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SPINAL CORD INJURY BC

WINTER 2020



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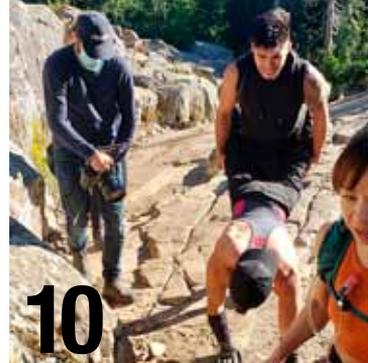
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COVER PHOTO: Staphylococcus aureus bacteria, one of the culprits behind chronic pressure ulcers.



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It moves slowly...but passes quickly

I've noticed that the subject of time comes up a lot during this COVID-19 pandemic. This isn't surprising, as the pandemic has forced us to reflect a lot on the passage of time: wondering how long we are going to be in this, remembering what times were like before the pandemic, wondering what our post-pandemic future looks like.

I've also noticed that, when time pops up in conversation, its quirky nature is often part of the discussion. As noted author and activist Alice Walker puts it, "Time moves slowly, but passes quickly." I suspect this is an observation shared by many of us these days. I've heard myself and so many others talk about how the pandemic is dragging on and taking its emotional and physical tolls on us as it does so. But lately, I also find myself thinking, and hear others asking the same question: "How is it December already?"

Reflections on the oddities of time are not limited to the pandemic, of course. We note them all the time, especially when we look back at the milestones in our lives. It seems like it's only been a couple of years since I was given the honour of working for SCI BC, which is why I can't believe a whole decade has passed since I joined the team. In a recent meeting, I was asked how long I had been serving as Chair of SCI Canada's Executive Directors Council. I was thinking it was about three years, but a colleague pointed out it has been five. I guess time really does fly when you enjoy what you're doing.

The oddities of time apply to organizational milestones, too. SCI BC recently celebrated its 60th birthday, but this year marks an even more significant milestone for the organization that founded SCI BC and all other SCI provincial organizations across the country.

That's right—in 2020, we celebrate the 75th anniversary of SCI Canada. It was 1945 when returning spinal cord injured World War II veterans banded together to incorporate the Canadian Paraplegic Association, now known as Spinal Cord Injury Canada, to provide better care and create a more accessible and inclusive world for people with SCI. Earlier that year, Toronto's Lyndhurst Lodge was purchased and became the world's first SCI rehabilitation centre. I encourage you to read about SCI Canada's incredible 75-year history at sci-can.ca/timeline.

I'm sure SCI Canada's founders would, in some ways, be pleased with how far we've come in this time, but they likely would have been disappointed with how slowly some changes have happened, and how many of the barriers and challenges they committed to overcoming remain today. At once, progress has come quickly and far too slowly.

The same can be said of the COVID-19. Never has progress against a global health threat been made so rapidly but with the feeling that it can't come soon enough.

With the winter solstice nearly upon us, we look forward to the return of the sun; a new cycle of brighter days ahead. We also eagerly anticipate the impending rollout of the promising vaccines that are critical for lifting us out of the pandemic. Time will tell how long it will take before we emerge from this crisis. While this time definitely can't come soon enough, there is reason to be optimistic that it won't be too long before it arrives.

—Chris McBride, PhD, Executive Director, SCI BC



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SENSORIA MAT

The Sensoria Mat is intended to help people with SCI lower their risk for pressure ulcers by helping them improve their pressure-relieving habits throughout the day. The system consists of a sensor mat that records critical pressure information and then relays it to a smartphone app using Bluetooth technology. Users can track both the quantity and quality of each pressure relief activity throughout the day. The sensor mat can be used under many existing cushions, or with an optional hand-made cushion developed for the system. The app, which is available for both Android and iOS smartphones, also provides feedback on correct pressure relief technique and reminds the user to perform weight relief activities regularly. A web-based dashboard allows clinicians and physical therapists to have the ability to assess their patients remotely. You can learn more at sensoriahealth.com/sensoria-mat.

