

the spin

SPINAL CORD INJURY BC

SPRING 2021

Breaking New Ground

With the addition of paraplegic excavator operator Shane Bunce to its cast, the hit made-in-BC reality show *Jade Fever* offers a new, diverse twist for its final season

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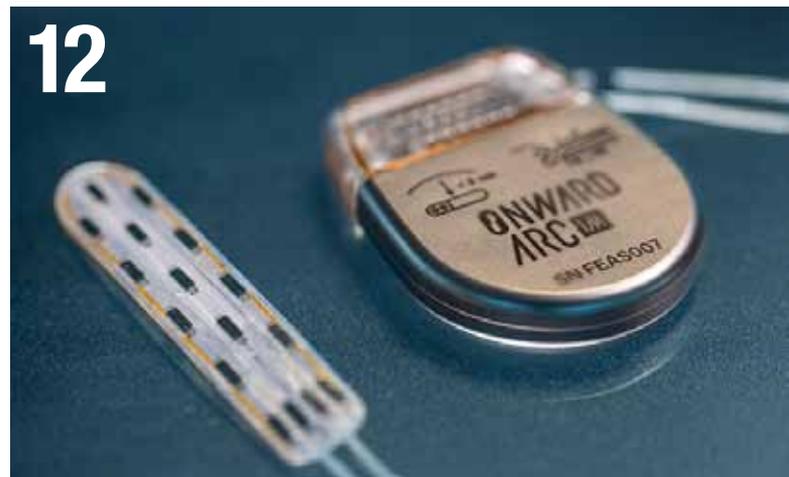
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COVER PHOTO: Prince George's Shane Bunce takes a break on the tracks of his excavator in BC's north country. (Ryan Kenny photo)

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Remembering Brad Jacobsen



The editorial I started writing was about the COVID-19 vaccination effort, but as most of you know all too well, life doesn't always go to plan. Nobody knew this better than former SCI BC Peer Program Coordinator Brad Jacobsen, and few have done more to help others adjust, adapt, and thrive after their life took a very unexpected turn.

Sadly, on February 17, the world lost Brad.

For those of you who knew Brad, you will, I'm sure, be reflecting on the influence he has had and continues to have on your lives. The heartfelt tributes and reflections from so many of you on

Facebook and elsewhere are testaments to just how much he meant to you.

There aren't enough words in this editorial to capture all of who he was and what he has given to the world. But for those of you who did not know Brad, I will try and provide a glimpse into his legacy with SCI BC.

Brad embraced his life as a quadriplegic, which he would often describe as an amazing reality that helped him realize in himself a strength he didn't know existed, and that set him on a unique path to enlightenment. He was a deeply caring, compassionate, spiritual, philosophical, contemplative, and honest soul who had a lasting, transformational impact on all who knew him—peers, clinicians, researchers, colleagues, friends and family alike.

His incredible charisma and motivation to help others see the potential they had within them helped make him such a great mentor and teacher. He inherently knew the power and magic of peer support, and in 2001, he, along with Stephanie Cadieux and others, successfully fought to bring SCI BC's Peer Program to life. For over 15 years he was a fixture of the Peer Program, and a key presence at GF Strong. The program we run today is a reflection of his vision for it, and a reflection of who he was.

There are so many ways and words to describe Brad and the impact he had on our community, but one that many have used is light. He brought light to the world. He brought light to people in their darkest times. He brought light to the end of very dark tunnels.

Brad saw the good and beauty in everyone, and had the gift of helping people to see the good and beauty within themselves. He has left us at way too young an age, but he has left an incredible legacy for the organization and for all who knew him.

In time, we will find ways to celebrate his life and the light he brought to our organization and those we serve. We will be posting tributes on our website and social media channels, and will honour him more fully in this magazine, which he named. When we can all gather together again, there will most certainly be a party in his honour.

For now, we will mourn the loss of our good friend and colleague while looking forward to the brighter days he would tell us were ahead.

Thank you Brad, and peace.

—Chris McBride, PhD, Executive Director, SCI BC



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TINA

TINA is an innovative assistive device that makes it easier to insert and remove tampons while allowing users to keep their hands sterile and clean. It's particularly useful for women with limited hand strength or function, as it can be used with just one hand and provides about four extra inches of reach. You simply press down on the tampon with TINA to snap it into place and ready it for insertion. Then, instead of using your fingers, you put your hand through the handle and slide along the track with your arm muscles. The tampon goes in correctly, comfortably, smoothly and easily. TINA also has the ability to remove a tampon with the same ease. Learn more at tinahealthcare.com.

Innovations

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



VESTA

The Vesta eating tool allows anyone with limited hand function to independently and easily use a variety of utensils and cutlery without any assistance. The simple device has two rings—one for the thumb and the other for the index finger. Once in place, the user applies a gentle squeeze to open up a channel that virtually any piece of cutlery can be inserted and locked into. The device is dishwasher-safe. See levelthecurve.com for more details and video.

KITCHEN SPREAD BOARD WITH SPIKES

This simple spread (or cutting) board, offered by UK-based NRS Healthcare, is ideal for one-handed use or for anyone with limited hand strength.

The stainless steel spikes, which can be easily removed for washing, hold food items securely for cutting, peeling or chopping. Raised lips on two sides help when buttering bread with one hand. The board's non-slip feet hold it in place on your kitchen table or countertop. It's made from dishwasher-safe polycarbonate, and measures 18 centimetres by 26 centimetres. A compatible grater is sold separately. You can see more details at nrshealthcare.co.uk.





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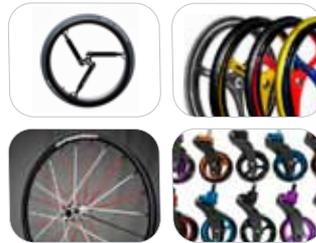
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Join our team wherever you are.

Once again, the pandemic dictates that our annual premiere fundraising event, the Scotiabank Charity Challenge, can't be held in a single location. But as last year makes clear, that won't make it any less fun or successful. You can challenge yourself and raise funds for SCI BC programs by joining our team and racing anywhere in BC between June 2 and July 5. Visit sci-bc.ca/charity-challenge-2021 to learn more, or sign up now by emailing Shelley at smilstein@sci-bc.ca.



Connect with your peers online.

While the pandemic grinds on to what we all hope is a resolution, we're still here to help you stay connected, get accurate info, and have a little fun. From casual coffee chats and fitness classes, to book clubs and expert sessions with health professionals, we've got something for everyone. Check out our ever-changing lineup of online activities on our events calendar at sci-bc.ca/events, or give our toll-free InfoLine a call at 1.800.689.2477 for more details about what's happening.



Join some great online events.

The Disability Foundation, one of our BC SCI Network partners, has a great lineup of online events in 2021. In April, the annual TetraNation competition will showcase volunteer-created assistive devices. In July, the next Strong X Virtual Concert Series will feature musicians with disabilities. Other events include ConnecTogether webinars, and the GrowABLE gardening program. To learn more, call 604.688.6464 or pay a visit to disabilityfoundation.org/events.

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Zoomed out? Facetime fatigue? We get it...give us a call.

If you're finding it hard to connect on Zoom, don't have internet access, or just prefer a one-to-one conversation, our Peer Program Coordinators throughout the province understand and are ready to talk, by phone, Monday to Friday, from 9 AM to 5 PM. When you call them, you'll be connecting with someone who, like you, lives with an SCI and can provide a wealth of information, services, and resources in your area.

LORI SLATER | Volunteer Peer Program Coordinator, Fort St. John | Tel: 250.787.1912 | Email: peervolunteerfsj@sci-bc.ca

"Being able to give my undivided attention in each unique one-to-one conversation helps people open up," says Lori. "One topic that comes up frequently is pain management—an issue that I know all about firsthand. The chronic pain cycle, the sleepless nights and depression that can come with it. It's helpful to talk to someone with lived experience in this and other areas. Together, we share ideas and learn from one another."



Brandy Stiles | Peer Program Coordinator, Prince George | Tel: 250.563.6942 | Email: bstiles@sci-bc.ca

"I find it amazing how resourceful, innovative and creative people are," says Brandy, who credits the peers she met after her injury with helping her learn how to live well. "It's wonderful to share this collective insight and knowledge gathered over the years through our network. At the end of the day, when people call, I know they've had the opportunity to have a conversation with someone who has an understanding of what their challenge is like. And this in itself can be really meaningful."



Ryan Clarkson | Peer Program Coordinator, Vancouver | Tel: 604.714.4185 | Email: rclarkson@sci-bc.ca

"Sometimes I play an active role in supporting the changes in their lives by providing tools or resources, and other times I just listen," says Ryan, who works at our office at GF Strong, where he connects with and supports people who are newly injured. "If a client isn't ready for support, their partner or family may come to me to find out what the right approach could be. It makes me smile when people have made so many improvements since discharge that I almost don't recognize them!"



