The Pain Puzzle

Why Halifax’s Dr. Christine Short believes SCI neuropathic pain can not only be treated, but prevented

Pressure Study Expands

Dr. Brian Kwon’s spinal fluid study becomes the SCI Solutions Network’s first multi-centre clinical trial
It’s time to take a break. In 2010, I turn over the reins of this network to the very capable hands of Bill Barrable, our new CEO. I’ve worked closely with Bill during the last couple of months as he prepared himself to take on the position, and I truly believe his appointment bodes well for us.

For me, the time has definitely come to step back. I’m hoping to continue playing a modest role in what I’ve come to call the “Solutions movement.” But after a career spanning more than 40 years, it’s time to take a deep breath and enjoy some down time—with my kids and grandkids, and my brothers and sisters back in Newfoundland.

Four decades ago, my brother became a quadriplegic, and I saw that programs, services and adequate supports for him just weren’t available. That’s what prompted me to help form the Newfoundland division of the Canadian Paraplegic Association (CPA). I never thought I’d be giving up my job as a marine engineer for more than a couple of years. But two years turns into 20, and 20 turns into 40, and so on.

Along the way, I was Executive Director of the Newfoundland and Alberta divisions of CPA, and I served for six years as CPA’s National Managing Director. I also was the Executive Director of the Alberta Premier’s Council on the Status of Persons with Disabilities for six years. And for the past nine years, I’ve worked with Rick Hansen to bring this network from a dream into reality.

Progress has sometimes seemed frustratingly slow. But when I look back at the entire block of time and take an inventory of all the changes that have occurred, it’s a different story. Our communities have become so much more inclusive and accessible. Supports and services have expanded exponentially. And our scientific understanding of SCI has quite literally moved out of the dark ages.

Of course, there remains much to do. Barriers still exist. A cure remains elusive. And the secondary health complications of SCI remain serious and life-threatening. But I believe that this network is the means by which we surpass the remaining hurdles. It represents the first time in Canadian history that people from across the SCI continuum—from people with SCI to their clinicians—have come together to find the necessary solutions. Meanwhile, around the globe, similar collaborations are emerging, and we’re all beginning to share information and resources.

For the first time, I think, the finish line is at least in sight.

Eric Boyd, CEO
SCI Solutions Network
CEO Appointment

The SCI Solutions Network is pleased to announce the appointment of Bill Barrable to the position of Chief Executive Officer, effective January 1, 2010. Bill is co-founder and director of Natalus Life Science Capital (VCC) Ltd. He was the Chief Executive of BC Transplant from 1994 to 2009, during which time it was honoured with the Canada Award for Excellence from the National Quality Institute. In 2001, he became the founding Chair of the Board of Directors of the Michael Smith Foundation for Health Research. He has been a member of numerous voluntary boards and holds a Bachelor of Arts (Honours) from Queen’s University, and a Master of Health Science in Healthcare Administration from the University of Toronto. He was previously named one of Canada’s Top 40 under 40.

Bill is currently wrapping up a term as Entrepreneur-in-Residence at Simon Fraser University. He is also spending as much time as possible throughout November and December with retiring CEO Eric Boyd as he gets up to speed with network operations and prepares to move into the position full-time in January.

“I’m very excited about joining the Network,” says Bill. “I believe that with hard work and enlightened cooperation among many committed partners, there will be a lot of opportunities to improve the lives of people with SCI. On behalf of our Board of Directors, I would also like to express our gratitude to Eric Boyd, who graciously postponed his retirement to shepherd the SCI Solutions Network during its first year and a half of existence. Eric has provided incredible leadership and vision during his many years of service with RHF and its innovations, and decades of service to all Canadians with SCI throughout his stellar career.”

Atlantic Canada Unites for SCI

In an effort to move forward with a region-wide SCI strategy, the Canadian Paraplegic Association’s (CPA) New Brunswick division hosted the inaugural CPA Atlantic Summit in Moncton from November 25 – 27. More than 50 delegates from CPA divisions in all four Atlantic provinces joined with SCI Solutions Network staff for two days of networking, knowledge and skill development, best practice sharing, and identifying regional priorities and opportunities for collaboration.

“I continue to be inspired by the energy and spirit among our Atlantic organizations and the SCI Solutions Network,” says Haley Flaro, Executive Director of CPA New Brunswick. “A very wise person remarked at the Summit that we may underestimate our abilities, our resourcefulness and impact in the Atlantic—and I believe that’s true. With energy and leadership, with a shared mission, with the meaningful engagement of the population we work alongside, and the ability to turn small resources into spectacular things, we definitely are making it happen.”

By the end of the meeting, the four CPA divisions reached an agreement to work collaboratively with the SCI Solutions Network to further develop the Solutions Model of supporting individuals with new SCIs, as well as active living and peer support and leadership components as part of CPA programming.

The event was officially recognized in the New Brunswick legislature on December 2 by Premier Shawn Graham. “Mr. Speaker, mobility-related disabilities are the most common disability in the Atlantic provinces,” the Premier said. “In fact, New Brunswick has the second-highest rate of disability in Canada, at just over 17 percent of the population...Congratulations to Executive Director Haley Flaro, the Summit organizing committee, and all members of New Brunswick’s chapter of the Canadian Paraplegic Association for hosting such a successful event.”

