

# the spin

SPINAL CORD INJURY BC

SUMMER 2016



## Cultivating with Cory

Chef, author and licensed cannabis grower Cory Parsons shares his knowledge of organic gardening and the pain-relieving properties of pot



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[www.sci-bc.ca/blog](http://www.sci-bc.ca/blog)

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“ Sexuality can be a taboo subject in any circumstance; however, the taboo factor seems to be exaggerated when it comes to the disabled community. ”

## Remembering Simon Cox

**B**C's disability community has lost a great leader. Not all heroes are famous. Some do their work quietly and selflessly. Their reward is the satisfaction of knowing they're making a difference for people. So it was with Simon Cox, who passed away on March 25, 2016.



If you search for his name on Google, you won't find much. In some ways this is fitting. Simon made so many of his incredibly valuable contributions quietly and unassumingly. He was a shy but determined leader who had time and compassion for everyone. You just have to ask anyone who knew him or who benefited from his work to understand what a hero he was.

Many readers knew Simon and of the invaluable contributions he has made to people with disabilities in BC. Some have been directly impacted by his work.

For those of you who didn't know Simon, he was instrumental in developing programs and services that directly improved the independence of people with disabilities. He accomplished this through his leadership of what became the BC Association for Individualized Technology and Supports for People with Disabilities (BCITS) and its two key programs: the Provincial Respiratory Outreach Program (PROP), which provides equipment and a wide range of supports to people who use ventilators and other respiratory equipment, and the Technology for Independent Living Program (TIL), which provides technology to assist with managing electronic devices in the home.

While it's easy to describe the work Simon did, it's much harder to describe the profound impact he had on the lives of people with disabilities in this province. How does one adequately put into words what regaining a level of independence truly means to one individual, let alone to the thousands of people Simon and his team helped achieve this? It's safe to say that, for so many British Columbians with disabilities, PROP and TIL have been the difference between a life at George Pearson Centre and a more independent life lived in the community.

Recently, Simon was recognized for his commitment to improving the quality of life of thousands of British Columbians. He received the Hal Rogers Fellow Award, the highest award given by the Kin Canada Foundation. He also received the ALS Society of Canada's Marcel Bertrand Exceptional Support Services Program Award for the life-changing work he and BCITS did to support people with ALS.

Simon's passing is a huge loss to BC's disability community. I had the pleasure of knowing Simon for a number of years and will miss his insights, balanced approach, and great sense of humour. However, he leaves behind a rich legacy of service and innovation that will continue to have a positive impact for British Columbians with disabilities well into the future.

It seems fitting to end with some of Simon's words, which BCITS recently published in their tribute to him. "One thing I know is that I have not done enough with my life. I think I had the capacity to make greater things happen, I could have travelled more, educated myself more, been more artistic, music loving and on and on. Only a great life comes from these things. Who cares when your life ends? It is while we are living that we can make change. After death, who really knows? Anyway, I'll be packing my bags for Mars." Lucky Mars.

- Chris McBride, PhD, Executive Director, SCI BC

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### OTTOBOCK C-BRACE

Unlike conventional orthotic leg braces, Ottobock's C-Brace uses sensor technology and an integrated microprocessor to support the user throughout their walking pattern. Designed for people with incomplete SCI and other neurologic conditions causing partial paralysis, the C-Brace extends from high on the hip down to a foot plate. At first glance, it looks like half an exoskeleton, probably due to the large knee joint. However, the power needed to walk comes from the user. The knee joint is large because it houses a microprocessor that monitors the user's gait pattern at the knee and ankle joints throughout the entire gait cycle, as well as a hydraulic piston designed to provide resistance at the knee to ensure the user's knee joint won't buckle. The microprocessor and sensors allow the C-Brace to adapt in a natural way to changes in walking speed, sudden obstacles, stairs and ramps, and uneven ground. Custom-moulded out of carbon fibre, the unit is lightweight, flexible and very sturdy. Power is supplied by a long-life lithium ion battery. More details at [www.ottobock.ca](http://www.ottobock.ca).



### EVAC+CHAIR

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# Innovations

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



### FLIP PILLOW

For many people with SCI, sitting up in bed independently is difficult. The Flip Pillow transforms into 10 different positions, including a backrest position to help you sit up in bed. By flipping its "lobes" into different positions, you can also use it as an elevation pillow, a bed pillow, and a knee and leg wedge. It's available in three sizes (standard, queen and king) and is filled with a soft hypo-allergenic fiber-fill. Machine-washable, microfibre custom-fit pillow cases are also available. Check it out at [www.contourliving.com](http://www.contourliving.com).

### TEK RMD

The Tek RMD is both an indoor powered mobility device and a standing frame for people with paraplegia. Users enter at the back, securing a thick padded strap around their hips to independently manoeuvre themselves into position. Once inside, users can stand up with just a gentle pull (and also easily return to a squatting position) thanks to a suspension system that balances their weight. While standing, the user's arms are left free. The device is compact and highly manoeuvrable with the user in the standing position. The Tek RMD is battery-operated, and can be guided by a remote control. Besides being a potential game changer for anyone needing to stand to work, the benefits may include the weight-bearing effect of standing, improved cardiovascular function, reduced incidence of pressure sores, and psychological importance of eye-to-eye interpersonal contact. Invented by Turkish researchers in 2012, the Tek RMD comes in five sizes and is now available in North America. For videos and more details, visit [www.matiarobotics.com](http://www.matiarobotics.com).



# Room for Debate



**Inclusive—or too elite? An inspiration—or a misrepresentation? Do the Paralympics influence the public perception of people with disabilities in a positive or negative way?**

As we prepare to watch the summer edition of the world's highest profile event for athletes with disabilities, we asked some of our peers, "Are the Paralympics a good thing for the average Joe (or Jane) living with an SCI or other disability? Do they create positive stereotypes, or do they leave the general public with the impression that all people with disabilities are superhuman and heroic?"



In 2008, I took part in the Paralympics as a wheelchair rugby coach. This was a very positive experience. The honour of representing Canada, the experience of the opening ceremonies, the pressure of every game and the feeling of pride at winning a medal (bronze) all made lasting impressions on me. Wheelchair rugby is a team sport, and the Paralympics is a team event. Being a part of such a large team is an experience I will never forget.

I will concede that one negative impression I was left with after the Games was that not all the competitors were, in my opinion, high performance athletes. They seemed like they were there because they came from a country where there was not a lot of competition for spots; they were there for the experience of the games. I thought that, if the public could see a lot of these athletes, they would be left with a negative opinion of the Games and the people with a disability competing in them. It was only after I mentioned this to someone who had been to both an Olympic Games and a Paralympic Games that my impressions changed. He said, "The Olympics are like that too." In other words, not everyone attending the Olympics is a medal hopeful, and many are just there for the experience. Perhaps the athleticism is slightly higher for these athletes because there is more competition to attend the Olympic Games, but they're still just there for the experience.

Are the Paralympics elitist? For Canadians, yes, but that's OK. We're able to offer many levels of competition for people who want to play sports, but only the very athletic and hardworking people ascend to the Games. Does this give people with a disability a bad name? I say no! In my opinion the people who give people with a disability a bad name are the people who think they're owed something just because they have a disability. I've lived with a disability since 1989, and I've been lucky enough to have been an athlete and coach in wheelchair rugby since. I have also been lucky enough to play a lot of sports in this time. I did not get to the Paralympics as an athlete, as I was not good enough. However, I can say that I have worked hard to get to where I am now, and anyone who thinks that my hard work gives people with a disability a bad name, shame on them!

– Adam Frost, New Westminster



I admit, I'm not big on sports, so this may make me a bit biased. I'm not against being active and do a lot of wheeling around, but I'm by no means a Paralympian. Though often people see me in a chair and suggest I should be: "You're so inspiring...you should be in the Paralympics! Those athletes are so incredible!"

The media love to highlight certain Paralympic athletes or sports and portray them as inspirational. But unlike the Olympics, it's not the athleticism portraying as inspiring, but the disability itself. I think that Paralympians are not just seen as athletes but as representatives of "people with disabilities." And I don't think it's accurate or fair—especially when it's the media who determines who is inspirational, and these are often people at the very "able" end of the disability spectrum.

Are these featured Paralympic athletes inspirational to me? Who is deciding what I should think of as inspirational? Are they just after ratings? Are they only showing some disabilities and not others? Is a person in a power chair travelling all over Vancouver less inspiring? Or the person raising a family and working? The person training and studying for a profession? The person fighting to just make it out of bed? I think the courage it takes to do any of these is inspiring. Why are so few of these people ever talked about—in the media, or even on Spinal Cord Injury BC's own Facebook page?

A lot of us folks in the background have worked hard to get to where we are in life. I was injured in a 1975 motor vehicle accident and have worked full-time in sawmill design, structural steel detailing, and construction since the late 70s. Today, I advocate for local accessibility and serve on the city's Universal Access-Ability Advisory Committee. Like me, many people with SCI just want to live their lives, and not have to kill or damage ourselves trying to get places and do the things we love.

After the Paralympics are over, we won't hear much about the athletes until the next set of games. Meanwhile, the rest of us go on doing what we always do. Why does the news never do stories on us? There are inspiring people everywhere—not just in sports. If the media want to paint an honest and inspirational portrait of disability, why not highlight more of the rest of us?

– Martin Schikora, Coquitlam

*Got an opinion? Visit us at [facebook.com/spinalcordinjurybc](https://facebook.com/spinalcordinjurybc) and weigh in on this and other topics. Plus, take our poll at [sci-bc.ca/poll](https://sci-bc.ca/poll) and see what others have said about the Paralympics and the perception of disability, as well as a variety of other contentious topics.*



### Hang with the guys.

Join other local men living with SCI on Saturday, July 9 at the Roundhouse Community Centre for our first-ever Guys' Garage. Show off your adaptive gadgets, equipment, cars, motorcycles and other manly gear. Challenge an opponent to a game of beer pong. Grab some grub from on-site food trucks. Get a free barber-shop haircut, and enjoy live music and cold beer. For information and to RSVP, contact Gillian at [gorris@sci-bc.ca](mailto:gorris@sci-bc.ca).



### Access the north.

Don't miss our inaugural Access North Day in Prince George on Saturday, July 23—and the delicious summer BBQ to follow! Celebrate the grand opening of the Great West Life Mobility Trail extension and launch of the new accessible campground at Doherty Creek. Check out the trails and then join SCI BC for our annual Peer Summer BBQ. For more info, visit [sci-bc.ca/events](http://sci-bc.ca/events) or email [bstiles@sci-bc.ca](mailto:bstiles@sci-bc.ca).