Scott Heron | Peer Support Specialist, Victoria | Tel: 250.812.0773 | Email: sheron@sci-bc.ca

"I feel like my role is a bridge between the individual and the community," Scott says. "I can help explain things that health professionals may not have the time to describe in-depth. When I'm working with someone who is newly injured, my role is to come alongside and help them become as independent and self-sufficient as possible. It's really a matter of being there to provide a scaffold of support as long as it's required, and being there again if it's needed down the line."



Alison Duddy | Volunteer Peer Program Coordinator, Quesnel | Tel: 250.255.0447 | Email: peervolunteerq@sci-bc.ca

"Doing volunteer work and helping people in a situation that's new to them is so important," says Alison, who is an active volunteer and advocate for people with SCI and other disabilities in her community. "When our peer network gets together to talk about our experiences and share ideas, we're really working together to solve problems. I love passing along what I've learned through the years to other people when they call for support."



Bert Abbott | Peer Program Manager, Nanaimo | Tel: 250.616.1186 | Email: babbott@sci-bc.ca

"I love what I do because of my own SCI BC peer counselor, Jamal," says Bert. "When I was in VGH during my second day in a wheelchair, Jamal arrived and said, 'Let's go for coffee in the cafeteria.' He made me wheel down the hallway to the elevator—I hadn't even been out of my room yet! To me, talking face-to-face with a guy in a wheelchair was huge, and finding out what was possible, made an enormous difference. If I can give back, and if I can do the same thing for someone else, I'm happy."



Teri Thorson | Peer Program Coordinator, Vancouver | Tel: 778.834.2056 | Email: tthorson@sci-bc.ca

"I know I personally don't have all the answers, so the SCI BC network is absolutely essential," says Teri. "When you're newly injured it's hard to imagine what life will look like. In my work with women with SCI, I've noticed that showing a sense of normalcy can be really important. Conversations open up when we talk about our kids, our partners, or even things like a cool pair of boots! I love working with people who really want to make changes by establishing goals, self-managing, and moving towards achieving what they want in life."



Scott James | Peer Program Coordinator, Okanagan | Tel: 250.308.1997 | Email: sjames@sci-bc.ca

"We talk about all aspects of life—health, work, family, relationships, sexual health, and bowel and bladder," says Scotty, who relied heavily on SCI BC peers after his own injury. "Really, no topic's off limit. The benefit of a one-to-one conversation is that there are no other dynamics to deal with. This is especially helpful for people who are quiet or have disabilities that make communication difficult. I love doing this because I really enjoy seeing people do things that they never thought possible."



If you can't find a Peer Program Coordinator near you, our InfoLine is open to everyone. Here you'll find Bert Abbott and Heather Lamb ready to help answer your questions and find resources related to SCI and living with a disability. They're available from 9 AM to 5 PM, Monday to Friday, at 1.800.689.2477, or via email at info@sci.bc.ca.

North Vancouver's **ANGELA CHOI** was attending UBC's pharmacy program in 2012 when she was injured in a skiing accident on Mount Baker. Rather than slow her down, her SCI inspired her to challenge herself even more academically. In December, she graduated medical school at the University of Queensland in Brisbane, Australia, and is now back in Vancouver, preparing for a career as a family physician.

"My injury definitely motivated me to go to medical school," explains Choi. "The physicians and surgeons I encountered throughout my recovery, from acute injury at VGH and Mount St. Joseph's to GF Strong Rehab Centre, were so smart and compassionate. They really make a difference in peoples' lives during their most vulnerable experiences. I actually did an elective with Dr. Yao at GF Strong five



years after I was discharged, and I learned a lot about physical medicine and rehabilitation. I even worked with the nurses and therapists that I encountered as a patient. It was a wonderful experience, both in terms of learning that specialty and being able to reflect on my own experiences and using that to help patients in similar situations."

Choi won't find out until April where she will do her residency, but she's hopeful it's somewhere in BC. So are we!



A mountain-sized shoutout to our former SCI BC colleague **JOSH DUECK**, who was recently named Canada's chef de mission for the 2022 Beijing Paralympic Games. The Canadian Paralympic Hall of Fame skier, who lives in Vernon, is no stranger to Paralympic success—he won gold in super combined and silver in downhill in 2014, as well as silver in sitting slalom in 2010.

"This is such a great privilege and responsibility to wear the hat of the chef de mission for the Canadian Paralympic Team heading to Beijing in 2022," says Dueck. "The team behind the team was there for me as an athlete, and to join them now in an effort to support and elevate this new batch of athletes preparing for the games is surreal."

Now 39, Dueck was injured in a ski accident in 2004. He works as the Executive Director of Free-style BC, and he continues to be a peer mentor and a motivational speaker.

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.

Peer Shoutouts

We first told you about **ANTONIO RAMUNNO** in our Spring 2019 issue, and how he had created the Wallgym—a unique, space-saving workout station that peers can mount in their home. Last year, with a new showroom and office, Rammuno expected to ramp up Wallgym sales, but as with many businesses that rely on hands-on demonstrations, the pandemic threw a damper on his plans. Undaunted, the 53-year-old incomplete quadriplegic used his extra time to design and complete a prototype for a second version of the system, geared more toward rehabilitation.

"This Wallgym is more for people with balance problems, learning to walk, needing parallel bars—guys like me," Ramunno explains.

Built with input from a physiotherapist, the second-generation Wallgym has been equipped with several innovative features, including drop-down parallel bars, a sit-to-stand bracket that holds the users' knees in place while they attempt to stand up, and a magnetic whiteboard and a mirror for practising shaving and brushing hair.

Ramunno uses his own Wallgym religiously, and credits it for much of his regained ability to stand and walk with a walker.

You can still see the Wallgym in person at Rammuno's storefront in North Kamloops, but given continuing pandemic precautions, he's also started the process of producing quality videos that clearly demonstrate the Wallgym and what's possible when using it. Visit wallgym.ca to learn more.





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This program is funded by the Government of Canada
and the Province of British Columbia.

Keeping the Pressure On

An international team of researchers, co-led by the University of Calgary's Dr. Aaron Phillips, has made an important breakthrough in the search for a treatment for dangerously low blood pressure in people with SCI.

How's your baroreflex? Chances are, if you have an SCI, it's not that great. Your baroreflex is the mechanism that keeps your blood pressure properly regulated. Think of your home's heating system—a thermostat switches the furnace on and off as required to maintain your home at just the right temperature. Like a thermostat, the baroreflex recognizes when blood pressure is too low or high, and switches on or off mechanisms in your body (for example, raising or lowering heart rate, and constricting or relaxing blood vessels) as required to maintain the ideal level.

We've known for decades that SCI, depending on its level in the spinal cord, can greatly compromise your baroreflex. There are two potentially serious implications—one is dangerously high blood pressure (orthostatic hypertension) resulting from autonomic dysreflexia or AD, and the other is dangerously low blood pressure (orthostatic hypotension).

They're triggered in two entirely different ways.

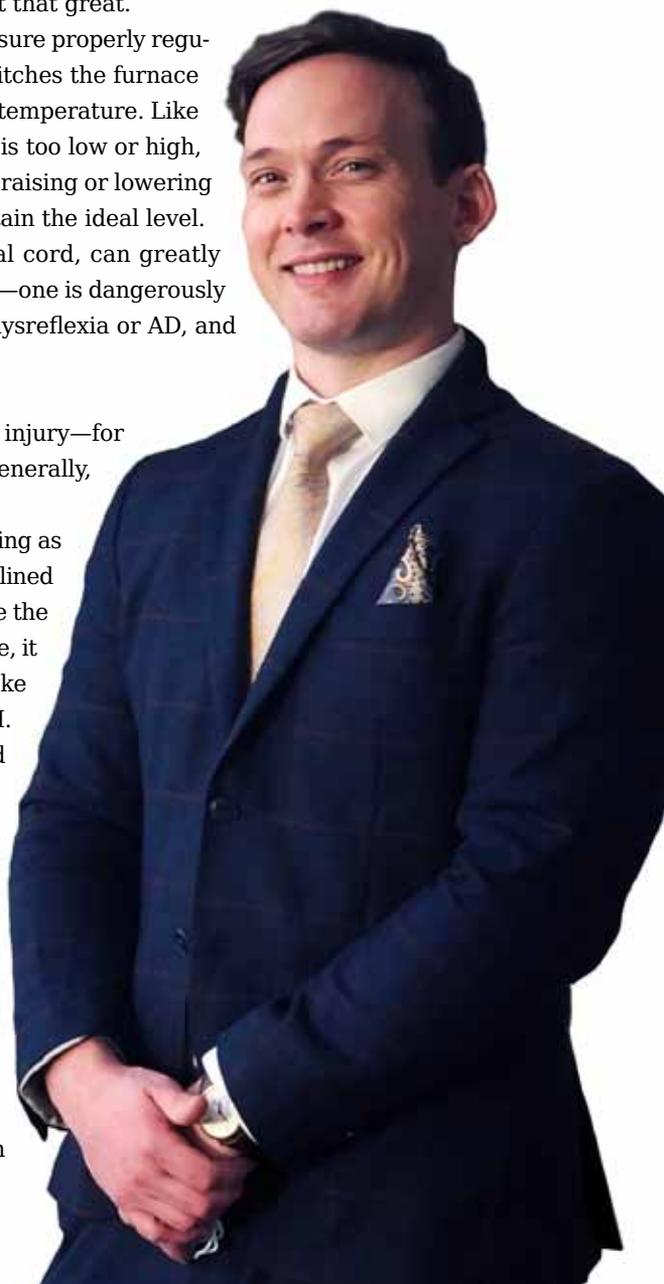
The culprit behind AD is usually an external stimulus below the level of injury—for example, a bladder infection or a pressure ulcer can trigger an AD bout. Generally, if the cause of the AD is recognized and resolved, the AD is resolved.

