical expertise to facilities, organizations, and care providers throughout the New England area that may not be as familiar in treating people with SCI. Each SCI patient discharged from a NESCIT facility and/or their families will be provided with a Toolkit to share with their providers/caregivers at their next destination (e.g., other hospitals, SNFs, or home). The treatment topics covered in the Toolkit currently include Patient/Family/Caregiver Education, Autonomic Dysreflexia, Skin Care, Bladder & Bowel Management, Sexual Health & Fertility, and Spasticity. Each topic includes the relative treatment standard of SCI care, minimum requirements for care to meet the standard, and a set of recommended resources.

Model System Post New Resource

The Northwest Regional Spinal Cord Injury System (NWRSCIS) recently posted the video *Get a Handle On It: Maximizing Hand and Arm Function after Spinal Cord Injury* as part of its SCI Forum Video series. The video features three occupational therapists from the University of Washington describing how rehab uses a combination of conventional therapy (strengthening, splinting, and use of adaptive equipment and strategies), upper limb electrical stimulation, and surgical intervention (tendon transfers) to achieve rehab goals. Many examples of devices and equipment are shown for enhancing independence in everyday activities at home. Visit the NWRSCIS website to view more than 45 online videos on a variety of SCI topics here.

NERSCIC Model System Contributes Quality of Life Assessment to Christopher & Dana Reeve Foundation’s The Big Idea

The New England Regional Spinal Cord Injury Center Model System (NERSCIC) is involved with *The Big Idea*, a revolutionary study that may change the way the scientific community views spinal cord injury. Researchers at the Kentucky Regional Spinal Cord Injury Model System have successfully used epidural stimulation to enable four individuals living with a chronic complete SCI to regain voluntary movement. *The Big Idea*, sponsored by the Reeve
Foundation, is a multi-year longitudinal study of 36 persons with spinal cord injury who will undergo epidural stimulation. The effects of this intervention on function and quality of life will be examined. NERSCIC is responsible for assessing quality of life reported by individuals participating in The Big Idea study. Click here for more information about the study.

Model Systems Researcher Works with Caltech Students to Create New AT Devices

Philip Requejo, Ph.D., co-director of the Southern California Spinal Cord Injury Model System Center, recently co-taught Designing for Independence from Disability, a course on designing, building, and modifying products for people with disabilities at the California Institute of Technology (Caltech). Dr. Requejo joined Ken Pickar, Ph.D., of Caltech and Andy Lin from the Rancho Emerging Tech Lab to lecture and mentor engineering and design students through the 10-week course. Building upon research from previous NIDILRR-funded projects at Rancho, students worked with individuals with disabilities, assistive technologists, and engineers to develop technology solutions for real-life problems. Read more about the final projects that were highlighted here.

Model System Researchers Awarded Grant by the Craig H. Neilsen Foundation

Researchers from the Southern California Spinal Cord Injury Model System (SC-SCIMS) were recently awarded a 2-year grant by the Craig H. Neilsen Foundation for Psychosocial Contributors to Pain Management and Physical Activity and after Spinal Cord Injury. Sara Mulroy, Ph.D., PT, principal investigator of the SC-SCIMS, together with co-investigators Philip Requejo, Ph.D., and Rebecca Lewthwaite, PH.D., will examine the quality of life after spinal cord injury is enhanced with physical activity and negatively impacted by chronic pain, fatigue, and depression. Their goal is to identify factors that facilitate physical activity and positive pain management strategies for persons with SCI to inform wellness and pain management programs for diverse populations.

SCI Model System Researchers Work Published in Archives of Physical Medicine

Researchers from the Southern California Spinal Cord Injury Model System (SC-SCIMS) recently collaborated on Evidence-Based Strategies for Preserving Mobility for Elderly and Aging Manual Wheelchair Users published in Topics in Geriatric Rehabilitation. View the abstract here.

Model System Researcher Discusses Connecting SCI Data around the Globe

Denise G. Tate, Ph.D., ABPP, FACRM, principal investigator and co-director of the University of Michigan Spinal Cord Injury Model Systems (U-M SCIMS) met with Drs. Fin Biering Sorensen and Julia Greve, Chief of the SCI Unit at the Hospital das Clinicas in Sao Paulo, Brazil, in April to discuss the use and implementation of the international SCI datasets in Sao Paulo. Brazilian colleagues from the University of Sao Paulo and the Lucy Montoro Rehabilitation Hospital will include these datasets within the existing electronic medical record systems. Both
Drs. Tate and Biering Sorensen presented on their experience with these datasets while visiting Brazil. With the support of the State Secretary for Disability Affairs, Dr. Linamara Batistella, this is likely to become a State project across several hospitals in the state serving persons with SCI.