Take the 30 Second Survey

The SCI Solutions Network is committed to research that leads to breakthroughs in the treatment and prevention of secondary complications of SCI—for example, pressure sores, bladder infections, sexual functioning, and pain.

You can help determine exactly where we focus our research efforts. The next time you’re online, take 30 seconds and tell us which secondary complications of SCI are most important to you.

We’ll include the results of this micro-survey in our 2010 business planning process.

To cast your vote, follow the links from our home page at www.scisolutionsnetwork.ca.
Honda Makes Strides
Honda engineers aren’t just standing around. The company recently exhibited prototypes of two innovative mobility devices that regulate walking strides and provide support to help people with disabilities walk, lift, and crouch. The Stride Management Assist device (top) straps around a user’s waist and thighs. It monitors the hip angles during walking to calculate the optimal stride length for ease of walking—and forces the wearer to use that stride. The device weighs about five pounds and can operate for about two hours at a time using a lithium ion rechargeable battery. It uses brushless motors to minimize weight and is currently available in three sizes to meet the needs of various body shapes. The Bodyweight Support Assist device (bottom) is a more extensive device that actually supports some of the wearer’s weight. This device doesn’t strap on, but rather is donned by wearing a special pair of shoes attached to an exoskeleton, which has a seat. It too runs on a rechargeable lithium ion battery. Both devices are based on designs and concepts first tested in Honda’s ASIMO humanoid robot, which was designed to be as human-like as possible as it performs a variety of common tasks. Honda is currently testing the mobility devices in conjunction with the Shinseikai Medical Group at Kasumigaseki-Minami Hospital in Kawagoe, Japan. Patients are trying the device and providing feedback, as are their physical therapists and doctors. The devices appear to be a promising avenue for improving mobility for people with incomplete SCI. Commercialization, however, is not on the immediate horizon. You can learn about the devices at www.honda.com.

A Really Big Wheel
A common complaint for many wheelchair users is that their front castors, while useful on indoor surfaces, are less than ideal for many outdoor settings. The FreeWheel Wheelchair Attachment easily locks onto your existing wheelchair and allows you to push over difficult surfaces and terrain. The FreeWheel is adjustable to fit your footrest. It takes only seconds to clamp it on, and you can store it on the back of your chair when you’re not using it. It’s reputed to be lightweight and durable, and it fits the footrests of most manual chairs, including Colours, Kuschall, Invacare, Quickie, TiLite, Top End, and more. For more details, visit www.gofreewheel.com.

Stik Around
TeleStik is a portable reacher that allows you to retrieve hard-to-reach items without requiring significant grip strength or dexterity. And it gets in tighter places than other reachers because of its sleek design and unique mechanisms. The device has three ways of attaching itself to an object. An adhesive disk will pick up items weighing as much as one pound—to restore stickiness after use, you simply wash the disk. There’s also a small but powerful magnet, which will pick up metal objects up to one pound. And the hook can also be used to pick up items such as clothing. The entire device retracts to a compact nine-inch length, so you can keep it in a purse, wheelchair pack or fanny pack. For more information, visit www.telestik.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.
Congratulations Are In Order

Congratulations and thanks to Professor Luc Noreau of Laval University’s Department of Rehabilitation, who has accepted the position of Scientific Director of the Centre for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRIS). Noreau will step down from his position as a member of our Research Management Team (RMT). He will, however, continue to lead research activities that he is committed to, including the SCI Needs vs. Service Utilization Survey, and the SCIRE III chapters on community integration.

“We congratulate Dr. Noreau on his new appointment and thank him for providing a much-needed voice to SCI community integration issues and research,” says CEO Eric Boyd.

Survey Says…

Canadians with SCI have a unique opportunity to help guide how the Canadian health and social services system meets their needs through a groundbreaking survey being conducted under the umbrella of the SCI Solutions Network and The Rick Hansen SCI Registry.

A team of Canadian researchers, led by Dr. Luc Noreau of Laval University, recently completed Phase I of the SCI Needs vs. Services Utilization Survey and will launch Phase II this January. The survey will be available online, and can also be taken via mail or telephone. It will take between 60 and 90 minutes to complete. Results will be shared with members of the SCI community, the Canadian Paraplegic Association, all Rick Hansen Registry sites, and other interested parties. Participants will be acknowledged with a $25 gift card and a complimentary subscription to Solutions magazine.

Find out more at www.sci-survey.ca.

Going Global

The SCI Solutions Network recently signed a memorandum of understanding with the Australia New Zealand Spinal Cord Injury Network (ANZSCIN). The memorandum outlines a commitment to working together in the true spirit of collaboration, and exchanging experiences to improve knowledge and help advance treatments for SCI.

“We would anticipate that if ANZSCISN receives federal funding, it will quickly align as an international collaborator and partner that will mirror our own mission, objectives and strategies,” says SCI Solutions Network CEO Eric Boyd. “In particular, it could become the focal point of our collaboration with Australia and New Zealand in SCI registry activity, stem cell guidelines, and clinical trials.”