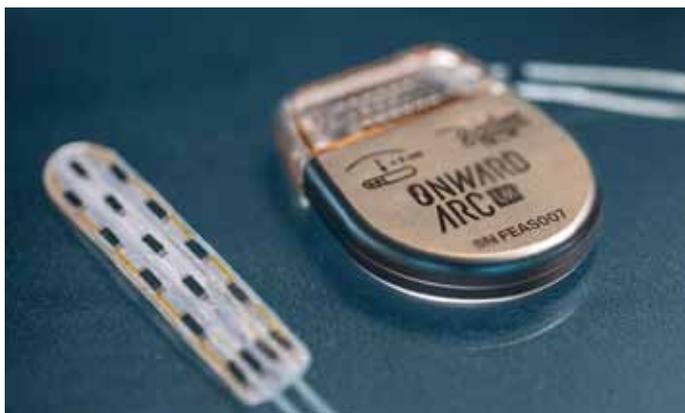
On the other hand, orthostatic hypotension, or OH, is triggered by something as simple as moving from a lying position to a sitting position, or even from a reclined position to sitting fully upright. Dizziness, confusion and even passing out are the clues that this is happening. But OH has more sinister implications—over time, it can lead to serious and sometimes fatal cardiovascular problems such as stroke and heart attacks, which are the leading causes of death for people with SCI.

OH is much more common than its high pressure counterpart—it's estimated that up to 75 percent of people with SCI experience symptoms of OH, and that estimate climbs to as high as 90 percent for people with quadriplegia.

Given that OH is so common and so potentially dangerous for people with SCI, strategies to treat it have been explored for decades—but with limited success. Blood pressure-regulating medication, compression stockings to prevent blood pooling in the lower extremities, and abdominal constriction belts have never been proven to be effective. In particular, medications have some undesirable side effects.

Now, new research is demonstrating that electrical stimulation at just the right point in the spinal cord may represent an effective and drug-free way of preventing OH for people with SCI. In January, an international research





Phillips and his colleagues are using an ONWARD Medical neuroprosthesis (left) in their research. Dr. Richi Gill (right) is the first person to have the device implanted on his spine for the purpose of regulating his blood pressure and preventing bouts of orthostatic hypotension.

team co-led by University of Calgary (U of C) neuroscientist Dr. Aaron Phillips published a paper in the journal *Nature* that explained how it had successfully developed an “neuroprosthetic baroreflex” using an epidural (implantable) stimulator. The team tested the device in two animal models, and most recently, a human—all with impressive results.

Phillips previously worked on blood pressure regulation after SCI after being recruited to join Dr. Andrei Krassioukov’s lab team at ICORD. While there, he and his collaborators had some success using spinal cord stimulation to elevate blood pressure in people with SCI who were experiencing OH.

During this time, he met Dr. Jordan Squair, an MD and PhD candidate who was also very interested in OH. In 2017, after accepting a position of assistant professor at the U of C’s Department of Physiology & Pharmacology and Hotchkiss Brain Institute, Phillips welcomed Squair to his new lab and team, and their work in OH gained momentum.

They also joined forces with prominent Swiss neuroscientist Dr. Grégoire Courtine and other researchers from the Swiss Federal Institute of Technology (EPFL) and University Hospital Lausanne, who had made some good progress using neurostimulation to restore various functions after SCI.

The collaboration focused on treating OH using an epidural stimulation device—one that’s implanted next to the spine. As outlined in their recent *Nature*

publication, Phillips, Squair (who was first author of the paper) and the rest of the team chose to work with already-available neuroprosthetic technology developed by Swiss company ONWARD Medical to restore walking function in people with SCI. They adapted the device for specific use with OH, determining the exact location on the spinal cord to apply stimulation to, and developing the closed loop feedback system that “instructs” the stimulus to fire and increase blood pressure when it senses OH is taking place.

“We have effectively engineered a new baroreflex using a prosthetic implant,” Phillips says. “The system constantly reads the blood pressure in the body and creates a set point where blood pressure should be. It is implanted onto the dural layer of the spinal cord over hemodynamic hotspots—the key regions that activate and control blood pressure—in the caudal area of the spine. A computational algorithm running in real-time monitors the blood pressure, and when pressure falls, it applies an appropriate level of stimulation to the hemodynamic hotspots, which then send messages to constrict blood vessels to raise blood pressure.”

The team tested this concept, first in rats, and then in monkeys, with both animal models yielding excellent results. And then came the coup de grâce: they applied the approach in a human—Dr. Richi Gill, an Alberta doctor who became quadriplegic after a boogie boarding accident during a family vacation in Hawaii three years ago.

OH had been a big problem for Gill since his injury. His OH bouts, which take place in the morning and later in the day, were often severe, forcing him to basically put his head in his lap or lie down until his dizziness and blurred vision retreated. Blood pressure medication helped a little, but the improvements were offset by its side effects.

Since having the device implanted last year, he’s been using it for about an hour each morning, and it continues to quickly elevate his blood pressure to safe levels. He no longer needs blood pressure medication, has been able to return to work as a physician, and says his quality of life has improved significantly.

Phillips and Courtine are now hoping to build on that first clinical success as they prepare to launch a series of clinical trials beginning this spring, in both Calgary and Switzerland. Phillips says the plan is to thoroughly test the procedure so it can be approved without delay by regulatory agencies, including Health Canada. The ultimate goal is that the device will be offered as a matter of course to anyone with SCI who suffers from OH.

“We’re aiming to have this therapy in the community in less than five years,” says Phillips. “This timeline is realistic because we have the support of DARPA and ONWARD Medical.”

DARPA is, of course, Defense Advanced Research Projects Agency—the massive U.S. military research organization acknowledged as one of the world’s most important scientific funders. Phillips is

one of several team leaders for a recently-awarded \$48 million contract by DARPA's Bridging the Gap Plus (BG+) program. The entire project is being co-led by ICORD scientist Dr. Brian Kwon, and is intended to develop new approaches for treating SCI (see the Winter 2020 issue of *The Spin* for details).

Phillips says the collaboration with ONWARD Medical (onwd.com) is also vital to their success—having the actual manufacturer essentially onboard as a team member means that the device can be quickly and efficiently adjusted and refined as needed.

The trial will seek to recruit only people with quadriplegia, as they are the most likely to experience debilitating OH. At the trial sites (Calgary and Lausanne, Switzerland), qualifying participants will have the device implanted during what is a relatively straightforward procedure.

"This is a 45-minute day surgery, where folks usually go home afterwards," explains Phillips. "In fact, this surgery can be done under local aesthetic. We need to

keep in mind that this surgical approach has been around for decades for people with chronic pain. There are many analyses of the safety profiles of this surgery. One of the largest was a recent review of 20 years of literature reporting on this surgery—it concluded that this intervention was safe and effective."

There will also be an opportunity for readers of *The Spin* to get involved as participants.

"People from BC with SCI will be eligible to participate in the trial," says Phillips. "We encourage folks from BC to reach out. For this phase, there will not be surgeries taking place in BC, but in subsequent phases of the roll-out, this will be likely."

While early successes—particularly with the single clinical participant we told you about on the previous page—provide a great deal of hope that this approach might produce a reliable, drug-free way of relieving OH, it's important to remember that there are no guarantees with any research.

In the issue of *Nature* that the research was published in, Dr. Patrice Guyenet, professor of pharmacology at the University of Virginia, Charlottesville, wrote an accompanying editorial that was complimentary of the results, but also contained a few cautionary notes.

"This bench-to-bedside study is unprecedented in many ways, and, as such, raises several questions," wrote Guyenet. "For example, the sensory afferent neurons stimulated by the prosthetic device are unidentified and the long-term effects of their stimulation are unknown. In addition, it needs to be established whether the device will have adverse effects on gastrointestinal and kidney function, which are regulated by lower thoracic sympathetic neurons. Finally, an invasive procedure is required for the placement of an epidural electrode in the spine, and its long-term efficacy is unknown." ■

If you're interested in learning more about this research, visit the Phillips Lab website (aaronphillipslab.com).



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PeerSAY!

“I wish I had known that!”

