RehabWire
News from the National Rehabilitation Information Center

The Model Spinal Cord Injury Systems
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NIDRR Grantees on the Cutting Edge

What is a Model Spinal Cord Injury System?

NIDRR has funded the regional model spinal cord injury systems since 1985. There are 14 in the current cycle (2006-2011) These centers research the spectrum of care and rehabilitation in spinal cord injury (SCI), from point of injury, through rehabilitation, to integration back into the community. Their research spans the areas of medical and vocational rehabilitation, assistive technology, community-based services, mental health, aging, and secondary conditions. Each center covers and accepts patients from a catchment area of surrounding states. All of the systems contribute data to a national statistical database, which tracks the long-term consequences of spinal cord injury.

Who conducts the research?

Model Systems designation is granted to institutions that are leaders in the development of rehabilitation and care interventions. The centers offer comprehensive care, with the goal of integrating patients with spinal cord injury into their communities. The investigators for these systems include neuroscientists, psychologists, physical and occupational therapists, engineers, surgeons, educators, and statisticians.

Who participates in the research?

Patients and research candidates are people with new and existing SCIs requiring care, rehabilitation, and support to return to functioning in the community. Patients may be admitted through affiliated hospitals, or referred by their physicians to the nearest Model System in their catchment area. For example: A patient with a new injury may be receiving care in a hospital in suburban Maryland. His physician may refer him to the National Capital Area Model Spinal Cord Injury System for comprehensive rehabilitation that may not be available through the admitting hospital. The 14 Model Systems are located in (moving NorthEast to NorthWest) Massachusetts, New York, New Jersey, Pennsylvania (2), DC, Georgia, Alabama, Ohio, Illinois, Michigan, Texas, Colorado, and Washington.

Let's take a look at the individual systems, their research projects, and some of the important publications they've produced in the last five years.

Texas Model Spinal Cord Injury System *The Institute for Rehabilitation and Research (TIRR)* (H133N060003) led by Daniel Graves, PhD and William Donovan, MD. Theresa San Agustin, MD, Project Officer.

Abstract: The Texas Model Spinal Cord Injury System includes a site-specific research project that is designed to provide high level evidence of the efficacy of a novel treatment to prevent bladder complications. The project is a randomized, double blind placebo, controlled parallel groups investigation of the effects of Botulinum toxin A treatment of detrusor external sphincter dyssynergia (DESD) during early spinal cord injury. Many patients with SCI develop neurogenic bladder dysfunction associated with detrusor hyperreflexia and DESD that can lead to long-term complications in up to 50 percent of patients. These complications include hydronephrosis, vesicoureteral reflux, nephrolithiasis, sepsis, renal insufficiency or failure, and even death. This investigation is intended to determine if the prevention of DESD in the early phase of recovery can prevent some of these complications. In addition, the TMSCIS includes a module designed to develop an outcome measure of trunk and postural control to be utilized in activity-based therapy programs like locomotor training. The outcomes of large scale clinical trials of locomotor training highlight the need for outcome measures that are designed to capture changes brought about by translational research that may not have been necessary for more traditional therapy programs. This scale development project incorporates item response theory methods as well as reliability and validity investigations in a minimum of four model systems.
Find out more at: **www.texasmscis.org**

The Rocky Mountain Regional Spinal Injury System *Craig Hospital* (H133N060005) led by Daniel P. Lammertse, MD and Susan Charlifue, PhD. Kenneth D. Wood, PhD, Project Officer.

Abstract: The Rocky Mountain Regional Spinal Injury System (RMRSIS) includes a site-specific study determines if high vs. low tidal volumes are more effective in achieving ventilator weaning for individuals with high level tetraplegia, using a randomized clinical trial design. A collaborative research module study involves the development of a reliable, valid measurement tool to assess community participation. RMRSIS includes two Level I trauma centers with specialized acute neurotrauma care facilities (St. Anthony Hospital and Swedish Medical Center) and the rehabilitation and lifetime follow- up services of Craig Hospital.
Find out more at: **www.craighospital.org/Research/SCIMain.asp**

Georgia Regional Spinal Cord Injury Care System *Shepherd Center, Inc.* (H133N060009) led by David F. Apple, Jr., MD and Lesley M. Hudson, MA. Dawn Carlson, PhD, MPH, Project Officer.

Abstract: The Georgia Regional Spinal Cord Injury Care System

The Model Systems fall under NIDRR's Health and Function priority. Their research, however, spans employment, participation and community living, technology, demographics, knowledge translation, and capacity building.

continues a long record of comprehensive and timely collection of data on subjects who meet the inclusion criteria in three categories: inpatient hospitalization; longitudinal collection at 1, 5, 10, 15, 20, and 25 years post-injury; and registry. In addition to continued model system research, the project conducts two site specific research projects: (1) Psychological Status During Inpatient Rehabilitation and One Year After Onset: Stress, Coping, and Expectation Hope for Recovery; (2) Development and Validation of a Clinical Measure of Wheelchair Seat Cushion Degradation. The project also manages a collaborative data collection research module entitled Impact of SCI on Labor Market Participation.
Find out more at: **www.shepherd.org**