### Get high...in Whistler.

From August 12 to 14, join more than 50 SCI BC Peers from Vancouver and Victoria, and their families and friends, for an overnight trip in Whistler. Take in the sights and sounds of this mountain paradise, and try your hand at kayaking, handcycling and trail riding. We'll wrap up the event with our massive Peer BBQ at Lost Lake Park on Saturday night. For accommodation and event details, contact Gillian at [gorris@sci-bc.ca](mailto:gorris@sci-bc.ca).

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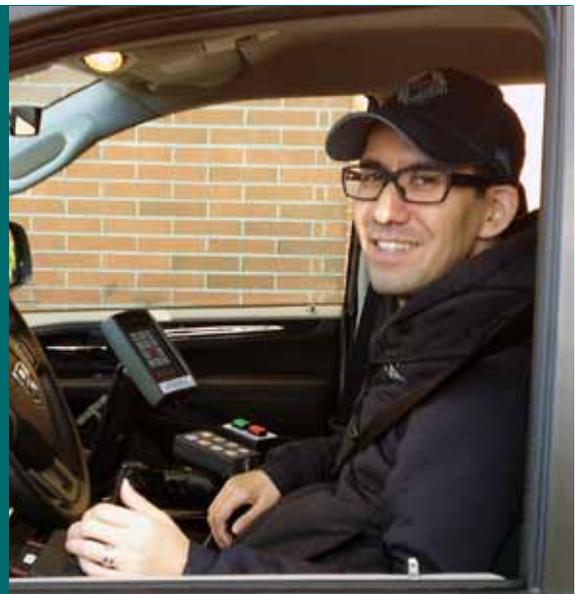
# Your key to independence.

Congratulations to DJ on completing his driver rehab program using JoySteer electronic driving controls. DJ is looking forward to getting a van so he can drive to his job as a Resource Coordinator at the Personal Injury Resource Centre in Vancouver.

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# Live Plan ~~A~~ Be

Is chronic pain making you feel like you're losing control of your life? Dr. Michael Negraeff, who speaks from the experience of being a pain specialist and living with his own SCI neuropathic pain, says an important technique to bring pain under control is self-management—and explains how Pain BC's new self-management online tool, *Live Plan Be*, can help you regain the upper hand.

**D**uring our recent annual SCI Forum, attendees had the rare experience of listening to the unique perspective of a physician and researcher who, like many of those in the audience, deals with SCI neuropathic pain every day of his life. Dr. Michael Negraeff's presentation was so powerful that we followed up with him in this issue of *The Spin* to give a wider audience a chance to hear his views on chronic pain, and to find out more about a subject close to his heart—Pain BC's *Live Plan Be* online self-management tool.

"The problem with chronic pain is you never expect you'll get it," says Negraeff, who lives and works in Vancouver. "After my SCI in 1995, it took about a year to feel like I had put my life back together. So I was feeling pretty good after a year being

back in (medical) training, getting active, and socializing. Then I needed one more surgery, and for whatever reason, the pain didn't go away after it."

Negraeff admits that, at first, he was deep in denial. But he already had a good knowledge of chronic pain thanks to his medical training, and one day he finally accepted that the pain wasn't ever going to go away.

"This was my 'You've got to be kidding me!' moment," he says. "After all this figuring out of mobility, bladder, bowel, spasms, sex, work, sleep and just getting back to my new normal, and now you're telling me I will have chronic pain on top of all that to deal with? I was very upset about that for quite a while, to put it mildly. It nearly ruined my honeymoon. I was not fun to be around. It was too much. I remember thinking in

the hospital right after my SCI, 'I can do this. I'm up for this.' But this pain wasn't part of the bargain."

And, he adds, this hammer blow happens to everyone who gets chronic pain unexpectedly after an injury, surgery, or illness—they simply can't believe it at first, and when they finally come to accept that their pain is permanent, it's a bitter pill to swallow.

At the time, Negraeff was already a physician, and was training as an anesthesiologist at UBC. After coming to terms with his pain, he decided to meet the challenge of life with neuropathic pain head on via a significant career alteration—he set his sights on becoming a pain specialist.

"My pain was definitely an influence on my decision to become a pain specialist," he says. "I had already developed an interest in pain management during my anesthesiology residency, but now I wanted to understand why some people get chronic pain and some don't, what causes it, and what can be done about it."

After completing his anesthesiology residency at UBC, he signed on for a Pain Fellowship at the Australian and New Zealand College of Anaesthetists, which he completed in 2001. In 2003, he moved to BC to take on a position at Vancouver General Hospital, where he's been ever since. Today, he's an associate member at ICORD, and a clinical associate profes-

sor and Head of Pain Management in the Department of Anesthesiology, Pharmacology & Therapeutics at UBC.

He's also a founding member and the current chair of the board of directors for Pain BC. Composed of people in pain, health care providers, and leaders from universities, government, business and the non-profit sector, Pain BC is a collaborative non-profit organization established in 2006 to improve the lives of pain sufferers through education, empowerment and innovation.

As one of BC's leading pain specialists, Negraeff has treated thousands of people with chronic pain, contributed to a growing body of research into chronic pain as it's increasingly been recognized for the devastating health problem that it is, and learned many lessons about neuropathic pain—his own, and that of others—and what can be done to manage it.

Among the most important pieces of knowledge that he's gleaned is that, while there's no total cure for anyone, most people can find some relief via a multitude of approaches that go well beyond simply getting a prescription.

"Research has shown that multiple solutions are definitely needed to help people live better with chronic pain, because chronic pain affects more than just our bodies," he says. "The traditional medical model doesn't address all the facets of complex pain—for example, the effects on close relationships, that people in pain are dealing with a super sensitized nervous system, the need for movement, and so on."

Among the strategies that he's found to be successful when employed in tandem are traditional pharmaceuticals, exercise, cannabis, mindfulness and meditation, counselling, and, perhaps most importantly, taking responsibility for your pain management—self-management, in other words. And that's the reason why, under his stewardship, Pain BC created the *Live*

*Plan Be* interactive online self-management tool.

"The seed for the idea of *Live Plan Be* was planted at Pain BC's Pain Summit in 2011, where much of the discussion was around strengthening the continuum of self-management support, especially as most pain self-management training is either location-based or short-term," says Negraeff. "After hearing from patients about their needs, and considering how we could support health care providers to better help patients, Pain BC saw the need for a tool that removed many of the barriers chronic pain patients face—for example, distance from resources, accessibility, financial issues, a lack of peer support, and a need to manage pain in their own manner. We also wanted to focus on evidence-based research and on making this information easy to understand and apply."

Negraeff stresses that, in the context of chronic pain, the term "self-management" is far from being a nebulous, untested concept—it's actually a strategy that's been validated through considerable research.

"We studied why some people live well with pain and others don't, even though their pain may be similar in severity," explains Negraeff. "We turned to the expertise of Dr. Bronwyn Thompson, a psychologist who conducted a literature review for us and contributed material for *Live Plan Be* around the biopsychosocial model of pain—a broad view that recognizes that pain and pain relief involve an interaction of biological factors, psychological factors and social factors. Different people have different paths on their journey with chronic pain. Dr. Thompson's research has shown that some people are able to move beyond a pain-focused life—although they're still in pain, it doesn't occupy the very centre of their lives. We looked into how these people in pain were able to do this, and

*"We looked into how these people in pain were able to (move beyond a pain-focused life), and Live Plan Be is the result."*

– Dr. Michael Negraeff





We know your pain is real.  
 We know every day can be a challenge.

- Learn about the science behind chronic pain.
- Keep track of your symptoms and their impacts.
- Develop a plan for better pain management and quality of life.
- Connect with a like-minded community of others who live with pain.

#### Open and Honest Discussions



Share your story, strategies, and questions in a safe, private discussion forum with people who've been there and understand what you are going through.

DISCUSS PAIN

#### Powerful Pain Science



Learn about the science of chronic pain, along with other topics such as sleep, mental health, medications, and treatment options. This practical knowledge will help you better understand your condition and how to manage it.

LEARN ABOUT PAIN

#### Personal Action Plan

Take action towards your wellness. The Pain Plan is an online tool that helps you set meaningful, realistic goals, and supports you in seeing them through.

CREATE YOUR PAIN PLAN

thanks to the framework provided by Dr. Thompson, *Live Plan Be* is the result.”

Negraeff stresses that, because research has demonstrated that those who take control of managing their pain have better outcomes, *Live Plan Be* is primarily about putting people back in charge of their lives.

“Regaining a sense of self after trauma or change, which are both components of chronic pain, is vital to wellness,” he says. “When you get back to living well, you find your identity again. We wanted to create a customizable tool to support people along the journey to reoccupy that sense of self—what is known as ‘flexibly persisting’ with pain. This means you still have pain flareups and setbacks, but you’re able to draw on a large bank of resources that enable you to live better and overcome those setbacks. We also want people to feel more empowered to communicate their needs and self management plans to their healthcare provider team so they are truly working together.”

So what can you do on the *Live Plan*

*Be* website? (And yes, in case you’re wondering, the name is an intentional play on words.) When you visit the *Live Plan Be* website for the first time, you’re greeted with some simple text:

We know your pain is real.  
 We know every day can be a challenge.

- Learn about the science behind chronic pain.
- Keep track of your symptoms and their impacts.
- Develop a plan for better pain management and quality of life.
- Connect with a like-minded community of others who live with pain.

Negraeff says that there’s no particular order or sequence when it comes to engaging in the website’s four primary functions.

“One of the key things we wanted to achieve with *Live Plan Be* was to create a tool that could meet people wherever they might be on their journey with pain. So there is no right or wrong way to move through *Live Plan Be*. For example, you might have just experienced a life-changing injury and need more information, so you would benefit from starting with learning more about pain science. If you’ve been living with pain

for many years, you may be ready to set more goals around exercise, for example, so you could start with the Action Plan section. The benefit of *Live Plan Be* is that you can choose your own entry point and tailor it to your needs.”

He’s particularly enthusiastic about the Assessment module. “This is definitely a vital part of the site where we’ve created an interactive version of the Brief Pain Inventory. This allows you, on your own, to track and compare your pain and your ability to function over time. This not only helps you see how your pain changes, but you can also show these results to your health care providers. Because the data is shareable, the advantage is that everyone in your health system can work from the same results.”

Another important component of the site is the Pain Action Plan. “This section employs a method of SMART goal-setting that puts you in the driver’s seat,” he says. “Self-efficacy is a major component of self-management, and an action plan supports you to set realistic goals. It provides clear structure, and allows you to

get specific about when, where, and how you'll achieve the goals. You can also rate your confidence levels and reflect on these—this allows you to take a step back as needed and readjust if you aren't in the right place yet. There is also the important element of accountability—the plans are meant to be shared, down to including a place for you to name who you'll share your goals with."