Chances are most of us have found ourselves saying, “I wish I knew then what I know now!”

The reality is that, in a world that’s still largely reluctant to mould itself to the needs of people with SCI, many of our peers have had to learn and adapt in order to thrive. We thought some younger readers might be interested in some hard-won knowledge from their peers with a few more years of life experience.

Our thanks to all those who contributed. If other readers have anything to add, send an email with your comments to us at thespin@sci-bc.ca—when we receive enough, we’ll do it again!

MARK HAMSTRA | 52 | C4-5 | Langley

“When I was in rehab, they told me to drink lots of water. I didn’t listen, not really; I didn’t like pure water. I drank coffee and juice and pop and alcohol. But water is the solution to many bowel and bladder problems, so I had to get used to drinking excessive amounts of straight water. Make it part of your routine. I have found it makes everything work better, and if emptying your bag worries you, there are a few automatic leg bag emptiers available on the market that can be used with a little ingenuity. Good luck.”

HUBERT ZAWADZKI | 53 | T11-12 | Quesnel

“I was getting an average of one UTI every six months. Finally, after experiencing a month-long UTI that would not go away despite taking three kinds of antibiotics (I became resistant to the first two), I decided to do intermittent catheterization six times every 24 hours, instead of five. Somehow, I have not experienced one UTI since September 2019 (knock on wood). I have no desire to go back to doing five ICs a day just to prove my point.”

SHERYL NEWMAN | 46 | T2-T7 | Surrey

“I wish I had known back when I had my first child that, when you’re a high para, it affects your capability to breastfeed. You cannot (or may not) produce milk! I would pump my breast for over an hour and wouldn’t even produce a full 250 ml bottle. It was exhausting and painful for me, and I did it for 14 months with my firstborn. It was sad that there was not one single medical professional who could give me the information of what a woman with SCI can or cannot do during motherhood. When I had my second child, I met Dr. Krassioukov of GF Strong. He was the one who shared the information that I was even lucky to produce milk and breastfeed my children. It turns out that breastfeeding is compromised for many women with SCI. There should be more advocacy, programming or information passed on to first time moms with SCI and shared with all OB gynecologists or doctors in general for their future SCI patients.”

BRANDY STILES | 46 | T11-12 | Prince George

“I’d like to offer one tidbit of advice—stretch! It wasn’t something I made enough of an effort to do in my younger days; I was just way too busy chasing kids, etc., and didn’t make it a priority. I found stretching challenging to do as my spasticity was quite strong, but not doing it enough undoubtedly contributed to my tone. I finally resorted to getting a Baclofen pump 20 years post-injury, and although that has helped, I still have decreased flexibility and range of motion. I can’t know for sure if stretching would’ve prevented me from making the decision to get a pump. I avoided oral medications for spasticity as I hated the side effects more than my spastic legs. As time went on, it just got harder to deal with. The pump has enabled me to do more stretching now without fighting spasms and I will continue to do this going forward.”

PAT HARRIS | 65 | T10 | Prince George

“I had many bouts of cellulitis over the years. I was even hospitalized and required IV antibiotics. If only I’d made the connection earlier that athlete’s foot and cracks between my toes were the culprit, I could’ve avoided a lot of suffering. Now I have a daily routine of applying an antifungal cream and haven’t had any problems in over five years.”

KARL BOJAHRA | 51 | Spina Bifida | Penticton

“I really wish I had developed a fitness/exercise routine earlier in life. Now that I’m 50+ the weight keeps creeping up. Growing up, all my physical activity was physiotherapy and it seemed like a lot of time doing therapy for the sake of doing therapy, with no discernable goals used to motivate. I guess my attitude was any exercise was therapy, and I got burned out on it. None of the therapists or doctors really spelled out why I needed to do this stuff.”

CALEB BROUSSEAU | 32 | L1 | Terrace

“For years I used condom catheters. I could void on demand but didn’t realize the damage that was being caused when the pressure was also refluxing urine back up into my kidneys. Whenever I tried doing an intermittent catheter I would get an infection, so I avoided this method. I discovered later the infections were caused by improper hygiene technique from reusing lubrication tubes. I had three years of constant bladder infections before I ended up getting bladder botox treatment, bladder augmentation and sling surgery. Now I use single-use intermittent catheters and no longer have issues with leakage or infections. Wish I would’ve learned more about bladder maintenance options and had this treatment done earlier before damaging my kidneys.”

NELSON JEWER | 33 | C5-6 | Prince George

“It’s important to keep active and engaged in something constructive post-SCI. Don’t allow yourself to sink into a negative state, as it’s very difficult once you get stuck in a rut. This will look different for everyone. Whatever your interests are, you may have to adapt. But find a way to get involved and surround yourself with positive people.”



Green Gold

The final season of the hugely popular, made-in-BC reality show *Jade Fever* offers viewers a new twist: excavator operator Shane Bunce, who joins the cast and single-handedly proves that people with SCI are up to some of the toughest jobs on the planet.

In 2015, the hit reality show *Jade Fever* debuted on the Discovery Channel. The production, which followed in the footsteps of the original mining reality show *Gold Rush*, quickly became a runaway success. Audiences around the globe began to tune in to watch the show's family-based crew face danger, financial risk and no shortage of equipment failures as they pursued the dream of striking the motherload of all jade deposits in Northern BC.



simply getting into the remote and rugged mine locations and continuing with the daunting challenge of locating and extracting the precious green stone before winter flies, have been beautifully captured on camera by Discovery Channel's production team.

A seventh and final season of *Jade Fever* has been completed (yes, it was shot during the pandemic in 2020—more on that later). While a firm release date hadn't yet been announced at the time of writing this, we do know that enthusiastic audiences in more than 180 countries around the world will be able to tune in at some point in March.

We don't know exactly what the new season has in store for viewers, but one thing we do know is that there's a new addition to the cast: Shane Bunce, nephew of Claudia and Robin Bunce.

Bunce, who lives in Prince George most of the year, sustained his L1 injury in 2013, when he fell asleep behind the wheel of his truck while driving back to logging camp. Since his recovery, he's continued to work as a heavy equipment operator and a home builder. But when his Aunt Claudia called him last April to see if he wanted to work on season seven of the show, he jumped at the chance and

put everything else on hold. He joined the rest of the crew in Jade City in May and worked with them at the mine until the end of August, when winter weather started to arrive.

Bunce concedes his adventure started on a sour note. During the 1,200 kilometre drive from his home in Prince George to Jade City, he aggravated a recurring pressure sore.

"The coccyx has always been a problem since I got my first sore there while still in VGH," he says. "But the rest of the summer was great; it healed within two months. I just had to be mindful of it and I never let my medical conditions restrict me from adventure."

Bunce spent the first week at Jade City, working with the crew to prepare the convoy bound for the mine site. At that point, he joined several other crew members who flew in by helicopter to open up the camp. The remainder drove the 12 hour trail with the equipment, fuel and supplies needed for the start of the season.

No stranger to camp life, Bunce knew what to expect—rugged terrain, zero accessibility, and long, exhausting days of work. But one unknown was how well the TV production crew, as well as his

Fans of the show enjoy the lively and colourful day-to-day exchanges between owner Claudia Bunce, her husband and mine manager Robin Bunce, and the members of their immediate and extended family who make up the mining team, as they work together to overcome the significant risks and challenges of finding and extracting jade.

For most of the year, the Bunces make their home in Jade City, located on Highway 37, just south of the BC/Yukon border. But for a short window of time each summer, the Bunce operation (which employs most of the tiny community's 35 residents) makes a pilgrimage into the nearby rugged Cassiar Mountains in search of jade, a precious stone which is mainly mined for and sold into the Asian market. Since 2015, their struggles and successes, beginning with



Shane's Uncle Robin and Aunt Claudia, the two principal cast members of Jade Fever (all photos by Ryan Kenny)

fellow miners, would accept and work with a new cast member who happened to use a wheelchair. As it turned out, he had nothing to worry about.

“The cast and crew were awesome—we drank well together, and Claudia wasn’t impressed her camera crew was hungover at constant intervals,” says Bunce with a laugh. “They loved the aspect of someone in a chair out in camp, running an excavator and dealing with the adverse terrain, making the camp accessible for the chair, building an accessible outhouse, and getting in and out of machines and jacked up work trucks.”

His first order of business at the camp was getting his own situation and needs sorted out in preparation for the grueling days and weeks of work ahead.

“The first couple days, I had to bum up the few steps into the cook shack and leap into the existing outhouse, but once my humble abode arrived on the back of the Bedford (AWD flat deck truck), I was at home. The eight foot by 14 foot ATCO building was easily made accessible—just a piece of plywood and I was in. We had to build ramps into the cook shack and

shower room and assemble an outhouse I pre-fabbed while in prep mode back in Jade City. The first day running the excavator, I dug the hole for the outhouse and off-loaded the ATCO and levelled it in place. Nothing is level in camp!”

