STIMULATING QUALITY OF LIFE | BC PARALYMPIANS SCORE | RELIEVING PAIN WITH POISON

thespin

SPINAL CORD INJURY BC

SUMMER 2014

the incomplete issue

Putting into perspective the mixed blessings of life with incomplete spinal cord injury

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editor's message

What symbolizes you?

I recently received a call from a provincial government employee who was wondering if her ministry should adopt the new, unofficial version of the International Symbol of Access, frequently referred to as the disability symbol. We all know the original symbol—a white stick person sitting in a wheelchair on a blue background, the one on accessible parking and bathroom stalls everywhere. The new symbol uses a more active version of the white stick figure in a wheelchair.

I was pleased that a ministry employee would take the time to consult community stakeholders on a matter like this. Unfortunately, I wasn't all that helpful because I really don't know what our members and readers think on this matter.

So, I said I'd ask. Ask you, that is. But what to ask? The original International Symbol of Access was developed to designate places and facilities that people with physical disabilities (particularly those using mobility aids) can access. It seems to do a good job at conveying this. So do we really need a new symbol? Does the wheelchair symbol even represent people with disabilities? Does it even matter?

Personally, I think that like words, symbols matter. Pictograms like the International Symbol of Access have become part of a universal language: they mean the same thing to everyone, no matter what language or dialect one speaks.

Or, at least that's the theory. Pictograms may cross the language barrier, but they can get caught up in cultural divides. Culture changes faster than language, which likely explains why there is a push to create a new version of the wheelchair symbol. Attitudes toward people with disabilities have changed a lot in recent decades, but there is still a long way to go, and constructive imagery and language must be used to build greater access and inclusion.

The complaint about the current symbol is that it evokes the perception of the person with a disability as passive, requiring special assistance from society—it's not exactly an image of independence and self-empowerment.

Newer versions of the symbol depict an active wheelchair user—the stick figure's arms are positioned so as to give the perception of motion. This implies that people with disabilities are active, independent participants in their communities. While the design (by a team in New York) has received glowing praise in the media, it's also being criticized for the fact that it looks like the figure is a high performance wheelchair athlete—dynamic, but maybe overly so. Some say it makes them feel excluded. Some quadriplegics with limited or no arm movement don't feel it represents them. In fact, some like the current symbol because it can be inclusive of those who use hand controls to maneuver their chairs.

In this day of political correctness, people tend to overthink things. Is the wheelchair symbol an example of this? Maybe. I'm pretty sure there are a lot of people out there who wouldn't even notice or care if the symbol changed. But there are many who do care, and for that reason alone, the debate is a good one.

It's pretty rare to achieve full consensus on any design, let alone one trying to represent such diversity as those with disability. Perhaps the more important thing with all of this is not actually the design itself, but the discussion it creates.

SCI BC wants you to be part of this discussion. In the coming weeks, we'll be inviting your thoughts and opinions on the International Access Symbol through an online poll we'll be running on our website, so keep an eye on www.sci-bc.ca, our social media pages and our electronic Peer Newsletter for info on how to participate.

– Chris McBride, Executive Director, SCI BC

thespin

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Spinal Cord Injury
British Columbia

QUADSTICK

The QuadStick is a mouth-operated gamepad, mouse and keyboard that will allow even high-level quadriplegics to play complex games such as Call of Duty. It features a single joystick, multiple sip & puff sensors, a lip position sensor, and a push switch, all of which are connected to a 32 bit ARM processor that converts the sensor inputs into USB and Bluetooth signals for PCs, Android devices and game consoles such as the PS3. Which input is assigned to which in-game button is configurable, although there's several prearranged setups built in. Gamers can use the straws to shift between different control methods, and it's also possible to use third-party voice recognition suites (like Dragon Naturally Speaking) to add in voice commands. At the moment, there are five working prototypes, and if the product reaches its funding goal of $10,000, it aims to make at least 25 units, with plans to scale up depending on how much is raised and the overall interest. Visit www.quadstick.com for details.

Innovations

New products, devices & aids to daily living that might make a difference in your life...

AVIN HANDYBAR

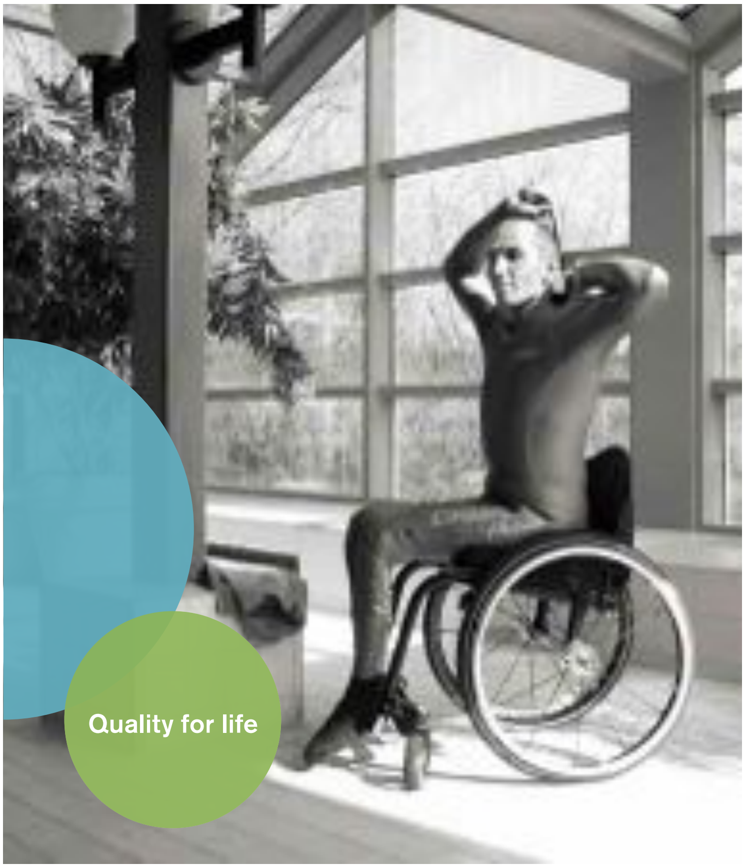
The Handybar offers support and safety for people with disabilities transferring in and out of their vehicles. Its universal fit ensures it fits securely into either the passenger or driver side of the door of almost all types of vehicles with no installation required—you simply slide the steel end into the locking mechanism or striker of the vehicle door frame, which is an incredibly strong component of all vehicles. It's constructed of heavy-duty steel covered with an ergonomic rubber grip. It comes with added safety features such as a window breaker and seat belt cutter in case of an emergency. For more information, visit www.avin.ca.

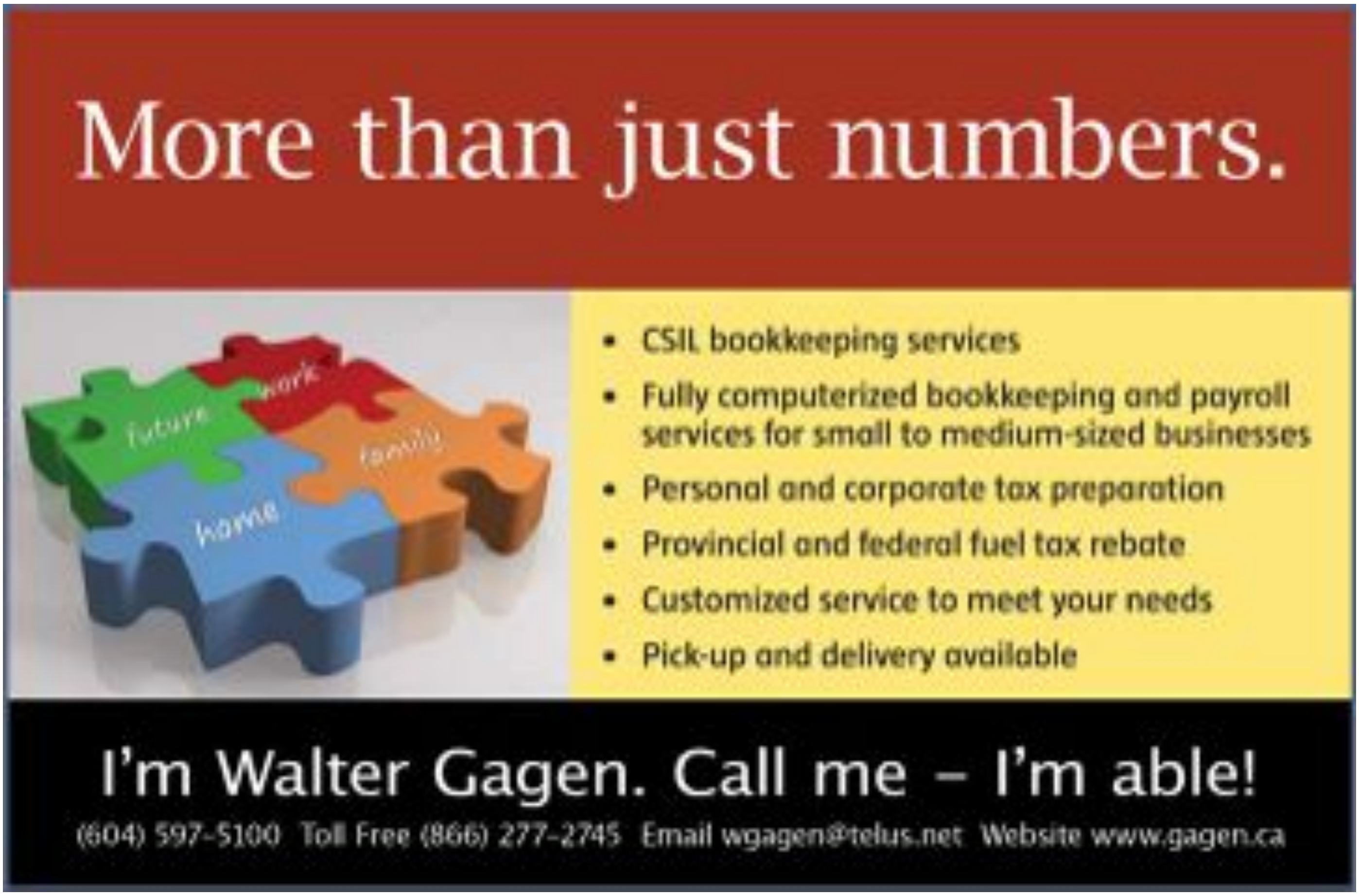
LASHER SPORT ATH-FS

The ATH-FS from Lasher Sport is a rugged full suspension handcycle with a durable magnesium frame and Fox Shox absorbers on all three wheels. It is specifically designed for off road adventures and offers a unique patent-pending front fork shock design that provides a smooth ride even in the most demanding conditions. Fully adjustable depth and angle settings allow a high degree of control and adjustment for maximum comfort and all wheel hydraulic disc brakes offer superior stopping power. Other features include a powder-coated magnesium frame, all wheel hydraulic disc brakes, adjustable back rest/seat base, WTB drive wheel, Spinergy Xyclone rear wheels, Shimano SLX components, and Schwalbe Albert Tires. The ATH-FS is also highly customizable and offers many upgrade options. Visit www.lashersport.com to learn more.

