Bridging the gap

An innovative program is reconnecting thousands of Canadians with SCI to sport

under pressure:
How we’re tackling the pressure ulcer problem
Mounting pressure...

Pressure ulcers. Quite simply, they are the bane of our existence.

There are many serious secondary health complications of SCI—autonomic dysreflexia, neurological pain, bladder infections, cardiovascular disease and osteoporosis are just a few of the conditions that come with the territory. But we believe that none of these have as much impact on people with SCI as pressure ulcers.

We’re not talking about a sore you can put a bandage on and get on with your life. We’re talking about wounds that can force you into bed for a few weeks. And that’s if you’re lucky, since many pressure ulcers can require months and even years of bedrest to heal. And it gets worse. Pressure ulcers kill people with SCI. One study estimates that they are the fourth leading cause of death for people with SCI.

This is coupled with the fact that pressure ulcers are a widespread problem, with evidence suggesting that as many as 80 percent of people with SCI experience at least one pressure ulcer in their lifetime. While poor health and failure to take the proper preventative measures clearly lead to greater risk, pressure ulcers are an equal opportunity affliction—even the most hale and hearty are at risk. And so too are the most functional of people with SCI, as pressure ulcers can bring down people with incomplete paraplegia as easily as people with tetraplegia.

All of this was made perfectly clear to me during a past career, when a colleague—an integral part of our team who has incomplete paraplegia—was diagnosed with a deep tissue pressure ulcer. When he was finally able to return to work and to other active aspects of his life, three surgeries and two years of recovery had been required.

What happens in these situations? Lives get put on hold. Careers and relationships falter. Other aspects of physical health deteriorate. Too often, depression and hopelessness set in. And a mind-boggling amount of money is spent in health care costs.

We understand the problem. So too does our funding partner, Health Canada. And that’s why one of our six core objectives is “a significant reduction in the incidence and severity of secondary complications associated with SCI.” Implicit in this objective is that we tackle the pressure ulcer problem head on. We are committed to finding new ways of preventing and treating pressure ulcers—and to ensuring that these methods become enshrined as best practices in our country’s health care delivery system. The work has started in earnest, and I urge you to read about our efforts in this issue of Solutions magazine.

Best wishes,

Eric Boyd, CEO
SCI Solutions Network
With the blessing of the Rick Hansen Foundation, the SCI Solutions Network is moving towards independence. In February, we were incorporated as a national not-for-profit organization. Our application for charitable status is in progress with Canada Revenue Agency—we anticipate approval in late 2009. Earlier this year, an inaugural core Board of Directors was appointed. We believe they truly represent the breadth and fullness of the Canadian SCI community.

- One member from Rick Hansen Foundation Board of Directors (to be determined)
- Dr. Armin Curt – Professor & Chairman, Spinal Cord Injury Center, University of Zurich, former ICORD Chair in Rehabilitation, former member of SCI Solutions Network Research Management Team
- Rajiv Das – former Chair of the SCI Solutions Alliance Board of Directors, businessman and former analyst with CIBC World Markets, individual with SCI
- Gary McPherson – former President of CWSA; former Chair of Alberta Premier’s Council on the Status of Persons with Disabilities; Executive Director, Canadian Centre for Social Entrepreneurship, University of Alberta; individual with SCI
- Harley Nott – former prosecutor with Ontario Ministry of Justice, former SCI Solutions Alliance Board Member, Member of Ontario LHIN Health Board, individual with SCI
- Daryl Rock – former Program Manager with Human Resources Development Canada; Associate Director of Knowledge Transfer for Canadian Council on Learning; individual with SCI
- Sam Sullivan – former Mayor of City of Vancouver, disability advocate, individual with SCI
- Marie Trudeau – former SCI Solutions Alliance Board Member, former Director with Human Resources Development Canada, former Executive Director with Quebec Paraplegic Association, individual with SCI
- Dr. David Williams – former astronaut with Canadian Space Agency, former Director of the Space and Life Sciences Directorate at the Johnson Space Center, Director of the McMaster Centre for Medical Robotics at St. Joseph’s Healthcare Hamilton, Professor of Surgery of the Michael G. DeGroote School of Medicine

The SCISN Board of Directors convened for the first time in April 2009, at which time Daryl Rock was appointed as Chair.

We’re seeking 3,000 plus Canadians with SCI to take part in the Spinal Cord Injury Needs vs. Services Utilization Survey, the most ambitious study of its kind ever done in Canada. The goals are to confirm the critical needs of Canadians with SCI – and determine how government and community programs are meeting those needs.

Why this survey matters: As a Canadian who has a SCI, this confidential and anonymous survey is a unique opportunity for you to have your needs known and voice your opinions about what’s working – and what’s not – in our country’s health and social support systems. The researchers involved in the survey are expected to publish a body of work that has the potential to improve the quality of life of people with SCI and benefit organizations that support Canadians with SCI.

How it works: The survey will take place in the Fall of 2009. Participants will be able to complete the survey online, by phone or questionnaire. It will take about 90 minutes to complete. Participants will be compensated for their time.

Who is conducting the survey: The survey is being conducted by a team of Canadian researchers led by Dr. Luc Noreau of Laval University, under the umbrella of the SCI Solutions Network and The Rick Hansen SCI Registry.

