

the spin

SPINAL CORD INJURY BC

FALL 2020

Street Music

Danny Sloan relies on talent, technology and tenacity to pursue his love of busking





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COVER: Dan Sloan with his busking rig at Sunset Beach (photo by Mehrezia Khazri)



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“Can you hear me?”

“Can you hear me?...I can hear you, can you hear me?...Can you hear me now?” For all of you who have been using online meeting services like Zoom, Skype, FaceTime, etc. for work, school, or staying in touch with each other during the pandemic, these questions are no doubt very familiar to you. If 2020 had an official phrase, “Can you hear me” might just be it.

But as frustrating as online meeting technology can be at times, there can be no denying that it’s been essential for keeping us informed, connected, and engaged in our social and professional lives. It’s also allowed SCI BC to serve even more people throughout the province, and we’ve heard from many of you that you’d like us to keep going with our online peer program offerings after the pandemic ends. We most certainly will.

The expanded reach of our services is one positive that has come from the COVID-19 pandemic, and despite the many challenges and hardships the global pandemic has created, there are other silver linings. Increased government supports for people on disability and income assistance is another example.

But perhaps the greatest potential silver lining from this pandemic lies ahead. Federal and provincial governments are preparing to lay out billions of dollars to aid the restart of our economies. Much attention has been given to the potential of these government investments to support the development of a greener economy. But almost no attention has been given to making sure the pandemic restart investments support the rebuilding our society and economy in a way that ensures access and inclusion for all.

When making decisions about restart investments, governments should not only apply a green lens to their decisions. They must also apply an access and inclusion lens when deciding how to maximize the impact of their contributions. As co-chair of BC’s COVID-19 Disability Working Group, I recently urged the provincial government to adopt such a lens when deciding how to invest the additional \$1.5 billion it’s making available to restart the economy in BC. I was encouraged that the suggestion was well received.

Now is the time to invest in accessible transportation, housing, community amenities, and so much more. And, if governments think about it, they will realize that investing in infrastructure that is accessible and inclusive not only increases community and economic participation by all, it also helps to create a built environment that is better prepared to deal with future pandemics. After all, hands-free doors and fixtures, wider hallways and sidewalks, and more accessible outdoor recreation spaces all help limit viral transmission while allowing for people to stay active and engaged in their communities.

We still have a way to go to before we emerge from the COVID-19 pandemic. We must all continue to do our part in limiting the spread of the virus while finding ways to safely participate in our communities. The challenges that continue to lie ahead will test us all. But it will come to an end in the foreseeable future, and there is a unique opportunity for our governments to invest in things that will make our communities, economy, and society much more sustainable, accessible, and inclusive than they ever were before.

The trick to making sure this happens is a bit like the start of so many Zoom meetings: “Can they hear us?” Let’s make sure they do.

—Chris McBride, PhD, Executive Director, SCI BC



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Innovations

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



SWITCHMATE

Wired magazine describes the Switchmate as “a ridiculous yet surprisingly compelling way to put some basic automation into your lighting without having to actually rewire anything.” We agree. You simply place the device on top of an existing light switch, where magnets keep it in place, and then control it with an app that you load on your smartphone. Inside the Switchmate, two AA batteries power a small motor which toggles the light on or off. It’s Bluetooth-based, so the range is limited and you can’t turn on lights on a whim when you’re not at home. You can, however, set a timer to have Switchmate turn on or off lights at any given time. Learn more at mysimpllysmarthome.com.

CLIP-ON FOOD GUARD

This simple device, made by Sammons Preston, makes it easier for anyone with limited hand function to eat. With its slightly curved design and three hooks, it snaps onto any place on any regular size plate, where it securely provides a backstop which allows you to scoop your meal onto a fork or spoon without accidentally pushing it off your plate. It’s constructed of dishwasher-safe, lightweight white plastic that contains no BPA, phthalates, or latex. You can purchase it at many online rehab equipment stores and Amazon.



THE ERGONOMIC WHEELCHAIR

This ergonomic wheelchair, designed by the US Department of Veterans Affairs Health Care System, is intended to reduce user shoulder injury and pain by relocating the push rim from the tire to a more comfortable position, which you can see in the photo. In addition to reducing shoulder pain, a study recently published in July reveals that the design also reduces the number of bacteria that users come in contact with—up to 26 times less than a standard manual wheelchair. A prototype of this chair was actually developed almost five years ago, but it just received patent approval—which could be an indication that you might see it further developed and commercialized. You can learn more by searching the VA website (va.gov).

WHY I GIVE...

When I was 10 years old I was injured in a riverbank cave-in. My family lived in Chase, BC, which is a rural community between Kamloops and Salmon Arm. Once a year, Stan Stronge from SCI BC would travel around the province and meet up with people like myself with SCI — to see how things were going and how he could help.

When I moved to Vancouver, SCI BC was my support group. The staff were all working, involved in sports, and in relationships. They were my role models and showed me what I could do in my post-injury life. I know these days, the programming at SCI BC makes these connections happen. It's about members helping members, peers helping peers.

You can't overestimate the power of the Peer Program. I've experienced this help firsthand and I know how it helps others. This is why I'm a monthly donor.

Pat Harris

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& Monthly Donor***

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Grab a cup of joe, online.

Our weekly online coffee groups are hosted by SCI BC Peer Coordinators throughout the province. Drop in to say hello to a familiar face or connect with someone new. These casual meetups are the perfect way to stay connected, swap stories, share advice and chat with people who get it. You can connect via Zoom video or call in by phone. View the full list of online coffee groups on our online events calendar at sci-bc.ca/events or email Teri at tthorson@sci-bc.ca for more information. We hope to see you soon!



Stay fit with the sweet science.

Join SCI BC peer Leo Sammarelli every Thursday at 11 AM as he leads a fun, fast-paced online adaptive boxing workout. Leo has more than 10 years of boxing experience, and his workouts incorporate a mix of strength and cardio exercises designed to improve flexibility and core strength. No equipment or previous experience is required, and workouts can be adapted to meet your needs. Learn more on our online events calendar at sci-bc.ca/events or call our InfoLine at 1.800.689.2477.



Come to our AGM—next year.

We always look forward to our Annual General Meeting (AGM) in October, but this year we will be delaying it until further notice. Because of COVID-19, the BC Registrar has extended the date for which a society must hold its AGM, so we're waiting to determine if it might be possible to hold an in-person event early next year. Meanwhile, we'll be making our *Annual Report* available in the next month to our members and supporters. And we'll continue to keep you informed about the format and date of our next AGM.



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peers ■

We'd love to have enough space to thank every single participant and supporter in this year's incredibly successful virtual version of the Scotiabank Charity Challenge, but since that's not possible, we'll limit ourselves to a huge shoutout for peer extraordinaire (and former SCI BC employee) **KIRSTEN SHARP**. While we were writing this, funds were still trickling in, but it was clear that Kirsten was going to be crowned as our top fundraiser, garnering more than \$10,000 in pledges. What's even more amazing is that she did all of this just weeks after her father, Brian, passed away. Not surprisingly, she chose to race and fundraise in memory of her dad who, along with his wife Jan, participated in the SCC every year. Friends and family sent beautiful messages to Kirsten on her fundraising page and honoured Brian with their donations.

Peer Shoutouts



Just as we were going to press with our last issue of *The Spin*, we got the news that two of our well-known peers, **DUNCAN CAMPBELL** and **SONJA GAUDET**, had been nominated for induction into Canada's Sports Hall of Fame. Duncan, who is originally from Winnipeg but has lived in Vancouver for years, is affectionately known as the Quadfather—or the father of wheelchair rugby. Not only did he play a key role in inventing “murderball” back in 1976, he's also been instrumental in promoting and coaching the game, which has become a wildly popular global phenomenon due in large part to his efforts. Sonja, meanwhile, is one of the most successful Canadian athletes of all time, capturing three Paralympic gold medals and three World Championships as a member of Canada's wheelchair curling team. The actual ceremony has been postponed until next year because of the COVID-19 pandemic, but we look forward to seeing Duncan and Sonja join nine other athletes and builders, including NBA legend Steve Nash, NHL great Sheldon Kennedy, and Olympian Diane Jones Konihowski, officially inducted in 2021.



forward to seeing Duncan and Sonja join nine other athletes and builders, including NBA legend Steve Nash, NHL great Sheldon Kennedy, and Olympian Diane Jones Konihowski, officially inducted in 2021.