With his basic accessibility needs taken care of, Bunce got down to work with his fellow crew members, grinding out long days in the quest for jade. Bunce quickly dispelled any doubts about his skill and comfort with his excavator, which can be controlled entirely by hand—there are even alternate hand controls for the tracks, which are normally operated with the feet.

He concedes that one challenge was getting into the cab without any type of lift or hoist.

“Getting in and out of the excavator was a learning process that I was able to perfect throughout the summer, relying on positioning and how wet everything was since there weren’t many days it didn’t rain the whole summer,” he says.

Despite the rugged, unforgiving surroundings and terrain, Bunce says he only had a couple of spills in his wheel-

chair. “Once they caught it on camera before I could get back in my chair,” he laughs. “Mud and adverse terrain aren’t very forgiving.”

Looking back, Bunce says the experience was incredible.

“Life in camp was a constant adventure. The mountains are breathtaking, everywhere you go. I’d say I enjoyed every moment of the summer, except maybe a few moments of discomfort like the 12-hour drive back to Jade City from camp, with no accessible bathroom facilities along the way. But I pulled it off without incident.”

As for shooting the season in the midst of the pandemic, Bunce says there were no issues.

“Because of the remote setting of Jade City and Two Mile Camp, it was easy after the two week quarantine,” he says. “Every member of the camera crew was tested before coming up from Vancouver, so it didn’t affect much at all.”

It’s likely that, by the time you read this issue, the final season of *Jade Fever* will be underway. For up to date scheduling information, visit discovery.ca. ■



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Higher Learning

If SCI has introduced a career crossroads in your life, there are more reasons than ever to consider some kind of post-secondary education. — by Miles Stratholt

Post-secondary education has long been—and continues to be—one of the cornerstones of my life. Nothing else has had the same impact in my quest for independence and success as a person with a disability. In fact, post-secondary education has been so important in my life that, when an opportunity arose, I decided to make a career change that would allow me to do what I could to ensure more people with disabilities can reap the benefits of it.

I think, as young adults or at some point in our journey, we all have to assess and make sense of our options and opportunities. For me, this occurred in the last few years of high school, when friends and relatives started asking those “What

do you want to do with your life?” questions. These were really troubling for me. I’d spent my teenage years coming to terms with my disability, and I had some serious anxiety about what the future held for me after high school. My lived experience to that point had included a lot of challenges, and these seemed to only loom even more ominously as graduation approached.

At the age of 11, I contracted a rare autoimmune disease which paralyzed my body from the diaphragm down. The doctors who treated me during the next few years in various hospitals and rehab centres made it clear that I shouldn’t expect to recover any lost function.

Being somewhat stubborn, I set out to challenge these expectations. After a lot of intense and painful physio, I regained enough



FIRST JOB: With degree in hand, the world of career choices opened up for me. I'll concede that the field work part of being a biologist had its share of challenges!

function to allow me to walk using braces and crutches. But as I recovered more of my function and identity, it became apparent that my academic progress had come to an abrupt halt at grade five. In the 1970s, it was pretty common for kids with physical and developmental disabilities to be warehoused in institutions. The facility I attended provided education in the form of correspondence courses—a poor substitute for the education I knew was being provided to my able-bodied siblings and friends. And so I returned full time to public school in grade nine.

I can't deny it: catching up was really tough. After the first week I approached the school counsellor and told her how much I was struggling. She suggested I drop back a year. As the only student at my high school with a visible disability, I was keenly aware of how I was scrutinized by my peers and by faculty. I felt that any failure would only further reinforce the stereotype that persons with disabilities were unable to compete. So, with some help from a tutor and many hours of extra time, I brought my grades up to near the top of the class by the end of the year. It was a real learning experience, and a bit of a turning point

for me—it reinforced my self-image as someone who could overcome barriers and be successful.

Nevertheless, as graduation began to get closer, I really didn't have a very clear idea of my path forward. Growing up, I had never seen anyone like me, a person with a visible disability, in a career. No teachers at school, or any of the other figures kids tend to idolize growing up—professional athletes, doctors, police, firefighters, pilots.

I wanted the freedom and prestige, as I saw it, of a legitimate career. It wasn't lost on me how, at the time, people with disabilities were perceived as needing pity and charity. I was determined not to contribute to that stereotype. I had an expectation I would work hard, support myself, and build a life which would come to include independence and security, just as my siblings and able-bodied peers were doing.

At that point, many of them were getting jobs in resource industries such as fishing, logging, and the booming oil industry in Alberta. Clearly, these jobs weren't available to me. I did, however, have a lot of confidence in my academic abilities. And so I came to the conclu-

sion that post-secondary education was my only real option. I had always been interested in the natural sciences, and so I enrolled in a Bachelor of Biological Science program at the University of Victoria, with the hope of one day working in fisheries management.

At that time, there were still significant accessibility issues on campus. All the science labs were set up with high benches and stools, and some buildings had no ramps or elevators. Fortunately, a decade on crutches had given me enough upper body strength to allow me to address most of these challenges—and participate in the field work and outside activity components that were an important part of my university experience.

Lack of accessibility was just one issue for students with disabilities at that time. There was little to no outreach or information made available about accommodations for students with disabilities, and my personal approach was to not ask for assistance. I was still operating with the attitude that I had to prove myself, that asking for "special" accommodation meant I wasn't able to reach my goals on my own. Remember, this was before the internet, and there were few students with disabilities in post-secondary education. I think I recall just one other student at that time who had a significant visible disability.

Despite the barriers I encountered, my experience as an undergraduate student was rich and fulfilling. I graduated with a first class undergraduate degree in Biological Sciences, and this success inspired me to continue and complete a Master's of Science degree at UBC, with my thesis on stress physiology in Steelhead, Coho and Chinook Salmon.

I was amazed at how my graduate degree opened so many career doors

for me. My first job was as a fisheries biologist with a consulting company on Northern Vancouver Island. The field activities of the job were demanding, and I had to overcome many frustrating barriers. But overall, I found the work engaging, satisfying and essential to my sense of self. It also paid much better than the limited employment options I had access to prior to university.

That first career experience led me to take a position as a BC government fish and wildlife protection biologist in the Lower Mainland. The job also entailed a lot of field work and site visits around Vancouver. I was met with yet more challenges and barriers, both physical and attitudinal. But my growing self-confidence and adaptive skills served me well. This was my first long-term job and it proved to be an excellent opportunity to learn and grow.

Later, I took a position in Victoria as a fisheries biologist and worked in the area of management policy and angling regulations.

Throughout my career as a biologist, I always looked back on my university years as such an important time of growth and self-affirmation. But I also remembered how academic success was hard-won—it hadn't come without challenges and roadblocks. I often found myself wondering how other students with disabilities experience post-secondary education—so much so that I kept in touch with the University of Victoria's Society for Students with Disabilities and often attended their seminars and workshops.

In 2008, my continuing interest in advanced education for others with disabilities inspired me to apply for a position with the BC government ministry that oversees advanced education. And that's how I found myself directly involved in the policy and management of programs for students with disabilities.

In the past 12 years, I've had the opportunity to contribute in a significant way to the educational system that was so important in helping me achieve suc-

cess and independence. I've been directly involved in the development of programs that provide funding, assistive services and adaptive technology to students with disabilities. I've gained a wealth of knowledge and experience through interactions with colleagues in other provinces and professionals working with students in post-secondary institutions. Through my work, I've developed an even greater awareness of the critical role a post-secondary education can play in helping persons with disabilities achieve economic stability and pursue meaningful employment opportunities.

So it won't be a surprise that I advise anyone with a disability who is looking for a path forward in their life or career to explore advanced education. The awareness and accommodation of students with disabilities in higher learning, while not yet perfect, is so much better than it was when I first went to university. There are many programs in place to level the playing field for students with disabilities—financial support,

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equipment and services, assistive technology, and assistance from post-secondary institution staff. There are many bursaries and scholarships to specifically help students with disabilities, including the impressive GRAGOPEAN Scholarship Trust that is administered by Spinal Cord Injury BC (see the ad at the bottom of the previous page). And there is a growing recognition that students with disabilities really belong in post-secondary educational institutions.

Not only that, today's job market is so much more inclusive of workers with disabilities—particularly when they're graduates of a recognized post-secondary program. Workplace diversity is becoming something to strive for by today's leading corporations, and there are even some federally-regulated industries where employers must make concerted efforts to reflect a diverse workforce that includes people with disabilities.

If you're interested in exploring your options for a post-secondary education and want to find out more about the kind of supports available to students with disabilities, there are far too many resources to list. My advice would be to contact the Accessibility Office at the school you're interested in attending. That's the best place to receive direction, assistance, and the opportunity to learn about and access programs for students with disabilities.

I wish you the best of success in your chosen educational and career journey. ■



Miles Stratholt is an SCI BC peer and Senior Policy Analyst in the Targeted Learners Support Unit, BC Ministry of Advanced Education, Skills, and Training.

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WHY I GIVE...