For more information and to get involved, visit: www.sci-survey.ca
Innovations

New technologies for people with SCI

**Hands-Free Steering**
The Balance Sport Wheelchair was created in 2005 by three industrial design students at the University of Illinois. The intent of the designers was to build a better wheelchair for sports—specifically, a chair that could be maneuvered without using hands, so that the user could be free to pass a basketball or return a tennis volley. To achieve that, they came up with a braking and steering system based on seat movement. As the user leans and shifts weight, pressure is applied to slow, steer or stop the chair. It’s not hard to envision how this feature would come in handy in daily wheelchair use as well. Last year, the innovative wheelchair won the gold medal in the Medical & Scientific Concepts category of the prestigious IDEA Awards, co-sponsored by *Business Week* magazine and the Industrial Designers Society of America. The chair is not yet commercially available, but one of the designers, Eric Larson, reports that a prototype has been making the trade show rounds and several manufacturers have been approached.

**Making the Grade**
MagicWheels have a patented gear mechanism that operates in much the same way as a bicycle gear. When you approach a hill, steep ramp, or rough terrain, you engage the low gear and negotiate the terrain using half the effort. The low gear mode also has an automatic hill holding feature, preventing your wheelchair from rolling backwards. As well, when you wheel down an incline using low gear, only half the usual force is needed to slow down or stop, allowing a more confident descent. An independent, U.S. government-funded research study validated that the system can result in reduced shoulder pain. Most manual wheelchairs can be easily retrofitted with MagicWheels. For more information, visit www.MagicWheels.com.

**A Good Listener**
The Moshi Voice Control (VC) Alarm Clock doesn’t just talk—it listens as well, allowing you to set the time and alarm by your voice alone. You can also ask for the time while getting ready in the bathroom, set the alarm or turn off the alarm without moving from the comfort of bed, and hear the current temperature all the way from the closet. There are no buttons and no complicated programming procedures. Simply activate Moshi by saying, “Hello Moshi”. Moshi will then politely respond with “Command Please.” You then choose any of the 12 voice-activated commands for telling you the time, setting the time, confirming alarm is on, turning on sleep mode, telling you the date, turning on a night light, and more. The Moshi Alarm Clock was awarded the VisionFree Award by the Stevie Wonder Foundation at the Consumer Electronics Show in 2009. But it appears to be a great gadget for anyone with limited hand function as well. For more information, visit www.moshilifestyle.com.

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.
Wheels In Motion

On Sunday, June 14, Canadians joined together in 48 communities across the country for the seventh annual Rick Hansen Wheels In Motion, presented by Scotiabank. These events, along with 36 other special events in support of Wheels In Motion, raised more than $1.2 million to help improve the quality of life of people living with SCI.

“So many people have united with a desire to make Canada a better place for people living with spinal cord injury, and we will make sure their efforts result in a country that is more accessible and inclusive,” says Rick Hansen, President and CEO of the Rick Hansen Foundation. “We are all on this journey together and it is incredibly inspiring to see thousands of people working together to change the lives of their fellow Canadians.”

Funds raised by Wheels In Motion support community-based projects that benefit local organizations and individuals, along with national initiatives that hold the promise of improving the quality of life of all Canadians with SCI. These funds will be administered by the SCI Solutions Network, and Solutions Teams across Canada are already hard at work identifying the priority needs of people with SCI in their communities.

Canadians have now contributed more than $10.8 million to Wheels In Motion since its inception in 2003 to support more than 850 national and local projects in communities from Victoria to St. John’s. For more information on Wheels In Motion, please visit www.wheelsinmotion.org.

Guest of Honour

In July, Canada’s first and only tetraplegic Member of Parliament, Steven Fletcher, paid a visit to the SCI Solutions Network offices at the Blusson Spinal Cord Centre in Vancouver. On hand to greet Fletcher were Rick Hansen, SCI Solutions Network CEO Eric Boyd, and SCI Solutions Network Board Member and former Vancouver Mayor Sam Sullivan. “In a nutshell, it was really an opportunity for us all to get to know each other,” says Boyd. “Rick told Steven about some of his plans for his 25th anniversary of the Man In Motion World Tour, and we learned of the work around disability that the federal government is doing. We gave Steven a thorough tour of the Blusson Spinal Cord Centre, and we believe he was impressed with what we’re doing to address SCI issues here.”

Knowledge Into Action: Funding Available

Recently, the SCI Solutions Network identified three priority areas where validated best practices were ready for implementation into clinical practice: standardized skin care protocols to better prevent and treat pressure ulcers, improving quality of and access to appropriate community-based care following hospital discharge, and comprehensive pain management services to better address this debilitating aspect of living with SCI.

On September 8th, 2009, the SCI Solutions Network issued a Request for Funding Applications (RFAs) to design, initiate, roll out, and evaluate an implementation plan involving one of the priorities described above. Up to three applications will be awarded, each with a maximum total budget of $175,000.

Successful applications will need to involve Knowledge Translation (KT) implementation across at least two different sites or jurisdictions. We encourage the use of an “integrated approach” where a multidisciplinary team (researchers, end users, KT experts) work together to shape the entire implementation process. If two projects use similar approaches on the same topic, we will encourage discussion about the possible merging of applications with the applicants.

Deadline for applications is 4 PM PST, November 2, 2009. Applicants will be informed of the results by January 11, 2010. For complete details, visit www.scisolutionsnetwork.ca.
Through individual equipment grants and research projects investigating new prevention and treatment methods, the SCI Solutions Network is tackling the pressure ulcer problem head on.

by Dylan DeMarsh
When Dennis Downey learned that a local woman living with a serious pressure ulcer had exhausted all avenues of funding for a much-needed pressure relief mattress, he knew there was a solution. As a member of both Local Solutions Teams in the southwestern Ontario communities of Kitchener-Waterloo and Elmira, Downey saw a way for funds raised in Rick Hansen Wheels In Motion events in the two communities to help.