Are you an SCI BC peer who has something to shout about? Or do you know a peer who has recently achieved something noteworthy? Send the details to thespin@sci-bc.ca.



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Heavy Burden

We've always known that Canadians with SCI shoulder hugely unfair costs when it comes to prescription medicines. But now a Canadian research team has determined just how much that burden is—and why it means that peers often end up not buying or taking enough of the medications they've been prescribed.

Canada, as most of you know, is having a conversation about national pharmacare. We believe SCI BC peers should pay attention and even join the conversation because, as new research demonstrates, they stand to benefit immensely.

Recently, Dr. Shikha Gupta, a Rehabilitation Sciences PhD graduate at Queen's University, completed a national survey of 160 Canadians with SCI about their prescription drug use and the out-of-pocket costs they have no choice but to absorb. The findings, which were recently published in the journal *Spinal Cord*, are shocking: individuals with SCI have to pay five times more in out-of-pocket expenses than the average Canadian household.

But that's just one part of the story. The survey also revealed that these costs, particularly when combined with the other extraordinary out-of-pocket expenses related to life with SCI (such as adaptive equipment, mobility aids and continence supplies) and incomes that are far lower than the national average, too often have the disastrous consequence of people rationing or even not purchasing medications that their physicians clearly want them to take.

Here's a quick look at some of the detailed results. The survey, conducted online, revealed that the 160 participants used an average of five medications, for which they paid out of pocket a median of \$197 per month (which is roughly five times the national average). This includes direct costs for those with no insurance, along with co-payments, dispensing fees and deductibles for those who had some form of drug insurance (of which more than 90 percent of participants had some form of). Perhaps most alarmingly, 37 percent reported cost-related nonadherence (CRNA) to their prescription medications—in other words, almost 40 percent of participants simply could not afford their meds. For comparison, the national average for CRNA is less than 10 percent.

The most common medications that were forgone due to cost included opioids, antidepressants, and drugs to control spasticity. Female participants, and those who had the highest monthly drug expenditures and additional healthcare costs, were more likely to report CRNA.

In addition to providing those eye-opening numbers, Gupta believes the study debunks three common myths.

"The first," she explains, "is that people with disabilities are 'welfare' recipients and, as such, benefit from full drug coverage. This study proved that many of them do not receive adequate drug coverage and spend a significant amount of money to purchase their medications. As well, it seems to be widely believed that drug insurance alleviates the financial burden to access prescription medications. However, the study showed that people face financial barriers to obtaining medications despite having drug insurance, due primarily to out-of-pocket costs in the form of co-payments, deductibles and premiums. Although these costs look nominal, they all add up and lead to CRNA. Finally, we tend to think that people don't discuss cost-related non-adherence behaviours with their doctors. In this study, people with SCI tried to actively seek help from their prescribers and asked them to find low-cost therapeutic alternatives."

The study also attempted to pinpoint the amount of money participants spent on additional healthcare above and beyond prescription medications.

"On average, they spent around \$400 per month on additional healthcare needs, which included costs for catheters, wheelchairs, special diet, or skincare supplies," says Gupta. "Note that these costs did not include those

for over-the-counter medications, home modifications, vehicle adaptations, attendant care, and the cost of other rehabilitation services that people with SCI may need."

Not surprisingly, Gupta says all of this together combines to significantly impact the lives and wellbeing of people with SCI.

"In my view, this study concludes that the financial burden on Canadians with SCI is prohibitive, which has negative consequences—not only for their health, but also for their overall quality of life. In a subsequent study, my participants shared that they felt they were trapped in a vicious cycle of financial scarcity and were facing constant stress about having enough money to pay for their medications and other essential needs such as food, clothing, wheelchairs, or catheters. These stressors deteriorated their health, caused exacerbation in their symptoms which ultimately impacted their quality of life, and caused them to use more healthcare services that could have been avoided."

Her message to readers is that, as we wait for news of a national pharmacare program that levels the playing field, there may be options.

"Forgoing your meds due to cost may have negative outcomes for your health," she advises. "Talk to your doctor if you are facing financial barriers to pay for your medications. They may be able to help you—for example, by applying for provincial drug programs or prescribing lower-cost alternatives."

Her message to pharmaceutical policy-makers at the provincial and federal levels is to eliminate the systemic barriers inherent in drug insurance schemes.

"For example, the processes to get coverage through the provincial drug benefit programs should be simplified. Public formularies should provide generous coverage to the drugs that are required by people with diverse disabilities.

The heavy deductibles to meet eligibility requirements for exceptional drug coverage should be reconsidered and wait times to get approvals should be minimized. People with disabilities may appear to have minimum basic income on paper, but in reality, they may not have enough money to meet the minimum standards of decent living. Therefore, any public assistance scheme, including national pharmacare, that does not consider the additional barriers faced by people with disabilities may not fulfill the intention of financial risk protection in a true manner."

For Gupta, who grew up and worked in India as an OT prior to coming to Canada in 2016, the subject has long been fascinating.

"In India, many low-income families incur catastrophic expenditures for basic essential healthcare, out of which around 60 to 70 percent goes to medications. This places most of families into debt. My interest in the topic of access to medicine emerged from there. When I came to Canada, I observed that health inequalities exist in every part of the world; that despite having free healthcare, Canada doesn't provide complete coverage of prescription drugs. When I started to follow this issue closely, I found absolutely no literature that explores medication cost burden on people with disabilities, which is why I pursued this study."

Not surprisingly, it's a line of research that she's already exploring further.

"Presently, I'm analyzing use of over-the-counter medications by people with SCI and the associated costs. My big plan is to apply for post-doctoral funding to develop a cost-sensitive electronic tool for physicians that can bring drug cost information to them at the point of prescribing. This tool will be embedded into the native workflows of prescribers and help them choose low-cost alternatives for their patients who are at risk of forgoing their medications due to cost. I am hoping to create this tool, which will bring patient-specific cost information, coverage restrictions and therapeutic alternatives at the point of prescribing." ■



Dr. Shikha Gupta



Busker Dan

Talent, technology and tenacity have allowed SCI BC peer Danny Sloan to become one of Vancouver's most well-known street musicians.

If you ask Danny Sloan about the perks of his workplace, it's location first and foremost.

"I love playing music, whether it's busking or not," says the 49-year-old Vancouver guitar player, singer and songwriter who has been earning part of his living as a street performer for the past ten years. "But if I were to list the things that make busking particularly special, I'd say this: your office window offers 360 degree views of the mountains, False Creek, Vancouver's night lights. Such stunning, beautiful views.

And the sunsets! I can't tell you how many I have seen."

But the stellar views are just part of the story.

"I get multiple memorable moments a week," adds Sloan, a T10 paraplegic. "Most of the time, they revolve around watching kids watch me. I keep timing with my head, as I can't tap my feet, so that sometimes creates a very memorable scenario where the kids watch my head and start bobbing theirs. Then their parents' phones come out. Honestly, I have had so many great moments, I can't even

count them. It's probably the most underrated job I can imagine."

He's quick to point out that, like any job, busking isn't without its challenges.

"I often times finish playing my ass off and no one claps or notices," he says. "It's okay; it's the nature of it, but it teaches you to not be so dependent on others for affirmation. It's also a production-type job. I play four to six hours a day, five days a week, so you get sick of yourself, naturally. You have to do things to motivate yourself while playing; you have to reach deeper inside yourself."

Although he started playing guitar when he was 20, it wasn't until he was injured seven years later that music became vitally important in his life.

"With the changes and extra time that my SCI brought me, at first music was a kind of soother," Sloan told us a few years ago when we published a profile of SCI BC peers who are musicians. "The ball then just kept rolling faster and faster. Songwriting and singing exploded for me in university and, when I was at my lowest point emotionally, I turned to music. It may very well have saved me when I made the conscious decision to dedicate myself to it as much as possible."

Over the years, Sloan has developed his own unique style that incorporates blues, rock, Latin and folk themes. He plays rhythm and lead guitars, both acoustic and electric. With his band Digger Dan & The Dirt Brigade, and via other collaborations, he's played countless gigs in and around Vancouver—and continues to do so. But over the years, he's found himself busking more and more, to the point where it's now become his own version of a regular 9-to-5—it's a never-ending gig as there's always somewhere to play, and someone to play for.

