inner VISION

Dr. Patrick Stroman’s pioneering work with functional MRI is providing new insight into the injured spinal cord

also inside:

SCI on the Stage
Wheelchair Skills Training
Getting Involved in Research
Quality of Life is Job One...

What does quality of life really mean? What can be done to improve the quality of life of Canadians who live with a SCI?

People with little or no knowledge of SCI might be tempted to think that the only way to improve quality of life for people with SCI is to “cure” or reverse paralysis.

People with SCI, however, know different. While an outright cure for SCI is an ultimate dream, it remains elusive and is, therefore, far from the only goal. And while measuring one’s quality of life is subjective and differs from individual to individual, we do know that significant improvements in quality of life often come from even modest breakthroughs in research or improvements in the way care and services are provided to people with SCI.

For example, we know that small gains in hand function can make a big difference in the lives of people with tetraplegia who are seeking more independence or to rejoin the workforce. We know that finding better ways to prevent and treat pressure sores would benefit the majority of people with SCI (and many others in the process). We know that reducing SCI-related chronic pain and spasticity would result in a huge improvement in the lives of many. And there are countless changes that can be made in our society that would improve the quality of life for Canadians with SCI—from improving basic accessibility to creating better access to care and support services.

There are avenues of research and emerging best practices that promise to yield progress in all of these areas. The SCI Solutions Network is committed to supporting this type of work, thanks to financial support from Health Canada, Western Economic Diversification, the Rick Hansen Foundation, and many provincial governments.

You can read about some of the work we’re supporting in this and every future issue of Solutions magazine.

Reaction to our first issue, published in March, was stellar. So once again, please tell your friends and colleagues about Solutions and let them know that receiving it is as simple as visiting www.scisolutionsnetwork.ca and clicking on the subscribe button. Please remember that Solutions is available free of charge, thanks to the support of our funders.

Sometimes, just getting the right information can make a huge quality of life difference.

Best wishes,

Eric Boyd, CEO
SCI Solutions Network
We’re seeking 15 people who have a spinal cord injury and live in the BC Lower Mainland to take part in the initial phase of 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 across the country 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. Some of the areas the survey deals with are accessible housing, attendant care, technical aids, specialized health care, transportation, peer support, active living, and education & employment. 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 Canadians with SCI and benefit organizations that support Canadians with SCI.

How it works:
We’re seeking 15 people who live in the BC Lower Mainland to participate in the focus group phase in June 2009. Focus group participants will ensure the survey is ready for the main phase, which will take place in the Fall of 2009 with 3,000+ participants from across Canada. As a focus group participant, you will complete the survey twice online (about four hours time will be required) and take part in a focus group session. 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

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Enjoy the View from Elevation
Elevation is a new wheelchair that can elevate users as much as 10 inches at the pull of a lever. The chair uses a unique hydraulic system to elevate users for better interaction or reaching ability, or decrease height for a better wheeling position. The Elevation also offers many other adjustability features: over 30 degrees of real-time adjustable backrest angle/tilt, zero to 10 degrees of adjustment to rear wheel camber, adjustable footrest height, and adjustable backrest height. It’s constructed of 7005 heat-treated aluminum and weighs in at just 24 pounds (the frame is constructed in Canada by mountain bike specialists). Other standard features include scissor-lock or push-to-lock brakes, Spinergy wire wheels, and Froglegs Softroll casters.

The chair is the brainchild of Vancouver’s Dr. Jaimie Borisoff, who spent four years designing and researching Elevation. His inspiration came from his academic and sporting pursuits. During grad school, Borisoff, who is paraplegic, was often in the lab and tried a standing chair to reach the lab benches, but he found it too awkward. He also plays wheelchair basketball, which requires a lower position for more maneuverability.

“It’s ironic that we hear from health professionals that we should adjust our posture and seating throughout the day, but that the people who sit the most aren’t able to do that with rigid chairs,” says Borisoff.

For more information on the Elevation wheelchair, visit the company’s website at www.useyourinstinct.com.

Get Closure
Sometimes, it’s the simple stuff that can make life easier. Take, for example, the E-Z Pull Door Closer. If you’ve got a door in your house that’s difficult to close after you wheel through, this low-cost device might be the answer. It’s easy to install with no tools required. The clear acrylic rod is strong, flexible and unobtrusive. An acrylic hook with adhesive backing is provided to store the E-Z Pull when not in use. For more information, visit www.e-zpulldoor.com.