Downey easily related to the experience that the woman in question was dealing with (she prefers to remain anonymous). Downey has lived with a SCI for 31 years, and has dealt with pressure ulcers of his own. Soon after his injury, Downey developed an ulcer that led to major complications during his rehabilitation. He developed another pressure ulcer just two years ago, which took a major toll on his life.

"It took a full year to resolve," says Downey. "It would almost heal, then slip, and I would have to start all over again."

Downey, who lives in Elmira and works full time for Manulife Financial in Kitchener, says he was lucky to have the support of his family, friends and co-workers during such a difficult time. "A pressure ulcer ends up taking away your independence," he says. "You can easily be cut off from the community, becoming increasingly isolated. Pressure ulcers are as debilitating mentally as they are physically."

In particular, Downey credits the support of his wife, who helped dress his wound, and his two children for his recovery. "A lot of other people aren't so lucky," he says. "The situation this woman was in was hopeless. She had truly fallen through the cracks and we realized we couldn't let this situation slide any longer."

Typically, funds raised by Wheels In Motion are used to finance solutions in the community where funds were raised, with an additional portion used to support National Solutions initiatives identified by the SCI Solutions Network. Since the majority of Elmira's funds had already been designated, Downey approached his colleagues on the nearby Kitchener-Waterloo Local Solutions Team with the idea of supporting the purchase of a pressure relief mattress.

"It really hit home for a lot of us," says Downey. "Within a week we had everything lined up."

The Kitchener-Waterloo and Elmira Local Solutions Teams quickly arranged to provide $2,300 each in order to purchase a Select Low Air Loss Mattress for the recipient. The woman, who lives in a small community near Kitchener, has been dealing with pressure ulcers on her hips since October, 2007. The mattress will allow her to lay on her side for extended periods of time without worsening her existing condition while preventing the development of more pressure ulcers.

"This project is an excellent example of solutions working at a higher level to address an unmet priority need for an individual with SCI," says Kevin Murphy, Community Liaison for the SCI Solutions Network. "Together, these two communities provided a very important piece of equipment for this person which will better enable her to reverse the negative effects of the pressure ulcer. For anyone, SCI or not, a foundation of good personal health is paramount to one's ability to successfully carry out the normal activities of daily living."

Pressure ulcers range from blisters on the skin to open wounds that can extend to—and even compromise—the bone deep under the skin and tissue. They’re caused by friction or maintaining one position for too long without moving. People living with SCI are particularly prone to developing pressure ulcers, usually on their backsides, due to spending extended periods of time in a seated or resting position. Several factors add to SCI-related vulnerability, including the loss of cushioning muscle mass due to paralysis, and the inability to feel pain during the early onset of a pressure ulcer. It’s estimated that 80 percent of people living with SCI will develop a pressure ulcer during their lifetime, with 15 percent sustaining one in the first year following their injury.

The most serious pressure ulcers can be fatal. A wound that develops deep in the tissue is more difficult to treat and can extend into bone and organs. Up to eight percent of deaths in persons with SCI have been attributed to complications from pressure ulcers. Even in non-fatal situations, pressure ulcers can forever alter the course of someone’s life. Treatment can involve surgery in extreme causes, but often consists of extended periods of bedrest, ranging from weeks in milder cases to months and years in more critical situations. This inactivity can greatly damage quality of life as a person withdraws from work and social situations, becoming increasingly isolated and dangerously prone to severe depression.

Beyond the human costs, the financial burden heaped on our health care systems in the treatment of pressure ulcers is staggering. The price of treating a single pressure ulcer can exceed $70,000, and it’s estimated that the costs of treating only SCI-related pressure ulcers can reach up to $3.6 billion every year in North America.

What’s most frustrating for those researching, treating, and dealing with pressure ulcers is that these costs could be...
Unfortunately, pressure ulcers remain a significant issue for people with both new and existing SCIs, causing great strain and limitations not only for individuals and their families, but also on local, regional, and national health care systems.

health care facility has a pressure ulcer at any given time, up to 70 percent had wounds that were preventable.

“This translates into untold patient suffering, extra work for health care providers and millions spent in health care dollars that could be directed elsewhere,” said Dr. David Keast, CAWC President, in a press release accompanying the findings of the study. “Clearly we have to take action.”

“Unfortunately,” says Murphy, “pressure ulcers remain a significant issue for people with both new and existing SCIs, causing great strain and limitations not only for individuals and their families, but also on local, regional and national health care systems. Prevention and reducing the effects of pressure ulcers must be top priorities.”

Indeed, the SCI Solutions Network is working in several areas to address the various problems presented by pressure ulcers. In addition to funding community-based solutions such as the pressure relief mattress near Kitchener, our Translational Research Program, with Health Canada funding, is supporting several research initiatives, including a white paper outlining a strategic approach to prevent and reduce the impact of pressure ulcers, and a recently announced research project to test the feasibility of an Internet Pressure Ulcer Clinic (see next page). Other projects will be funded as they are identified. We’ve also provided funding to several individuals to offset their costs of participating in a promising pressure ulcer research trial taking place at the University of Alberta (see page 10).