I was injured over 20 years ago, so I'm a lifer. You get to a point after your injury when you realize the best way to move on with things is to talk to other people with spinal cord injury. SCI BC helped me do that.

Now that I'm a little older, I think back on everything and believe we need to give back—that's why I'm a monthly donor. SCI BC has always been there for me and it's really important to make sure this continues for younger people.

My life changed so much after my injury. I was living on Salt Spring Island, so I was cut off from a lot of things when I returned after rehab. Over time I started to get more involved and I learned that SCI BC had a Board of Directors. I thought it would be another great opportunity to learn from others, in the same way I learned from peers when I was first injured. I applied and ended up serving on the Board for 16 years.

Now, I look at where SCI BC has gone with the younger generation and I see a lot of opportunities. You can go up to Whistler, you can get *The Spin* magazine, learn about research and so much more. It's a lifelong community, so I think it's important that we help out wherever we can. We do it for the young people because we know what it was like when we were first injured.

Gerry Price
SCI BC Peer & Donor

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Complete Control



The Tetra Society has been hard at work during the pandemic, bringing its netClé system ever closer to commercialization.

How do you efficiently and independently use a computer if you're someone with quadriplegia or another disability that limits or completely takes away your hand and arm function?

Over the years, many alternative input devices and controls have been created for people who can't use off-the-shelf keyboards and mice. But often, these devices aren't suitable—for several reasons.

One is that people with high level disabilities have a wide range of different abilities and needs, so a one-size-fits-all solution isn't practical. Additionally, sometimes people need to combine and use several devices for the best solution, but connecting all of these devices to a

computer—and making them play nice together—has been a challenge. And there's also the issue of cost—existing specialized technology like this often has a high price tag that's just not realistic for too many of the people who really need it.

Enter netClé (pronounced net-clay), a unique customizable system that consists of a central hub and a range of alternative input devices that connect to it, all of which work harmoniously together to allow someone with quadriplegia to use their computer independently and effectively. netClé has been under development since early 2019, when a group of Tetra volunteers realized just how much a device like this was needed. Work got underway in earnest when the

Government of Canada agreed to provide funding for development.

Today, netClé is in its final testing phase, and the Tetra Society's goal is to offer an affordable finished product on its TetraGear site by this summer.

At the heart of the netClé system is the small hub which houses a hardware-printed circuit board attached to a micro-controller, and ports where you can plug in a variety of input devices.

The input devices provide a number of ways to move and click the onscreen cursor—using touch, or movement from a user's single digit, limb, or even head. There are several input devices to choose from, and they're selected based on a user's needs.

For example, there are two joysticks—one large, one small—that can be easily used by someone who has some hand and arm movement, even if they're lacking the ability to grasp. For those with no hand or arm movement, a gyro that attaches to a hat or glasses can also be used to move the cursor around the screen—the user simply moves their head up, down or to one side. And there are sensors and buttons that can respond to even the lightest tap from a finger or knuckle or fist in order to mimic a "mouse click". All of these input devices can be used in concert with the others.

Once everything's connected, including the USB connection from the hub



to the computer, netClé's innovative companion software allows for total customization of each input device to meet the user's unique needs, abilities and purposes.

Additionally, Bluetooth compatibility allows for the potential to control devices such as smartphones and tablets, or switch on lights, appliances and other electronics. This device can be used in conjunction with other applications such as voice dictation software, which give clients the flexibility and variety in their computer usage. Based on the client's needs, adjustments can be made to the functionality of the device so they are able to use it with other existing commercial devices they are using.

It's compatible with Windows, Mac and Linux laptops or desktops.

We saved the best for last—the anticipated low price.

“We're striving to price the finished product from \$100 to \$200,” says Emily Chambers, Program Coordinator. “Currently, the only device similar to netClé is the Tecla-e. This device operates as a compact hub designed to work with numerous smart technology devices to help people with physical disabilities. It retails at \$499 for the hub alone!”

There are several ways to learn more. You can visit tetrasociety.org/netcle, or you can email the program at info@netCle.ca. But perhaps the best way to really understand how the system might benefit you is to visit YouTube and search for “netClé”. The Tetra Society has prepared 12 excellent videos for YouTube, ranging from an introduction to the system to specific ways that it can be used depending on your needs.

If you end up deciding that netClé is for you, you'll be assessed via Zoom by one of the Tetra Society's technicians or occupational therapists. This assessment will take about an hour. Your netClé system will then be configured specifically to meet your needs and mailed to you. Once you've received it, you'll have a follow up Zoom installation appointment to get some instruction and ensure everything is working well. ■

ask the SPIN DOCTOR

We've been getting a lot of questions from peers about COVID-19—about its implications for people with SCI, and about the vaccine rollout. We reached out to Dr. Kim Anderson-Erisman for some answers. As Director of the Northeast Ohio Regional SCI Model System, professor at Case Western Reserve University, current President of the North American Spinal Cord Injury Consortium (NASCIC), and someone who lives with SCI, she is imminently qualified to shed some light on COVID-19 and SCI.



People with SCI have every reason to be wary of COVID-19. After all, it's generally acknowledged that we have compromised immune systems and are at a greater risk from any disease that compromises the cardio-pulmonary system.

That's why we made a decision here at NASCIC to assemble a white paper of all current evidence-based information and knowledge about COVID-19 and SCI. Our goal was to understand the concerns about the pandemic among people with SCI, assess case studies of those with SCI who have contracted COVID-19 to determine if we are at greater risk, and attempt to shed light on the impacts of lockdowns due to COVID-19.

Here's the essence of what we discovered.

First and most importantly, it's fair to say that, so far, people with SCI do not necessarily experience more severe symptoms or higher risk of death from COVID-19 than anyone else. Surprisingly, the cough and fever reported by people with SCI may not be as severe as those experienced by the general population. Additionally, people with SCI do not appear to be at a higher risk of getting infected with the COVID-19 virus in the first place.

The early symptoms people with SCI experience can often be confused with urinary tract infection, or UTI. So if you think you've got a UTI, be open to the idea that it actually might be COVID-19 instead.

Clearly, there is also a great need to remain vigilant while we wait for vaccines and see how they protect against the various variants, some of which appear to be more contagious and less responsive to vaccines. It's still vital to minimize the risk of exposure by washing hands, wearing a mask, and social distancing.

Of course, many people with SCI need personal care and have the added concern of being exposed via a caregiver. We know it's difficult for personal care attendants to socially distance themselves when assisting individuals. But this added risk can be reduced by diligent use of personal protective equipment (PPE), worn by both parties. And handwashing also remains vital.

Although difficult to quantify, it seems likely that people with SCI may have an elevated risk to their mental and emotional health because of isolation. This is why it's vitally important to virtually connect with family, friends, and peers.

Finally, as for concerns about the vaccine roll-out, this is an area that wasn't addressed in the white paper (which was based on data available at the end of November). At the time of writing, I was not aware of any adverse reactions experienced by people with SCI that were different than what the general population may experience—and here in the USA, many (including me) have been vaccinated, including patients at the Department of Veterans Affairs' SCI centers.

Vaccines have long been recommended for people with SCI as the risks of preventable illnesses like the flu and pneumonia for people with decreased lung function far outweigh any known vaccine risk. No published data indicates a specific risk for people with SCI, and for many reasons, mRNA (Moderna and Pfizer) vaccines might be a bit safer. mRNA has previously been used for decades as part of cancer treatment, indicating it is safe for those who are immune compromised. And because they don't introduce any live or inactivated virus into the body, there isn't even a tiny risk of contracting the virus from the vaccine.

Considering the risks of any type of lung infection to people with SCI, there are many good reasons to have a COVID-19 vaccine as soon as it's available to you.



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Maximum Sensation

The TOMAX procedure to restore genital sensation for people with low level SCI has flown under the radar since it was introduced almost two decades ago. Hopefully, this is beginning to change.

We'll confess that, when one of our readers and peers, James Shaw, informed us he'd been approved for the TOMAX procedure, we were pleased for him—but without really knowing much about it. Somehow, despite it being developed more than 20 years ago, we'd really never heard much about TOMAX.

Shaw, who lives in the Kootenays' Slocan Valley, also had no knowledge of the procedure until he stumbled on it while searching online last year. But when he did, he suspected that it might be something that could help him, and so he set out to learn more.

Shaw sustained a low level incomplete SCI two years ago in a car crash. Like many people with similar injuries, he retained the ability to have an erection—but lack of sensation in his penis meant that he was unable to meaningfully feel the sexual experience and reach a fulfilling orgasm. And his frustration with that is how he ended up online, searching for answers.



James Shaw

"I carefully worked through my search results and read many peer-reviewed papers," says Shaw, who is 42. "The TOMAX procedure kept coming up, so I read everything I could about it. I was shocked that there wasn't a single health care professional in BC that I spoke to that knew about this surgery."