Say Goodbye to Handrims
NuDrive is a new lever-drive propulsion system that installs on any manual wheelchair with 24 inch spoked wheels. It allows users to propel themselves forwards and backwards, and manoeuvre and brake, by pushing levers instead of gripping handrims. The product, designed in the UK, debuted last October and subsequently won first place in the Independent Living Design Awards from the British Healthcare Trades Association. A recent study funded by the U.S. National Institute of Disability in the USA shows that lever-drives such as NuDrive shift the shoulder loading and can reduce shoulder degradation and injury. In addition to reducing shoulder wear and tear, NuDrive is said to reduce the force needed to self-propel by up to 40 percent. Other benefits include protecting the hands and wrists, and improving hygiene. For more information, visit www.nu-drive.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.
Scoping Disability Policy Review
A new report completed by Mary Ann McColl, Professor at the School of Rehabilitation Therapy at Queen’s University, compares disability policy and government programs from all Canadian provinces and territories.

The report, titled A Scoping Review of Disability Policy in Canada, was funded by the SCI Solutions Network.

“Disability policy is one area that holds strong potential to make significant changes in the lives of thousands of people with SCI,” says Dr. Luc Noreau, a member of the SCI Solutions Network’s Research Management Team. “However, this field is perceived as unnecessarily intricate with wide variations across provincial and federal jurisdictions. This review sheds light on disability policies in critical dimensions of the journey toward community participation and full citizenship. It is a first step towards a better understanding of strengths and weaknesses of the ‘policy’ system but should also be used as a directory to inform people with SCI about the policies in their province of residence.”

To download the report, visit http://chspr.queensu.ca.

The First 72 Hours After SCI
The Consortium for Spinal Cord Medicine has released “Early Acute Management in Adults with Spinal Cord Injury,” a guide to managing the critical first days after spinal cord trauma. During the first few days after a SCI, efforts at preserving life, limiting the severity of the injury’s effects and improving long-term outcomes are vitally important. This guideline, which encompasses the myriad disciplines needed to care for a person from the time of injury through the critical first few days of care, provides informed recommendations for optimal treatment during this period.

The document’s development was led by an expert review panel chaired by Dr. Peter Wing, orthopaedic spine surgeon at Vancouver General Hospital.

The guideline is published by the Paralyzed Veterans of America (PVA). It can be downloaded at no cost from PVA’s web site (www.pva.org).

New SCI Clinical Trials Network
The North American Spinal Cord Injury Network (NASCI Net), formed on March 17, 2009, plans to test promising therapies to restore function in people with chronic SCI in the United States, Canada, and Mexico.

One of the driving forces behind the new network is Dr. Wise Young, Director of the W M Keck Center for Collaborative Neuroscience at Rutgers University.

NASCI Net is seeking FDA approval to conduct a phase 3 clinical trial in the United States that parallels a ChinaSCI Net phase 3 trial to test the use of umbilical cord blood and lithium therapy in chronic SCI. Several prominent hospitals have expressed interest in the trial.

For more information, visit www.nascinet.org.

SCI Population: Five Times Greater?
Roughly one in 50 Americans has some degree of paralysis, and five times more Americans than previously thought are living with SCI, according to a study released in April.

Previous estimates of Americans with SCI were in the range of 250,000. The study, completed by University of New Mexico researchers and funded by the Christopher and Dana Reeve Foundation, concludes the actual number is about 1.3 million.

The Reeve Foundation plans to use the findings to push for health policy changes, including ending a federal requirement that disabled workers wait 24 months before getting health care through Medicare. Also on its target list: insurance policies that forbid $400 air cushions for wheelchairs until someone’s already suffered a pressure-caused skin ulcer that can require a $75,000 hospital stay.

Current estimates of Canadians living with SCI range from 38,000 to 45,000. There is, however, no conclusive way to determine if these numbers are accurate. If one were to extrapolate the U.S. findings to Canada, the result would be about 145,000 people living with SCI.

But it’s important to note that there are many factors that could render such a comparison invalid—for example, differences between American and Canadian health and reporting systems.

Sitting in the BC Legislature
People with SCI in British Columbia should be pleased to find a peer in the BC legislature. Stephanie Cadieux emerged as the new B.C. Liberal MLA in Surrey-Parorama Ridge after May 13th’s provincial election.

Cadieux sustained a SCI when she was 18. She’s following in the footsteps of the late Doug Mowat, a tetraplegic who was a Social Credit MLA from 1983 to 1991.

Like Mowat, Cadieux also worked for the B.C. Paraplegic Association, where she was Director of Marketing and Development. She becomes the first woman with a disability to serve as a BC MLA.

Tetraplegia or Quadriplegia?
Several readers have commented about our use of tetraplegia instead of quadriplegia. While many of us have historically used quadriplegia to describe SCIs that result in paralysis of all four limbs, the SCI Solutions Network has opted to use tetraplegia for several reasons. First, it’s more commonly used around the world—not just by researchers and clinicians, but by people with SCI outside of North America. Second, quadriplegia mixes words from Greek and Latin words—quadri comes from the Latin word meaning four, and plegia comes from the Greek word meaning a blow. This is a kind of linguistic faux pas in many parts of the world. Tetraplegia, on the other hand, is derived entirely from Greek roots. Send us an email at info@scisolutionsnetwork.ca and tell us what you think.
Real Drama

James Sanders and the Realwheels Theatre Company are using the stage to present SCI and disability to the public in a new light.

by Dylan DeMarsh

The award-winning stage production *Skydive* has wowed audiences with stunning effects and a riveting story of two brothers who experience a skydiving freefall that goes horribly wrong.