Innovations

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



NEURALINK

Tesla and SpaceX inventor extraordinaire Elon Musk recently received the FDA's "breakthrough therapy designation" for Neuralink—an implantable brain/computer interface that promises to allow users to control computers, electronic devices and mobility aids with their thoughts. The FDA designation, which Musk announced during a press conference in August, is intended to expedite the approval process for technologies that are "intended to treat a serious condition and preliminary clinical evidence

indicates that the drug may demonstrate substantial improvement over available therapy." The system includes an external module that wirelessly receives information from thin flexible electrode threads embedded in the brain, which would be embedded by a robotic surgeon. Musk also announced that Neuralink's first round of clinical trials will involve participants with SCI. Visit neuralink.com to learn more.



SMOOV ONE

The SMOOV one is a new entry into the manual wheelchair power assist market. Designed by Invacare subsidiary Alber in Germany, The SMOOV one has a range of 20 kilometres, a 10 kilometre per hour maximum speed, and a weight of 7.2 kilos. The device's Bluetooth controller is mounted on your wheelchair—users tap it to start and stop, and twist a dial to increase or decrease the speed. The SMOOV one also uses smart technology—the unit will automatically shut down if you grab your pushrims to stop, and it will also slow down if it senses you're entering a turn. Power is provided to the integrated hub motor with a lithium ion rechargeable battery. The device easily mounts on the rear of your chair's frame using a quick release mechanism. Once in place, the unit is able to freely rotate on its mount—you can still wheelie up a curb, with the device rotating to allow this, while its weight keeps the drive wheel firmly in contact with the surface you're on. Visit smoov.com/us-en to see more.





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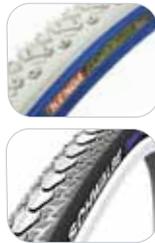
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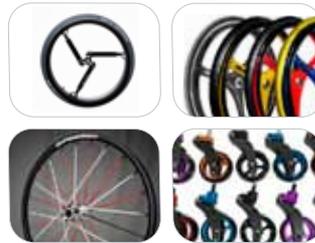
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Embrace winter.

Experience a winter wonderland with our friends at Whistler Adaptive Sports! They'll be offering a range of Para-Nordic programming starting in January. A top priority is to keep athletes, participants, volunteers and coaches healthy and safe, so all programming will follow provincial and regional health protocols as well as viaSport COVID-19 Safe Sport Guidelines. For more details, please email info@whistleradaptive.com, call 604.905.4493, or visit Whistler Adaptive Sports online at whistleradaptive.com.



Join your peers online.

With the pandemic restricting our ability to gather in person, our online programming will continue into the New Year with more fun and informative events for everyone. Join us for online coffee groups, book club nights, fitness classes, special guest speakers and more! There's something happening every weekday, with new events popping up all the time. Have an idea of your own? Feel free to send your suggestions or feedback to Jenna at jwright@sci-bc.ca. We hope to see you online soon!



Get a direct connection.

We get it: group Zoom calls and meetings aren't for everyone. If you need information or support but would prefer a one-to-one conversation, please don't hesitate to contact your local Peer Coordinator between 9 AM and 5 PM on Monday to Friday (you can find contact details for all regions at sci-bc.ca/contact). You can also connect with our InfoLine (1.800.689.2477) Monday to Friday during the same hours. Our staff are always happy to lend an ear and answer any questions you may have.



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peers ■

A legislature-sized shoutout to **FIVE BC POLITICIANS WITH SCI** who have continued blazing a trail



Left to right: Stephanie Cadieux, Dan Coulter, Spring Hawes, Michelle Stilwell and Sam Sullivan

started by Doug Mowat, one of the founders of SCI BC who became the first MLA in Canada to use a wheelchair when he was elected here in BC in 1983. Leading up to our recent provincial election, **STEPHANIE CADIEUX**, **SAM SULLIVAN** and **MICHELLE STILWELL** were battling to regain their respective seats for the Liberal party, while **SPRING HAWES** and **DAN COULTER** were seeking first terms as MLAs for the NDP.