As Shaw dug deeper, he became convinced that he was an ideal candidate for

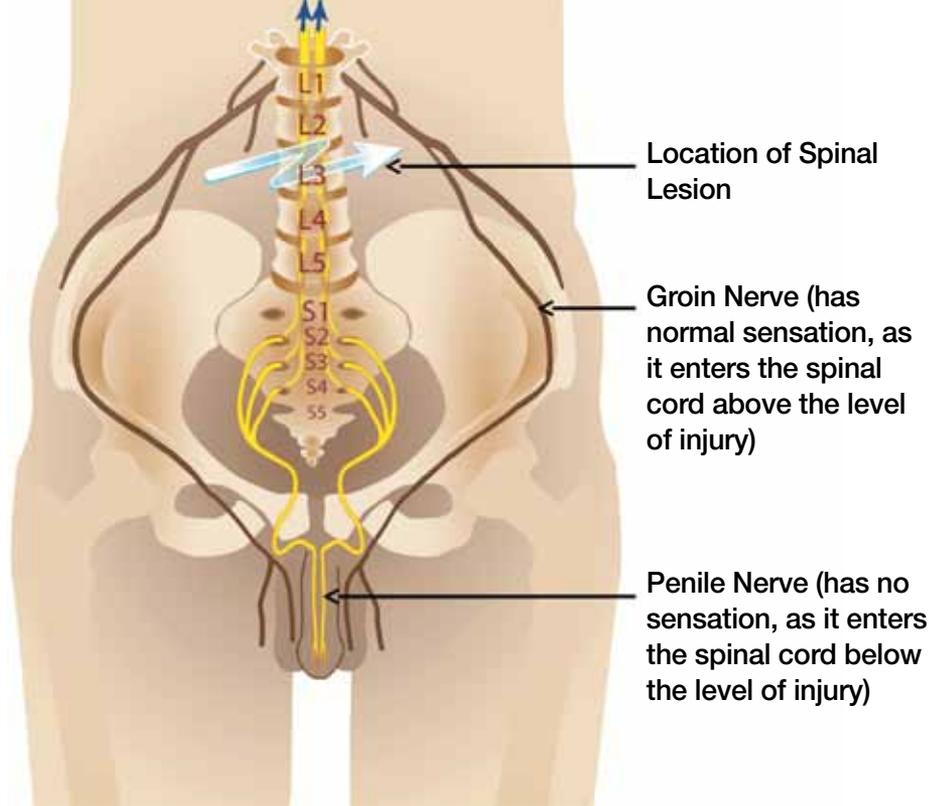
the procedure, which will only benefit someone with an injury below L1 (which is where Shaw's is) or those with spina bifida. So he sent a detailed enquiry to the plastic surgeon who developed the technique, Dr. Max Overgoor, at his clinic in Zwolle, Netherlands. An initial phone consult was set up, and Overgoor confirmed that Shaw might benefit from his innovation.

"It's physiology," explains Shaw. "I'm a lower level, incomplete SCI, with normal sensation in my groin and reduced sensation in the glans penis. And so, aside from being long in the tooth and overweight, I'm an ideal candidate."

From there, Shaw worked with Overgoor and his staff, along with some key BC-based specialists, to make arrangements for the surgery. While some of the details had yet to be worked out at the time of writing this, we know that Shaw plans to travel to the Netherlands for the surgery in May.

At that time, Overgoor will perform what is essentially a nerve transplant. He began developing the procedure, which he named TOMAX (TO MAXimize sensation, sexuality and quality of life), in 2001. A colleague, urologist Dr. Tom de Jong, asked him if he could do anything for his young patients with spina bifida who had the ability to form an erection, but couldn't feel anything in their penis. Intrigued, Overgoor began exploring solutions and expanding the scope of his work to include people with low level SCI. Borrowing knowledge from other nerve transfer surgeries, he continued to develop TOMAX—he operated on his first patient in 2001 and has been performing it ever since.

TOMAX involves transferring a branch of the functioning nerve that supplies sensation from the thigh skin to the non-functioning nerve leading to the glans at the tip of the penis. Note that everyone has a set of these target nerves—left and right. The procedure can be done using the nerves of just one side for those who are in danger of losing existing sensation, or for ideal candidates, both sides for maximum effect.



“By connecting the nerve in the groin with the nerve in the penis, many men with a low spinal lesion due to SCI or spina bifida can feel their penis again,” explains Overgoor, who trained at Utrecht University and is currently working in Isala Hospital in Zwolle. “This is because the groin nerve ends higher up in the spinal cord (above the injury site) than the penis nerve (which is below the injury site).”

If it goes well, the nerve in the penis is reactivated and, to varying degrees, some sensation is restored. Sensation, if it materializes, shows up in one of two places—about 60 percent of those who gain sensation do so in the glans of the penis itself, while about 40 percent experience it in the groin area (in other words, despite the penis being stimulated, the sensation reports to the brain as coming from the groin area).

“According to Dr. Overgoor, the returned sensation will not feel the same as it once did—it will be a different kind of sensation,” Shaw says. “So, I’m prepared

for that. I look forward to more powerful orgasms. And I think that having my sexuality restored—even partially—will mean a kind of restoration of my identity as a sexual being. I am married, and, in my opinion, healthy intimacy is a critical part of a happy, functional marriage.”

The tough part, says Shaw, will be waiting for the result, since it won’t be immediately obvious if the procedure will be a success. As with all nerve transfer surgeries, it takes many months of healing and nerve growth for the connection to begin to be established.

“The nerve of the groin must grow into the nerve of the penis,” explains Overgoor. “This is a slow process. If it works, men only get their feeling back after four to six months.”

Full results, he adds, might not be apparent for a year.

Based on the procedures completed to date, there’s a good chance that Shaw will experience some type of improvement. Since 2012, Overgoor has performed TOMAX on 80 men (he’s also

done the surgery with four women—more on that in a moment). The procedure has also been performed by other surgeons in the USA, but Overgoor only has data on the procedures he’s personally done.

“More than 70 percent got feeling back, and 60 percent say it really helped, but it is different for everyone,” says Overgoor. “For some, it’s the sense of feeling that’s restored and they realize that the penis is a part of the body; others are able to gain greater enjoyment from sex again. Patients reported more satisfaction with their erections, masturbated more frequently, and had more pleasurable sensations and sometimes orgasms. This led to more frequent and more satisfying sexual activities, and a more meaningful sexual relationship. The new sensation significantly enhanced their quality of life and sexual satisfaction. Everyone has their own story.”

But he’s quick to point out there are no guarantees of a successful result. “This is great and rewarding work, but I am very realistic since it does not work with everyone,” he cautions. “Sometimes it is a disappointment, and then I realize that, while the concept is good, in reality it is not a success for everyone.”

Up until now, there have been no major complications, although some pain and discomfort is normal for the first few weeks.

“My wish is that some day, in every country, there will be a doctor who can perform this operation. The procedure itself is not very complicated. I have documented it in detail and a good plastic surgeon who regularly operates on nerves can perform the surgery.”

– Dr. Max Overgoor



We mentioned above that Overgoor has done the procedure with four women. In this case, the groin nerve is transferred to the clitoral nerve.

“Until now the female TOMAX procedure is still being done under scientific study control and ethical approval,” he says. “We operated on four older female patients up to this point, but since we did not publish the results yet in a scientific medical journal, I can’t tell you too much about the results yet. What I can tell is that the most regained sensation is in the clitoris, the clitoral hood, and some also in the first part of the vagina. This is really something absolutely new and has never been done before. We just have to wait a little longer to know what these new feelings will mean to these female patients. I am confident that the procedure will have a positive effect on many women worldwide in the future.”

So if you’ve been reading this and thinking you might be candidate, what can you do?

At the moment, your only option is to contact Overgoor’s clinic and start a conversation to determine your suitability. If it appears you are a candidate, you’ll then have to work with your own healthcare provider and, ultimately, a BC-based specialist, to arrange for some preliminary testing. Then, if everything still looks okay, you’ll have to find the means to travel to the Netherlands, and pay for the procedure itself—both of which represent significant costs.

In Shaw’s case, he found a sympathetic ear with ICBC, which is funding his procedure as part of his settlement from his injury-causing collision. And he’s also been vetted and supported by two Vancouver-based specialists—physiatrist Dr. Viet Vu and urologist Dr. Alex Kavanagh.

“I’m still jumping through hoops,” says Shaw. “But, I would say that, at least in this case, being open, honest and as detailed and comprehensive as possible was critical in attaining the funding. I was also lucky enough to garner the support of Dr. Vu and Dr. Kavanagh. And I think that having all of the documentation and letters of support organized made the

Need a sex mentor?

Got questions about sexuality and intimacy as a person with SCI? Consider getting in touch with our Sexual Health Peer Mentorship program.

Created in partnership with sexual health clinicians from the Sexual Health Rehabilitation Service and Vancouver Coastal Health, our new initiative aims to connect peers with others who have experience and wisdom to share when it comes to dating, relationships, fertility, and all things sexual health-related.

