Paddling is for everybody

also inside:

*ReJoyce: long distance rehab*

*GRASSP for better hand function measurement*

*SCIRE 2: best practices in SCI rehabilitation*
Welcome to Solutions!

Welcome to the first issue of Solutions, the flagship publication of the SCI Solutions Network—SCISN for short.

This magazine marks our first widescale efforts to publicize the good work being done throughout our Network—work that’s being done by Canadians with SCI, committed researchers, dedicated clinicians and other health professionals, concerned organizations and institutions, and visionary governments and other funders, all working together in an unprecedented collaboration.

In this issue and in future issues of Solutions, you’ll read about the numerous research initiatives that SCISN is funding. You’ll also learn about the various ways we’re identifying and providing solutions for Canadians with SCI. We’ll keep you abreast of the good work being done for Canadians with SCI by our many partners across Canada. And we’ll provide you with newsworthy updates from around the world of SCI.

It’s important to note that this is not a scientific journal. We’re writing it in such a way that everyone—people with SCI, our funders, researchers, clinicians, service providers and other interested Canadians—can see at a glance what we’re doing and the benefits of our work.

The publication’s name is fitting—as an organization, we are committed to finding solutions that minimize disability and maximize the quality of life of Canadians with SCI. Solutions is available free of charge, thanks to the support of our funders. Tell your friends about Solutions and let them know that receiving it is as simple as visiting www.scisolutionsnetwork.ca and clicking on the subscribe button. If you’re seeking the publication in French, please visit our website at www.scisolutionsnetwork.ca to read the translated version.

Most importantly, please let us know what you think of this issue and future issues—with your feedback, we’ll make solutions more relevant and informative.

Best wishes,

Eric Boyd, CEO
SCI Solutions Network

Solutions magazine — Spring 2009

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The SCI Solutions Network does not endorse or recommend any devices, equipment, or procedures described in Solutions unless specifically indicated.

The SCI Solutions Network is funded by Health Canada, Western Economic Diversification, and the Rick Hansen Foundation.
Who we are
We are a Canada-wide collaboration of people with spinal cord injuries (SCI), researchers, health care professionals, and service providers committed to addressing priority needs and generating solutions for people with SCI.

Where we’ve come from
With investments from Health Canada and Western Economic Diversification, the Rick Hansen Foundation created the SCI Translational Research Network (SCI-TRN) and the SCI Solutions Alliance. In April 2008, a decision was made to combine these two entities into a single organization, which is more effectively and efficiently addressing priority needs and generating solutions for people with SCI. This merger represents an integrated approach that strives for synergy and best use of the approximately $70 million that has been invested in our work.

Our objectives
Approximately 41,000 Canadians live with a SCI, and approximately 1,200 new injuries occur every year. The SCI Solutions Network strives to minimize disability and maximize the quality of life of these Canadians. We have six primary objectives that all of our work is focused on achieving:

- a significant reduction in the incidence and severity of permanent paralysis resulting from SCI
- a significant increase in restoration of physical function following SCI
- a significant reduction in the incidence and severity of secondary complications associated with SCI
- a significant increase in level of satisfaction with quality of life and community participation among people with SCI
- ensuring that responses to priority unmet needs are available to 100% of individuals with SCI throughout their journey to full participation
- establishing a world class Canadian SCI registry and data management platform by 2012.

Our work
To achieve its six objectives, the SCI Solutions Network works in three primary areas:

- we identify, fund and facilitate solutions that address priority needs of Canadians with SCI
- we identify, support and fund promising Canadian SCI translational research projects—in acute care and treatment, rehabilitation, and community integration
- we promote adoption of best practices at all points on the continuum of treatment, care and support for people with SCI.
Innovations

New technologies for people with SCI from around the globe

Think of Sigourney Weaver wearing the exoskeleton in the movie *Aliens*, and you’ll get the concept of ReWalk, made by Israeli company Argo Medical Technologies. The ReWalk probably won’t let users take on extra-terrestrials in hand-to-hand combat, but it does allow people with paraplegia to walk and even climb stairs. The system’s motors are controlled by a lightweight computer worn in a backpack and powered by rechargeable batteries. Users maintain balance using a set of crutches. The company is aiming for commercialization in 2009. The technology seems to have many people excited on the various SCI forums and bulletin boards, but the ReWalk’s anticipated high costs and slow pace may be seen as deterrents. See video for yourself at www.argomedtec.com.

You can find glowing reviews of Ride Designs’ Custom Cushion in New Mobility magazine (July 2007) and on various SCI bulletin boards, like www.carecure.org. The company’s approach is to combine orthotic and prosthetic principles into an individually customized cushion in order to provide superior pressure sore prevention. Each cushion is made with lightweight Brock™ composite material, which assists in wicking heat and moisture away from the body. The cushion contours can be adjusted to maintain off-loading of bony prominences and improve postural alignment and control. Custom-fitting is carried out by trained Ride Designs Certified providers in the US and Canada. Once fitted, no adjustment is required by the user. The cushion, which weighs in at under three pounds and is available for most sizes of seating, can be cleaned with a simple wash, rinse and dry process. A breathable zip cover can be machine washed and dried. The company says that all Canadian provinces will provide funding under their respective programs. For more information, visit www.ridedesigns.com.