Regional Spinal Cord Injury Center of the Delaware Valley
Thomas Jefferson University (H133N060011) led by Ralph Marino, MD. Theresa San Agustin, MD, Project Officer.
Abstract: The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) research activities are designed to develop and validate upper and lower extremity outcome measures for use in clinical trials. Specifically, RSCICDV: (1) contributes to the National Database by enrolling an estimated 50 new subjects per year into the database and by collecting follow-up data on previously enrolled subjects; (2) conducts an on-site research project whose focus is to develop and validate the Capabilities of Arm and Hand in Tetraplegia (CAHT), an objective test of arm and hand functional capabilities needed to conduct clinical trials for neurological recovery in SCI; (3) participates in a collaborative module on evaluating an automated phone follow-up system for people with SCI; (4) participates in a collaborative module on validation of an outcome measure for motor recovery in incomplete SCI; and (5) develops educational resources for patients, healthcare providers and researchers.
Find out more at: **www.spinalcordcenter.org**

Midwest Regional Spinal Cord Injury Care System (MRSCIS)
Rehabilitation Institute of Chicago (H133N060014) led by David Chen, MD. Kenneth D. Wood, PhD, Project Officer.
Abstract: The Spinal Cord Injury Rehabilitation Program at the Rehabilitation Institute of Chicago and the Acute Spinal Cord Injury Program at Northwestern Memorial Hospital conducts two site-specific research projects: (1) Development of Low-Cost Devices to Increase Delivery of Intensive Treadmill Training, and (2) Disparities in Access to and Outcomes of Rehabilitation Care for Medicare and Medicaid Beneficiaries with Spinal Cord Injury. In addition, the project includes collaboration on one research project, Assistive Technology for Mobility (ATM) Module. MRSCICS has the capacity to enroll 140 individuals from culturally diverse backgrounds with new spinal cord injuries annually into the Spinal Cord Injury Model Systems database, and collect follow-up data on individuals enrolled between 1973 and 2000.
Find out more at: **www.ric.org/research/centers/MidwestRegionalSpinalCordInjuryCareSystem/MRSCICS.aspx**

Northeast Ohio Regional Spinal Cord Injury System
MetroHealth System (H133N060017) led by Gregory A. Nemunaitis, MD. Dawn Carlson, PhD, MPH, Project Officer.
Abstract: The Northeast Ohio Regional Spinal Cord Injury System (NORSCIS) at MetroHealth Rehabilitation Institute of Ohio in collaboration with Case Western Reserve University and the Cleveland FES Center conducts research to further develop the effectiveness of an innovative Model Spinal Cord Injury Care System and to demonstrate how the application of advanced assistive technology can benefit persons with disabilities. A site-specific project studies advances in functional electrical stimulation (FES) technology to document improvements in function, health, and wellness. An innovative focus on trunk muscle stimulation targets specific clinical problems, including seated stability and mobility, reachable workspace, and pulmonary function. A collaborative research project with UPMC-SCI, is directed at testing and collecting the data needed to understand the impact of coverage changes and to fully explore the issue of disparity in assistive technology for mobility prescription. A collaborative project with Craig Hospital involves the development of a reliable, valid measurement tool to assess community participation. The goal of these hypothesis-driven research and demonstration projects is to develop and measure the effectiveness of new intervention strategies at both the individual patient level and overall systems of care for persons with spinal cord injury.
Find out more at: **rehab.metrohealth.org/norscis**

University of Pittsburgh Model Center on Spinal Cord Injury
University of Pittsburgh (H133N060019) led by Michael L. Boninger, MD. Theresa San Agustin, MD, Project Officer.
Abstract: The UPMC-SCI continues its research focus on assistive technology (AT) for mobility. Pilot data collected during the previous funding cycle highlighted disparity in wheelchair prescription. Individuals from minority groups and people with low socioeconomic status received less and lower quality equipment. So that interventions can be developed, the project continues and expands this research to delve into the reasons for disparity. In addition, it investigates the impact of recent Centers for Medicare and Medicaid Services (CMS) changes for AT reimbursement. These changes will likely have a critical impact on the AT provided to individuals with spinal cord injury (SCI). Finally, the project develops a tool to determine how far, how fast, and when people travel in their wheelchairs. This data is related to the type of wheelchairs used, to the number of wheelchair failures, and to measures of participation. From these findings, researchers determine how the wheelchair prescribed impacts participation, and if greater use leads to greater failures. This data can be used to push for improvements in manufacturing and changes in coverage. UPMC-SCI also conducts a randomized, controlled trial to determine if following the Consortium of Spinal Cord Injury Medicine Guidelines on Upper Limb Preservation leads to decreased pain. These guidelines are applied to acutely injured patients who are followed for the first six months after injury. Validation of the guidelines' effectiveness helps assure that they become the standard of care across the country.
Find out more at: **www.upmc-sci.org** or **www.rehabmedicine.pitt.edu**

UAB Model Spinal Cord Injury Care System *University of Alabama/Birmingham* (H133N060021) led by Amie B. Jackson, MD. Kenneth D. Wood, PhD, Project Officer.
Abstract: The University of Alabama at Birmingham Spinal Cord Injury Care System (UAB-SCICS research includes one collaborative research module and two in-house research projects, all of

which ultimately aim at improving the health and function of its constituents. The collaborative research module involves the validation of an outcome measure for functional recovery. One in-house research project involves the assessment of the predictive value of key parts of the neurological exam for return of bladder function; the second is an investigation of the effect of nicotine on different types of SCI pain. The project continues to benefit from the active involvement of persons with SCI in the design and execution of the proposed activities. Project results are disseminated via a variety of accessible formats and venues for both professionals and persons with SCI and their families. A detailed plan of operation ensures timely completion of project goals and tasks. Finally, an evaluation plan has been designed to assess the quality and timeliness of project outcomes and dissemination, as well as short and long term impacts of project activities. Activities of the UAB-SCICS reflect an active partnership both within the components of UAB's health system and between UAB, the Lakeshore Foundation, and the Birmingham VA Medical Center. The project continues as a participant in data collection activities for the National Spinal Cord Injury Statistical Center.
Find out more at: **main.uab.edu/show.asp?durki=10712**