SOFTWHEEL ACROBAT

The Acrobat brings to rear wheels what Frog Legs brought to castors—suspension for a softer ride. The Acrobat incorporates a selective suspension mechanism that acts only when an impact above a certain user-set threshold is encountered. In normal conditions on standard floors or pavement, the suspension mechanism remains static, with the Acrobat acting and feeling like a high-end, rigid wheel. When rolling off of a curb or when any other impact is encountered, the wheel's hub shifts from its central location and develops a cushioning effect that dramatically absorbs and lessens the impact. Once the obstacle has been passed, the hub shifts back to its central location smoothly, automatically, and seamlessly. The wheel regains its rigidity and responsiveness, and the user continues moving efficiently. The Acrobat is being developed by SoftWheel, an Israeli company. For more information, visit www.softwheel.co.il.


Quality for life


future
work
family
home

Be a great sport.

Try your hand at a variety of outdoor activities on August 27 when SCI BC hosts its 2014 Multi-Sports Day at Vancouver's Jericho Beach. From tennis and badminton to handcycling and lawn games, there's something fun and active for everyone. The Disabled Sailing Association will also be on hand to introduce Peers to the water. Everyone's invited to re-energize with a group barbeque near the beach. Contact Alfiya at 604 326 1212 or abattalova@sci-bc.ca for details.

Northern exposure.

Bring on the great outdoors (and the s'mores!) From August 15 to 17, our Prince George Peers head out to beautiful Bear Lake for their Northern Camping Trip. The yearly outing is literally a breath of fresh air, offering camping, fishing, kayaking and canoeing, ATVing, and other outdoor activities. All Peers, families, and friends are invited to this free northern event. To learn more and sign up contact Karen at 250.563.6948 or kmarshall@sci-bc.ca.

Tee to green.

On July 14th, the annual Doug Mowat Memorial Golf Tournament returns to the Point Grey Golf & Country Club in support of the BC Paraplegic Foundation (BCPF). Participating golfers in this fun-raiser will compete for excellent prizes while helping British Columbians with SCI adjust, adapt and thrive post-injury. Proceeds support BCPF scholarships and SCI BC's provincial programs. More information can be found online at www.mowatmemorial.com.

Four stimulated guys (left to right): Andrew Meas, Dustin Shillcox, Kent Stephenson and Rob Summers. (Photo courtesy University of Louisville)

STIMULATING Quality of Life

The recent media blitz we saw on a promising epidural stimulation research project focused largely on restoration of leg movement. We believe there are other implications that are more intriguing.

“A spinal cord injury treatment breakthrough moves legs!” cried the headline in the May 2 issue of the *Legal Examiner*. “This Might Be The Cure For Paralysis,” shouted the *Business Insider* on May 20. “Paralyzed patients successfully move legs after breakthrough treatment,” exclaimed *PBS NewsHour* on May 9th.

No doubt you read or heard at least one or two variations of these headlines in your own regular news sources. And, like us, you may have realized that mainstream media missed the mark when it came to the significance of the research in question.

Then again, maybe it’s hard to sell newspapers with headlines such as “Spinal Cord Injured Man Regains Ability to Take a Leak” or “Paralyzed Man Gets Erection” or “Breakthrough Treatment Helps People with SCI Avoid Autonomic Dysreflexia.”

Regardless, it’s left to us to tell you about the most promising, real-life benefits that you might be able to enjoy one day as the result of the research project that’s been taking place at the University of Louisville in Kentucky.

To date, the work has centered around four young, spinal-injured American men who received a surgical implant of an electrical stimulation device in their lumbar spine. The device, known as an epidural stimulator, is made by Medtronic and is widely available off-the-shelf for pain relief. But for these four men, it yielded a completely different and unexpected result—it appears to have reawakened their spinal cords’ innate ability to control certain motor functions without direct input from the brain.

The premise behind the research is that our spinal cords are to an extent "smart" and, when properly activated (in this case, with electrical impulses), can remember and execute certain functions. Think of a baby suspended with feet on the ground—he or she instinctively begins to make stepping movements, even though his or her brain isn't developed enough to direct this movement. This is the spinal cord's "smartness" in action.

Rob Summers, who is quadriplegic and had no movement but some sensation in his lower body, was the first to receive the implant. The goal of the researchers involved was to answer some questions about nerve pathways after SCI. But to Summers' surprise, he was suddenly able to stand three days after he had his array activated. With more stimulus and locomotor treadmill training, he began to take supported steps. You may remember that this created somewhat of a media sensation back in 2009 when it was reported. Then, seven months later, he realized he could move his toes when the stimulator was on.

All of this astonished the researchers overseeing the project, University of Louisville neuroscientists Dr. Claudia Angeli and Dr. Susan Harkema. No less surprised was UCLA's Dr. Reggie Edgerton, whose groundbreaking epidural stimulus work in animal studies preceded Angeli's and Harkema's work in humans. Interest grew, and the University of Louisville was successful in finding funders to see if they could replicate the results they saw in Summers.

Over the course of five years, Andrew Meas, Dustin Shillcox and Kent Stephenson agreed to be participants. All three had no movement below their injury, and Meas had no sensation. Again to the surprise of the researchers, all three regained the ability to stand and take some assisted steps on a treadmill. The researchers clearly appeared to be on to something. The results from all four participants were most recently summarized in the April issue of the journal *Brain*, and that's when you no doubt read about the work in the media, which had a field day with the research—particularly the idea that the four men

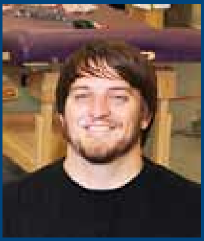
In their own words...

The work in epidural stimulation is being partially funded by the Christopher & Dana Reeve Foundation. Recently, the Foundation published firsthand accounts of the first four participants of the trial, and have graciously granted us permission to reprint those accounts.

ROB SUMMERS Portland, Oregon

On the third day in the clinic after the surgery, they said, "Let's just see how it goes to stand." They put me in a harness over the treadmill, my weight suspended 100 percent. They lowered it down and down until I'm standing, full weight-bearing. It was just an incredible feeling. I hadn't moved anything in four years. My legs were supporting me. There was nothing to help me balance. I could feel my legs working, I could feel my feet under me on the treadmill. At first I didn't comprehend the significance, but I soon realized what an incredible thing this was. It was like a giant weight was lifted off my shoulders. I had worked so hard for so long, and to be standing for 15, 30 seconds, it was so emotional for me in many ways. After seven months we found out that while the stimulator was on, I was able to voluntarily control my toes, ankles, knees and hips, on command. This was something that was completely unexpected. There were other benefits, too. One day I realized I could sweat again, and regulate my temperature, feel hot and cold. I could also feel light touch. I regained control of my bladder, bowel and sexual function and my circulation improved. I'm not 100 percent but the changes really impact my quality of life. I'm happy to have been part of the experiment and be able to help the scientists streamline their techniques. After seven months I could take steps; Dustin, patient number four, could step in the first week. I joke with (lead researcher) Susan Harkema, "by the time you get to patient number 1,000, they will be running out of the lab in five days." If I were to address a person with a new injury I would say without a doubt, this will change the quality of your life. We are not quite there yet, but cures are just around the corner if we continue the research efforts and experimental trials.

KENT STEPHENSON Mt. Pleasant, Texas



On June 9, 2009, I was practicing and getting ready for my summer motocross racing season, which started the following week. But everything changed that day. Going off the face of an 80-foot tabletop jump, the motor on my dirt bike locked up, causing me to crash. I did several cartwheels and in my landing broke T5 and T6 in my back. I was paralyzed from the chest down—T4 Asia A. I went to Craig Hospital in Denver for my inpatient rehab and came home from there in August. I was home for a week, then went to Frazier Rehab in Louisville, KY to start Locomotor Training and therapy. I did the [Reeve Foundation] NeuroRecovery Network training and community fitness program for a year at Frazier before I became aware of the epidural stimulation research, which of course was being done right there. I went through the screening and was selected. The first time they turned the stim on I felt a charge in my back. I was told to try pull my left leg back, something I had tried without success many times before. So I called it out loud, 'left leg up.' I felt a sort of charge go down my leg and then a tightness. This time it worked! My leg pulled back toward me. I was in shock; my mom was in the room and was in tears. Words can't describe the feeling that overcame me at that moment—an overwhelming happiness. I had been told by doctors that because I was an ASIA A I would never be able to move voluntarily. The feeling is amazing. It really gives you back that part of yourself you feel you lost when you became injured. When this all started, my injury was supposed to be a life-ending deal, really, that is how the doctors told it to were standing and stepping.

Largely lost in all the media frenzy was the meaningful health and quality of life benefits that each of the four participants had experienced. Yes, it's true that they regained leg movement, and the ability to stand and step has helped them restore muscle mass and cardiovascular health.

Remarkable, yes. But it's highly unlikely that these men will ever walk on their own as a result of this research.

However, every person with SCI should be intrigued by the health and quality of life benefits that each participant has experienced since receiving the implant. These include measurably improved autonomic function and blood pressure regulation; improved bowel, bladder, and sexual function; increased mobility and trunk strength; and for one participant, an important gain in temperature regulation.

"All four individuals have seen improvements in these secondary functions," explains Dr. Claudia Angeli, a senior researcher at the Human Locomotion Research Center at Frazier Rehab Institute who, along with Harkema, co-leads the project. "These changes seem to be long-lasting since they don't require the stimulation to be on, but they gradually improve as the individuals start and continue training with the stimulation. These changes are very gratifying to see, and are very important for the research participants because they have a direct impact on their quality of life."

In other words, Angeli and her colleagues understand that these quality of life impacts are a very important aspect of their work—perhaps even the most important. "We're starting to look at all these things in more detail and developing projects around these improvements," says Angeli, "because regardless of our success in obtaining independent stepping, quality of life changes might be sufficient for a faster translation of this research into clinical practice."