Natural-Fit handrims, built by Arizona-based Three Rivers, have been long-touted by the company and its customers to be more comfortable and efficient than standard handrims. Two recent papers back up these claims. One paper was published in 2006 in the journal *Assistive Technology* (Volume 18, pp. 123-143), and another was published in 2008 in the *Journal of Spinal Cord Medicine* (Volume 31, pp. 62-69). Both conclude that the Natural-Fit handrims benefit users by improving grip, making wheelchair propulsion more efficient, and reducing pain in the hands and wrists. The papers are based on comprehensive questionnaire studies conducted with users of the Natural-Fit. Links for these studies, along with detailed product information, can be found at www.3rivers.com.

Some of the earliest manual wheelchairs were front wheel driven. Looking at Trekinetic’s K-2 All Terrain, which offers a revolutionary departure from today’s conventional manual wheelchairs, you can begin to understand why—a front wheel design has no little castors at the front to get hung up on rocks or other inhospitable terrain. The K-2 takes the concept much further, with the end result being a chair that provides excellent stability and ability to negotiate uneven terrain. Other features include a nitrogen shock absorber on the rear castor, a lightweight carbon fibre seating system, and an ingenious dynamic braking/steering system which is operated via two hand levers, which also lock the chair when stationary. The footrest retracts to ease entry. A transfer plate for drivers is available. The wheels are quick release and the components can be folded in less than ten seconds. Unfortunately, Canadians may have to go to some lengths to get their hands on this innovation—Trekinetic is a British company that is only in the process of trying to find a North American distributor. Visit www.trekinetic.com for more information.

The SCI Solutions Network in no way endorses, recommends, or approves the products described above. Consumers are urged to perform their own research prior to purchasing these or any other products.
Cethrin Update
Dr. Michael Fehlings, one of the members of SCISN’s Research Management Team, along with colleagues in Canada and the United States, recently wrapped up a phase I/Ia clinical trial to study the safety and feasibility of Cethrin as a new potential therapeutic for acute SCI.

Cethrin is a man-made recombinant protein drug that appears to promote regeneration in the damaged nervous system. It’s the first such drug to be studied in humans. The injured spinal cord has the inherent capacity to repair itself, but the hostile environment that develops after SCI limits this ability. The promise of Cethrin is that it prevents Rho, a key enzyme, from impeding axon regeneration after SCI. In this study, 37 patients with severe cervical or thoracic spinal cord injuries were treated with different doses of Cethrin immediately after their injury. In addition to looking at the safety of Cethrin, the investigators were also able to collect some preliminary data about the effectiveness of the therapy in the recovery of function after SCI.

Results indicate that many of the patients that were treated with Cethrin improved in terms of function and sensation below the level of their injury. This is preliminary data, and more extensive trials to examine the therapeutic potential of Cethrin are planned for this spring.

Landmark Caregiver Ruling
An Oregon quadriplegic has won a landmark decision that may influence how much caregivers across the United States (and perhaps Canada) are paid. In an agreement made public September 29, 2008, the state of Oregon agreed to pay Clay Freeman’s caregivers $3 more than the state-sanctioned rate. Freeman, a 34-year-old quadriplegic and ventilator user, sued the Oregon government under the Americans with Disabilities Act. He and his lawyers successfully argued that the state’s rate of $10.30 per hour was insufficient for his care — he and his caregivers $3 more than the state-sanctioned rate.

Prior to launching the lawsuit, Freeman was having difficulty hiring caregivers at the lower rate. Not only did he have to pause his college education, he was at risk of being forced to move to a nursing home.

Freeman hopes to return to Western Oregon State College to complete his sociology degree and become a crisis counsellor.

Ciprofloxacin: Use Caution
Ciprofloxacin is a common antibiotic often prescribed to people with SCI for urinary tract infections (UTIs). Recently, the American Food and Drug Administration (FDA) issued a warning about the antibiotic because it may cause tendon ruptures, particularly in joints like the shoulder rotator cuffs. This is an overworked and critical joint for people with SCI, and any damage to its tendons would have disastrous consequences.

The problem, it seems, is that ciprofloxacin is chondrotoxic — in other words, it removes magnesium from tissue. Magnesium is critically necessary for healthy cartilage.

The FDA warns that any signs of inflammation at the critical joint sites should be a sign to stop using the drug immediately. Your doctor may not yet be aware of this report, so don’t hesitate to bring it up if you’re being treated for a UTI.

New Ontario SCI Resource Centre
If information is power, then CPA Ontario and Toronto Rehab are doing their best to ensure Ontarians with SCI are a force to be reckoned with. In September 2008, the two organizations launched the Spinal Cord Injury Information and Resource Centre, which provides basic and specialized SCI information and is intended to benefit people with SCI and their families, health care providers and the general public. The Centre’s underlying philosophy is to “promote self-management and foster the exchange of knowledge to increase independence and opportunities for people living with spinal cord injury.”

The Centre has a warm, non-clinical atmosphere, and features two public access computers which are fully equipped with adaptive technology. Other resources include pamphlets, books, DVDs, and videos. For information, contact the Resource Centre at 416.422.5644 ext. 267.