"I came to busk while I was living in the Okanagan and had these melodies, but didn't know how to sing. I felt self-conscious singing at home, but less so outside. So I started with a very simple acoustic guitar set up—some days I wish I went back to that!"

As for the pandemic, Sloan says he's overcome his initial fears and now uses a

common sense approach in order to continue busking—something he believes has become that much more popular given the current lack of more formal and indoor entertainment options.

“At first I was freaked, like most people, and kept indoors. Then I lost my fear, and decided to go out. I just went to two places—Olympic Village and Harbour Green Park. It was kind of weird. It was like an open air pub in Olympic Village. Everyone carrying bags of booze. It didn’t feel a lot different though. I did begin interacting more with people during that time, and found people particularly appreciative because, of course,

live music events were cancelled.”

Wondering how a musician with paraplegia gets himself and his gear to a location and set up? The answer is his rig—a power wheelchair that’s been amazingly outfitted so that he can move a ton of equipment to a location using public transit, set up with virtually no assistance from anyone around him, and play a full day of music. See below for a visual overview of his rig.

“It allows me to be totally independent when I busk,” he says. “Occasionally I get someone to hang the bag on my back, but it’s pretty rare. I have several setups for the power and even the manual wheel-

chair in the event that I have a problem with my chairs.”

He adds that he’s always thinking of ways of improving the efficiency and usability of his rig, and he’s making small adaptations all the time, often with the help of those who helped him create it in the first place.

“I’d like to send out a big thank you to Ed Bell (Bell Tech), Doug Gayton (Vancouver Resource Society), Dave Joseph (CS Mounting Systems), and the Neil Squire Society for helping me with my rig,” he says.

To see and hear Sloan play online, or learn more about him, his rig, and his upcoming gigs, visit diggerdanmusic.com or [instagram.com/digger_dan_music](https://www.instagram.com/digger_dan_music). ■

DANNY’S BUSKING RIG



Chest pack for picks, capo, hearing protection, a plastic bag to go over Danny’s controller in the event of rain, a headlamp, spyglass, multitool, wallet, keys, change purse, etc.

Lightweight, made-in-Canada Yorkville EXM Mobile Amp, powered by lithium ion batteries.

Rugged MEC 60 litre duffel bag hooks onto the on the back of Danny’s chair with carabeener and contains cables, effects pedal board with attached sign, music books, tip box, a foldable step stool, and music stand.

Heavy duty Quantum Q6 Edge power wheelchair with larger batteries to carry extra weight. “It’s purple. I call it The Purple People Eater. PPE...my kinda PPE.”

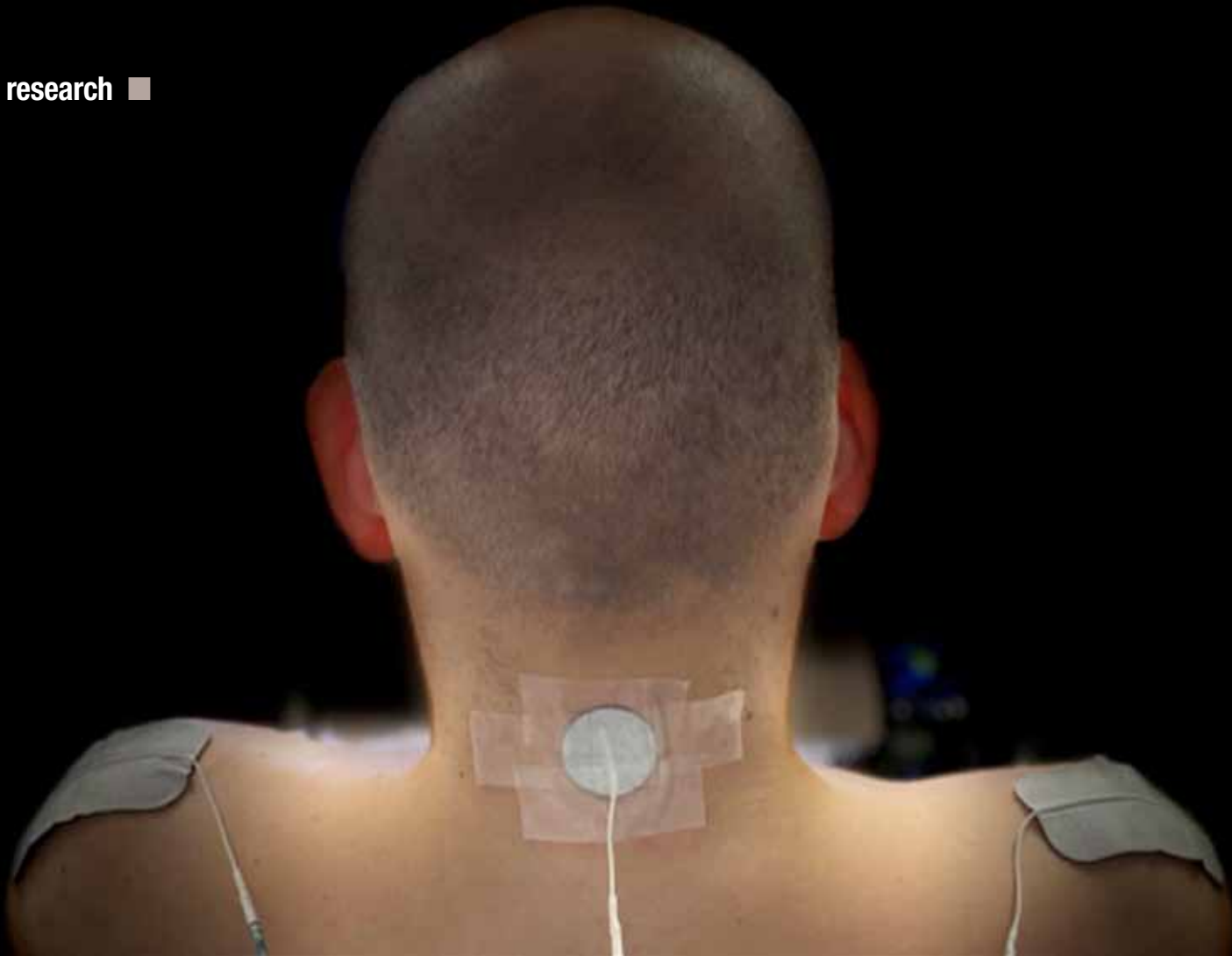
MONO Tick 2.0 bag attached to front of guitar case contains tools, cables, power adapters, extra batteries, a second mic clip, guitar straps, string cleaner, a clip on night light, wind clips, spare strings, and a string winder.

Custom MONO case for two guitars—one acoustic, one electric. “I mix it up between both because electric guitar is easier on my hands and voice as I solo more and sing less than on the acoustic.”

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- OTHER GADGETS, HACKS AND MODS (NOT SHOWN):**
- Three mounting systems from CS Mounting Systems
 - Custom effects pedal board, made from wood with velcro across it to hold pedals
 - Velcro on the side of amp to hold a variety of items within arm’s reach
 - Velcro on cables to prevent them from hanging/wearing out input connectors
 - Mic stands that hold a variety of things, including a camera to record “the often funny random goings on while busking—children dancing, weird adults, etc.”

Mehrezia Khazri Photo



Breathe Easier

Neuromodulation, also known as neurostimulation, has emerged as a viable way of improving many critical functions after SCI. UCLA researchers have now shown that breathing and coughing ability is yet another function that could be improved with this approach.

We've devoted a lot of ink in the last couple years to research that demonstrates neuromodulation—and more specifically, transcutaneous or non-surgical methods of neuromodulation—is a safe and effective method of reawakening neural circuitry to improve a number of critical functions in people with SCI.

Dr. Reggie Edgerton, the UCLA professor who is acknowledged as being

the “father of modern spinal neuromodulation,” along with his fellow UCLA collaborator, Dr. Parag Gad, continue to be at the forefront of this work. Not only that, in order to support their research, the duo have developed their own proprietary transcutaneous neuromodulation device, TESCoN (an acronym for Transcutaneous Electrical Spinal Cord Neuromodulator). Their goals are to continue demonstrating the potential of

neuromodulation in improving function for people with SCI, as well as the efficacy and safety of their device in order to have it receive FDA approval—all with an eye to bringing it to market with their privately-held company, SpineX.