Only Cadieux and Coulter were successful in their campaigns. Cadieux successfully won her seat in South Surrey and continues her 11-year career as an MLA (she's also been appointed Caucus Chair and Critic for Gender Equity, Accessibility & Inclusion). Coulter is now the new MLA for Chilliwick (and newly appointed Parliamentary Secretary – Accessibility). Sullivan and Stilwell didn't fare as well in their respective ridings of Vancouver-False Creek and Parksville-Qualicum, both losing well-fought contests to their NDP opponents. And Hawes fought a very competitive battle to win former Premier Christie Clark's old riding of Kelowna West, but came up short in the Liberal stronghold.

While it's a bittersweet result for three of our peers, we believe it's vital that all five be commended for their efforts and achievements in the political arena and, as Mowat did so many years ago, leaving no doubt in the collective public mind that politicians with SCI are up to the job.

Peer Shoutouts

It's not the first time we've given North Vancouver's **LEO SAMMARELLI** a shoutout, and considering the way he continues to challenge himself, it probably won't be the last. Recently, Sammarelli made headlines for becoming the first person to complete the gruelling Grouse Grind using only his hands and arms. It took him six hours to scale the

2,830 steps of the 2.9 kilometre climb (which has an elevation gain of 853 metres) while a pair of helpers took turns holding his legs in a wheelbarrow position.

A world-class boxer, Sammarelli became a paraplegic in 2017 during a drive-by shooting. Along his road to recovery, he has become a huge contributor to BC's SCI community.

"Doing The Grind was initially a fundraiser to raise money and publicize West Coast Wheelchair Adaptive Boxing, and raise awareness for the sport both locally and globally," says Sammarelli. "On a personal level, it was done as a message to people proving that anything is possible when putting your mind to it. I also meant for it to be a sign of hope and encouragement during these times of uncertainty."

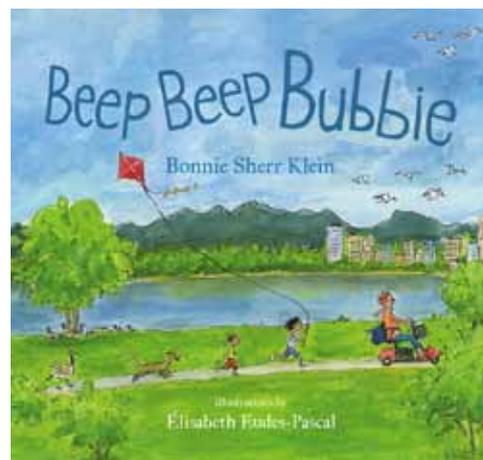
Are you an SCI BC peer who has something to shout about? Or do you know a peer who has recently achieved something noteworthy? Send the details to thespin@sci-bc.ca.



We're not sure how Vancouver's **BONNIE SHERR KLEIN** managed to publish a children's picture book during a pandemic, but we're glad she did. *Beep Beep Bubbie* is a story about Bubbie and her grandkids Nate and Kate. When Bubbie starts using a motorized scooter, Nate is quick to get on-board, but Kate not so much. During an outing to Granville Island, Kate begins to see the scooter in a new light. The trio's adventures are cleverly illustrated by Montreal artist Élisabeth Eudes-Pascal.

Sherr Klein, who has used a scooter since 1987, wrote the book to entertain—but also to spark family conversations about aging, disability, climate change and feminism. It's receiving glowing reviews, including one from singer and entertainer Raffi Cavoukian, who describes it as a "heartwarming story, beautifully illustrated—a book you and your kids will love!"

Sherr Klein is an award-winning documentary filmmaker and writer and co-founder of KickstART Disability Arts and Culture. *Beep Beep Bubbie* is her first children's book. It's available in many bookstores and online retailers, including Chapters Indigo and Amazon.