*Live Plan Be* also allows users to check in and reflect on their path and strive for continuous improvement. "It's not about success or failure," says Negraeff, "but about reflecting on the experience and really looking at why things worked or didn't. Maybe you just weren't ready, so you can take a look at that, and *Live Plan Be* can then support you to get ready."

A great deal of effort was also made during development to make it easy and rewarding for site visitors to share their stories and learn from others.

"Our Real Stories section is particularly powerful as we showcase the stories of those coping well with pain. We've in-

cluded these real experiences of people with different types of chronic pain, from those who have grown up with it or experienced it later in life. These stories also present different strategies for coping. We have not sanitized what people have said and feel that the stories are impactful, relatable and helpful. They encourage people to see that they're not alone.

"Meanwhile, the Forum is also an important 'sharing' component of the site. Pain BC has a wonderfully supportive Facebook community, but the *Live Plan Be* Forum answers the need for anonymity. The idea of the Forum is definitely to let people see they aren't alone—but also to provide an opportunity for peer leaders to share what's worked for them and how they've handled different situations. People in pain are experts in their own experience. This peer support and sharing is vital to self-management, because everybody's story is so different. People need to see lots of different ideas and suggestions so they can find

what works for them. The Forum creates a safe, moderated space to share these stories, ideas, experiences, and questions. Creating a network of coping strategies, opening your mind to different ideas, and taking an active role where you can—all of this helps you take back control of your life. Sharing your own experience and questions is in turn valuable for others."

Negraeff concedes that *Live Plan Be* is not intended to replace expert medical advice. If you're completely overwhelmed by your pain, particularly to the point where you find yourself in a state of depression or withdrawing from the world around you, don't hesitate to seek help from your medical team. But Negraeff has witnessed firsthand—and experienced for himself—that those who become an active participant in their personal pain management are usually those who are the most successful with easing pain out of the centre of their lives. And to that end, *Live Plan Be* is a great way to regain this control. ■

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## safety ■

**P**eople with disabilities face unique challenges when it comes to emergency preparation, evacuation, shelter, and the recovery process. By planning ahead, you can more confidently protect yourself when disaster strikes.

Create a support network of family and friends who can help in an emergency. Give each member a **spare set of house and car keys** and include a contact who is near enough to help, but far enough away to be unaffected by the same crisis.

Work with your support network and caregivers to develop a plan. Be sure everyone knows where you keep your emergency supplies, medications, medical devices and assistive technology, and what to do if you require oxygen or mechanical ventilation. Talk with your property manager and employer about how your building evacuation procedures include people with disabilities. Practice your plan, including using evacuation chairs, just like you would a fire drill.

Prepare an up-to-date emergency kit and store it in an easy-to-find location. Your kit should include the following:

- **Flashlights, hands-free headlamps, or battery-powered LED lanterns.** Keep these in different areas of your home—and don't forget **extra batteries!**
- **A wheelchair repair kit**, including a **tire patch kit**, a seal-in-air product, inner tubes and tires, and a **manual tire pump**. Include **heavy gloves** for wheeling over sharp debris, and latex-free gloves for anyone providing you with personal care. Throw in some **hand sanitizer**, too.
- Medical supplies, including spare catheters and **medication for 72 hours** or longer. Make a list all food/drug allergies and current medications (dosage, frequency, generic name, medical condition being treated and contact info of prescribing physician), and share this list with your support network. Plan with your doctor for emergency prescription refills and have a strategy for medications that require refrigeration. Use a **smartphone app** to set up an easy-to-access personalized medical ID specifically for emergencies.





# Emergency!

The “Big One” is coming. Experts agree that it’s not a matter of if, but when. So what should people with disabilities do to prepare for an earthquake, power outage or other unexpected crisis?

- **Water in transportable bottles** (two litres per person per day) and **non-perishable, ready-to-eat foods** that won’t spoil. For cans, include a manual can opener.
- **A first aid kit** including a personal assessment checklist identifying areas of your body that have reduced sensation and may need to be checked for injury.
- A working **corded telephone** or battery-powered charger for your mobile phone. To conserve battery power, lower the brightness, close inessential apps and, unless you need immediate Internet access, put your phone in airplane mode. Put your phone to sleep, rather than turning it off.
- Warm clothing and **emergency blankets**. Additionally, cloth blankets and **rope** can help transport you during an emergency, **reflectors** can improve visibility, and **duct tape** can do virtually anything.
- A paper copy of your **emergency plan and contact information** including phone numbers, email addresses, and social media info for your family, friends, caregivers, neighbours and important medical contacts. Include local emergency contact numbers as well as 1.888.POWERON (1.888.769.3766) for reporting an outage.
- A **whistle** or personal alarm in case you need to call for help.
- External battery packs, **chargers** and generators. Keep a spare deep-cycle battery handy for motorized mobility devices or life-sustaining equipment.
- Games, cards, and **books** can help alleviate anxiety (and boredom) while you wait.

**Tag or label** essential equipment that will need to be used, moved, or maintained by those providing assistance during an emergency. If you have a pet or service animal, remember to plan for its needs. And keep a **recent photo of your service animal** on hand in case it gets separated from you.

Finally, check with your municipal office to find out if emergency shelters in your area are wheelchair accessible, and notify your regional health authority and BC Hydro about your needs. To determine the type of help you’ll need in an emergency, do a self-assessment at [gov.bc.ca/preparedbc](http://gov.bc.ca/preparedbc) or visit [sci-bc.ca/stories/blog](http://sci-bc.ca/stories/blog) for more emergency preparedness tips. ■

A photograph of Cory Parsons, a man with glasses and a beard, looking towards the right. He is wearing a dark jacket over a white t-shirt. The background is filled with green cannabis plants, some of which are in the foreground, slightly out of focus.

# Cultivating with Cory

Chef, author and organic gardener Cory Parsons shares his knowledge of the pain-relieving properties of cannabis, choosing the right strains and dosages, the importance of organic growing, and the best ways of taking your daily medicine.

## Cory Parsons is a name familiar to most of us.

He's the author of the popular *Cooking with Cory* cookbook, and we've published several stories about him in the past few years—he provided his best kitchen techniques for other cooks who are quadriplegic, and he's allowed us to showcase his superb accessibility renovations in his Nanaimo home.

More recently, Parsons was one of several SCI BC Peers we recruited to speak candidly about their experiences about using cannabis as a viable treatment for SCI-related neuropathic pain (our feature, titled "Good Medicine", ran in the Summer 2013 issue of *The Spin*). Since then, Parsons has delved even deeper into the pain-controlling properties of cannabis. As a long-time legal grower of cannabis for his own medical purposes, he's been in the unique position of being able to experiment with strains that work best to relieve pain, dosages that relieve pain without rendering a person so high that they can't function in a 9-to-5 world, alternative methods of treatment such as edibles, and how to grow organically without the use of potentially harmful chemicals and fertilizers.

For this issue, we asked Parsons to let us pick his brain. In the true spirit of peer support, he generously agreed to share his hard-won knowledge. Because we know that many SCI BC Peers also rely on cannabis as a pain reliever (or are interested in trying it), we welcome Parson's point of view, and encourage more research to better understand pot's analgesic abilities and how they can best be maximized.

## Can you describe your particular brand of neuropathic pain, and the steps you've taken over the years to tame it?

My injury occurred in 1998 as a result of a diving accident in shallow water. I broke my neck at C5-C6, rendering me quadriplegic with sensory sparing below my injury without motor control. My new normal included often severe neuropathic pain that can best be described as a burning sensation.

Initially, doctors attempted to treat my pain with prescription drugs such as gabapentin, antidepressants, and even opioids. None of these brought any type of significant benefit that would offset their many negative side-effects.

Then I discovered a psychotherapy called Eye Movement Desensitization and Reprocessing, or EMDR, which was originally developed for people with PTSD. And I also began using medical cannabis. These two treatments have allowed me to manage my pain on a long-term basis, without using prescription meds.

## How did you discover that cannabis could help control your pain?

I'd used cannabis for many years prior to my injury. I knew its effects and its ability to help deal with discomfort, insomnia, anxiousness, and even sadness or depression. So it was a

natural consideration for me to try using it to combat my pain and discomfort following my injury. Within a few months of being discharged from rehab, I was regularly using cannabis to treat my pain and insomnia, and help me relax during my transition back to home and my new life.

### **What's your understanding in terms of the mechanism that allows cannabis to control neuropathic pain?**

There is mounting scientific evidence confirming the positive effects of medical cannabis and its ability to help treat pain—and a host of other ailments. Evidence is even starting to emerge about its potential to be a treatment and a cure for some types of cancer.

I'm no scientist, but my understanding of its function as a pain relieving agent is that, once introduced into our bodies, cannabinoids act as a kind of synaptic circuit breaker—they reduce the abnormal neuron activity that's behind neuropathic pain. They do this by binding to the cannabinoid receptors that are an important part of our nervous systems. Once in place, they block the release of neurotransmitters that have been found to trigger pain. There's lots of great information online for anyone interested more in the science of cannabis pain relief.

### **What should people trying cannabis for SCI pain for the first time realistically expect?**

As with any treatment, every individual is going to feel differently and have different levels of sensitivity and tolerance. I am increasingly surprised at the variety of ways that different strains of cannabis affect people differently.

For someone using cannabis for the first time, a good outcome would be one that meets their reasons for introducing cannabis into their treatment. If someone is seeking relief of insomnia, then a good result would be a restful night's sleep. Others seeking to improve their appetite and energy may get those benefits as well. The key to good outcomes, I believe, is arming yourself with good information, sourcing a quality product that promises to meet your specific needs, and doing

some informed trial and error experimentation until the best results are achieved.

### **What are the negatives or downsides of using cannabis for pain relief? In your mind, are there any safety concerns?**

It's really dependent on the dosage and frequency used. As with most things in life, excess can lead to uncomfortable outcomes, and high doses of cannabis can lead to nausea, anxiety, and an overall sense of discomfort. But it's really important to note that there has never been a single death associated with medical cannabis use. That's not to say that you shouldn't take a cautious approach when combining with prescription medications or other drugs such as alcohol.

### **What are the most important things you've learned along the way, in terms of the best strains for medical use?**

When it comes to sourcing the best strains, several factors should be considered, including the effects desired.

There are two important active ingredients—THC, which is short for tetrahydrocannabinol, and CBD, or cannabidiol. Indica dominant strains have more THC, while sativa strains have more CBD. Many modern strains are known as hybrids, as they have both THC and CBD.