In previous studies that we've written about, Edgerton and Gad (along with other researchers around the globe) have had successful outcomes using their approach to transcutaneous

neuromodulation to restore a number of critical functions after SCI. These include bladder function, hand function, trunk control, blood pressure regulation, and standing ability.

Now, it appears you can add breathing and coughing to the list. The UCLA duo recently published a paper in the *Journal of Neurophysiology* that outlines how they went about using TESCO_N to improve the breathing and coughing function of a single study participant who is quadriplegic.

“It’s the first time we demonstrated that impaired breathing and coughing can be improved in someone with severe SCI using a non-surgical approach, with long lasting effects, with the potential for a huge impact on their quality of life,” says Gad, who is a biomedical engineer. “And we believe that many others could benefit. People with low cervical or high thoracic injuries can breathe independently because of intact diaphragmatic function, but they have significantly reduced lung capacity, expiratory flow and coughing strength due to paralysis of their intercostal and abdominal muscles. This decreased respiratory performance often leads to a compromised sense of well-being and even continuous anxiety—not surprising, since it’s an important contributor to respiratory-related disease and even

death. Simply put, the ability to cough out phlegm voluntarily has a significant impact on people’s quality of life.”

The idea for this case study more or less presented itself to the duo.

“During previous studies involving other functions like bladder control, several participants reported anecdotally that their coughing and breathing was better, even though we never targeted these functions specifically,” says Gad. He adds that, since previous studies showed that respiratory function in people with quadriplegia could be improved using epidural spinal cord stimulation (an approach that relies on a stimulation device being surgically implanted under the skin directly on the spinal cord), it was reasonable to assume that their approach, which requires no surgery, might offer the same benefit without the risk and high cost.

As stated in their paper, their hypothesis was that “transcutaneous electrical neuromodulation of cervical spinal neural networks can facilitate the activation of intercostal and diaphragmatic muscles, thus increasing inspiratory and expiratory capacities and improving coughing ability.”

They set out to test their hypothesis by first recruiting a 39-year-old male participant who, as a result of a complete C5 injury in a diving accident nine years

earlier, had impaired respiratory function, along with decreased ability to cough and to clear phlegm—especially while lying down.

The participant agreed to a four-week study with three phases: a one-week assessment to establish his baseline respiratory function, followed by a two-week course of TESCO_N therapy, and a one-week post-therapy assessment to determine the extent of any improvements in his breathing and coughing function.

Once the initial week of assessment was finished, the therapy portion of the study commenced with work to determine the best location for the electrodes on the skin above the spine, along with the ideal intensity of stimulation. The therapy was then delivered with one 60 minute session daily, five days per week.

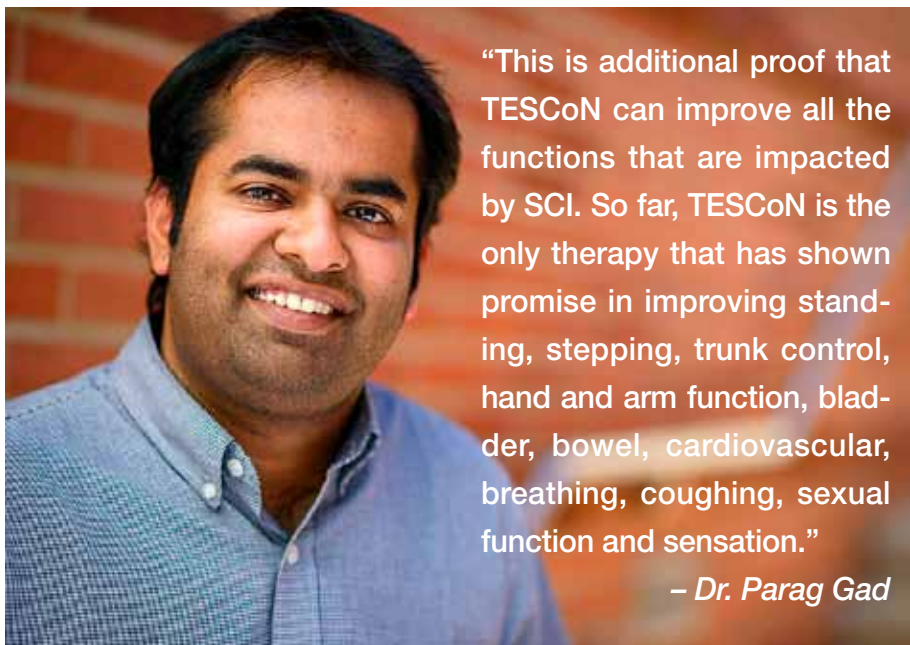
“Our participant was free to read, work or sleep while the therapy was underway,” notes Gad.

The participant’s peak airflow during expiration, the volume of air during a forced exhalation, blood pressure, heart rate and oxygen saturation were carefully recorded throughout the entire four weeks.

“We almost immediately observed an improvement in breathing and coughing function,” says Gad. “The participant was able to take a deeper breath with more control, and was capable of exhaling in a controlled manner. While attempting to voluntarily cough, he was able to engage most of his trunk and abdominal muscles, resulting in louder and deeper coughs. And during and after a TESCO_N therapy session, the patient looked more energetic and seemed to have a glow on his face.”

The actual data from measurements confirmed the benefits of significantly improved breathing and coughing ability.

These objective changes were also reinforced with subjective improvements noted by the participant himself: he believed that he needed less effort to breathe and had more energy throughout the day. Also, prior to the study, the participant needed to have his chest



“This is additional proof that TESCO_N can improve all the functions that are impacted by SCI. So far, TESCO_N is the only therapy that has shown promise in improving standing, stepping, trunk control, hand and arm function, bladder, bowel, cardiovascular, breathing, coughing, sexual function and sensation.”

– Dr. Parag Gad

and head elevated in order to cough while laying down. Within three days of TESCO_N therapy, he reported that, for the first time since his injury, he was able to cough without having his head and chest elevated. This phenomenon was sustained during the one week follow up period.

Gad says it's reasonable to believe that, based on previous studies, these improvements in breathing and coughing function will last two to four days after a therapy session.

"Additional studies are needed to optimize the frequency and duration of the therapy session for each person," he adds. "Meanwhile, these data are encouraging in that, with continuing efforts to further refine the treatment and to apply the procedures for more prolonged periods, there is considerable potential for this intervention to significantly and safely elevate daily respiratory functions of people with an injury of such severity—especially those that may not qualify for existing neuromodulatory options."

He also explains that, in the future, TESCO_N may also be used to help people with even higher levels of injury lessen or even eliminate their dependence on a ventilator.

"This is additional proof that TESCO_N can improve all the functions that are impacted by SCI," says Gad. "So far, TESCO_N is the only therapy that has shown promise in improving standing, stepping, trunk control, hand and arm function, bladder, bowel, cardiovascular, breathing, coughing, sexual function and sensation. Meanwhile, our company, SpineX, has made progress on multiple fronts, including engineering improvements of TESCO_N necessary for FDA validation studies. One of our primary goals remains achieving FDA clearance in order to offer this device for home use by anyone with an SCI or their caregivers. That is definitely a direction we are very interested in, and we'll continue to explore what the logistical, regulatory and reimbursement hurdles are."

Learn more at www.spinexmed.com. ■

ask the SPIN DOCTOR

Dustin on Vancouver Island asks, "I'm ambulatory but I didn't figure out that braces could help me with walking until I was out of rehab. How do I find out what braces are the best fit for me?"

There are many braces, or orthoses, that can help you walk. The goal is to prescribe the least restrictive device that allows for safe stepping or standing and normal muscle and walking patterns. During rehab, you might test drive some braces to see what might work for you before you buy your own. After rehab, you can talk with your physiatrist about braces in order to get a referral to an orthotist. Braces prescribed by a physician are often covered by funding sources.

People with incomplete injuries are the most common users of braces, and their needs depend on the level and completeness of injury, and whether they have spastic (upper motor neuron or UMN) or flaccid (lower motor neuron or LMN) paralysis.