The peer mentors who have volunteered for the new program have received training in mentorship and sexual health, and are happy to share information, answer questions, discuss concerns, and offer non-judgmental peer support. They’re available to connect one-to-one by request.

If you’d like to learn more about the program or get in touch with a mentor, or if you’re interested in being a sexual health peer mentor, please reach out to Rachel Nicoletti (rachel.nicoletti@vch.ca) or Teri Thorson (tthorson@sci-bc.ca).

difference. I also constructed a detailed itinerary and budget that seemed to have helped. Honestly, my (ICBC) case manager was great! She was very supportive throughout, and despite the months-long drama of awaiting approval, the process was fair and straightforward.”

Shaw says he’ll look forward to sharing with readers what is hopefully a good result from the surgery later this year, in the hopes it will raise awareness within the peer community. And it’s that type of awareness that may ultimately make it possible for peers to some day be able to access the procedure without leaving BC.

“My wish is that some day, in every country, there will be a doctor who can perform this operation,” says Overgoor. “The procedure itself is not very complicated. I have documented it in detail and a good plastic surgeon who regularly operates on nerves can perform the surgery.”

Overgoor has published his results in several respected journals, and from these, he expected more surgeons to inquire about and learn the procedure in order to offer it in their part of the world. That hasn’t happened to any great extent, and it’s become clear to him that he needs to create more awareness in candidates for the surgery—people such as Shaw.

“I realize that publishing in medical literature is not the way to get potential

candidates informed,” says Overgoor. “As we speak, I’m finishing a website about the TOMAX procedure with all the necessary information to make a good decision. This is still in Dutch but will be in English soon too. I am planning to send this website to all SCI, spina bifida and cauda equina-related organizations around the world so they can share with their people. This might be the way to get this information spread. If doctors in Vancouver are interested they are always welcome to contact me, and I can come over and teach or they can visit me to get experience.”

We hope to bring you more news about TOMAX and Shaw’s results by the end of this year. Meanwhile, if you’re interested in learning more, Overgoor invites you to contact his clinical staff, by email (tomax@isala.nl). ■

TOMAX: are you a candidate?

People with SCI who are good candidates for the TOMAX procedure must have a spinal lesion below L1, and absolutely no sensation in the glans penis but absolutely normal sensation in the groin area. Also, you must never have had any surgery in the groin area—for example, repair of an inguinal hernia. Additionally, the best results have been seen in younger candidates, and although several people older than 55 have had the procedure, none have experienced any benefit.

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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.

A Behavioural Support Intervention to Promote Participation Among Family Support Providers of People with SCI

Overview: ICORD researcher Dr. Heather Gainforth and PhD student Rhyann McKay are interested in evaluating the acceptability and usefulness of a brief one-on-one intervention aimed at promoting participation among family members, partners, and friends who support someone with an SCI. Participation is defined as involvement in life situations ranging from self-care (e.g., exercise) to activities in one's community or society (e.g., spending time with friends).

What to expect: Participants will take part in two brief behavioural support sessions to explore barriers to participation in activities and come up with a plan to address those barriers. These sessions will be followed up with questionnaires and an interview to discuss participants' perceptions of the intervention. The behavioural support sessions and interview will occur over the phone or via Zoom. The total time required for this study is between two hours to two hours and 45 minutes. The sessions will be scheduled one week apart. Follow-up, including the questionnaires and interview, will take place two weeks and one month after the last session.

Who can participate: You may be eligible to participate in this study if you are 18 years of age or older, speak English, share a close relationship with someone with an SCI (e.g., family member, partner, spouse, friend), and provide emotional and practical support to someone with an SCI. You may not be eligible to participate in this study if you are an employee of a formal caregiving agency or the person you provide support to is less than one year post-injury.

Why participate: By participating in this study, you may learn strategies that may help you engage in activities that are important to you. The results of this study may inform tools and resources for family support providers of people with SCI in the future. Participants in this study will receive \$50 gift card.

Location: Participants will participate remotely via phone or Zoom.

For more information or to sign up to participate: Contact Rhyann McKay at rhyann.mckay@ubc.ca or phone 1.866.835.8979 (mailbox # 91042).

Burden of Intermittent Catheterization

Overview: Researchers in Dr. Andrei Krassioukov's lab are interested in exploring the effect of intermittent catheterization on the health of individuals with SCI, specifically in regards to the presence of urinary tract infections (UTIs) and episodes of autonomic dysreflexia (AD). The primary purpose of this part of the study will be looking at the impact of re-using catheters of intermittent catheterization on the rate of UTIs and urinary bacterial levels.

What to expect: Participants/caregivers will use intermittent catheterization and a swab for bacteria over a three-day period. The study involves three visits (one hour each), and three consecutive days of at-home swabs taken by family members/partners (nine total swabs, three per day).

Who can participate: You may be able to participate if you're 18 years of age or older and have an SCI; have a family member or partner who will perform intermittent catheterization for the management of urinary bladder drainage; and are able to speak and understand English. For more information on who is eligible, visit icord.org/studies/2020/04/intermittent-catheterization/.

Why participate: Complications from neurogenic lower urinary tract dysfunction (NLUTD) following SCI, such as UTIs, are associated with dangerous episodes of increases in blood pressure, known as AD. Dr. Krassioukov and his team propose individuals with SCI are at an underestimated risk for UTIs by re-using catheters for intermittent catheterization. It is hoped that your participation in this study will help inform best practices regarding re-use of catheters in intermittent catheterization and its effect on microbiological burden. No monetary compensation will be provided, but the resulting information may benefit participants and future individuals in making choices regarding catheter re-use.

Location: The study will take place at ICORD (Blusson Spinal Cord Centre), 818 West 10th Avenue, Vancouver

For more information or to sign up to participate: please contact Rachel Lai by email (rachel.lai@ubc.ca) or call 604.675.8856.



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Silver Lining

How can it be that life's greatest joy could arrive in such a time of darkness? That was certainly the case for me and my wonderful husband Mustafa, when we were blessed by the birth of our daughter Malika last June.

— by *Jana Husseini*

I was born with spina bifida. Despite two operations when I was a child to improve my quality of life, I have no sensation below my knees, and I use a wheelchair for mobility.

Even before Mustafa and I got married two years ago, we contemplated having a baby with excitement—but also with trepidation, given the challenges that might present themselves because of my disability.

Deep down, we knew we deserved a child to love and nurture as much as any couple. I was confident we would make great parents because of the way we love and care for each other. But I couldn't prevent doubts from creeping into my mind—doubts that, after I became pregnant, led me to question every member of my team of specialists. I fired out every anxious thought and ridiculously improbable scenario to whoever would listen. I'm eternally grateful for their patience.

Eventually, I found calm, reassured by the realization that mothers come in all abilities, not to mention colours, sizes, shapes, races, socioeconomic backgrounds, and nationalities. No one should be considered more worthy of motherhood than another, and if that's what you've been led to believe, then you're living in a sad world that's making people feel broken.

When I first saw Malika, the world was mine; I felt love so potent that I forgot I just gave birth. For the first time in what felt like a lifetime, I forgot about all my worries and insecurities, and had a moment of clarity I'd never had before.

I will be honest—labour was a lot harder than I anticipated. It was a gruelling 20-hour process. But somehow, I loved every minute. As soon as I saw Malika's face, I was overcome with motherly love. In a flash, it melted away the sadness of the COVID "No Visitors" rule, not being able to celebrate with a baby shower, and delivering during a pandemic while my own mom was stuck in Lebanon and couldn't be here with me. All I could think about was, no matter what, Malika's father and I were going to endure whatever chaos this world presents to protect our miracle baby.

Why do I call her a miracle? Again, I won't downplay that this was a trying journey. But it represented my determination

to overcome the adversity brought by my disability. My pregnancy was far from easy, but just knowing that my disability didn't take away from my choice to conceive has helped me learn so much. I believe this world presents people with hardships that can help us understand the value of what we have in life. Accepting and understanding this gave me the strength to endure my daily morning sickness, monthly gynecologist appointments, dozens (maybe even hundreds) of other appointments, invasive tests, difficulties getting pregnant in the first place, and the ongoing bouts of insomnia that plagued me throughout the ensuing nine months after we conceived. Yes, she is a miracle—one that I have so many people to thank for.

Mustafa! You have been our rock. Thank you for always listening and understanding this journey. I love you so much. Alhamdulillah—praise be to God. We could not have done this without the tawfeeq (acceptance and blessing), patience, and strength from Allah.

To my amazing labour and delivery nurses at Lions Gate Hospital, thank you. I couldn't have done this without angels like you. Thank you for understanding the needs of mothers with disabilities. You are my heroes.

Dr. Lipp, I'm so thankful to have you as my gynecologist. Without an epidural, it was a very long and painful labour, but you handled it with loving expertise. Thank you for making this journey and dream possible. Thank you so much for taking care of us.

Above all, Malika, thank you for making me a mother, and Mustafa a father. ■

Jana, Mustafa and Malika live in Surrey.



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