

# the spin

SPINAL CORD INJURY BC

FALL 2015

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# contents

FALL 2015

## features

- 11 Spasticity & Chemodenervation**  
Are botulinum toxin, phenol or alcohol injections an effective treatment for spasticity?
- 14 Cover Story**  
Five SCI BC Peers share their experiences with pregnancy and motherhood.
- 20 Driving Your Way**  
Access Driver Rehabilitation specializes in helping people with high level injuries get back behind the wheel.
- 24 Softer Touch**  
Harvard researchers have come up with a fresh, softer take on the robotic glove for people with quadriplegia.
- 28 If I Knew Then...**  
Eight years after her injury, quadriplegic athlete, model and cupcake baker extraordinaire Jessica Kruger shares what she wishes she'd known from the start.
- 30 Instant Diagnosis: Part Two**  
A new handheld scanner can diagnose pressure ulcers long before they can be seen on the skin.

## departments

- 4 editor's message**  
Do we need a Canadian version of the ADA?
- 6 gear & gadgets**  
New products, devices and aids to daily living that might make a difference in your life.
- 7 room for debate**  
Is the Scalevo stair-climbing wheelchair a good thing?
- 8 events**  
Important dates for your calendar.
- 32 ask the SPIN DOCTOR**  
Strengthening your coughing ability and lung volume.
- 33 Participate in Research**  
ICORD research that could benefit from your involvement.
- 34 last word**  
Stockholm's Dignified Entrance project is creating equal access to the city's heritage sites and buildings.

Cover Photo: Yasaman Best with her newborn son Alex. Photo Credit: Jasalyn Thorne Photography



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## If I were Prime Minister (or Premier)...

Disability is a label. But does it mean anything anymore? Is it still useful? Or does it hinder us?

The term disability is increasingly being used to encompass an incredible diversity of conditions. It lumps together people with permanent physical disabilities with people with sensory disabilities, mental health issues, severe allergies, intellectual disabilities, developmental disorders, temporary disabilities, and more.

In fact, the United Nations Convention on the Rights of Persons with Disabilities, which Canada signed onto in 2010, defines disability as an enormously broad umbrella term "covering impairments, activity limitations, and participation restrictions" both permanent and temporary. Under this definition, almost all Canadians, at some point in their life, could be defined as having a disability.

There is clearly as much diversity between those that fall under this label as there is in the general public. Which is fine as a convenience, but when it comes to answering the calls of many for a Canadians with Disabilities Act, does the broadness of the label help or hinder us?

The 25th anniversary of the landmark Americans with Disabilities Act (ADA) has sparked debate as to whether we need similar legislation here in Canada. The ADA has brought many benefits, but some negatives as well. Canada is also governed in a very different way than the USA, with much of what would need to be enacted in disability rights legislation falling within provincial jurisdictions.

This begs the question: do we need a Canadians with Disabilities Act, legislation for BC, or both? Both is probably the answer, but what falls within the two pieces of legislation needs to be carefully thought out.

The name "ADA" makes it sound like it's just for Americans with disabilities. Same thing in Ontario and the Accessibility for Ontarians with Disabilities Act. Both use labels (disability) that segregate to create protection and equality. And therein lies the tension—labels may help us protect rights and enforce equality, but do they create attitudinal barriers that work against equality and inclusion?

I believe that legislation like the ADA and Accessibility for Ontarians Act shouldn't be thought of as just for Americans or Ontarians with disabilities. They are really for all Americans or Ontarians, who collectively benefit from increased accessibility, inclusion, and participation. When protecting citizens' rights, we need to go beyond segregation created by labels. We need to promote cultural shifts that remove barriers and that lead to true equality and inclusion.

I don't expect any disability legislation from the federal government anytime soon. But BC, through its Accessibility 2024 initiative, has signalled its plans to incorporate what's been learned from Ontario and the US in an effort to make legislation here stronger and more relevant for people with disabilities. SCI BC will be happy to help inform this process and to bring your ideas to it.

My first suggestion to BC will be to ditch any thoughts of using segregation-promoting labels to legislate rights and freedoms for people with disabilities, and instead focus on enacting laws that promote access and inclusion for everyone. For example, instead of creating a British Columbians with Disabilities Act, let's create a BC Access and Inclusion Act—let the focus be on access and inclusion rather than disability.

At the heart of the disability rights movement is equality and inclusion, leading to the removal of stigmas and barriers and the provision of opportunities that allow full participation in Canadian society. Labels tend to promote the opposite. Disability legislation like the ADA is probably a necessary tool to achieve this, but in the end, don't we really want society to move beyond laws and labels and foster access, inclusion, and security for all Canadians?

- Chris McBride, PhD, Executive Director, SCI BC



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*Go behind the scenes*

## TOYOTA HUMAN SUPPORT ROBOT

Toyota's new Human Support Robot, or HSR, desperately wants to pick up after you. Toyota engineers developed the HSR with a single goal—develop a robot that picks up and transports objects for people with disabilities. The HSR's single, folding mechanical arm can grasp objects of various shapes and sizes, and also picks up smaller items with a tiny suction cup. Standing at one meter, the HSR can telescope upwards to about 1.5 meters. It can also scoot in any direction, much like R2-D2 of *Star Wars* fame. It's operated either locally or remotely using a tablet or smartphone. Users can see and hear what the robot sees, thanks to several front-mounted cameras and a microphone array. A color display and speakers allow anyone in the care of the helper robot to see and communicate with the operator. Pay a visit to [www.toyota-global.com](http://www.toyota-global.com) for more information.



## SHERPA ELECTRIC POWER TRIKE

The Sherpa is a low-cost, 11-kilogram electric tricycle front wheel that can be attached to various types of manual wheelchairs. Hung Cheng-ching, a Taiwanese inventor who has an SCI, used graphics software and 3D printing technology to develop the device. It won a gold medal at The International Exhibition of Inventions of Geneva in April 2014, and is now being sold commercially. The Sherpa consists of a sturdy frame, a front tire, a powerful electric motor and lithium battery, and handle bar controls. It quickly clamps securely to the wheelchair frame, and once in place, lifts the front castors of your wheelchair off the ground. Safety considerations include brakes and a system that prevents you from rolling backward when going up a slope. Visit [www.sherpa.net.tw](http://www.sherpa.net.tw) for more details.



# Innovations

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

## SIXTH DIGIT

The Sixth Digit is a stylus ring that's ideal for using smartphones, tablets, keyboards, microwaves, or anything that requires precise control. It's designed to be worn at all times—you can even push a manual wheelchair with it in place on the finger of your choosing. The Sixth Digit is the brainchild of Josh Smith, a mechanical engineer who became quadriplegic just over a year ago after a diving accident. Smith intends to fully commercialize the device, and is funding its development with a Kickstarter campaign. If you'd like to get one on your finger, simply contribute \$20 to the campaign and you'll receive the Sixth Digit in exchange. Visit [www.kickstarter.com](http://www.kickstarter.com) and search for "Sixth Digit" for details.



## AUTOADAPT TURNY EVO

Sweden's Autoadapt recently introduced a new twist on its Turny Evo swivel seats. The company believes the safest way for drivers and passengers to travel in a vehicle is seated in the car seat using a seat belt, and since 2012, the Turny Evo has allowed wheelchair users to do just this. The company says its new version is more comfortable and easier to install, and has been

crash-tested to an even higher standard. The device is actually not a seat, but a device mounted under the existing seat that enables it to be rotated out of the door opening and lowered to the wheelchair seat height. This allows users to easily transfer independently or with assistance into the car seat. It's powered by the vehicle's battery and operated by remote control. It fits in practically all mass-produced cars using the existing seat bolt-hole pattern, which means that the original configuration can be fully restored in the event of a sale of the vehicle. Visit [www.autoadapt.com](http://www.autoadapt.com) for more information and images.



# Room for Debate

## Is the Scalevo stair-climbing wheelchair a good thing?

Welcome to our Room for Debate—a column we’re introducing to examine controversial disability-related topics from different perspectives. From time to time, when a potentially contentious topic crops up, we’ll publish a new Room for Debate. In this first installment, we focus on the Scalevo—a stair-climbing power wheelchair that’s been developed by Swiss students. The Scalevo ([www.scalevo.ch](http://www.scalevo.ch)) balances on two wheels while driving on even ground, but has tracks that are lowered to keep the user level while it climbs or descends stairs. Arguing for the Scalevo is SCI BC Peer Gord Rant, who lives in Victoria. Arguing against is Montreal blogger and accessibility activist Nicolas Steenhout. Both use wheelchairs. Do you think the Scalevo is a good idea? Take our poll at [sci-bc.ca/poll](http://sci-bc.ca/poll) and see what others are saying.



### “Nothing short of revolutionary.”

The Scalevo stair-climbing wheelchair is nothing short of revolutionary. This technology will give users almost endless opportunities to go wherever they desire.

I’ve been a walking quad for 20 years—I was born with cerebral palsy and sustained an SCI as a teenager. Today, accessibility is something I’m always thinking about. I’m thankful that sometimes I’m able to “cheat” and leave my chair at home. That said, it does not make accessible environments any less important to me. I often find places—especially washrooms—difficult to navigate.

In all my years spent dealing with life’s curve balls, I have seen society move from turning a blind eye to people with disabilities, to becoming more sensitive and inclusive to us. Doors I was unable to open became electric doors that opened for me; ramps began to appear beside stairs. We’ve come a long way. But there is still further to go.

As a wheelchair user I can only see positives coming from this fantastic addition to the somewhat stagnating family of mobility aids. By no means does it signal that we should stop striving to make the world accessible for everyone. But it does provide one more option to help us deal with some of the hurdles some of us face every day. No longer will stairs be an impassable obstacle; no longer will we hear, “We’re just going to run upstairs, be back in a second!”

The thing that excites me the most about this chair is its potential to promote inclusion and bring freedom and independence to users. Victoria has many heritage buildings only accessible via stairs, so there are many instances this new chair would come in handy. Two of my favourite inaccessible places are Victoria’s Inner Harbour and Fisherman’s Wharf. There are many large bumps at these locations that leave regular wheelchairs at the top of the gangway. I think the stair-climbing chair could help to bypass those obstacles and get the user closer to the action—which is where I’d like to be.

After seeing this technology, I can’t help being excited about what’s still to come. I mean, if students from Switzerland can come up with this design, who’s to say what’s coming to market next? Exoskeletons perhaps? We truly are lucky to be alive at this point in time.

– Gord Rant

### “Doesn’t address the problem.”

A lot of time, effort and money went into developing this so-called solution that is only going to work for some people, some of the time. I wish all these bright minds applied themselves to building a society where a stair-climbing wheelchair wasn’t necessary.