Petitclerc Named Top Canadian Athlete
What do Rick Hansen and Chantal Petitclerc have in common? The duo are the only two wheelchair athletes to ever receive the coveted Lou Marsh Trophy.

In December, Petitclerc became the 72nd recipient of the honour, which is given annually to Canada’s most successful athlete by a panel of sports journalists and luminaries from across the country.

During the Beijing Paralympics, Petitclerc won an astonishing five gold medals — two of them within a 90 minute span (she set two world records in the process). Petitclerc has won 14 golds and 21 total medals over a career that’s spanned five Paralympic games.

The panel selected Petitclerc over a number of other more prominent able-bodied athletes, including soccer star Julian de Guzman, two-time NBA MVP Steve Nash, and world figure skating champion Jeffrey Buttle. Last year’s winner was Pittsburgh Penguins star centre Sidney Crosby.

For the record, Rick Hansen shared the Lou Marsh Trophy with Wayne Gretzky in 1983 after winning eight gold medals and setting eight world records at the first ever Pan-American games for athletes with disabilities.

Spring 2009
Imagine an online resource that a clinician or a person with a SCI could access for free and, in minutes, find the most scientifically-validated methods of dealing with a wide spectrum of SCI-related health or rehabilitation issues.

If this sounds like fiction, think again—SCIRE 2 is that resource.

In 2004, a group of Canadian experts in the field of SCI came together to discuss a challenging problem: how could busy front-line clinicians, facing oceans of research findings and information, somehow determine the best SCI rehab treatments for their patients?

The result of their brainstorming and two years of work that followed was the Spinal Cord Injury Rehabilitation Evidence, or SCIRE. Published in 2006, SCIRE was an unprecedented evaluation of the vast amount of knowledge specific to SCI rehabilitation from around the globe—and a summary of “the best of the best” into a single document.

“There was a great need for disseminating information differently to clinicians,” says co-editor Janice Eng, ICORD researcher and Professor, Department of Physical Therapy at the University of British Columbia. “With SCIRE we provided accurate information about the effect of rehabilitation healthcare for people with SCI by using a systematic and transparent procedure to assess and synthesize the evidence of the effects of rehabilitation interventions in SCI.”

This was no easy task. First, the SCIRE team had to develop an accurate and impartial evaluation tool. Only then could the work begin in earnest—every SCI rehabilitation intervention described in the scientific literature would be carefully screened with the evaluation tool to determine what works—and what doesn’t—in the world of spinal cord injury rehabilitation.

A Canadian research collaboration is bringing much-needed clarity to the world of spinal cord injury rehabilitation.
world of SCI rehabilitation.

The effort involved the review of some 14,000 articles. Of those, approximately 1,200 met the criteria for inclusion in SCIRE. In addition to the editorial team, more than 60 experts in the field of SCI rehabilitation from across Canada assisted with writing the chapters.

The entire undertaking was a collaboration between Vancouver’s GF Strong Rehab Centre, London, Ontario; St. Joseph’s Health Care, the International Collaboration on Repair Discoveries (ICORD), Lawson Health Research Institute in London, University of British Columbia, and University of Western Ontario.

The finished project was made freely available on the Internet, and within two years, it had been viewed online more than a quarter million times.

But the SCIRE team wasn’t thinking about resting on its laurels. Early in 2008, the team went back to work on version two. The goals were to bring SCIRE up to date with new techniques and to be more inclusive of the range of SCI rehabilitation interventions. SCIRE 2, released in October 2008, is more than 1,000 pages and features updates to the original 22 chapters and new chapters on assistive technology, aging with SCI, physical activity, and community integration.

“The rigor and quality of the work have been recognized by the academic community with invitations to submit our work to their journals,” says Eng. “To date, we have 18 peer-reviewed journal articles published or in review, and have presented at over 20 conferences.”

Eng is quick to point out that SCIRE will continue to evolve. “For the SCIRE project to remain useful, it will be critical to keep the work updated, in addition to adding new topics which emerge as practice evolves,” she says. “We’re also beginning the process in using SCIRE as a platform to springboard a number of new projects which will advance knowledge translation in this field.”

“We knew that, by starting with a continually updated platform of evidence, we’d be able to create other important products to move the field of SCI rehabilitation forward,” says co-editor Dalton Wolfe, Associate Scientist in the Program of Aging, Rehabilitation and Geriatric Care at Lawson Health Research Institute in London, Ontario. “Even from the start, we envisioned SCIRE as means to produce various applications that might inform research and knowledge translation activities—as well as assist in the development of standards of care relating to both practice and outcome measurement.”

While it’s true that SCIRE was primarily intended for health care professionals, the document has proven to be a valuable resource for people with SCI, who are increasingly interested in playing a role in their own health care.

“SCIRE is certainly a tool that can help people with SCI and their families get a better understanding of their healthcare and take an active role in maintaining and improving their health and quality of life,” says Wolfe. “We encourage everyone with a SCI to take a look at SCIRE—and to ensure that all of the members of their health care team know of its existence.”