Sativa strains provide a more elevated or uplifting result, and may improve appetite, energy, creativity, and pain relief. Indica strains are generally more effective at enhancing relaxation, treating insomnia and suppressing anxiety, although they can also improve appetite and provide pain relief. Many hybrids are available that have been designed specifically to incorporate the best from both of these plant qualities, and the choices have become nearly endless.

If you're growing yourself, other factors to consider are your available space (sativa strains are generally much taller), resistance to pests and moulds, and the period of time necessary for proper maturation and overall yield quality.

My personal preference is hybrids with roughly 70 percent sativa and 30 percent indica. I find this combination

to be uplifting, somewhat energy boosting, and pain suppressing—it gives me an enjoyable, creative, cerebral stimulation that allows for extended hours of gardening and cooking.

### **What about the best methods of treatment?**

Traditionally, cannabis has been smoked. Aside from the potential health hazards of ingesting any burnt substance, cannabis has been shown to be far more medicinally effective when ingested by alternative methods such as vaporizing and eating, once it's been transformed into an absorbable form such as oil or butter that can be used in almost any recipe. Brownies and cookies are the most popular edible. When consumed orally, CBD and THC are absorbed into the body with greater anti-inflammatory and disease-fighting properties, and a much higher medicinal effect for treating pain.

### **How do you arrive at the optimum dosage?**

I believe this may be the most important factor in a successful treatment regime—one that gives you relief while ensuring the least amount of negative side effects. Anyone who has ever overindulged can tell you with conviction that a "green out" is a most undesirable experience.

My advice? Start cautiously—it's easy to add a little more, but impossible to take it away once you've eaten too much. Starting with what might seem like ridiculously small amounts and slowly increasing the dosage according to one's comfort and the medicinal effects desired is my recipe for a healthy and happy relationship with medicinal cannabis. When used like this, you'll have a near absence of feeling high or losing cognitive function—your awareness of the cannabis in your system will largely be restricted to a reduction in pain or improvement in the symptoms you're attempting to treat.

### **Speaking of getting too high, a recent research study suggests that, when it comes to pain relief, too much can be ineffective. Is this your experience?**

Again, I can't stress enough the importance of a minimal starting dosage with

adequate absorption periods of time between additional doses (about 90 to 120 minutes), as overexposure can result in an uncomfortable sensation. Speaking for myself, when treating my neuropathic pain, I find the greatest benefit comes from very minimal doses that help “switch off” my focus on my pain, as opposed to heavier or larger doses which tend to cause me to fixate on the pain. I have even felt that higher doses exacerbated my body’s sensation of pain.

**What are the biggest misconceptions about cannabis and pain relief?**

Many people believe it has to be smoked to be effective, or that they need to be completely stoned to experience the medicinal benefits. Nothing could be further from the truth! Once again, for most people, implementing a micro dose or low dose of medicinal cannabis has been incredibly effective in alleviating pain, with very little noticeable cerebral or “high” or “stoned” sensations. I’ve personally witnessed people living in excruciating and unbearable pain treated with a very low oral dose of medicinal cannabis and then returning to a normal daily routine, living a happy and healthy lifestyle.

A great example of this is the well-documented story of Charlotte, a young girl who was living with extreme epileptic seizures. A hybrid plant was bred to alleviate her seizures without impairing her ability to function as any child should. Another excellent success story I’ve personally witnessed is that of an 85-year-old man who has successfully treated his neuropathic pain from spinal stenosis, without getting high—something he was very concerned about.

**When did you apply for your medical license? Why did you want to grow yourself?**

Originally, I requested a prescription from my doctor in order to possess cannabis legally. He told me about the option to have someone grow it for me or, if I was capable, to legally grow it myself. Since I’d grown it outdoors prior to my injury, I decided to try it. Of course, hiking into



the mountains to grow wasn’t an option anymore, but once I got my legal status, I began growing in my own backyard.

**As a grower, can you describe the learning curve that you’ve gone through?**

In the beginning, I was frustrated with many common obstacles that anyone faces when they attempt to confine mother nature to a small space—pests, moulds (entirely due to poor airflow), and, of course, the obvious smell.

Twenty years ago, good information on growing properly, safely, and effectively was only available by word-of-mouth from extremely tight-lipped older generation growers who held on to their secrets as tightly as the Illuminati! You truly had to know someone in the industry in order to get accurate information, and your only other option was to go to a hydroponic

gardening store and request information on how to grow your “tomatoes”.

Obviously, the Internet has opened the doors completely, and the information shared freely online is excellent. This is due in large part to more relaxed laws and the opportunity to now legally grow medical cannabis for personal use. I’ve taken good advantage of these resources, and through better technique, proper testing and examination, I’ve had great success in the past few years growing some of the most effective medicinal cannabis I’ve ever experienced.

I guess I’ve become one of the older generation—I’ve been affectionately named the Quadfather by some of my friends—but the difference is that I take great pleasure in sharing my expertise to those wishing to embark on their own organic gardening adventures.

**Speaking of organics, you're a staunch advocate of organic growing. How did you come to believe so passionately in it?**

What I've found to be the true benefit of growing organically is a measurable and obvious difference in quality, regardless of what's being grown—tomatoes, fennel, corn, or medicinal cannabis. Organic growing is also much more sustainable, and results in a higher nutrient value. Think about the difference between the tomatoes we buy in the winter, and the tomatoes that we either grow organically ourselves or purchase from an organic grower in the summer months.

I can't advocate strongly enough for medicinal cannabis to be grown organically and ethically if it's to be truly considered a medicine. Large corporations are producing medical cannabis on an enormous scale without consideration of the benefits of organic growing, and I believe this is a tremendous mistake. Anything less than an organic product could potentially increase or influence health conditions negatively, instead of treating or curing them.

Organic farming is very simple in that only certified organic nutrients can be used, and no harmful chemicals are permitted throughout the farming process. As for cost, purchasing organically certified nutrients for your farming needs can be slightly more expensive, but this can be offset with composting, worm castings, and incorporating natural ingredients such as seaweed and manure.

**Recently, medical self-growers won an important legal battle. Can you describe that victory and why it was so important?**

In 2014, the former Conservative government introduced a law that would prevent patients from growing cannabis for their personal medical use. Four brave British Columbians challenged the regulations in Federal Court, and in February of this year, a judge sided with them and struck the regulations down.

This is an incredible victory as it alleviates the concern of growing illegally in order to have access to an affordable, high-quality, chemical-free and organic

source of medicinal cannabis. Many of the commercial production licensed facilities are growing vast amounts of cannabis that is low-grade, low-quality and, in my opinion, should not be considered medicinal due to toxic growing practices and unethical treatment of this amazing plant. And, if that isn't enough, they're charging nearly double the price that people have considered as being fair.

**How do you see mainstream legalization unfolding in Canada?**

It's been the hope of many Canadians that our new Prime Minister would remain true to his word and push forward with legalization. This is certainly easier said than done and I for one do not personally see it actually unfolding as envisioned.

It's been proven in Colorado and other states that legalization can provide an incredible economic boost and make the availability of medical cannabis much more widespread. But bureaucracy and government roadblocks will no doubt slow this process in Canada.

In my opinion, the importance should be placed upon decriminalization instead of legalization, as people jailed for possession of minor amounts of cannabis should not be in prison with murderers, rapists and other violent criminals.

My greatest fear is that, since this industry has proven to be a viable source of revenue, our government will attempt to appoint itself as the sole legal provider—and all self-growers who continue to operate will have to do so illegally.

**To sum up, why should other people dealing with SCI pain consider using cannabis?**

Up to this point, neuropathic pain from SCI and other sources has largely been treated with cocktails of prescription meds with few positive outcomes, and many negative side effects. Meanwhile, cannabis has increasingly been shown to have positive effects when treating pain associated with SCI—and also insomnia, anxiety, poor appetite, and spasticity. With the proper dosing regimen using medically-appropriate strains, there are

no known negative side effects reported in adults—only effective outcomes.

**Why should people consider growing themselves? Is the effort worth it?**

It's a personal issue for every individual—it depends on your financial situation, the quantity of medicine you need on a daily basis, and your willingness to learn a skill that's not without its challenges. But those of us who have made the investment have experienced cost savings, tremendous satisfaction, and peace of mind that comes from knowing exactly what's contained in our medicine.

As a long-time organic grower of everything in my own garden including medicinal cannabis, I encourage everyone to grow organically. It's extremely rewarding and offers the security and comfort of knowing the source of your medicine and food is grown responsibly in a way that ensures quality and avoids chemicals and pesticides. As with anything worth doing in life, it comes with some trials and tribulations, but the rewards are clear and obvious.

With the incredible amount of information available online and, of course, from some of us "old timers," it's now easier than ever to learn all the necessary techniques. Other good information resources include hydroponic growing stores, and medical dispensaries.

**Are you personally willing to share your knowledge with any SCI BC peers?**

I've lived for two decades with an SCI, and I've learned a great deal about how to manage SCI pain and other complications. Over the years, I've made it one of my missions to share my knowledge, including my expertise in organic farming of all kinds. As a published cookbook author, I'm also able to offer excellent recipes and cooking tips that enhance independence and allow medical cannabis to be introduced into our daily diets. If anyone wants to connect with me about living with an SCI, cooking tips and interest in my cookbook, or organic growing, please feel free to contact me at [cookingwithcory@shaw.ca](mailto:cookingwithcory@shaw.ca). ■

# In the Moment

Mindfulness has helped me tame my chronic pain—and allowed me to improve so many other aspects of my post-SCI life.  
by Jaisa Sulit

was injured in a motorcycle accident in 2010. Like so many others with SCI, I was rudely welcomed to the world of chronic pain—a consequence of SCI that is poorly understood by the public, let alone modern medicine.

I initially used prescription medications, but like many of my peers, quickly experienced unpleasant side effects—which I then tried to treat with additional medications.

So I quickly rejected the pharma approach, and tried instead to manage my pain with a mix of other methods that included hot and cold packs, massages, acupuncture, natural herbs, and the occasional Tylenol. These helped to decrease my pain, but the relief was short-lived and ineffective for pain prevention.

As I began to seek out alternative ways of dealing with this unwanted burden in my life, I began to see a lot of references to something called mindfulness. In fact, it was hard to ignore, as mindfulness has lately been a pretty hot topic in self-help circles and the media, with no shortage of guru-authored books on the subject. But I quickly learned that, as one of the core practices of Buddhism dating back to the 6th century BC, it's far from a fad or modern phenomenon.

Intrigued and optimistic, I signed up for an eight-week program in mindfulness, with the hope of learning effective pain management tools. To my surprise, it not only worked, but became much more than just a way of coping with pain. Daily mindful practice has become a way for me to connect deeply with the innate strength, wisdom, compassion and power for self-healing that's accessible within each of us, even when we're facing formidable physical and emotional challenges.