According to SCI Solutions Network CEO Eric Boyd, the prevention and treatment of pressure ulcers is a top priority for the organization. “Education and research are key in the ongoing movement to reduce the effects of pressure ulcers,” says Boyd. “In the SCI community, everyone needs to participate in educating people with new SCIs, those with existing SCIs, front line health care workers, and home care staff in an effort to raise awareness on prevention and proper treatment of pressure ulcers. The majority of pressure ulcers are preventable. Research on this devastating and expensive health threat is providing some much needed relief in the form of better treatment procedures and equipment, and more accurate information on exactly what causes pressure ulcers and how they progress.”

Saving Skin with Electrical Stim

Electrical stimulation therapy (EST) uses specialized electrodes and equipment to deliver low-level electrical current to a wound. The therapy can help speed wound healing by increasing capillary density and blood delivery, improving wound oxygenation, and encouraging development of the tissue that fills in a wound.

It has been long-validated as an effective treatment of advanced pressure ulcers in several studies. Despite that, EST hasn’t been widely adopted in the Canadian health care system, according to Dr. Pamela Houghton, a University of Western Ontario researcher who specializes in pressure ulcers and skin care.

One of the reasons may be that EST has never been tested in a community health care model or the home setting. Recently, Houghton set out to do exactly that. Her study, titled "Management of Pressure Ulcers in Community Dwelling Individuals with Spinal Cord Injury: Demonstration of a Community Care Access Centre Driven Model of Delivery of Electrical Stimulation Therapy," was completed in 2008 and strongly suggests that the treatment is viable at the community care level.

The study recruited 34 Ontarians with SCI who were living in their communities and dealing with long lasting pressure sores. All participants received, in their homes, the standard pressure sore treatment from a team of health care professionals—the pressure sore environment was optimized for healing, good eating habits were encouraged, and strategies for preventing further skin damage from excess pressure or friction were introduced. In addition, approximately half of the participants received EST as part of their treatment.

On average, pressure sores were 75 percent smaller in the participants who received EST compared to those who did not receive EST. Sixty nine percent of the pressure sores treated with EST healed completely, compared to 22 percent of those without EST. The pressure sores of those who received EST healed much faster than those of the other participants, whose sores were only 36 percent smaller after three months. On average, participants with EST received wound closure after 17 weeks of EST, administered four and a half hours a day.

As an added benefit, EST was economical—the cost was $1,600 per person, which is 11 percent of the average cost paid out by Community Care Access Centres (Funded and legislated by the Ontario Ministry of Health and Long-Term Care) to provide standard wound care to subjects enrolled in the study over the same time period ($13,000 for 252 days).

Participants, as well as their family members, caregivers, and/or community health care professionals, received written instructions on how to administer EST. This patient-centred approach meant that not all participants received the EST treatment in the same manner, but it helped people to follow recommended EST treatment practices, and it enabled people in rural areas to participate in the study as well.

Results of the study were presented at the National Spinal Cord Conference in November, 2008, and have been submitted for publication in a peer-reviewed scientific journal.
The SCI Solutions Network recently made a significant commitment to evaluate an Internet Pressure Ulcer Clinic.

The rationale behind the Internet Pressure Ulcer Clinic is straightforward: many Canadians with SCI live in locations at great distances from health care facilities that specialize in the treatment of pressure ulcers. As a result, it’s believed that many of these Canadians are not getting timely access to the expert care required to minimize the impact of these potentially devastating wounds.

“There are many problems with the existing system,” says principal investigator Dr. Dalton Wolfe, Associate Scientist in the Program of Aging, Rehabilitation and Geriatric Care at Parkwood Hospital in London, Ontario. “Depending on where the patient is and the jurisdiction, the general practitioner or family doctor may be dealing with pressure sores with a lack of specialized knowledge. Meanwhile, those living at a distance to a specialized centre are less likely to get a referral—and if they do, they may be reluctant to act on the opportunity if that service is a significant distance from their home. And while some patients may be treated in their homes, their home care providers may not have specialized knowledge relating to SCI and pressure sores.”

The essence of the concept is that home care providers will work in concert with a highly specialized team, both using a host of high-tech tools including digital photography and digital video, with the internet being the communications medium.

The initial site will be Parkwood Hospital in London, Ontario, where the wound care team already has more than 10 years experience with telemedicine, most recently through the Ontario Telemedicine Network. “Patients who otherwise would have to travel for hours to a specialized centre to receive assessment and recommendations for care can be seen in their own community or home,” says lead clinical investigator Dr. David Keast, Director of the hospital’s Aging, Rehabilitation and Geriatric Care Research Centre. “Even here within Southwestern Ontario, patients often have to travel over two hours each way to be seen and assessed in our specialized clinic here in London. Furthermore, we’re unable to assess patients in their own environment. And environmental factors can be very important when looking at the prevention and treatment of pressure ulcers in SCI patients.”

The two-year project will begin with a six month design phase to determine technology needs and procedures. That will be followed by a six month implementation phase, beginning with training for the community care provider, and moving on to patient assessment and treatment. What’s learned in the process will then become the basis for three more sites—one in Fredericton, one in Winnipeg, and one in Calgary.

Each jurisdiction has a system for using a particular group of community care providers,“ explains Wolfe. “Partnerships will be created with the existing service providers and the local specialist team will conduct training. We expect initial patient visits will be focused on doing a pre-assessment—asking specific questions, showing the patient how to use the system to answer questions, taking initial pictures and videos if necessary. The follow-up visit will include completion of the assessment but under the guidance of the specialist team, and will perhaps require the home care provider to shoot video showing environmental assessment of potential risk behaviours that might lead to pressure ulcers, and conduct a seating assessment. Remaining visits will be focused on carrying out the treatment plan—dressing changes, and continued assessment.”

