

SCI SIG NEWSLETTER

APTA Neurology Section
Spring 2009

MESSAGE FROM THE CHAIR

If you were in Las Vegas and were able to stick around for our SIG business meeting and presentation on Thursday afternoon you have already heard my hope for mobilizing the SCI SIG to action regarding the limitations to rehabilitation dictated by insurance.

I am convinced that we do not have the functional outcomes from SCI rehabilitation that we used to routinely achieve.

I am convinced that individuals with new SCI are being discharged from rehabilitation with insufficient functional skills and insufficient education about how to live life fully and take care of their health.

I am convinced that therapists who have been practicing over 10 years in SCI are well aware of this.

I am very afraid that therapists practicing less than 5 years are NOT aware of this.

I believe that most people who enter physical therapy and have a leaning toward neurologic rehabilitation are motivated by caring, and wanting to help people, and wanting the work they do daily to feel rewarding. Those that gravitate toward SCI may have a bit more of an aggressive streak; tending to be louder and pushier than those who may work with a population that tends to be older or less male dominated.

However, we (SCI therapists) are getting walked on. We are taking it. We are being given patients in SCI inpatient rehab who are sicker and less stable due to limited lengths of stays in the ICU (average stay is now 15 days) and we are 'adapting'. We try our best to do what we can with the time given; as inpatient rehabilitation lengths of stays decrease (average length of stay is 30 days).

We have acquiesced to discharging patients from

inpatient rehab while still in TLSOs and agreeing that patients can 'come in for advanced rehab' after getting the immobilization device off, or resume therapy on an outpatient rehab basis but with limited visits.

Yet we KNOW that individuals can learn to self cath and manage their own bowel care while in a TLSO. Indeed an individual with paraplegia can learn to transfer off the floor and manage curbs while in a TLSO and not break spinal precautions.

We KNOW about learned non-use, we KNOW about maladaptive neuroplasticity and we KNOW about motor learning and activity induced recovery and yet we are not arguing.

We are not fighting this societal morph into accepting that SCI means dependency.

I worked for 20 years with veterans and I know many individuals who have lived with SCI for over 20-30 years fully independently and with cervical complete injuries. These folks thought we already fought this battle. The ADA has made life more accessible and the revolution in equipment has made living with SCI easier but we MUST return to sufficient rehabilitation to allow newly injured people to adjust to injury, maximize recovery but also learn to live maximally within physical limitations and participate fully in life.

As the APTA moves to embracing the ICF model I think we need to get off the bench and ACTIVELY advocate for our patients.

I think a starting point is to collect stories. I believe individual therapists are advocating for individual patients, gaining more time or better equipment and making significant functional changes for the patients. Let's start collecting that information. Please send your stories in to share in the newsletters. jhastings@ups.edu

CSM 2009 Programming Report

It was another year of great programming for the SCI SIG at CSM. On Thursday morning, Sue Ann Sisto, PT, MA, PhD from Stony Brook University and Alison Lichy, PT, DPT, NCS from the National Rehabilitation Hospital's Neuroscience Research Center led a lively discussion on "Bone Mineral Density following SCI and its Impact on Physical Therapy Interventions." This topic is of great importance for anyone working with people with SCI as bone mineral density has the potential to impact the safety of our interventions. Yet there are no established standards for when bone density is so low that we are placing our patients at risk for fractures.

On Thursday afternoon during the SCI SIG meeting, Deborah Backus, PT, PhD from the Shepherd Center and Emory University, and Therese Johnston, PT, PhD, MBA from the University of the Sciences in Philadelphia and Shriners Hospitals for Children in Philadelphia presented a research update entitled "Health and Wellness Following Spinal Cord Injury: An Update on the Current Literature." Therese Johnston reviewed the literature on the health risks that the SCI population faces, including cardiovascular disease and metabolic syndrome. Many issues faced by our patients, such as adiposity, altered

lipid profiles, hypertension, decreased muscle mass, and decreased physical activity increase the risk for cardiovascular disease and metabolic syndrome. Physical therapists can have an influence on these risks, but more research is needed on optimal interventions. Current literature on the status of our knowledge of bone density was also discussed, as well as potential measurement issues and interventions. Debbie Backus then provided an excellent talk on exercise and what we can do to decrease the risks of these common medical complications. She reviewed the literature on the potential positive effects of FES cycling, treadmill training, and other exercise interventions, as well as precautions with these interventions. She stressed that we need to be advocates for our patients with these interventions not only for the potential functional benefits that are gaining support within the literature, but also the possible long term health benefits.

Thanks for everyone who attended our sessions. Despite having the SCI SIG meeting at the end of the last day of CSM, we had a great turnout.

Therapy Leadership Council in Spinal Cord

The Therapy Leadership Council in Spinal Cord Injury (TLCSCI) is a professional network for therapists (OT's, PT's, and KT's) who work with individuals with spinal cord injury and disorders. TLCSCI members include clinicians from the private sector, SCI Model Systems, and the VA System. TLCSCI strives to improve clinical skills and encourages standardized, evidence based practice methods throughout the continuum of care to maximize functional outcomes.

TLCSCI began as a small meeting of VA SCI therapists in 2004 and has developed into a group of therapists from every region that represents the continuum of SCI rehabilitation from research to clinical settings and from VA to private and academic sectors.