“We are delighted to have signed this agreement with the SCI Solutions Network,” says Stephanie Williams, ANZSCIN CEO. “We see SCISN as an inspirational model for our young organization and we are very much looking forward to working together. Early goals include collaboration particularly around the STASCIS trial and the Rick Hansen SCI Registry. Through improving communication across the globe we hope to combat a range of major SCI issues.”

Rubbing Shoulders

The Christopher and Dana Reeve Foundation, one of the world’s largest contributors to SCI research, recently held its “Magical Evening” gala at New York’s Marriott Marquis. Among those on hand were Daryl Rock, Chair of the SCI Solutions Network’s Board of Directors, and fellow Board Member and ex-Vancouver Mayor Sam Sullivan.

They were impressed by the number of actors who were present to lend their support. These included two-time Oscar winner Meryl Streep (photographed below with Sam and his wife Lynn Zanatta). “Meryl Streep wandered into the room by herself, looking pensive,” says Sullivan. “She came up to Lynn and I and started talking about how she keeps expecting to see Christopher and Dana come around the corner. She seemed genuinely troubled by the fact that they had both passed away.”


Rock and Sullivan were invited to attend by Henry Stifel of the Reeve Foundation’s Board of Directors, and they were glad to have made the trip.

“The day after the gala we participated in their conference where we learned about the important work being done in SCI research,” says Sullivan. “We all agreed that we needed to work closer together to make sure we address the real needs of the spinal cord community. We were extremely impressed with the team they had assembled and innovative work they were doing.”
Burning, searing, shooting, constant neuropathic pain: it’s an unbearable problem for thousands of Canadians with SCI. Halifax’s Dr. Christine Short believes it can be treated—and prevented.
When it comes to neuropathic pain, Dr. Christine Short has seen enough to last a lifetime.

"My patients tell me consistently that pain is their most disabling symptom," says Short, a specialist and Chief of the Division of Physical Medicine and Rehabilitation QEII Health Sciences Centre in Halifax. "One patient in particular recently summed it up nicely. He told me, 'I can deal with the paralysis—that's no problem. It's this pain I can't deal with.' His pain is so severe he can't stand the touch of clothing against his skin or the bed sheets. Some days his pain is so bad that all he can do is lay on his bed, naked, and not move because it hurts too much. This is not a unique but all too common story."

Neuropathic pain is a complex, chronic pain that results from an injury to the nervous system that leads to damaged or dysfunctional nerve fibres. These nerve fibres send incorrect signals through the spinal cord to pain centres in the brain. The result is often severe pain that can be burning, shooting, squeezing or tingling. This pain can be so extreme that some who suffer from it contemplate suicide.

A well-known example of neuropathic pain is phantom limb syndrome, when the brain still gets pain messages from the misfiring nerves that originally carried impulses from a missing limb. Likewise, SCI often leads to abnormal nerve pathways and function that can cause pain to develop and be maintained.

How big of a problem is it? Short says that about 40 percent of people with traumatic SCI will develop neuropathic pain.

"As far as the wish list of 'fixes', that's a no brainer," she says. "My patients with neuropathic pain rate it number one on their list, far above an outright cure, or improvements in walking or bowel, bladder and sexual function."

But how do you fix or alleviate the pain when there is no external trauma—and when it’s almost impossible to pinpoint exactly what part of the nervous system is generating the pain? Better yet, how do you prevent it from happening in the first place? For Short, answering these questions has become a quest.

"I became interested in neuropathic pain as I read and researched the literature in an effort to try to help my patients with neuropathic pain from a variety of neurologic disorders, including SCI," she explains.

For almost two decades, she’s watched hopefully as a variety of treatments have been tested, ranging from pharmacological interventions to alternative treatments, including acupuncture. Along the way, she began to see increasing evidence that a group of drugs known as anticonvulsants, commonly used for preventing seizures in conditions such as epilepsy, were also effective in controlling neuropathic pain. One of those drugs was gabapentin. In the mid-90s, Short began using gabapentin to treat neuropathic pain, with some good success.

In 2006, a related drug, pregabalin, was released in Canada. Designed as a more potent successor to gabapentin, pregabalin is marketed by Pfizer under the trade name Lyrica.

Here’s how Wikipedia describes pregabalin: "Like gabapentin, pregabalin binds to the α2δ (alphadelta) subunit of the voltage-dependent calcium channel in the central nervous system. This reduces calcium influx into the nerve terminals. Pregabalin also decreases the release of neurotransmitters such as glutamate, noradrenaline, and substance P (Australian Medicines Handbook)."

In plainspeak, it appears that pregabalin binds to receptors in nerve cells and decreases the ability of those cells to send pain signals.

"Pregabalin is similar to gabapentin but has some advantages—one being that it’s more potent in its ability to bind to the receptors it acts on in the nervous system," says Short. "As well, its pharmacologic properties have some advantages over gabapentin. It’s also the only drug available that has been studied in SCI and has a listing for central neuropathic pain in SCI."