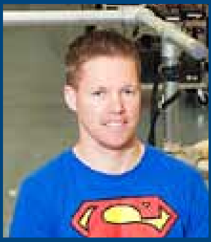
In fact, as this research moves forward in an effort to validate the results, Angeli says that the secondary health improvements will take on a greater prominence. "We currently have

me. But in fact, it has been an adventure. Being a part of the stim program has really changed my life and enables me to do all the things I used to do, like deer and duck hunting, going off-roading, running heavy machinery at work, everyday 9 to 5. I wasn't 100 percent sure I wanted to give up two years of my life to go through the training and everything. But it has totally been worth it. I got a fortune cookie recently after my injury. It said, "Everything's impossible until somebody does it." I still have that note in my wallet, and always recite it in my head when I'm trying new things.

ANDREW MEAS Louisville, Kentucky

I broke my neck seven years ago. It was dusk, I was cruising about 35 miles an hour on my motorcycle. I got hit head-on by a car. I flew 100 feet almost to the other side of the highway; I did a superman dive, landed on my head. I broke my neck at C6-7. After complications with pneumonia—I almost died while on the breathing machine—I was weaned and eventually transferred to Frazier Rehab, where I stayed for three months. Of course, I heard about Locomotor Training right away, it's done right here. I participated, but my insurance only paid for two weeks. I was put into the lottery, I guess you'd call it, for the research program there. Once I was picked, they had me do 80 sessions of Locomotor Training, to make sure I had no motor function below the lesion level. I did not. I got the surgery and waited a few weeks. Once the stim was turned on, I could stand on my own. It was amazing. I forgot how tall I was. It was very emotional to be standing after sitting in the chair for so long. Then, on command I was able to lift up my legs—pretty easily, even without the stim. I can't describe it, it was just incredible. Yes, leg function is a spectacular feature of epidural stimulation but for me the most important benefit is in managing my autonomic dysreflexia [AD, a dangerous blood pressure problem for people with injuries above T6]. Before the stim, I could sense when my bladder was full. If I waited too long to empty it, though, I would get a pounding headache, a sign of AD, and a painful reminder that this could lead to stroke. Now, I can hold my bladder longer and have no AD symptoms. Bowel function has improved a little bit. As far as sexual function goes, that has improved greatly – everything is possible now, and there is no AD.

DUSTIN SHILLCOX Green River, Wyoming



I was in a car accident on August 26, 2010, on the interstate near Green River, WY. I was driving a work vehicle when the tire blew out and the vehicle rolled. I was ejected from the car and paralyzed at level T-5, ASIA A. A few months after being discharged from the hospital, I saw a news report that researchers had for the first time enabled a paralyzed person to stand on his own. Once I found out about Rob Summers, I called and had my name put in the pool so I might have a chance to be a part of the study. The following summer I got the call. I packed my car and headed for Louisville. The feeling I get when I turn the stim on is amazing; when I stand or work on walking I feel great because I'm doing things that I was told would never happen again. The ability to move my legs is awesome and it makes me excited for the future because the four of us in the epidural stim program all keep making progress. I have also had progress in improved bowel, bladder, and sexual function – this alone has given me a strong self-confidence. The stimulator makes me feel normal. It's like I'm back. If I talk with someone who has a new spinal cord injury I'd tell him or her about how exciting the research is and how important it is to stay healthy and keep involved with therapy. I tell people—and show them by my example—that scientists are making great improvements for people with a spinal cord injury.

funding to replicate the initial study in another four individuals—these will involve four individuals with matched clinical characteristics to the four already implanted," she explains. "The basis of this will be replication of results. But we also have additional funding for four more participants with a focus on the secondary effects—specifically the cardiovascular function. These will be cervical injuries with significant cardiovascular deficiencies."

While the research to date is intriguing and promising, Angeli cautions that the hardest work lies ahead. "There's still a lot to learn and a long road ahead for us conducting the research, but we are working extremely hard to one day be able to translate this to the clinic. For me personally, it's extremely gratifying—I get the benefit of being in the lab almost every day with these individuals, and seeing what we would have defined as unlikely milestones happening very frequently and how excited the participants get every time they can do something more. Knowing that every day might be the day I get to see something amazing happen helps me get to work every day."

Meanwhile, other offshoot projects of the research are moving forward. "We have a team of engineers working on improving the technology and developing new stimulators and interfaces to reduce some of the limitations we've found," says Angeli. And while her team will continue working with surgically-implanted stimulators, the bioengineering institute at the US National Institutes of Health is funding research to develop non-invasive stimulators which can deliver electrical pulses through the skin.

Forgive us for speculating, but is it possible that all of this could eventually lead to a wearable device that would allow many people with SCI to stand and somehow achieve weight-bearing exercise, while yielding significant improvements in functional abilities that greatly improve health and quality of life? Obviously, this won't happen in the immediate future, and without a great deal of work. But it appears to be possible.

Finally, yet another exciting offshoot of the work is taking place at UCLA, in the labs of Edgerton and colleague Dr. Daniel Lu. The two scientists recently received a $6 million, five-year grant to study the same epidural stimulation for restoring hand function in people with quadriplegia. In fact, experiments with five participants have already taken place, and while data have not yet been published, Edgerton is optimistic.

"Our hypothesis with the upper extremity," Edgerton recently told The Christopher & Dana Reeve Foundation, "is that the cervical spinal cord probably will respond to interventions similar to what we have established in the lower spinal cord. Our results were better than we expected; we saw improvement in function including hand grip strength but also the ability to control that movement."

Stimulating news, indeed.

Conquering Canada

Like the famous Spanish explorers of the 15th and 16th centuries, Barcelona's Manu Heras struck out across the Atlantic to find his fortune.

For most of us in the western world, human nature dictates that we stick pretty close to the comforts of home throughout our lives—if not in the city or region we grew up in, then almost certainly in the country we were born in. Rare are those who actively seek out adventure by moving abroad to another country.

Manu Heras is one of those wayfaring types. He was born and raised in Barcelona, Spain, one of the most beautiful Old World cities. At the age of 18, he was injured in a motorcycle accident, which left him with T4 complete paraplegia. Undaunted, he pursued post-secondary education and rebuilt his life in Spain.

But he had a secret desire.

"When I was child, I dreamed of travelling to Canada," says Heras, now 35. "I never forgot that dream. In 2012, the opportunity came when I was granted a working holiday visa through International Experience Canada."

The program allows younger people to work and travel in Canada for one year. Heras' girlfriend also obtained a visa and accompanied him. The couple bought a camper van and travelled extensively throughout BC. Ultimately, they broke up, with Manu's girlfriend returning to Spain. Captivated by BC's beauty and the people he met, Heras opted to stay. He's made the most of his opportunity.

When he arrived, he couldn't speak or write English. He's tenaciously tackled the language barrier, and today he not only speaks excellent English, he reads and writes it as well. As for work, he's found a home at Wheelin' Mobility, the Lower Mainland's only mobile 24-hour on-call wheelchair and scooter repair service. He's a travelling technician for the company, which is sponsoring him while he's in Canada.

He's also taken on the ambitious task of introducing Stricker Handbikes to Canada. Stricker is one of the oldest handcycle companies in Europe, and its products—manual and electric handcycles, and manual and electric attachments to convert wheelchairs to cycles—sell in 30 countries worldwide, but not yet in Canada.

"I worked for Stricker before in Spain," says Heras. "When I arrived in Vancouver, I discovered that nobody knew about this attachment, so I decided to import Stricker to Canada.

"I like both of my jobs and I learn every day with them," he adds.

Beyond work, Heras' passion is adventure and athletics. "I love sports," he says. "All my life I've played sports. I started playing wheelchair basketball about 10 years ago—I played in all divisions in Spain, and one year in France during my studies. So in Vancouver last season, I played a lot of basketball. But I'm doing many others sports—sometimes for competition, sometimes just for fun. I've been handcycling, scuba diving, kayaking, offroad handbiking, and paragliding."

He's also embraced the Canadian winter (albeit a mild one in Vancouver). "This year, I played sledge hockey, and went skiing and cross country skiing," he says. "It was so fun! I'm always looking for new adventures."

And while he's living in Vancouver, he still wants to see as much as he can of the rest of the country. "I love the greenness of Canada, the nature, and the people too. I like to travel so much—last June I bought a van to travel to and work in the Okanagan Valley as a cherry packer."

He concedes that he thinks often of Spain. "Yes, I miss Barcelona—my family, my friends, my Catalan and Spanish languages. But I'm happy to improve my English every day. I'd like to live in Vancouver for as long as I can. Who knows what the future will bring?" ■

Visit www.stricker-handbikes.de/en for more information on Stricker Handbikes. For more details about Wheelin' Mobility, visit www.wheelinmobility.com.

AN incomplete AFFAIR

High anxiety and mixed blessings have been the cornerstones of my life with incomplete quadriplegia.

– by Richard Holicky

Looking back at the past 25 years, I see my life with incomplete SCI as a wild affair with a mistress who has been by turns voluptuous, incredibly jealous, sultry, and vengeful. At her best, she has been an incredible seductress. At her worst, she's been hell-bent on making me pay dearly for any transgressions or infidelity.

When I got to rehab in 1989, the prognosis wasn't bright. My C5 fracture left me unable to touch my chin with either hand, let alone feed myself.

Yet five years later I was going through my days doing the stuff of life—cooking, cleaning, vacuuming, gardening—unassisted and, more often than not, standing up. I drove to work in a van with a lift and once there, walked to the bathroom on crutches. My injury had become so incomplete that I was often called a fake quad and occasionally, almost apologetically, referred to myself as one.

I didn't travel to some far flung destination for stem cell surgery or some other exotic, miracle procedure. I didn't turn my life and future over to a higher power. Nor do I possess indomitable will and determination. I simply believe that chance left me with an incomplete injury.

My optimism soared two months into rehab when sensation and ability started coming back. I'd go to bed at night wondering what improvement I'd get the next day. I'd be ecstatic if more movement came, and down in the dumps after two or three days of no change. It was to be my life for several years. Quite the rollercoaster ride—manic depression on the installment plan.

I didn't know what to think when I took those first few shaky steps in the parallel bars a year after injury. It was several days before I trusted them enough to tell anyone. I didn't know what these steps meant, or if they would disappear or get stronger. I didn't know whom I could share these feelings and fears with. Each step meant more hope with no guarantees, enormous expectations with little reality, and more distance from my SCI friends—and yet no genuinely new access to the mainstream which I craved a return to.

These are all the small flashes of my incomplete experience: no peer group, little certainty, nothing to trust, lots to be thankful for. High anxiety and mixed blessings.

Beyond the initial elation I experienced after those first few steps was a great deal of ambivalence. They demanded that I bust my butt for another year or two to see if anything would come of this latest trick. But what I wanted was a life, not more therapy; a job, not an endless series of appointments and exercise schedules. What I wanted was some certainty about my future.

I was weary of the big tease. I was tired of having my life on hold. I wanted to have some fun, to make some plans. I wanted to be rid of the anxiety. I was in my 40s, and I wanted answers to the existential teenage questions of who and what I was.