Wolfe adds that the primary outcome of this study will be determining the satisfaction level of each stakeholder—patients, specialists, and community nurses—being satisfied with the technologies employed. “The biggest hurdle will be working with each team to figure out the best way to integrate information technologies into their current clinical pathway. This will take a lot of analysis, design and development work with clinicians to analyze their current processes, accept change and adopt new approaches.”

This study is only designed to test out the technology so that a truly effective and sustainable system can be designed. In the longer term, says Wolfe, such a system has the potential to see better patient outcomes with faster healing and improved prevention of future ulcers, along with reduced clinic visits and corresponding reductions in health care costs.
In the near future, your underwear could be your best defence against pressure ulcers.

Earlier this year, you may have seen a news story about “smart” underwear that can detect and prevent pressure ulcers. The technology, developed by a team of researchers led by University of Alberta cell biologist Dr. Vivian Mushahwar, has been featured in the news media across Canada.

Perhaps no other group is more affected by pressure ulcers than people with SCI. The most dangerous of pressure ulcers—those that develop deep under the skin—typically form when a person stays in one position for a long time without shifting or turning over. With SCI, several factors elevate the risk: loss of muscle mass to cushion pressure-sensitive areas, inability to pressure shift often and unconsciously, and inability to feel pain or discomfort in areas of pressure. The result is that a potentially deadly infection, such as the one that is reputed to have led to the death of Christopher Reeve, isn’t noticed until it’s too late.

In SCI, the location of such a pressure ulcer is almost always the backside. Mushahwar’s approach has been to develop an undergarment that can sense pressure in critical areas, and, in turn, electrically stimulate muscles in those areas to circulate blood and prevent pressure ulcers from developing. Generous funding provided by the Alberta Heritage Foundation for Medical Research, as well as the Canada Foundation for Innovation and the Alberta-based Spinal Cord Injury Treatment Centre Society, have allowed Mushahwar’s team to make significant progress in the last couple of years.

At this point, phase one of the testing has been completed, with 23 people with varying levels of SCI volunteering to take part in the testing. The SCI Solutions Network, through our Access to Research program, has made a modest contribution in this regard, as we’ve provided approximately $15,000 in funding that has allowed five study participants to travel significant distances to Edmonton in order to take part in the study.

“It’s not easy to recruit study participants,” says Mushahwar. “The (SCI Solutions Network) funding is critical in our experience—it really opened things up and brought some key participants out.”

As we told you in the last issue of Solutions magazine, one of those who we provided funding to is Calgary’s Randy LeBlanc. Our support allowed Randy, who is tetraplegic, to offset his travel and accommodation costs to visit Edmonton and make a contribution to the project.

“Knowing some people are unable to do pressure relief techniques is a big part of what encouraged me to take part in the study,” says Randy, who had a pressure ulcer during his rehab but has been diligent in his prevention efforts ever since. “Being up and around doing any sort of activity is crucial to a healthy life. It was very interesting to find out my body was showing great response to the treatment that I was getting.”

It turns out Randy was no exception. “We were so excited to see the outcomes we were getting,” says Mushahwar. “We had incredible results, even with participants with a great deal of muscle atrophy, and with a wide range of SCIs.”

As this issue goes to press, the phase one study is in the process of being submitted for publication. Mushahwar expects people will read it, at least online, before year end. Meanwhile, her team isn’t sitting still. Phase two is expected to begin by June 2010, and will involve testing across the SCI continuum, from intensive care (Foothills Hospital in Calgary), to rehab (Glenrose Rehabilitation Hospital in Edmonton), long term extended care (Allen Gray Continuing Care Centre in Edmonton), and, of course, individuals living in the community.

In preparation for that, Mushahwar and her team are working on a viable prototype of the undergarment that can be used on a daily basis. “The focus now becomes developing something that people can take home with them,” she explains, adding that several hurdles remain, including passing CSA approval—necessary as the device will be used in settings outside the laboratory.

Watch for updates in future issues of Solutions magazine.
Here’s a fact that doesn’t seem to be well-known, at least in the general public: the initial trauma of SCI—the impact that either crushes or tears the axons of the spinal cord—is just the beginning of the destruction of spinal cord tissue that leads to varying degrees of paralysis.

The initial trauma triggers a series of biological events that last for many days and extend the area and severity of damage above and below the injury site, ultimately increasing the degree of disability. These events of secondary damage include restricted blood flow, excitotoxicity (over-excitation of neighbouring neurons to the point of permanent damage), inflammation, release of free radicals (oxygen molecules which attack and disable other molecules that are crucial for cell function), and apoptosis (cellular suicide).

Many people might also be surprised to learn that, when it comes right down to it, there are very few treatments that can be applied during the first few days after SCI, when this second wave of damage is occurring. Certainly, the spinal cord can be immobilized and bone fragments can be removed to prevent further damage.

In the past two decades, the steroid methylprednisolone has been administered to the injury site in the hopes of reducing inflammation, but its efficacy has been questioned in recent years.