Northern New Jersey Spinal Cord Injury System *Kessler Medical Rehabilitation Research and Education Corporation (KMRREC)* (H133N060022) led by David S. Tulsky, PhD. Dawn Carlson, PhD, MPH, Project Officer.
Abstract: The Northern New Jersey Spinal Cord Injury System (NNJSCIS) conducts both a site-specific research study and a collaborative module. These studies contribute to evidence-based rehabilitation interventions and clinical and practice guidelines that improve the lives of individuals with SCI and consist of the following: An innovative rehabilitation intervention utilizing technology to prevent respiratory disease in persons with SCI, now the leading cause of death and the third leading cause of hospitalizations in this population; a collaborative module that adapts, develops, and validates an innovative and promising outcome system for use in SCI intervention research; and the NNJSCIS coordinates with the NIDRR-funded Model Systems Knowledge Translation Center to provide scientific results and information for dissemination to clinical and consumer audiences. This project is a cooperative effort of the Kessler Medical Rehabilitation Research and Education Corporation (KMRREC), the Kessler Institute for Rehabilitation (KIR), the University of Medicine and Dentistry of New Jersey - The New Jersey Medical School (UMDNJ- NJMS), and UMDNJ-University Hospital.
Find out more at: **www.kmrrec.org/KM/nnjscis**

The New England Regional Spinal Cord Injury Center *Boston University Medical Center Hospital* (H133N060024) led by Steve Williams, MD. Kenneth D. Wood, PhD, Project Officer.
Abstract: The New England Regional Spinal Cord Injury Center (NERSCIC), based at Boston Medical Center (BMC) conducts a site-specific research project involves designing an improved outcome instrument in SCI research. This project applies contemporary measurement methods (CATS) to initiate a major transformation in the outcome assessment technology used to assess Activity Limitation frequently monitored in SCI research. Once the SCI-CAT has been developed using data collected front major field study, a demonstration of the SCI-CAT evaluates its respondent burden, acceptability to patients and clinicians, as well as its breadth, precision, sensitivity to change, and validity with inpatients and outpatients with SCI who are receiving care from NERSCIC. Comparisons are made between the FIM and SCI-CAT over a 6-month follow-up period. Additionally, this site- specific project will be integrated with the NeuroQoL collaborative module, in order to expand and improve both projects and to avoid developing competing computer adaptive testing instruments. This project is now referred to as the QOL/SCI-CAT Combined Project. Lastly, NERSCIC is a participating site in the SCI Collaborative Participation Module, led by Gale Whiteneck at Craig Hospital, to address the importance of participation given the current absence of a standard acceptable measure of participation. This collaborative SCI module identifies the best existing measure of participation or combines the best items from existing measures of participation to form a new and improved tool with better psychometric properties validated in the SCI Model Systems to ensure broad acceptability in future SCI outcomes research, and to allow for meaningful testing of clinical interventions.
Find out more at: **www.bumc.bu.edu/Dept/Content.aspx?DepartmentID=91&PageID=332**

Mount Sinai Spinal Cord Injury Model System *Mount Sinai School of Medicine* (H133N060027) led by Kristian T. Ragnarsson, MD. Dawn Carlson, PhD, MPH, Project Officer.
Abstract: The purpose of this project is to (1) demonstrate and evaluate a multidisciplinary system of rehabilitation care for persons with spinal cord injury (SCI) in the New York City metropolitan area, including innovative programs for community integration; (2) contribute longitudinal data to the SCI National Database; (3) create and evaluate SCI quality of life assessment and participation assessment measures, and collect information on the labor force and economic impacts of SCI; and (4) evaluate the treatment of neuropathic pain using modified-release morphine. The research program of MS-SCI-MS is designed to advance the understanding of SCI and its consequences, and to develop better methods of treatment of secondary conditions of SCI, especially pain. The site-specific project studies modified-release formulation of morphine sulfate for neuropathic pain after spinal cord injury through a randomized, double-blind crossover trial of modified-release morphine and placebo for patients with uncontrolled neuropathic pain of three types. In addition, three module projects are executed in collaboration with SCI model systems elsewhere.
Find out more at: **www.mssm.edu/rehab/spinal**

National Capital Spinal Cord Injury Model System *National Rehabilitation Hospital and MedStar Research Institute* (H133N060028) led by Suzanne L. Groah, MD. Kenneth D. Wood, PhD, Project Officer.
Abstract: The National Capital Spinal Cord Injury Model System (NCSCIMS) serves Washington, DC and the nation. By focusing on the frequent and costly complication of pressure ulcers (PU), the NCSCIMS leverages two unique strengths: an existing Rehabilitation Research and Training Center on SCI that focuses on reduction of secondary conditions, and the population of Washington, DC, which is predominantly composed of underserved individuals. The Center includes two site-specific and one modular project and describes a system of care that meets SCIMS priorities: Site Specific Project 1 is a Practice- Based Evidence (PBE) project