Tim Matheson photo
It's often been said that art imitates life. But that isn't always the case when it comes to portrayals of people with disabilities in the dramatic arts.

Disability is stereotypically presented in one of two ways on the stage and screen. At one end of the spectrum, the person with a disability is often portrayed as someone to be pitied—for example, think of Maggie Fitzgerald in the film *Million Dollar Baby*, who chooses death over life as a tetraplegic.

At the other end is the classic "triumph over adversity" approach that tells the "inspirational" story of a person with a disability who overcomes all odds to become a "hero". Think of the 1999 screen adaptation of Jeffrey Deaver's *The Bone Collector*, and you'll get the idea. We would all probably have enjoyed seeing Lincoln Rhyme, a tetraplegic who can only move two fingers, solve a brutal series of murders from his bed. But the ending is typical Hollywood: when the murderer catches Rhymes alone and tries to kill him, Rhymes tricks the man into coming close enough so that he can grab him by the throat with his teeth, and manages to hold on long enough for the heroine to come and complete the rescue.

These and most other portrayals of disabilities were written and acted by people without disabilities.

James Sanders, the 39-year-old founder and Artistic Director of the Vancouver-based Realwheels Theatre Company, is working to change the misconceptions that result from these stereotypical portrayals of disability.

"Disability is largely represented as a negative in media that must be overcome," says Sanders. "The result is a false representation of the true needs of people living with disability. They want to be accepted and embraced for the people that they are, not for what they are able or not able to do."

His solution? Produce world-class theatre that deepens the audience's understanding of the disability experience through respectful and accurate representations.

Sanders' motivation is the result of personal experience. He's led an artistic life—he was an avid musician as a child, and he continued exploring his artistic side following high school by enrolling in theatre school. During his third semester, Sanders became a tetraplegic after sustaining a SCI. Undaunted, he returned to his studies, but discovered that the barriers he faced were more attitudinal than physical.

The school quickly embraced my wheelchair with ramps and lifts, but there was a clear shift in the perception of me as an actor and the scope of roles, exercises and expectations that were presented to me," he says. "There was a clear assumption that, as an actor with a disability, I would now be asked to play characters with a disability, and by that I mean the characterization of disability, which at the time, seemed to be based on anger and in fear."

These experiences led Sanders to launch Realwheels in 2003 with a vision of normalizing disability through innovative storytelling. "I see theatre as a mechanism to establish a natural character fighting with universal issues, represented by a performer with a disability, that will enable a greater awareness of the common concerns that all people share and, by doing so, offer a deeper understanding of the disability experience," says Sanders.

Sander's vision was realized in 2007 with the debut of *Skydive*, Realwheels' inaugural production, at the PuSh International Performing Arts Festival in Vancouver. *Skydive* offered festival-goers a unique take on the disability experience and challenged audiences to question their views on disability issues.

The award-winning play, which continues to impress audiences, eschews the "triumph-over-adversity" theme in favour of telling a story about universal issues around sibling rivalry and family reconciliation. The story of a free-fall parachute jump gone awry, *Skydive* combines dazzling aerial choreography with a deeply moving story about two brothers coming to terms...
with the differences between them. It speaks to the spirit of people rather than their physicality.

“If I use the representation of disability within the context of a universal story, I have the ability to feed the audience with images of disability within the natural context of their imaginations,” reasons Sanders. “This will hopefully provide a link to the everyday, where an audience having seen a Realwheels production may draw a closer tie to people with disabilities who they encounter in their day-to-day lives.

“I have friends living with SCI, who work in wonderfully interesting careers, as an air traffic controller, a politician, a scientist and a mechanic. I also have many friends living with SCI who don’t work at all. All these lives and lifestyles are valid and I believe all these people and personalities would have emerged in all their creative ways regardless of their disability.”

_Skydive_ has impressed critics as well as audiences, winning three Jessie Richardson Theatre Awards and the Canadian Institute of Theatre Technology’s Award for Technical Merit. More than 90 performances of _Skydive_ have taken place in six cities in front of over 30,000 people.

“The response from people with SCI watching _Skydive_ has been the ultimate reward,” says Sanders. “I’ve received emails and letters from people with SCI, who share their appreciation for a story that rings close to home, but in essence speaks to their spirit, not just their physicality. Positive feedback from my peers in the arts community is important, but reinforcement from my peers with SCI is vital to the health of Realwheels. It’s also what keeps me inspired and energized to do this work, especially during the long days doing administrative work and producing between performances.”