Instead, what I got were a host of new insecurities that were layered on top of the ones that originally came with SCI, not to mention all those that I had lived with since long before that fateful day. Am I doing enough to maximize return? If I find work, can I still pursue walking and getting more function? Do I have the money for all this therapy? How will I know when I've reached maximum function?

After watching me shuffle along in a walker for three months with no improvement, a veteran physical therapist told me I was wasting my time. Six months later, a different PT had me walking some with crutches. Who knew? No one had all the answers, so I had to find them and define them for myself.

Dealing with pressure and misunderstanding from friends, family and significant others became more of a chore as I made more of my own treatment decisions—which therapies to pursue, which to reject. "How can you know you're maxed out?" they would ask. "How can you be sure?"

Well, I couldn't be.

As long as I was experiencing return, I could stay in some denial and avoid depression. On the other hand, the incompleteness—because I couldn't predict the future—bred more anxiety. Quite a trade-off: anxiety for depression and a player to be named later. Reality is for those who can't handle drugs, denial or that Elvis lives.

Fritz Perls, the noted German-born psychiatrist and psychotherapist who died in 1970, claimed that our task in life is not to rid ourselves of anxiety, but to learn to live with the anxiety that constitutes life. Ah, yes, the human condition. I cursed it then, and occasionally still do.

As I approached maximum function and a physical plateau, depression and anger began to return. Slowly I began to realize that it was probably time to throw in the towel and start getting on with life.

Once I made that decision, friends and family would inevitably want to know why. "So, you're just going to give up?" they would ask. I knew they meant well, but I'm sure these questions always had more to do with their own acceptance of seeing me in a chair. After three years, I knew what the score was and so my answer usually included some mention of a concept called reality.

But still, as it had from the beginning, the seduction of more return of function continued to whisper. "Why can't I have just a little more?" I would find myself asking. My incompleteness had been borrowing for several years; now the loan was due with interest coming in the form of some serious blues. Rehab shrinks I know say this is pretty common, putting off initial intensity of pain, loss and adjustment as something to deal with down the road.

What tempered all these negative emotions for me was that player to be named later—the realization and acknowledgment of how truly lucky and blessed I've been. Yes, it's true that I've always needed to wear a leg bag. I spend over two hours every other day doing bathroom ablutions. I've never had much sexual function without pharmacology. But when friends with complete injuries teasingly disowned me as a fraud and suggested I got off with a mere flesh wound, I grudgingly agreed and felt a bit guilty.

After all, for years I could get up a couple steps, walk through a two foot doorway or stand up to reach something on the top shelf. I worked nine to five, rafted, skied, travelled at will, camped and rode a tandem bike. It was a life in full, based on optimism and irrational exuberance that was my coping strategy. I lived alone for years, did stuff, built stuff, gardened and maintained home and yard with very little assistance.

And it's safe to say that the freedom that came from standing and the ability to ambulate short distances and some stairs literally changed my life. I highly doubt my wife and I would have ever been able to get together had I not been able to walk some. Stairs and architectural barriers alone would have made effectively wooing her difficult if not impossible.

But back then, few places were inaccessible to me, and my level of function provided a sense of confidence that made most anything seem possible. I could travel by myself for weeks on end and I lived freely with few modifications to home or vehicle. Transfers were mostly standing pivots, which meant I could get into full size SUVs with little problem, and most of the cooking I did was done standing up. I convinced myself that transferring with my legs would save my shoulders.

My wife and I painted rooms together, hung photos together and built shelves together, all at eye level. For weight control and mental health I walked daily on a treadmill for 30 to 40 minutes. I still had quad plumbing, but I functioned as a para and was always extremely aware of my good fortune and how much larger my world had become. I marvelled at the

THEN AND NOW: *Gardening and other chores were a little easier for me a couple of decades ago. These days, I'm sitting a lot more.*

will, strength and resourcefulness of people with complete injuries and limited function.

Of course, it turned out that my charmed existence was somewhat temporary. I began to feel the toll of age and years of sitting. When my shoulders began hurting enough for me to begin limiting what I did, I bought a pair of power-assist wheels on the cheap from eBay, though at the time I told myself they were for "sometime down the road."

About the same time—five or six years ago—things began to change, and my world started to become considerably smaller and different.

I began to experience system failures: first a bad gall bladder, then scar tissue on the cord which began to inhibit function and increase spasticity, then uncontrollable spasms that led to implantation of a baclofen pump, then another surgery due to complications with the pump, followed by a mild stroke and yet another pump failure. As for my power-assist wheels, "down the road" showed up in less than a year, with the neck surgery—much quicker than I ever envisioned. The wheels were quickly paired with a ramped van.

Each setback slowly chipped away at my function, optimism and confidence; bouncing back became more challenging each time. The neck surgery, the pump surgeries and the stroke all involved two to three week hospitalizations, and a couple also required in-home care and PT.

Getting over surgery at 62 and older was much more difficult than original rehab at 42, and not just physically. I was quickly aware of both waning will and discipline. Following the stroke my trunk muscles weakened—either from the stroke or simply and more logically, from aging and overuse—and the spasticity increased to new and often overpowering levels.

Following very short walks on the treadmill, I'd experience full body spasms so strong they took a six foot tall, muscular PT struggling mightily to overcome them and keep my pudgy, five foot seven body upright. I no longer felt safe negotiating my way from the bottom of my stair glide to my basement chair, or trust my ability to get on and off the treadmill, much less safely use it. I thought it prudent to stop walking.

I quickly began losing strength in my legs, which made transfers more difficult and tenuous. Extra pounds replaced daily exercise, exacerbating the problem. Trunk weakness left me so floppy I could no longer roll over on my own and now relied on a slatted headboard to help me turn in bed. I found myself mentally preparing for each transfer, struggling to sit up straight, and getting ready for bed by 8:30 or 9:00 after once again wincing throughout the day with intense shoulder pain—the bitter residue of crutch and treadmill walking. I knew that I'd soon need to start driving from my chair, as the transfer to the driver's seat became more tenuous each day. My PT repeatedly lobbied me to give up the power assist wheels and buy a power recliner.

And the costs continue to mount. Following another surgery and a struggle to find a tolerable and effective dosage to control another bout of severe spasticity, I've found the cost of exercise, denial and irrationality now seems to be new frontiers of pain approaching debilitating levels.

Today, I'm still a fake quad, but I'm growing much closer to the genuine article every day. I suspect the pain, the fatigue and the shoulder problems are in no small part due to walking and standing and pushing the limits. Had I not done so much for so long, I suspect my world might have stayed larger, safer and more pain-free considerably longer.

I'd been warned about the possible price I'd pay and have to admit the estimates have been all fairly accurate. I now find myself filled with feelings of anxiety similar to those I felt a year out of rehab when I didn't know where my limits might end. Now, on the downside, I fret about how severe my limitations will become along with some of the same feelings of denial I felt early on. In turn, that invariably leads me to a resolution to do something about it.

Recently, I began a significant two day-a-week exercise regimen, coupled with near daily use of a table-top handcycle, therabands and stretching. Within a week or two I noticed marked improvement and ease with transfers, dressing, balance and most all other aspects which constitute the stuff of life. About the same time I began meeting with a PT to address my failing skills, which I quickly realized were failing due to de-conditioning.

At the end of our first session, after seeing me move about, stand and walk in the bars some, she allowed that I had "potential." I was instantly hooked, longing to convince and console myself in the belief that with enough work, effort, will and discipline I could once again get back to where I once was. In turn, these thoughts triggered my inherent insecurity and eagerness to please or not disappoint the expectations of others. With newfound confidence and a bit of encouragement of my regained skills, I once again asked myself if I just gave up.

Of course, this type of rosy thinking leads to overconfidence, occasionally resulting in a call to the local fire department to get me back into my chair. The firefighters know my name and are kind enough to forgo using the siren or lights. And of course, I once again remember the concept called reality, which precipitated throwing in the towel twenty years ago. And the voice—reason, logic or perhaps age—questions if once again striving to regain mobility and function will be worth all the effort, commitment and anxiety. "Do I really want to do this?" I ask myself.

And so the inner conflict continues to roil around inside me. My days now feel suspiciously like the first few months of rehab, filled with uncertainty and anxiety. I sense the possibility of hired assistance in the not-so-distant future.

I also know I'm not the first crip to experience these losses and ravages of aging and overuse, and frequently engage in gallows humor with other geezer wheelers, if only to ease the sting.

We, all of us, able-bodied and disabled alike, age; few who wheel independently for years get off pain-free or superlimber. It's a helluva thing, gettin' old. I continually remind myself that life with disability is a constant negotiation requiring grace, humour, good sense, self-knowledge, and a realistic awareness of one's capabilities and function, at the very least for safety's sake.

Yes, looking back, I see my wild affair with the mistress of incompleteness with some regrets.

Yet even knowing all the hard lessons she's taught me, and all that she's cost, I suspect if she came knocking today I'd probably go all wobbly, get out my wallet, and be seduced all over again. ■

Richard Holicky is a writer and editor who lives in Denver, Colorado. He's currently a Community Editor at New Mobility *magazine, and has previously written for* The Spin.

Do you trust your doctor?

The potential of stem cell therapies for chronic SCI has been a source of hope for many. But by Canadian medical standards—and those of most other western countries—stem cell therapies are far from being ready for use. The bottom line is that we don't know if they're safe (there have been many cases of disastrous consequences), let alone if they work. Clinics in less regulated countries that offer stem cell and other unproven therapies do so for a hefty fee, convincing people of their safety and effectiveness through the use of emotion-evoking patient testimonials instead of solid science.

Despite the risk, many people with SCI, including many Canadians, travel abroad for these unproven therapies, including stem cell transplants, often ignoring the advice of their doctors and other health care providers in the process.

There are many possible reasons for this—for example, a sense of self-determination and impatience with the slow process of stem cell research on the part of those who travel for the therapies, highly effective emotion-evoking marketing techniques employed by the foreign clinics selling these therapies, and media reports about these therapies that are either unethical or not based on fact.

Two UBC researchers—Dr. Judy Illes and Dr. Brian Kwon—want to better understand how the trust relationship between doctor and patient is affected by the discussion of experimental therapies for SCI. By listening to the perspectives of individuals with SCI and of doctors who care for individuals with SCI, they hope to form evidence-based guidance for doctors who are in the critical path of responding to patient questions about experimental treatment options such as stem cells for SCI.

The researchers are seeking English-speaking adults over 19 years of age with SCI from across Canada and the United States to participate in a 30-minute interview, which can be conducted by telephone, in person, or by Skype. The purpose of this interview is to learn more about the kinds of questions you ask your doctor about experimental therapies like stem cells.

