

# the spin

SPINAL CORD INJURY BC

SPRING 2017



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[www.youtube.com/spinalcordinjurybc](http://www.youtube.com/spinalcordinjurybc)

## This May, please keep it civil.

I'm not a worrier by nature; I tend to be an optimist. But lately, I've started to worry more and more about, well, us. And by us, I mean society.

With a provincial election looming in May, it is society to which I am addressing this appeal for the return of civility to our democratic processes.

In recent years, truth has become less precious, and "alternative facts" (lies or deliberately irresponsible misrepresentations of truth) have become increasingly influential. Today, everything has to be presented in extremes just to get our attention, and respectful exchange of ideas and contrary viewpoints has been replaced by highly personal attacks that incite hate, shame, division, and fear.

All of this is serving to undermine civil society. Our rich diversity of opinions, ideas, cultures, and abilities is no longer being celebrated and harnessed for its strength; instead, it is being used as an excuse for cowardly attacks and division.

Governing a democracy is a tricky business. There is always a delicate balance between representing the best interests of society versus those of individuals, and between addressing the needs of the people and the money available to meet those needs. These are not easy equations to balance and different political ideologies take different approaches to them. As a result, government decisions rarely please everyone. This is as it has always been and likely always will be.

What is different in the current era is the way that many of us are expressing our displeasure—not just with government decisions, but also with those elected to represent us. Personal, vitriolic, and unrestrained attacks on politicians are being launched by constituents and interest groups, primarily through social media. British Columbians with disabilities and formal and informal disability advocacy groups are very much amongst the offenders.

This isn't to say that their views are wrong—there's a lot that requires improvement in BC when it comes to disability supports, accessibility and inclusion. What I take issue with is the way some people and groups are choosing to express their concerns—very personal, often inaccurate, hateful and even threatening attacks on individual politicians that often transgress into their personal lives.

Politicians often don't do themselves any favours, as they increasingly use highly charged, often abusive rhetoric, innuendo, and "alternative facts" to get attention or to score cheap political points. The media feeds off it all.

Why is all of this important? Because when we aren't constructive and respectful, we can create more barriers than we're trying to remove. After all, it's hard to fight for respect when being disrespectful. If we want to move disability issues forward and promote a society that is accessible and inclusive, we require that society to be civil. We require it to be open to new ideas and be willing to change attitudes and stereotypes. We require it to listen and be reflective. We require it to challenge what we think is wrong and unjust but to do so in a constructive way that is respectful of people, encourages the progressive removal of barriers, and promotes greater inclusion.

It's okay to disagree with government. In fact, it can be healthy—disagreement is often at the heart of progress. This is true for science, which teaches us to be objectively critical and to challenge theories and hypotheses for which there may not yet be enough evidence to support. Mostly this happens in a way that isn't personal and does not devolve into deeply offensive hate talk or threats of personal harm. Instead, scientists embrace constructive criticism as a way to improve their work and ensure knowledge and innovation progresses in a competitive yet collegial environment. In other words, scientific progress depends on a civil academic society.

Politicians, the media, interest groups, ordinary citizens— we are all causes of an increasingly uncivil society. As with most elections these days, the upcoming provincial election is sure to get personal and nasty. So instead of being the cause, let's turn the tide and be the cure.

- Chris McBride, PhD, Executive Director, SCI BC



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Spinal Cord Injury  
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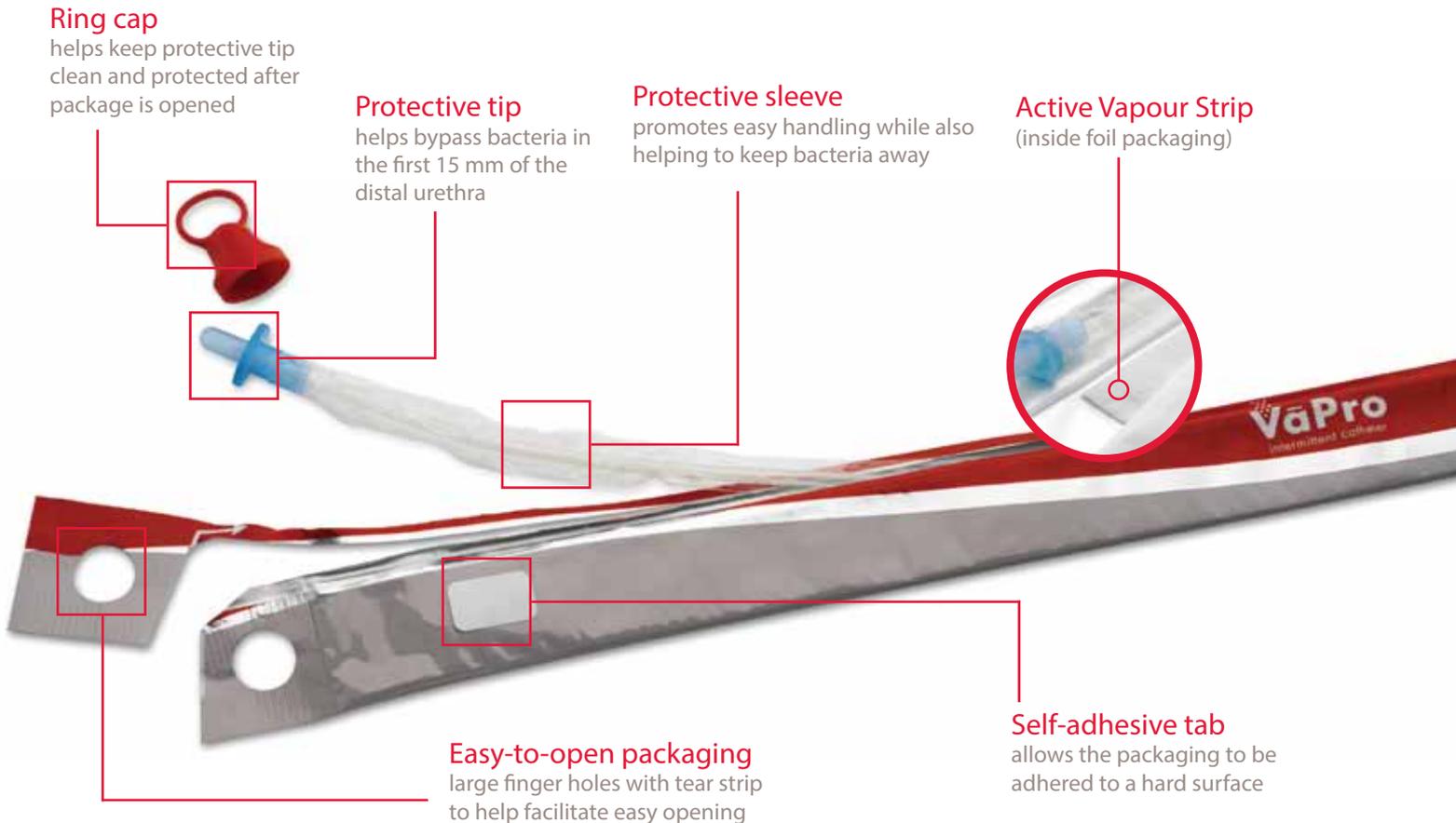
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### THE UPSCALE

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### QUADTOOLS

California-based Quadtools develops and produces a diverse range of high-quality, powerful and precise reachers and grabbers for people with quadriplegia. Every tool is custom-fitted to each individual user. Products include several versions and sizes of the company's original Crippler, which relies on wrist flexion to activate the grip, along with several newer products, including a sip-and-puff-actuated powered reacher for higher level quadriplegics with little or no wrist movement or strength, a Quadknife for the kitchen, and garden shears. All Quadtools are made from aluminum and stainless steel, and can be put on and taken off easily as there are no straps. Check out [www.quadtools.com](http://www.quadtools.com) for details, or email local rep and SCI BC Peer Muj Saloojee at [muj@quadtools.com](mailto:muj@quadtools.com)

# Innovations

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

### SESAME SMARTPHONE

"Touch is overrated," say the Israeli makers of the Sesame Smartphone. Some of our readers might agree—it's pretty tough to use a touchscreen phone when you can't move your fingers or hand. Enter the Sesame phone, a hardware/software combination consisting of a standard Google Nexus 5 and the company's pre-loaded software which allows the phone to be controlled by voice and motion via the front-facing camera and microphone. Because the Sesame software overlays everything else loaded on the phone, you can use it with all of the millions of Android apps available on Google Play. As for mounting it on your ride, it's compatible with many commercially-available products including the popular Bamboo Mounts. Get the full details at [www.sesame-enable.com](http://www.sesame-enable.com).



### LIFTWARE LEVEL

The Liftware Level is an adaptive, powered utensil that relies on tiny sensors and a built-in computer to keep the head (either a spoon or a fork) level no matter how your hand twists and bends as you lift it and your food from table to mouth. The level's oversized handle is easy to grasp for people with limited hand function, and it also contains all the utensil's mechanisms, including processor, battery and motor. A strap can also be used by those with very limited hand function or weak grip. The device's battery is simply recharged with a USB charger. The fork and spoon attachments are easily detached for washing by hand or in the dishwasher, and the base can be wiped down with a damp cloth. The company, which is a subsidiary of Google, also makes another version, the Liftware Steady, which has stabilizing technology for people with hand tremors. See [www.liftware.com](http://www.liftware.com) for details and video.

# Room for Debate

■ opinion

## What's your take on devotees—men and women who are attracted to and turned on by people with disabilities?

As many readers know, devotees aren't an urban myth. They are men and women from all walks of life who are sexually and emotionally attracted to people with SCI and other physical disabilities such as amputation. Devotees can be turned on by the disability itself, the mobility equipment that people with disabilities use, or perceived traits of a person with disability—for example, tenacity or vulnerability. Is this creepy? Or is there an upside to this attraction? For this edition of Room for Debate, we ventured outside of our usual readership to get the discussion started.



I'm Ruth and I literally wrote the book on devoteeism. My novel (*Whole*) is about a young devotee girl and a handsome paraplegic surfer.

There is a misconception that devotees only care about your disability or wheelchair and nothing else. For the majority of devotees, that isn't true, though we can become distracted by your hotness! I've had times where I tried to force a relationship to work when there wasn't any compatibility—I persevered just because of how hot the guy was.

To us, you are supermodel hot, so you can sometimes attract the attention of someone who is just drawn to your beautiful body. But most devotees are hoping for a well-rounded relationship among equals. Yes, some are creepy. I think you'll find that's the case in any demographic. Sometimes it's social awkwardness. Many devotees have never had the opportunity to be around someone so attractive and they can come on too strong.