“I had an e-mail from the Japan Spinal Cord Association saying that their consumers found SCIRE to be a valuable link,” says Eng. “It certainly has a worldwide following.”

This global presence will be reflected in future versions of SCIRE. The team now includes SCI experts from Australia and is increasingly partnering with other researchers and clinicians from around the world.

“We look forward to building on the success and collaborating with others to build an even stronger SCIRE,” says Eng. “SCIRE 2 is available for free online viewing or in hard copy (on demand). Visit www.icord.org/scire for details.”

The SCI Solutions Network has made a commitment to provide further support for SCIRE updates. “We recognize the important contribution made by SCIRE in advancing SCI best practices,” says Eric Boyd, SCISN CEO. “The entire team is to be commended for their contributions. As well, the visionary financial support initially provided to the SCIRE project by ICORD, The Ontario Neurotrauma Foundation, and The Rick Hansen Foundation must be acknowledged.”

**Evaluating Acute Care in SCI**

A SCISN-funded team of SCI acute care and treatment researchers are working on a body of work that will complement SCIRE.

Ideally, anyone with a traumatic SCI would receive the highest standard of care from the time of injury right through to surgery and transfer to the ICU. But in Canada, this pathway of care can sometimes be inconsistent. An initial survey of Canadian hospitals has shown that there are several centres of excellence specifically equipped to provide high quality treatment for SCI, but there are many other centres that can’t provide the same level of care.

SCISN believes there is a need for a set of evidence-based best practices that all emergency response workers and facilities can use to care for patients who’ve sustained a SCI. To this end, we’re helping to orchestrate the massive task of systematically reviewing the many different areas of SCI acute care: pre-hospital care, which includes transfer from the scene of injury to the hospital; imaging and diagnosis; the timing of surgery; and the issues involved in ICU care. The authors involved have reviewed thousands of scientific and clinical peer-reviewed articles and will present the work as a set of best practices for the care of patients with SCI.

Dr. Michael Fehlings, a member of the SCISN Research Management Team who is leading the project, says that the systematic review “will serve as a benchmark for the professional community and will define best practices for acute SCI.”

Also included in the systematic review is an evaluation of scientific discoveries in SCI acute care treatments and therapies, with the goal of identifying the best candidates for translation into clinical trials. “These systematic reviews will provide a comprehensive assessment of the basic science literature related to repair and regeneration of the injured spinal cord,” says Fehlings. “This work will inform future research strategies for the SCISN.”
Paddling is for everybody

Dartmouth, Nova Scotia is one of Canada’s canoe and kayak hotspots. Now, with a new accessible dock, paddlers of all abilities can get on the water. by Dylan DeMarsh

There’s a strong case to me made that Canada’s national pastime was developed on the frozen waters of Lake Banook in Dartmouth, Nova Scotia. It’s here, some historians claim, that British soldiers and local children donned skates and slowly modified the game of hurley into what we now know as hockey.

Today, the pristine lake is a focal point for another sport: paddling. Nestled in the heart of Dartmouth, Lake Banook is the bustling centre of the Halifax region’s thriving paddling scene. It’s home to three paddling clubs and features a kilometre long world-class flatwater paddling course which has hosted the Senior World Championship and World Marathon Championship for canoeing.

And now, paddling at Lake Banook is an equal opportunity sport, thanks to the Canoe Kayak Canada’s PaddleALL program, Rick Hansen Wheels in Motion, and the SCI Solutions Network. The partnership made it possible to build the Halifax area’s first accessible boat dock, which is providing opportunities for paddlers of all abilities to participate together in kayaking and canoeing.

Among those benefitting from the new facility is Nicole Durand, an 18 year old student who has spina bifida. “I had tried paddling when I was younger and I really enjoyed being free on the water—and I loved the serenity of the scenery,” says Durand. “Now, with this new dock in place, I have the chance to combine the peacefulness of the area with my competitive side.”

Durand began paddling competitively last summer as part of the Atlantic Division of Canoe Kayak Canada’s PaddleALL program, which promotes participation for individuals with disabilities in canoeing and kayaking.

“I really enjoy the competitiveness as well as meeting people who participate in the PaddleALL program,” she says. Heather Robertson Corrigan, coordinator of PaddleALL for the Atlantic Division, says that paddling provides a unique opportunity for people with disabilities to participate and compete.

Above: Nicole Durand prepares for a paddle using the accessible dock, with fellow paddlers (left to right) Jeff Van Horne, Sarah Cameron, Emily Reardon, Laura Lewis and Julie Marks give her a hand. Right: This summer, when Nicole competed for the first time, Olympic canoeist and Dartmouth native Andrew Miller was on hand to cheer her on.
together. “The kayak equalizes abilities as the task to paddle can be completed without the use of the leg muscles,” says Corrigan.

Not only that, adds Durand, the sport allows disabled and non-disabled athletes to participate together. “Being a person with a disability, this means a lot, because many times there are programs that are for each group, disabled and able-bodied,” she says. “But now, because of the dock, they can be together and feel like they’re not different.”

The accessible dock allows paddlers with disabilities to enter their boats at the same location as all of the other paddlers. “The idea is to provide the paddlers with the ability to gain entry into their boats as independently as possible, just like all of the other paddlers,” says Corrigan.