The cost of an average power wheelchair varies a lot depending on model, but you can get away with paying about \$5,000. The anticipated cost of the Scalevo will be about \$26,000. That’s leagues above what most people with disabilities can afford to pay. Even insurance tends not to pay these kinds of prices. A previous wheelchair that climbed stairs and could balance on two wheels, the iBOT, was selling for US\$22,000, but US Medicare deemed it worth only US\$6,000 according to a 2009 story on *NBC News*. Henry Claypool, then director of the US Federal Office on Disability, was quoted in that story as saying: “The iBOT episode also sends a cautionary signal about pricey innovation. New technology requires scientific evidence that it changes users’ lives in ways existing alternatives cannot.”

I simply can’t see how the Scalevo is going to change wheelchair users’ lives in ways alternatives can’t, even if many journalists would like us to believe it would. Richard Gray in the *Daily Mail* suggested ramps will no longer be necessary. “The technology will mean access ramps and stair lifts outside public buildings and in people’s homes could become increasingly unnecessary,” he wrote.

To me, it’s putting the onus for accessibility firmly back on the individual with a disability (an ableist attitude if I’ve ever seen one), and ignoring the fact that ramps and lifts aren’t just about wheelchair users. What about the elderly woman using a walking frame? What about the parents of a child in a stroller? Heck, what about the courier delivery guy lugging a dolly-full of heavy boxes? Are they all expected to get a wheelchair that can climb stairs?

So forgive me for not being as excited about this innovation as most of the media appears to be. It’s a neat design. But it doesn’t address the problem with stairs in a way that works for most people. It’s a half-decent solution for the wrong problem. We don’t need wheelchairs that climb stairs. We need barrier-free access for all.

– Nicolas Steenhout ([www.incl.ca](http://www.incl.ca))



### Become a master chef.

Make yourself at home in ICORD's state-of-the-art accessible kitchen once a month for a free cooking class and dinner. Pick up tips for SCI nutrition and delicious meal preparation. Then gather round and dig in! Don't miss our fall cooking sessions with professional chefs and surprise guests. Classes take place monthly at the Blusson Spinal Cord Centre in Vancouver from 6 pm to 8 PM. Contact Alfiya at [abattalova@sci-bc.ca](mailto:abattalova@sci-bc.ca) to sign up or head to [www.sci-bc.ca/events](http://www.sci-bc.ca/events) for details.



### Relive a great year.

Join SCI BC members, friends, family and supporters to celebrate our highlights from the past year. This year's AGM, themed "The Great Rewind", will take place Thursday, October 22 from 6 to 9 PM at the Blusson Spinal Cord Centre. Enjoy great conversation, photography exhibits, amazing food and drinks, inspiring videos, and information about research projects! Visit [www.sci-bc.ca](http://www.sci-bc.ca) to RSVP or contact Maureen at 604.326.1225 or [mbrownlee@sci-bc.ca](mailto:mbrownlee@sci-bc.ca).



### Get musical.

The Vancouver Adaptive Music Society (VAMS) offers a wealth of free programs. Try adaptive lessons on drums, guitar, keyboards and more. Polish your music, songs, or spoken word with VAMS staff and volunteers—then record your work in a professional studio. Join like-minded peers in the VAMS community choir and reap some of the health benefits associated with singing. And learn about free VAMS concerts throughout Vancouver. Head to [www.vams.org](http://www.vams.org) for more info.

## Good Reads: *Me, Myself, and My Brain Stem Tumour*

Bayan Azizi, a 26-year-old SCI BC Peer from North Vancouver, recently published a compelling memoir that chronicles his life journey to date since being diagnosed with a tumour on his brain stem when he was just nine years old.

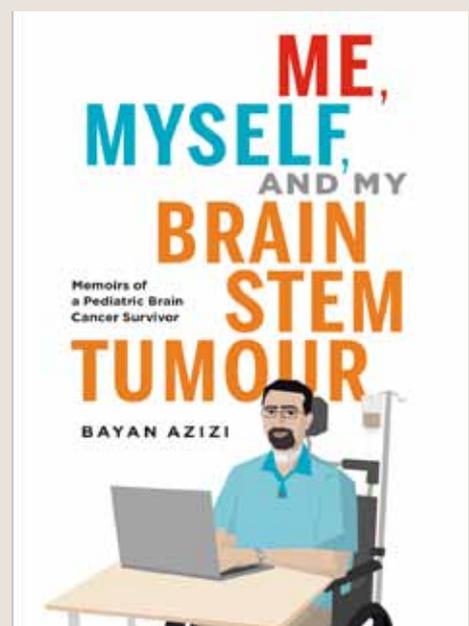
The tumour wasn't cancerous, but because it was located in such an important and easily-damaged part of his brain, outright removal was impossible. At the time of his diagnosis, Azizi was given little hope of survival. Needless to say, he defied the odds. But, as you'll learn in his book, Azizi endured much in the last 17 years—three brain surgeries, chemotherapy and radiation treatment, and long bouts of rehabilitation to regain ability. Today, he breathes through a tube in his neck, speaks with a whisper, relies on a wheelchair for mobility, regularly experiences seizures, and has limited physical ability—he can type with just one finger, which is why it took him three years to complete the book.

Azizi's tumour is in remission. But that hasn't deterred him from chasing his dreams, of which writing his memoir to date was just one. He's attending Capilano College, and also works part-time at a North Vancouver moving and storage company.

*Me, Myself, and My Brain Stem Tumour* is a poignant and sometimes humorous self-examination of what it's like to deal with such a devastating illness at such a young age. It's also a testament to Azizi's tenacity and determination.

"I hope the readers of my book will understand that nobody should be limited just because of their disabilities," Azizi told the *Vancouver Sun* in May, just after his book appeared. "There are always opportunities open for everyone, no matter what position you're in. I hope my book will help people reach their full potential."

*Me, Myself, and My Brain Stem Tumour* is published by Everywhere Now Press. You can find it in bookstores and at [www.amazon.ca](http://www.amazon.ca).



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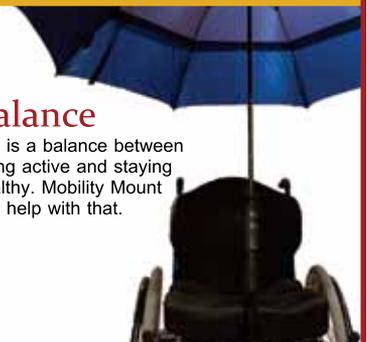
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# Treating Spasticity with Chemodenervation

Fed up with side effects from oral drugs, more and more people with SCI are turning to botulinum toxin, phenol or alcohol injections in an attempt to stem their spasticity.

But are these treatments effective?



In the world of medical research, things can sometimes get murky. In particular, when it comes to testing the effectiveness of a medicine or drug, it's not uncommon to find that dozens—and sometimes even hundreds—of studies have been completed. Dig deeper and you'll see that some studies confirm a drug's benefits, while others appear to contradict those findings and suggest there are limited or no benefits.

Enter the systematic review. Wikipedia defines a systematic review as “a literature review focused on a research question that tries to identify, appraise, select and synthesize all high-quality research evidence relevant to that question...Systematic reviews of high-quality randomized controlled trials are crucial to evidence-based medicine.”

In other words, a systematic review is a scientifically-rigorous attempt to find all completed research studies of a particular drug or intervention, and see if there's any agreement about that drug or intervention's effectiveness.

Recently, three researchers at ICORD—Jordon Lui, Michael Sarai and Dr. Patricia Mills—completed a systematic review of research studying the effectiveness of chemodenervation for spasticity in SCI.

Chemodenervation is an increasingly common technique in which a pharmacologic-

al agent—phenol, alcohol or botulinum toxin (also known as BoNT, as well as the Botox or Xeomin tradenames)—is injected in the body to paralyze a muscle or group of muscles. It's an alternative to treating spasticity with oral medications such as Zanaflex, which can often have significant side effects for some individuals.

The results of the review were published this past April in the journal *Spinal Cord*.

“The use of BoNT has been well studied in individuals with spasticity from other causes such as stroke and cerebral palsy,” explains Dr. Patricia Mills, physiatrist, ICORD principal investigator, assistant professor at UBC's Faculty of Medicine, and the review's lead author. “However, we know that the patterns of spasticity—what muscles are affected and how—that occur as a result of SCI are different than the patterns experienced in individuals with spasticity from other types of conditions such as stroke or cerebral palsy. Therefore, we wanted to understand what was the current evidence available to support or not support the use of chemodenervation agents for treatment of spasticity specifically in those with SCI.”

Mills expected to find positive results, given her own personal experience prescribing chemodenervation. “When the right person is selected, and the right muscle groups and dosage of medication for those groups are selected, I have seen generally good outcomes,” she says.

For the most part, that's what she and her colleagues found in the research studies that were included in their review. The problem, however, is that they really didn't find a lot of studies that fit their criteria—and those that did weren't completed using rigorous standards.

“The most surprising finding was that there were no high quality studies, as in randomized controlled trials, that attempted to determine whether botulinum toxin or phenol is



Dr. Patricia Mills

useful for treatment of spasticity specifically in those with SCI,” she says. “This was especially surprising since the use of these agents is fairly common practice in this population.”

Not surprisingly, the major conclusion of the review is that research in this area is sorely needed.

“A randomized, double-blinded, placebo-controlled trial would be the ideal type of study,” says Mills. “This means taking a group of individuals with problematic spasticity—spasticity that affects them in some negative way—and randomizing them into two groups. One group would receive an injection with the medication being studied, for example BoNT, and the other group would receive a placebo, or an injection without the medication being studied. These two groups would then be compared.”

The term “double-blinded” means that participants wouldn’t know whether they’re receiving the medication or not, nor would the researchers assessing the response. “This decreases the chance of a bias occurring,” says Mills. “These types of trials are the best way to determine how well a medication works or does not work for a given problem.”

She adds that, to the best of her knowledge, there are no studies of this nature, specifically using participants with SCI, underway. “This type of research is very expensive to conduct and requires a large number of participants, who can be difficult to find. This likely explains why it has yet to be conducted.”

Does all this mean that Mills will be less likely to consider chemodenervation as an option for a patient who has unsuccessfully run the gauntlet of other types of treatment?

“The answer to that question is, ‘No,’” says Mills. “Although there isn’t much published evidence, there is what we call clinical experience, and that can be just as important as what’s in the literature. From my clinical experience, I have definitely seen individuals with SCI improve with chemodenervation. The ones who tend to improve are those who have a few specific muscle groups that can be targeted, or ‘focal’ spasticity. It’s not as useful for what we call ‘global’ spasticity, where there are many muscles involved. The clinician would be able to provide an opinion as to whether or not the individual is a good candidate for chemodenervation.”

Mills offers some good advice for anyone who would like to pursue chemodenervation.