The advantage in a relationship with a devotee is that they appreciate you as a whole. They don't need to "see beyond" your disability. I think most humans are initially drawn to someone based on physical attraction and then the emotional connection grows. With a devotee, you have the chance to be in a relationship with compatibility, both emotionally and physically.

It's my experience that, the more comfortable someone is with his or her disability, the more comfortable they tend to be with the concept of devoteeism.

Let me tell you about a man I met on a dating website who was a veteran and a double leg amputee. Within a couple of dates it was clear that we had a lot of fun together and good physical chemistry, but no long-term compatibility. We saw each other casually until he moved away. We stayed in touch (he is now married with a baby). It was all normal to me but I didn't realize how vulnerable he was feeling from his injury. I didn't know at the time how healing it was for him to have a fun little fling. He later said that my treating him like any other good-looking guy helped him accept his new body.

Never feel obligated to anyone who makes you uncomfortable, but remember that, with a devotee, you hold most of the power in the relationship. So strut your stuff with pride!

—RUTH MADISON, Boston, USA



Eight years ago, when I discovered that there were men who found me attractive because of my missing hand, I was shocked and angry. Since then, I've become a little less emotional about the issue, and I'll even go so far as to concede that, given there is honesty, openness and mutual respect between a devotee and a person with a disability, I can take no issue with any relationship they choose to develop.

But I do think people with disabilities need to go into these relationships cautiously and knowing the realities and risks.

First, you need to be aware that, regardless of who the devotee is and how upfront they are about themselves, they are objectifying you as a person with a disability. In other words, there's a good chance that they're not attracted to your beauty, sparkling personality or your wholeness as a person. Instead, they're attracted to your disability. Some might be okay with that; I, for one, am not. Regardless, be realistic about this.

Second, not all devotees are straight arrows. My own experiences make it clear that some devotees use subterfuge to make contact, lie about their intentions, and are capable of behaviour that can only be labelled as stalking. The internet is chock-full of these stories. So please take heed.

Third, some devotees are members of part of the "devotee scene" and, as such, communicate among themselves online and in person for the sole purpose of sharing photos (maybe even photos of you, taken with or without your permission) and stories of conquests. If you doubt this, give your head a shake. Better yet, have a peek at [www.amputeep.com](http://www.amputeep.com).

Fourth, your own lack of self-confidence may be compromising you. At one point in our lives, most of us with a disability have had a poor self image and have experienced doubts about our attractiveness. In the midst of this, hearing an argument from a less-than-scrupulous devotee along the lines of, "I'm the only one who is ever going to find you sexy and attractive" might resonate with you. If so, recognize that you might need some help to see yourself in a better, more realistic light.

While devoteeism isn't for me, I don't judge those who choose to embrace it—providing they do so with eyes wide open.

—CHARLOTTE FIELDER MBE, London, England

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



### Discover your passion.

What's your leisure love? Writing, travel, sports, photography, woodworking, cooking—we can't wait to share these (and more) with you at this year's annual SCI BC Forum, titled How We Do Stuff. Whether you're looking for a new pastime or want to connect with Peers who share yours, join us on April 22 for free workshops, demos, lunch, and more. Contact Ryan at [rclarkson@sci-bc.ca](mailto:rclarkson@sci-bc.ca) for details.



### Set a Walk 'n' Roll record.

Last year, 78 amazing Walk 'n' Rollers raised a record-breaking \$55,843 for SCI BC during the annual Scotiabank 5K Charity Challenge. This year, we're back—and believe we can set the bar even higher. Join our Scotiabank 5K Charity Challenge team on June 25 as we race our way back into the record books. For more information or to register, contact Michelle at [msmith@sci-bc.ca](mailto:msmith@sci-bc.ca).



### Hit the slopes.

If you're serious about improving your adaptive skiing or boarding abilities, you won't want to miss the 2017 CADS Ski & Snowboard Festival, scheduled for March 26 to March 31 at Sun Peaks Resort. Daily lessons, clinics, certification courses, and opportunities to meet national team athletes are all on the agenda. More details can be found at [www.disabledskiing.ca/events/festival](http://www.disabledskiing.ca/events/festival).

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# LipSync



While the ubiquitous smartphone has become an invaluable tool around the globe, many people with quadriplegia or any other disability that limits hand function believe the technology has passed them by. That's why the Neil Squire Society teamed up with Google to create an affordable solution that works for those with the highest levels of SCI. And readers of *The Spin* who act fast can get in on the ground floor.

In the Summer 2016 issue of *The Spin*, we told readers about the breakthrough LipSync technology being developed right here in BC by the Neil Squire Society—and that Google had recently awarded an \$800,000 USD grant to the society to help perfect the device and make it available to those who need it most.

Since then, Neil Squire Society staff have been working hard to perfect the LipSync, which is essentially a mouth-controlled joystick interface with sip and puff controls that allows anyone with little or no hand function to control portable devices such as a smartphone or tablet, as well as desktop and laptop computers. Powered by your device's USB connection or a USB battery charger, the LipSync is completely portable and can easily be adapted to mount on virtually any power wheelchair. (See sidebar on the next page for a full description.)

Less than a year later, the Neil Squire Society is now ready to roll the technology out. And if you hurry, you can be among the first 150 people to get a LipSync at little or no cost through the society's initial pilot project.

## Open Source: Key to Low Cost

Six years ago, when the Neil Squire Society developed the first LipSync prototype, the goal was to manufacture and sell the LipSync at the lowest possible cost to consumers.

"We had it ready, we set up a relationship with a manufacturer to help make and distribute them, and then the manufacturer went out of business," explains Chad Leaman, Director of Development at the Neil Squire Society. "We had this thing that was really almost commercial-ready, but the business model didn't work. We had this innovation literally sitting on the shelf."

That's when Leaman and his colleagues at the Neil Squire Society decided to make an abrupt course change.

"In 2015, Google.org had an 'Impact Challenge' focused on disability," explains Leaman. "Their question was, 'How could new technologies transform the lives of people with disabilities?' We submitted a challenge specifically about creating an input method for touchscreen devices for those who can't use their hands, and releasing it open source. Then we had some follow-up conversations around the

technical nature and the ways we could scale the deployment, and they agreed to support us in this new initiative.”

Google’s support allowed the society to begin working out the details of an open source distribution model.

“We chose to go the open source route because we want the LipSync to be accessible,” explains Leaman. “That means not only accessible in use, but cost, and ease of access. We’re taking this innovation and instead of commercializing it, we’re open sourcing it. This means they can be made for a couple hundred dollars at the local community level, instead of costing thousands of dollars like current medical devices. So the vision is that people can download the schematics and plans for the hardware, and assemble it locally, in their communities.”

Specifically, the device’s 3D printer files, component lists and microcontroller code are being made public. Leaman says the housing can be easily 3D printed, the electronic components are readily and cheaply available, and the assembly is as straightforward as possible.

“In addition to assembly instructions, we have included instructions on how to mount a LipSync,” says Leaman. “A combination of off-the-shelf and custom 3D-printed components are provided to help makers create a fully-integrated and customized solution for the user.”

He adds that a LipSync can be built in as little as a day.

## Makers Making Change

You might be wondering how anyone lacking technical expertise, let alone the use of their hands, is supposed to make use of this open source material and actually end up with a working LipSync. Don’t worry. The second part of the equation is matching individuals who need a LipSync with volunteers who have the technical expertise to build and customize a finished device. Think of the concept as a Tetra-style approach, but on a much larger scale (Tetra is, in fact, one of the society’s partners moving forward).

“It’s really about connecting people with disabilities to skilled people in the

community, so it’s skilled philanthropy,” says Leaman. “We’re partnering with Tetra on this to help with some of the builds, and believe a model of connecting the maker to a person with a disability not only reduces the cost, but gives skilled people the opportunity to apply their skills to change someone’s life.”

Leaman believes that, in addition to the Tetra Society and its chapters throughout

Canada and also in some US states, makers will come from three other groups: university student groups, with engineering students the most likely volunteers; corporations that encourage and support volunteerism within their employee ranks; and hackers, hobbyists and other members of the DIY community.

The Neil Squire Society’s plan is to formalize this volunteer approach into

*Don Danbrook, SCI BC Peer and member of our Board of Directors, became the first owner of a LipSync last November.*



## What Exactly is LipSync?

Touchscreens are the key to modern smartphones and other portable devices. This technology has revolutionized how we interface with our tiny, powerful computer companions—but it requires considerable hand and finger dexterity from the user. That, of course, has left people with quadriplegia somewhat in the cold.

Enter the LipSync, an electronic device developed by the Neil Squire Society that allows quadriplegics the ability to use compatible devices without the use of their hands. LipSync users manipulate a cursor on their device screen using their mouth and their breath. The mouthpiece is attached to a precision miniature joystick sensor that requires only a very slight pressure on the shaft in order to move the computer cursor up and down, or side to side. The mouthpiece is also hollow, which allows a person to perform taps or mouse button clicks by puffing or sipping into the tube. A short sip simulates the “tap” action, and a puff simulates hitting the back button. Longer sips and puffs activate secondary features including “tap and drag”, “long tap and drag”, and other specialized functions.

The LipSync is designed specifically for portable devices including smartphones and tablets, but it will work with desktop and laptop computers as well. It connects to devices either via a USB port or Bluetooth.

With Android devices, this works easily because they allow cursor function. Unfortunately, Apple operating systems are a challenge, as they don’t have external mouse support, and don’t recognize LipSync. The Neil Squire Society concedes this is something that needs to be addressed, and is currently working on a couple of possible solutions.

Recognizing that wheelchair frames come in a large variety of shapes and sizes, the LipSync has been developed so that it’s able to be mounted in a variety of different ways.

a program known as the Makers Making Change initiative. "Makers Making Change has the goal of creating one-on-one relationships between makers and people with disabilities," says Leaman. "The initiative will provide the infrastructure to connect makers, open assistive technologies, and people with disabilities in their community to make a local impact. Makers will be able to meet people with disabilities in their community and work with them to deliver a solution."

One exciting component of the initiative is promoting sponsored "buildathons" during which larger institutions and corporations work to make LipSyncs for a group of recipients—they pay for the parts, and employees or team members do the builds as a day of service.

### And Finally, the Opportunity

As we told you from the outset, there is an excellent opportunity for readers of *The Spin* who are interested in acquiring a LipSync and are willing to act fast.

"Through Google's support, we are piloting 150 LipSyncs in the Pacific Northwest," says Leaman. "This will help us accomplish two things: make sure the technology itself works well, and make sure our distribution model of connecting makers to people with disabilities to build the LipSync works."

Leaman adds that, in the future, people interested in having a LipSync built for them may have to come up with enough money to purchase the necessary parts. But with this initial pilot project, the cost of all parts is being absorbed by the society.