### What exactly is mindfulness?

It's actually a simple practice that involves paying attention to the current moment and acknowledging without judgment what's presently there—what's occurring in our surrounding environment, and what's occurring internally

with our emotions, thoughts and sensations. Central to the practice is the continuous re-focusing of attention to a particular object or action of choice that is occurring in the present moment—for many, the act of breathing is ideal. Meditation and yoga are two popular practices by which many learn mindfulness.

According to Jon Kabat-Zinn, creator of the Mindfulness Based Stress Reduction (MBSR) program and father of the modern mindfulness movement, mindfulness means “paying attention in a particular way.” So mindfulness is not necessarily about what you are doing, but how you are paying attention to what you are doing. Whether you're meditating, brushing your teeth, or having a conversation with someone, what makes the experience a mindful one is your intention to pay attention to the present experience, without judgment, and instead with a beginner's mind—with acceptance, trust, patience, openness, and fresh eyes.

### Mindfulness for Health

How does mindfulness improve our wellbeing? Today, we know conclusively that there is a mind-body connection, and that worry and stress can result in mental illnesses such as depression and anxiety. In turn, worry and stress can lead to poor physical health. Mindfulness-based interventions, according to many large population-based research studies, are effective in the reduction of worry and stress.

Over the last 40 years, scientists around the world have published thousands of research articles describing the effectiveness of mindfulness as a treatment for a large number of mental and physical illnesses. There are too many to list, but notable for people with SCI are chronic pain, anxiety, depression, fatigue and sleep disorders.

Based on this knowledge, clinical psychologists and psychiatrists around the globe have developed a number of therapies that use mindfulness. Mindfulness programs have been widely adapted

in schools, prisons, hospitals, veterans' centres, and even the business world—Google, Aetna, and Target are just some of the prominent corporations which ensure that their executives and employees are provided with opportunities to learn mindful practices through yoga and meditation.

Meanwhile, the combination of scientific evidence relating to mindfulness, along with the shared personal experiences of those who live mindfully, has caught the public's imagination, resulting in a surge of media attention. The topic of mindfulness has been featured on NBC's *Dateline*, ABC's *Chronicle*, Oprah's *SuperSoul Sunday* and CBS's *60 Minutes*. Mindfulness has also been featured in various print and online media including *TIME* magazine, *Maclean's*, *Scientific American* and *The Huffington Post*.

### Mindfulness: A Personal Journey

For me, becoming adept at mindfulness has helped me to cope better with the challenges of living with an incomplete injury and its related complications—spasticity, chronic pain, and limited endurance.

Early in my post-SCI life, these complications brought me stress, frustration and anger (especially when I was in pain), anxiety over what the future would



bring, grief over the loss of what I could no longer do, and phases of depression and despair.

But with daily mindfulness practice, I'm learning to accept myself as I now am. Mindfulness reminds me to welcome whatever sensations, emotions or thoughts I'm experiencing in each present moment with curiosity, openness and patience. If I'm feeling angry or anxious, I no longer judge those feelings, and instead I now give myself the freedom to feel whatever I'm feeling. If I'm experiencing physical pain, I no longer resist it (which often leads to the pain persisting), and while I don't like being in pain, I have become better at accepting the reality of it.

The practice of bringing mindful awareness to my daily experiences has taught me how to ride the waves of my physical and emotional pain instead of drowning in them as I used to.

This allows me to view my life with more clarity and wisdom. Consequently, I'm better at putting my limited energy into the things that I can change—for example, practicing better self-care habits.

Most importantly, mindfulness has given me the ability to develop greater intuition and compassion. The more trust, kindness and respect I have learned to give to myself, the easier it has become to establish nourishing habits of self-care. Since beginning my mindfulness practice, I've become a stronger advocate for how self-compassion and self-care provides a great foundation for the healing and growth that is possible after an SCI.

## The Barriers to Mindfulness

Despite mindfulness being a simple practice, it can be challenging to learn. Human beings are creatures of habit. And for those of us who live in the fast-paced Western World of busy schedules and endless to-do lists, we have developed strong habits of auto-pilot “doing.” Whether it's the need to be productive, to achieve, or to succeed, there's an underlying need to do, do, do. In all this doing, sometimes we forget what the late Dr. Wayne Dyer had

to remind us of: “I am a human being, not a human doing.”

The good news is that, just as we have developed habits of doing things on auto-pilot, we can just as effectively develop habits of being aware. Neuroscience has revealed that the brain has the power to rewire itself over time, based on how we think and act. This process is known as neuroplasticity. As we practice a particular thought pattern or action (healthy or unhealthy) over and over, our brains

change in order to allow us to practice that behaviour more efficiently. So with practice and dedication, becoming less caught up in “doing” and more mindful becomes easier and easier.

## The Gift That Keeps Giving

I know I'm not alone in saying that, when I'm in pain and in a bad mood, I'm not a fun person to be around. However, when I'm feeling awesome and am full of joy, I have all of that to give—and I'm defin-

## My Mindfulness “Aha!” Moment

I'll never forget one particular moment when I first stepped into this space of awareness and the clarity it provided. It was the winter of 2012, and I was walking through the snow with my boots. I was feeling increasing pain in my feet and back. I was becoming frustrated and angry. The pain sucked. My life sucked. I then decided (at first with reluctance) to try bringing mindful awareness to the moment. So I first brought my attention to the feeling of my body breathing and then I observed, without judgement, the following: “There's a sharp hot radiating pain on the inside of my ankles; on a pain scale of one to ten, it feels like a five. There's a warm throbbing in my lower back that feels like a four out of ten. I'm having emotions of frustration and anger. And I'm having thoughts like, ‘this pain sucks’ and ‘my life sucks.’”

And then, with just that simplicity of stepping back to gain a broader perspective of my own mind-body experience, I gained this insight: “My life doesn't suck! I'm just having thoughts that my life sucks. And thoughts are not fact!”

From the stance of an impartial observer to my own experience, I also realized I had been walking for a duration of time without sitting down even once to rest, and that I was not wearing my ankle foot orthoses (AFOs) because I was in denial that I really needed them for pain management.

And so with these insights, I was able to move from feeling frustrated to feeling a sense of control and what I call “response-ability.” Knowing this, I realized that, in the future, if I was to minimize the pain experience, I would have to listen to my body better, slow down, and rest often. And while I still do not love wearing my AFOs, I do wear them daily simply because they are what my body needs to feel better.

Fast forward to today. I now have a fun list of self-care habits that I commit to daily which not only helps to minimize pain but also helps my mind, body and soul to feel amazing. Everyone's self-care list will be different, so I won't bother listing mine. But I will say that it involves eating, moving, and thinking in ways that make me feel better. The point is, with mindful awareness, we start to see more clearly which of our daily habits are depleting us and which of our habits are nourishing and make us feel good.



itely more fun to be around. So for the sake of both myself, and my family and friends, I must be mindful to take good care of myself daily.

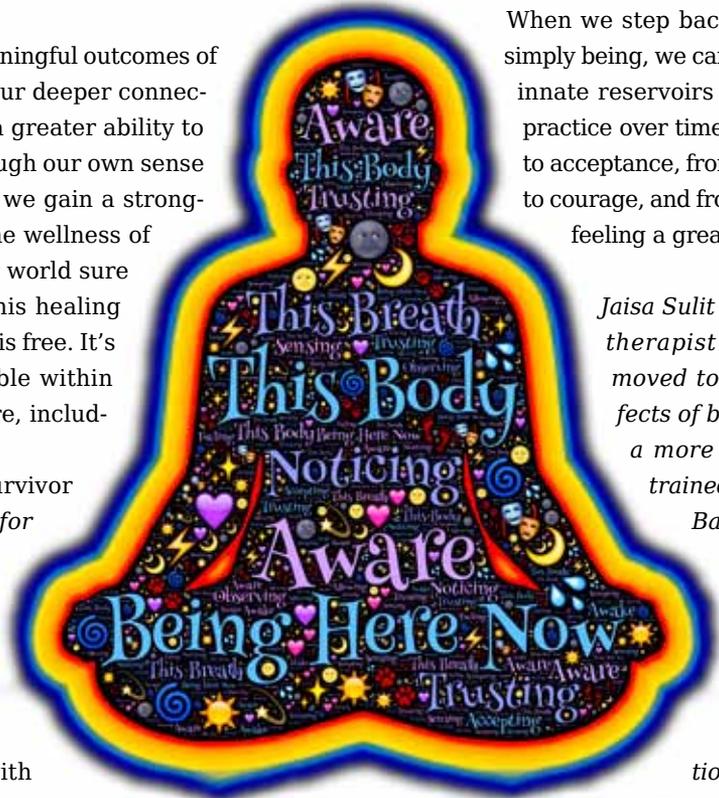
Perhaps one of the most meaningful outcomes of mindfulness is that, through our deeper connection with ourselves, we have a greater ability to connect with others. And through our own sense of improved overall wellness, we gain a stronger capacity to contribute to the wellness of the world—and right now, our world sure needs healing. Fortunately, this healing comes at no cost. Mindfulness is free. It's always available and accessible within each of us—anytime, anywhere, including right now.

Viktor Frankl, holocaust survivor and author of *Man's Search for Meaning*, once wrote, "Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom."

Mindfulness provides us with this space. It gives us the chance to exert our freedom to choose how we respond to what life presents in each moment. This space is the difference between

reacting in automatic, habitual and often destructive ways, and instead responding with clarity, wisdom and compassion.

When we step back and into this inner space of simply being, we can connect more deeply with our innate reservoirs for strength. So with mindful practice over time, we can move from resistance to acceptance, from suffering to coping, from fear to courage, and from having no sense of control to feeling a greater sense of choice. ■



*Jaisa Sult is a neuro-rehab occupational therapist from Toronto who recently moved to Vancouver to explore the effects of bringing her rehab routine into a more natural environment. She is trained in teaching the Mindfulness Based Stress Reduction (MBSR) program and has taught mindfulness to both patients and professionals in various health care settings. She is currently on sabbatical to refocus on her own rehabilitation and to publish her first book.*

*You will most likely find her at the beach doing qigong, yoga, pilates and meditation with her bare feet on the sand.*

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# Size Matters!



Interested in saving your shoulders from the wear and tear of wheeling? Perhaps you should consider the size of your chair's casters.

**D**espite how it's often described in the mainstream media, a wheelchair is anything but confining. Given a relatively accessible environment, most manual wheelchair users view their ride as a tool of liberation, not one that takes away their freedom.