“The first question is whether the spasticity is problematic or non-problematic. If the answer is problematic, define what the problem is, and what your goal for successful treatment would be. Ask your health care provider to refer to you to a medical specialist with experience in treating spasticity—usually a specialist in physical medicine and rehabilitation. There are also spasticity clinics across the country—for example, there is the Interdisciplinary Spasticity Management Service at GF Strong—and depending on where you live, you can be referred to one of these clinics for assessment. This will allow you to discuss your options with a specialist who can provide you with information on the risks and benefits of proceeding with this type of treatment.” ■

## World’s First Accessible Food Truck?

Aleem Syed initially believed his career as a chef was up in smoke when he sustained an L1 SCI in 2008. But perseverance and an inspirational visit from renowned paraplegic chef Pascal Ribreau helped Syed realize that, in fact, he could continue his outstanding culinary career.

Syed was classically trained in French cooking at Le Cordon Bleu in Ottawa, and cooked at some of the best restaurants in North America, including Toronto’s Canoe Restaurant and BLT Prime in New York City. At the time of his injury, Syed was working at Origin North, the Toronto restaurant owned by chef Claudio Aprile of *MasterChef Canada* fame. After rehab, some soul-searching, and a visit from Ribreau, Syed soon found himself back at work, albeit sitting instead of standing, in the Origin North kitchen.

But he wanted his own business, and he decided the best way to do just that was to get into Toronto’s burgeoning gourmet food truck industry. The first step was to actually get an accessible food truck. He turned to Kashif Tejani of Curio Design Group for the design. Zoran Danilovic and Advanced Motion Industry Inc. then built the truck based on Tejani’s design.

The result is The Holy Grill, which is believed to be the first fully-accessible food truck in the world. Among its features are a retractable entry ramp, a wider passage that allows the chef to turn his wheelchair 360 degrees, lowered work surfaces, and space for his chair next to the driver’s seat.

The Holy Grill began operating on Toronto streets earlier this year, serving up gourmet eats-with-a-twist to rave reviews. Dishes include Mum’s Butter Chicken Poutine, The Holy Poutine, and Green Chilli Chicken Tacos. Everything on the menu is Halal—food that has been prepared in such a way that it’s permissible for Muslims to eat under Islamic law.

Food trucks are making a splash throughout North American cities, and BC cities are no exception. Wouldn’t it be great to see an aspiring young chef with SCI debut a similar accessible food truck here?



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# Oh, Mommy!

We have big news! Women with SCI are able to become pregnant and give birth to a perfectly healthy baby. What's more, they've been doing just that for decades.

**H**ere's a couple of interesting facts: a woman's ability to get pregnant after injury is approximately the same as prior to injury, and most women with SCI do not require any special services or procedures to get pregnant.

Still, women with SCI who are considering getting pregnant have a lot to think about—from medications, mobility, and physical wellbeing during pregnancy, to labour, delivery, postpartum and beyond. And finding information related specifically to SCI and pregnancy can be a real challenge. That's why Spinal Cord Injury BC has partnered with the BC Women's Hospital and Health Centre, Vancouver Coastal Health, and the Rick Hansen Institute to bring you a comprehensive SCI pregnancy resource. Our new pregnancy and SCI booklet, available for download at [sexualhealth.sci-bc.ca](http://sexualhealth.sci-bc.ca), highlights a number of things for women with SCI and their families to keep in mind, from preconception until after the baby is born, to maintain health and wellness for themselves and their babies.

We've been told already that the guide is invaluable. But with our long history as a "peers helping peers" organization, we also know that, sometimes, the best advice and encouragement can come from others who have travelled the same road. That's why we've asked another set of experts—mothers from our own SCI community throughout BC—to share their pregnancy adventures and anecdotes with us. Our five mothers range from complete to incomplete SCI, from new moms to second-time moms, and from an expecting mom to the mother of a young bride-to-be. They all have one thing in common: after a string of challenges, they experienced a reward greater than any of them anticipated.

## Jessica Vliegenthart (pregnant)

*“I think if you’re prepared for your life to change rather drastically without much notice, you’ll be fine.”*

As I write this, I’m 33 weeks pregnant. My due date is September 19, 2015, but I will be induced at around 37 weeks, which will be sometime at the end of August.

I’m a T9 complete paraplegic with no sensation or movement below my line of injury. I’ve been married for six years and have just established a career as a lawyer, which is a demanding field, so while this pregnancy was definitely planned I was a bit nervous heading into it because my life is jam-packed already! Obviously, I know that things will change when the baby is born, but I’m also very aware that pregnancy is a serious medical event that can result in unexpected things—which it has for me.



I knew that I would have to go off some of the medication that makes my life bearable. My physiatrist and I struggled with finding a short-term solution and I went through some very, very painful months with little to no sleep until we got it relatively sorted out. I still have a lot of pain, and sleep is elusive, but not as lacking as it was when I first went off the medication. I think if my life was a bit more relaxed, and I wasn’t working a demanding job with long hours, going off the medication would have been less of an issue because I could have adapted my days to feeling terrible. As it was, I just pushed through it.

I have no expectations for the birth process. My plan is this: Do what they tell me. I’m quite comfortable letting the docs tell me what is best. They will be giving me a prophylactic epidural to ensure I don’t become dysreflexic. I’ve never had dysreflexia before, but my doctors are worried that labour could trigger it, so better safe than sorry.

The biggest challenges I’ve had in pregnancy (so far) have been mobility changes and dealing with my bladder. Some transfers have become impossible, and it’s frustrating. For example, I haven’t been able to transfer into my SUV since 30 weeks. It’s not that I’m not strong enough, it’s that my belly is now physically in the way and I can’t lean far enough forward to make the jump. I didn’t expect my belly to be the problem, but it really is. Think of all the transfers you normally do with your stomach very close to your thighs—for me it was a lot! Now imagine you have a watermelon in between your legs and your torso. I am much less flexible and bendy than before.

My bladder has also been a challenge. I normally get Botox every five to six months to help with my neurogenic bladder. This is not an option when pregnant, so I’ve had to increase how often I go to the washroom. I won’t lie—it’s exhausting.

Aside from actually meeting our future son or daughter, I am most excited about getting my bladder back to normal!

I have only gained 23 pounds thus far. I played basketball and tennis right up to six months pregnant and would have continued, but medically could not. My appetite increased, but I continued to eat the same things I always have, so weight gain has been pretty minimal. My chair size has not been affected by this weight gain (it’s mostly in my belly).

Preparing for pregnancy was fairly simple, aside from figuring out medications—and I was prepared for that to be a challenge. I think if you’re prepared for your life to change rather drastically without much notice, you’ll be fine. As pregnancy and SCI is still rare, things can and do come up. For example, I’ve been hospitalized for observation for the past three weeks because I’ve had regular contractions. An able-bodied woman would have sensation to know if she’s in real labour, whereas I do not—so into the hospital for me.

Overall, my pregnancy was fairly easy until 29 weeks, when I was admitted to hospital. Going off the medication I had been on for 10 years was literally agonizing, but it was to be expected and occurred before I got pregnant. I think the most challenging time of pregnancy for SCI moms will be the last eight weeks, as it is for the majority of women.

As for pregnancy timing, I will do everything in my power to avoid a late summer baby the next time around. It’s very hot and sweaty. It’s also really frustrating to be stuck inside when it’s beautiful out! 🌞

*Ed. Note: On August 31, Jessica and Jon welcomed their baby boy, Remy. Congratulations!*

## Yasaman Best and Alex (three months)

*“After my first meeting with the Maternal Fetal Medicine (MFM) team at the BC Women’s Hospital, I told my husband that, for the first time, I felt included.”*

Our son was born in June—his name is Alexander Nima Best, but we call him Alex. At first, the idea of getting pregnant ter-



rified me. I was injured 13 years ago, when I was 21. My injury level is C6-C7—I’m complete mobility-wise but incomplete sensation-wise. I was worried that my SCI would hurt the baby. I was worried that my transfer, leaning forward, would hurt the baby. I was worried about how I could take care

of the baby when my husband goes back to work. I read many pregnancy books and articles, but always felt left out. None of the books answered my questions; none of the examples and information included a mother with an SCI.

Before getting pregnant, I met with sexual health clinician and RN Shea Hocaloski from Vancouver Coastal Health’s Sexual

## Shawna McCardell and Rachel (17 months)

*“I do my best to adapt and balance motherhood and rehabilitation.”*

Becoming a mother has been one of my greatest joys. While I’ve certainly faced challenges through the journey, just basking in my little girl’s smile makes it worthwhile.

Just over four years ago, I had a complete disc herniation at L5-S1 which compressed the nerves of my spinal column.



After surgery, I was left with cauda equina syndrome. Years of physiotherapy, walking aids and hard work enabled me to slowly regain most of my mobility, but I struggle daily with neuropathic pain and am unable to move quickly.

Despite the pain, I was determined to not let my disability stop me and my husband

from starting a family. Before getting pregnant, I felt I had to stop using my pain medication. It took time to recognize my limitations and find ways to manage the pain, but through the help of my doctors I managed to stay off prescription medication throughout my pregnancy.

I also expected to be pretty inactive throughout the pregnancy. While I was more limited and sore toward the end, it was manageable. A good diet and Pilates with a physiotherapist helped me stay as strong as possible.

My biggest concern was the delivery itself. Doctors felt a natural birth was too risky for my vulnerable condition, so I knew I would be having a Caesarian birth. Unfortunately, the next surprise was to learn that an epidural was also too risky, and I had to deliver under general anaesthetic. It was painful to learn that I would not be able to witness or really experience my daughter’s birth. Nevertheless, the procedure went smoothly and my husband and I welcomed a beautiful little girl in April 2014.

Life with a child has its challenges. I struggled to focus on my recovery while caring for my baby. I have always tried to predict what I would struggle with and problem solve ahead of time. For example, I was fortunate enough to have my crib modified through the Tetra Society so I could easily use it without straining my body. I was also very careful when selecting a stroller, paying particular attention to height and ease of movement.

My daughter is now 17 months old. As she gets heavier, busier, quicker and more stubborn, the challenges change, but I do my best to adapt and balance motherhood with rehabilitation. I am also lucky to have a supportive husband, family and friends for when I need time to recover—or when our daughter needs to be chased! 🏃‍♀️

Health Rehabilitation Service. She referred me to the amazing Maternal Fetal Medicine (MFM) team at the BC Women’s Hospital. I discovered that this team has so much experience with pregnancy and SCI. The doctors and nurses were completely aware of the related risks: autonomic dysreflexia, UTIs, low blood pressure and other issues. After my first meeting, I told my husband that, for the first time, I felt included.

During my pregnancy, I tried to eat healthy and stay active. Fortunately, maternity pants are easy for a quad to put on—there is no button or zipper, only an elastic waist.

The OTs at GF Strong were amazing. They help you adapt based on your limitations, so you can be as independent as possible. Danielle, my OT, even adapted my changing table, baby carrier, and baby clothes so I can do everything by myself. The Tetra Society also modified our crib so I can easily use it.

The third trimester was the hardest for transferring—you feel heavy, you can’t lean forward much, and you feel so helpless. Also, I developed a UTI, and had to be hospitalized at 34 weeks when the infection became sepsis, which was very scary.