specifically focused on PU prevention for all individuals with SCI and/or disease (SCI/D) during the acute and rehabilitative phases of care (to evolve to the community in later phases). The PBE approach allows a detailed examination of the effects of methods, modalities, and therapies utilized in rehabilitation to prevent PUs, which are often based on evidence-based medicine, but in reality may not be extrapolated to the broader population with SCI/D. In this project, researchers aim to utilize a PBE approach to augment evidence based practice while addressing a critical secondary complication for individuals with SCI. Site Specific Project 2 is an SCI Navigator pilot project that combines elements of Peer Mentoring and Patient Navigation to decrease the occurrence of PUs once the individual has returned to the community. In this project, an SCI Navigator assists people with newly-acquired SCI in the transition from inpatient rehabilitation to the community, within the framework of an, at times, dysfunctional healthcare system. The NCSCIMS works with the Model System at the University of Pittsburg to explore Assistive Technology for Mobility (ATM). In this project, researchers investigate the degree to which inadequate wheelchair technology is the factor preventing people with SCI from doing more, work to understand the impact of changes in wheelchair reimbursement, and fully explore the issue of disparity in ATM prescription.
Find out more at: **www.sci-health.org or www.ncscims.org**

University of Michigan Model Spinal Cord Injury Care System *University of Michigan* (H133N060032) led by Denise G. Tate, PhD. Theresa San Agustin, MD, Project Officer.
Abstract: The overall purpose of this project is to provide comprehensive rehabilitation and community participation services and to generate new knowledge through research, development, and demonstration designed to improve outcomes for persons with spinal cord injury (SCI). A site-specific research study is conducted in partnership with faculty from the University of Michigan Depression Center, Department of Psychiatry, and the Molecular and Behavioral Neurosciences Institute. This study is a randomized clinical trial study designed to evaluate the efficacy of a pharmacological agent, Venlafaxine HCl also known as Effexor XR, as a preventive agent for reducing depression among persons with SCI. This clinical trial addresses a major need in the field as there are no randomized clinical trials currently available on the effectiveness of antidepressants in persons with SCI. In this study, the drug's effects on pain are also assessed. An outcome of this study is the formulation of recommendations for antidepressant medication use in SCI and implications for clinical practice guidelines.
Find out more at: **www.med.umich.edu/pmr/modelsci/index.htm**

Northwest Regional Spinal Cord Injury System *University of Washington* (H133N060033) led by Charles H. Bombardier, PhD. Theresa San Agustin, MD, Project Officer.
Abstract: The University of Washington's Northwest Regional Spinal Cord Injury System (NWRSCIS) includes a site-specific project is a randomized controlled intervention study evaluating the effect of proactive, structured, telephone-based counseling and care management on rehospitalization rate and quality of life during the first year after discharge from acute rehabilitation. This study builds upon successful experiences with telephone counseling for both people with traumatic brain injury and multiple sclerosis. This research is particularly important because the lifestyle changes and health care behaviors required for successful living after SCI are tremendously challenging, rates of rehospitalization are high, and many people (especially in rural regions) lack ready access to knowledgeable advice, behavior change support, and specialty care sufficient to maintain their health. A modular project studies the natural history of major depression under conditions of usual care during the first year after SCI. This project establishes reliable and valid means of screening and diagnosing major depression soon after SCI. It examines the impact of depression on rehabilitation efficiency and compares the effect of standard treatment to clinical practice guideline level care of depression. This study describes depression treatment preferences among people with SCI and lays the foundation for a multi-site clinical trial. The RWNSCIS also includes a collaborative, multisite, randomized, double-blind, placebo controlled trial of venlafaxine XR (Effexor XR) in adults with SCI and major depressive disorder (MDD). The purpose of the study is to examine the efficacy and tolerability of venlafaxine XR as a treatment for MDD.
Find out more at: **sci.washington.edu**

Current Literature
Selections from REHABDATA

Cowan, R., Boninger, M. (2008) **Preliminary outcomes of the smartwheel users' group database: A proposed framework for clinicians to objectively evaluate manual wheelchair propulsion.** *Archives of Physical Medicine and Rehabilitation, 89(2), 260-268.* NARIC Accession Number: J54157. Project Number: H133N000019.
Abstract: Study describes a standard clinical protocol for the objective assessment of manual wheelchair propulsion, establishes preliminary values for parameters derived from the protocol, and develops graphical references and a proposed clinical application process. Subjects propelled a wheelchair from a stationary position to a self-selected speed across a hard tile surface, a low pile carpet, and up a ramp that complies with the requirements of the Americans with Disabilities Act. When a module is completed, the SmartWheel clinical software generates the following key parameters to describe a client's propulsion: velocity, average peak resultant force, push frequency, and stroke length. This method provides a general technique that clinicians can use to compare a client's propulsion with that of a larger population and/or to compare a client's propulsion before and after an intervention to assess the effects of that intervention.

Lequerica, A., Forchheimer, M. (2008) **Ways of coping and perceived stress in women with spinal cord injury.** *Journal of Health Psychology, 13(3), 348-354.* NARIC Accession Number: J54399. Project Number: H133G020060; H133N060032.
Abstract: Study assessed the relationship between the coping strategies of positive reappraisal, escape-avoidance, and seeking social support and perceived stress in 44 women with SCI. The Ways of Coping Questionnaire (WOCQ) was used to measure coping style and stress was measured using the Perceived Stress Scale. Results showed that the Positive Reappraisal, Escape-Avoidance, and Seeking Social Support scales on the WOCQ significantly accounted for variance in perceived stress.