"We are now actively recruiting the first 150, so the big call to action is to find people with a high level of disability that limits their ability to use a phone, and get them to say they want a LipSync. That can be done easily online at our website."

To express your interest in acquiring a LipSync as part of the pilot project, or for more information on the device, visit [www.neilsquire.ca/lipsync](http://www.neilsquire.ca/lipsync). ■



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# The Modern Face of SCI

A spinal cord injury can happen to anyone...and anywhere.

It's no surprise, then, that the face of physical disability in BC is as diverse and multicultural as the people who call our province home. In this issue, we asked a sampling of Peers from across BC to share how disability is perceived in their home countries and cultures. How do people in their ethnic groups view people with SCI? And what are the particular challenges, and upsides, to living life with a physical dis-

ability in their cultural communities? Eight SCI BC Peers, ranging from first-generation Canadians to refugees and new immigrants, picked up their pens and opened up their worlds to our readers. Their colourful and diverse stories offer a glimpse of how disability is accepted in countries and cultures around the globe—and provide insight into why people with disabilities should not take life in Canada for granted.

## DEPENDENCE DAY

**Name & Age:** Arnold Cheng, 30

**Culture:** Chinese

**Injury:** T-9; sustained in his 20s

**Home:** Steveston, BC

**Born:** Hong Kong

**Years in Canada:** 25

**Occupation:** Wheelchair repair technician and online video producer

**Status:** Single

**Languages:** Cantonese and English

Growing up in Canada in an Asian family, I noticed that there was a difference in what we consider positive and negative traits. For example, independence is not always seen as a positive in Asia. In many Asian cultures, they value interdependence and emphasize the family structure over individuality. This had an impact on how I experienced disability



because I am more of a lone wolf. When I am out in Asian areas of town, there is a sense of curiosity and fascination from those who are not accustomed to seeing people with disabilities alone.

Sometimes I feel like I don't belong, because being alone does not fit in with the cultural norms of disability. "Are you alone?" is a question I get asked a lot.

The idea of group dynamics can impact

## NO GREAT EXPECTATIONS

**Name & Age:** Yasaman Best, 35

**Culture:** Iranian

**Injury:** C6-7; sustained in 2002

**Home:** Vancouver, BC

**Born:** Tehran, Iran

**Years in Canada:** 15

**Occupation:** Rehab engineer

**Status:** Married

**Languages:** Farsi, English

On January 2, 2002, I went skiing in Iran with a group of friends. On the way back, the driver decided to drag race with another car and passed three cars at the same time. She lost control and we fell into a valley, coming to a stop 10 meters below. My friend in the back wasn't wearing her seat belt. She fell on my seat, and broke my neck. My friends didn't wait for paramedics and decided to pull me out of the car and transfer me to the hospital themselves. This made my injury, and adapting to my disability in Iran, worse.

Unfortunately, the physios back home do not teach you how to be independent. They mostly focus on people with incomplete injuries and helping them to walk. A physio visited me in the hospi-

tal and told my parents that he wouldn't waste his time with me because I would never walk again. Another physio mostly focused on stretches and finding a way to make me stand so somehow I could miraculously gain more function. Iran has no universal health care, so everything is paid out of pocket.

After your injury, you spend a few months in the hospital recovering and then you go home. From that point, you're on your own. If you have money you can hire a physio; if you can't afford it, there is no help. No one teaches you how to transfer in and out of the bed, how to manage your bowel or bladder, how to get dressed. There is no rehab centre or peer support program. Your family is expected to take care of you forever.

I was a university student at the time of my injury. I had to quit because my school was not accessible. I couldn't leave home, other than going to the hospital, because there weren't any accessible places. All the malls, schools, and public buildings have stairs; there is no such thing as an accessible bathroom or accessible parking. You can no longer go to work, and automatically lose your job, because you can't enter your building. You're stuck at

issues like accessibility. For instance, many restaurants have restrooms that are "accessible" only to those who are able to walk. This is perfect for many Asian families who have elderly parents who may have mobility issues—they are quite visible in places like Richmond, which can shape how restaurant owners think about disability. In addition, mobility with assistance is needed in many places in Asia, which heavily influences accessibility planning and philosophy. During my recent trip to China, I found that having a family member to help was not only a must, but fully expected. In many places I saw, accessibility had only partial independence in mind, at best.

Back in multiethnic Metro Vancouver, I also have to change my expectations and mindset between cities. Each culture seems to see me differently. For example, because I'm of Chinese descent, in areas

where many people are Chinese or Korean, I get a less verbal reaction but a bit more staring. However, if I go to an Indian area, I often get a more verbal reaction, such as awkward greetings and offers of too much help. The reactions are usually well-meaning and almost always stem from not being used to seeing someone in a wheelchair. Travelling between these different cultures (in the same urban area!) requires me to do some mental gymnastics, in which I have to factor in my own position of being Chinese and how that relates to my surroundings.

I prefer to be in Canada for its accessibility and progressiveness. At the same time, Canada got to where it is today because of increased awareness and education about disabilities. Sometimes that makes me wonder what I can do to further the understanding of disability in my own culture.



home 24/7. And you become a miserable human being who always needs another person to help you with everything.

As a result, people in Iran always have a negative view of people with disabilities. They pity you and feel sad for you—which is just another reason why people with disabilities don't go out.

I came to Canada nine months after my injury. I spent three and a half months at GF Strong, where I finally learned how to be independent. Through the SCI BC Peer Support Program, I met people with the same level of injury as me and I learned so much from them. I finished my master's degree in 2013.

In contrast to Iran, when I applied for my current job, one of my employer's first questions was, "How can we accommodate you, so you can do your job better?" Once hired, my supervisor found adapted equipment for me so I could do my job despite my limited hand function. And when my husband and I had our baby, the amazing rehab team at GF Strong adapted our nursery so I would be able to take care of my son independently.

I feel lucky to have access to the best healthcare professionals and community support systems. I'm forever grateful that Canada gave me a second chance at life.



## COMMUNITY SUPPORT

**Name & Age:** Kiran Aujlay, 34

**Culture:** Born in Canada to Punjabi-Sikh parents from India

**Injury:** T9; sustained in 1988

**Home:** Delta, BC

**Born:** Winnipeg, MB

**Years in Canada:** 34

**Occupation:** Teacher

**Status:** Single

**Languages:** English, French, Punjabi

It's difficult for me to be critical of a culture and a community that has shown love, support and, in most instances, open-mindedness. I am a Canadian, born to Punjabi-Indian immigrants who moved to Canada in their 20s. Both were university-educated professionals and because of that, we were raised with open minds and a progressive approach to life. I also come from a culturally diverse upbringing, as I was raised in a small farming town in southern Manitoba. The town was predominantly Ukrainian and German, and small French speaking communities surrounded it. Because of this, my childhood is filled with multicultural memories. It also helps that my family, though not devout, practice Sikhism, a faith that promotes equality and the act of spreading kindness to others.

In terms of physical barriers that I have faced within the confines of my

culture, there have been few in Canada. At cultural centres and places of worship, the majority of buildings here in Metro Vancouver are wheelchair accessible. It's a tradition that, after service, we share a meal in our dining hall in the temple. We all sit on the floor and eat together in an act of equality as a reminder of the importance of humility. However, temples have made accommodations so that those with mobility issues can sit at tables, if need be.

However, if you look at the culture from a belief's perspective, there is room for growth. Often, when I go to community gatherings, if I pass by a row of seated elderly women, I will hear them "tsk" in pity and say "bachaari", which means "poor girl" in Punjabi. Don't get me wrong. I'm sure people of all ethnicities feel pity for another individual at times. In my culture, however, we are less subtle at showing it. I often garner a lot of stares as well, and even after I make eye contact in the hopes of starting a conversation, people will often continue simply to stare.

Perhaps one of the most painful cultural beliefs that has hurt me is the fact that some populations of Indian people believe that those with disabilities are living out a curse from a wrong committed in a previous life. When a friend once told me this, it truly hurt. To think that I was somehow deserving of my injury was a hard pill to swallow.

However, because I have such a loving and supportive family, I wasn't allowed to dwell on this ridiculous myth. In fact, my parents offered me a different viewpoint. Many of the people arriving in Canada are from one specific part of India and have spent their entire lives in that one spot. India is a vast land and often these people who hold these beliefs have not explored anything outside of their small farming communities. People, in an act of ignorance, will turn to supernatural beliefs, simply because they have no other way of explaining why we face adversity in life. But this attitude isn't shared countrywide. In fact, in doing research, I discovered that in other parts of India, there are many adaptive sports organizations. There are also organizations that work to get people with disabilities back into the workforce. Top officials in the police force, politicians and athletes are individuals with disabilities. India is changing.

I leave with one thought. The best way to dispel any misguided beliefs is to show individuals a different way of life. I am fortunate that I have a university education, am gainfully employed and completely independent. Because I have a job as an educator, I get to expose generations of children to the notion that the human spirit is resilient and that we are all capable of living rich, fulfilling lives so long as we believe we can.

## COMMUNIST CONUNDRUM

**Name & Age:** Vincent Vavrina, 31

**Culture:** Slovakian

**Injury:** T3-4; sustained in 2006

**Home:** Vancouver, BC

**Born:** Bratislava, Slovakia

**Years in Canada:** Less than one

**Occupation:** Self-employed

**Status:** Single

**Languages:** Slovak, German, English

In Slovakia, barriers await wheelchair users wherever they move. Whether it's on the way to the grocery store, the restaurant or anywhere else, you always have to think about some fundamental questions: Will I get there? Is there access for the disabled, or are there curbs or obstacles on the way, and can I manage them on my own? The entire community is not taught to perceive the needs and problems of people with various disabilities. If it does not apply to you, you don't deal with it; frankly, even I did not deal with it until I used a wheelchair myself. But all this is just a picture of the times and system that existed in Slovakia.

The biggest problem is that in Slovakia there was communism, and people with different handicaps were pushed back to the edge of society. The environment was not created and built in cooperation with people with disabilities, so that created routes with high curbs without ramps, unnavigable for us wheelchair users and an absolute no-go for mothers with baby strollers. Nowadays, it's already changing course—installing curb cuts wherever it's possible; changing the buses and trams for newer models with low floors.

Still, many Slovak people take good health for granted, not realizing the impacts of ill health on human life. They don't meet directly with people with disabilities, so they don't consider the needs, constraints and barriers that these people have to overcome every day. In Slovakia, when you meet someone, whether it's at work or even on the street, people will automatically look at you like, "The poor man is in a wheel-

chair." They pity you and don't know how to handle this situation.