Sanders and Realwheels are currently working on _Spine_, their follow up to _Skydive_, which will have its world premiere at the 2010 Cultural Olympiad in Vancouver in March, concurrent with the Paralympic Games.

_Spine_ continues the precedent set by _Skydive_, combining a personal story with larger societal issues. _Spine_ deals with the virtual reality of the online world where people can recreate themselves behind avatars and created identities. It takes a cue from Mary Shelley’s _Frankenstein_, updating the classic gothic tale for the 21st century while dealing with several issues of importance to people with disabilities.

“_Spine_ explores the loss of identity and the loss of human connection,” says Sanders. “Day-to-day physical meetings, family mealtimes and casual encounters have been replaced by conference calls, fast food and extended Facebook sessions. Each step removed from the human connection threatens us with a loss of personal identity and changes in how we relate to others.”

This loss of identity, says Sanders, is one that people with SCI face in their journey to come to grips with life with their new body. “Who they were before their accident may come into question when they look at who they are now and who they want to be,” he explains.

_Spine_ also aims to explore the complexities of cure-chasing—a sometimes reckless and expensive pursuit of scientifically questionable treatments—through the examination of what is “real” in a modern, mediated world, where the human connection takes a backseat to the limitless possibilities of the virtual world. _Spine_ explores our changing relationship with our bodies and the perils of messing with nature in a multimedia theatrical presentation that takes place live onstage and in the virtual reality world of “Second Life”.

“Cure-chasers are often more afraid of living than dying and will seek experimental treatments to escape what ails or constrains them from leading a healthy quality of life.”

“Cure-chasers are often more afraid of living than dying and will seek experimental treatments to escape what ails or constrains them from leading a healthy quality of life,” says Sanders. “I’ve spent two years researching the motives behind cure-chasing. Individuals will cross borders in search of the miracle cure with often tragic and sometimes fatal results.”

For Sanders, the issue of cure-chasing goes beyond the health risks associated with experimental surgeries and medications. He believes that people with SCI will continue to be tempted to take dangerous chances until disability is viewed simply as one of a person’s many physical attributes rather than a defining characteristic. “What saddens me more than the individuals who find themselves in worse positions than before (their treatment) is the stark reality that our society is driving these people to escape their bodies, by not embracing disability as a societal norm,” he says.

Realwheels represents a true collaboration across the spinal SCI community. In addition to the feedback from people with SCI, Realwheels researchers spent time at ICORD, interviewing scientist and engineer Jamie Borisoff, as well as SCISN Managing Director Chris McBride, to ensure _Spine_ is accurate technologically and sociologically. _Spine_ has also been funded in part through a grant from the SCI Solutions Network and Rick Hansen Wheels In Motion.

With the premiere less than a year away, Sanders is looking forward to seeing the reaction to _Spine_ and is hopeful for a reception similar to the one that _Skydive_ received.

“We want people to come out of a Realwheels production with their minds open to possibilities for change within themselves, by inspiring them with fantastical images and humorous stories of love and hope. Our hope with _Spine_ is to have a sociological discussion about cure-chasing in the narrative of an interactive source of entertainment. At the same time, we hope to educate our audience of the real possibilities that exist to improve the quality of life of people with SCI.”

_Spine_ debuts as a co-production with the University of Alberta at the Timms Centre for the Arts in Edmonton for 10 performances from February 4–14, 2010. The production then travels to Vancouver to play in the 2010 Cultural Olympiad, co-presented by Simon Fraser University and co-commissioned by VANOC. The Vancouver run will take place March 12–21, 2010, for ten performances at the Fei & Milton Wong Experimental Theatre. Visit www.realwheels.ca for more information.
In the weeks and months following a SCI, people are asked to absorb a tremendous amount of critical information about managing their own care and health—for example, how to avoid infections and pressure sores, learning a bowel and bladder routine, operating a wheelchair, and maintaining physical fitness. The expectation that all of this can be absorbed during rehab is often unrealistic for many who are simply struggling to come to terms with their new reality.

Toronto’s John Shepherd was overwhelmed by the amount of information presented to him after becoming tetraplegic in a 2003 car collision. “There’s so much going on during the period following an injury and during the rehab process that it’s difficult to absorb everything,” says Shepherd. “It’s incredibly important for newly-injured people to be able to access important self-care information—when they’re ready.”

Following his rehab, Shepherd looked for an online resource to help him learn the important self-management skills he needed to maximize his independence. He discovered that few such resources existed. And many traditional references he found—books, manuals or CD-ROMs—were already obsolete.