(2008) ***Spinal cord injury update, Spring 2008.*** NARIC Accession Number: O17211. Project Number: H133N060033.
Abstract: Newsletter of the Northwest Regional Spinal Cord Injury System, a model SCI care system, covers topics related to SCI for both healthcare providers and consumers. Topics covered in this issue: choosing a cell phone, hypnosis for SCI pain, emergency preparedness, and 14 abstracts on SCI topics.
Full text of this document is available to download at naric.com

Krause, J. (2007) **Self-reported problems after spinal cord injury: Implications for rehabilitation practice.** *Topics in Spinal Cord Injury Rehabilitation, 12(3), 35-44.* NARIC Accession Number: J51770. Project Number: H133A011108; H133N060009.
Abstract: Study describes the self-reported problems of people with SCI, their relationship with aging after SCI, and how they change over time. Both cross-sectional and longitudinal data were evaluated using data collected from a multicenter collaborative longitudinal study. Factor analysis of the data revealed 4 factors reflective of emotional adaptation, dependency, health problems, and the environment. Four scales based on this analysis were compared over time and between cohorts based on years post injury. Areas in which participants cited the greatest number of problems included pain, lack of income and money problems, spasticity, stress and worries, and their sex lives. These problems do not appear to be highly correlated with aging or years since injury.

Whiteneck, G., Forchheimer, M. (2007) **Quality of life and health in the last years after spinal cord injury.** *Topics in Spinal Cord Injury Rehabilitation, 12(3), 77-90.* NARIC Accession Number: J51774. Project Number: H133A011108; H133N060032.
Abstract: Study examined longitudinal trends in quality of life (QOL) and health among people aging with SCI. Over the course of the 15-year study, only 1 in 4 reported poor or fair QOL, and only 1 in 10 reported not being generally health. The findings suggest that even in the last years of life, people with SCI can be healthy and have good QOL.

Krause, J., Morrisette, D. (2007) **Pain interference in ambulatory spinal cord injury.** *Topics in Spinal Cord Injury Rehabilitation, 12(3), 91-96.* NARIC Accession Number: J51775. Project Number: H133G010009; H133N060009.
Abstract: Study compared differences in pain interference as a function of ambulation and examined the relationship between pain interference and aging parameters (current age and years since injury). Subjects who were independent of personal assistance in ambulation reported lower levels of pain interference and were less likely to use prescription medication to treat pain. No simple relationship was observed with aging, although pain interference was more problematic for the partially ambulatory group with increasing years since injury when compared with those independent in ambulation.

Jensen, M., Kuehn, C. (2007) **Symptom burden in persons with spinal cord injury.** *Archives of Physical Medicine and Rehabilitation, 88(5), 638-645.* NARIC Accession Number: J52412. Project Number: H133N000003.
Abstract: This survey study examines the nature and impact of various symptoms commonly reported by people with SCI. The survey included measures of the frequency, severity, and recalled course of seven symptoms: pain, fatigue, numbness, weakness, shortness of breath, vision loss, and memory loss, as well as a measure of community integration and psychological functioning. The frequency and average severity of each symptom was computed, and the frequencies of each type of reported course were noted. Analyses estimated the associations among the symptoms, and between symptom severity and measures of patient functioning. Results showed that the most common symptoms reported by respondents with SCI were pain, weakness, fatigue, and numbness. The most severe symptoms were pain and numbness. Pain, weakness, fatigue, and memory loss were the symptoms most closely associated with patient functioning. All symptoms were reported to remain the same or to get worse more often than they improved once they began.

Kim, M., Burns, A. (2007) **The assessment of walking capacity using the walking index for spinal cord injury: Self-selected versus maximal levels.** *Archives of Physical Medicine and Rehabilitation, 88(6), 762-767.* NARIC Accession Number: J52720.Project Number: H133N000023; H133N060011.
Abstract: The Walking Index for Spinal Cord Injury (WISCI) was used to assess the frequency and magnitude of differences between self-selected and maximal walking capacity in 50 subjects with chronic SCI. Velocity, physiological cost index (PCI), and total heart beat index (THBI) were calculated and compared between the 2 walking levels. For 36 subjects, maximal WISCI was higher than self-selected WISCI; 21 subjects showed an increase of 3 levels or more. Velocity was higher and PCI and THBI were lower, compared with maximal WISCI.

Bryce, T., Ragnarsson, K. (2007) **Spinal cord injury.** *In R. L. Braddom (Ed.), Physical medicine and rehabilitation, third edition, 1285-1349.* NARIC Accession Number: J53147. Project Number: H133N060027.
Abstract: Chapter provides a comprehensive overview of the latest advances and techniques relevant to SCI. Discussion includes the epidemiology, anatomy, classification, medical complications, treatment, rehabilitation, and outcomes of SCI. This chapter is intended as a resource for physiatrists providing care to people with SCI.

Lammertse, D., Dungan, D. (2007) **Neuroimaging in traumatic spinal cord injury: An evidence-based review for clinical practice and research.** *Journal of Spinal Cord Medicine (JSCM), 30(3), 205-214.* NARIC Accession Number: J53167. Project Number: H133N060005.
Abstract: Article presents an evidence-based review of the literature on neuroimaging techniques used in SCI clinical practice and research. A list of clinical and research questions posed by NIDRR were used by the committee conducting the article review. These questions related to the role of the following techniques in the assessment of SCI: magnetic resonance imaging (MRI), MRI-diffusion weighted imaging, functional MRI, magnetic resonance spectroscopy, intraoperative spinal sonography, and positron emission tomography. The committee's recommendations on specific

neuroimaging modalities were made at the SCI Measures Meeting sponsored by NIDRR on June 24, 2006, in Boston Massachusetts.