After an injury, your entire progress (adapting to new life conditions, treatment of injuries, or participation in various sports activities and subsequent integration into society) depends to a large extent on funds, of which Slovakia has little. Rehab in Slovakia is on quite a good level—if you can afford to pay. Many young people are educated in this direction, but you have to pay privately because rehabilitation in state institutions is inadequate. If someone has suffered an accident and has no family or help, they usually do not have the funds, and inadequate housing or food.

Here in Canada, there's a big difference in the perception in the community of people with SCI. People smile and they take you as an equal, although they see that you have a disability, and they help you if you need help with anything.

I've never had the feeling that I would be somehow pitied.

Overall, the environment is ready for you, too—be it sidewalks or the whole system of public transport, with which I was very pleasantly surprised. I did, however, have a little problem finding accessible accommodation.

Finally, there are adaptive sports, which I hadn't encountered in my country. If you want to do any kind of sport, you just show up and they have all the equipment, and you just do what you like. These are the things and organizations that Canadians should appreciate and not take for granted.

When I look back, my coming to Canada wasn't essentially so hard. I was more afraid of the unknown and had psychological concerns of how I would handle it all. Luckily, there were more than a few people who helped me along the way!



## FAMILY TIES

**Name & Age:** Karen Apsassin, 51

**Culture:** First Nations Cree

**Injury:** T-12; injured in 2013

**Home:** Fort St John, BC

**Born:** Dawson Creek, BC

**Occupation:** Homemaker

**Status:** Common Law

**Languages:** Cree, English

I have always had great support from my family. I was born in Dawson Creek in 1966. Growing up, we were taught to look out for one another. We all had to chip in to help with our elders and anyone who had a disability. We were never taught specifically about disability and how it worked—we were just taught to respect it and help if we could. My grandmother took in an elderly lady when her husband passed (she was so little and blind).

Before the quad accident that resulted in my injury, I never realized how many people there are in wheelchairs, and how important it is that everyone should be educated about this. I have two other family members in wheelchairs in our community. Not long after my accident, a long-time family friend was walking in the bush. He slipped and fell, and is now a paraplegic. When I was very young, our neighbours had a son in a wheelchair. For years he lived a normal life—he even looked after us when our parents weren't home—but when I was 11, he took his own life. I never understood why.

Anything at any time can happen. I am thankful for what I have. I can still use my arms. It's hard for a wheelchair to get around Fort St John—most places aren't equipped for wheelchairs or meant for navigating alone. So I've learned to give myself time and to get a head start. Before I came back from rehab in Vancouver, my brother Keith braved the freezing cold to build me a ramp at my mom's house. With family helping all the time, I find it's not so hard.

I have a very, very large family, so I am never alone. My great grandparents had 19 children, my grandparents had 12, and my parents had seven children, so



I have a lot of support and love. That's what I get and that's what I give back. Every day, my thanks and love goes to my four daughters, my six grandchildren, my mom, and my spouse for their never-ending love and support!

Cree is spoken often in our house. I talk to my kids and grandkids; I let them know that English is a second language.

## BAD KARMA

**Name & Age:** Randeep Sharma, 38

**Culture:** Indian (Punjabi) Hindu

**Injury:** C6-7, sustained in 2001

**Home:** Surrey, BC

**Born:** Bassi Pathana, Punjab, India

**Years in Canada:** Seven

**Occupation:** Peer Support Specialist

**Status:** Single

**Languages:** Punjabi, Hindi, English

Life with a disability in India is very complex. Most people in Indian society are very compassionate about the disabled. To be disabled is considered the outcome of bad Karma, so families overprotect their disabled members, and the community pities or feels sorry for people with disabilities.

A person with a disability is never considered equal. The government reserves job vacancies for the disabled as they are considered less competent. Even at school, long before I had my injury, I remember our teacher never punished students with disabilities. Other than

We still go hunting for game, and we also make moose jerky (we call it "dry meat"). All of our family still goes out to my grandparents' trap line and camp, too. We make dry meat, and my mom makes moccasins with real moose hide. I help with the beading. Not long after I returned home from rehab, we went out for a whole week. In the springtime, we killed a moose—it wasn't very big but enough to make dry meat. That was a great start to the summer.

We each have our own horses, too. Our horses are still being broken, and I haven't had a chance to try to ride mine yet. I haven't been on a quad either, since the accident. My spouse is trying to find a proper seat for me—one that we can transfer onto the skidoo, too.

Since the day of my accident, I have met some great people along the way. I want to thank all who were involved with me throughout my ordeal. I'm so grateful for my culture, my family and my community.

in a hospital, the presence of a disabled person is a surprise to others and can sometimes be uncomfortable. For a long time after my injury, I never felt comfortable to be seen publicly in my wheelchair. Entry to my classroom or at the university café was nerve-racking as every eyeball was fixed on me and my wheelchair. I remember the time I went to get my passport at the passport office. "Why do you need a passport?" I was asked. Of course, I like to travel like any other person!

To this day, my home country looks like a utopian nation where you might not wit-



## IRRATIONAL INCLINATIONS

**Name & Age:** Mohee Mataji, 52

**Culture:** Persian (Iranian)

**Injury:** T12-L1; sustained in 1985

**Home:** Vancouver, BC

**Born:** Nowshar, Mazadaran province, Iran

**Years in Canada:** Four

**Occupation:** Law Counsellor

**Status:** Single

**Languages:** Farsi, English

Based on my unique mentality and outlook on life, I decided to reach my life goals, despite my disability. I understood the “why” of life and learned “how” to live. I continued to study, established my business, and went to university and got my master’s degree in international law. Sound simple? It wasn’t. You’d have to live in Iran to realize just how hard it was. We have no accessible sidewalks; no accessible buses. About 95 percent of public places are not accessible. The two universities I graduated from were

ness a single person with a wheelchair or mobility aid. Before my injury, I never saw a single wheelchair in the university. But after my injury, I realized why—because there wasn’t any access for the wheelchairs. Restaurants, schools, colleges and universities, public transit, places of worship, and sports arenas are not accessible. Even with valid tickets, I couldn’t watch a cricket match because the “world class” Mohali Cricket Stadium is not wheelchair accessible! I somehow managed to complete my degree thanks to a ramp at the Department of Art and Theatre, which they used to transport their heavy stage equipment.

The positive is that Indian families care for their disabled relatives. Family members and friends share the emotional pain, and try to help wherever they can. They often visit and make jokes out of the situation to ease the agony. But Canadians are the best people on this planet! They welcome the disabled and embrace disabilities. A stranger gives you a ride home without expecting anything or asking a single question about your disability.

no exception. My friends had to lift me to the fourth floor!

People in Iran are generally kind to the disabled. More than empathy, they have sympathy. After eight years of war with Iraq, we had almost 200,000 people with SCIs and amputees in wheelchairs. People respect them, but the collapse of the Persian Empire, which spanned from Greece to India, had very negative effects on people’s mentality. The Iranian culture is very complicated and very different. It is not based on rationality—ours is a chronically problematic culture and an irresponsible nation.

Iran is unlike Canada, where most of the disabled are married. Women think it is some kind of sacrifice or the love of God to partner with a man with a disability! Marriages do happen, but more in small cities or rural areas, or in very rare cases, between two educated people that see the equality in human dignity rather than the physical disability. (My case was the latter, though we

(However, my community members might ask personal questions about my disability, marital status, and even my income.)

In India, rehab focuses solely on the medical model of treatment after injury or disability (e.g., surgery, or different therapies like physio and OT). However, rehabilitation in Canada has a more holistic and versatile approach which includes the physical, emotional, recreational, and personal needs of a person in the rehab process. I like for people to treat me equally and accept me as I am.

When I moved to Canada for university, my parents felt comforted that I had a cousin living “nearby” (my cousin lived in Surrey; I was studying in Prince George). But it wasn’t hard to find other people from the Indian community! Gurudwaras, or Sikh places of worship, were the best places to find my community members. People from all faiths are welcomed in Sikh gurudwaras.

Of course, there were some challenges in moving to Canada—not least of them the cold. But don’t worry, Tim Horton’s Double Double is here!



didn’t have common interests to bind us and the relationship ended in divorce.)

The majority of people don’t know the details of life with a disability and are afraid. They ask themselves, “Why should we give up our easy life to care for a person with a disability? Why should we deprive ourselves of walking hand-in-hand on the sand? Why should we renounce a sweet sexual relationship?” After my injury, when I kissed a lady and we ended up in bed, she was surprised and said she didn’t know that people with disabilities can have sex, too. There’s still a lot of ignorance—both in Iran and in Canada.

My dream was to move to the West. I didn’t see it as a utopia, but Canada is one of the best places in the world. We have a liberal, rational democratic system, and everything is from and for the people—people decide how to manage and handle their country, people are cultured and educated, and people intentionally limit their personal freedoms in favour of the greater good of society.

I am very happy to live in Canada, and will be honoured as a Canadian citizen in the near future. In the four years I’ve been here, I haven’t faced any discrimination based on my race or disability. That said, I think there is always a need for people with disabilities to show our potential and limitations off to society, and diminish the misconceptions about disabled people. Both in Canada and in Iran, we need to educate people to accept us without fear, to let them know that we are able to love and be loved.

## MACHO, MACHO MAN

**Name & Age:** Roberto Molina, 42

**Culture:** Latino (El Salvadorian)

**Injury:** T7-T8, sustained in 1979

**Home:** Vancouver, BC

**Born:** San Salvador, raised in Los Angeles, moved to Vancouver in 1988

**Years in Canada:** 29

**Occupation:** Rehab Consultant

**Status:** Single

**Languages:** English, Spanish

In 1979, when I was injured as a child, the war had broken out in San Salvador. My mom was working for an American company and had a US visa to get me to Los Angeles. After that, we lived illegally for about nine years.

When I arrived, people with disabilities were still put into “special schools” for people with mental disabilities, physical disabilities, and anything else. I was one of the first two kids to be integrated into regular schools; we were like the guinea pigs. As much as they say America is a melting pot, there’s still a lot of segregation. I grew up in South Central Los Angeles where there’s still a lot of racism. To most people, everybody looks Mexican; being Latino and in a wheelchair was just kind of a double whammy. My mom decided to head to Vancouver in Canada to claim Refugee Status in 1988.

In 2013, I finally flew to El Salvador for the first time since I’d left. I wanted to play international basketball, but the amount of training and travel required to play on Team Canada makes holding a job impossible. Instead, I contacted El Salvador and flew down for tryouts. I made the national team, but El Salvador made quite an impression on me.

I was injured at a young age. When you’re little you want to climb and do what everybody else does, so I learned to do all that and it felt natural: jumping out of the chair, onto the floor, moving around like a little monkey, adapting and problem solving on the go. But coming back to El Salvador from Canada, I realized just how inaccessible the country really is. Everything’s changing slowly, but we’re



in 2017 and it’s just changing now.