For people with complete UMN injuries, brace-walking is challenging—it requires a tiring walking pattern that relies on the upper body to bear their body weight as they use a walker or crutches. Knee-ankle-foot orthoses (KAFO) are the most common braces used, with variations for higher injury levels. These rely on splints that immobilize the knee, ankle and foot, with hinges for knee bending. Some variations of these provide trunk support and have spring locks that allow the user to swing through at the hip joint. KAFOs are generally used for short distance stepping and weight bearing.

Several types of braces are prescribed for those of various injury levels with some lower leg strength that provides the potential to stand or step. The right brace will depend on strength, joint position, spasticity and where/when the brace will be used.

Solid ankle-foot-orthoses (AFO) stabilize the ankle and enable the front of the foot to clear the ground while stepping. Rigid AFOs, suitable for those who need more support, are often thicker and provide more ankle and foot control, and are also available with a hinge at the ankle to allow for a more normal gait. Spring AFOs are made of lighter materials and do the same thing, but allow some flexibility of the ankle for easier climbing of stairs or inclines.

Dynamic AFOs are made of strong but flexible lightweight materials that allow a more natural range of motion while using the spring action of the materials to assist with push off from the ground and raising the foot. These are for users with at least minimal strength in the muscles that pull the leg back.

Dictus is a soft AFO for users who have ankle stability. They have a short ankle strap that connects to the top of the shoe or a brace on the foot to hold the front of the foot up when stepping through. Leaving the ankle free enables the user to use hip extensors and help with toe push off from the ground. Heel lock ankle braces are an off-the-shelf product that prevent the ankle from rolling, offering stability and preventing injury. Knee braces are frequently used to control knee hyperextension and protect the joint when standing.

Finally, neuroprostheses are also available which incorporate electrical stimulation with a brace to cause a muscle contraction while stepping.

It's essential to speak with your physiatrist, and physiotherapist and orthotist, when considering new bracing options. And if you do start wearing braces or change to new braces, don't forget to check your skin for signs of breakdown every time you use them.

—*Jocelyn Maffin, SCI BC Resource Centre Manager, with assistance from GF Strong Rehab SCI physiotherapists*



Cannabis & AD

Could cannabis be an effective treatment for controlling autonomic dysreflexia? An intriguing case study recently published by ICORD researchers suggests that this might be possible and provides a compelling argument to study the effect on a larger scale.

For decades, SCI BC peers have been using cannabis as a form of therapy—primarily to control pain and spasticity. Countless readers of *The Spin* have reported excellent results. Nevertheless, scientific confirmation of the benefits has been difficult to obtain. Fortunately, legalization in Canada and other parts of the world is improving the situation, and slowly but surely, there's now a small but growing body of scientific evidence to support these personal observations.

Some of that work has been done right here in BC by ICORD Principal Investigator Dr. Andrei Krassioukov and members of his research team, along with members of SCIRE (Spinal Cord Injury Rehabilitation Evidence). Of note is a comprehensive systematic review of studies from around the globe involving cannabis as a treatment for SCI secondary conditions (the review results were published in April in the journal *Current Neuropharmacology*). In the course of working on that study, one of the mem-

bers of Krassioukov's research team, Dr. Tom Nightingale, came up with the idea of assessing the ability of cannabis to regulate blood pressure and reduce the impact of autonomic dysreflexia, or AD, in people with SCI.

"Anecdotally, we were aware of a number of individuals in BC with SCI who were using cannabis to self-manage secondary conditions associated with SCI—primarily pain and spasticity," says Nightingale, who, after two years in Vancouver, recently moved back to



"This absolutely warrants further investigation, particularly in light of the fact that current pharmacological approaches to relieve pain, spasticity, and AD for people with SCI are expensive, are often ineffective, and can result in adverse effects and drug/drug interactions." – Dr. Tom Nightingale

his native United Kingdom to accept an assistant professorship at the University of Birmingham. "During an in-depth discussion with one of our research participants, we were intrigued to hear that conventional and approved treatment options to manage the plethora of conditions he commonly experienced offered little success or relief. These conditions had knock-on effects on his health-related quality of life—sleep deprivation, fatigue and anxiety. To his surprise, smoking cannabis offered a considerable therapeutic benefit, relieving not just neuropathic pain and muscle spasms, but also reducing his bouts with AD."

The participant, a 41-year-old man, had a complete C5 injury that occurred 21 years ago. He described to Nightingale how he has been using cannabis daily for 13 years, vaping about 1000 mg of cannabis concentrate throughout the day, and also consuming two or three edibles, which each contain about 2000 to 2500 mg of THC. He has developed his own formulations with what he believes to be the right mix of THC, cannabidiol (CBD),

and specific terpenes (organic compounds produced by a variety of plants—for example, terpenes are responsible for the scent of pine trees).

"He self-reported a very high degree of efficacy and consistency, and also that his secondary conditions resurfaced with cannabis abstinence when he travelled to a different country or couldn't access specific cultivars, for example," explains Nightingale, who was so intrigued that he asked the participant if he'd be willing to take part in a case report intended to determine the specific impact of cannabis use on AD, along with other secondary conditions associated with SCI.

The participant agreed, and the study was done between September and October of last year. His blood pressure stability was recorded using a 24-hour blood pressure monitor, which he wore on his left upper arm on four separate occasions—twice while he adhered to his standard cannabis routine, and twice after abstaining from cannabis, once for three days and once for seven days.

The results, which were published in

the *Annals of Internal Medicine* on June 16, are eye-opening. It turns out that cannabis use reduced the frequency of the participant's AD by 80 percent—from 57 episodes per day to 11. Cannabis also reduced the severity of his remaining bouts of AD by 36 percent. And that's not the end of the story.

"We found that cannabis use reduced global pain intensity, spasm frequency and spasm severity, says Nightingale. "It also improved sleep and overall well-being by reducing anxiety, impairment, confusion and sensation and enhancing motivation and attention."

As for the actual mechanism responsible for reducing frequency and intensity of AD bouts, Nightingale says he and Krassioukov believe that cannabis stabilized the participant's blood pressure by reducing the intensity and frequency of known AD triggers such as pain and spasms.

"The results are particularly striking, but I wouldn't say I was surprised given the human endocannabinoid system is comprised of cannabinoid receptors found throughout the central and peripheral nervous system and immune system, and the potential wide-ranging effects these cannabinoid compounds can have on bodily functions," says Nightingale.

Naturally, Nightingale is the first to point out the limitations of the study. For one, it was just that—a case study involving a single participant. Also, the participant's blood wasn't sampled to measure THC levels to confirm he had truly abstained in the days when he was asked to. And the effect of withdrawing from cannabis during the days of abstinence can't be ruled out.



Nevertheless, he believes the results are so compelling that the case study should be followed up with a larger, more rigorous research project.

“This absolutely warrants further investigation, particularly in light of the fact that current pharmacological approaches to relieve pain, spasticity, and AD for people with SCI are expensive, are often ineffective, and can result in adverse effects and drug/drug interactions. In our review, we conclude that the majority of existing evidence indicates cannabinoids significantly improve pain and spasticity in individuals with SCI—but the quality of this evidence is only graded poor or fair. Thus, we advocate that long-term, double-blind, randomized controlled trials assessing a wider range of outcomes should be conducted to better understand the effects of cannabinoid use in people with SCI.”

He concedes that one wrinkle to iron out with a potential double-blind placebo trial is that it would be really tough to convince people in the placebo group

they were actually being given cannabis—the lack of its distinctive euphoric effect might be a dead giveaway.

“Perhaps,” says Nightingale, “this is easier to achieve in studies investigating the non-psychoactive cannabidiol (CBD), which produces less intoxication and identifiable side effects than psychoactive THC.”

Understandably, Nightingale is keen to play a role in expanding this line of research. He’s a co-applicant with Krassioukov for a grant application for funding to support a larger scale cannabis study at ICORD to better understand usage patterns and therapeutic potential. But he concedes that, given that cannabis legalization is unlikely anytime soon in the UK, it may prove to be difficult for him to be meaningfully involved.

Meanwhile, if you’re someone reading this who deals with chronic AD (or other issues like pain and spasms) and have decided that cannabis might be a therapy worth investigating, Nightingale offers up a few cautionary words.