Dyson-Hudson, T., Kadar, P. (2007) **Acupuncture for chronic shoulder pain in persons with spinal cord injury: A small-scale clinical trial.** *Archives of Physical Medicine and Rehabilitation, 88(10), 1276-1283.* NARIC Accession Number: J53359. Project Number: H133N000022.
Abstract: Study examined the efficacy of acupuncture in the treatment of chronic musculoskeletal shoulder pain in 17 manual wheelchair users with SCI. Participants were randomly assigned to receive 10 treatments of either acupuncture or invasive sham acupuncture. Changes in shoulder pain were measured using the Wheelchair User's Shoulder Pain Index. Results showed that shoulder pain decreased significantly over time in both groups and there were no significant differences between the two groups. There was a medium treatment effect associated with the acupuncture, which suggests that it may be superior to sham acupuncture in relieving shoulder pain.

Holicky, R. (2007) **Living well: Measuring participation after SCI.** *PN/Paraplegia News, 61(10), 22-24.* NARIC Accession Number: J53461. Project Number: H133N060005.
Abstract: Article describes a new SCI Model Systems study underway to identify or develop the best possible measure of the level and quality of participation by people with SCI. a study sample of 625 people from 1 to 30 years post-injury will be interviewed. Data collection is underway and should be completed by mid-summer 2008, with findings published by early 2009.

Richards, J., Siddall, P. (2007) **Spinal cord injury pain classification: History, current trends, and commentary.** *Topics in Spinal Cord Injury Rehabilitation, 13(2), 1-19.* NARIC Accession Number: J53489. Project Number: H133N060021; H133N060027.
Abstract: Article reviews the history of SCI pain classification schemes and describes current efforts to develop a unified classification scheme and an accompanying set of diagnostic procedures. Translational research related to SCI pain and the benefits and limitations of current animal models of SCI pain are discussed. Several of the authors provide comments on the direction they think the field needs to take to develop a unified, internationally endorsed classification system for SCI pain.

Magasi, S., Heinemann, A. (2007) **Participation following traumatic spinal cord injury: An evidence-based review for research: Report of the national institute on disability and rehabilitation research spinal cord injury measures meeting.** *Journal of Spinal Cord Medicine (JSCM), 31(2), 145-156.* NARIC Accession Number: J54516. Project Number: H133B040032; H133N060014.
Abstract: Article describes an evidence-based review of participation outcome measures that have been used in SCI clinical practice and research. The rehabilitation literature was searched for instruments used by at least 2 independent SCI researchers since 2000. Only 3 instruments met the review inclusion criteria: the Craig Handicap Assessment and Reporting Technique, the Assessment of Life Habits, and the Impact on Participation and Autonomy. Each instrument was reviewed by 2 people; one person evaluated the scale and documented the level of use and psychometric properties and the second person verified the values and made suggestions for changes. Each of the instruments reviewed incorporates different perspectives in the measurement of participation.

Graves, D., Bombardier, C. (2007) **Improving the efficiency of screening for major depression in people with spinal cord injury.** *Journal of Spinal Cord Medicine (JSCM), 31(2), 177-184.* NARIC Accession Number: J54517. Project Number: H133N000003; H133N000004; H133N000005; H133N06003; H133N060033.
Abstract: Study explored the most efficient way to identify major depression among individuals with SCI using the Patient Health Questionnaire-9 (PHQ-9). Data obtained from 16 SCI model system centers for 3,652 subjects with SCI were analyzed using confirmatory factor analysis, item response theory graded response model analysis, and sensitivity and specificity analysis classification. The confirmatory factor analysis showed that the 9 items in the PHQ-9 do form a single dimension. A scale comprised of items 1, 2, and 6 from the PHQ-9 has a relative efficiency index of 0.67, meaning that two-thirds of the information is available with one-third of the information. The relative efficiency of the 9-item scale is 0.88 for women compared to men; the 3-item scale increases the relative efficiency to 0.93. Using this 3-item scale and a cutoff score of 3 or 4 provides acceptable sensitivity and specificity and presents options for decision making within a particular clinical setting. In addition, the 3-item scale reduces the effect of response bias caused by gender.

Ferretti, E., Cooper, R. (2007) **The effects of social and physical barriers on community participation of individuals with spinal cord injury.** *30th Annual RESNA Conference Proceedings.* NARIC Accession Number: O16980. Project Number: H133N000019.
Abstract: Study investigated the frequency of the social and physical barriers on community participation among individuals with spinal cord injury who use wheelchairs for mobility. Analyses focused on differences in the frequency of social and physical barriers between individuals who used manual versus power wheelchair as well as differences between individuals with tetraplegia versus paraplegia. The findings indicated that accessibility of shelves and freezers was the most common physical barrier limiting participation at the grocery store. Tables too close together in restaurants and the width of the aisles in clothing stores were also reported as common physical barriers. A greater number of power wheelchair users than manual wheelchair users reported lack of personal assistance as a social barrier that limits their participation in their place of employment and in the grocery store. A greater number of power wheelchair users also reported lack of special equipment as a physical barrier that limits their participation in shopping malls. No significant difference was found between individuals with tetraplegia and paraplegia regarding the frequency of social and physical barriers to community participation.