But as thousands of veteran wheelchair users have discovered later in life, pushing a manual chair is not without its risks. The motion involved in pushing is far from natural, and the most vulnerable part of the body involved in wheeling is the shoulder.

Depending on the source, research studies reveal that from 30 to 75 percent of manual wheelchair users experience pain from wheeling, with prevalence increasing with years of use. The most common injury is a tear in the rotator cuff—an often excruciating injury that can sometimes be repaired by surgery, although success isn't guaranteed.

Little wonder that older manual wheelchair users are always diligent about preserving their shoulders. If you've only recently started using a manual wheelchair, you may

want to take a cue from your more seasoned peers and seek out even the slightest advantage when it comes to getting around.

Recently, at ICORD's annual research meeting, we stumbled across an impressive poster presentation that offered some rare insight into an often overlooked option to consider for those buying or outfitting a manual chair.

The poster, titled *Caster Size As It Relates to Ease of Rolling*, showcased the research of Mehdi Eshraghi, a graduate research assistant at ICORD and master's student at UBC, and Franco Chan, a rehabilitation engineer at ICORD.

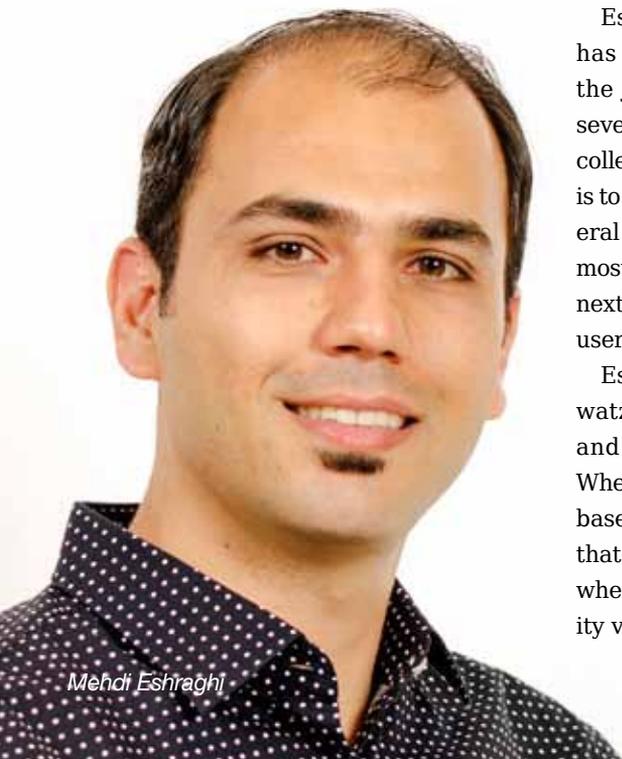
"Dr. Bonita Sawatzky is the principal investigator who came up with the idea of comparing the rolling resistance of wheelchairs on different surfaces," says Eshraghi. "In a previous study, we determined that smaller casters significantly increased rolling resistance on smooth treadmill surfaces. She wanted to see whether the same holds true on actual indoor and outdoor surfaces. From her experience, she found that wheeling on rough surfaces

with small casters requires more effort than with larger casters.”

Eshraghi and Chan developed the test protocol. Three caster sizes—four, five and six inches—were studied in use on three indoor surfaces and three outdoor surfaces. A manual wheelchair was passively pulled along each surface at just over one metre per second by a power wheelchair, and the rolling resistance of the manual wheelchair was measured using an extremely accurate calibrated force transducer. The process was repeated three times for both indoor and outdoor environments.

“To standardize the protocol, we had a 60 kilogram weight in the manual wheelchair being towed, and the amount of weight distribution was 20 percent on the front casters and 80 percent on the rear wheels,” says Eshraghi. “This was important for comparing our result with the data from the previous study that was done on a treadmill.”

The results showed that the four inch casters had the highest rolling resistance on most surfaces, which wasn’t too surprising given the previous research. Somewhat more surprising was that the five inch casters had the least rolling resistance on most indoor surfaces—even less than the six inch casters. However, the six inch casters had the least rolling resistance on most outdoor surfaces.



Mehdi Eshraghi

We asked Eshraghi to quantify the greater effort required by the smallest casters. “The four inch casters,” he explains, “required about 16 percent more effort than the five inch casters on indoor surfaces. The four inch casters also required about 16 percent more effort than the six inch casters on outdoor surfaces.”

Sixteen percent might not seem like a lot more effort, but factor it by a couple decades of wheeling and the number grows in significance. So although four inch casters are most popular among active wheelchair users (probably because many users feel they look least dorky), these results should lead manual wheelchair users to make a more informed decision about the best caster size for their specific lifestyle and use.

“In general, people who are interested in preserving shoulder and arm function should choose casters more carefully,” says Eshraghi. “They should choose the casters based on the surfaces that they wheel the most on. If you do most of your wheeling outside, six inch casters might be your best bet. But if you spend as much time inside as outside, then it might be worth considering the five inch caster.”

He concedes that larger casters can sometimes get in the way of the footplate for some wheelchair users, or make it more difficult to get closer to kitchen cabinets and vanities.

Eshraghi says that this study, which has been accepted for publication by the journal *Ergonomics*, is the first of several related studies which he and his colleagues have in the pipeline. “Our aim is to educate wheelchair users about general wheelchair setup and choosing the most suitable wheelchairs,” he says. “Our next study will be to educate wheelchair users about wheelchair maintenance.”

Eshraghi is also working with Dr. Sawatzky, along with Dr. Ben Mortenson and Lynda Bennett, on the I-WHEEL Wheelchair Maintenance Project, a peer-based knowledge translational program that will bring knowledge about manual wheelchair maintenance to the community via [www.iwheel.ca](http://www.iwheel.ca). ■



## Google Kickstarts Neil Squire

The Neil Squire Society has been awarded an \$800,000 grant from Google.org, Google’s philanthropic arm, to bring to market a smartphone access device for people who can’t use their hands.

The grant will allow the Neil Squire Society to release LipSync, a mouth-controlled input device that allows people with quadriplegia and other disabilities to operate a mobile device.

An estimated one million people in North America have limited or no use of their arms. Up to this point, they’ve been excluded from using the many touchscreen devices on the market and benefitting from the growing number of incredibly helpful apps and services.

The LipSync designs will be released open source so that manufacturers can affordably make the solution available to anyone who has difficulty using their hands to operate a smartphone or other mobile device.

“The support of Google.org will enable us to take our LipSync from prototype in our R&D department into the lives of people with disabilities,” says Dr. Gary Birch, Executive Director of the Neil Squire Society. “Mobile technology has changed the lives of everyone, but can be a new barrier to people that are unable to use their hands. The LipSync solves this problem, and our model of releasing it open source will ensure it is an affordable option that can be customized to the specific needs of people with disabilities worldwide.”

For more information on the LipSync Project, please visit the Neil Squire Society website, [www.neilsquire.ca/lipsync](http://www.neilsquire.ca/lipsync).

# ask the SPIN DOCTOR

Nick from Vancouver writes, “I think I’m guilty of ignoring my feet – I guess it’s a case of, ‘If I can’t feel them, they must be okay.’ At any rate, I have a friend who ended up with a pretty bad pressure sore on his heel, so I made up my mind to learn how to take better care of my feet. Can you offer any advice?” To answer this issue’s question, we turned to Bonnie Venables, Clinical Resource Nurse/Nurse Continence Advisor – Outpatients at GF Strong.

I’m glad you’ve realized that feet are body parts that warrant special care and even pampering if you’re a person with an SCI. Feet are vulnerable, and any small problems you ignore can quickly spiral into major problems.

The following guidelines assume that you’re able to inspect and care for your feet yourself. If that’s not the case, simply ensure your caregivers include the various steps in your daily regimen.

The first thing you need to do is to carefully wash, dry and inspect your feet daily. Find a time that works well, such as your bath or shower time. Wash them with warm water with mild, non-perfumed soap. Remember to always check water temperature before putting your feet in, and do not soak your feet. Once clean, dry them well—especially between the toes. Then inspect them. Look carefully for any red areas, cuts, swelling, blisters, rash, cracks, or signs of infection such as increased redness, pain, and drainage. Use a mirror for hard to see areas. Once you’re satisfied that there are no concerns, moisturize with non-perfumed lotion—this will keep your skin soft and supple. The only place you shouldn’t moisturize is between your toes.

If you do see any cuts or sores, treat them immediately, even if they appear to be minor or inconsequential. And naturally, if you notice any injury that is clearly not minor (increased swelling in your legs, cuts, blisters, bruises or pressure injuries) speak to your doctor, nurse or spinal cord injury team as soon as possible.

Once a week or as required, you should also use this washing and inspection time to cut your toenails. Please be careful—and ask for help if needed. To prevent ingrown toenails, cut your nails straight across, as opposed to rounding them as you would fingernails. Remember: nail clippers only, no scissors or sharp objects!

After you’ve washed, dried and inspected your feet, you should get them covered and protected (unless, of course, your next stop is your bed). Even indoors, appropriate socks and shoes are vital to keep your feet and toes safe from bangs, bruises, heat and cold—particularly if you can’t feel these things.

Pay attention to your socks, as good quality will help wick moisture and keep your feet dry. Socks should be made from natural fibres like cotton or wool. They should be



loose around the top and never leave marks on the legs. While it might be a fashion faux pas, wearing socks inside out can reduce marks and soreness caused from seams. If you’re prone to swelling, compression socks can help you keep your blood flowing. Put them

on in the morning and take them off before going to bed. Ensure they are fitted correctly, and follow directions for cleaning and replacement.

When it comes to shoes, it’s a good idea to get your feet measured and seek advice from your treating physiotherapist or occupational therapist before trying or buying shoes. Always wear shoes that offer good protection—you should always have footwear with a closed toe. Wearing one size larger to prevent pressure issues is best. Buy shoes late in the day as feet tend to swell. Remember that sizing can differ between styles and brands, so take nothing for granted and try on every pair of shoes before purchasing. Consider Velcro fasteners—so much easier to put on. A wide toe area and non-slip soles will also make your life easier. If your shoes are new, check your skin more frequently for redness. Shake out your shoes before putting them on—that pebble that you can’t feel could do a lot of damage if left in place for a day.

Throughout your day, be vigilant to protect your feet from hot surfaces and burns. Heaters, hot concrete, hot metal foot plates are all hazards. Do not use hot water bottles, electric blankets, space heaters or heating pads on your legs or feet, as these may cause burns.

Finally, we suggest that you see a podiatrist or foot care nurse regularly—they’ve been trained to quickly identify any problems that may not be obvious to you. If you have any history of diabetes, this is doubly important.