“While this preliminary work is extremely encouraging, it’s important to note that there are also potential negative side effects and harms associated with cannabis use—particularly for individuals who haven’t used it before and are cannabis naive,” he says. “In the case study, the participant uses a relatively large dose of THC. This may not be appropriate for other individuals, and many questions remain regarding the most effective or minimal therapeutic dose for certain indications.

“In some individuals, lower doses or different compounds might provide sufficient treatment efficacy, without the side effect of getting too high. For people who are cannabis naive, it’s important to individually and gradually titrate their dose in order to balance efficacy and tolerability. This reduces the chance of adverse events for people who exceed the therapeutic window, or a lack of efficacy in individuals in whom a conservative fixed dose might be insufficient.” ■

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“You’re not disabled”





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The public—and even some of your friends and family—assume you’ve won the disability lottery. But as someone who’s living with an incomplete SCI and can walk, you know that isn’t exactly the reality.

“An incomplete SCI is life-changing; you might seem normal to others, but your life is not—and never will be—as it used to be or could have been.”

These are the words of Vancouver SCI BC peer Susan Cush, an incomplete C2-3 quadriplegic who is ambulatory—in other words, she can walk for limited distances. Yet she admits that, for many years, she did her best to convince herself and others that she was anything but disabled. It was only much later in her 43 year post-injury journey that she realized her denial. You can read more of Cush’s thoughts on the next page, where we’ve given her and three other peers a mini bully pulpit to set the record straight about being someone with an SCI who can walk.

As SCI BC’s Resource Centre Manager, Jocelyn Maffin is in contact with many of our peers who are in the same boat as Cush—people who, at some point, have no choice but to acknowledge and come to terms with the many unique challenges of having an ambulatory SCI.

For many, says Maffin, these challenges begin in rehab with high expectations for recovery—their own expectations, and those of their friends and family. It’s often a painful pill to swallow when it becomes clear that there’s a limit to how much function they’ll regain.

“Returning to their communities post-injury, a really common theme I see is the struggle between expectations of recovery and the realities of everyday life,” says Maffin. “The uncertainty about recovery is huge, and the journey back with ambulatory SCI can feel really unclear. Can I work? Do I need major adaptations? Whether the pressure is from within or outside, it seems that many ambulatory peers don’t know what to expect of themselves and struggle with the perception of others around them. In many ways, I think it’s harder for this group to adjust to their new lives, not knowing exactly how much return of function they’ll get; not having a generally accepted and predictable journey like we see with folks who have more paralysis.”

She adds that others’ perceptions and misconceptions about this type of injury contributes to the problem. If you can get up out of your wheelchair, why do you need one? If you can walk, who cares if you tire easily, or struggle controlling your bowel and bladder? What’s a little pain when you can get around on your own two feet?

“For many, it’s a big struggle—the invisibility of what they’re dealing with to those around them,” she says. “Those of us using wheelchairs most or all of the time can feel underestimated, but our validity as someone in need of support isn’t questioned. Our chairs are the proof of our membership, but it’s not so obvious for ambulatory peers. That makes things complicated when people around you see you walking again to some degree and consider you recovered. Ambulatory peers tell us that people around them forget they have a permanent disability, and expect them to be their old self, keep up physically, or manage family roles the same way they always did. Meanwhile, they’re also dealing with the invisible complications of SCI: pain, fatigue, sexual dysfunc-

tion and bowel and bladder issues, for example, without the external validation of the struggles they're dealing with, in the form of a wheelchair."

Enter the process of aging, and all of its unique complications. Legs and balance that don't work as well as they used to. Loss of bone density due to SCI and subsequent fractures. Secondary complications like pain, spasticity, and bowel and bladder dysfunction that get steadily worse, forcing people to consider major changes like using a wheelchair full-time at a time in life when many non-disabled people think of themselves at their prime.

All of this, says Maffin, can create a perfect storm—people with incomplete SCI often seem to struggle with asking for help in the first place, and when they finally realize they need to, they overcome their discomfort at doing so only to discover there's often not a lot of support out there that's specific to their situation.

"Falling through the cracks almost seems to be a rite of passage for ambulatory peers," she says. "They initially seem to spend less time in hospital and often miss out on the connection with other people with SCI, and with our SCI resource centre, and the important edu-

cation they'd get at SCI-specific rehab. I hear, 'I didn't realize there were other people out there like me' or 'I didn't know what I was dealing with was considered a spinal cord injury until now.' When you don't truly understand the implications of your injury, it's profoundly difficult to learn about it, figure out how to manage it and find people like you to learn from—and this seems to be intensified for older people, after a life of downplaying disability and fiercely maintaining independence."

Little wonder that many experience an internal struggle when they're trying to

Setting the Record Straight...

We asked a few of our SCI BC peers who are incomplete and can walk to answer one question: if you had a short opportunity to tell the public—and even your friends and family—about the nature and implications of your injury, what would you say? Our thanks to Gord Rant, Noreen Segui, Susan Cush and Lisa Hislop for sharing their insights about their post-injury lives.

GORD RANT Victoria, BC C5 incomplete, 25 years post-injury

If I could have my family, friends, and members of the public know just one thing about my disabilities it would be that they don't define me. They've given me the opportunity to grow and persevere through many challenging situations, and have taught me many valuable life lessons that I may not have learned had I not had them.

That being said, I have an incomplete injury and can walk a little bit, and a lot of times that gives members of the public the impression that I don't need my wheelchair or other sorts of mobility aids—which is untrue and frustrating a lot of the time. When I go to sit in my wheelchair after going for a walk, or stand up from my chair to stretch, a lot of people give me some dirty looks.

I think people just need to take a little more time to understand that disabilities are all different and present themselves in different ways.



NOREEN SEGUI Vancouver, BC C2-C5 incomplete, four years post-injury

I had a very difficult recovery. I have chronic pain, am very slow when I walk, and can't walk far. I still have hypersensitivity that also won't go away.

The most common questions I get from people that I meet who don't know me is, "What's wrong with your legs?" or "Did you hurt your legs?" I get tired of explaining to people that I actually have an incomplete SCI. I can explain what had happened, but I'm not really sure if they understand my situation. I want them to know that there is more to this than meets the eye—the chronic pain, hypersensitivity around the area of injury, fatigue, both legs feeling very heavy, etc.

When I became an SCI BC member, I learned to communicate my situation better because I talked to people who have the same experiences as I do. Walking or non-walking, we have common experiences that made me realize that I'm not the only one going through these problems.



figure out where they fit within our SCI community.

“Many people speak about feeling guilty or uncomfortable that they regained walking function, while so many others haven’t,” she says. “Also, we often joke about how every conversation eventually devolves into talk about your bathroom needs when you’re with a big group of peers. But this off-colour humour or frankness that comes from a shared inability to conceal our body’s dysfunctions can take on a whole other meaning when you’re struggling with all of the issues of life being someone who is

incomplete and can walk, and you’ve always tried to conceal or downplay these types of issues.”

Here at SCI BC, we think we’ve always had an open door for people with incomplete injuries who can walk. But we know we can do better. And given that the number of these types of injuries are rapidly increasing, we have to do better. And that’s why we’re stepping up our efforts to provide meaningful support to peers with these types of injuries.

“We’ve had ambulatory peer groups for awhile now,” explains Maffin, who is part of SCI BC’s effort to understand and

support this population. “The old Walking Invisible coffee group was very well-liked but wrapped up when members moved on to other things. We have a Facebook group for incomplete SCI ([facebook.com/groups/IncompleteSCI](https://www.facebook.com/groups/IncompleteSCI)) that is a gathering place for ambulatory peers as well, which we created when we realized how few options there are. But we’re committed to doing more. I recently had an aha! moment while meeting up with an ambulatory peer who had been to a few of our events and was feeling kind of frustrated. As we talked, suddenly I realized: our events were so wheelchair user-focused

SUSAN CUSH Vancouver, BC C2-C4 incomplete, 43 years post-injury

I tried so hard to be “non-disabled”. During my 30 years of working hard as a nurse, I didn’t talk about my injury. Instead I pushed on through the pain of contractures in my feet and legs. I didn’t question that the painful lumbar spine at L4 L5 was anything other than a work-related injury. I didn’t clue in to the fact that the urgent surgery to fuse my neck in 2018 at C2 C3 C4 C5 was related to a common problem of spine fractures—breakdown at the fracture site. Nor did I realize that osteoarthritis in my left knee was anything more than an inherited familial flaw. I should have realized that I didn’t have anything to prove physically.