I was apprehensive about giving birth. I have had many surgeries—including Harrington rods from my scoliosis surgery, which I had 10 years prior to my injury—and I didn’t want the birth of my son be yet another surgery.

I met with the knowledgeable anaesthesia team at BC Women’s Hospital beforehand. They told me that they must use an epidural due to risk of autonomic dysreflexia during the birth. Usually, epidurals are not effective when Harrington rods are present, but the team said they were willing to give the epidural and a C-section a try.

However, my baby decided to surprise me and came three weeks early! I was working until 36 weeks. At 37 weeks I went to hospital thinking I had a UTI and was leaking. It turned out my water had broke and that my baby was coming. Luckily, Melanie Basso, one of the nurses at the BC Women’s Hospital, had written a very detailed birth plan so there were no surprises for the nurses and doctors on call. And, luckily, the epidural worked. My son was born eight hours later by natural birth, with the help of forceps.

The moment my son was born, my life changed forever. I know it won’t be a cakewalk but I feel incredibly lucky to have the support of my loving husband, Robert, and my family. Robert, who I met four years after my injury, has accepted that he will have more responsibilities: midnight diaper changes, helping with the baby, doing chores around the house. I’m fortunate to have a supportive partner to be there for me emotionally and physically. And I’m grateful to have a mom and dad who went above and beyond to help me during my pregnancy, and continue to do so now that Alex is born.

I’m also so lucky to have access to such incredible health professionals, including Dr. Stacey Elliott and the team at the Sexual Health Rehabilitation Service, the Maternal Fetal Medicine team, and the incredible OTs at GF Strong.

Being a mom is the most amazing experience. 🏡

## Karen Hodge and Colin (6) and Laura (2)

*“After my first pregnancy, I vowed that other moms shouldn’t have to experience the same uncertainty and isolation that I had felt.”*

I always wanted to have children. Like many couples, after a few years together my husband and I decided to start a family. Unlike most people, I have lived with an SCI since I was a teenager, when I developed an arteriovenous malformation in my spine. Fortunately, I’m pretty determined, and strive to live my life to the fullest. Pregnancy for me was the next step on this journey.

Prior to becoming pregnant, I was excited and eager to learn as much as I could about pregnancy and any special considerations related to my SCI. My friends were all easily finding



fertility and pregnancy information online, so I figured I would have the same experience. However, I soon discovered there was very little information available. I began to feel quite isolated and alone. Most health care professionals I spoke to had very limited information.

Fortunately, I am happy to say I am now the proud mom of two healthy children—one boy and one girl. Both pregnancies had their challenges, but I loved the feeling of the babies kicking and growing in my belly. And, in the end, I did not require intrusive interventions to help either of them enter safely into this world.

After my first pregnancy, I vowed that other moms with SCI shouldn’t have to experience the same uncertainty and isolation that I had felt. I contacted the various professionals I’d met who had the most clinical experience in this area. Together, we created the SCI and Pregnancy Perinatal Interest Group, of which SCI BC is a participant. This small, dedicated group of individuals has worked hard to help increase knowledge and raise awareness. We hosted a full day workshop for interested health care professionals, researchers and women with SCI, created a YouTube video to raise awareness that pregnancy after SCI is possible (<http://goo.gl/78LVFr>), and published a client-oriented brochure and information booklet ([www.sexualhealth.sci-bc.ca/scipregnancy](http://www.sexualhealth.sci-bc.ca/scipregnancy)).

So how do I find the time to reach out to other women with SCI while juggling work, raising two kids, and trying to find time for the occasional date night with my husband? I do this work in the hopes that women who are thinking about pregnancy will realize that they can do it and that they are not alone. Motherhood is an amazing rollercoaster journey of excitement, fear, joy, frustration, and love. If you decide to become a mother, there are many of us that would like to welcome you to the crazy world of motherhood and we are more than happy to help show you the ropes. 🛖

## Christie Ewen and Alaura (25)

*“The funny thing is, when they handed me my baby girl, I felt no pain at all.”*

I’ll never forget the day that we found out that I was pregnant—I was overjoyed!

It was really a great pregnancy. Moving around wasn’t an issue as I’m a T12 paraplegic. I spotted once in my first trimester and once in my third. Both times I went to the hospital to have an ultrasound. Other than that, we did all the usual stuff: we went to the OB/GYN monthly for check-ups and did prenatal classes with other expecting parents, which was fun!

On January 19, 1990 at 4 PM we packed up and went to the hospital. Unlike most of my pregnancy, my baby’s birth was hardly a smooth ride. She had decided to present herself in brow position, with the largest area of her head trying to fit through my pelvis. My doctor tried a suction vacuum to bring my baby’s head down. That didn’t work, so then he tried forceps—but he didn’t want to risk injuring the baby. So, after having had such a perfect pregnancy, I had to have an emergency C-section.



The anaesthesiologist gave me an epidural, which unfortunately didn’t work due to being a T12 paraplegic. I could feel a lot of the C-section. At 9:13PM, our baby girl was born. But, after the baby was delivered, I started to bleed and had to have a blood transfusion. The funny thing is, when they handed me my baby girl, I felt no pain at all. It was an amazing experience, even though I had to stay in the hospital for five days (until you have that celebratory BM, you can’t go home).

When I was in the hospital, I tried carrying the baby laying down on her back on my lap. But she sure didn’t like it! So I found a nice wide cloth belt that I could tie around my waist with the baby in a sitting position, and she seemed to like it right from the start. She was able to hold her head up, my strong little baby. I had bought a sling—a large piece of cloth that goes over your shoulder and hangs down the front just like a hammock for the baby—and this worked perfectly. It’s a great place for the baby to sleep close to your body, and I was able to wear it inside my coat—fortunate, as she was born in January.

Our nursery was set up with a crib bassinet and changing table. My husband made the change table so that I could roll under to get good and close for changing diapers and bathing our baby in a portable bathtub. I was able to pick our baby up easily from the bassinet, and we kept it near our bed so it was easy to lift her, change her, and breastfeed her from our bed. As she got bigger, and it was time to put her in her crib,

I always made sure she wore a snug-fitting sleeper so that I could reach over and pick her up using the material over the chest. She was used to this and never put up a fuss.

There is a support group called La Leche which helped to teach me how to breastfeed. Learning how to breastfeed correctly was wonderful as it omitted the use of all bottles. However, there is definitely a knack to learning how to breastfeed properly.

Our baby girl, Alaura Grace, began using my wheelchair to pull herself up at around six months, so we taped foam rubber on my foot pedals and the sidebars of my wheelchair so that she would not bang her face. She walked very early because of this, which was wonderful because she just followed me

around. Alaura never ran away from me like so many people had warned me about. She just seemed to know that her mom was a little bit different than other moms.

As far as raising a child and having a family goes, it was no different for us than any other AB family. We camped, we hiked, we skied, we snowboarded, we played soccer, and we swam. Alaura is 25 years old now and recently engaged to a wonderful young man. Boy, does time fly! 

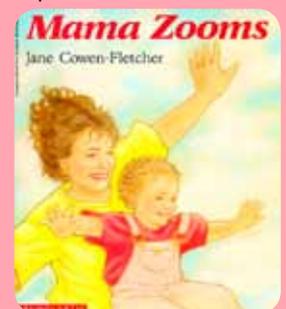
*For more info on how to modify your crib, change table and other baby necessities, visit the Tetra Society at [tetrasociety.org](http://tetrasociety.org). Plus, learn what SCI mom Karen Hodge wishes she knew before she got pregnant on our blog at [sci-bc.ca/stories/blog](http://sci-bc.ca/stories/blog).*

## PARENTING HACKS from our featured moms

- **Don't attempt to be alone** with your fragile newborn in the first eight weeks—you'll exhaust yourself trying to keep them (and yourself) safe. Accept help until they're bigger and stronger.
- **Modify your crib** to include an opening on the side. A sleigh bed can also allow you to slide your little one up and over the edge without having to fully lift them or worry about sharp edges.
- Don't be hard on yourself if you are **unable to breastfeed**. Consult your care team about whether breastfeeding is possible given your level of SCI and explore breastfeeding support services. Regardless of feeding method, talk to your support team about how to continue to encourage a positive feeding and bonding experience.
- **Get a co-sleeper** (bedside bassinet) so your baby is within arm's reach at night to minimize transfers.
- **Use wraps or ring slings** to hold and carry your newborn, or to feed them and put them to sleep on your chest. (Just make sure that your baby is in a good position to breathe!)
- **Keeping your baby's soother in your bra** keeps it warm, clean and accessible.
- **Get a double stroller** so you can go for walks with other new parents—both babies go in one stroller that the AB pushes!
- Pay attention to the **height of your stroller seat**—the higher up the baby sits, the easier it is to move them in and out.
- Consider **bathing your newborn in a salad or chip bowl** on the dining room table.
- Don't bother with an **infant car seat that can come out of the car**—it's too heavy and awkward to move.
- Instead of buying a change table, **opt for a simple table or computer desk** with height-adjustable legs, topped with a cushioned waterproof pad.



- If you're ambulatory, **set up a change table on your main floor** to avoid carrying your baby up and down the stairs.
- **Use a BabyBjörn** to safely strap your bigger baby to your chest, with the baby facing forward and their legs resting on your lap. Undo and fold down the top straps as your baby grows.
- Once the baby has good head and neck control, **dress them in overalls to pick them up easier**. If the straps aren't secure enough, sew them on!
- Learn to **change wet and dirty diapers with your baby sitting on your lap**. You'll be glad to avoid public change rooms in odd locations, where the tables are often too high (and germ) anyway.
- Instead of a Jolly Jumper, **consider an Excersaucer**. Your little one can still move and play, but it's easier to lift and slide them out.
- When they're big enough to walk and explore, let your child roam in a **backpack that has an attached leash**.
- Can't lift your children into their car seats? **Encourage them to climb up and in on their own**, or dangle a small toy or a snack above the seat to give them that extra push.
- **Keep a playpen close to the bathroom** so you can still see your child with the bathroom door open.
- Need a good bedtime book? **Mama Zooms** tells the story of a small boy and the adventures he shares with his mom, who uses a "zooming machine" wheelchair.





## Do you want to enhance your wheelchair skills?

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# Driving Your Way

Access Driver Rehabilitation specializes in helping people with high level injuries get back behind the wheel, thanks to the most innovative electronic driving system available. Not only that, they'll bring driving assessment and training services right to your door.

The husband and wife team of Dean and Dianna Robertson believes everyone should have the opportunity to get back behind the wheel after an SCI—and that includes people with high level quadriplegia.

“Over the years, we’ve met many individuals who were either told or assumed that they couldn’t drive,” says Dean, who, along with Dianna, owns and operates Vancouver-based Access Driver Rehabilitation. “Often, the key to enabling their independence in driving is finding creative solutions. We pride ourselves on thinking outside of the box with the goal of finding ways to overcome physical barriers. One question we’re often asked is if sip and puff driving is possible; to the best of our knowledge, it’s not. However, if you’re able to use one extremity to operate a joystick on a power wheelchair, you’re likely a candidate for driving.”