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Catch & Release

Findings from Switzerland create hope for new non-antibiotic treatments for urinary tract infections.

If you think about it, you can draw some parallels between fossil fuels and antibiotics. Throughout the 20th century, we relied heavily on both—after all, one seemed to be a risk-free, unlimited source of energy, while the other was thought of as a miracle treatment that makes short work of virtually any bacterial infection. But the perils of that reliance are now obvious. Fossil fuels are at the root of our catastrophic climate change. Antibiotics, meanwhile, are losing effectiveness as microbial resistance grows. The “carpet bombing” approach of antibiotic treatment (in which bacteria we need in and on our bodies to thrive are killed along with harmful bacteria) is increasingly recognized as sometimes doing more harm than good.

We’ll continue to use fossil fuels and antibiotics as stopgaps while we identify and develop safer and more effective alternatives. With energy, that means relying more on electricity generated via renewable means such as wind and solar power. But what about fighting bacterial infections? Answers aren’t as obvious, but new possibilities are emerging. Case in point: new research that reveals the reason why some of us are able to natur-

ally keep at bay one of the most troubling bacterial infections for people with SCI—urinary tract infections, or UTIs.

Many readers know full well the vicious circle created in our lives by UTIs, which many are predisposed to because of long-term catheter use and the inability to completely void our bladders. Typically, you develop an infection. When it’s diagnosed, you usually get prescribed an antibiotic. If you’re lucky, the antibiotic works, without thoroughly disrupting your gut biome. But infections often return, growing more resistant each time, and sometimes contributing to more serious issues such as bouts of AD and even bladder cancer.

The culprit behind most UTIs are *E. coli* bacteria. A powerful infection occurs when enough of them cling to the walls of the bladder, ureter or urethra using hair-like appendages known as pili. But what if there was a way to prevent them from attaching themselves in the first place?

It turns out that many of us have this ability. All humans naturally produce a protein called uromodulin, which resides in our urine and has the ability to prevent the culprit bacteria from attaching to cells inside our urinary tract. And roughly 70 percent of humans carry a

gene variant which allows them to produce uromodulin in large enough quantities that it significantly lowers the risk of contracting a UTI. (While we’re not aware of any research that confirms this, it may well be that people with SCI who are most susceptible to UTIs probably are those who don’t produce adequate amounts of uromodulin.)

But until now, we haven’t really been able to understand the mechanism behind uromodulin’s ability to prevent *E. Coli* from establishing colonies in our urinary tract.

A team of Swiss researchers has now shed light on that mystery. In the process, they have confirmed the beneficial effect of uromodulin and opened new avenues for developing non-antibiotic treatments—perhaps by mimicking uromodulin’s action with another medicine, or finding ways of boosting uromodulin production, particularly for people who don’t have the gene variant that results in large scale production in our bodies.

The researchers, from ETH Zurich, the University of Zurich and the Children’s Hospital Zurich, captured images that reveal uromodulin’s structure and how it goes about neutralizing *E. coli*. Their findings were published in August in the journal *Science*.

First, the researchers set out to discover how uromodulin binds to the bacterial pili at the molecular level.

“We already knew that a bond is formed and that this presumably plays a part in uromodulin’s protective function, but nobody had studied this in greater detail,” says Gregor Weiss, a doctoral student in molecular biology at ETH Zurich and one of the study’s lead authors.

What Weiss and his colleagues found was that the culprit bacteria appear to be tricked into attaching themselves to uromodulin instead of the wall of a cell. The bacteria’s pili recognize certain sugar chains on the surface of the uromodulin and bind to them extremely readily and strongly.

Using cryo-electron tomography, an imaging technique that produces detailed

3D views of extremely small biological structures, the researchers revealed that uromodulin forms long filaments of protein molecules strung together. Each link of this protein chain contains a characteristic pattern of sugar chains which bacterial pili find extremely attractive.