Regardless of how you feel about medical tourism, or if you've ever travelled or are considering travelling abroad for stem cell or other unproven therapies, you'll be interviewed with impartiality, without judgement or condescension, and with privacy guaranteed.

To participate in or learn more about this study, please contact Karen Jacob, National Core for Neuroethics, by email at karen.jacob@ubc.ca or by phone at 604.827.3690.

INCOMPLETE SCI:
You're not alone.

Recently, one of our peers who's lived with an incomplete injury for just a couple of years had an opportunity to meet a few others who also have incomplete SCI. The encounter was an eye opener for him—up to that point, he hadn't realized that there were so many others like him out there in the community, and that the challenges they struggled with were so similar to his own.

This is the essence of the incomplete problem: incomplete injuries are becoming more and more common; they bring complex challenges—they bring high incidence of pain, fatigue and other health issues; they lead to uncertainty over how much functional recovery to strive for; they are poorly understood by the public; and, compared to other more obvious and disabling levels of SCI, they bring a sense of isolation and few opportunities for peer support. On the surface, people with incomplete SCI appear to be the lucky ones, but this belies the very real challenges masked by what is often an invisible disability. As one of SCI BC's Peer Coordinators has been known to say, "If it was just about the walking, spinal cord injury would be easy."

Here at SCI BC, we're trying to change that, and we'll be looking for ways to expand our services to make them even more available and relevant to people with incomplete injuries. Please check out the Events section at www.sci-bc.ca to learn more.

The most important message, we think, is to let you know that you're not alone. We hope that the preceeding story by Richard Holicky helped clarify that for you. But we also want you to know that so many other British Columbians share your challenges. We asked four of our peers for a brief account of their lives with incomplete injury, and all four responded enthusiastically, agreeing to share details about their injuries and the challenges they've met head on. Our thanks to Tristan Smyth, Fernando Romero, Kristina Shelden, and David Parke for selflessly sharing their stories for our readers' benefit.

– Chris McBride, Executive Director, SCI-BC

Tristan Smyth, Vancouver

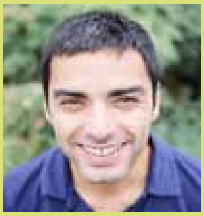
Wheelchair athlete
Age: 27
Age at Injury: 24
Injury Cause: Skateboarding accident
Injury Level: L1-T12 incomplete

I have gradual return of some muscle function in my legs, but little to no return in my calves, feet, and glutes. I can walk, but without the ability to push with my feet, I can't run or jump. I'm slower than most people. If I walk or stand for too long I feel it in my knees, then cramping in my quads the next day. I used a wheelchair before I began walking and for a while after, then mixed with using a cane. Now I just need to make sure I take breaks and rest and try not to put myself in situations where I have to walk too far. Regarding bowel and bladder, I digitally stimulate, use catheter for emptying, but probably not as much as I really should.

I don't like to think I'm better than someone else. It's just a different set of things to deal with. But yeah, it could always be worse. Sure, there are definitely good things about appearing able-bodied, but at the same time I don't look obvious. So I feel like maybe I have to explain myself too often, or feel guilty making use of disability aides and benefits in the public eye. Initially with recovery and with the uneducated public perception, as soon as people see you're walking again they assume you're "healed" and everything is better now. Then there's times where people around you forget when you're out doing something, and you end up getting left behind because you can't keep up or need to take a rest. It is what it is, though, and I don't like to complain.

You can't change what's already happened. You can only look forward and make the most of what you can do. You don't really have a choice. I'm busy now with other things to think about. I still miss skateboarding. But yeah, I'm doing something new now with wheelchair racing.

Check out my athlete Facebook page www.facebook.com/tristansmyth86 , and "like" it if you want to follow what I'm up to with racing.



Fernando Romero, Vancouver

SCI BC Contract Peer Services Manager
Age: 42
Age at Injury: 30
Injury Cause: Mountain biking accident
Injury Level: C6–C7 incomplete

I regained lower limb movements before being transferred to GF Strong from Vancouver General Hospital—about two weeks after I was injured. My functional return is significant—when people ask for percentage, I say 85 percent because I do have some functional limitations and loss of function. I have general weakness of the left half of the body, and my hand function is limited to about 50 percent, both left and right. I also have lost body mass—my hands lost a lot of muscle and my wedding ring slips off often, and an overall loss of about 30 pounds which I can't add back on. I'm extremely susceptible to cold, which causes significant increases in spasticity and full body rigidity. In cold, my drop in core temperature is fast—hyperthermia can set in very quickly. Sleep, or the lack of, is an issue, and spasticity issues wake me regularly—every time I roll over, I wake. I am easily fatigued and experience chronic fatigue issues as well.

I have some gait abnormalities and balance issues, and it's difficult to walk on uneven surfaces and up or down stairs. Bowel issues include constipation and irregularity, and I also have inconsistent urinary function—voiding is difficult always. Sexual function is almost normal.

I have neuropathic pain, every day and all day long. This is by far the worst part of having an SCI, and very common with incomplete SCI. It never goes away; it impacts every single aspect of my life. People who don't have pain don't understand what this pain is like—they have no idea how encompassing it is.

Even with these issues, I feel incredibly fortunate to have what I have now. I work with people whose level of injury is very similar to mine and some are using a sip and puff chair. Am I happy? Yup. Do I get frustrated? Of course I do, but I have never complained of where I am today in terms of recovery. I have always done the complete opposite. I have always made an effort to speak positively especially when speaking with others with an SCI because I know how shitty it is; I know what's it's like to be in chair and not be able to pick up your own fork to feed yourself. Although my time in that situation was brief, I remember it vividly.

The downside of an incomplete injury for me is, mentally, I feel my body should be able to do a lot more, but I have to accept that physically it can't. There is a huge discrepancy between mind and body when dealing with the physical aspects, and that is freaking frustrating. Emotionally, it has been a roller coaster; psychologically it has been very difficult. I've had to confront many, many issues and it hasn't been easy. Some I have yet to deal with, and I may never, but that's my life. I have developed some coping skills but some days life in general is a challenge. You throw in all the issues I have to deal with on a daily basis due to my SCI with the everyday challenges of being a parent, working, and commuting, and things can get tough.

In terms of meeting all these challenges, I wouldn't use the word successful. I cope and strive to meet the challenges head on and see what happens the next day.

A couple of people I know call me the walking wounded, and there are many of us out there. We are not alone, many people have these issues, physical and psychological. The circumstances are different but how we deal with them, that is what it is. We don't advertise it; we generally try to hide the fact because we don't want people feeling sympathy for us. I don't need empathy either, but what I would like is for people to understand—that's all.

Kristina Shelden, Vancouver

Personal Injury Resource Coordinator
Age: 30
Age at Injury: 24
Injury Cause: Motor vehicle accident
Injury Level: C4-C5 incomplete

My functional return ended up being somewhat miraculous. I was five weeks at VGH, only seven weeks at GFS, and I walked out. Well, limped out. Today, for the most part, my disability is invisible. I do have a permanent limp, but visually that is the only noticeable sign. I can walk, but it's largely dependent on my fatigue levels. Sometimes I can only make it to the bathroom and back. But other days I'm much more mobile. I've actually even managed a trip backpacking through Spain.

I don't rely on any mobility devices. But now that I'm almost six years post injury, I do regret denying myself access to that help. Sometimes I desperately wish I had, the fatigue gets so intense. I do have permanent tone, spasticity, nerve pain, and patchy sensation as well.

My bowel and bladder have returned to almost normal although I am still quite susceptible to UTIs. I do still have challenges, but I am seriously grateful for the return I have had.

Regarding sexuality, I want to be blunt because I worry there are others out there like me who are feeling alone in this. Sexual function is a challenge. My body no longer responds as it used to. I can no longer orgasm, and I need lubrication now, as well. I wonder sometimes if it's now become a mental problem, as can be the case with many women, spinal cord injured or not. Or if, in fact, I've simply lost that function. The biggest trouble I've found is that once the confidence is shaken, it's hard to find your footing again. It's also hard because I've found there isn't a ton of research out there in regards to this important, if not entirely comfortable, topic.

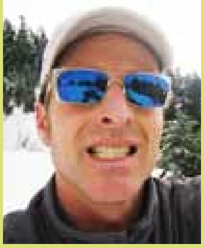
I certainly feel fortunate to be incomplete. But every injury has its challenges. And it's difficult to even apply the word 'fortunate' to a spinal cord injury. I find it creates an instant urge to compare oneself to others, and comparison is never a good plan—especially when it comes to the unique differences of each SCI. It's more about accepting the challenges you're individually faced with, and learning how to deal with, or overcome them.

Among my biggest challenges is fatigue. I simply don't have the energy to do everything I want to do. Another challenge is being 'invisibly' injured. On the outside, I seem like a perfectly healthy young woman. At most, people think I've hurt my knee or sprained an ankle. And even for people who know and love me and have gone through the last six years with me, it's still a struggle to understand that I constantly face challenges they're unaware of. Never mind what it's like to deal with the general public. For example, I can no longer take transit. I get glares and get into arguments when I use the handicap seating. I have difficulty standing on a bus in motion and have fallen before. And when I do manage to make it through the whole scenario, by the time I get to my destination I'm too pooped to do anything but fall asleep. I've been made to cry from customs agents, people who thought I'd illegitimately parked in handicap parking stalls, and even friends who just couldn't wrap their heads around it.

And lastly, one of the biggest challenges is myself, and the very fluid diagnoses of "incomplete". Learning to accept my limitations and potential limitations hasn't been easy—especially since no one could or can tell me how limited I would or will be. I am a mystery and I find that difficult, because there is no closure. I've lived with 'possibility' and 'potential' and 'who knows, maybe you will' for so long now that it's left me in a no man's land of acceptance. In fact, this resulted in a pretty serious breakdown over the winter. I'd been saying "my injury" for five years. This very small but important word had a huge impact on me emotionally. "Injury" implies that one will get better. It's temporary. And it very well could have been for me. But after five years it finally came crashing down on me that I was, in fact, permanently disabled. I didn't realize that after five years I could emotionally crash as deeply, if not deeper, than I had at the initial outset.

Things are improving. I now know how to better respond to strangers who challenge my disability. I aim to educate rather than be hurt by their ignorance. I try to respond with kindness. I've developed long-lasting and incredible friendships with people who have proven themselves to be understanding. The fatigue is an ongoing challenge, but as I age I find it's less important to me to get out and do as much anyway.

I'm grateful for my level of recovery. But I think I will always strive to improve what I have even more. I think this is a double edged sword; this insatiable need for more. I think it's part of the reason I recovered as well as I have, and yet I think it's holding me back in an emotional sense from feeling at peace with what I've got. All I know is that this is a process. And my ultimate goal is to find a balance between my drive and my acceptance. I wouldn't say I'm there yet, but I would say I'm on my way.