Short began prescribing Lyrica to patients with neuropathic pain, including many with SCI, and she’s had good success as a result. "It’s been helpful for pain, and we also see a lot of people notice improved spasticity control on this drug," she says.

Then an idea to use the drug in
The study began recruiting in November. It’s a single site, double blind randomized placebo control trial being carried out in collaboration with Dr. Sean Christie and Dr. Steve Casha of the centre’s neurosurgery department. A total of 30 patients, who will be enrolled within two weeks after injury, will either be given pregabalin or a placebo. Outcomes will then be measured at regular intervals.

“What makes this study unique in SCI is that, up until now, studies have focused on treating pain once it has started,” says Short. “It’s the whole idea of a preventative treatment that makes our study unique. Phase one will help us get some early data. Once we have phase one running, we’ll be seeking funding to get phase two going—this will be a multi-centre Canadian trial. We need this to get enough numbers to really answer the question if pregabalin can prevent the development of neuropathic pain following SCI.”

Short will also be using the study to determine if the drug has a measurable benefit on spasticity. “Spasticity is not a listed indication for the drug, but spasticity is another area of interest for me, and in our study we’re following spasticity as a secondary outcome.”

The SCI Solutions Network will report on outcomes of the study as they become available.

Meanwhile, Short encourages people suffering from neuropathic pain to hang in there. “There’s so much research happening in neuropathic pain right now, and it’s very exciting. As we understand pain better, we’re able to treat it better. There’s always a new treatment just around the corner, so don’t lose hope and keep in touch with your treatment team so you get access to new treatments as they become available.”

As the SCI Solutions Network’s IT Director, Vancouver’s Rob Hickling is leading development of the highly anticipated web-based data collection platform that will form the backbone of the Canada-wide Rick Hansen SCI Registry. In almost all major SCI acute care and rehabilitation hospitals in all major cities across Canada, clinicians will soon be able to use this elegant, versatile and SCI-specific data collection tool to efficiently gather critical data from patients with SCI. In addition to pure Registry use, the platform will also be used as the collection tool for multi-centre clinical trials, beginning with the recently announced bio-marker study led by Dr. Brian Kwon.

Among Hickling’s previous employers is Seattle-based Boeing. There he led a team of software developers and architects working on various IT innovations, including a system that could visually demonstrate the value of Boeing aircraft to clients.

In 2008, when Hickling was approached by the SCI Solutions Network to lead development of the data collection platform, he agreed—and quickly tried to determine if key members of his former team at Boeing were available. Two of those specialists—senior software architect Jim Wheaton and senior developer Eduardo Echeverria—were intrigued. And so the team was reunited in Vancouver to work on a project that holds great promise to benefit people with SCI across Canada.

“Jim and Eduardo are like Gretzky and Lemieux,” says Hickling. “Getting them on board was a real victory for us. At the same time, the Registry offers a unique opportunity for them—it’s a chance to for them to determine how they work on project, and they have more freedom to utilize what they’ve learned in their careers, instead of having a larger client dictating to them how the product will be developed. That’s allowing them to be very creative and innovative in the development process.”

Hickling adds that the entire project is a breath of fresh air for all of them. “To be totally frank,” says Hickling, “this is exciting and interesting, creating something that’s clearly beneficial to science and medicine, rather than something that’s commercial. That’s a big plus for all of us.”

The team was recently rounded out with the addition of quality assurance developer Rick Zhong, who was previously part of the Rick Hansen Foundation’s IT team.

“I really don’t think there’s anything like what we’re creating,” says Hickling. “The breakthrough is simplifying the process of coding very complex forms, and making them available online. Entering data in the hospitals will become a much more logical process, as we’ve incorporated best practices in data flow, usability, and human interaction. Jim is making it simple on the back end, and Eduardo is making it simple and elegant on the front end. This is hard to do, and only the best can achieve it.”

The ability for researchers to use Registry data immediately, along with the prospect of data being collected in real time using state-of-the-art privacy and security protocols, are other important features of the platform.

Rollout is expected in the Spring of 2010.

Left to right: Hickling, Echeverria, Wheaton and Zhong.
The SCI Solutions Network is taking a giant step forward with the launch of its first multi-centre clinical trial, led by Vancouver’s Dr. Brian Kwon.

In the last issue of Solutions magazine, we told you about the work being done by Dr. Brian Kwon, orthopaedic spine surgeon and University of British Columbia neuroscientist. Kwon’s work involves blood pressure and flow around the site of an SCI, and the use of biomarkers in the cerebrospinal fluid (CSF) as a way of predicting how a person will recover in the months following an SCI.

Earlier this year, the SCI Solutions Network provided Kwon with a $100,000 Rapid Response Award to do preliminary work in this area. Recently, the SCI Solutions Network’s Research Management Team made a decision to support Kwon in his quest to expand this work into a two-year, multi-centre trial that is scheduled to begin in the spring of 2010.

The study, “Spinal Cord Perfusion Pressure Monitoring in Acute Spinal Cord Injury”, has five possible sites beyond Vancouver General Hospital—Calgary, London, Ottawa, Montreal and Halifax. Over the course of two years, the goal is to recruit at least 40 patients in a wide-spread collaborative initiative to expand upon Kwon’s pioneering work in the field.