Other docks at Lake Banook are about 12 inches off of the water, making it difficult for people using wheelchairs to transition to their boats. “Ease of entry is best when the docks are six to eight inches from the water to the dock surface,” says Corrigan.

The dock was funded in part by the Halifax Rick Hansen Wheels In Motion event held on June 8, 2008. A portion of the funds raised by Wheels In Motion are used to support Solutions for people living with SCI. Solutions are identified and provided through the SCI Solutions Network.

Solutions address the most important, self-identified, unmet needs of people with SCI—needs that can’t be met by traditional programs, services or funding sources. Solutions are developed and implemented by Local Solutions Teams that bring a broad range of experience and expertise to the process.

In some cases, Solutions may be on a larger scale, with Solutions Teams investing in community-based organizations to support their goal of helping many people with SCI. The accessible dock project is a perfect example of this type of project.

For more information, visit www.scisolutionsnetwork.ca.
Restored hand function,” says Dr. Arthur Prochazka, “is at the top of the wish-list of people with tetraplegia—and also many people who are partially paralyzed due to stroke and multiple sclerosis.”

Even small improvements in hand function, says Prochazka, can have huge implications, such as becoming employable or being able to live more independently without full-time attendant care. Besides the obvious quality-of-life improvements for individuals who are able to regain some hand function, there’s also potentially significant cost savings for Canada’s health and employment insurance programs.

Prochazka, a professor at the University of Alberta’s Centre for Neuroscience and Department of Physiology, has spent much of his career searching for new and better ways of helping people with paralysis regain function. For example, in the late 80s, he and colleagues at the U of A developed the Bionic Glove, a wearable prosthesis that employed functional electrical stimulation (FES) to restore the ability to grasp for people with tetraplegia (the Bionic Glove has since been upgraded and is at various stages of testing and commercialization).

Along the way, it became clear to Prochazka and other researchers that stimulating key paralyzed arm and hand muscles, in combination with a daily hand exercise regime carried out over several months, can significantly improve hand function. In other words, repeatedly stimulating paralyzed hand muscles can lead to clear and lasting improvements in hand function—without any outside intervention or stimulus once the regimen is finished.

The reasons for this, says Prochazka, are largely unknown. “Several lines of evidence indicate that neuronal circuitry in the spinal cord is reorganized so as to strengthen the effect of residual descending commands from the brain,” he explains, noting that up to 80 percent of all SCIs are incomplete, which means that some residual connections between the brain and neurons below the level of the injury are retained. “However,” he adds, “some of the improvement could also be biomechanical in nature—for example, muscles innervated by spinal cord neurons above the injury making movements that enhance stretch reflexes or passive forces in muscles innervated by neurons below the injury.”
Regardless of the underlying reasons, the emerging benefits warranted a serious discussion of how this type of rehab regimen could be made feasible. The hurdles were obvious. For instance, what about the high cost of delivering this type of rehabilitation over a period of several months at an institution? What about the transportation and scheduling problems faced by participants, particularly if they live in a rural community?

The solution, reasoned Prochazka, was to somehow allow the participant to perform the regimen in the comfort of their own home. And that's exactly what he and a dedicated team of young scientists, therapists and engineers have achieved with the ReJoyce—a unique system that combines FES with in-home tele-rehabilitation (or teletherapy).

In particular, Prochazka singles out Jan Kowalczewski, one of his graduate students, for conceiving the ReJoyce final design and playing a crucial role in every stage of its development.

What is the ReJoyce? Picture yourself sitting in front of a workstation set up in your home. Also in front of you is a spring-loaded, jointed arm that presents you with a number of manual tasks of varying difficulty. An FES wristlet, triggered by a wireless behind-ear sensor that detects small toothclicks, stimulates the paralyzed hand muscles required to complete these tasks. All of your movements are measured with sensors, and using a standard Internet connection and webcam, your progress is also guided, monitored and evaluated by a therapist working perhaps hundreds or even thousands of miles away. Each daily session is an hour long, but the time passes quickly, since all of your movements are controlling skill-based computer games on the screen in front of you.

“If you’re injured at the C5, C6 or C7 level injury and have some upper-arm control but poor or absent hand function, a few weeks of daily FES-assisted exercises, playing computer games on the ReJoyce system, may noticeably improve your hand function to the point where you’ll be able to open your hand more and grasp objects more firmly,” says Prochazka. But he’s careful not to oversell the benefits.

“Initially, study participants are excited, with high expectations, regardless of what we say. As the weeks and months go by, they accept the fact that the improvements in hand function, though significant and very welcome, still fall short of what they might have expected. Nonetheless, most of our subjects, after going through the 16-week protocol, have opted to go through it again for their second hand. This speaks for itself.”

The first randomized controlled SCI trial of the ReJoyce system has just been completed in Alberta, Saskatchewan and BC. It was funded by the International Spinal Research Trust. In December, Rehabtronics Inc., a U Of A spin-off company, shipped five ReJoyce systems to Melbourne, Australia for a study funded by the Victorian Neurotrauma Initiative. Six more systems have recently been ordered for pilot studies in each major city in Australia and New Zealand. Another system is being sent to the Miami Project to Cure Paralysis.