While many scientists world-wide are focused on therapies to regrow and reconnect the axons of the injured spinal cord (for example, stem cell therapies), many others are focused on how to limit the secondary damage done in the days and weeks following a traumatic SCI—and consequently minimize the resulting disability in the long term. One of these is Vancouver’s Dr. Brian Kwon, a spine surgeon and University of British Columbia neuroscientist who divides his time between patient care at Vancouver General Hospital and research in spinal cord repair at his ICORD laboratory at the Blusson Spinal Cord Centre.

Of all the mechanisms of secondary damage, Kwon is intrigued by the drop in blood pressure and flow at the injury site—and by finding ways to prevent this. Earlier this year, the SCI Solutions Network’s Research Management Team and Research Advisory Committee made a recommendation to support Kwon’s work in this area, with the result being that Kwon was awarded a $100,000 Rapid Response Award in January.

Specifically, Kwon’s work focuses on minimizing or preventing ischemia—a shortage of blood supply to an organ. In the injured spinal cord, ischemia can lead to further serious nerve cell damage because of a compromised delivery of oxygen and nutrients, and build-up of toxic metabolic wastes. Kwon’s approach is to prevent ischemia by lowering runaway intrathecal (the area around the spinal cord) pressure by carefully draining cerebral spinal fluid, or CSF. Buildup of CSF is what leads to massive swelling in the injury site, which, in turn, prevents blood flow.

In a recently completed and published study, Kwon tested the safety of and established preliminary procedures for using an intrathecal catheter to drain CSF in acute SCI.

Currently, with his Rapid Response Award project, Kwon and his team are enrolling acute SCI patients and inserting an intrathecal catheter to drain and monitor CSF. Kwon has two main goals for the project.

The first is to further validate the procedure and determine how it affects blood pressure at the injury site.

The second is to test the use of CSF analysis as a predictor of long-term functional outcomes—Kwon has discovered that there are a series of proteins within the CSF that are elevated in accordance to injury severity. The potential is for a relatively simple analysis that could be a very efficient way of determining which patients are ideal for a particular treatment or participation in a clinical trial. Remember that, through conventional physical assessment tools, it usually takes a long time after injury to determine functional outcomes.

During the time elapsed since Kwon received Rapid Response Award funding, he has developed plans to advance his work into a second phase involving multiple sites in Canada.

“Given that providing the injured spinal cord with enough blood and oxygen by keeping the blood pressure high is one of the only treatments that clinicians can offer acute SCI patients, it would seem obvious that we should be doing this in the best manner possible,” says Kwon.
Bridging the Gap

Photo courtesy Wheelchair Basketball Canada
Wheelchair sport is a great way for people with SCI to maintain health and fitness—and get involved in their communities. But getting back into sport after SCI often isn’t easy. Bridging the Gap is a unique program that’s helping to pave the way.  

by Dylan DeMarsh

In 2005, an email arrived in Heather Glowacki’s inbox, offering her a chance to try her hand at a few wheelchair sports. She was excited by the opportunity.

A competitive gymnast and recreational figure skater as a child, Glowacki had continued an active lifestyle as she grew older, taking an interest in skiing, tennis and other outdoor sports.

A collision with an impaired-driver in 1991 changed everything. Any thoughts of continuing an active lifestyle took a backseat to the challenges she faced adapting to life with SCI. A lengthy rehabilitation process was followed by a slow reintegration into her community.

Glowacki rose to the challenge, gradually regaining function in her hands and arms, and getting on with life. She got married, and gave birth to a son in 1998. Immersing herself in peer work, Glowacki began working as a mentor with the Canadian Paraplegic Association (Ontario), and sharing her story with high-school students to demonstrate the dangers of drinking and driving.

Still, sport was missing from Heather’s life until she received the email inviting her to a “Have-A-Go Day” in Kitchener. Organized by Bridging the Gap, “Have-A-Go Days” are held regularly in rehab and community centres across Canada to demonstrate adapted sports and let anyone interested try them out.

“I didn’t really enjoy rugby, and I’ve never been particularly good at basketball, but I really liked playing wheelchair tennis,” says Glowacki. “I knew right away that I had found something I could do and have fun while getting some exercise.”

Glowacki is one of thousands who have participated in Bridging the Gap programming since it began a decade ago. Developed by the British Columbia Wheelchair Sports Association (BCWSA), Bridging the Gap has since expanded nationally, allowing Canadians living with SCI the opportunity to try wheelchair sports in a relaxed and supportive atmosphere.

“What we’re trying to do is make people aware of the value of sport,” says Duncan Campbell, Bridging the Gap National Coordinator (and one of the inventors of wheelchair rugby). “There are so many benefits to sport in addition to the physical fitness aspects, from simply having fun to building new relationships and gaining self-confidence.”

During the 1990s, BCWSA identified several barriers that were preventing people from taking part in wheelchair sport—lack of individual support, lack of financial resources, lack of equipment, lack of programming, and lack of awareness of available programs and resources. Bridging the Gap was designed to address each of these barriers, and its approach soon caught on throughout BC.

Following the success of the program on the west coast, BCWSA began promoting Bridging the Gap to other wheelchair sports organizations across Canada. The Ontario Wheelchair Sports Association added Bridging the Gap programming in 2004, and it soon spread to other provinces. In 2007, the Canadian Wheelchair Sports Association received funding from Sports Canada to expand the program across the country. Today, Bridging the Gap operates in every province in Canada.

Lending to its success is its collaborative approach. Bridging the Gap represents true partnerships throughout the SCI, disability, and sports communities. Diverse organizations such as Tennis Canada, Wheelchair Basketball Canada, the Canadian Wheelchair Sports Association (representing wheelchair rugby) and the Canadian Paraplegic Association have all worked together to make Bridging the Gap a success.