Dijkers, M., Brown, M. (2007) ***Focus: Technical brief number 19: Getting published and having an impact: Turning rehabilitation research results into gold.*** NARIC Accession Number: O17152. Project Number: H133A060028; H133A070033; H133B040033; H133N060027.
Abstract: This article suggests strategies that rehabilitation researchers can use to maximize their work, to turn "research results into gold", particularly in terms of being effective in reaching and convincing a target audience to utilize the findings. In the disability and

rehabilitation research community, it is important for researchers to be cognizant of how published results of research studies can facilitate or limit their use in answering important evidence-based questions.

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Cardenas, D., Jensen, M. (2006) **Treatments for chronic pain in persons with spinal cord injury: A survey study.** *Journal of Spinal Cord Medicine (JSCM), 29(2), 109-117.* NARIC Accession Number: J50771. Project Number: H133N000003.
Abstract: Study participants were asked whether they had ever received any 1 of 26 different pain treatments, including 10 oral medications, 8 other standard pain treatment modalities, 7 alternative pain treatments, or any other treatment for pain. Participants also indicated the amount of relief each treatment provided and the length of time that any pain relief usually lasts. The medications tried most often were nonsteroidal anti-inflammatory drugs and acetaminophen. Opioids produced the greatest degree of pain relief but were unlikely to be continued by those who tried them. Although 38 percent of respondents had tried gabapentin, only 17 percent were still using it, and average pain relief was only moderate. Seventy-three percent of the respondents had tried at least 1 of the alternative pain treatments; the most frequently tried were massage, marijuana, and acupuncture. The relief from most treatments tended to last only minutes or hours; however, pain relief from treatments such as massage, acupuncture, and hypnosis was reported to last for days in 25 to 33 percent of those who tried these treatments.

Hedrick, B., Theresa L. (2006) **Employment issues and assistive technology use for persons with spinal cord injury.** *Journal of Rehabilitation Research and Development (JRRD), 43(2), 185-198.* NARIC Accession Number: J50944. Project Number: H133N060014.
Abstract: Study examined the relationship between the ownership/use of assistive technology (AT) and employment for individuals with spinal cord injury or dysfunction (SCI/D). Data were collected by survey from two groups of working-age adults (civilian and veteran) and analyzed to determine associations between AT cost, underwriting, ownership, use, employment, and employer accommodations. Results indicated that AT ownership and use relates to and is important for the employment success of people with SCI/D. AT devices identified as important to work were 3.5 times more expensive than other devices. The mean cost of AT devices was 68 to 124 percent greater for people who were self-employed than for any other type of employment. Access to workplace accommodations appeared to have been quite good for both groups, and AT satisfaction levels for all respondents were very high regardless of employment status and employment history.

Biering-Sorensen, F., Charlifue, S. (2006) **International spinal cord injury data sets.** *Spinal Cord, 44(9), 530-534.* NARIC Accession Number: J51672. Project Number: H133A060039; H133N060021.
Abstract: Article presents the background, purpose, and process for the development of the International SCI Data Sets. A combined meeting of the American Spinal Injury Association and the International Spinal Cord Society was held to develop a process for the selection of data elements to be in International SCI Data Sets. The overall structure and terminology was developed following the format of the International Classification of Functioning, Disability and Health. This included definitions of the Core Data Set, as well as modules with basic questions or data sets and expanded data sets. Standardized international data sets are necessary to enable consistency in the design and publication of multi-center clinical research studies in the future.

Johnston, M., Diab, M. (2005) **Preventive services and health behaviors among people with spinal cord injury.** *Journal of Spinal Cord Medicine, 28(1), 43-54.* NARIC Accession Number: J49478. Project Number: H133N000022.
Abstract: Cross-sectional survey documents the receipt of selected preventive services and health behaviors of community-dwelling adults with SCI and compares them to the general adult population. Study examined the provision of screening services for colorectal and prostate cancer and oral health examinations, as well as safety- and health-related behaviors including prevention of additional injury, obesity, and smoking. Most rates of service provision and risk behaviors in the SCI sample were similar to those found in the general population. People with SCI need the same general screening and safety services recommended for all people.

Jackson, A., Sipski, M. (2005) **Reproductive issues for women with spina bifida.** *Journal of Spinal Cord Medicine, 28(1), 81-91.* NARIC Accession Number: J49479. Project Number: H133N000017.
Abstract: Article reviews research on the reproductive issues facing women with spina bifida. More than 150 titles and abstracts were reviewed. Paper were chosen if they provided information on menarche, menstruation and sexual maturation, gynecological issues, sexual function, birth control, pregnancy outcomes, and menopause. Seventy-five studies met the criteria for inclusion. These were then reviewed and classified by level of evidence. In general, little research has examined the reproductive issues of women with spina bifida and similar disabilities.

Drainoni, M., Houlihan, B. (2004) **Patterns of Internet use by persons with spinal cord injuries and relationship to health-related quality of life.** *Archives of Physical Medicine and Rehabilitation, 85(11), 1872-1879.* NARIC Accession Number: J46796. Project Number: H133N000024.
Abstract: Reports results of a survey conducted to explore patterns of computer and Internet use and the effects of Internet use on health-related quality of life (HRQOL) among people with SCI. Results showed that most respondents owned computers, had Internet access, and used the Internet regularly, primarily for email, disability and health information, and shopping. Analysis showed a significant relationship between Internet use and 4 HRQOL indicators: self-perceived health status, social integration, satisfaction with life, and depression.