As life progresses, we increasingly become the “walking wounded”. We fall easily and are affected not only by frequent ongoing injuries but also by the non-visible problems of other quadriplegic people—neurogenic bladder and bowel, and autonomic dysreflexia. An incomplete SCI is life-changing; you might seem normal to others, but your life is not—and never will be—as it used to be or could have been.

Today, I use a walker and have for the past 10 years plus. I am very cognizant of accessibility with regard to stairs, scatter rugs, carpet, etc. After outpatient physio at GF Strong last year, the physiotherapist and OT both recommend that I move to get an electric wheelchair because of frequent falling. So far I’ve been pushing back on this as I am mobile and I don’t honestly have a wheelchair-friendly kitchen and bathroom. I’d be interested in hearing what other incomplete quads have to say about these things—the electric wheelchair option, frequent falls, and their solutions to common problems we face.



LISA HISLOP Vancouver, BC T12/L1 incomplete, 20 years post-injury

The hardest part about having an incomplete SCI is that my adaptive needs are inconsistent. As someone who uses a wheelchair, but can walk with almost no impairment, I don’t fit the description of a disabled person, let alone a wheelchair user. So, when I’m in a place where I’m doing both, and people don’t know me, I have to be careful. Something as simple as getting up from my wheelchair and going for a walk during a break can feel to others like a real betrayal of their trust.

This seems like a bit of a dramatic claim, but some people have boldly accused me of faking to get attention—which I suppose is an understandable reaction, considering how few people I have seen rise from a wheelchair and walk. At the same time, I don’t want to have to delve into my personal history to satisfy their need for an explanation, or pretend that my injury is more severe than it is to avoid confrontation. If I could share one piece of advice with the public, it would be to consider the person getting up from their chair (or sitting down in one) as being completely honest with you, rather than completely fake. No explanation needed.



that we never brought outdoor rec equipment that allowed him to use his feet and legs. All handcycles, no bicycles. We often forgot to put out enough chairs to sit in, and of a kind that a walking peer—who might have the same issues with pain, skin and circulation that most SCI peers have—would be comfortable sitting in. I felt profoundly embarrassed after all this time talking about every kind of diversity in our community and realizing that we have so much to learn about building a community that ambulatory peers, an increasing portion of our community, would feel supported in.”

Ambulatory peers reading this can expect to see our events, both virtual and in-person when we return to that, more relevant and prepared for them. They can also expect to find more relevance in our various information resources and communications vehicles, including our social media pages and *The Spin*.

“I think we’ve begun to recognize the need to create some peer support time to connect ambulatory peers to each other, in addition to ensuring that our events are welcoming to them,” says Maffin. “We know these peers are scattered across the province, making it even harder to provide them that opportunity to connect with another ambulatory peer at an event near them. In the short term, SCI BC is starting a monthly ambulatory peer group this fall via Zoom to connect peers to each other. Ryan Clarkson, SCI BC’s Peer Coordinator at GF Strong, is hosting. We’re planning a retreat geared toward ambulatory peers (as soon as public health guidelines allow), so that we can draw in folks from around the province for a fun weekend of recreation, and a chance to feel that ‘click’ of peer support that happens when you talk with someone who really gets you.”

Beyond that, we’re also going to do our best to stimulate more research around this unique form of SCI with the goal of creating better recognition of the accessibility and healthcare needs for peers who are ambulatory.

In fact, that’s already underway, as we’ve teamed up with ICORD Princi-

pal Investigator Dr. Ben Mortenson to conduct a study that attempts to better understand their needs and the gaps in support they experience.

“I did some research to find other examples of peer support or recreational programming geared toward ambulatory people with SCI,” explains Maffin. “I stumbled across a publication of Ben’s on PubMed about outdoor recreation and people with MS. What drew me to it was the community-oriented approach that looked at all angles—what their participants got out of these events, but also what they needed; what made them feel most supported. Joining together on a project seemed like a good chance to learn from our community, and in turn, share the knowledge.”

Maffin reached out to Mortenson, and found a more-than-willing researcher.

“Jocelyn suggested that we dig into the experiences of people with incomplete SCI,” says Mortenson, who has a PhD in Rehabilitation Sciences. “The needs of people with incomplete SCI are frequently overlooked and are poorly understood by others. Previous research in this area suggests people with incomplete SCI experience difficulty reintegrating into their community, have barriers that limit their participation in desired activities, and have unique challenges because they are living with an invisible disability. All of these factors can have a significant impact on individuals’ quality of life, and current services and support may not be very helpful in mitigating these impacts. Historically, most programs and services for people with SCI have focused on those with more complete injuries, and thus individuals with incomplete SCI may feel that these supports don’t meet their needs or feel that they’re not welcome to participate. So our study seeks to address this gap in knowledge and use what we learn to improve supports for this group.”

A primary goal of the study, says Mortenson, is to disseminate the findings with the goal of increasing awareness about the needs of people with SCI who can walk, helping the SCI community ad-

vocate for practice and policy changes that may ultimately improve their quality of life, and giving organizations like SCI BC a tool they can use to provide better peer support and encourage inclusion within the community.

The study, which you can learn more about on page 28, will rely exclusively on interviews with people with incomplete SCI.

“They are the experts given their own learned experiences, and thus are the best resource for identifying gaps and suggesting improvements,” says Mortenson.

Maffin hopes the results will be an important tool as SCI BC ramps up peer-to-peer support for a group of people who are often unsure if they fit in, don’t feel supported, and may find themselves isolated later in life as their needs intensify.

“This kind of isolation isn’t uncommon, and in some ways typifies the ambulatory experience,” she says. “For example, I hear from a lot of ambulatory or semi-ambulatory folks that they resisted getting more adaptive equipment or using a wheelchair because they thought they’d feel more disabled if they did. Instead, it helped them feel more control and independence. Sometimes that’s a stereotype that comes out of our own heads. My hope is that, no matter how peers are getting around, they realize we get what they’ve been through and the invisible SCI stuff they deal with. It gets easier when you know you’re not alone in dealing with it. What I’d say to them is to try a peer event or zoom session once and treat it like a ‘check in’—share your ninja skills and you might find that you’ll learn some yourself. I find that when we can help connect folks to someone they click with on a peer-to-peer level, those negative messages or stereotypes kind of fall away.”

For more details about our ambulatory peer sessions and other efforts to improve our services for ambulatory peers, check out our online events calendar at sci-bc.ca and future issues of *The Spin*. You can also reach out at any time to Ryan Clarkson (rclarkson@sci-bc.ca). ■



"I'm lucky enough to have family and friends that are willing to go for walks with me, and when the second wave hits, that will likely be my only form of exercise because the adaptive gym I attend will probably be forced to close down again."

GORD RANT, Victoria

"I use a NuStep T5XR accessible and adaptive crosstrainer safely inside my house. It's completely manual though, and does not do the work for you. Even if you can't use your legs, the arms allow full motion. You can learn more at nustep.com/international/products/t5xr."

GORD SHARKEY, Kelowna



"I use my arm ergometer on the counter. I have two different tension bands with handles that wrap around my door handle for strengthening exercises, and I'm having fun with the Wii sports and resort games—I like the boxing, bike racing, tennis, kayaking and sword fighting. It's an awesome workout! I bought two wristbands for my hands and the controls slide underneath them and stay in place, as being a quad limits my grip"

LISA SCHULTZ, Kelowna

"I have strength bands that I use in the bathroom, and my physiotherapist gave me some non-weight bearing exercises to do on my bed. I don't feel comfortable going to the rec centre right now. That's how I'll cope."

JANET O'NEILL, Kelowna



PeerSAY!

Given that many experts are sounding the alarm about the possibility of a second wave of COVID-19 this fall and winter, we posed this question to a few of our peers: if this becomes a reality, and if it brings another set of restrictions, how do you think you'll stay fit? Do you have some tried and true methods that work well for you, or are you planning on trying something different?