With a little vigilance and by acquiring some daily good habits, you can have happy feet—and keep them in a state of bliss.



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# Autonomic Dysreflexia: Botox to the Rescue

In the past few years, Botox has emerged as a widely-respected drug in the world of SCI medicine. Now, ICORD researcher Dr. Andrei Krassioukov and his colleagues have confirmed yet another use for Botox—reducing and even eliminating the potentially deadly danger of autonomic dysreflexia.

In popular culture, Botox and the people who use it for cosmetic reasons are often mocked—it is, after all, the treatment of choice for those seeking to defy age, but it often leaves many with a telltale expressionless or blank face as a result.

However, in recent years, it's gained increasing and widespread respect in most medical circles—and particularly in the world of SCI.

In past issues, we've told you about Botox and its ability to calm severe spasticity and relieve urinary incontinence from neurological detrusor overactivity—NDO for short. (Botox is pharmaceutical giant Allergan's trade name for Botulinum toxin, or BTX.)

Now, a team of UBC and ICORD researchers have confirmed yet another benefit of Botox—reducing and even eliminating the incidence of autonomic dysreflexia, or AD, which is a serious and even deadly elevation of blood pressure experienced by up to 90 percent of people with an SCI at T6 or above.

The discovery is directly related to the use of Botox to treat NDO, so it's important to first review just how that works.

The average person doesn't give urination much thought. When the bladder is full, it signals the brain that it requires emptying. When that happens, the person finds a socially-acceptable location (hopefully, anyhow) to void. At that point, the person makes a conscious decision to have the brain instruct the sphincter muscle at the bladder exit to relax and, at the same time, the detrusor muscle to contract. This combination results in the release of urine.

The entire process is regulated by the nervous system. But when the nervous system is compromised by SCI or another condition, such as MS, urinary incontinence due to detrusor overactivity can result. In plain speak, during NDO, the detrusor muscle involuntarily contracts, increasing the pressure in the bladder and decreasing the volume of urine the bladder can hold, which causes the individual to leak urine unexpectedly.

Enter Botox, which is actually a power-

ful neurotoxin produced by the bacterium *Clostridium botulinum*. Botox, which causes temporary paralysis within tissue it comes into contact with, is administered with a series of injections into the detrusor muscle. This prevents the bladder from spontaneously contracting and, for a period of up to ten months, can free a person of incontinence. The result is a greatly improved quality of life for people who respond well to the treatment.

About ten years ago, physiatrist and ICORD researcher Dr. Andrei Krassioukov was among the scientists studying the effects of Botox. At the time, he suspected a strong link between NDO and AD, and he surmised that, in addition to alleviating NDO, Botox injections might also reduce the incidence of AD. Unfortunately, at the time, Krassioukov struggled to secure funding to carry out the study.

But he persevered for the next decade, during which time the link between NDO and AD became clear (NDO is now believed to be the cause of 85 percent of all AD episodes). He was finally rewarded for his patience last year when Allergan agreed to fund a study of Botox and AD.

Krassioukov and five ICORD colleagues— Dr. Daniel Rapoport, Renée Fougere, Dr. Katharine Currie, Dr. Mark Nigro, and Dr. Lynn Stothers—began by recruiting 22 men and women with SCI for the study. Of these, 12 men and five women completed the study.

The participants were first assessed with several standard tests including urodynamics studies, or UDS, which is the most widely-accepted assessment of a person's bladder function. During UDS, the bladder is filled using a catheter, and the participant's blood pressure and heart rate are monitored simultaneously. In this manner, UDS was used to confirm the presence of NDO and AD in the participants.

Two weeks later, the participants were given a series of Botox injections into the detrusor muscle of their bladders. Then, after another month, the participants were again as-

sessed using the same tests, including UDS, to see if there was, in fact, a reduction in AD symptoms.

Here's how the researchers described the study's findings, which were published in the March 2016 issue of the *Journal of Neurotrauma*: "The main finding from this investigation was a reduction in AD severity and frequency during bladder-related events...Following the Botox treatment, 59% of our sample no longer experienced AD during the UDS assessment (i.e., AD was eliminated), whereas the remaining 41% experienced a reduction in AD severity (i.e., AD was attenuated)."

Keep in mind that these results were in addition to a significant improvement in continence—prior to the Botox injections, 53 percent of the participants reported being continent, and after treatment, 88 percent reported being continent.

The message for anyone considering Botox treatment for incontinence is that you might receive another major benefit in the process—reduction or elimination of AD bouts. On its own, AD is potentially life-threatening. And another recently published research study concludes that repetitive bouts of AD can lead to immune system suppression, which may explain why some people with SCI are at such a high risk from diseases like pneumonia.

Is it possible that anyone with both chronic NDO and recurring AD might benefit for the rest of their lives with Botox injections delivered every nine months, which is roughly the length of time it remains active?

"It certainly is conceivable," says Rapoport, one of the urologists who



Dr. Andrei Krassioukov

contributed to the study. “Many patients with SCI who are candidates for Botox have injuries at T6 or higher and may also benefit from the positive effects of Botox on AD. However, long-term response rates are not yet known. Specifically, we only have short-term results for AD.”

The research team notes that the promising results now point to a need to conduct a larger-scale, randomized controlled trial to confirm these findings and demonstrate longer-term benefits for reducing AD.

Meanwhile, the study adds to the growing body of evidence that Botox is an effective treatment for NDO.

“Botox is becoming a standard management option for SCI patients with incontinence due to bladder overactivity,” says Rapoport. “We’re treating increasing numbers of SCI patients in this manner, and response rates, efficacy and safety are proving to be favourable. We have evidence that response rates remain very good with over five years of treatments.



Dr. Daniel Rapoport

Longer-term evidence is developing.”

So who makes a good candidate for Botox treatment?

“In the SCI population, Botox is indicated for those with highly overactive bladders resulting in incontinence,” says Rapoport. “It’s usually considered if first-line measures such as oral medications fail. It’s primarily used by those

who perform—or have the ability to perform—intermittent catheterization, as there is a risk of making it difficult to empty the bladder otherwise.”

While it’s proven to generally be a safe treatment, Rapoport points out that some people do experience an allergic reaction from Botox, and another potential, albeit rare, side effect is myasthenia gravis—an autoimmune neuromuscular disease characterized by varying degrees of weakness in muscles. Also, women who are pregnant can’t receive Botox treatment.

As for funding, Rapoport says that Botox is a benefit of the Medical Services Plan for anyone with NDO.

“Those with SCI are covered,” he says. “Botox itself is covered by Pharmacare, although there is usually a deductible that needs to be reached to get full coverage. Those who wish to explore the option of bladder Botox further should request a referral to a urologist. Many urologists in BC are able to provide this service, and more continue to learn this.” ■

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# Mister Mobility Mount

Gerry Price designed his ingenious Mobility Mount system so that he could be more active and independent, but his peers quickly caught on that they could benefit from it as well.



One of the products you've probably seen regularly advertised here in *The Spin* is the Mobility Mount. It's a clever system that consists of a base that fits under a wheelchair's seat cushion, and a series of attachments designed to securely hold a variety of everyday items and tools, leaving the user's hands free for wheeling or navigating by joystick.

Some long-time readers know the history behind this ingenious device, but those that don't might be surprised to learn that it's a product that was designed and is still marketed by one of our long-time SCI BC Peers, Gerry Price, who started off by simply trying to make his own life a little easier.

"They say that necessity is the mother of invention," says Price, who lives with his wife Evie in Parksville on Vancouver Island. "But for me, it's always been frustration."

When he was an 11-year-old growing up on Vancouver's North Shore, Price gashed his knee just above the kneecap so badly that he couldn't even lift his leg. "It was the first day of summer break, and there was just no way I was going to be stuck using crutches," he recalls. "So I designed and built a walking stick with a foot holster fastened to it, which would lift my leg each time I stepped. I couldn't go in the water, but I spent the summer on the water in a canoe or on a paddleboard."

After he finished school in the mid-80s, Price moved to Salt-spring Island, where, for the next 20 years, he brought his ingenuity to his job with the Engineering & Operations branch of the Capital Regional District. Then, in 1995, he was injured in a workplace fall and became a quadriplegic.

After a lengthy stay in acute care and rehab, he came home and tried to make sense of his new life. One primary source of frustration was lack of hand dexterity—he quickly discovered that it was difficult for him to hold onto everyday objects and tools and use them at the same time, particularly when he needed his hands free for navigating his wheelchair. The answer, he reasoned, lay in some kind of portable mount to hold objects. He saw a few commercially-available products on the market that offered partial solutions, but nothing that would work for everything on his wishlist.

He'd already found an ally in the Neil Squire Society, which had set him up with a computer system powerful enough to use a computer-assisted design (CAD) program. Armed with that, he began designing the Mobility Mount.

From his earliest prototype, the Mobility Mount soon evolved into what it is today—a simple, sturdy and durable system that Price describes as "a great equalizer."

"Mobility Mount has been developed so that wheelchair users can stay healthy by living more active lifestyles," he says. "It can be used on power chairs or manual chairs, and it allows you to easily hold a variety of items—a retail



store hand-held shopping basket that I've called the LapShopper, a wind-proof and UV-blocking umbrella, or your camera."

He loved the freedom his new invention gave him, but he wasn't alone. "My peers liked the system because it works, and it was being built and used by a guy who also uses a wheelchair," he says. "For example, my friend Jon, whose injury is a little higher than mine, has very little dexterity and limited use of his arms. When he came home from rehab, he had a hard time simply reading. We soon found out that my mount allows him to hold his tablet or reader securely in any position, so he can independently turn the pages, holding a stylus."

With more and more interest from peers, Price began building more Mobility Mounts and started marketing them from his newly-formed company, Adaptive Design Ventures.

Surprisingly, his success with Mobility Mount has been modest. Recently, he's had some interest from a rehab hospital in the United States, but up to this point, his sales have been largely restricted to fellow Canadians. Right now, he's sitting on the fence when it comes to pursuing expansion south of the border.

"To qualify to sell in US wheelchair stores, I'm required to carry product liability insurance that includes \$6 million dollar umbrella coverage," Price explains. "Is my product going to be a commercial success if I have to sell it at 50 to 60 percent mark-up to cover my insurance costs? I'm not sure."

But commercial success or getting wealthy has never been the end game for Price, who tirelessly donates his time to a number of causes important to him—he's been a member of Spinal Cord Injury BC's Board of Directors, President of the Accessible Wilderness Society, and a member of the City of Parksville's Advisory Design Panel.

"The reason I continue to produce these mounts is because they allow users like Jon and myself to do some things independently and stay active," he says. "I choose to stay busy and active, involved with many good people doing important things—we are all going down the same road."