The Latino culture is coming along, but the stigma of being in a wheelchair means someone having to do everything for you. The way people see it, if you’re in a wheelchair, you have some kind of mental disability. And if a man in a wheelchair tries to talk to a female—the mentality is just so different. The women feel like, “Oh, you’re in a wheelchair, that means I have to take care of you.” And our culture, being Latin, is very macho. The man is meant to be head of the house, and the mentality is, “If you have a disability, how are you going to do all that?” Because El Salvador is really not accessible. Most people with jobs down there have very low-end jobs, like little office jobs or small menial tasks, and that’s because the government finally tried to implement a work program. Long story short, if you have a disability, you can’t be that man who takes care of

the house, or contributes to society.

But I feel that sport has opened people’s eyes and changed the way they view people with disabilities. When they see a high level of international wheelchair sports at tournaments or on TV, they are amazed. They think, “Oh my god, these guys are insane. They’re not just pushing a little wheelchair trying to get around.”

In El Salvador, sport helps to reverse that macho mentality. El Salvadorian athletes don’t have the benefits, resources or opportunities that people with disabilities have here in Canada, so every time I go down, I try to take some donated sports chairs with me. Slowly I’m building my team up with good equipment—equipment that’s up to par. Sport is the game changer, and there are a lot of good athletes down there. Let’s just say they’re still using wooden shoes, while other athletes are using Nikes. ■

## DO YOU SPEAK A LANGUAGE OTHER THAN ENGLISH?

We’re looking for SCI BC Peers and family members to help Peers feel connected in their own language at our events and in the community. If you’re interested in lending your experience in a language other than English, contact Jocelyn at [jmaffin@sci-bc.ca](mailto:jmaffin@sci-bc.ca).

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**PROVIDING AN ACCESSIBLE  
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# Retooling the Shoe

Unsatisfied with existing choices of adaptive footwear, Seattle's Billy Price brainstormed a bold new design that's ridiculously easy to zip on and off, fashionable, and universally appealing.

Shoes have always been a huge source of frustration in Billy Price's post-injury life—but not anymore.

Price, who grew up and lives just down the I5 in Seattle, was born with an analytical, mechanical mind. After high school, he decided to put his problem-solving and tinkering abilities to good use in the University of Washington's mechanical engineering program. But he was barely into his first year when he fell out of a third story window onto the sidewalk below.

The result was C6 quadriplegia—and a five month stint in rehab where he experienced many dark days contemplating how he could ever move forward with his life and career aspirations.

But move forward he did. Soon after his discharge, he was back in university, where he ultimately earned his degree. He discovered during an internship with Boeing that he enjoyed working in the aviation industry, and in 2003, he was recruited by the US Federal Aviation Administration (FAA).

His career flourished at the FAA. He took on increasingly challenging projects and responsibilities. Today he's a Program Implementation Manager with the FAA's operational arm, the Air Traffic Organization.

Price credits his mechanical aptitude for much of his success in a prestigious career—and for maintaining a high level of independence in his daily life as a quadriplegic.

"With that mechanical mind, I not only got through college, but figured out ways to make it through daily living successfully," says Price. "As a C6 quad with (limited) hand function, I figured out how to put on pants, button shirts, type, hold a fork, hold a pen, and other tasks typically requiring dexterity."

But one troublesome exception was putting on regular shoes independently. And he found the few examples of commercially-available adaptive footwear to be clumsy and unfashionable.

"I suppose," he says, "I could have conceded and accepted Velcro with finger loops for laces, and then have the size substantially larger so I could put my foot in. But I wasn't interested. If I were to wear shoes, I wanted them to look good—and normal like everyone else's. So with that stubborn position, I gave up on trying to put shoes on by myself and always sought assistance. Meanwhile, I continued to stare at my feet, trying to conjure up an answer. And then the simple idea of a zipper along the side and around the toe of each shoe came to me."

Around the same time, Price got reacquainted with an old childhood friend, Darin Donaldson. He quickly discovered that, by some stroke of synchronicity, Donaldson had become somewhat of a shoe entrepreneur and had learned the art of shoemaking at ShoeSchool in Port Townsend, Washington.

"In December of 2011, Darin threw a Christmas party and invited me over," says Price. "While we were catching up, he mentioned he was working on a shoe project. Being an entrepreneur at heart, he put it as a challenge to himself to see if he could make it work. And all the while he was describing what he was doing, I couldn't help but think about my shoe idea. So I pitched it to him. And that's how we started down our company path."

That path, Price concedes, has had a few twists and turns. The duo quickly realized that starting a shoe company would be incredibly costly. So they opted to begin modestly with another of Price's ideas—a unique glove system that would keep disabled skiers' hands warm while using outrigger skis. They figured a Kickstarter campaign was a great way to minimize risk and test the waters, and they soon exceeded their fundraising goal.

"The plan was to generate revenue through the gloves to fund the shoe project, which we were getting anxious to start," says Price. "And then I started to get weird emails."



The emails were from the producers of *Quit Your Day Job*, a reality TV show shown on the Oxygen channel in the US.

“They saw our success on Kickstarter and wanted to know more,” says Price. “In addition, they wanted to know if we had more than just the glove. And that’s when the shoe came down off the shelf.”

With the prospect of the show and the publicity it could bring, it quickly became apparent that the duo would need to get a prototype made.

“We took two simultaneous tracks. One, we bought a simple shoe, cut it apart and sewed in a zipper just to see if our concept actually worked. And two, we reached out to a shoe manufacturing contact that Darin had already established from his previous project and asked them to make us a sample.”

And that’s when the Aha! moments happened for Price.

“I remember them vividly,” he says. “These moments came when I tried on my home-job sample and then the manufactured sample. The shoes went on exactly like they were supposed to. It was the first time I had independently put my shoes on in 18 years. After that, I knew we were onto something big.”

From there, it was full speed ahead, first filming the reality TV show, and then moving the shoes into production. The goal was to have product ready for purchase by the time the show aired.

“From our initial prototype, we created twelve different silhouettes with



*BILLY Footwear's product line will expand in 2017 with many more styles, sizes, widths and colours.*



many different material types and colours. The total number of models was about 50. And of those 50, we narrowed down our selection to seven—two kids', two women's and three men's."

And thus, BILLY Footwear came to life. The shoes are stylish, functional, and have an innovative, patent-pending common feature—a zipper, which runs the length of each shoe and around the toe, and has a loop that allows someone with even very limited hand function to operate.

As you can see in the photos, the shoes don't shout "adaptive" or "disability"—and that's vitally important to Price.

"We're not making adaptive shoes," says Price. "We're making shoes that have adaptive characteristics. To me, there's a big difference. Adaptive refers to something niche, so by extension, if you don't need something adaptive, why would you use something that carries that title? But if a product has adaptive characteristics, it refers to something that's easier to use—and that's a trait that all can enjoy. Take a smartphone, which you command by voice. Nearly everyone has one these days. And we don't think of these devices as adaptive equipment just because they have adaptive functions. A friend of mine who is blind uses that voice command all the time—and so do others who can see perfectly. So I'd say the voice command is a universal feature, meaning it works for everyone. And so do our zipper shoes."

This, says Price, is crucial for success. "One, it creates a sense of normalcy and equality between all patrons. And two, with a universal product, our audience is substantially larger, which betters our chances of succeeding. I felt that the only way we could be successful in taking on the shoe market was to create a product that works for and appeals to everyone."

Price believes that BILLY Footwear is great for young children, older people, and anyone else who might have difficulty

with conventional footwear. But we'd have to add that the shoes definitely have a "cool" aspect that make them appealing to just about anyone. So we weren't surprised when Price told us that, after roughly one year of sales, about half of all customers have been people who are able-bodied.

And there have been many customers, says Price. "We get more and more exposure every day. The shoes are currently only available through e-commerce, however, we're hoping that will be changing very soon. In other words, look for us in brick and mortar stores come this August."

The company is currently raising money to create more designs, add more sizes and increase inventory. "The pipeline has expansion of what we've already started. This summer, we will have huge growth in our kids' line—at the moment we only have two models to offer. Our next manufacturing run will have eight to 14 more options. In addition, we want to expand our adult line and incorporate width options, based on valuable customer feedback we have received."

Price and Donaldson still juggle BILLY Footwear with their day jobs, and they've hired several part-time employees to handle logistics and sales. But he concedes that, if demand expands, they'll be forced to make some tough decisions.

"I do love working for the FAA," he says. "It's been a wonderful job and one that I would be happy to continue. But as the shoe business continues to grow, it will be harder and harder to do both. And I look forward to that day because it means our shoes and apparel are reaching a much greater audience!"

Price adds that, in the few spare moments he has, it's satisfying to reflect on the company's early success.

"Seeing concept become success has been a dream come true! But it's also been a wild rollercoaster fuelled by leaps of faith. We have certainly had hurdles along the way, but we continue to press forward. Our success has been hinged on the support from so many."

We asked Price if he could offer any advice to readers who are would-be entrepreneurs. "Wow, well, I did not seek out to be an entrepreneur, it just kind of happened," he says. "And now that it has happened, I'm very happy it did."

"I think the real challenge for anyone who is coming up with inventions is they need to satisfy a gap that is more than just your own. Finding a solution to your own struggle is the perfect starting point—it's a powerful story because no matter who critiques your product, you know it works and changed your life. The problem lies when you want to mass produce it. Manufacturers have minimums, and the minimums are often rather staggering. So before you launch into making a thousand widgets, make sure you do your homework and know in your bones your audience actually exists. So, with all that said, look before you leap into the pool. But when you do leap into the pool, keep swimming and don't look back." ■

*You can shop for BILLY Footwear online at [www.billyfootwear.com](http://www.billyfootwear.com), and also at [www.amazon.com](http://www.amazon.com).*

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# board meeting

The second annual International Surfing Association World Adaptive Surfing Championship, held from December 8 to 11 in California, featured athletes from 22 countries including Canada. We asked Team Canada Manager Gerry Burns, who is one of our own SCI BC Peers, to put on his reporter hat and be *The Spin's* colour commentator for the event.

In recent years, the adaptive surfing scene has really been a rapidly growing global phenomenon. New surfers are being continuously introduced to the sport, and it's awesome to see adaptive surfing's growth at the competitive level as well. This was certainly underscored at the inaugural World Adaptive Surfing Championship in 2015. I watched video of the entire competition and was completely stoked by all the countries represented, the camaraderie, the wild board adaptations, and the crowning of new world champions.

In fact, I was so intrigued that I made it my mission to get involved in helping Canada develop a team to compete in the 2016 World Adaptive Surfing Championships, presented by the International Surfing Association (ISA) and apparel company Stance.