The SCI Solutions Network is also supporting the project, and has funded ten ReJoyce systems for a study taking place in Vancouver and Montreal. And a group at Imperial College in London, England is planning a study involving five ReJoyce systems.

Prochazka says commercialization is important to ensure the success of ReJoyce and allow it to be used by as many people as possible. He expects it will be launched commercially in Canada in mid-2009, and is working with Bioness Inc., a California medical devices company, which will act as the distributor outside of Canada.

“In-home teletherapy provides a new treatment option whereby rehabilitation can be maintained after patients leave hospital. It also represents an exciting opportunity for enterprising physiotherapists and occupational therapists to set up their own businesses, providing remote therapy into peoples’ homes, from locations convenient to them. Therapists love the freedom of being able remotely to treat patients in their own homes at mutually convenient times.”

Here in Canada, Prochazka is hopeful that ReJoyce will be adopted throughout the provinces as a standard clinical practice—something he feels will help speed global acceptance.

“FES-assisted teletherapy really does improve hand function,” he says. “Global implementation is a lofty goal in itself and will take much effort and at least a decade or more. In the meantime, it’s great to see the in-home teletherapy concept working on a daily basis, and being accepted as the wave of the future by more and more of our colleagues around the world. It’s also great to hear our SCI participants say that their hands are getting better.”

For more information on Dr. Arthur Prochazka and his work, visit his website at www.ualberta.ca/~aprochaz/hpage.html.
People with tetraplegia have made it clear that improved hand function can make a real difference in their independence and quality of life. Even a slight improvement can mean the difference between writing, operating a computer, or dressing yourself—or needing someone to do these things for you.

Around the world, SCI translational research projects are focussing on improving hand function after SCI. These include procedures and treatments immediately following injury, tendon transfer surgery, pharmaceutical options and improved rehabilitation techniques and tools, such as Dr. Arthur Prohazka’s ReJoyce system described on the previous page.

But how do you measure improvement to see what works—and what doesn’t?

Up to this point, there’s been no accepted standard for researchers and clinicians attempting to measure hand function. Several different measurement tools, such as the Quadriplegia Index of Function (QIF), are in use around the world.

Sukhvinder Kalsi-Ryan, a PhD student and registered physical therapist at Toronto Western Hospital in the Krembil Neuroscience Program, says that the limiting factor of all these tests is that they only determine whether an individual can perform a task or not. "The shortcoming of this method is that these measures do not assess how an individual performs a task," says Kalsi-Ryan. "Therefore, if impairment is changing, it’s not necessarily picked up by a functional measure."

She explains that specialists working in the field have long realized that current measurement tools aren’t sensitive enough. To address the problem, the Christopher and Dana Reeve Foundation, the North American Clinical Trials Network and ICORD cosponsored an upper limb workshop in May.
2006. Upper limb specialists from Canada, USA and Europe came together to discuss the need for a more sensitive impairment measure of the hand and arm—a measure that could be used to gauge the success of several promising drug trials and other interventions.

Kalsi-Ryan was invited to attend based on her Masters work on a Tetraplegia Hand Measure. At the meeting’s end, a task force of six individuals was struck, with Kalsi-Ryan playing a lead role. Other members of the GRASSP Research and Design Team are Claudia Rudhe (who, like Kalsi-Ryan, also contributed her Masters work on a Link Hand Function Test), Susan Duff from Thomas Jefferson University, Dr. Michael Fehlings (one of the members of the SCI Solutions Network’s Research Management Team), Dr. Armin Curt, and Molly Verrier, M.H.Sc. (Kalsi-Ryan’s graduate supervisor).

Together, the team carefully analyzed a number of existing hand function tests and combined the most trustworthy and complementary of these approaches into a single, comprehensive battery of tests, now known as the GRASSP (short for Graded Redefined Assessment of Strength Sensibility and Prehension).


Using a specialized GRASSP toolkit, a trained clinician can now perform an extremely sensitive and comprehensive test of hand function in about 45 minutes.

“The benefit of the GRASSP,” says Kalsi-Ryan, “is that it provides an impairment profile of the hand that incorporates sensory, motor and integrated components of hand function, which can inform us as to why hand function is poor and allow us to make decisions around appropriate interventions for an individual.”

Another benefit is that the GRASSP can distinguish between neurological change and functional change. Functional change occurs when an individual can perform a task faster or with less assistance, whereas a neurological or impairment change occurs when there is a physiological change in a person’s sensation or strength.

“Functional measures may show someone is performing a task faster or more efficiently,” says Kalsi-Ryan. “But this can be due to practice or a person perfecting the technique, and not necessarily due to a change in sensation and strength. An improvement in function can occur without a change in the neurological state. However, to determine if interventions are having an impact, we need to determine if the impairment is changing as well.”

Kalsi-Ryan explains that the reliability and validity of the GRASSP have been clearly established and were expected be published before the end of 2008. “In comparison to some of the other SCI measures available,” she explains, “the GRASSP is well validated and can be promoted as a best practice even while the remaining testing is ongoing.”