"I hook up my GoFreeWheel and go for a wheel—either on the rail trails here in the Okanagan, or to one of the many trail systems that I have found to be fairly accessible and where I can also take my dog for a run. Depending on the level of exercise I want to have on any given outing, and along with my GoFreeWheel, I can also add my Smart Drive to my chair—and then I can venture off on trails that typically would be too difficult. Going for a handcycle ride is also another great option."

SONJA GAUDET, Vernon



"I have a couple of cuffs and a 12-pound dumbbell and I use them on occasion (should be a lot more). COVID has definitely had an effect on my working out, as I used to exercise five days a week. Now it's maybe once a week and only one exercise really. If COVID-19 gets worse with regards to a lockdown, then I would say I could use bands, or I know that there are some videos online through PARC that show different ways to exercise."

KENT GOULET, Vancouver

"I just moved to Kelowna in November 2019 and just started my fitness routine as the pandemic got started. I tried to get basic exercise equipment but found that was near impossible. Lucky I finally found a stationary handcycle and purchased it along with a set of dumbbells. So to keep my activity up and fitness goals somewhat inline, I cycle three to four times a week and weight train as often as possible. Now with the summer going all out I have headed down to the waterfront and wheeled around, working on my balance and mobility. The pandemic has been stressful but, with these few pieces of equipment, I have been able to keep from gaining weight and losing strength."

ROBB PULLEN, Kelowna



Have you ever wanted to find out how others tackle those everyday challenges of SCI life? Let us find you an answer from SCI BC's peer community. Email your questions (and suggestions) to jmaffin@sci-bc.ca.

Participate in Research

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

At ICORD (International Collaboration On Repair Discoveries), SCI research is also about improving bladder, bowel, and cardiovascular health; taming pain and autonomic dysreflexia; enhancing sexual health and fertility; new assistive technologies; wheelchair design and ergonomics; and much 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.

Understanding the Experiences of Individuals with Incomplete Spinal Cord Injury Who Can Walk

Overview: There is a growing number of individuals who have incomplete SCI who are able to walk. Having an incomplete SCI comes with challenges including living with a potentially hidden disability, and there are questions about the suitability of programs for people with incomplete SCI (which were originally developed for people with complete SCI). Researchers in Dr. Mortenson's lab are proposing a study with the following objectives: to identify the distinct needs and strengths of people with incomplete SCI who are able to walk, and to explore potential supports, services and programs that would best assist this population to adjust, adapt, and thrive in the community.

What to expect: Participants will take part in a semi-structured interview, provide demographic information and complete standardized questionnaires about their quality of life, level of function and health. Data collection sessions will take place over the phone or online via Zoom. Total time commitment is approximately 75 minutes.

Who can participate: You may be able to participate in this study if you have an incomplete SCI, are able to walk short distances with or without aids, and are 19 years of age or older.

Why participate: Findings from this study will identify ways to improve the experiences of people with incomplete SCI who can walk by increasing awareness about their needs. In addition, the findings will help the SCI community advocate for practice and policy changes that may ultimately improve their quality of life. The results of this study will also be significant for our community research partner, SCI BC, as they anticipate using the findings to provide better peer support and encourage inclusion within the community.

Location: Remotely (online survey/phone/video call).

For more information or to sign up to participate: Please contact Jodine Perkins by email (Mortenson.lab@ubc.ca) or call 604.737.6491.



SCI Research Participants' Views on Data Sharing Survey

Overview: Researchers in Dr. John Kramer's lab are investigating how individuals with SCI feel about researchers using their data. Specifically, they want to learn how you feel about data sharing. Data sharing is when the data collected in one research study is anonymously shared with others, meaning that a researcher allows others to see and use an individual's data, after deleting any information that could identify the individual (name/birth date). Medical information is provided in full. As it is your information that would be shared (anonymously), the research team is very interested to find out your opinions on data sharing.

What to expect: This study involves filling out an online questionnaire that asks about your health and SCI status, your opinion on the potential benefits and risks of data sharing, your preferences regarding informed consent and privacy protection, and your level of trust in researchers and others. Information will be collected about you, your health, and your injury to learn about the characteristics of the people who took this survey.

Who can participate: You may be able to participate in this study if you have an SCI and live in Canada or the United States.

Why participate: Through this anonymous survey, you are able to add your voice to the debate around data sharing in the SCI community.

Location: Remotely (online survey/mail in survey/phone survey). The survey is available in English, Spanish, or French upon request.

For more information or to sign up to participate: Please contact Dr. Freda Warner by email (kin.SCIsurvey@ubc.ca) and include "SCI Data Share" in the subject line of your email in order to receive a secure survey link. In the email, please confirm that you have an SCI. If you prefer, you can also call Dr. Warner at 778.814.1401 to complete the survey by telephone.



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

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Be Heard!

An opportunity to let governments know about your needs and concerns related to COVID-19

A second wave of COVID-19 this fall and winter seems likely, and as we contemplate that, many researchers and community organizations (including SCI BC) are sounding the alarm over the potential health impacts and greater support needed for Canadians living with disabilities.

Getting a handle on these challenges is the goal of a Canada-wide survey being conducted this fall via a collaborative effort between UBC researchers and the Abilities Centre, an Ontario-based disability resource organization.

“We are deeply concerned for individuals struggling with increased social isolation and reduced access to services that support their health, well-being and needs as a result of COVID and COVID restrictions,” says UBC Okanagan professor Kathleen Martin Ginis, who is leading the National COVID-19 Disability Survey. “We need to fully understand the scope and complexity of these challenges as the pandemic continues for the foreseeable future.”

The initial 20-minute confidential survey is intended for Canadians who identify as having a disability (physical, cognitive, or sensory) or having a child or family member living with a disability in their household. Participants will be asked to share their unique experiences and concerns while navigating the COVID-19 pandemic.

There’s an opportunity for participants to complete an additional series of questionnaires while the public health measures remain in place to help evaluate and enhance new policies and community support programs.

“It’s imperative the voices and concerns of Canadians living with disabilities are reflected in the public

health response to COVID-19,” Martin Ginis says.

“This is a great opportunity for SCI BC peers to let our governments know how this pandemic has impacted them,” says SCI BC Executive Director Chris McBride. “In particular, we think anyone who has had difficulty or concerns staying safe with their caregivers, obtaining PPE, and even simply having enough

funds on hand to stay prepared and safe should act on this opportunity.”

The survey will be repeated monthly for the next year or so as COVID recovery continues.

To participate in the COVID-19 Disability Survey, visit abilitiescentre.org/disabilitysurvey. For more information, email disabilitysurvey@abilitiescentre.org or call 1.866.639.1858. ■

COVID-19 & Spinal Cord Injury

Having a spinal cord injury may put you at greater risk of COVID-19 complications given compromised immune and respiratory systems. Here's what you can do during this time.

For detailed information, check out: scoreproject.com/community

Prevention

- Practice **physical distancing** and avoid close contact with people who are sick (2m/6ft).
- Wash your hands** often with soap & water for at least 20 secs or use an alcohol-based hand sanitizer.
- Ask attendants to wash their hands upon arrival and before providing you with any assistance and **send home** those who are unwell.
- Ensure attendants have **not travelled** outside of the country in the past 14 days.
- Clean surfaces you often touch: phone, doorknobs, and commonly touched surfaces on your wheelchair and other assistive devices.
- If you have limited hand function, **avoid using your mouth** to grasp things.
- Consider using a **face mask or covering** when out in public spaces.

Keep 30 days of medical supplies (e.g., catheters) and medications on hand.

Have a back up plan for if you are unable to receive the assistance you need.

If you use a ventilator, CPAP, or cough assist device, speak to your health care provider about what precautions should be taken in your home:

- Clean your equipment and replace filters regularly as per your device manual
- Ensure an adequate supply of filters and tubing

Symptoms

Early research shows that COVID may present differently in SCI. Common symptoms include:

- Fever ($\geq 38^\circ\text{C}$)
- Difficulty Breathing
- Fatigue/Weakness

If you have symptoms

- Isolate yourself at home and avoid visits with older adults or those with medical conditions.
- Call ahead before you visit a health care professional or call your local public health authority; many are using tele-health.
- If your symptoms worsen, contact your health care provider right away and follow their instructions.

SCORE Community Information received as of SPINAL CORD INJURY RESEARCH EVIDENCE 15/JAN/2020

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— Kevin

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