**Model System Researcher Presented at the American Urological Association Press Program**

Anne Cameron, MD, urologist of the University of Michigan Spinal Cord Injury Model Systems (U-M SCIMS), recently presented at the American Urological Association (AUA) Annual Meeting held May 15-19, 2015 in New Orleans, LA. During her presentation, she highlighted the difficulty that spinal cord injury patients face in obtaining care and the obstacles to maintaining good health in this high-risk population. Read more [here](#).

**Model Systems Work Published in Two Publications**

Researchers from the University of Michigan Spinal Cord Injury Model Systems (U-M SCIMS) recently published The Severity of Bowel Dysfunction in Patients with Neurogenic Bladder in *Journal of Urology*. This publication examines how patients with neurological conditions often suffer from severe debilitating lower urinary and bowel dysfunction in addition to their physical disabilities. However, only the bladder has received the attention of medical providers with neurogenic bowel being poorly understood and characterized. Access the abstract [here](#). *Patient perceptions of physical and emotional discomfort related to urodynamic testing: a questionnaire-based study in men and women with and without neurologic conditions* was published in *Urology*. This article seeks to determine predictors of physical and emotional discomfort associated with urodynamic testing in men and women both with and without neurologic conditions. Access the abstract [here](#).

======Traumatic Brain Injury (TBI)=====

**Resource Highlight: Vision Problems after Traumatic Brain Injury**

Do you know someone who has vision problems after sustaining a traumatic brain injury? Refer them to the *Vision Problems after Traumatic Brain Injury* factsheet. Access the factsheet [here](#).

**Model System Researcher Presents at NABIS**

Researchers from the Rusk Rehabilitation Traumatic Brain Injury Model System recently presented the poster, *Examining Language Preference and Acculturation and Implications for the Continuum of Care for Patients with Traumatic Brain Injury (TBI)* at the North American Brain Injury Society (NABIS) Annual Conference on Brain Injury held April 29-May 2, 2015 in San Antonio, TX. Read more information on the poster [here](#).
Resource Highlights: MSKTC Releases Three New Consumer Factsheets

The MSKTC has released three new factsheet that support individuals living with burn injury.

- **Exercise After Burn Injury** was developed by Karen Kowalske, M.D., Radha Holavanahalli, Ph.D., Gretchen Carrougher, R.N., M.N., Oscar Suman, Ph.D., and Cindy Dolezal, P.T., MLS in collaboration with the MSKTC. The factsheet describes the importance of exercise and stretching after a burn injury and describes activities that can be used to improve strength and flexibility.

- **Help Your Child Recover—Build Your Child’s Resilience After a Burn Injury** was developed by Shelley Wiechman, Ph.D., A.B.P.P. and Lynne Friedlander, M.Ed. in collaboration with the MSKTC. The factsheet provides information and tips for parents and professionals who work with children with burn injuries to help them build resilience after a burn injury.

- **Going Back to School After a Major Burn Injury** was developed by Lynne Friedlander, M.Ed. and Shelley Wiechman, Ph.D., A.B.P.P. in collaboration with the MSKTC. The factsheet provides advice and resources for parents on how to plan and help prepare their child’s return to school.

The factsheets are available on the MSKTC website in English and Spanish, and may be reproduced and distributed freely with appropriate attribution.

Model System Researcher Presents at American Burn Association Conference

Shelley Wiechman, Ph.D., A.B.P.P., investigator of the Northwest Regional Burn Model System (NWRBMS) and UW Medicine Regional Burn Center attending psychologist presented at the 47th Annual Meeting of the American Burn Association held on April 21-24, 2015 in Chicago, IL. Dr. Wiechman presented NIDRR-funded research at a Plenary Session in which the top six abstracts of the meeting were featured. She also spoke on the primary reasons for distress following injury in adult burn survivors. With this information, the burn care community can establish appropriate treatment interventions aimed at the issues with the greatest impact on quality of life and ability to return to work.

Upcoming Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 27-30</td>
<td>2015 Annual Conference on Independent Living (NCIL)</td>
</tr>
<tr>
<td>Sept 7-9</td>
<td>2015 American Spinal Cord Injury Professionals (ASCIDP) Conference</td>
</tr>
<tr>
<td>Oct 21-24,</td>
<td>27th Annual Phoenix World Burn Congress</td>
</tr>
<tr>
<td>Oct 25-30</td>
<td>92nd Annual American Congress of Rehabilitation Medicine (ACRM) Conference</td>
</tr>
</tbody>
</table>