A couple of years ago, I'd made the tough decision to "hang up my board" because of some sketchy breathing situations I was experiencing as a C1/C2 incomplete quad. Getting involved more in the development of adaptive surfing would be kind of a cool, full circle experi-





*LEFT: Nate Smids from Thamesville, Ontario catches a nice wave en-route to a 9th place finish in his division. BELOW: SCI BC Peer Victoria Feige angles into a clean wave. BOTTOM LEFT: an aerial photo from a drone captures the scene on the beach. BOTTOM RIGHT: Victoria Feige and Team Manager Gerry Burns enjoying the moment in La Jolla. (Photo credit: Sean Evans)*



ence—a great way to give back to a sport that made for the best years of my life.

I clearly remember being in rehab and someone telling me about quadriplegic surfer Jesse Billauer and his non-profit foundation, Life Rolls On, which has grown into an annual tour of epic surf and skate events for wheelchair athletes. Jesse's example instantly gave me tons of hope. I'd go on to meet Jesse and surf with him. I became incredibly passionate about adaptive surfing, and I soon found myself heading down to Mexico on my own, with my bags, my surfboard and my walker. I was unable to even get on beaches by myself, but always found ways to meet local surfers who'd help me, paddle me out to the waves, and take me out to some of my favourite secret spots that I loved surfing able-bodied 20 years prior. That was living life again!

So I contacted the Canadian Surfing Association to express my interest in helping out. President Dom Domic was super stoked about the growth of adaptive surfing and the prospect of a Team Canada competing in 2016. He also told me about Pascale Martineau, a surfing enthusiast from Quebec who also wanted to be involved in the development of Team Canada. We were in contact a lot and soon the adaptive surf committee within the Canadian Surfing Association was formed.

Our immediate goal was to create Canada's first-ever adaptive surfing team to participate in the 2016 Championship. But looking forward, we realized there were longer-term goals within reach. The inclusion of surfing into the 2020 Olympics also means there's a good possibility of adapted surfing being added to the Paralympics in 2024. Clearly, the popularity

of the World Adaptive Surfing Championships will have a direct impact on the sport being included in the Paralympics, not to mention creating greater interest and access to the sport across Canada.

The parameters developed by ISA allow each national team to field a maximum of eight surfers, who can participate in six different divisions based on disability and function. Our team ended up consisting of four athletes: Nathan Smids, a below knee amputee from Ontario who already had some international success; Victoria Feige, an incomplete para athlete from Vancouver; Scott Patterson, a double leg amputee and two-sport Paralympian from Vancouver; and Daniel Shoemaker, a full-arm amputee from Victoria who is also a member of Team Canada's adaptive snowboard team.

With the organizational work done, I drove down to La Jolla, just outside of San Diego, eagerly anticipating the event and finally getting to meet our surfers and my fellow organizer Pascale. Not surprisingly, they turned out to be a totally cool bunch of peeps!

The event kicked off with an opening ceremony held along the seawall by the beach. The vibe was electric as an amazing community of surfers, supporters and team officials from all over the world cruised down the sea wall towards the park, waving their countries' flags. Our flag bearer, Victoria, along with Nate, was called to the stage for Canada for the traditional "sands of the world" ceremony. Nate added a jar of our local Cox Bay sand from Tofino into a tank with sand brought by the other 21 nations. A symposium and barbecue followed—a great opportunity to meet long-time surf friends and make new ones.

The next day I attended the managers meeting to hear the details about scoring and rules from a panel of judges. Meanwhile, a surf clinic was held at the beach in front, with the goal of introducing newer surfers to the sport of adaptive surfing.

Finally, the first day of competition arrived. La Jolla beach was crowded with flag-waving supporters, spectators, and surfers taking to the water for their heats.

## Adaptive Surfing FAQs

- Most beginners can learn to surf using a rental long board with some help from a few friends.
- People seeking to become proficient usually end up buying and customizing their own board.
- Customizations can be quite diverse—handles, deck pads for comfort, no-slip surfaces if you're laying down, and foam or custom blocks to help position your body if your movement is more restricted.
- Competitive adaptive surfers often further modify their boards with custom shaping and fin placements.
- The internet is chock-full of adaptive surfing websites, videos and images—search for "adaptive surfing" and prepare to be amazed.
- To learn how to get involved, contact the Canadian Surfing Association at [domadomic@gmail.com](mailto:domadomic@gmail.com) or reach Gerry at [burner5353@gmail.com](mailto:burner5353@gmail.com).

All surfers got in a couple of 20 minute heats making the most of the waves they had on hand. It was awesome seeing our Canadian surfers representing out there on the world stage! Seeing all the pure stoke from the surfers, the great camaraderie between the nations, and the impact the event had on all the spectators was really rad.

On day two, the waves started off cleaner and bigger, building into the afternoon. It was really cool every time the announcers mentioned one of our Canadian surfers in the water, but I really loved when I heard the extra shoutouts like, "Surfer in blue, that's Scott Patterson of Canada eyeing up the big outside wave, yes, he's caught it, and that has to be the biggest wave of the morning!"

I was fascinated watching our surfers work their adaptive styles to the best of their abilities—making great moves riding the waves from top to bottom, carving some nice fluid cutbacks, changing stances to display their variety of moves, and sometimes gunning it down the line fast in great form. Nate finished off one of

his impressive heats right on the finishing horn with a perfectly timed floater move, and Victoria caught a wave in the final seconds too, riding it right into the beach while changing her stance to no-hands for some sweet extra points.

At the end of the day, we were all excited for Nate when it turned out that he had advanced to the quarterfinals.

All of our team, friends and some family were all there bright and early on day three to cheer Nate on. It was a great quarterfinal battle. Nate just missed advancing to the semi-finals by one point. But he earned himself 9th place in his division—no small feat when you're competing against the world's best!

For the remainder of the day, our entire team joined the crowd on the beach to cheer on all the surfers through the semi-finals and the finals. It was incredible seeing each new champion surfer carried overhead in celebration up the beach, holding their board up high, their country's flags waving around them!

With the competition officially over, the closing ceremony was held on the beach with the top four in each division final awarded medals. The talent level of all these finalists was off the hook and it was sweet to see the diversity of disabilities represented.

Next, team awards were presented to the top four nations based on the combined scores of their team members. I know every member of our team already felt so proud to be a member of Canada's first ever world adaptive surf team, but placing well in the team standings against so many powerhouse surf nations would be a fantastic bonus. In the end, Canada placed 11th out of 22 nations—an excellent result for our team's first year.

As spectators on the beach dispersed and surfboards were being packed away, new and old friends said their goodbyes until next time. I took it all in from the beach, totally appreciating the moment and reflecting on how proud I was of our team—and how far we'd come in a year.

Adaptive surfing in Canada has caught a wave, and hopefully it's only going to grow in the future! ■

# Liquid Skin

ICORD's Dr. Aziz Ghahary, a world-renowned leader in the field of wound healing, has been working on a liquid skin composite to promote healing in deep pressure ulcers. With safety and efficacy already confirmed in animal studies, Ghahary hopes to test the compound in humans as soon as possible.

**T**he worst pressure ulcers are like icebergs: what you see on the surface is just the tip of what lies deep underneath.

It's these types of pressure ulcers, known as stage IV pressure ulcers, that can put people with SCI flat on their back (or their stomach) for weeks and even months. The culprit is lack of sensation in paralyzed areas of the body—legs, feet, and, more often than not, butt. Lack of sensation means you're not warned when you're putting too much pressure on a problem area. And it also means that, even well after the initial damage, you might remain unaware of a big problem growing under the skin until you finally notice telltale redness on the surface. By then, it's likely too late to get off scot-free.

"Sometimes the size of the wound on the surface is very small, but underneath is a cavity," says Dr. Aziz Ghahary, ICORD principal investigator and professor in the Department of Surgery and Division of Plastic Surgery at UBC. "It's much deeper, because with a pressure ulcer, the wound starts from the bottom and works towards the surface. The pressure damage is in the tissue under-

neath the surface, and then it gradually works to the surface and opens. And when it's open, that means underneath is a big cavity."

And it's this cavity, or void, that makes these pressure ulcers so difficult to heal—so much so that they're sometimes referred to as non-healing wounds.

When it comes to healing damage to our skin and other connective tissue, our body's main weapon is the fibroblast—a specialized cell that produces more than 100 different molecules for healing. In a non-healing pressure ulcer, fibroblasts gather at the edge of the wound, but they're unable to start the healing process because there's simply no infrastructure in the cavity that they can travel on or mobilize within.

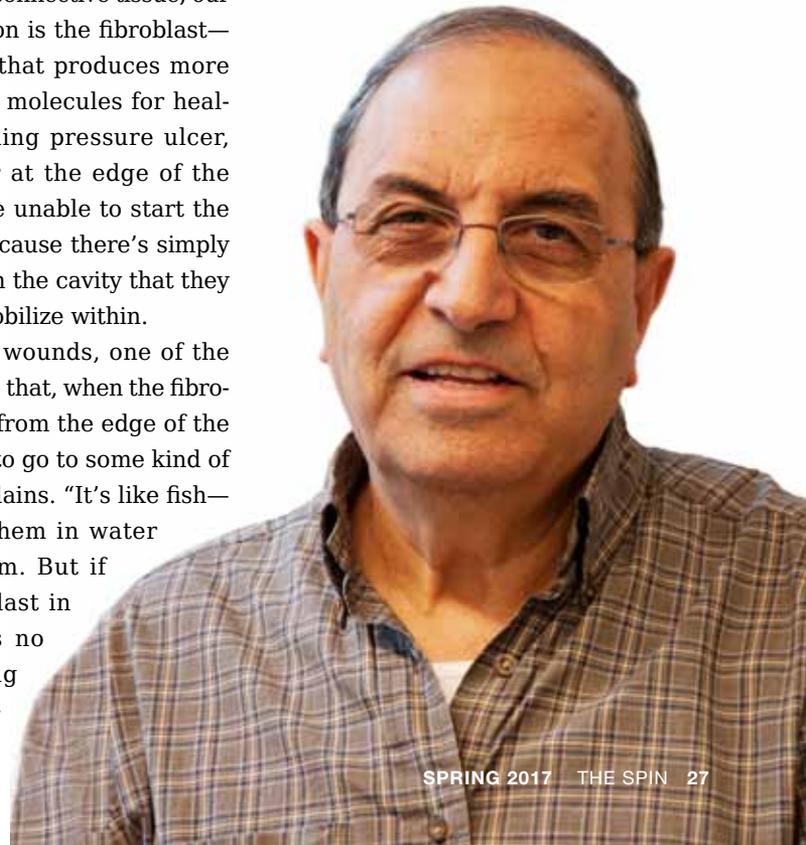
"In non-healing wounds, one of the biggest problems is that, when the fibroblasts are coming from the edge of the wound, they have to go to some kind of a scaffold," he explains. "It's like fish—you have to put them in water or they can't swim. But if you have a fibroblast in a cavity that has no scaffold, it's going to die. It's not go-

ing to go anywhere. So they need to go into a three dimensional scaffold. When they're put into a scaffold, they begin to build their own scaffold. When you give them some ground, they begin to build their own nest. And when they build their own nest, it's much stronger than any scaffold that is commercially available. You have to give them something to grow in and proliferate, and basically make their own collagen and their own scaffold."