David Parke, North Vancouver

Film technician, Recreation Studies student at Langara College
Age: 48
Age at Injury: 44
Injury Cause: Mountain biking accident
Injury Level: C5-C7 incomplete

My return has been significant overall, with 20% reduced sensation in feet and hands. I'm able to walk for hours without aid, though descending stairs is problematic. I am independent with respect to bowel and bladder function, and sexual situation.

I do have neuropathic pain throughout my body, night spasms and sleeplessness, burning pain in hands and feet, proprioception issues, poor coordination, and poor fine motor skills with hands—very frustrating when dressing. I also deal with depression and fatigue.

That being said, things have gradually improved. I am more used to this new body and I realize how my luck was incredible based on conversations with professionals in the field. I feel fortunate to be alive and incomplete, though my symptoms and disability are invisible. I'm hugely grateful for the luck of circumstance; to walk, feed myself, go to the bathroom independently.

The invisibility of my disability is the most challenging. Working and providing for my family is the biggest challenge today. My employer won't accommodate me, and government offers less than I thought to assist with securing employment. I am funding school in hopes of working in a new career, but meanwhile raising a family on a meager income which is unsustainable. All of this has drained our retirement and investments. The government and my family doctor don't view me as being disabled or eligible for receiving tax benefits. I am still an incomplete quadriplegic; it doesn't stop or instantly improve as there are daily struggles regardless of good returns.

It's a frustrating place to be; I want to work 30 hours a week in a position that can accommodate me, leaving me time to look after my family. It's not just like starting over, but it's a challenge with my age and a disability that is invisible and unsupported by government, my doctor, and employers.

Despite this, I want to stress that I appreciate everyone and everything way more than I knew possible.

David Parke is undertaking a massive bike ride from Dease Lake to Vancouver as a fundraiser for SCI BC programs and services. You can read about his ride on page 30, and check out his progress online at www.sci-bc.ca/ride-for-spine.

Raising the Bar

BC athletes helped lift Canada to a third place finish at the surprisingly accessible and overwhelmingly successful Sochi Paralympics

Pride of the Vernon Curling Club: Lead Sonja Gaudet delivers against Finland while third Ina Forrest looks on. (photo courtesy Canadian Paralympic Committee)

Josh Dueck was in a tough place: competing halfway around the world, but stuck in his own mind.

Days earlier, on the 10-year anniversary of the ski accident that left him a T11 complete paraplegic, the sit-skier had braved the balmy conditions and soft snow at the Rosa Khutor Alpine Centre to lay down a massive silver medal downhill run. But the following day, on track for a gold medal, Dueck made a small mistake and wiped out just two gates short of the super-G finish line. From there, his confidence and energy levels sagged, and so did his race times. Dueck couldn't let his error go.

And then, on the morning of the super-G portion of the super combined, he felt a change.

"I woke up and the first thing that I thought of was rehearsing the Canadian anthem because that's how good I felt,"

Josh Dueck blasted down Sochi's intimidating super-G course enroute to a gold medal in the super combined. (photo courtesy Scott Grant/Canadian Paralympic Committee)

says the freckle-faced, 33-year-old Vernon resident. "I was like, I have to have this on lockdown—there can't be any falters or fails up there. I know the anthem well, but I have to make sure that it's perfect."

His instinct was bang on. Fifth after the slalom portion of the super combined, Dueck went on to ski the super-G in just one minute, 18.27 seconds, leaving his competitors out of the running. It was that in-the-moment attitude that got him the gold and, later, earned him the honour of being Canada's flag bearer at the Paralympic closing ceremonies. For the young husband and new father, it was a story-book finish to what have been widely acknowledged as the best Paralympic Winter Games to date.

Today, three months after the end of the 2014 Paralympics, held from March 7 to 16 in the Black Sea resort city of Sochi, the spotlight on our athletes has dimmed. In Russia, the Olympic bubble has burst, uncovering long-brewing Russian-Ukrainian tensions. In Canada, the snow caps have melted off the mountain tops, the outside ice rinks have drained, the town curling clubs are closed for the summer.

Yet the words of International Paralympic Committee President, Sir Philip Craven, imparted upon athletes and officials from a record 45 national Paralympic delegations, and upon millions more watching the opening ceremonies at home, still resound: "The sport you witness here will change you. Not just for now, but forever."

Already, the difference is tangible. If the media can be blamed for speculation and exaggeration, from political alarmism to the infamously unforgiving #sochifail social media hashtags, it can also be credited with making these Games the most accessible and accessed Paralympics to date. More than 8.8 million Canadians tuned in to this year's Paralympic coverage: 90 hours of TV broadcasts and more than 250 hours of online content, enhanced by skilled commentary on ice sledge hockey, alpine skiing (and snowboarding,) cross-country skiing, biathlon, and wheelchair curling.

"Hopefully the media will see that if they make the coverage accessible, they have the interest and they have the viewers—they just need the opportunity to view it," says three-time Paralympic Wheelchair Curling champion, Sonja Gaudet, 47. "Suddenly, we've created some great awareness about the Paralympic Games, and we have people in our communities saying, 'Why can't we watch this all the time? Holy mackerel, this is crazy! They're thinking that what they saw wasn't enough."

Terrace's Caleb Brousseau conquered a treacherous course to capture a bronze medal in the super-G (photo courtesy Scott Grant/Canadian Paralympic Committee). Inset: Sochi organizers have been praised for their progressive and positive portrayal of Paralympians.

The blond-haired, blue-eyed curling sensation knows the magic power of the media. Gaudet's own trip to the Games started with a brief but unwelcome surprise: her team was on the tarmac in Toronto when they learned that Canada was pulling its Paralympic athletes from competition. A series of misdirected emails and tweets stemming from an opinion story had socially shared itself into hard news, but it turned out to be completely false. Gaudet not only made it to Sochi but, as Canada's flag bearer for the opening ceremonies, she proudly led her team into Fisht Olympic Stadium.

Now back in Vernon, Gaudet works as a Peer Coordinator with Spinal Cord Injury BC and cross-trains regularly. A T5-T6 paraplegic, Canada's most decorated curler can relate to Josh Dueck's abrupt drop from the Paralympic pedestal and the mental strength it takes to get back up—on the last day of competition, the heavily-favoured Canadian Wheelchair Curling team, led by experienced skip Jim Armstrong, found itself down 4-0 in the semi-final game against China.

"Everything right down to the environment inside the venue is so detailed that one little half a degree of temperature can change the ice," says Gaudet, noting that although weather patterns are only visible in outdoor venues, swinging temperatures still very much affect the curling rink. "The ice was quite heavy and it sort of had a weird, gripping sensation to it, so you had to be able to throw the rocks a lot harder than you would normally."

Fortunately, the Canadian curlers stayed calm and rallied, coming back in the last four ends to beat China 8-5. Any frustrations they may have felt were gone by the time the Armstrong rink took to the ice just hours later for the final match against Russia. "There was never an anxious feeling of, 'Oh my god, this is the gold medal game,'" recalls Gaudet. "It was just our best game ever. Ever. Individually and as a team effort it was incredible, for all of us."

With the ice finally cooperating, and team expertise and dynamics solid once more, the Canadians pulled out an 8-3 victory against their hosts. Paralympic gold, again. Basking in the golden moment with Gaudet was fellow Vernon-based curler Ina Forrest, who also shared the podium with her in Vancouver.

Another BC athlete who fared well in Sochi was Caleb Brousseau of Terrace. Brousseau held his own on the treacherous downhill terrain and came up with a bronze medal finish in the super-G. (Incidentally, it was the same course on which Dueck and many experienced skiers before and after him crashed.)

All in all, the 54-member Canadian Paralympic team came home with 16 medals, seven of them gold, placing right behind Germany and finishing third overall. But it was Russia, which in 1980 refused to host the Paralympic Summer Games claiming there were "no disabled citizens in the USSR," that soared into the top spot with 30 first place finishes and, arguably, a 180 degree outlook on accessibility and inclusivity.

"Russia did an amazing job of messaging our games the way that I think they should be messaged: around ability and around possibility," says Gaudet. "They went over and above in making it accessible for us; they highlighted the Paralympic athlete."

Not only was the Athletes' Village specially constructed and fully accessible, but the 2010 trend to market the Winter Olympic and Paralympic games together made for a noticeable resurgence. On the ground, spectators were open-hearted and volunteers knowledgeable—and even willing to divulge a few stage secrets. "They said, 'The closing ceremony is for both Games, and people are going to be blown away,'" says Gaudet. "(Russia) viewed the Olympics and the Paralympics as one big sporting event—they weren't separate events to them. And that was really, really cool."

Four years from now, the 2018 games in PyeongChang, South Korea, will provide another opportunity to disarm misconceptions and build upon the exposure and performances in what Sir Philip Craven deemed "the best Winter Paralympic Games ever." Other facets of the Paralympic games are also gaining momentum: Last June, the International Bobsleigh and Skeleton Federation (FIBT) petitioned for sliding sports to be included at the PyeongChang Games. The International Paralympic Committee (IPC) declined, but invited the FIBT to reapply in the future. The sliding sports, including skeleton and modified bobsleigh, could very well be on the schedule for 2022.

Meanwhile, in Vernon, our two Canadian flag-bearers—bookends to a near-perfect games—aren't thinking that far ahead. Gaudet can devote more time to her hobbies (handcycling, kayaking, yoga) and to the community that has followed her story and supported her from the day of her accident. Josh, too, gets recognized. "I had a really good games," he admits. "If I was to write a story, I couldn't have written it any better."

He'll get his chance to try, though. Topping off a long list of summer activities with his 8-month-old daughter Nova and wife, Lacey, Dueck is working on a book about his life lessons and adventures. (He was the first sit-skier to complete a backflip, for starters.) He's also travelling to Barcelona, where he's been asked to be on the board of directors for the International Paralympic Ski Committee as an athlete advisor.

As for competition, this coming season Canada will host the IPC Alpine Skiing World Championships at Panorama Mountain Village, conveniently in Dueck's backyard. For Gaudet, the 2015 World Wheelchair Curling Championships are bit further away, scheduled for next February in Lohja, Finland.

Gaudet and Dueck know they might not top their Sochi performances—in these next competitions, or ever. That doesn't matter. It's when they're doing what they love that the white letters on the 2014 Paralympic posters truly come to life: "It's not what's missing. It's what's there." ■

Want the inside scoop from Paralympic champions Sonja Gaudet and Josh Dueck? Head to www.sci-bc.ca/stories/blog to read our full-length interviews.