Through a combination of professional accreditation, decades of experience, a significant investment in technology, and a new “we’ll come to you” business model, the Robertsons are uniquely qualified to bring anyone’s driving dreams to reality. While Access Driving Rehabilitation has been in existence since 2012, the company has recently retooled—it’s purchased one of the world’s most state-of-the-art electronic driving systems installed in a new accessible van, and adopted a new focus on offering assessment and training services in a client’s own community, regardless of where they live in BC, Alberta or the US Pacific Northwest.

Many readers will recognize the Robertsons. Dean, who has been a Certified Driver Rehabilitation Specialist (CDRS) since 2002, worked as the coordinator of the Driver Rehab Services at GF Strong Rehabilitation Centre from 2007 until last November, when he moved full-time to Access Driver Rehabilitation (he’d been more or less part-time until that point). Dianna, who has had her CDRS designation since 1997, had been the company’s principal employee until 2013, when she graduated from the

UBC Law faculty and began working as an injury lawyer at Murphy Battista LLP in Vancouver. Dianna is also an occupational therapist—in 2009, she graduated from Dalhousie University with a Masters of Research in Occupational Therapy, with her thesis in the area of driver rehabilitation. Today, she works primarily as a lawyer, but still works part-time in the couple’s business, restricting her involvement to clients who have not been referred as a result of litigation. She’s also the driver rehab module instructor at the UBC Faculty of Medicine’s Occupational Therapy Program.

“It’s funny how things have worked out,” says Dianna. “Dean and I have pretty much switched our work schedules. He recently left working regular hours and I’ve gone back to it! But we both embrace change and challenges, as this is what keeps us on our toes and in this dynamic area of practice.”

Dean admits it was difficult to leave his position at GF Strong, but he has no regrets.

“I have a great deal of respect for clinicians working in the public system who really want to help individuals with disabilities, but there are structural pressures that can be challenging to work within,” he explains. “For example, working regular business hours didn’t allow us to meet the needs of clients who weren’t able to travel to Vancouver or who might be best served by an appointment on a weekend. Over time, I realized that the opportunities to use my skills with complex clients and expand my expertise were limited at GF Strong, due to program constraints and aging equipment.”

With Dean’s decision made to work exclusively within Access Driver Rehabilitation, the couple then took a long, hard look at how to move forward.

“We’ll continue to provide services to a wide range of individuals,” says Dean. “Essentially, anyone with a functional impairment that impacts their driving or community mobility in a vehicle may benefit from our services. We’ll continue to provide services to paras and those with incomplete SCI. That said, we will

be focusing on making people with higher levels of disability a priority.”

Dean explains that, after the GF Strong van became obsolete about six years ago, the wait list of individuals for van training continued to grow—but funding for a new van wasn’t on the horizon.

“This group of clients is a small portion of the overall driver rehab population, so there’s been little incentive for private companies or rehab centres to invest in this type of capital equipment that requires frequent updating,” he says. “Dianna and I felt so strongly about the need to provide services to these individuals that we threw caution to the wind and decided to borrow against the equity in our home and invested over \$100,000 in a high tech assessment and training van. We believe our clients are worth it.”

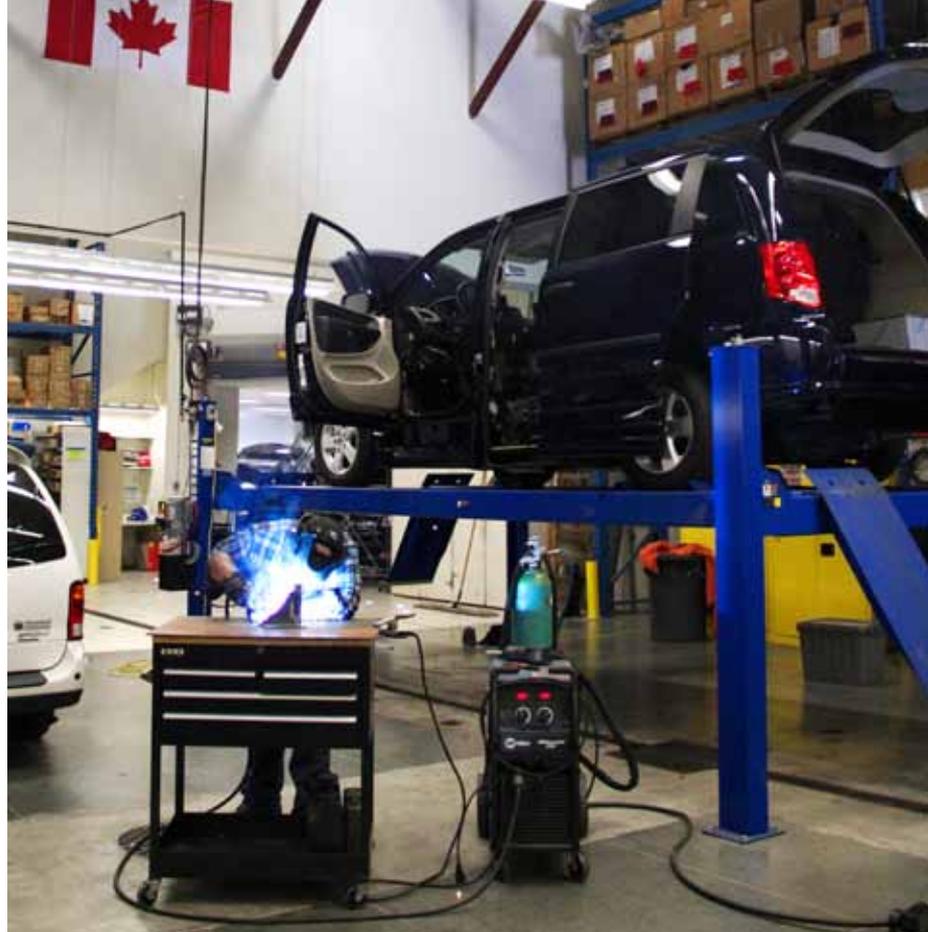
In June, the couple received a huge vote of confidence when GF Strong confirmed it will begin to refer its complex van clients to Access Driver Rehabilitation. “We’re pleased that they recognize our expertise in this area,” says Dean.

During August, as we were preparing this issue of *The Spin*, Dean was working hard to operationalize the centerpiece of the retooled business—a newly purchased Dodge van, modified with a Braun conversion that features a side ramp entry system and lowered floor. Completing the van will be a Joysteer electronic driving control system—a state-of-the-art “drive-by-wire” system made in Switzerland that allows people with minimal hand function to control a vehicle with a single joystick.

“I first drove the Joysteer system at a driver rehab event in Columbus, Ohio in 2013,” says Dean. “I thought it was very innovative and would be great for many of our clients. When I made the decision to work full-time with Access Driver Rehabilitation, I knew I wanted the Joysteer system in an accessible van that would accommodate as many different individuals and sizes of wheelchairs as possible. Our assessment van is an extra tall version, which means that it will accommodate the bigger and taller clients. We’ll also be using the Joysteer



*TOP: The Joysteer technology is complex, but the end result for the driver is an incredibly simple interface that can be used by people with only minimal ability. RIGHT: The Robertsons' new wheelchair accessible van is being outfitted with the Joysteer system at the Shoppers Home Health Care Automotive Division shop in Burnaby.*



voice activation system for secondary controls in our new van.”

In July, Dean attended an Association for Driver Rehabilitation Specialists (ADED) conference in Louisville, Kentucky, where he obtained certification in the Joysteer system. In early August, a team of Joysteer technicians made the trip from Switzerland to oversee the final installation of the system in the Robertsons' van. They also provided more intensive training for Dean and Dianna, along with Larry Bowen, the former Driver Rehab Coordinator at GF Strong Centre for over 30 years, who will also be able to prescribe the system.

Both Dean and Dianna also have practical experience and certification in the popular EMC driving system, and are able to recommend either system depending on the needs of the client.

As for other equipment, Dean and Dianna use assessment tools that are consistent with the standards of practice of ADED, and update these on a regular basis to stay current with research. They also have a wide selection of driving aids and equipment demo units, three styles

of manual hand controls to choose from, and several options for accessing the secondary controls.

“Sometimes it’s the small details,” says Dean, “like using our ROHO cushion designed for vehicles, or choosing the right style of steering aide, that can make a huge difference in function for driving.”

Along with the new van, the company has another modified vehicle, a Cadillac CTS Sedan, which is used to assess and train drivers with lower levels of disability. The company also has a Honda Scooter and several hybrid bicycles which are used for assessment purposes, and has business relationships with truck and motorcycle driving schools for clients who need these assessments.

In addition to comprehensive functional driving assessments and training, the company offers a range of other services: equipment and vehicle modification assessments, driving anxiety desensitization treatment, commercial driving assessments, motorcycle driver assessments, adapted equipment recommendations, wheelchair securement training for organizations, and functional

cycling assessments for injured cyclists. The assessment clinic is located in the King Edward Mall across the street from GF Strong in Vancouver, BC.

Dean concedes that accessing driver rehabilitation services can be tricky—which is why he’s also made a commitment to help people learn to navigate the system.

“There are complex and interdependent issues that need to be considered,” he explains. “Specific forms often need to be filled out by the client’s physician, there are medical and assessment requirements from RoadSafetyBC, and there are licensing and road test requirements through ICBC. This is why we offer free educational seminars about once per month at our clinic. These seminars provide information to individuals and families, so that they can proactively and efficiently navigate the system.”

If you’re living somewhere outside of Vancouver, Dean will arrange for you to attend via Skype.

And then there’s perhaps the greatest hurdle of all—figuring out how to pay. “One of the biggest challenges is funding,

not only of the assessment and driver rehab, but also of these vehicles and equipment,” says Dean. “The more high tech, the higher the cost. The reality is that these types of vehicles are much more prevalent in the USA, where there’s funding through vocational rehab services, and a much larger population base. In Canada, we access funding from ICBC, WorkSafeBC, Road-SafetyBC, private individuals, service groups, and lawyers. Where we receive a referral at the request of RoadSafetyBC, they will sometimes fund the cost of the assessment. There are also government programs such as WorkBC and Technology@Work which may provide funding for equipment and modified vehicles—applications are available at the Neil Squire Society.”

Regardless of who pays, Dean says the first step is to learn more about your options.