Because he'd simply like to see more people benefit from the Mobility Mount, Price is exploring ways to involve other wheelchair users in its distribution, and he's also interested in partnering with other entrepreneurs with disabilities.

To learn more about Price and his Mobility Mount, please visit [www.mobilitymount.com](http://www.mobilitymount.com). ■

## Pregabalin Linked to Birth Defects

Pregabalin, also known by its trade name Lyrica, can be an effective treatment for some people's neuropathic pain from SCI and several diseases. But new research is raising concerns about the drug's potential to result in birth defects when used by expecting mothers.

It's believed that pregabalin works by reducing the release of neurotransmitters that are implicated in pain.

Animal studies have revealed that pregabalin contributes to increased incidence of birth defects. Now a new study suggests that it may have the same result in humans. The study, which was published on May 18 in the journal *Neurology*, included 164 women who took pregabalin during their first trimester of pregnancy—115 used it to treat neuropathic pain; the remainder for other disorders such as depression. The majority of these women started taking it before they became pregnant, but stopped an average of six weeks into their pregnancy.

The results from these women were compared to a control group of 656 pregnant women who didn't take the drug. Among the researchers' findings was that women taking pregabalin were six times more likely to have a baby with a major defect in the central nervous system than women not taking the drug. Other birth defects linked to pregabalin included cardiac abnormalities.

However, the results are not conclusive, according to Catherine Jutzeler, an ICORD postdoctoral fellow.

"This is an important paper providing some evidence for the potential of pregabalin to be teratogenic (result in birth defects)," says Jutzeler, who is investigating the impact of pain on neural plasticity after SCI. "However, the conclusion drawn from this paper should be interpreted with caution. I see several limitations. First, the small sample size is a problem. Also, only 19 participants were treated with pregabalin only, with the remainder being treated concurrently with another drug that may have influenced the outcome. These include antiepileptic drugs, benzodiazepines, antidepressants, and alcohol. Some of these drugs are known to be highly teratogenic. Again, to rule out the teratogenic effect of co-medications or interactions between co-medications and pregabalin, a bigger sample size is required."

She adds that the study also does not address the fact that the condition being treated with pregabalin—for example, epileptic seizures and chronic pain—can themselves have negative effects on the development of the fetus.

Should women with SCI who are pregnant, or contemplating pregnancy, avoid pregabalin?

"During pregnancy, unless there is an urgent indication for a drug, doctors would advise against taking most medications," says Jutzeler. "So it would only be in the case of extreme neuropathic pain that pregabalin would be prescribed to anyone who is pregnant. Balancing the drug-related versus disease-related risks is unavoidable, and the administration of pregabalin—or not—has to be decided for each individual patient."

# Participate in Research

SCI research is about much more than test tubes, stem cells, and a far-off cure.

At ICORD (International Collaboration On Repair Discoveries), SCI research is also about improving bladder, bowel, and cardiovascular health; taming pain and autonomic dysreflexia; enhancing sexual health and fertility; new assistive technologies; wheelchair design and ergonomics; and much more. In other words, it's about maximizing recovery, independence, health, and quality of life. But it doesn't happen without you. That's why SCI BC and ICORD are partnering to help raise awareness and increase participation in world-leading research. Working together, we can make SCI research more meaningful and move it along at a faster pace, and we invite you to be a part of it.

## Bowel Care and Cardiovascular Function After SCI

**Overview:** Dr. Victoria Claydon and her team recently conducted a survey of bowel care practices and cardiovascular responses to bowel care in individuals with SCI, and learned that bowel care and blood pressure control were areas of frustration following injury. Now they are testing the effect of a medicated lubricant on blood pressure changes during bowel care routines conducted at home.

**What to expect:** The study involves two at-home visits (the length of time per visit will vary depending on bowel care duration). Participants will have complete privacy for the duration of their bowel routine, and will be asked to complete questionnaires before and after.

**Who can participate:** To take part in this study, you must be over 18 years old and have a high thoracic or cervical spinal cord injury that was sustained at least one year ago.

**Why participate:** Ultimately, this research may help provide clearer guidelines for bowel care practices, but in the meantime, you will have the opportunity to meet with the study's Nurse Continence Advisor and can receive up to \$200 for participating in the study.

**Location:** Your involvement in the study will take place at your home (if this is not convenient or desirable, other options are available).

**For more information or to sign up to participate:** You can watch a short video about the study at [icord.org/bowel-care-cardio-function](http://icord.org/bowel-care-cardio-function) and contact the study coordinator, Vera-Ellen Lucci, by email ([vera-ellen\\_lucci@sfu.ca](mailto:vera-ellen_lucci@sfu.ca)) or call 778.782.8560.

## Can exoskeleton training improve balance and postural control?

**Overview:** The purpose of this study, led by Dr. Tania Lam, is to determine the effect of overground exoskeleton-assisted gait training on the recruitment and training of muscles used in postural control. There are two parts to this study. In Part 1 of the study, we hope to determine how different exoskeletons, including the Lokomat and Ekso, engage your abdominal muscles. Part 1 of this study involves 6 sessions. In Part 2 of the study, we hope to determine how training on either the Lokomat or Ekso exoskeleton improves your seated balance and other similar functional abilities.

**What to expect:** You can choose to participate in Part 1 and/or Part 2. For Part 1, participants will be asked to complete 4-6 sessions in the Human Locomotion Lab at ICORD over the course of 2 weeks (approximately 9-13 hours total). You will be trained on how to use each of these robotic devices while your abdominal activity is monitored using EMG surface electrodes. For Part 2, participants will be asked to complete 30 sessions in the Human Locomotion Lab at ICORD over the course of 10-12 weeks. Each week you will be tested on your seated balance to monitor for changes and/or improvement. This second part of the study lasts 10-12 weeks.

**Who can participate:** Adults with SCI and those who do not have an SCI can participate. If you have an SCI, you must be 19-65 years old, have had an SCI at least 6 months ago above T6, have enough strength in your arms (motor-complete below C7 or motor-incomplete with good upper limb strength), use independent sitting as part of your typical daily activities, be able to tolerate an upright posture for 30 minutes (with or without breaks), and be in good general health. If you don't have an SCI, you must be 19-65 years old, be able to stand without difficulty, and be in good general health.

**Why participate:** Try the Lokomat and/or Ekso exoskeleton and receive an honorarium of \$15 in the form of a Starbucks gift card.

**Location:** Human Locomotion Lab at ICORD (Blusson Spinal Cord Centre).

**For more information or to participate:** Contact study coordinator Alison Williams by email ([awilliams@icord.org](mailto:awilliams@icord.org)) or call 604.675.8814.



Learn more about what makes ICORD one of the biggest and best SCI research centres in the world, and the research they are doing, by visiting [www.icord.org/research/participate-in-a-study](http://www.icord.org/research/participate-in-a-study)

# Something to Share

## Will the sharing economy include people with disabilities?

In the Sesame Street song *Share*, Cookie Monster grows, “Me got some something that you want. You got some something that me want. Put both somethings together and share.” Ernie quickly buys into the concept.

But when it comes to the rapidly-emerging sharing economy, the concept of sharing means something a little different: one “something” is usually something an individual has that happens to be available or underutilized, and the other “something” is usually money. This doesn’t actually sound like sharing to me—it’s more like a different way of doing business, or perhaps going back to a really old way of doing business.

The sharing economy (sometimes more aptly called the peer economy) is mainly about online businesses enabling individuals to do business directly with other individuals—renting out a house, providing rides, and selling goods or services.

The internet, big databases, and the hardware to access them have allowed the rise of Airbnb, eBay, Craigslist, Uber, Turo, and a host of others.

These stars of the sharing economy have opened up a lot of opportunity for suppliers and consumers alike, but not everyone can benefit—especially people with disabilities who may not be able to participate because of lack of accessibility of the technology or service, or its cost. The general lack of regulation imposed on these new businesses means that they aren’t necessarily subject to the same accessibility standards as those in long-established business models, such as the hotel and taxi industries.

On the other hand, the peer economy may provide previously inaccessible opportunities for people with disabilities to generate revenue by making their accessible vehicles, homes, and adaptive sports and mobility equipment available

within this new marketplace. Why let all of these items sit idle when they could be used by other people with disabilities and make you some extra money?

Of all the new businesses that have emerged through the peer economy, Airbnb and Uber seem to have attracted the most attention. This is likely because they’ve challenged and disrupted well-established and regulated business sectors. They’ve also been successful, both on the supplier and consumer sides of the business equation.

But in the absence of established regulation, how inclusive will they be?

The good news is that some sharing companies are attempting to embrace accessibility—in part, I’m sure, because regulation will eventually require them to do so, but also because they recognize the economic incentive in doing so.

Take Uber, which is not operating in BC yet. Recognizing the need to make sure their ride-sharing service meets the needs of all customers, Uber recently worked in partnership with SCI Ontario and SCI BC to co-host a series of successful accessibility forums in Toronto and Vancouver. Our role was not to take sides, but to encourage discussion of the challenges and potential solutions. Through the broad range of expertise of the disability community members who participated, a rich dialogue led to a better common understanding of how to improve accessible transportation.

Details on the forum can be found on SCI BC’s and Uber Canada’s blogs, but key takeaways were that public-private partnerships will be essential, that there is an opportunity for Uber to bring more accountability into the Vancouver transporta-

tion space by ensuring transparency of operating procedures and results, and that riders with accessibility needs expect reliable travel at the same price point as those without accessibility needs. A follow-up forum will be held this summer.

SCI BC has a long history of helping to bring about improvements to accessible transportation. In 1968, our advocacy efforts helped lead to the removal of speed restrictions imposed on drivers with disabilities, and in the 1980s and early 90s, we helped usher in a fully-accessible bus fleet for Vancouver. These experiences taught us that it’s a lot harder to make improvements to existing services than it is to build them in at the outset.

In Toronto and other cities, Uber already offers accessible products like uberWAV (Wheelchair Accessible Vehicles) and uberAssist, which offer accessible rides at the same price point as their main product, UberX. (There are added incentives to drivers to help ensure riders with disabilities are not passed up.) But the company is still proactively reaching out to BC’s disability community to help improve accessible transportation before they launch their service here (if they get approval to do so).

Will people with disabilities be able to share in the brave new world of the sharing economy? Time will tell, but let’s hope that companies follow Uber’s encouraging lead. After all, those that ignore accessibility will do so at their own peril—eventually, regulators must insist on accessibility, and those that fail to see people with disabilities as customers will miss out on a large market demographic.

Did you know that, in 2012, travelers with disabilities contributed \$81.7 billion to the global economy? That’s a lot of “something” that could be shared.

– Chris McBride, Executive Director



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