Sochi Paralympics by the numbers

1 in 4	Number of Canadians who watched the Paralympics
90	Number of hours of Canadian TV Paralympics broadcasts
250	Number of hours of Canadian online coverage
Third	Canada's final medal standing
Seven	Number of Canadian gold medals won
16	Total number of medals won by Canadian athletes
Five	Number of different Paralympic sports
Nine	Number of days of Paralympic competition
11	Number of Winter Paralympics to date
15	Average daily high temperature in Celsius during the Paralympics
54	Number of Canadian athletes who competed in Sochi
692	Total number of athletes who competed in Sochi
9,584	Number of kilometres from Vancouver to Sochi
51	US dollar cost in billions of the Sochi Olympics and Paralympics

Vernon's golden duo: Sonja Gaudet (above) opened the games for Canada, and Josh Dueck (right) carried the flag during closing ceremonies. (photos courtesy Scott Grant/Canadian Paralympic Committee)

Relieving Pain with Poison

An Australian scientist has moved one step closer to developing a powerful neuropathic pain relieving drug based on cone snail venom.

The venom of certain species, including frogs and snakes, has been a focal point for research for decades. But it's the venom of a common snail that may yield an incredibly important medical breakthrough—a powerful oral drug that may relieve excruciating neuropathic chronic pain, without side effects or risk of addiction.

The work is being led by Professor David Craik, a group leader at the University of Queensland's Institute for Molecular Bioscience. Craik presented his latest work in the field during the recent National Meeting & Exposition of the American Chemical Society (ACS).

Craik's work is layered on top of existing knowledge of the analgesic properties of the venom of conus—a family of predatory snails that includes some 600 species. These snails, which live in the tropical areas of our seas and oceans, hunt using a harpoon-like appendage to inject a paralyzing neurotoxin into their prey—fish, worms and other molluscs—before engulfing and consuming them. The venom of several of the larger varieties are deadly to humans, and there are numerous documented cases of deaths of unsuspecting people who have picked up live cone snails to admire their intricately beautiful shells.

The analgesic properties of cone snail venom were discovered in the 1980s by Dr. Baldomero Olivera, a neuroscientist at the University of Utah. Fast forward to 2004, when the FDA approved the pain reliever ziconotide. It's the only drug approved for human use that's created from conotoxins, the tiny proteins or peptides contained in the cone snail venom that have been long recognized as the "active ingredient" when it comes to pain relief.

Ziconotide, which is sold under the trade name Prialt, has one major drawback—it has to be injected directly into the fluid of the spinal cord using an invasive, expensive and risky procedure.

Craik and his colleagues set out to investigate the possibility of using conotoxins in an oral drug that would be effective in relieving the most troublesome of all pain—

chronic, neuropathic pain. Unlike acute pain, which is the pain you feel immediately following an injury, neuropathic pain results from damage of the nervous system and is extremely difficult to treat. It can be triggered by chronic diseases or conditions, including diabetes, MS and SCI, and can ravage a person for long periods of time. As many readers of *The Spin* know, existing treatments for neuropathic pain are hit and miss, and can have serious side effects.

Over the course of years of research, Craik and his colleagues studied an African plant that's long been brewed into a tea by witchdoctors seeking to speed up labour and childbirth. The active ingredient in the plant is a peptide with an unusual shape: a circle, which makes it more stable than most peptides. Inspired by this, Craik learned how to modify conotoxin peptides into a circular chain. He then confirmed that these modified peptides—which are essentially tied into a loop—are extremely stable and resistant to enzymes in the body, which allows them to arrive intact at the part of the body where they can relieve pain.

And then came the breakthrough. Craik and his team administered a single, small oral dose of a prototype drug based on one of these looped conotoxins to a group of rats with neuropathic pain. The results were significant—the prototype drug, which Craik has named IMB007, appeared to be about 100 times more potent than morphine or gabapentin, the two drugs considered to be "gold standard" treatments for neuropathic pain. Furthermore, no serious side effects were noted, and the scientists were also able to determine that the drug didn't result in any addictions.

"This is an important incremental step that could serve as the blueprint for the development of a whole new class of drugs capable of relieving one of the most severe forms of chronic pain that is currently very difficult to treat," Craik said in a news release when the results were published.

To understand how IMB007 works, first remember that neuropathic pain is associated with inappropriate, highly excited transmission of signals between damaged neurons. Craik explains that the modified conotoxin peptides block these transmissions by binding to receptors in damaged neurons.

"The particular receptors that IMB007 acts at are known as GABAB receptors," he says. "These are a normal part of the nervous system involved in the transmission of nerve responses. By binding to the receptors, the drug 'dampens down' the nervous system and stops the transmission of aberrant signals from the site of nerve damage, or neuroma."

At this stage of the research, IMB007 has only been tested in rats that have been inflicted with a traumatic neuroma in the laboratory. So other sources of neuropathic pain—for example, diabetes or SCI—have not been tested with the drug. But Craik believes "it is entirely possible" that it will work with these different sources of neuropathic pain.

Armed with positive results, Craik and his colleagues are moving forward with plans for human clinical trials. "We believe that our molecules will be good candidates for human clinical trials because they are extremely potent and act by a different mechanism, at different receptors, than other analgesics such as morphine or gabapentin," he says. "We therefore think that they are unlikely to have some of the serious side effects and addiction in humans that are seen in molecules like morphine. Our next step to taking the lead molecule to clinical trials is to apply for what is known as an IND, or Investigational New Drug status. This involves a package of data that we will present to the US Food & Drug Administration to show that the molecules are safe in a range of different animal models. This requires around $2.5 million of funding, and we are currently attempting to raise this so that we can progress the molecule further."

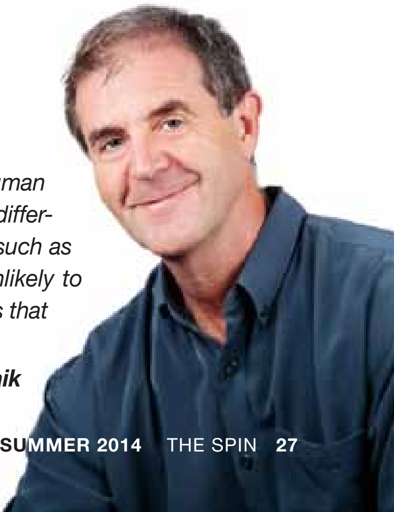
Since the results were published, Craik has been inundated with requests to try the drug from people who are desperate to relieve excruciating forms of neuropathic pain. He admits that this has been an eye opener for him, and it's made him appreciate even more the great need for an effective therapy for neuropathic pain. But he cautions that the drug is in no way ready for any type of human testing, and that human clinical trials are at least two years away even given the best case scenario.

A final note: cone snails are a threatened genus. Collectors kill millions of the animals each year for the decorative shell trade, and their primary habitat of coral reefs is under increasing threat from human activities. That's why it's important to point out that the drugs that Craik and his team have developed do not depend on a supply of cone snail venom.

"The molecule was originally discovered using a tiny amount of cone snail venom," says Craik, "but ever since the discovery, we have worked purely with synthetic molecules—molecules we make chemically in the lab using a technique called solid-phase peptide synthesis. Incidentally, in the longer term, we are looking at the novel idea of being able to express these sorts of molecules in plants so that patients might be able to swallow a seed as a 'bio-pill' or make a medicinal tea based on the peptide being produced in the leaves of plants. This is a long way off, but we think will be a very attractive possibility for patients with chronic pain." ■

"We believe that our molecules will be good candidates for human clinical trials because they are extremely potent and act by a different mechanism, at different receptors, than other analgesics such as morphine or gabapentin. We therefore think that they are unlikely to have some of the serious side effects and addiction in humans that are seen in molecules like morphine."

– Dr. David Craik



BC Doctors Train for Pain

A new training program is creating much-needed awareness of chronic pain—and giving family doctors the tools they need to better help you deal with it.

Next time you visit your family doctor looking for relief from chronic pain, you might get a better response than, "Take two aspirins and call me in the morning."

Doctors of BC—formerly the BC Medical Association—has implemented a new chronic pain medicine program. The program teaches doctors from across BC about the latest chronic pain management research and therapies. Recently, 57 physicians completed the program. In turn, these physicians are returning to their own communities where they'll train more than 500 other family doctors by the end of 2014.

The program is a response to a general lack of knowledge about chronic pain within the ranks of BC's general practitioners. As many readers know, some family doctors don't seem to have been provided with adequate training in this area. That assertion is reinforced by results of a study published in 2009 in the journal *Pain Research & Management*, which determined that Canadian veterinary students received five times more pain management training than Canadian medical students.

Dr. Michael Negraeff, a pain specialist at Vancouver General Hospital and co-founder and chair of the board of the non-profit Pain BC, lobbied for and contributed to the development of the program.

"Pain is a symptom of everything and, as a result, nobody takes ownership of it," says Negraeff, who deals with his own chronic pain as the result of living with an SCI. "Because it's a symptom, it's never thought of as a disease in its own right. When pain becomes chronic, there are characteristics of it that make it look more like any other chronic condition or disease. There are pathophysiologic changes in the nervous system that are not present in acute pain. There are psychological problems such as depression, anxiety, insomnia, interpersonal distress, shame, and stigma. There are physical problems of inactivity, muscle weakness, spasticity, loss of cardiovascular reserve, weight gain or loss, and metabolic and endocrine disturbances. There are social elements of judgement, stigma, isolation, misunderstanding, loss of role and financial hardship. Combine all of these and you truly do have a bio-psycho-social disease state."

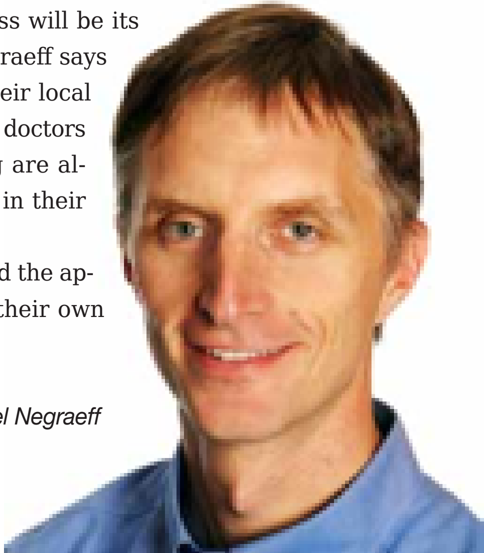
Despite this, and despite the fact that an estimated 20 to 30 percent of all adults experience chronic pain, Negraeff says it's not treated as a chronic disease in medical school or in any other undergraduate training.

While that is slowly changing, Negraeff says programs like this can have an immediate effect. He explains that the program's goal is to give doctors skills and techniques to help patients right away—for example, learning how to screen for different types of chronic pain, and determining what medications are useful for those specific types. But he adds that part of the training emphasizes to doctors that they may not be able to completely eliminate someone's pain, particularly through pharmacology. For these cases, he says, doctors will be given techniques that will focus on quality of life improvement—for example, through non-traditional practices such as breathing exercises, meditation, mindfulness and functional goal setting.