The process involves the insertion of a tiny catheter into the spinal canal at the lumbar (lower back) level. The catheter has two purposes—it allows the pressure of the CSF to be continuously monitored, and it also provides the ability to obtain CSF samples that can be analyzed in the laboratory.

Why is monitoring CSF pressure important? Kwon has documented surprising increases in CSF pressure after SCI, which may prevent the delivery of oxygen and nutrients via the blood supply to the injury site. The lack of oxygen and other nutrients to the injured spinal cord contributes to further secondary damage to the cord. During this multi-centre study, Kwon and his co-investigators will try to determine the effect of various interventions on CSF pressure, so that they can provide new guidelines on how to treat acute SCI in order to maximize the chance for neurologic recovery.

As for taking samples, Kwon’s work already strongly suggests that CSF from the injured spinal cord contains biomarkers which give a surprisingly accurate prediction of the extent of neurological damage and what functional outcomes are likely for a specific patient. These outcomes, which have been virtually impossible to predict in the past, are expected to be extremely useful in helping determine which treatments could be employed for a specific patient, and whether or not a patient would make a good candidate for other clinical trials early in the acute phase of injury and recovery.

Looking down the road, Kwon believes that the procedure may eventually allow clinicians to maintain an ideal pressure for CSF, which could in turn maximize blood flow to the injury site and optimize recovery.

The study represents another first for the SCI Solutions Network, as it will rely on the Rick Hansen SCI Registry’s data collection platform (currently in development—see page 8) as the primary method of tracking and sharing results.

“Along with my team here in Vancouver and my colleagues across the country, I’m tremendously excited about the opportunity to expand this work on a larger scale,” says Kwon. “This is the type of collaboration that’s required to answer some of the most important and clinically-relevant questions about SCI. And it’s the kind of collaboration that we in Canada are uniquely able to undertake."

Eric Boyd, SCI Solutions Network CEO, agrees. “When Health Canada and the Rick Hansen Foundation worked to develop the funding framework that brought our Network and the Rick Hansen SCI Registry to reality, this is the type of cooperation they envisioned being possible,” he says. “This is a huge step forward for our Translational Research Program, and for Canadian SCI research in general.”

At the moment, Kwon and his team are working out the details of the study. This includes finalizing enrollment procedures (expected to be challenging since patients must undergo the procedure within 48 hours of injury), developing an automated device to monitor CSF pressure, finalizing the sites, and working out the logistics of shipping CSF samples to the laboratory in Vancouver for analysis.

Watch for updates in future issues of Solutions magazine.
For André Després, losing his independence for the second time put his patience and determination to the test. Here at the SCI Solutions Network, we’re happy we had the opportunity to play a role in helping this proud Canadian get back in the driver’s seat.

Most Canadians choose where they live and how they participate in their communities. People with SCI, on the other hand, often face barriers that challenge their ability to live completely on their own terms—and as independently as they would like.

André Després, who lives in Moncton, New Brunswick, knows this well—he’s been tetraplegic for more than 20 years.

“Independence,” says Després, “is everything to someone with a spinal cord injury.”

In 1988, as a 17-year-old living in Chatham, New Brunswick, Després crashed headfirst into the boards racing for a loose puck after a faceoff. The life he’s led since that fateful day is proof positive that hard work and perseverance can help a person overcome almost any challenge.

After his injury, Després was transferred from hospital in New Brunswick to Lyndhurst Hospital in Toronto. There, he spent 11 months in rehabilitation. During this period, while he was coming to grips with living with SCI and all the massive life changes it would entail, Després completed his last year of high school via correspondence.

He sensed that more education would provide him with the means to an independent life. After leaving Lyndhurst, he was accepted into the kinesiology program at the University of Waterloo. Then, before Després even obtained his degree, he secured a job with world renowned neurosurgeon and SCI researcher Dr. Charles Tator (who, incidentally, chairs the SCI Solutions Network’s Research Advisory Committee, or RAC).

After he graduated with a bachelor of science degree, Després sought to increase his independence, and he knew that driving his own vehicle was the key. He learned about the programs and services available through the Ontario government and was encouraged with what was available.

“I wrote a proposal to secure funding to retrofit and adapt a van to allow me to get back and forth from work,” says Després. “After an interview with Ontario Vocational Re-

back on the road

For André Després, losing his independence for the second time put his patience and determination to the test. Here at the SCI Solutions Network, we’re happy we had the opportunity to play a role in helping this proud Canadian get back in the driver’s seat.
adapted Chevy Uplander van. The Després family with their new lengthy challenge. All told, Després he could drive.

$57,000 required to retrofit it so that dent that he could raise the further with his own money and was confi-

a new Chevrolet Uplander van obstacle to overcome. He purchased this would prove to be just another
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ontario—and that he would have to

the level of support provided by the New Brunswick government pales in comparison to the support offered in ontario—and that he would have to

Després quickly discovered that the level of support provided by the New Brunswick government pales in comparison to the support offered in ontario—and that he would have to

Després, who was long accus-
tomed to facing challenges and con-

out funding proposals for monetary assistance. The sudden loss of liberty was a shock.