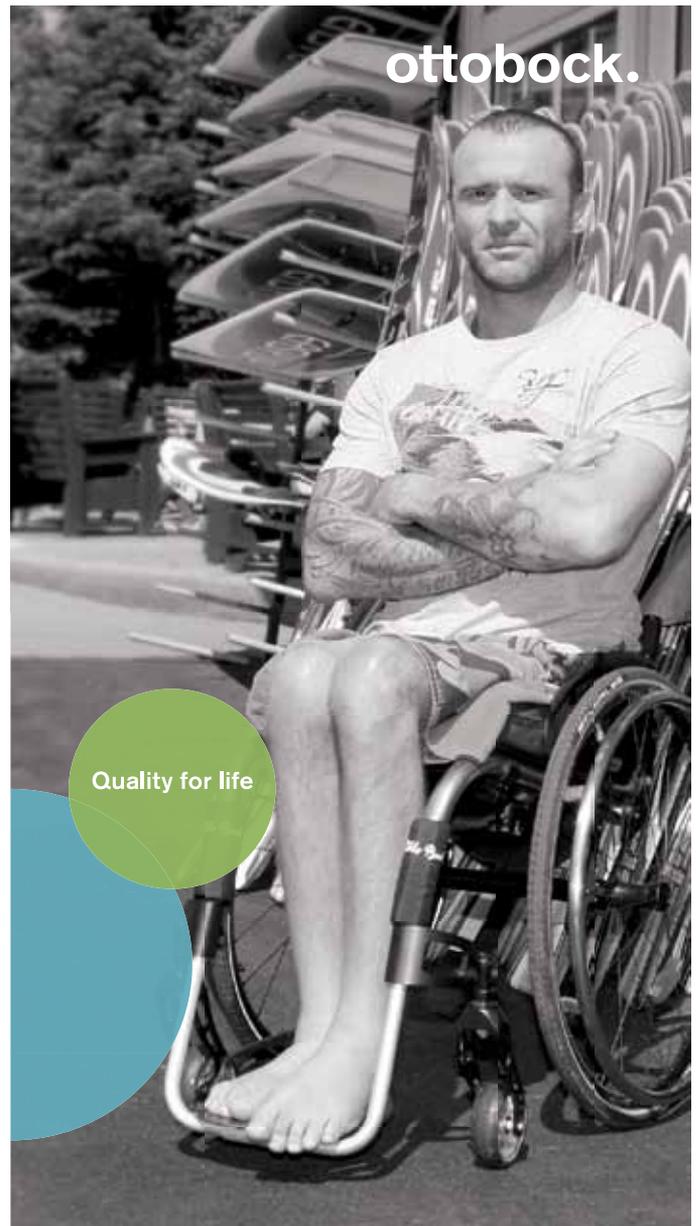
“We invite people to take a look at our website for more information and to download a referral package. We can also be reached by email or phone. If people call our office, please leave a message, as we are often out with clients during the day, and typically return calls in the evening.” ■

*For more details, visit [www.AccessDriverRehab.com](http://www.AccessDriverRehab.com), email [AccessDriverRehab@gmail.com](mailto:AccessDriverRehab@gmail.com), or call 604.263.5218.*

## Driving and Buying: Avoid These Blunders!

With some 35 years of experience between them, Dean and Dianna have seen people with disabilities make many mistakes during the process of getting behind the wheel. Here are some of the most common:

- **Failing to contact a certified driver rehab specialist early in the process:** “Even if it’s too early for an assessment, guidance can be provided early on to avoid the common pitfalls that we see when we’re brought into the process later on,” says Dean.
- **Delays in licensing:** “We recommend that a new driver take their Class 7 learner’s test for driving as soon as possible, as they often face a one-year wait until they can take the Novice Road Test in a modified vehicle,” says Dianna.
- **Wrong vehicle purchased too soon:** “We recommend that a Vehicle Modification Assessment be conducted before an individual or their family purchases a vehicle for ‘transport only’ or if the vehicle is purchased before the client’s recovery has plateaued,” says Dean. “If the wrong style of vehicle is selected, this vehicle may not end up being suitable if the individual progresses to the point where he or she may be a driver. If a vehicle is purchased before the client obtains their permanent wheelchair, there may be issues with the chair not fitting on the ramp or in the vehicle or with head clearance.”
- **Internet purchases:** “We don’t recommend that people purchase equipment or vehicles over the internet—particularly from out of country,” says Dean. “There are often issues with importing equipment and vehicles into Canada, as they do not meet Transport Canada requirements.”



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research ■



# Soft Touch

Harvard researchers have come up with a fresh, softer take on the robotic glove.

**W**e've been writing about robotic gloves since the early nineties, when researchers at the University of Alberta debuted the Bionic Glove, a wearable but somewhat clumsy powered device that gave people with quadriplegia the ability to grip and grasp.

Despite the promise of this device and others like it, and despite the fact that people with quadriplegia have repeatedly identified restoration of hand function as a top priority, there's been little progress in bringing an affordable and effective robotic glove to market.

Recently, a team of engineers at the Harvard John A. Paulson School of Engineering and Applied Sciences (SEAS) and the Wyss Institute for Biologically Inspired Engineering debuted a new, promising robotic glove that could finally yield a solution for the masses.

What separates this new glove from previous efforts is the type of robotic actuators it uses. Older gloves have made use of "hard robotics" that rely on electric actuators to move the fingers with rigid connecting rods and joints. In contrast, the new glove developed at Harvard makes use of the rapidly developing field of "soft robotics" that offer lighter weight, greater comfort, and more precise and natural grasping movements.

"Soft robotics is a rapidly growing sub-field of robotics, and our application is an example of how the technology is useful for applications when robots need to intimately interact with people," says team leader Conor Walsh, Assistant Professor of Mechanical and Biomedical Engineering at SEAS, founder of the Harvard Bidesign Lab, and a core faculty member at the Wyss Institute. "Our goal is to use soft materials, and this brings a number of benefits. It makes the device very easy to fit and adjust to the human hand, and thus, when assistance is applied, it's very comfortable for the wearer."

The core component of the soft robotic glove is a silicone tube that, when pressurized with fluid or air, bends in the same approximate way as the fingers and thumb do when grasping.

“Basically, we mold silicon tubes or balloons and add specially-patterned reinforcements with Kevlar fibers and other inextensible sheets that cause them to take particular shapes when inflated,” explains Walsh. “Normally, when we force air into the silicon tubes, they would just expand equally in all directions. But adding the reinforcements allows us to mechanically program the actuator so it gives the desired motion and force when pressurized.”

The tubes are designed and manufactured to mimic the size and range of motion of each individual finger and the thumb. They are then sewn into a easy-to-don glove. The tubes are each connected to small hydraulic supply hoses which, in turn, are connected to a small battery-powered compressor and controller. When fluid is pumped into a single tube, the finger or thumb attached to it within the glove performs a grasping or pinching motion. When fluid is pumped into all tubes, all fingers and thumb perform the grasping motion. When the pressure is released, the fingers and thumb relax to the original, open position.

“We’re not trying to overpower the person,” says Walsh. “We’re trying to put a light, flexible actuator on them that, in this case, when it’s pressurized, has kind of a similar motion to the one they would be trying to

do (if they weren’t paralyzed), so it works naturally and synergistically with them. The way I think about soft robotics is that it really opens up new possibilities, new market



opportunities, and new application areas where you’re not looking to fully support people—you’re not looking to help a paralyzed person stand up; you’re not trying to help someone carry two hundred pounds. Instead, you’re asking, ‘How do I use this small and flexible robot that can move but not apply too much force, and find application areas where it could actually be beneficial for people?’ It’s those small types of gains that lead to big functional improvements for people that allow them to be more independent and lead to a higher quality of life.”

The glove’s beginnings date back about four years, when Walsh, who is originally from Ireland, completed his Ph.D. in mechanical engineering at MIT and moved into his current positions at Harvard. While at MIT, Walsh was extensively involved in hard robotics and exoskeleton research. But by the time he went to Harvard, he had become convinced of the superiority of soft robotics for specific applications. Inspired by the work of soft robotics pioneers George Whitesides and Rob Wood, he set out to find suitable real-world applications for the rapidly emerging technology. He and his team made it a priority to get out of the lab and engage people with disabilities in their own homes and communities to see how soft robotics could make an impact in their lives.

They quickly confirmed that hand function was a top priority for people dealing with quadriplegia, as well as those with stroke or muscular dystrophy. Walsh believed that soft robotics could help, and,

as part of one of his classes, he and his students developed an early glove design.

That early prototype was continuously refined to make it feel more comfortable and natural to users. Over several iterations of design, the actuators were made smaller and modified to distribute force more evenly over the wearer’s fingers and thumb. The ongoing dialogue with people with disabilities continued throughout this process—Walsh was adamant that this was vital to ensure the glove would be useful and easily accepted, rather than being an esoteric device developed in a lab that would ultimately fail to be embraced by consumers in the real world.

One outcome of this consultation was the team’s realization that users wanted the glove to not just work well—they also wanted it to look good.

“They’re always very excited about it, but they also want it to look cool,” says Walsh. “But with these technologies, it’s a trade-off between how much benefit does it give you, versus how does it look, versus how difficult is to use and interact with. If something gives you amazing abilities, you’ll sacrifice more of those other things. It’s always about trying to get that balance right between cost and benefit.”

It appears that Walsh and his team have found that balance. Not surprisingly, they’re optimistic about the possibilities of making a finished glove available on a wide-scale basis.

“We’re already seeing a lot of exciting proof-of-concept experimental results,” says Walsh. “My research group focus-



Conor Walsh

es on developing technologies that we believe have the potential to be commercialized and brought to patients and clinicians in the future. This project falls into this category. Of course, right now, we just have a proof of concept device where we have demonstrated that the technology can help a patient grasp objects, and much work remains to have the device robust enough for much wider use. So at the moment we have an engineering team focused on refining the technology, which we then hope to use to do a ten-patient pilot study within a year. If we're successful, then we'll seek a commercial partner who will then help take the device to market."

Refining the technology, adds Walsh, will focus on three areas. The first is to make it even smaller, lighter and more comfortable. The second is to develop new actuator designs that are able to deliver more force, allowing a user to grip heavier objects. And finally, a more streamlined method of controlling the glove is a top priority.

At the moment, the glove is controlled by a portable, lightweight switchbox that can be worn using a waist belt or attached to a wheelchair. But manually switching the glove's various grasping functions can be cumbersome—particularly for someone who already has difficulty operating a switch because of the very limited hand function that the glove is designed to overcome. That's why Walsh and his colleagues are working on control strategies that will allow the system to detect the wearer's intent and activate without manually flipping a switch.

"We're still exploring what is the best way to detect the intent of the wearer," says Walsh. "One potential solution is to leverage surface electromyography (EMG) using small electrical sensors in a cuff worn around the forearm. The electromyography sensors detect residual muscle signals fired by motor neurons when the patient attempts a grasping motion, which would be used to directly control the glove."

At the time of writing this issue of *The Spin*, the team's EMG control work was being presented at the International Conference on Robotics Research in Singapore, where it captured the best paper award. We'll explore this work further in a future issue.

Down the road, and beyond the immediate goal of commercializing the device and making it widely available to people who could really use it to enhance their independence, the team is interested in developing it into a rehabilitation tool to improve hand function in people with a wide range of disabilities. And Walsh also believes that the glove could eventually lead to development of soft robotic systems that aid impaired elbow and shoulder function as well.