Shepherd resolved to make a difference. His solution was SCI-U, an online resource that uses high quality streaming video to offer comprehensive, easily-understood information on living with SCI. He developed the concept and a working prototype as a research project supported by the Ontario Neurotrauma Foundation (ONF).

When it’s completed, anyone, regardless of where they live in Canada, will be able to visit SCI-U and learn about important aspects of SCI self-management, at a time and pace that suits their individual needs. Content will include expert-reviewed information and real life testimonials from people living with SCI. Being web-based will allow SCI-U to be easily updated with fresh content as required.

Support from Wheels In Motion and the SCI Solutions Network, along with contributions from ONF, the Canadian Paraplegic Association (Ontario), and Toronto Rehabilitation Institute, will allow Shepherd and a team of clinicians, consumers and researchers to complete and evaluate the project’s pilot phase, which will consist of six modules: SCI and You, Bladder, Bowel, Skin, Nutrition & Healthy Eating, and Choosing & Using a Wheelchair. These modules will be developed and evaluated in 2009. When completed, SCI-U will include up to 18 modules.

Each module features a video presenter who guides users through the content. CBC journalist Joanne Smith, former host of Moving On, is the presenter for the beta modules. Navigational controls and links to different sections and resources can be easily customized to meet each user’s needs. The modules also contain a searchable glossary and a quiz which reinforces the material learned.

Shepherd’s business background—he has an MBA from Harvard—was instrumental in the development of SCI-U. “The e-learning approach is incredibly popular and effective in the corporate world,” says Shepherd. “It’s also being used to educate healthcare workers, but no one seems to be using this type of platform to empower patients.”

Shepherd is looking to others in the SCI community to ensure that SCI-U reflects the needs of its users. “SCI-U involves stakeholders from across the country,” he says. “The extensive involvement of consumers will ensure that SCI-U is meeting the needs of people with SCI.”

Look for updates in future issues.

A screenshot from the beta version of SCI-U.

John Shepherd
Imagine having the ability to not only see a detailed image of the injured spinal cord, but to be able to study in great detail how it’s actually functioning—or not—above and below the injury site.

If it sounds like the stuff of science fiction, think again. While we may be a few years away from Dr. “Bones” McCoy’s medical tricorder, exciting new technology is allowing a truly up close and personal view of the human spinal cord in action.

It’s called fMRI, or functional magnetic resonance imaging. Most people are familiar with MRI, which has been used successfully for noninvasive medical diagnosis for decades. MRI relies on a powerful magnetic field, radio frequency pulses and a computer to produce detailed pictures of virtually all internal body structures including the spinal cord. While a relatively new procedure, fMRI uses much of the same equipment and procedures as conventional MRI. But in addition to providing a detailed image of the body’s internal structures, fMRI can measure the tiny metabolic changes that take place in the central nervous system. The result is an unprecedented view of neural activity.

Up to this point, research on the use of fMRI has focused primarily on the brain, and it’s quickly evolved into a proven method for mapping brain activity. But Dr. Patrick Stroman, Director of Queen’s University’s MRI Facility in Kingston, Ontario and Canada Research Chair in Imaging Physics, sees great potential for fMRI as a diagnostic test for SCI.

“My interest in spinal fMRI began in 1997 when I first started working at the Institute for Biodiagnostics, National Research Council of Canada, in Winnipeg,” explains Stroman. “At that time, fMRI was quite a recent development, and a co-worker, Dr. Lawrence Ryner, suggested we try fMRI in the spinal cord to see if it would work. Maybe it was from growing up in British Columbia, and hearing a lot about Rick Hansen when he did his Man In Motion tour around the world while I was a student at the University of Victoria, but for whatever reason, I was really drawn to the idea. I don’t think I’ve stopped thinking about it since.”

While the standard MRI can show details of structural tissue changes in the spinal cord as a result of an injury, Stroman says that the potential for recovery can only be inferred from it. “The key benefit of fMRI is that it can also show where the spinal cord is still working after an injury, even in parts of the spinal cord that can no longer relay signals to the brain. How can you hope to fix something if part of it is hidden from you? The possibility of doctors being able to have more complete information to guide treatment decisions is something that I expected would be of great interest to people with SCI.”

The basic science behind the imaging is that, when nerve cells (neurons) are active, they consume more oxygen, which results in an increase in blood flow to regions of increased neural activity—haemoglobin in red blood cells carries oxygen to the active nerve cell. This increase in haemoglobin can be measured magnetically, using an appropriate series of fMRI pulses.

Since fMRI can be done with the same imaging equipment at the same time as conventional MRI, it will add only about 15 minutes to a typical MRI session. All MRIs are non-invasive, and don’t use radiation or require injections. During the fMRI, the subject lies still while images are acquired repeatedly and an automated device applies different temperature sensations to various points on their skin. “The method even works if the patient is asleep—I’ve had lots of volunteers fall asleep during studies, and presumably it would also work if the patient was unconscious, although I’ve never tested this,” says Stroman.