“for me, the ability to drive is not a luxury,” says Després. “it’s a neces-
sity for my job and health. The reality is that it’s very difficult to be spontan-
eous when you have a spinal cord in-

considerable to the support offered in ontario—and that he would have to

Finally, in August 2009, Després was able to complete the retrofit of his new van and once again get behind the wheel. “It’s a tremendous feeling,” says Després. “i feel whole. i’m a hus-

Though it was a difficult period in his life, the year and a half that he was unable to drive did help con-

Després was able to raise more than $12,000 through donations from friends and family, with his employer contributing an additional $10,000 to match funds Després had already raised. Charit-

Dr. Darryl Baptiste of our Research

The van, which he purchased in 1995, was equipped with a wheel-

But in May, 2008, after 13 years on the road, the van’s adaptive technol-

Again, Després began researching his options and discovered that a new retro-fitted van was prohibitively

The only option was a new van.

The van was a reliable friend that saw Després through many important life events—it moved him back to Moncton in 1996, where he was married in 1997 and became the father of twin girls in 2004.

While he was without a vehicle, Des prés had to cancel several medical appointments and inform his em-

Després had already raised. Charit-

Solutions Network, and the Rotary Club of Moncton, also provided fund-

“for the twins everywhere,” he says. “it made me feel like I couldn’t contribute to my family’s needs and, frankly, it made me feel like less of a husband and father. it was incredibly discouraging to al-

As Després’ ordeal moved into its second year, some glimmers of hope began to appear. Després was able to

Stem Cell Therapies: Your Input Needed

The Stem Cell Global Blueprint Conference, sponsored by the SCI Solutions Network and other leading Canadian research organizations including Ontario Neurotrauma Foundation, is an international two-day meeting that will be held at Toronto’s MaRS Centre on May 21-22, 2010. The event will bring together scientific researchers, clinicians, regulators, policy makers, industry representatives, legal and ethical specialists, media, and consumers from around the world to discuss measures to ensure that stem cell therapies for SCI and related neurological disorders are developed in a safe and timely manner.

Leading up to the meeting, the conference organizers invite consumers and

Dr. Darryl Baptiste

Leading up to the meeting, the conference organizers invite consumers and other stakeholders to help identify critical issues that need to be addressed. You can participate in a survey to gauge perceptions about stem cell therapies for SCI, and you can also take part in a Delphi process that’s intended to result in consensus for solutions to current barriers for safely moving stem cell therapies into human clinical trials.

“It’s critical that we have enough consumers voice their concerns about individual tolerance and demand for such promising yet potentially risky therapies,” says Dr. Darryl Baptiste, who, along with Dr. Michael Fehlings of our Research Management Team, is organizing the conference.

For more information, or to get involved in the survey, the Delphi process or the conference, visit www.

stemcellglobalblueprint.net.
The first ever Winter Paralympic Games took place February 1976 in Örnsköldsvik, Sweden. Just 250 athletes from 16 countries took part in those inaugural Winter Games, competing in two events—alpine and nordic skiing. Canadian athletes brought home a modest three medals from those games.

Fast forward more than three decades to Vancouver 2010. The extravaganza that athletes and viewers will be treated to this March will bear little resemblance to those first games in Sweden. The Paralympics have become the world’s second largest sporting event. While a large part of this growth is attributed to the Summer Games—4,200 athletes competed at the 2008 games in Beijing, compared to 400 at the inaugural Summer Games in 1960—the Winter Games have also developed considerably over the past 34 years. More than 1,300 athletes and officials from 40 countries will travel to Vancouver and Whistler to take part in five events: alpine skiing, biathlon, cross-country skiing, wheelchair curling, and sledge hockey.

In Vancouver, it seems likely that Canada will continue to build on its successes at recent Winter Paralympics. In 2006, Canada won 13 medals in Turin, Italy, including the coveted gold in the premiere event of sledge hockey. Overall, we finished sixth in the medal standings, which is considered exceptional given our relatively low population compared to the countries which finished ahead of us.

Here at the SCI Solutions Network, we’re proud of the fact that we’ve helped to support development of some of the Paralympians you’ll see competing in Vancouver. Along with the Rick Hansen Foundation and Rick Hansen Wheels In Motion, we’ve made a commitment to adaptive sports and recreation, giving a boost to some of Canada’s most successful athletes in the process.
In conjunction with Rick Hansen Wheels In Motion, the SCI Solutions Network has contributed more than $1.3 million to support 363 grassroots sport programs and equipment purchases since 2003. When it comes to winter sports in particular, the SCI Solutions Network and Wheels In Motion have supported 86 grassroots winter sports programs, ranging from the Eastern Townships Disabled Skiing Foundation in Quebec to the Edmonton Rocks Wheelchair Curling team in Alberta.