Support from the SCI Solutions Network, along with the Ontario Neurotrauma Foundation and the Physiotherapy Foundation of Canada, is allowing GRASSP testing to be finalized in 2009. The SCI Solutions Network is also examining how it can help promote the GRASSP as a best practice here in Canada and throughout the world.

**SCISN People: Sukhvinder Kalsi-Ryan**

Sukhvinder Kalsi-Ryan has been a registered physical therapist for 13 years and has worked in the Krembil Neuroscience Program at Toronto Western Hospital for the past ten years. She’s also a PhD candidate funded by the Toronto Rehabilitation Institute Scholarship Fund and the Physiotherapy Foundation of Canada Scholarship. In 2008, she also held an Open University of Toronto Fellowship.

“I’ve always enjoyed the neurosciences and found individuals with spinal issues of particular interest, as the nature of the pathology and the clinical presentations are so broad,” says Kalsi-Ryan. “My personal gratification is the being able to provide an individual with something that enhances their life, whether it’s education or the ability to grasp again.”
When it comes to improving cardiovascular health, reducing secondary complications and even staying off the effects of aging for people with SCI, the jury’s in for some time: getting and staying in shape can make a huge difference.

But for people with SCI, maintaining physical fitness can be challenging. Limited numbers of accessible fitness programs and facilities, high cost of specialized fitness equipment, and few guides for wheelchair-based exercise all combine to limit people’s enthusiasm for getting in shape.

Dr. Kathleen Martin Ginis, a kinesiologist at McMaster University in Hamilton, was determined to find a solution. She reasoned that Canadians with SCI would be motivated to improve their fitness if they had access to a personal fitness counsellor who could teach them about the many ways of staying fit while providing motivation and encouragement to make the necessary lifestyle changes. Such a service, she believed, could be easily offered via telephone to all corners of Canada.

Last year, Martin Ginis presented her vision to the SCI Solutions Network and the Rick Hansen Foundation. An early investment grant of $100,000 was provided, and the Get in Motion physical activity counselling service became a reality in June, 2008.

“The service begins when an individual makes contact with Get in Motion via voicemail or email,” explains Martin Ginis. “A physical activity counsellor then initiates a follow-up telephone call to obtain some background information, such as age, injury level and current physical activity level. At this point, a call frequency contract is established to determine how often the client wishes to receive a support call. We encourage our standard contract, which consists of calls every week for the first two months, bi-weekly calls for the next two months, and monthly calls thereafter.”

In addition to individualized counselling, participants also receive a free physical activity toolkit which includes two therabands (an effective tool for resistance training from a sitting position that can be used in any setting) and information on physical activity specific to people with SCI. And, as Get in Motion is also a research project, participants are also invited to complete a survey to help establish the effectiveness of Get in Motion.

Results from the first six months of the program were announced in December. Thirty four participants—15 women and 19 men—took part. They ranged in age from 33 to 67, and had injury levels ranging from C2 to T12. As a group, they reported significant improvements in both the number of days per week they are physically active, and in the intensity of their workouts.

“Overall, increases have been observed across the board in both the number of days of exercise performed per week and the amount of time allotted to each exercise bout,” says Martin Ginis. “After two months of using the Get in Motion service, clients were physically active, on average, four days per week. It’s particularly encouraging to see increases in heavy intensity activity, as this type of exercise may yield the greatest health and fitness benefits.”

She adds that many participants report that receiving a weekly call from the activity counsellor makes them more accountable for their physical activity, and motivates them to be more active. Some participants have also gained assistance in developing exercise plans, connecting to physiotherapists in their area, and joining exercise facilities and organized sport groups.

“With such promising preliminary results, the Get In Motion team encourages Canadians with SCI to contact us,” says Martin Ginis. “We can provide ongoing telephone support to help you become more active and we can answer specific questions you may have regarding physical activity. Whether you’re considering becoming physically active, have just begun a physical activity program, or have been physically active for a while, you can benefit from the services provided by Get in Motion.”

Based on the early results and future potential of the Get In Motion program, the SCI Solutions Network has expanded its commitment to the fitness telehealth concept. We have designated this approach as a National Solution for funding via a portion of this year’s Wheels In Motion net proceeds. Future possibilities for the program include using video conferencing so that fitness counsellors and participants can enjoy a visually powerful medium during the counselling process.

For more information or to take advantage of this free service, contact Get in Motion at: 1-866-678-1966 (toll free voicemail), motion@mcmaster.ca, or www.sciactioncanada.ca
Motivated.

“Motivated” would be an appropriate word to describe 27-year-old Jennifer Gabrysh. Since the 2007 swimming pool accident that resulted in tetraplegia, Gabrysh has tackled every challenge that stood in the way of regaining her independence. Her motivation also extends to research—she made a personal commitment to get involved in any relevant projects that had the potential to benefit her and others with SCI.

Last year, Gabrysh learned about Dr. Arthur Prochazka’s ReJoyce trial at the University of Alberta’s Centre for Neuroscience and Department of Physiology. The study was designed to determine the efficacy of the ReJoyce system, which holds the promise of improving hand function for people with tetraplegia. Jennifer jumped at the chance to get involved.