Spinal fMRI is still under development and hasn’t yet been used for diagnosis or treatment planning, so for now Stroman can only
propose specific areas where it might become invaluable. “One way I foresee it being used,” he says, “is to supplement conventional MRI to give a doctor functional as well as structural information, to support decisions about the best course of surgical intervention, treatment strategies, and eventually rehabilitation therapy. Another very important use will be in demonstrating changes in function over time, particularly in the first six months after injury. Changes in function will show the effects of spontaneous recovery, and the effectiveness of treatments, even if these changes do not result in a noticeable change in the patient’s sensations or movement abilities.”

In particular, Stroman points to current regeneration research as an area likely to benefit greatly from fMRI. “New treatment strategies that are being researched to promote healing and re-growth of neurons across a site of injury, or implant materials to bridge an injury site, may benefit greatly by having the knowledge of what function remains on the far side of the bridge, so to speak,” he explains. He’s also enthusiastic about the possibility for fMRI to help determine causes and treatments for SCI-related chronic pain.

With a $97,000 grant from the SCI Solutions Network, Stroman and co-investigators Dr. Michael Fehlings, Dr. David Mikulis, Dr. Ronald Pokrupa, Dr. Karen Smith and Dr. Omar Islam are continuing work to validate fMRI as a clinical tool in SCI acute care. The pilot project will seek to include fMRI scans in the standard MRI battery of tests given to people with SCI at three locations in Ontario—Queen’s University MRI Facility, Kingston General Hospital, and Toronto Western Hospital.

“Recruitment of volunteers with SCI is underway, and the first participants will be imaged in June,” says Stroman. “We will image as many participants as possible at all three sites until next May. Although the results we get from each patient will not yet be used for diagnosis or treatment decisions, results from a large number of patients with a wide range of injuries will confirm how reliable and sensitive the results are for showing each patient’s condition.”

Results will be compared closely to traditional methods of determining function after SCI, including measuring sensation throughout the body with pinprick, assessing muscle function, and using electrical impulses to determine the capacity of nerves to carry signals between brain and extremities.

Stroman believes that this research will ultimately demonstrate that spinal fMRI is practical for use in hospitals.

In this sense, his work is breaking new ground. “Most of the fMRI research that is going on is focused on areas of the brain, and there are a number of groups working to develop fMRI into clinical tools for assessing various neurological conditions, although none are yet in wide-spread use,” he says. “In comparison, there are very few groups in the world working on fMRI of the spinal cord. This project is definitely ground-breaking for fMRI of the spinal cord, and may even be considered ground-breaking in terms of the clinical use of fMRI in general. If the results of this project are as expected, it will demonstrate that fMRI should be included with MRI for assessing every SCI.”

For more information on fMRI, visit Stroman’s website at http://post.queensu.ca/~stromanp/index.html.

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1 fMRI of a healthy, undamaged spinal cord and brain. The subject is being stimulated with heat at the shoulder level, and the resulting neural activity indicates the sensation is registering in the upper region of the spinal cord and in the brainstem.

2 fMRI of a spinal cord with injury at the C5 level (the injury site is in the highlighted circular area). As with image 1, the subject is being stimulated with heat at the shoulder level. As this is above the injury level, neuronal activity is similarly shown in the upper part of the spinal cord and in the brainstem.

3 fMRI of a healthy, undamaged spinal cord. The subject is being stimulated with heat on the little finger side of the hand. The sensation is clearly registering low in the cervical spinal cord corresponding to where the nerves enter the cord.

4 fMRI of a the same spinal cord shown in image 2. The subject is also being stimulated with heat on the little finger side of the hand, but as the signal for this sensation has to travel up and across the injury site, there is little neuronal activity registering.
Wheelchair skills training is a simple and low-cost strategy for enhancing independence and safety for people with SCI.

When it comes to simple, inexpensive ways to maximize the independence of people with SCI, it’s hard to beat the Wheelchair Skills Program.

Experience tells us that the majority of people with SCI and other mobility disabilities receive only the most basic of training when they first begin to wheel. The unspoken assumption seems to be that people will naturally learn the necessary skills and finer points. But perhaps wheeling shouldn’t be taken for granted—evidence has shown that learning wheelchair skills in a formal setting is more effective than learning through trial and error. And that’s the premise of the Wheelchair Skills Program, developed by Dr. Lee Kirby and other members of Wheelchair Research Team at the Nova Scotia Rehabilitation Centre in Halifax.

“I began my career as a rehabilitation-medicine specialist over 30 years ago,” says Kirby, a Dalhousie University professor in the Department of Medicine’s Division of Physical...
The Wheelchair Skills Program is the most exciting thing that I’ve been involved with during that time. Wheelchairs are the single most important intervention we use in rehabilitation—the greatest good for the greatest number of people with severe disabilities.