For more information, search YouTube to view the excellent videos that Walsh and his team have produced to explain the soft robotic glove and showcase it in action. You can also learn more about Walsh and his research by visiting [www.seas.harvard.edu/directory/walsh](http://www.seas.harvard.edu/directory/walsh). ■

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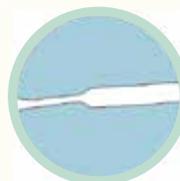
### Bulges

in the urethra prevent an easy passage of the catheter and increase the risk of injury.



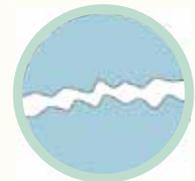
### An enlarged prostate

or a spastic sphincter make passing the catheter into the bladder even more difficult.



### Strictures

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# If I Knew Then...

Eight years ago, she woke up a cheerleading, softball-playing, running 15-year old. By that afternoon, all of that had changed forever. Nearly a decade later, quadriplegic athlete, model and cupcake baker extraordinaire Jessica Kruger shares what she wishes she'd known from the start.

## “You’re never going to walk again.”

It’s a line that many of us in the SCI community have probably heard. Seven words that, when combined together, have the ability to flip your life upside down and leave you feeling broken.

When I first heard those words I had just turned 15. I was lying in intensive care, and wasn’t ready to hear them. At the time, I was still in shock, surrounded by a frenzy of beeping monitors, frantic nurses and devastated faces—I didn’t know what to think.

When the morphine haze wore off and the hours stopped merging together, I began to consider the impact of those words. At first I took it as a challenge—“I’ll show you!”—and spent the next five months focused on the one baby toe that I could wiggle. That toe was hope for me in the beginning. But hope soon turned to frustration, and I didn’t understand why my hard work wasn’t paying off.

I was injured in a fall—I fainted at the top of a 20-foot ladder while painting a house—at the end of June, and I had Softball Provincials coming up at the beginning of August. Up until the last week of July, I was 100 percent convinced that I would be “up and running” in time to play.

But the realities conflicted with the idealizations. And the one toe didn’t lead to all ten of them following suit as I had intended it to.

After I realized that I wasn’t going to be “okay” in my own interpretation, I focused on being “okay” in everyone else’s definition. I worked on getting stronger to satisfy my physio, did hand exercises to reassure my occupational therapist, put a smile on to convince my family, and cracked jokes to distract my friends. Maybe I could persuade everyone else that this wasn’t really happening, and

then I wouldn’t have to acknowledge that it was.

I thought that it had worked: over time I forgot that I had been acting and began to believe that I was living. I returned back to high school, got involved in wheelchair sports, volunteered, got a boyfriend, spent time with friends and family, and everything seemed “normal.”

I was always busy, rushing from one place to the next, barely able to keep up, let alone stop and think. One day, after a series of days feeling very unwell, I woke up with a collapsed lung and was rushed to the hospital.

Once there, I was put on a ventilator and moved to intensive care. The doctors explained that my persistent cough was actually a symptom of pneumonia, and neglecting the symptoms and lacking the diaphragm muscles to clear my lungs had led to a large amount of phlegm buildup, which ultimately caused the collapse of one lung.

I drifted in and out of consciousness over the next three weeks and began to question the “I’m okay” mantra I had been living by. I wasn’t okay. I was a 17-year-old quadriplegic lying in a hospital bed, relying on a machine to help her breathe, and all I really wanted was to get out in time for my high school graduation.

Fortunately, I did get out in time to don my black and white mermaid-fit gown and join my classmates in crossing the stage, allowing me to once again slip back into a content oblivion.

It wasn’t long after graduation that I contracted a UTI. I went to the doctor, took a bout of antibiotics and attempted to carry on with my life. A week after the first infection came another, and then another after that and more after that. This string of infections lasted nearly three years, and throughout that period my body grew resistant to all oral antibiotics, which meant that I was forced to go in for IV treatment every time I had a new infection. The meds not only stole my time, but also my energy, once again interrupting the comfort of the denial I had so masterfully constructed.

During that time, I hit my rock bottom. I found myself in a place of self-pity, anger, frustration, and confusion. I asked myself the question that had been lingering just beneath the surface for nearly

three years: “Why me?” There was no answer, but that was okay, because it was the question that allowed the realizations that led to the healing. I didn’t want to pretend to be happy anymore—I wanted to genuinely feel happy.

Slowly, with time, I began to acknowledge that I was likely never going to walk again; rather than devoting my energy to pretending I wasn’t really in a wheelchair, I began to accept that I was. Previously I had believed that socializing with other people in my circumstance was admitting defeat, but now I was ready to give it a chance. I dedicated myself to wheelchair rugby, spending hours and hours a week with my teammates. I listened to them gossip about everyday “quad problems” and rather than cringing in fear that someone walking by might overhear, I was relieved to know that I wasn’t alone.

Eventually my friendships with my fellow quads and teammates grew stronger, and they pushed me to be more independent. With time I learned to transfer from my day chair to my rugby chair without help, traveled with the team without a friend or family member for back up, and traded my ramp van in for a car. I didn’t realize it was happening, but being surrounded by independent, successful, driven men and women in chairs changed my percep-

tions. I was proud to be a part of this community, and owe them for the confidence that I now have.

Looking back on that day eight years ago, I wish I could tell myself everything that I know now. I wish I knew what I was capable of, that the accident was going to make me stronger and leave me so much richer. I wish I knew that one day I would wake up and forget that I was supposed to roll over and walk to the bathroom, that I was still going to be able to travel and see the world, just in a slightly different way and with a whole lot more adventure.

I wish that I knew what having an SCI really meant. I wish I could have understood the perks—no, not the prime parking or shorter lineups, but the friendships, the community, and the satisfaction and pride that come years later in a moment of reflection. This life, with all of its highs and lows, is the one that was meant for me, and I am grateful to be able to live it. ■

*Are anniversaries important to you? Do you do anything special every year to mark the date of your injury? Take our anniversary poll at [sci-bc.ca/poll](http://sci-bc.ca/poll). Plus email us at [thespin@sci-bc.ca](mailto:thespin@sci-bc.ca) to let us know what you wish you had known from the start.*

*LEFT: Celebrating my graduation from Simon Fraser University with a BA in English. MIDDLE: Through quad rugby, I have found friendship and fitness—and renewed my competitive spirit. RIGHT: In 2013, I became the new face of Lise Watier’s “Something Sweet” perfume.*





# Instant Diagnosis

## PART TWO

A new handheld scanner can diagnose pressure ulcers long before they can be seen on the skin, when they can still be easily treated.

In the last issue of *The Spin*, we told you about a diagnostic device being developed locally at ICORD that can instantly detect the presence of a bladder infection.

In this issue, we provide further proof that Dr. “Bones” McCoy’s famous tricorder diagnostic scanner is indeed moving from the fictional universe of *Star Trek* to reality. Bruin Biometrics (BBI), a California-based company, has recently commercialized the SEM Scanner—a unique device that appears to effectively detect the pres-

ence of a pressure ulcer in its early stages, long before it appears on the surface of the skin.

Pressure ulcers, also known as pressure sores or bedsores, result after prolonged pressure cuts off the blood supply to the skin. Pressure ulcers typically affect skin and underlying tissue that cover bony parts of the body—heels, hips and tailbone. And, as our readers well know, people with SCI are most at risk, thanks to a combination of a lack of fleshy padding in suspect areas, lack of ability to relieve pressure through frequent and sometimes unconscious

movement, and an inability to feel pain from a developing pressure ulcer.

Detected at an early stage, pressure ulcers can typically be treated by simply removing the pressure that caused them. But without early diagnosis, pressure ulcers can quickly become serious—at a minimum, they can force a patient to take weeks of bed rest, and at worst, they can become septic and deadly.

Recent estimates in the United States alone suggest that up to 2.5 million Americans are impacted annually, at a staggering cost of \$11 billion. So any device that offers a chance of early diagnosis could save a lot of health care dollars, let alone the personal suffering that the individual with a serious pressure ulcer is left to deal with.

Enter the SEM scanner—a lightweight device that, after being placed and activated on a person's skin where damage is most likely to occur, can instantly determine the presence of an impending pressure ulcer.

"The SEM Scanner is a hand-held, portable, point-of-care diagnostic tool that measures increased or decreased fluid content within the skin and underlying tissue, which is known as subepidermal moisture or SEM," says Mark Bruns, Vice President of Sales and Commercial Operations at Bruin Biometrics. "SEM can serve as a biophysical marker of inflammation that occurs prior to serious skin damage and pressure ulcer formation. In clinical studies, the SEM scanner has been shown to identify pressure-induced tissue damage—including pressure ulcers—up to 10 days before damage becomes visible on the skin's surface. In turn, early detection of pressure ulcers with the SEM scanner can lead to targeted interventions, reduced ulceration severity, early recovery, as well as reduced length of stay in hospitals."

The device is the brainchild of Barbara Bates-Jensen, professor of nursing and medicine at the University of California who was frustrated with the ineffective way that pressure ulcers are diagnosed in the hospital setting.

"Pressure ulcers are a major financial burden, not to mention the suffering of patients, and yet we still have a gold standard that looks at the redness of skin. It's just crazy," Bates-Jensen told the *Nursing Times* earlier this year.

Bates-Jensen worked with colleagues from her university's engineering and computer science departments to create a prototype scanner. With proof of concept secured, the device was then taken forward by Bruin Biometrics for further testing and commercialization, which, according to Bruns, is proceeding at full speed.

"In November of 2013, we received approval to begin marketing the SEM Scanner in European countries," he explains. "Our commercial efforts were focused initially on launching the product in Ireland and the UK. We launched in Ireland in July of 2014 and the UK in January of 2015."

In the UK, Bruin Biometrics currently has 13 Pressure Ulcer Reduction Programs operating at various hospitals and institutions, with an additional 27 scheduled to start in the near term. "There are approximately 100 devices currently committed to these programs," says Bruns. "Generally, each device is utilized on 10 to 20 patients per day, which means we are currently scanning around 1,000 to 2,000 patients on a daily basis."

The Pressure Ulcer Reduction Programs include a comprehensive evaluation process of the efficacy of the scanner. To date, the results are excellent, says Bruns. "Two UK Trusts have completed BBI's Pressure Ulcer Reduction Program and documented 100 percent reduction in hospital acquired pressure ulcers."

In addition to efficacy, these programs also seek to evaluate ease of use for the staff involved. As it turns out, the nurses involved with daily testing speak in glowing terms about the scanner's uncomplicated operation.

Armed with these promising results, Bruin Biometrics is now proceeding with a North American rollout.

"We received Canadian regulatory approval in mid-June and have begun early

market development with the intent of identifying early adopter accounts and reference sites before the close of the third quarter of this calendar year," says Bruns. "A Canadian distribution partner is being appointed at some point in August. As for the US, we are in active discussions with FDA for marketing clearance, and we're hoping to be launching the SEM Scanner into the US market in 2016."