In addition, Wheels In Motion has contributed more than $100,000 since 2004 to Bridging the Gap programs in Ontario and British Columbia. Developed by the British Columbia Wheelchair Sports Association (BCWSA) in the late 1990s, Bridging the Gap allows people living with SCI the opportunity to try wheelchair sports, such as curling, in a relaxed and supportive atmosphere. Bridging the Gap “Have-A-Go Days” are held regularly in rehab and community centres across Canada to demonstrate adapted sports and are often the entry point into wheelchair athletics for people who have sustained an SCI.

Darryl Neighbour, who hails from Richmond, British Columbia, is one of those people. And he just happens to also be one of the 55 Canadian athletes who will represent Canada in Vancouver and Whistler.

Just two months after Neighbour threw his first stone at a Bridging the Gap Have-A-Go Day, he found himself competing for the British Columbia Wheelchair Curling Team at the 2003 National Championships in Toronto. Seven years later, Neighbour is preparing for Vancouver 2010 as a member of the Canadian Paralympic Wheelchair Curling Team.

“There are times when I ask if this is really happening,” says Neighbour from his home in Richmond during a rare break from training. “I never would have imagined five years ago that I would be representing Canada at the Paralympics.”

Though Neighbour is competing at the highest possible level, his story is shared by hundreds of Canadians living with SCI for whom sport has provided a means of rehabilitation, an opportunity to participate more in their community, and a general improvement in quality of life.

“Sport is the greatest thing that ever happened to me,” says Neighbour, who sustained a SCI in 2001. “It helped me get out of bed when I needed it most, and now it’s providing me with opportunities I could never have imagined.”

Neighbour has seen firsthand how Wheels In Motion and the SCI Solutions Network provide opportunities to athletes living with SCI. Wheels In Motion funds have been used to improve accessibility and support an international wheelchair curling bonspiel at the Richmond Curling Club where he trains and competes.

In communities across Canada, the SCI Solutions Network is providing opportunities for all athletes with SCI, from the Paralympians of tomorrow to those who just want to ski with friends once a week.

“Without the support of events like Wheels In Motion, many of us might not have this opportunity,” says Neighbour. “If you have the chance to participate in Wheels In Motion, make sure you take part.”

Rick Hansen has made a difference in the lives of millions of Canadians. Now, Hansen will share with fans across the country the compelling and heroic stories of others who have made a difference in the lives of Canadian Olympic and Paralympic athletes.

Hansen will host the English version of a 17-part CTV series entitled The Difference Makers, which will air daily on television, radio and online during the Olympic Games. The Difference Makers pays tribute to the extraordinary coaches, teachers, parents, siblings and even rivals who have helped Canada’s Olympians and Paralympians overcome their greatest personal and athletic challenges.

Two-time Olympic silver medallist Alexandre Despatie will host the French version, entitled Faire la différence.

The first of the 17 features will air during the pre-show prior to the Opening Ceremony and will focus on the “difference maker” in Hansen’s life—his coach, the late Stan Stronge. Hansen will join Olympic Prime Time host Brian Williams on-set to launch the series and profile the man who got Hansen out of a hospital bed 36 years ago and encouraged him to make a difference in the lives of others.

“I’m thrilled to be hosting The Difference Makers, helping to share the incredible stories of people who have made a difference in the lives of Canadian Olympic and Paralympic athletes,” says Hansen. “As Canadians unite during the 2010 Games, I am proud to help acknowledge and thank those people who have encouraged our athletes along the way; who have contributed to their journeys and helped them achieve their dreams.”

On March 21, the last day of the Paralympic Games, the broadcast consortium will air a one-hour tribute to Hansen, celebrating 25 years to the day that Hansen left Vancouver to begin his Man In Motion World Tour.

In addition to his role as host of The Difference Makers, Hansen will also appear throughout coverage of the Vancouver 2010 Paralympic Winter Games.
Food Fix

Could a high-fat, low-carb diet immediately following SCI make a difference in a person’s functional recovery?

A recently completed study concludes that a high-fat, low-carb diet, also known as a ketogenic diet, speeds recovery in injured rats.

The study, conducted by Drs. Wolfram Tetzlaff and Femke Streiger, ICORD researchers based at the Blusson Spinal Cord Centre in Vancouver, was presented at the 2009 Society for Neuroscience meeting in Chicago. The findings were subsequently reported in ScienceDaily.

“Our results suggest that a ketogenic diet might be an appropriate initial treatment to improve outcomes in human SCIs,” Tetzlaff says.

Typically, people recovering from SCI are given high-calorie, high-sugar intravenous solutions, despite the fact that this approach has never been scientifically validated, and that previous studies have shown that fasting is beneficial after incomplete SCI in rats.

Fasting, of course, has been difficult to test in humans immediately following SCI, as patients and clinicians have been reluctant to try it—it’s difficult to contemplate starvation when the body is already losing so much weight. So Tetzlaff and Streiger investigated the ketogenic diet as an alternative to fasting.

Rats were fed with either a standard or ketogenic diet immediately after an SCI. The rats on the ketogenic diet showed markedly better recovery—after 14 weeks, 54 percent used their injured paws 15 times more frequently than the rats in the control group.

The underlying mechanism involved remains a mystery, says Tetzlaff. “But we know from the work of others that a ketogenic diet is a fuel that burns cleaner in the cells with less undesired oxidation,” he adds.