Regardless of where it’s offered, an important component of Bridging the Gap is its wheelchair loan program, which allows people to participate in sports that may otherwise be cost-prohibitive.

“Cost was identified as one of the main barriers that prevents people from getting involved in wheelchair sports,” says Campbell, noting that sport wheelchairs can cost thousands of dollars and aren’t funded by any insurance or government programs. “Most provinces operate a wheelchair loan program through Bridging the Gap, and have built an inventory of chairs for each sport that people are able to rent for a nominal fee.”

“Have-A-Go Days” are just the beginning for people who get involved in Bridging the Gap. Following the introduction to wheelchair sports, people are given the opportunity to develop a further interest in the sports of their choice through introductory level competition as well as recreational programming.

Glowacki has continued her involvement with Bridging the Gap and wheelchair tennis since her participation in the “Have-A-Go Day” back in 2005. This past summer, she began taking part in a Bridging the Gap tennis program at the University of Western Ontario in London. “I love it,” she says. “I’ve been improving every week, which is good because I was pathetic the first week!”

Tennis is one of the most popular wheelchair sports throughout the world, largely due to the fact that nearly anyone can play the sport regardless of whether they use a manual or electric wheelchair. Another key to its popularity is that it can be played indoors or outdoors and at any
time of the year depending on the availability of indoor tennis courts. Wheelchair tennis follows the same rules as able-bodied tennis, with the only exception being that wheelchair players are allowed two bounces before returning the ball. Along with rugby, basketball and athletics, tennis is one of the four core sports offered by every Bridging the Gap program across Canada.

Glowacki describes herself as stubborn and determined, and adds that she’s feeling great from the exercise and is really enjoying the social aspects of the program. She’s been particularly impressed with the quality of instruction she’s received.

The athletes who teach sports for Bridging the Gap are identified by local coordinators and include some Paralympic athletes. “They must represent their sport well,” says Campbell, pointing out that the instructors are the face of wheelchair sports for the participants in the program and are given training to ensure that they can positively influence others. “They’re good speakers and role models, all of them.”

The Bridging the Gap mission statement is “to introduce and support continued involvement of individuals with physical disabilities in wheelchair sports and recreational opportunities, promoting an active healthy lifestyle and improved quality of life.” The mission is clearly being accomplished—more than 1,000 people with disabilities have participated in Bridging the Gap in the first four months of 2009, with approximately 25 percent already becoming regular participants. Generally, 75 percent of participants are living with an SCI, with the remainder living with another mobility impairment.

Campbell, along with program coordinators across Canada, is constantly refining the program, adapting it to meet the needs and wants of people with disabilities. Going forward, he’s looking for a donor who can offer more sustainability and security for the program, which currently operates on a year-to-year basis, as it’s dependent on government, community and individual funding.

For Glowacki, Bridging the Gap continues to open new doors. “I wouldn’t mind joining a recreational league once I get to a level where I can compete,” she says.

Until then, she has set her sights on a very meaningful match. “My ten year old son loves tennis. I can’t wait until I’m able to play tennis with him.”

Bridging the Gap has helped Heather Glowacki rediscover her love for tennis. Now she’s looking forward to taking on her son.

Vancouver Ramps Up for Paralympics
Vancouver, Whistler and Canada are getting ready to welcome the world to the X Paralympic Winter Games, scheduled for March 12 to 21, 2010.

The Opening Ceremony for the Paralympic Games will be held on March 12 at BC Place in Vancouver. The Closing Ceremony will be held on March 21 in Whistler.

The Paralympic Winter Games will feature 650 of the world’s best athletes from more than 40 countries competing in five Paralympic Winter Sports at six venues: ice sledge hockey at UBC Thunderbird Arena, wheelchair curling at Vancouver Paralympic Centre, alpine skiing at Whistler Creekside, cross-country skiing at Whistler Paralympic Park, and biathlon at Whistler Paralympic Park.


With funds raised via Wheels In Motion events across Canada, the SCI Solutions Network has provided grants totalling approximately $160,000 to support Bridging the Gap programming since 2003.
Seeing is believing

When Kevin Rogers traveled to Japan in February 2006 to speak at a conference hosted by the Japan Association of the Quadriplegic, he included a short video in his presentation on assistive technology. The slick two-minute production featured a fifth-generation farmer in southern Alberta who continued to maintain his farm despite sustaining a SCI in 1991. Cutting between first-person accounts from the farmer and action shots of him working on his farm, the video managed to capture the spirit of someone refusing to give up in the face of adversity while imparting an important message of determination for others in a similar situation.

The response to the video was overwhelming. “People were blown away,” says Rogers, Information Resources Coordinator for Canadian Paraplegic Association (Ontario). “Both the content and production of the piece made a big impact on the people in attendance.”

Half the world away in Calgary, the video’s producer, Russ Bray, was hard at work cutting together similar pieces for the groundbreaking Odyssey website (www.cpa-odyssey.org). Since 2003, Canadian Paraplegic Association (Alberta) has been supplementing their Odyssey Peer Program with a website to showcase clients who had successfully re-entered their community. Bray, Odyssey’s Technical Administrator, has turned the website into a one-stop shop for multi-media peer support and SCI information. It’s an electronic extension of the Canadian Paraplegic Association’s decades-old emphasis on the power of peer support.