“I had been looking at what clinical trials are available because I want to see research proceed in all aspects of SCI, and I was excited to find a study which was not too far away,” says Gabrysh.

After she was accepted into the study, she made her first trip to Edmonton, driving 800 kilometres up the Yellowhead from her home in Regina. But travelling more than eight hours by car proved to be too much.

“I decided that I would get my father to drive me to Edmonton and try to stay with relatives. But I quickly discovered that my plan wasn’t going to work. I found after one trip by car that it was really hard on my body to sit for that period of time, and when I needed to be there every two weeks for the study, I realized that I was going to have to give up on it. I wanted so badly to be a part of this study.”

Before she could withdraw, Dr. Prochazka told Gabrysh about the “Access to Research Studies” program, which is funded through Rick Hansen Wheels In Motion and delivered by the SCI Solutions Network.

Gabrysh found out that she could apply for funding from the program to cover the costs of air travel and accommodation for her and her family while taking part in the study. “Being able to fly plus have accommodation at a hotel, which enabled me to be able to rest properly after the session at the university, was invaluable,” she says. “I wouldn’t have been able to take part without this funding.”

The program is one part of the SCI Solutions Network’s commitment to creating connections between Canadians with SCI and researchers. The SCI Solutions Network works to ensure that Canadian researchers clearly understand the needs, concerns and desired outcomes of people with SCI, as well as make Canadians with SCI aware of the excellent work being done by researchers across our country. The SCI Solutions Network also works to stimulate greater participation in research projects.

“Canadians with SCI have clearly expressed their desire to participate in research, but often aren’t able to because of the personal costs involved,” says Eric Boyd, CEO of the SCI Solutions Network. “The price of travel and related expenses often prevents people from participating in worthy trials and studies and contributing to an important body of knowledge. That’s why we put the program into place in 2007.”

For Gabrysh, access to this funding was crucial for her participation. Now she hopes that others will get involved because of it. “There are exciting things happening in SCI research, and it’s unfortunate to hear that sometimes there is a shortage of people able to take part in these studies,” says Gabrysh. “I would encourage anyone to take part in a study—it’s interesting, and quite possibly will benefit you and hopefully many others with spinal cord injury.”

Funding is Available.

If you or someone you know is interested in taking part in research related to SCI, visit www.scisolutionsnetwork.ca to learn about current Canadian SCI research studies, important facts to consider before you participate, and details on the program’s eligibility criteria and the application process. You can also download an application form.
Hi-Tech Home

The SCI Solutions Network has a new home: the recently completed, state-of-the-art Blusson Spinal Cord Centre at Vancouver General Hospital.

After 20 years of dreaming, ten years of planning and five years of building and preparation, BC Premier Gordon Campbell officially opened the new $45 million, six-story Blusson Spinal Cord Centre on Tuesday, November 18, 2008. Among those on hand to assist Premier Campbell were Rick Hansen, outgoing Vancouver Mayor Sam Sullivan, and Stewart and Marilyn Blusson, the facility’s patrons whose donation allowed a dream to become reality.

The Blusson Spinal Cord Centre represents a truly visionary approach to advancing research and providing care for people living with SCI. It was inspired by Rick Hansen’s vision and brought to life through a unique partnership between the Rick Hansen Foundation, UBC, ICORD, Vancouver Coastal Health, Vancouver Coastal Health Research Institute, VGH and UBC Hospital Foundation, the Canada Foundation for Innovation, and Dr. Stewart Blusson and his wife Marilyn. Many individuals worked tirelessly to bring the project to completion, notably ICORD Director Dr. John Steeves who helped articulate the vision and oversaw the design and construction processes.

The Blusson Spinal Cord Centre is home to the largest and most comprehensive interdisciplinary SCI research and care program in the world. Over 300 SCI researchers and practitioners from the sciences, medicine, surgery, rehabilitation, engineering, and community-based humanities and services work closely with people with SCI under one roof to facilitate the discovery and implementation of solutions to improve functional recovery, mobility, community integration and quality of life for people with SCI.

Blusson Spinal Cord Centre tenants include:

- the SCI Solutions Network, located on the sixth floor.
- ICORD, which occupies four of the Centre’s six floors to conduct broad-based research in basic preclinical discovery, human-based discovery, acute clinical interventions, chronic care and rehabilitation, and community integration and participation.
- The Brenda and David McLean Integrated Spine Clinic that delivers specialized care for people with painful, disabling spine diseases and conditions and SCI.
- Rick Hansen Wheels In Motion, Ambassador and Let’s Play programs.

The entire building has been designed to function as a testing ground for new accessibility technologies. Everything from light switches and environmental controls to simulated living and working environments are being evaluated inside the building. People with SCI will experience the unique convenience of a “one-stop shop” outpatient clinical care centre. Coordinated bookings to see a variety of specialists on the same day and/or to participate in clinical studies can be made through one person with a single phone call. And there are no wheelchair symbols to be found anywhere in the building, since the entire facility is wheelchair accessible: a ramp accesses all public spaces, elevators can be operated with bumper buttons, outlets and light switches are located three feet above the floor, all work and lab benches are fully adjustable, and all washrooms are accessible.

www.scisolutionsnetwork.ca