“This diet also increases pathways protecting the cells from oxidation and dampens over-excitation of nerve cells, which is known to be damaging.”

Tetzlaff says that it’s particularly important to note that the ketogenic diet is used clinically for children with seizures who no longer respond to any medication. “About 60 percent of these children show effective reduction of their seizures, and some are even cured,” says Tetzlaff. “What’s more remarkable is the observation that a transient treatment for six months in these kids can be enough. The data in children have been generated to the highest clinical standards through randomized and controlled trials.”

At first glance, it all seems like research and knowledge that would be easy to translate into a human SCI study. Tetzlaff cautions, however, that there are many wrinkles to iron out before a trial could be proposed to spine surgeons. These include determining which ketogenic formulation is best and how long it should be given, and gaining a better understanding of which levels of injury severity respond best.

“We need another year for the consolidation of our animal experiments,” explains Tetzlaff. “Hopefully somebody will replicate our studies—or at least one. And assuming the data are as strong as they appear based on our first three experiments, with over 60 rats so far, we will present this to the SCI Solutions Network.”

It’s also clear that such a trial would require multiple centres across the country. “The problem is that, every time you want to run a trial with an intervention that’s given early after injury, you need large numbers of patients,” says Tetzlaff. “Why? Well, the spontaneous recovery after injury makes it difficult to predict what level of recovery a patient would have reached even without treatment.”

Tetzlaff’s research in this area has been supported up to this point by the Christopher and Dana Reeve Foundation, the Craig H. Neilson Foundation, and the Canadian Institutes of Health Research.

Congratulations...

...to Dr. Andrei Krassioukov, ICORD and UBC researcher, for capturing the Alan T. Brown Award from the American Spinal Injury Association (ASIA) in recognition of his research contributions in the area of autonomic dysreflexia, one of the most serious secondary complications of SCI. Krassioukov has authored and co-authored more than 100 peer-reviewed manuscripts, book chapters and reviewed articles on autonomic dysreflexia. His research is supported by numerous national and international agencies such as Christopher and Dana Reeve Foundation, Heart and Stroke Foundation of Canada, and the SCI Solutions Network. For the past four years, he has been Chair of the ASIA/ISCos Autonomic Standards, which is developing standards of autonomic assessment for inclusion in the already-established neurological evaluation of individuals with SCI.
People living with SCI in St. John’s, Newfoundland, now have access to state-of-the-art exercise equipment, thanks to the combined efforts of the YMCA-YWCA, Rick Hansen Wheels In Motion, the SCI Solutions Network and the Miller Centre, Eastern Health.

A portion of the funds raised at the 2008 Wheels In Motion event have been used to purchase an Uppertone exercise system for the YMCA-YWCA of Northeast Avalon.

“This is one of the best things to happen in this area in a long time to benefit people like me,” says Dion Regular, a St. John’s resident who has been living with an SCI since 1999. “Since leaving rehab, the only exercise equipment I’ve had access to has been free weights strapped to my wrists. This machine allows me to do many different exercises without any assistance.”

Created in 1990 by a person with SCI, the Uppertone allows users to independently exercise their upper bodies. The Uppertone is currently used in rehab facilities and exercise centres in more than 20 countries.

The purchase of the Uppertone was spearheaded by Jennifer Shears, a physiotherapist working at the Miller Centre, Eastern Health, which is Newfoundland’s only tertiary rehabilitation centre for people recovering from traumatic SCI. Shears and the St. John’s Wheels In Motion event committee (of which Shears also serves as event leader) have worked closely with the YMCA to provide exercise possibilities for people with disabilities outside of the rehab setting.

“It’s incredibly important for people living with SCI and related disabilities to live active and healthy lives,” says Sherry Thompson, YMCA-YWCA General Manager of Health, Fitness & Recreation. “Having adapted equipment at our ‘Y’ aligns with our values of caring, respect, responsibility and inclusiveness. Thanks to the support of Wheels In Motion, we’re now able to provide increasingly independent exercise opportunities for people living in our community.”

Even prior to the installation of the Uppertone, the YMCA-YWCA of Northeast Avalon provided a range of exercise opportunities for people with disabilities on its fully accessible first floor. The YMCA is currently looking to expand its accessible services even further and is working with Wheels In Motion to purchase an electric exercise mat which will allow clients in wheelchairs to transfer from their chairs onto a surface for stretching and bed mobility practice.

The Uppertone was installed in the spring of 2009 and is already being put to good use. Nearly 30 participants in the Miller Centre’s Rehabilitation Day Services have come to use the equipment, as have people from the Eastern Seals Fit-Ability program and the Newfoundland Brain Injury Association.

While Regular has been using the machine frequently, he does have one complaint. “The only problem I have with the equipment,” he says with a laugh, “is that I can’t afford to purchase one myself.”
We cannot change lives.

Other events ask you to stand up for them, we’re asking you to sit down. On June 13, sit down and support Rick Hansen Wheels In Motion, presented by Scotiabank.

SIT DOWN
CHANGE LIVES

Visit wheelsinmotion.org to register for an event in your community.