The SEM Scanner isn't the only device being developed to provide instant diagnosis of pressure ulcers. A "smart bandage" has been developed by researchers at University of California Berkeley, and General Electric Global Research has teamed up with the US Department of Veterans Affairs (VA) Center for Innovation to develop a sensing device to assess and monitor the progression of pressure ulcers.

Like the SEM Scanner, the smart bandage appears to be able to predict a pressure ulcer long before it's visible to the naked eye. It's fabricated by printing gold electrodes onto a thin piece of flexible plastic that's attached to the skin. In contrast to the SEM Scanner, which works by detecting moisture, the smart bandage creates a spatial map of the



Lindsey Burroughs, Tissue Viability Nurse with the WWL NHS Foundation Trust in the UK, uses the SEM Scanner with a patient. (Photo: Business Wire)

underlying tissue based upon the flow of electricity at different frequencies, a technique called impedance spectroscopy. Early results have been positive, but we can't help but notice that it's intended to be applied to and left on a specific location, as opposed to the SEM Scanner, which can be quickly used to scan and evaluate all suspect areas of a patient's body.

It's difficult to find many details about the scanner being developed by GE Global Research, but the few details we managed to find suggest the device is more complicated than the SEM Scanner and uses a number of different methods to measure pressure ulcer formation or to determine if a formed ulcer is healing.

We'll look forward to hearing about these technologies, but in the meantime we'll continue to follow the SEM Scanner and its ongoing evaluation and rollout, particularly here in Canada. We're impressed with the early positive results, the fact that it's already commercialized and being used effectively in hospitals, and that it may soon be put to good use in our country.

Readers who are prone to pressure ulcers may find themselves asking, "How can I get my hands on one of these?" At this point, it's not likely. While we hope that the SEM Scanner quickly finds its way into the hands of hospitals and even family clinics, Bruns explains that it's not designed for consumer ownership and use.

"Yes, the SEM Scanner can be used in non-acute care settings as effectively as acute care settings, with as equally important improvement in clinical and financial outcomes," he says. "But at this time, the device is not considered a self-use device and requires the assistance of a caregiver."

However, he concedes that it is "very simple to use, requiring minimal technical skills for operation" and does not rule out the option of creating a home use version at some point in the future.

For more information, visit [www.bruinbiometrics.com](http://www.bruinbiometrics.com). ■

## ask the SPIN DOCTOR

*"I'm a high level quadriplegic and dread cold and flu season each year," says Brad from Vancouver. "I've heard that there may be a way to improve my ability and strength to deal with these types of seasonal diseases. Can you help?"*

*For this issue's answer, we turned to Shannon Sproule, a physiotherapist at GF Strong Rehabilitation Centre and Vancouver's Access Community Therapists Ltd. She is currently on a leave of absence from GF Strong to work in a term position as National Clinical Liaison for the Rick Hansen Institute.*



Like many people with quadriplegia, you probably have a healthy respect for seasonal illnesses because of a compromised ability to cough and clear your lungs.

Lung Volume Recruitment (LVR) Kits, also known as Breath Stacking Kits, are an excellent tool to improve your ability to manage secretions and avoid chest infections during the times of year when chest infections are prevalent. You can use an LVR kit when you're actually dealing with a cold or a flu, but it's recommended that you use it regularly as a health maintenance and preventative procedure throughout the year—even when you're healthy. Besides improving lung volume, coughing ability and secretion clearance, regular use of the LVR kits can improve your speaking volume and also help you maintain the flexibility of the trunk and rib cage.

Breath stacking consists of periodically filling your lungs to their maximum capacity, beyond what the intact muscles can achieve on their own. The LVR kits consist



of a manual resuscitator bag, a one-way valve that allows for breaths to be "stacked" on top of one another, flexible corrugated tubing, a mouth piece, and a nose clamp. While most people will use a mouthpiece or mask, breath stacking can also be done through a tracheostomy site with a special valve connection.

While LVR kits can be assembled by a knowledgeable health

professional using readily available parts, they're actually commercially available for less than \$50 from Trudell Medical International, a Canadian-based company specializing in respiratory medical equipment ([www.trudellmed.com](http://www.trudellmed.com)).

Typically, three breath stacks are given, followed by an assisted cough to aid with secretion clearance. It sounds straightforward, but I would recommend that you get taught how to use the LVR kit by a health professional (often a respiratory therapist or physical therapist) as there are some precautions and contraindications that should be screened. Some individuals can perform breath stacking by themselves, but caregivers or family members can also be easily taught how to assist with the technique. Again, it's important for people to talk to their health care providers to determine what is the best method for them to use.

A good online source for more details and instructions is The Ottawa Hospital Rehabilitation Centre's Institute for Rehabilitation Research and Development website ([www.irrd.ca/education](http://www.irrd.ca/education)). As well, Hamilton Health Sciences has a great consumer booklet called *Keeping your lungs healthy: A guide for you after spinal cord injury and other neurological conditions* that can be downloaded free online ([www.hamiltonhealthsciences.ca](http://www.hamiltonhealthsciences.ca)).

# 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, much more. In other words, it's about maximizing recovery, independence, health, and quality of life today. And 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. Please read about these studies below.

## Factors influencing physical activity behaviour—what gets people moving?

Visiting PhD student Jasmin Ma and ICORD principal investigator Dr. Christopher West are leading a survey aimed at examining factors that influence physical activity participation and the role of your physiotherapist in promoting an active lifestyle. You are invited to participate in the survey if you are 18 to 60 years old and have a chronic (more than one year) traumatic SCI. The survey takes approximately one hour to complete and compensation is provided. Location: anywhere in BC. Compensation for participation: yes. Contact: Jasmin (email: [jma@mcmaster.ca](mailto:jma@mcmaster.ca); phone 613.329.1849).



## Effects of physical activity on cardiac function in individuals with chronic SCI

ICORD principal investigator Dr. Christopher West is leading a research study to determine the relationship between physical activity levels and cardiac health in people with cervical or low thoracic SCI. Sessions include two visits, each two hours long, where measures of heart and autonomic nervous system health, daily physical activity levels, and submaximal treadmill wheeling will be taken, in addition to seven days of physical activity monitoring. If you are 18 to 60 years old, have a chronic (more than one year) traumatic SCI above T1 or below T5 and are interested, please get in touch with the research team. Location: Blusson Spinal Cord Centre; in your community. Compensation for participation: yes. Contact: Laura (email: [west.lab.icord@gmail.com](mailto:west.lab.icord@gmail.com); phone: 604.675.8809).



## CHOICES: Cardiovascular Health/Outcomes: Improvements Created by Exercise and Education for SCI

ICORD researcher Dr. Andrei Krassioukov is leading a multi-centre study on the effects of exercise interventions on the cardiovascular health of individuals 18 to 60 years old with chronic, motor complete traumatic SCI at the C4 to T6 level. Location: Blusson Spinal Cord Centre. Compensation for participation: yes. Website: [www.choicesproject.ca](http://www.choicesproject.ca). Contact: Cameron Gee (email: [cgee@icord.org](mailto:cgee@icord.org) or [choices@icord.org](mailto:choices@icord.org); phone: 604.675.8856).



## MRI Study on SCI Neuropathic Pain

Researchers at ICORD's Brain and Spinal Cord Imaging Laboratory (Drs. Kramer, Laule, Kollind and MacMillan) are conducting a study to assess damage in the spinal cord after injury and how this might influence whether or not you experience neuropathic pain (e.g. burning in the legs). The researchers are seeking participants with SCI (paraplegia or tetraplegia) between 19 and 65 years old who live with and without neuropathic pain. Location: UBC MRI Research Centre. Compensation for participation: no. Contact: Dr. John Kramer (email: [kramer@icord.org](mailto:kramer@icord.org); phone: 604.675.8876).



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)



# No More Back Doors

**Stockholm's Dignified Entrance project is creating equal access to the city's heritage sites and buildings—and a template for other municipalities to follow.**

**W**hen it comes to disability, Scandinavian countries are renowned for their inclusiveness and accessibility. As a result, they're often looked to for inspiration by other countries and governments seeking to improve opportunities for their own citizens.

Yet another shining example of this has been taking place in Sweden's capital city of Stockholm, home to the Dignified Entrance project (Värdig Entré in Swedish).

The project is an important step in addressing the problem of people with disabilities being forced to access public venues through service elevators and back doors. Important historic buildings and landmarks, in particular, have been recognized as being highly inaccessible. Enter Dignified Entrance, a collaborative project run jointly by the Swedish National Property Board, the City of Stockholm and the non-profit organisation EIDD (Design for All Sweden). The main goal of the project is to ensure that people with disabilities are able to enter these buildings

in a dignified manner through the main entrance, just like everyone else. But solutions must be elegant and maintain respect for the buildings' heritage value.

The project targeted four specific properties, which are owned by the

*Liljevalchs konsthall, an art gallery in Stockholm, now offers access to wheelchair users via a glass and steel lift and carefully designed ramp. Previously, visitors unable to use the stairs had to use the staff entrance in the basement at the back of the building.*

National Property Board and the City of Stockholm. These are the Boställshusen which is now home to the Hotel Skeppsholmen, the central bank building Södra Bankohuset which is now the head office of the National Property Board, the Liljevalchs konsthall/Stockholm art gallery, and the Stockholm City Hall.

To date, the art gallery Liljevalchs konsthall/Stockholm and the Hotel Skeppsholmen have been made fully accessible. The projects have been completed with industrial designers, curators, architects and people with disabilities working together to find high-quality solutions.

Many historic buildings in Victoria and Vancouver, along with other cities in BC and throughout Canada, sorely lack a dignified means of access for visitors with disabilities. Inspiration for solutions may come from Stockholm's Dignified Entrance project, and similar projects completed or underway throughout Scandinavian cities. ■

## AGM Notice: Thursday, October 22, 2015

The Annual General Meeting of the Canadian Paraplegic Association (BC), operating as Spinal Cord Injury BC, will be held Thursday, October 22nd 2015 at the Blusson Spinal Cord Centre, 818 West 10th Avenue, Vancouver BC. Elections for the Board Directors for the next two-year term from October 2015 will be held. Nominations for Directors may be made in writing and must be received by SCI BC 10 days prior to the AGM. Nominations may also be made at the Annual General Meeting by voting members in good standing provided that the person nominated is present at the meeting and consents to such nomination, or the person nominated has previously consented in writing to the nomination and such consent is presented at the meeting.

Registration will begin at 6:00 pm, with refreshments and displays following the meeting (see The Great Rewind, page 8). Please contact Maureen (604.326.1225 or mbrownlee@sci-bc.ca) for further information regarding the nomination procedure or to RSVP. You can also visit [www.sci-bc.ca/events/](http://www.sci-bc.ca/events/) for more details about the evening.

*A voting member is defined in the Association's Bylaws as a member who has paid an annual fee. Registered in BC as a Society under Canadian Paraplegic Association (BC), we operate as Spinal Cord Injury BC.*

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*Richi Sahey, Montreal*

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