"All of these techniques can be tremendously useful with practice," he explains. "We want the doctor and patient to get on the same page with functional goals and agreeing on pulling in the same direction toward improved quality of life."

Key to the program's success will be its "train the trainer" model. Negraeff says that, with the assistance of their local Health Authority teams, the 57 doctors who just finished the training are already spreading the message in their own communities.

"They've tried the tools, liked the approach, and seen benefits in their own



Dr. Michael Negraeff

practice," says Negraeff."So it's still early, but positive so far."

As for SCI neuropathic pain training, Negraeff says there is nothing specific included in the program. "There was lots of discussion of what to include. It was very challenging to narrow it down. In the end, we took a fairly broad strokes approach to chronic pain without too much disease or condition-specific information. We're targeting GPs and specialist doctors that aren't familiar with dealing with chronic pain. That said, we did include some information and a screening tool for neuropathic pain which is a common SCI pain complaint and something many doctors fail to accurately diagnose."

What about other health care professionals? Pain BC has already moved to get pharmacists on board, forming a partnership with the BC Pharmacy Association to train 160 community pharmacists to become pain champions in their community.

"Pharmacists will be a vital component to increase the quality of care in large and small communities, working in conjunction with family doctors," says Negraeff. "The elements of the pharmacist program and the family doctor program are similar, so all are in the same boat. Obviously, there's a greater emphasis on medications, but they also learn about self-management and the importance to encourage patients to understand that meds are just one tool to help support function, and not a cure-all."

He says that discussions are just underway with the Canadian body that represents physiotherapists to develop a similar program with similar goals. And expansion to other disciplines is the ultimate goal.

"Pain BC's goal is to work with all the professional bodies—nurses, massage therapists, doctors, PTs, psychologists, OTs— to increase the training, understanding and skill set to treat people in a multidisciplinary way so they can all work better together in the community, even if not co-located in the same building. This will increase the number of better outcomes, lead to more timely treatment, and increase safety as well."

Is there a role for you as a person with SCI? Absolutely, says Negraeff.

"Readers of *The Spin* should ask their doctors if they have heard about PSP (Practice Support Program) and, if so, if they've heard of or done the Pain Module. They should ask about Pain BC and go to the Pain BC website or Facebook for resources and education. There's a pain conference for doctors or anyone else in healthcare can attend each year in October put on by Pain BC—this year's theme is "Confronting the Challenges of Chronic Pain." So readers should encourage their doctor, physio or other provider to attend, get involved, and work together as a team."

For details, visit www.painbc.ca. ■

ask the SPIN DOCTOR

Frank asks, "I remember in rehab that someone told me that smoking was really bad for people with SCI. I'd like to know if this is true, and why—hearing the cold, hard facts might give me the push I need to quit." To answer this issue's question, we opted to look online and found an excellent summary of smoking's specific dangers for people with SCI at the website of Craig Hospital, located in Denver, Colorado (www.craighospital.org). Part of our response to Frank is based on the information we found there.

People smoke for many reasons: to cope with life challenges, for pleasure, or simply because they're dependent on nicotine. Whatever your reasons, please know that the risks associated with smoking are real for everyone—and doubly so for people with SCI.

First, smoking lowers bone density and increases the risk of osteoporosis. SCI also leads to lower bone density. Together, smoking and SCI are a double whammy that can lead to even more fragile bones. Besides the greater risk of fractures, smoking will almost certainly result in longer healing times.

Second, people with SCI often have impaired cardiovascular function—their bodies aren't as efficient at moving blood to all their extremities. Smoking heightens the risk. Impairing blood flow even more allows for more plaque buildup in your arteries. And plaque is the culprit behind blockages, heart attacks, and strokes.

Third, respiratory function is already impaired from SCI. Smoking adds fuel to the fire, as it irreversibly destroys lung tissue. This further compromises lung capacity, and makes people all the more susceptible to pneumonia—which happens to be the leading cause of death in people with SCI.

Smoking also heightens pain—both neuropathic pain from a damaged nervous system, and musculoskeletal pain from overuse injuries. Once again, smoking compromises blood flow. And without adequate blood flow in painful parts of the body, severity of pain is increased.

Another concern is skin health. People with SCI are already incredibly susceptible to pressure ulcers. Healthy skin requires the best possible blood circulation. Smoking impairs blood flow. The bottom line is that smokers with SCI are more likely to get pressure ulcers, and once they do, they take longer to heal.

Quitting isn't easy and may take a few attempts, but I believe that you learn a little bit more about what works for you each time you quit. Help is available. The relatively new BC Smoking Cessation Program (811) covers the cost of smoking cessation aids for 12 weeks a year for eligible BC residents. QuitNow is another fantastic resource, offering smoking support 24/7 by phone (1.877.455.2233), online (quitnow.ca) and even by text.

One final note: e-cigarettes are increasingly being promoted as either a safer alternative to traditional smoking, or as a method of quitting. It's vital to note that Health Canada, The World Health Organization and other Canadian and international health organizations have all advised the public against using e-cigarettes.

Ride for Spine

Vancouver's David Parke undertakes a massive cycling journey to raise funds for SCI BC programs and services

David Parke has counted on support from SCI BC since a mountain bike accident left him with incomplete quadriplegia in 2010. This June, he's showing his appreciation by embarking on a grueling 1,700 kilometer bike ride from Dease Lake in Northern BC to Vancouver to raise funds for SCI BC programs and services.

Parke, who is married with two children, hopes to raise $50,000, along with awareness of the challenges faced by British Columbians with SCI who live in rural communities, through the Ride for Spine fundraiser.

His lifelong love affair with cycling continues, despite it being at the root of his SCI.

"After four years of recovery and learning to walk again, I'm able to ride a bicycle again," says Parke, who works part-time in the film industry while attending the Recreation Leadership program at Langara College. "Although free-riding is out, I cross country mountain bike and cycle commute on a cyclocross bike several times a week."

Parke hit the road with a skeleton support crew on June 2. The original plan was to cycle from Whitehorse, but challenges along the way forced Parke, no stranger to unforeseen circumstances, to recalibrate and start a little south of the Yukon. Funds that he raises will help spinal injured British Columbians attain adaptive housing, recreational options, education, mentoring and peer support.

He's incredibly enthusiastic about the prospect of raising money for our organization. "During my recovery, and for countless others out there enjoying life after SCI, SCI BC has provided amazing support, funding avenues, mentorship and assistance throughout the province," he says. "It's an amazing organization that provides a voice and support for spinal-injured people. As little or as much as readers can donate is greatly appreciated. Help me fundraise for SCI BC and many people will benefit as a result."

"We're deeply grateful for David's efforts," says Chris McBride, SCI BC Executive Director. "It's incredibly rewarding to have someone who has benefited from our services give back in such a meaningful way. Thank you, David, and thanks to all who support David's ride and the important impact SCI BC makes everyday in communities throughout BC."

To learn more about David Parke's Ride for Spine fundraiser, or to make a contribution to the campaign, please visit www.sci-bc.ca/ride-for-spine.

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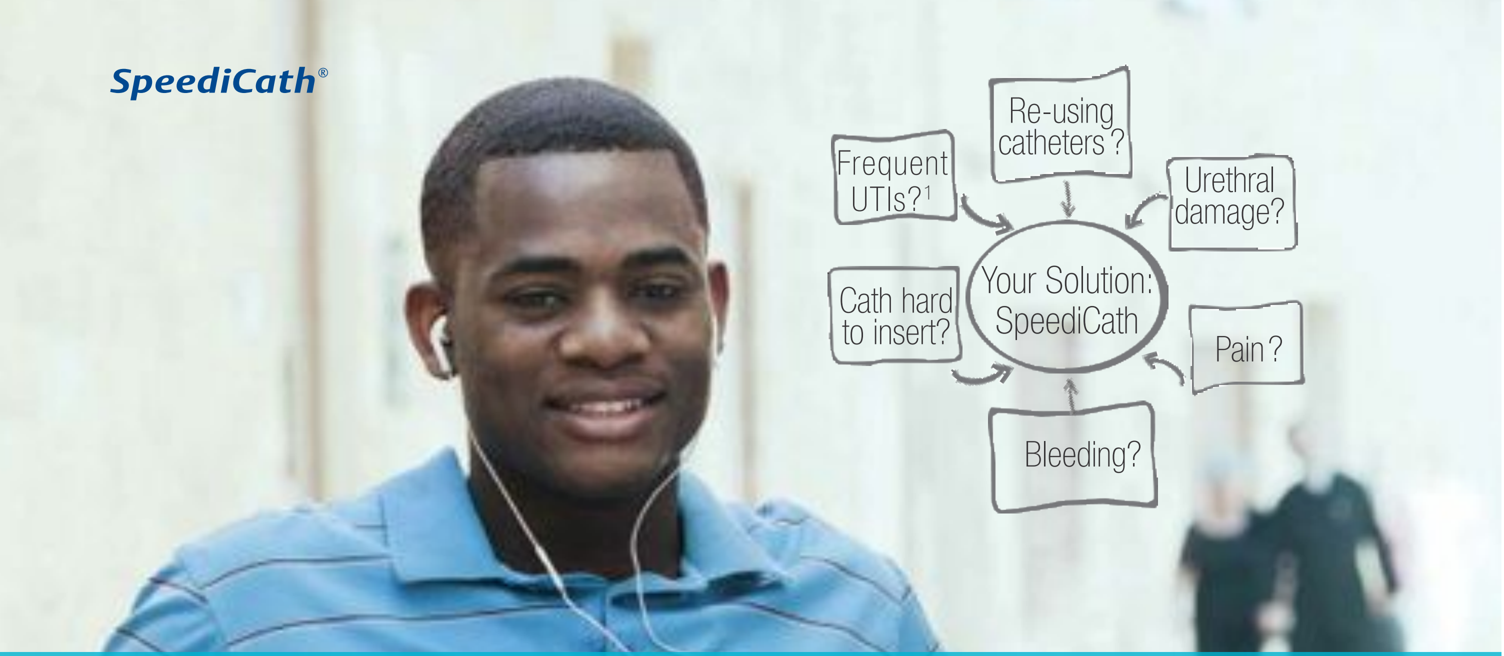

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[1] De Ridder DJ, Everaert K, Fernández LG, Valero JV, Durán AB, Abrisqueta ML,Ventura MG, Sotillo AR. Intermittent catheterisation with hydrophiliccoated catheters (SpeediCath) reduces the risk of clinical urinary tract infection in spinal cord injured patients: a prospective randomised parallel comparative trial. Eur Urol 2005;48:991 -995.

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