“The goal of the website is to help and support people with SCI, especially the recently injured, with information on how to get on with their lives,” says Bray. “Having these videos available online gives people the luxury of viewing the stories in the privacy of their own space at a time that’s convenient to them.”

The videos, usually five to ten minutes in length, feature people with disabilities addressing the camera to share their personal stories. Each video is accompanied with background information on the featured person, such as education and details of their injury.

Using a home video camera, Bray began creating video profiles in 2005, with the focus being people with SCI talking about their experiences and successes in the areas of employment and education. Within a year of its debut, the site quickly expanded its scope. “CPA clients let us know that there was other valuable information we could be sharing,” says Bray. “We introduced new categories such as sports, recreation and leisure, housing modifications, and adaptive vehicles.”

In addition to first-person testimonials, the Odyssey site also features videos focused on community resources, special events and research. These profiles focus on organizations, trends, and news, rather than individual stories.

The site has grown considerably over the past six years. “In the first full year the website was up and running, we had a little over 5,000 hits,” says Bray. “Last year we had 22,000 hits. With outcomes like that, we know it’s making a difference.”

The quality of the production has also increased significantly, thanks to a generous donation which allowed Odyssey to buy a high-quality digital video camera. “The original videos were done on a small, family-type video camera, but with my photography background I knew we needed professional equipment to produce quality videos,” says Bray.

Bray’s passion for his work is obvious and he views his commitment to the Odyssey program as a way of contributing to a community that strongly supported him after he sustained a SCI. “I was off work for about two years and was going nuts rehabbing, so I decided to do some volunteer work with the Canadian Paraplegic Association,” says Bray. “After the great care I received, and meeting other people in wheelchairs with similar injuries to mine, I wanted to give something back.”

Bray has received a great deal of positive feedback on the site from around the world, and regularly fields calls from people wanting more information about a certain video or to learn how they can get in touch with clients profiled on the website. Going forward, he’s hoping to build on the success of Odyssey and expand the scope of the site even further, featuring stories that can be used in hospitals and rehab centres.

Video producer Russ Bray
When it comes to SCI research, the subject of stem cells creates a lot of excitement. In simple terms, stem cells are capable of producing almost any cell type within the body, including the neurons of the spinal cord. Understandingly, efforts to introduce stem cells into the injured spinal cord in the hopes of restoring connections across the injury site are being eagerly investigated around the world.

While not the case in North America, stem cell research has moved beyond animal studies into human clinical trials and studies in many parts of the world. For this reason, the promise of stem cells has become an area of interest for the SCI Solutions Network, given its mandate to support SCI translational research—translating lab discoveries into human therapies and treatments.

That’s why we’ve provided significant funding for a Global Blueprint for Stem Cell Translation. Development of this blueprint will commence with a conference in Toronto next May, which will allow leading stem cell researchers and key SCI stakeholders from around the world an unprecedented opportunity to discuss the innovation, translation and commercialization of stem cell research.

The concept of this project was developed by Drs. Michael Fehlings and Darryl Baptiste of Toronto Western Hospital (Dr. Fehlings is also a member of the SCI Solutions Network’s Research Management Team). Other funding partners are Ontario Neurotrauma Foundation (ONF), and McEwen Centre for Regenerative Medicine.

According to Baptiste, the need for such a blueprint is clear. Various research groups and businesses around the globe are actively offering stem cell therapies—often at a high financial cost to hopeful individuals with SCI. These procedures occur under varying protocols and in some cases without patient follow-up. Without applying the scientific rigor of a randomized clinical trial, it’s very difficult to assess the therapeutic effectiveness of stem cell approaches for SCI and other neurologic conditions.

“In various countries, stem cell clinics provide global ‘direct-to-consumer’ marketing via the internet regarding the promise of stem cells,” explains Baptiste. “Because the biology of stem cells is not yet clear, there is concern that the complete picture is not being fully disclosed to patients. Meanwhile, positive testimonials from patients who have engaged in ‘stem cell tourism’ have been offset by accounts of adverse effects including tumor formation. Until a tightly-controlled clinical trial is run, the benefits and risks will remain unclear.

“Earlier this year, the world’s first SCI human embryonic stem cell trial was set to be launched by Geron in the USA. But before the first participant could be recruited, the Food and Drug Administration (FDA) announced that Geron’s trial would be placed on hold—this despite the submission of a 22,000 page protocol. This indicates the difficulty this leading health regulatory body is having judging the safety and merit of stem cells.”

Baptiste also says that the translational path for advancing stem cell therapies is far from clear. “For example, answers to questions pertaining to ideal models to test the cell therapies, purity of cell population, number of cells to transplant, route of cell delivery, and timing of cell administration will greatly guide research and industry groups in their quest to develop stem cell therapies.”

Enter the Global Blueprint for Stem Cell Translation project, which will include a wide range of key stakeholders—for example, clinicians, rehabilitation professionals, consumers and public policy makers—from Canada, USA, Australia, Europe, China, India, and Brazil.

“Canada is one of the world’s top contributors to academic stem cell research, and the volume and impact of our research puts us in a position to take a leadership role in developing global standards for advancing stem cell therapies into the clinic,” says Baptiste. “The conference will provide opportunity to have international input to best harmonize the ‘rules of engagement’, thereby providing stakeholders a means to advance stem cell therapies in a safe and timely manner as decided upon by academic and industry world leaders in the field, while taking into consideration the demands and risk tolerances of consumers.”

More news on the Global Blueprint for Stem Cell Translation can be found at www.stemcellglobalblueprint.net.