The Wheelchair Skills Program consists of two components: a Wheelchair Skills Test and a Wheelchair Skills Training Program, for both manual and power wheelchair users. The test evaluates a person’s ability to negotiate less than ideal terrain—for example, curbs, gravel and even stairs—and to transfer. In turn, the Training Program seeks to develop confidence in those skills within a formal setting. Ideally, once training is completed, the test is given again to see how the participant improves.

The program officially kicked off in 1996, but Kirby explains that it evolved out of work on wheelchair safety that began in the 80’s.

“Some of our early studies were on the epidemiology of wheelchair-related injuries,” says Kirby. “These showed that tip-over accidents were the most common cause of injury.” He adds that the vast majority of these accidents took place when the wheelchair user was in motion, as opposed to sitting stationary.

“When we recognized that dynamic stability was more relevant than static stability, the next question was which activities to use to assess dynamic stability. That led to development of an obstacle course and the Wheelchair Skills Test. When we saw how poorly many wheelchair users performed during the test, we began looking at the best ways to train people to perform the skills. That became the Wheelchair Skills Training Program.”

From its permanent home at the Nova Scotia Rehabilitation Centre, the Wheelchair Research Team offers the program to wheelchair users and to their caregivers, while continuing efforts to improve and validate the program.

But the Wheelchair Research Team isn’t waiting for people to come to them. Since inception, the Wheelchair Skills Program has received scores of testimonials about its effectiveness, and its approach has also been carefully scientifically validated. As a result, the team has been encouraged to spread the word to health care professionals across Canada and around the world in the hopes of seeing more people able to benefit from the training.

“Our wider knowledge-transfer efforts aimed at health-care professionals are two-fold,” says Kirby. “We use our website for the knowledge, and workshops for the practical training. We’ve had a lot of interest in the workshops, including some work in less resourced settings. For instance, we’re off to Bosnia to do some training there.”

As part of its mandate to promote best practices in the SCI field, the SCI Solutions Network recently funded a “wheelchair boot camp” at the Blusson Spinal Cord Centre in Vancouver. The event, organized by UBC Occupational Science and Occupational Therapy Associate Professor Bill Miller and hosted by ICORD, allowed Kirby and his team to offer a day-long “train the trainer” session to 17 OTs and PTs from across British Columbia. In addition, about 80 health care professionals and administrators attended a noon lecture.

“The feedback was excellent,” reports Kirby. “We’ll be sending a fol-

Wheelchair Skills Program: Skill Training Examples

- Brakes
- Armrests
- Footrests
- Rolling
- Turns in place
- Moving turns
- Sideways maneuvering
- Reaching
- Increase rolling resistance
- Transfers
- Fold/unfold wheelchair
- Doors
- Obstacles
- Cross-slope
- Pot-holes
- Inclines
- Level changes
- Wheelies on level terrain
caregiver and a willing trainer can start today. In fact, there is no excuse for not doing so!”

However, Kirby adds that several Canadian rehab centres have been setting aside space for indoor obstacle courses.

There are many interventions that hold promise to improve the lives of people with SCI—for example, stem-cell research, new medications, treadmill training and functional electrical stimulation. “Some of these will stand the test of time and others will not,” says Kirby. “The old adage ‘hope for the best and plan for the worst’ is a good one. The worst is that people may need to use wheelchairs in a less than perfect environment. With the help of training programs like the Wheelchair Skills Program, people can live lives that, although different in some ways, are as rich and full as they had before their injuries.”

Cody Tresierra and his wife Elvie pose with Cody’s paintings at the ColourWheels Art Gala in Vancouver on April 19, 2009. Cody was one of nine artists with SCI who showcased their work at the gala, which raised more than $6,000 for Rick Hansen Wheels In Motion.

More than 250 people attended the event at the Blusson Spinal Cord Centre to enjoy painting, photography, sculpture and live music—all created by people with SCI.

After sustaining a SCI in a motor vehicle accident, Cody took up mouth painting as a form of therapy. Today, as an active member of the Mouth and Foot Painting Artists of Canada, Cody continues to paint, creating oil paintings sold as cards and prints and shown in exhibitions across the country.

Last year, Cody presented the City of Vancouver with one of his paintings to symbolize Vancouver’s Olympic-sized spirit and celebrate the returning Paralympic athletes.
Last year, Randy LeBlanc noticed a story in *Spinal Columns*, CPA Alberta’s magazine, about the SCI Solutions Network’s “Access to Research” fund. Since then, he’s made good use of the fund to take part in two promising rehabilitation research projects.

LeBlanc was injured at C6/C7 as the result of a 2001 motor vehicle accident in Drumheller, Alberta. He spent two months in intensive care at Foothills Hospital in Calgary. Once stabilized, he underwent almost a year and a half of intensive rehabilitation, first at Foothills, and then in Drumheller.