Ghahary adds that the other problem is that, without a scaffold, the wound lacks a "roof" that allows it to be sealed from moisture and contaminants.

There have been many research forays exploring the idea of introducing an artificial, biodegradable scaffold into these wounds. For various reasons, and despite some limited success, these efforts have never yielded a viable or reliable product for clinical use.

Ghahary and his team of researchers at ICORD and UBC may be on the verge of changing that. Building on previous research, they've developed a unique liquid skin material that provides a scaffold in the non-healing wound, allowing fibroblasts to mobilize within the wound cavity, begin the healing process, and close the wound.



The liquid is composed of collagen, the main structural protein found in skin and other connective tissues, along with some other key ingredients including GAG (glycosaminoglycan), a protein that helps maintain and support collagen, and PVA (polyvinyl alcohol), which allows the liquid to have excellent film-forming, emulsifying and adhesive properties (think of it as the “glue” that holds everything together).

“It’s impossible to introduce any scaffold into the wound as a sheet or a skin graft or something like that,” says Ghahary. “So the beauty (of our liquid skin) is that you can basically inject the scaffold into the cavity where it will fill up everything. The advantage to this compared to whatever else is on the market is that liquid is going to penetrate to all cavities at the bottom (of the wound) or the wound bed. And then, at the edge of the wound, the fibroblasts can then migrate into the scaffold and rebuild the skin from bottom up.”

The liquid skin has never been tested in humans. But it has been thoroughly tested in animal models by Ghahary and his team. And their published results are impressive.

“We tested this on diabetic mice (with ulcers) and we showed significant improvement in healing,” he says. “In the mice model, the time of healing is basically half. With regular healing, it may take three to four weeks. And then we showed within ten days the healing is going to be done when you have this scaffold.”

The team also closely analyzed the liquid skin for safety. Standardized tests for elevated white blood count and liver enzyme levels were entirely negative, showing that it is indeed safe. And they have also determined that there’s no danger of the body rejecting it.

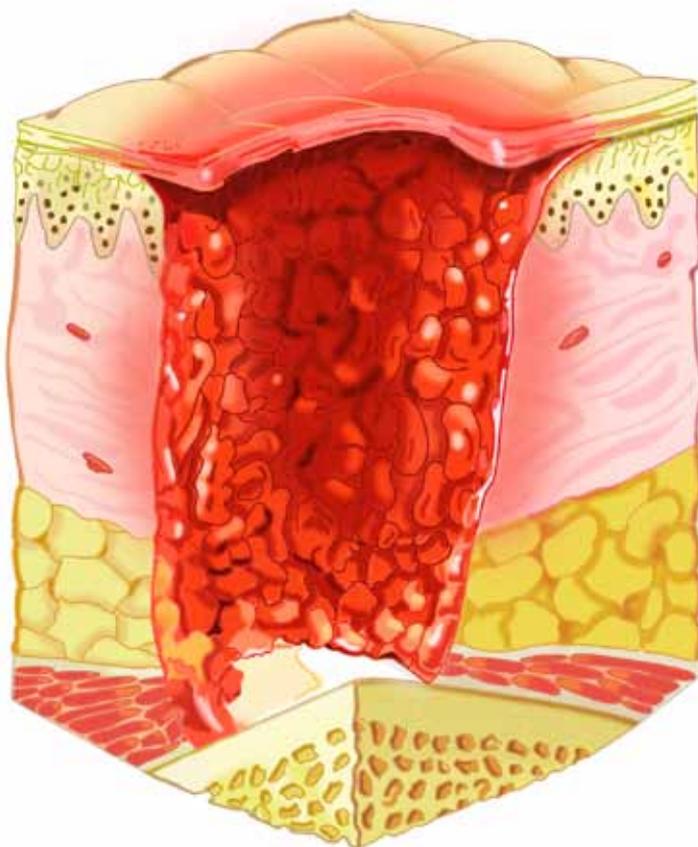
However, one problem soon became apparent during the team’s research.

“We realized that it’s very difficult to send this liquid from one location to another because it has to be kept very cold,” says Ghahary. “If it’s cold, it remains a liquid, but if it’s put at room temperature or 37 degrees C—body temperature—it solidifies. So therefore it’s logistically difficult to send it from one centre to another centre. So what we decided to do was use a system to dry it out—equipment called a Lyophilizer. This Lyophilizer basically gets rid of all the moisture and water, so we can have it as a powder. Now you can ship it anywhere—you can put it in FEDEX and send it to any corner of Canada or anywhere else, with no degradation.”

Once received at the destination, it’s simply a matter of rehydrating the powder with the correct amount of double distilled water, and then injecting it into the wound site where it soon solidifies.

The entire compound and the dehydration process has been patented by Ghahary and his team. The next step, he says, is to test it with humans.

“Right now, what we’re doing is exploring a pilot study of five to 10 patients. We are talking to Health Canada and human ethics committees to see how we can go about it, and we’re



*An artist’s rendering of a stage IV pressure ulcer illustrates the depth of the wound cavity. (National Pressure Ulcer Advisory Panel)*

working with Dr. Anthony Papp, a Vancouver plastic surgeon who sees many patients with these types of pressure ulcers. I don’t know how long it’s going to take. But if everything goes right, we’re hoping it will take less than a year to get ethics approval.”

That may sound like a pipe dream to those familiar with how painfully long it can take to move a drug from lab bench to bedside. But Ghahary explains that regulatory bodies don’t consider the liquid skin to be a drug.

“It’s much easier to get ethics approval because they consider it as a device,” he explains.

The liquid skin is a very promising treatment for non-healing pressure ulcers—one that could cut your treatment time in half if you’re ever unfortunate enough to develop a serious wound. We’ll have to wait and see if it makes it that far. But if it does, it wouldn’t be the first time Ghahary, who acquired his early education in his native Iran before moving to Canada and getting his PhD and post-doctoral fellowship at the University of Manitoba, has developed a real-world treatment. He has already developed a cream which decreases scarring for burn patients and those recovering from surgery. Another focus of his research is type 1 diabetes; he has shown that blood sugar levels can be controlled by transplanting insulin-producing cells into a diabetic patient’s kidney, eliminating the need for insulin injections.

To learn more about Dr. Ghahary and his work in wound care, visit [www.icord.org/researchers/dr-aziz-ghahary](http://www.icord.org/researchers/dr-aziz-ghahary). ■

# ask the SPIN DOCTOR

David from Victoria asks, “It seems like the older I get, the more I’m slouching in my chair. Is it my chair? Cushion? Or just my bad posture? Any tips on sitting straighter? To answer this issue’s question, we turned to Jo-Anne Chisholm (top) and Joanne Yip, who are both OTs and seating specialists with Vancouver-based Access Community Therapists Ltd.



How you sit—and what you sit on—is super important. Your posture is what helps determine how comfortable, mobile and functional you are in your chair. If your posture is slouchy, or you tend to lean one way (maybe because you tend to do most things on one side, like driving or computer work), then there’s room to improve your posture.

Odds are you look in a mirror every day to groom. But do you look at your posture? If you make it a habit to check your posture, you’ll notice if there is any change.

While there is no perfect posture for everybody, there probably is a best way for you to sit in your chair. Usually this means sitting evenly side-to-side, with weight distributed from your buttocks down your thighs—no knees in the air! This will help prevent pressure ulcers. You should also be supported so that you don’t have to use one hand for balance. This can often be achieved by having your seat base angled with the front higher than the back so that your upper body tends to lean back into your backrest. Having a stable base of support (a cushion) and some side support on your torso can

also keep you steady and balanced. Hands-free sitting will make it easier to do work, transfer, wheel, and stay comfortable and less fatigued.

Part of ensuring good posture is making sure your wheelchair, backrest and cushion are doing their job. This means taking charge of your equipment. Just as you have a vehicle checked and repaired as needed, your chair needs attention and care. Everybody’s equipment is different; yours should be tailored to your needs. The frame should fit your body and be easy to push, the brakes should be in good working order, the tires should be in good shape (not bald or flat), casters should spin freely and not be bound up with dog hair (a common problem), and there should be no loose or missing parts such as armrests, clothing guards, footrests, bolts and screws. Your backrest and cushion also need to be in good repair—this means that the foam should not be compressed or worn, the seat upholstery not torn or sagging, the cushion not sitting askew, and the backrest not slipped down the canes or positioned with one side higher.

There are a large variety of cushions, and different ones have different life spans. Your 12-year-old air cushion with the bicycle patches might still be doing its job, while a two-year-old foam cushion might require replacement because it’s compressed. How do you tell? Look to your body first—if you have no new redness or discomfort and your posture is the same, then your cushion is probably still okay. If you’ve noticed any of these body changes, then there’s a problem, either with your cushion or whole seating arrangement.

## Tips To Help Keep You Sitting Healthy

1. Know your habitual posture. Check yourself out in a mirror or take photographs from the front, side and back. Do you appear even side to side? Are your shoulders and hips level? Is your back upright or slouched forward? Is your head balanced over your shoulders and torso, or sitting forward or to one side? Is there equal space side to side in your wheelchair, or do your hips drift to one side? Is your back centred in the backrest?
2. Try to improve your sitting posture. Avoid always doing things on the same side. Set up your workspaces to do things front on rather than diagonally. Learn and practice postural stretches such as rolling your shoulders back and tucking your chin in. Try to stretch out tall in your chair periodically. Your sleep posture affects your sitting posture too—use a good mattress and pillow, and avoid sleeping curled up on the same side.
3. Know and protect your skin. Practice twice-a-day daily skin checks of your buttocks, feet and other at-risk areas—use a mirror or take a picture. Regular weight shifting is recommended by leaning forward, side to side, tilting back or doing a full lift. Hold your weight shifts up to two minutes.
4. Take charge of your equipment. A quick daily check before you get in your chair will help you see any problems. Learn to do simple tightening and repairs yourself or with help. Keep a basic wheelchair toolkit handy (screwdriver, Allen keys, wrench, tire pump). Keep your equipment clean and in good working order.
5. Know your local equipment resources. Keep a list of who to contact if something breaks—a wheelchair vendor, or a local hardware or cycling store. A yearly maintenance check with a wheelchair service is a good idea.
6. Know your local health resources. If you’re having any problems with your skin, posture or equipment, contact a health professional. Figure out who to contact before you have problems and keep this information handy. You can call your local health centre or a specialized rehab centre such as GF Strong. You can make an appointment with your doctor, or you may have a local OT.
7. Get a full seating assessment when you’re replacing any of your mobility equipment. This can head off problems before they’re serious, and help you justify equipment changes to funders. If you notice a change in your posture, balance, comfort, pressure, ability to push your chair or sit hands-free, get assessed by a health professional (OT or PT) with training in seating.