TLCSCI, in conjunction with the American Association of SCI Psychologists and Social Workers (AASCIPSW), the American Paraplegia Society (APS), the American Association of SCI Nurses (AASCIN), and the American Spinal Injury Association (ASIA) will be presenting the

2009 Congress on Spinal Cord Medicine and Rehabilitation from September 24-26, 2009 in Dallas, Texas. Information and registration can be found on www.spinalcordcongress.org

In October 2009, TLCSCI will be one of four associations that will comprise the Academy of Spinal Cord Injury Professionals (ASCIP). The other associations are the American Association of SCI Psychologists and Social Workers (AASCIPSW), American Paraplegia Society (APS), and the American Association of SCI Nurses (AASCIN). Because ASCIP is comprised of 4 professional associations, it allows for interdisciplinary promotion of research, education, and practice guidelines.

To join the TLCSCI listserve, contact [Joan Winkler \(JoanW@PVA.org\)](mailto:JoanW@PVA.org).

For more information on TLCSCI, contact Amy Icarangal at aicarang@u.washington.edu or Jackie Wolz at jacqueline.wolz@va.gov



Abstract submission for the 2009 Howard H. Steel Conference is available online at www.PedsSCI.com.

On behalf of the co-chairs, you are cordially invited to submit an abstract for consideration as a paper presentation, e-poster presentation or an instructional course lecture. Please note: the **Call for Abstracts will close on June 1, 2009**.

Held once every three years, the Howard H. Steel Conference provides a unique opportunity for the exchange of knowledge and dissemination of research throughout the international community that is focused on Pediatric Spinal Cord Injuries and Dysfunction.

On December 3-5, 2009, the three-day conference will include a variety of educational opportunities such as paper presentations, debates, lectures, symposia and instructional course lectures. Electronic posters, standard posters and technical exhibits will also be available at the conference.

Preceding the conference, on December 2nd, co-chairs David Pleasure MD, PhD, Amer Samdani MD and Randal Betz MD will host a one day course titled *Spinal Cord Regeneration: Injury Modulation, Repair Strategies and Clinical Trials*.

Please visit the course website to submit an abstract and for up-to-date information.

We hope you join us for this exciting educational opportunity in beautiful Lake Buena Vista, Florida. Located just outside the city of Orlando, it is an ideal backdrop and provides a variety of social activities.

Cordially,

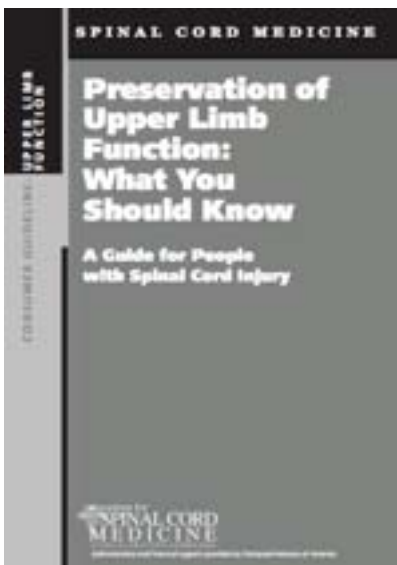
Co-Chairs

MJ Mulcahey, MS, OTR/L

Randal Betz, MD

Craig McDonald, MD

Lawrence Vogel, MD



People with spinal cord injuries and their caregivers have a new resource to help with improving the quality of their lives: [Preservation of Upper Limb Function: What You Should Know](#), new from the Consortium for Spinal Cord Medicine.

Strain on the upper limbs is prevalent among wheelchair users, with the impending risk of experiencing a painful and potentially disabling injury.

This expert guide offers:

- Recommendations on selecting and setting up equipment
- Exercise routines to maintain strong and healthy arms and shoulders
- Tips on arranging your environment to lessen stress on arms
- Guidance and positive tips on staying healthy

This consumer guide is a companion to the clinical practice guideline, [Preservation of Upper Limb Function Following SCI](#). Published by Paralyzed Veterans of America (PVA) on behalf of the Consortium for Spinal Cord Medicine.

Download the Upper Limb consumer guide at **no cost** today: <http://www.pva.org/site/News2?page=NewsArticle&id=9451>

Newsletter Update

A new issue of the *Spinal Cord Injury Update* newsletter has been posted on the Northwest Regional Spinal Cord Injury System's Web site at http://sci.washington.edu/info/newsletters/09_spring.asp.

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The Pain Issue

As anyone with SCI knows only too well, chronic pain is a frequent problem after SCI and often causes more disability than the paralysis itself. Pain after SCI can be so severe and disabling that some people have said they would give up the possibility of neurological recovery in favor of pain relief. Because chronic SCI pain is such a widespread problem and so difficult to treat, this issue of *SCI Update* is devoted to pain after SCI: understanding it, treating it and living with it.

- [Understanding pain and spinal cord injury](#)
An overview of the types, causes and treatments for SCI pain.
- [Pain and the Brain](#)
What brain science tells us about why we feel pain and how we can change it. A conversation with Mark P. Jensen, PhD
- [In their own words: Stories — and advice — from people living with chronic SCI pain](#)
Individuals with SCI talk about the different ways they manage their pain.
- [Treating SCI pain: What the research says](#)
A review of the research literature from the last two years on treating SCI pain.
- [Literature Review: 13 abstracts on SCI topics](#)
- [Download a printer-friendly version of this newsletter \(502 KB PDF\).](#)
- Announcements
 - [New SCI support and information group starting in Seattle](#)
 - [Grant to study aging with disabilities](#)
- [Participate in research](#)
Opportunities for individuals with SCI to participate in UW research studies.

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