“Eighteen months in hospital sure gives you a new outlook on life,” says LeBlanc, who is now 31 years old and makes his home in Calgary.

The life-altering experience of SCI compelled LeBlanc to find ways of making contributions to his community. For example, he currently serves on the City of Calgary’s Advisory Committee on Accessibility, and the Calgary City Police’s Chief Advisory Committee for Persons with Disabilities.

He also made a decision to try to make a difference in the world of SCI research. In particular, he recently learned of two University of Alberta studies in Edmonton that were relevant to his situation. One was Dr. Arthur Prochazka’s ReJoyce study testing a novel method of restoring hand function for tetraplegics. The other was Dr. Vivian Mushahwar’s project on prevention of pressure sores using electronic stimulation of paralyzed muscles of the buttocks.

But an obstacle that limited his participation in these two projects was the cost of getting involved. The expense of travelling, finding accommodation and eating in restaurants all but ruled out taking part in any studies that were outside of Calgary.

Fortunately, he found out about our Access to Research fund and, with assistance of both Prochazka and Mushahwar, successfully applied to the program. Since then, he’s taken part in both studies and experienced a great deal of satisfaction from getting involved.

“These studies have proven to have great results—not just for me, but for all who can benefit from them,” says LeBlanc. “I gained more hand function and increased sensation from doing the ReJoyce study.”

For LeBlanc, however, the improvements to his own personal situation are simply an added bonus. “I do these studies all in the name of research, and if it doesn’t apply to me or help me, it will help someone,” he says. “So being part of the studies was very rewarding, not only from the benefits of my own increased hand function and sensation, but knowing that the findings from these studies will one day advance into improvements in the hands and butts of many people with needs, big and small.”

LeBlanc is grateful for the support that allowed him to get involved. “The funds were used for my transportation, accommodations and meals during the study,” he says. “I could never have done this on my own.”

His advice to other Canadians with SCI? “My messages to others would be to do all you can, along with help from others, to fight the battle in overcoming life with a SCI.”

If you’re thinking about participating in a research project and think you could benefit from our “Access to Research” fund, visit us at www.scisolutionsnetwork.ca, email us at info@scisolutionsnetwork.ca, or call us at 1.604.707.2100.
During a recent meeting to the Blusson Spinal Cord Centre, federal Minister of Health Leona Aglukkaq discussed progress of the Rick Hansen SCI Registry with Dr. Marcel Dvorak, Medical Director. The Registry is funded by Health Canada through the SCI Solutions Network.

The numbers tell the tale...

The Rick Hansen SCI Registry (RHSCIR) has been making impressive strides towards Canada-wide implementation.

RHSCIR is the first and only Canada-wide platform intended to collect important data on the incidence, treatment and care of SCI. It’s expected to provide exciting new insight into best practices across the entire SCI care continuum when fully deployed in all major SCI acute care and rehabilitation centres throughout our country.

Promising developments have taken place within the last six months—primarily the completion of comprehensive data-sharing agreements with many key institutions which will collect data, and real progress in the development of a world class, web-based data collection platform.

Data-sharing agreements are now in place for Calgary, Halifax, London, Saskatoon and Winnipeg. Similar agreements are now pending for Hamilton, Ottawa, Vancouver and St. Michael’s Hospital in Toronto. And discussions are well underway in Edmonton, Montreal, Quebec, St. John’s, and several other institutions in Toronto—Toronto Western Hospital, Sunnybrook Health Sciences Centre, and the Toronto Rehabilitation Institute.

Development of the web-based data collection platform is being led by the SCI Solutions Network’s own IT team. In addition to being truly universal and portable, this state-of-the-art platform has comprehensive data validation and management functions, along with strict privacy and security feature sets that will meet the requirements of all sites as well as provincial and federal privacy legislation. Completion and full deployment is expected in 2010.

“The Registry is a critical component of the entire SCI Solutions Network,” says Eric Boyd, SCI Solutions Network CEO. “The dream of a national SCI registry has been long-held by researchers and people with SCI. It’s now close to moving from a dream to reality, thanks to the vision of Rick Hansen, our major funders such as Health Canada, and the hard work and dedication of all those who are working on implementation, here in Vancouver and across our various partner sites.”

“Bringing the Registry to life has been a sometimes slow and frustrating process,” says Dr. Marcel Dvorak, spine surgeon at Vancouver General Hospital and RHSCIR Medical Director. “We’re grateful to all those who have worked through the process, and we believe you will all be rewarded for your commitment. In short order, the Registry will begin to live up to its potential of allowing all of us—researchers, clinicians and people with SCI—to better understand SCI and the effectiveness of specific treatments, practices or programs for improving functional outcomes and quality of life after SCI.”