# Transformative Experience

After a fellow transgender Peer shared her powerful story in the last issue of *The Spin*, another of our readers was inspired to wheel out of the shadows and finally come out to the SCI community.

**W**hen Trevor Flynn read Taylor Straw's story in the Winter 2016 issue of *The Spin*, it was a pivotal moment.

"It was cool because I always kind of felt like I was the only trans person who is part of SCI BC," says Flynn.

The 32-year-old Vancouverite has been living as a trans man for nearly nine years. But with the exception of his family and some close friends, few people were aware of Flynn's background. Unsure of how to broach the subject and worried that coming out of the closet could result in him being excluded, he'd kept most of his Peers at SCI BC in the dark, too.

"When I read the article, I was like, 'Holy crap, these are spaces that I can actually come out in and they're going to be safe spaces,'" says Flynn. "And then I had a split moment thinking, 'Damn, I should have been the first! I've been with these guys for like four and a half years, why didn't I come out sooner?' I knew that not everybody knew, so I knew it was going to be quite a shock to people. But I knew it was time, and a safe place, and so I thought, 'Why not do it

with the organization that just accepted me as me, whether they knew it or not?'"

Flynn, who was born with mild spina bifida that didn't prevent him from walking, first realized he was different when he was five years old. He enjoyed playing with his boy cousins and always wondered why his mom clothed him in dresses. Before



he started school, he simply assumed he was, like his cousins, a boy.

In kindergarten, Flynn was surprised to find separate washrooms and change rooms for boys and girls. He found himself wondering why he was meant to use the girls' bathroom—the boys' room felt like a more natural fit. He hated games that called for "boys against girls" and was offended that he was always relegated to the girls' side.

By junior high, a teen-aged and painfully female Flynn knew that something wasn't right, but he lacked the asking ability of Google Search or the inclusive language of an updated sexual health curriculum. Instead, he settled into a "tomboy" identity.

When he was sixteen, Flynn's school welcomed a new student—a boy who regularly wore girls' skirts and proudly identified as "trans". For Flynn, the term clicked. After graduation, he met another female-to-male trans friend online, found a group of like-minded peers, and began participating in a regular drag king show.

In 2006, Flynn got accepted to the University of Alberta and received a referral to a psychiatrist in Edmonton. (Like many transgender people, Flynn was being treated for depression.) He chose to share his gender dysphoria with his new psychiatrist, who arranged for a brief and voluntary hospital admission to get his medications sorted out before the beginning of classes.

But at the hospital, Flynn was in for a disturbing intervention. "She believed I had multiple personality disorder," recalls Flynn, who discovered his elderly psychiatrist had certified him under the *Mental Health Act*. "She said, 'It's impossible for a girl to be a boy. Your other personalities could be dangerous to you or other people around you.'" He spent the next year in hospital, undergoing treatments ranging from discredited gender conversion therapy to electroconvulsive therapy. The make-up classes and requisite girls' clothing only made him more confused.

After a year had passed, Flynn's psychiatrist retired and everything changed.

His new doctor subscribed to a modern school of thought and quickly recognized Flynn as being transgendered or gender dysphoric. From there, things finally progressed. His psychiatric team worked to undo the damage done. He moved back to Calgary, began living as a male, and changed his name to Trevor. After starting testosterone injections, his voice dropped and body hair sprouted. And finally, he underwent a massive surgery and had the weight of his former female self lifted off his chest.

Before going under the knife, Flynn had written his family a sort of "coming out" letter. "At the end of the letter, I said, 'This is nobody's fault. This has nothing to do with how my childhood was...this has nothing to do with how you treated me. Please don't think you did something wrong. The best thing you can do right now is just support me, whether you agree with it or not.'"

His dad was quiet on the subject, but respectfully switched to the appropriate pronouns. His mom, though supportive, found it challenging at times to think of Trevor as her son and not her daughter.

"She'll still mess up pronouns or call me by my birth name," says Flynn. "She lost a daughter. So I think the thing I try to tell other trans people is that people have to mourn and they do have a right to be upset about it."

By 2012, Flynn had relocated to Vancouver, found friends and a job and, now passing as a male, neatly stored his past female life back in the closet. That same year, he went into hospital for a standard surgery—and awoke unable to move his legs. Suddenly, his doctors were talking about full-body examinations, and Flynn, who knew they wouldn't find what they were expecting down below, felt the burden of coming out all over again.

But neither his doctors nor his rehabilitation staff were disconcerted. "GF Strong was so respectful," says Flynn. "They never brought it up; they never made a big deal about it. All the nurses knew about it, but it was never an issue. They never screwed up pronouns, that was always respected."

That made it easier for Flynn, who was having a difficult time dealing with a loss of independence and the resulting body dysphoria. The experience left him feeling exposed, and he was relieved when he began to heal and regain control over his personal care routine.

"Being in a chair, when it first happens, everyone thinks, 'I can't live like this,'" says Flynn. "But I got established with SCI BC, and they introduced me to sports, and I started playing basketball. The chair is no big deal anymore—if I never get out of the chair, I never get out of the chair."

His newfound connections in the SCI world came with a revelation—he came to understand that, prior to his injury, he had never truly come to terms with being transgendered.

"I felt accepted, which was strange, because even in groups where I fully came out to people, I never really felt accepted. But I found that my calling, and where I felt most at home, was in the SCI community. That's where I've built my chosen family."

Now that he's found his support network and joined a family that welcomes him, Flynn feels it's finally time for him to start coming out to them, too. "It's like the one last thing about myself that is a really big part of me that I'm hiding from people. And if these people are my close friends like I think they are, they're still going to be there after I tell them."

For Flynn, it's the last step to acceptance—of his own situation, and from a community that means the world to him. Still, he admits he's nervous.

"I really hope it doesn't change anything, because I'm still the same person," Flynn says. "The only difference is that this might make me more confident, and maybe I might be able to be a better peer mentor to somebody as opposed to hiding behind something."

"That's why I'm doing this article. There might be one person that picks up this magazine in our community who's been thinking about transitioning, and now sees that it's okay to transition in this community, too." ■

# Participate in Research

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

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

## Investigating the Peer Mentor-Mentee Relationship

**Overview:** In this study, ICORD and UBC Okanagan researcher Dr. Heather Gainforth is investigating the role that peer mentorship plays in supporting people with a SCI and promoting social participation.

**What to expect:** Participants will be asked to complete a 20-minute survey asking them to list characteristics of effective and ineffective peer mentors in different settings, as well as characteristics that should be considered when matching a peer mentor with a mentee.

**Who can participate:** You can participate in this study if you are 18 years of age or older, speak and understand English, have an SCI, and are a peer mentor or a mentee within SCI Ontario, SCI British Columbia or SCI Alberta.

**Why participate:** Participating in this study will help to provide insight into ways that SCI peer mentorship programs through SCI Alberta, SCI Ontario and SCI British Columbia can be improved in both hospital and community-based settings. For completing the survey, participants will receive a \$10 gift card to the retailer of their choice (e.g., Tim Hortons).

**Location:** The surveys can be completed from your home via a phone interview.

**For more information or to participate:** Please contact Dr. Heather Gainforth by email ([abc.lab@ubc.ca](mailto:abc.lab@ubc.ca)) or call 250.807.9352.



## Motherhood After SCI

**Overview:** Breastfeeding positively impacts the emotional and physical well-being and quality of life (QOL) of mothers and their babies. However, many women with SCI face unique challenges in lactation and breastfeeding, and there is still a lack of knowledge of the underlying reasons for these challenges. A preliminary study by Dr. Andrei Krassioukov and his research team revealed that nearly 78% of women experienced these difficulties. Barriers to breastfeeding may impact mothers' QOL, and there is still a lack of information and support available for women attempting breastfeeding after SCI. They now wish to identify hindering factors for breastfeeding after SCI, how those barriers affect mothers' QOL and identify the needs of postpartum women with SCI to ensure their independence and community living.

**What to expect:** This study involves two surveys requiring approximately one hour to complete. The surveys can be completed online.

**Who can participate:** You may be able to participate if you are over the age of 18, have a good command of English, have an SCI, and have attempted to breastfeed your child(ren) either successfully or unsuccessfully. Note: Women who have previously participated in our preliminary study are still eligible.

**Why participate:** Your participation will help us understand the specific SCI-related challenges to breastfeeding and the support that new mothers require in clinical care, information access and community support. With these findings, we hope to build on the foundation of knowledge that will eventually improve the quality of life of mothers with SCI, and develop guidelines for optimal maternal care and SCI management. A \$100 Visa gift card will be awarded to participants who complete both surveys.

**Location:** The surveys can be completed from your home.

**For more information or to participate:** Contact study coordinator Amanda Lee by email ([icordlactationstudy@gmail.com](mailto:icordlactationstudy@gmail.com)) or call 604.354.3397.



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)

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# social climbers

With some help from the Canadian Adaptive Climbing Society, our intrepid SCI BC Peers hit the climbing gym to challenge themselves...and came out on top.



## IN JANUARY,

some adventurous SCI BC

Peers descended on the Edge Climbing Centre in North Vancouver to give adaptive climbing a go with local climber Brent Goodman and volunteers from the Canadian Adaptive Climbing Society. Established by Goodman in early 2016, the non-profit society aims to increase inclusion and accessibility in the rock climbing community, offering a variety of adaptive tools and techniques that enable climbers with disabilities.

The event was a chance for first-time rock huggers to push their limits and for former climbers to get back on a rock face. "I'm leaving here with excitement to continue climbing—and I never knew that was possible for me until today!" said Jaisa Sulit, who was a rock climbing enthusiast before her SCI. "And I'm really leaving here with a new appreciation for my body and knowing that I'm capable of much more, and especially the most paralyzed parts of myself are capable of much more than I knew."

For information about upcoming adaptive climbing sessions, visit [canadianadaptiveclimbing.com](http://canadianadaptiveclimbing.com) or follow @Canadian.Adaptive.Climbing on Facebook. ■

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