Estores, I., Sipski, M. (2004) **Women's issues after SCI.** *Topics in Spinal Cord Injury Rehabilitation, 10(2), 107-125.* NARIC Accession Number: J46852. Project Number: H133N000017.
Abstract: Article summarizes gender-specific problems, effective interventions, and gaps in knowledge found in current literature on women with SCI. Gynecologic, endocrine and metabolic, urologic,

musculoskeletal and mobility, aging and preventive care, and psychological issues are discussed, as well as concerns regarding sexuality, domestic violence, community reintegration, and quality of life for women with SCI.

Thapar, N., Warner, G. (2004) **A pilot study of functional access to public buildings and facilities for persons with impairments.** *Disability and Rehabilitation, 26(5), 280-289.* NARIC Accession Number: J47531. Project Number: H133N000024; H133N50014.
Abstract: Survey study measured functional access to public buildings and facilities for people with and without disabilities. Participants included: one person who used a wheelchair, one with a mobility impairment who did not use a wheelchair, one with a visual impairment, and one with no known impairments (control). Functional access was measured by the number of tasks performed, the time and distance required to complete the building challenges, and reports of barriers and facilitators for each building challenge and task. The wheelchair user demonstrated a lower task performance (81 percent) in comparison to the control subject (100 percent) or the person with mobility impairment (97 percent) or the one with a visual impairment (98percent). There was little difference in mean values for time and distance to complete tasks. More barriers were reported by the person with visual impairment, the wheelchair user, and the non-wheelchair user; highest facilitators were reported by the person with visual impairment and the wheelchair user. The control reported the lowest barriers and facilitators.

Developing Cutting Edge Tools for Research and Practice

Research Tools Developed by the Model Systems

Tool: Walking Index for Spinal Cord Injury (WISCI)
Developed by the Regional Spinal Cord Injury Center of the Delaware Valley H133N000023/H133N060011
Goal: The RSCICDV has led the development and validation of the WISCI which is the most advanced and promising measure of walking function after spinal cord injury. This will be an extremely important method of determining if new treatments, drugs, and physical therapy are effective.
Validation: Ditunno Jr., J., Barbeau, H. (2007) **Validity of the walking scale for spinal cord injury and other domains of function in a multicenter clinical trial.** *Neurorehabilitation and Neural Repair, 21(6), 539-550.* NARIC Accession Number: J53525. Project Number: H133N000023; H133N060011.
Abstract: This study documents the concurrent, predictive, and construct validity of the Walking Index for Spinal Cord Injury (WISCI) scale in relation to improvement in physical impairment and other measures of walking function. Data were provided by blinded observers in a prospective multicenter clinical trial of a walking intervention for patients with SCI. Primary outcome measures included: the Functional Independence Measure (FIM), 50-foot walking speed, and 6-minute walking distance assessed 3, 6, and 12 months after entry to the study. Secondary measures were the Lower Extremity Motor Score (LEMS), the Berg Balance Scale, the WISCI, and the FIM locomotor score. Concurrent validity of the WISCI scale was supported by significant correlations with all other measures at 3, 6, and 12 months. Correlation of change scores supports predictive validity. The LEMS at baseline was the best predictor of the WISCI score at 12 months and explained most of the variance.

See also Ditunno Jr, J., Ditunno, P. (2000) **Walking Index for Spinal Cord Injury (WISCI): An international multicenter validity and reliability study.** *Spinal Cord, 38(4), 234-342.* NARIC Accession Number: J39440.

Morganti, B., Scivoletto, G. (2005) **Walking index for spinal cord injury (WISCI): Criterion validation.** *Spinal Cord, 43(1), 27-33.* NARIC Accession Number: J48686. Project Number: H133N000023.
For more information visit **www.spinalcordcenter.org/research/wisci.html**

Tool: Capabilities of Arm and Hand in Tetraplegia
Developed by the University of Pittsburgh Model Center on Spinal Cord Injury, H133N000019/H133N060019
Purpose: Evaluation of arm and hand function in tetraplegia suffers from lack of reliable and sensitive assessment instruments. Such an instrument is important to evaluate effectiveness of clinical trials of neuroregeneration in SCI, and in detecting changes in function.
Goal: This tool is in the development phase. The development and validation of the CAHT may be one of the most advanced and promising measures of upper extremity function after spinal cord injury. This will be an extremely important method of determining the effectiveness of new treatments, drugs, and interventions.
Current Publication: Tolerico, M., Ding, D. (2007) **Assessing mobility characteristics and activity levels of manual wheelchair users.** *Journal of Rehabilitation Research and Development (JRRD) (formerly the Bulletin of Prosthetics Research), 44(4), 561-572.* NARIC Accession Number: J53565. Project Number: H133F040006; H133N000019.
Abstract: Study investigated the mobility characteristics and activity levels of manual wheelchair users in the residential setting and at the National Veterans Wheelchair Games (NVWG), to provide a better understanding of the activity levels achieved by manual wheelchair users and insight into factors that may influence this activity. Fifty-two manual wheelchair users with a wide range of disabilities completed a brief survey, and their activity was monitored over a period of 13 or 20 days with a custom data logger developed by the Human Engineering Research Laboratories. Participants were found to travel significantly farther and faster and were active for more hours during an average day at the NVWG than in the home environment. Participants who were employed covered more distance, accumulated more minutes, and traveled a greater average maximum distance between consecutive stops than those who were unemployed.

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