Employing the same imaging technique, the researchers then took a closer look at what happens when the bacteria comes into proximity with uromodulin. They discovered that the uromodulin filaments literally envelop a bacterium, and that a single uromodulin filament can dock with several pili of a bacterium.

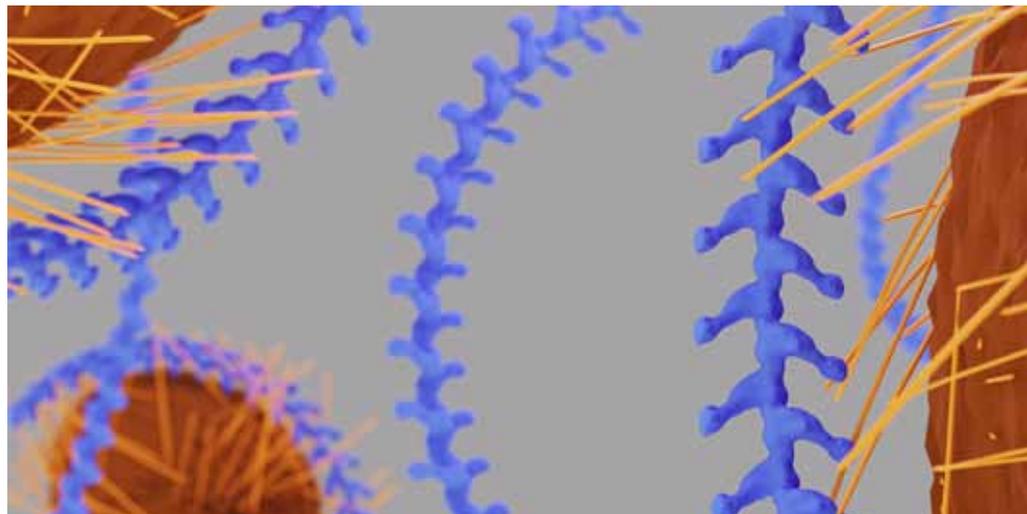
“This neutralizes the pathogens,” Weiss explains. “Once the bacteria are shielded in this way, they can no longer bind to the cells in the urinary tract, which means they can’t cause infection.”

Under a standard optical microscope, the team also noted the formation of large clumps of hundreds of uromodulin filaments and *E. coli* cells, which are then presumably simply excreted with urine.

These processes were all observed in the lab, so the researchers also checked to see they could be confirmed to occur in people. They analyzed urine samples from UTI-infected patients provided by the Children’s Hospital in Zurich and found exactly the same interactions between uromodulin and the bacteria.

The researchers believe it’s possible that their findings could eventually lead to alternative treatments to antibiotics.

One way forward might be finding ways to boost uromodulin production



A 3D visualization shows how uromodulin filaments (blue) envelop an *E. coli* cell, thus preventing the pathogen’s pili from docking on the cell walls in the urinary tract and causing an infection. Image courtesy ETH Zurich.

in people lacking that ability. “Ways to temporarily increase uromodulin in a tunable (adjustable) manner would be a possibility in the future to increase protection via the body’s innate immune response with uromodulin,” says Jessica Stanisich, doctoral student and another lead author of the study. But she adds that there might be challenges to overcome with that approach.

“As with everything in biology, it’s all a trade off: people who carry the protective promotor variant (that leads to higher uromodulin production) are better protected from UTIs in youth, but may be at a higher risk for chronic kidney disease later in life,” says Stanisich. She notes that a paper came out in 2018 that suggested cranberry extract increases the production of uromodulin in kidney cells;

she also notes that this has yet to be corroborated by other studies.

Another possibility could be introducing sugars in the urine that, similarly to uromodulin, might present a decoy that bacteria find irresistible. As many readers know, the sugar mannose and extracts like D-Mannose have been used for just this purpose for chronic UTIs. It turns out that mannose is, in fact, one of the sugars presented on the uromodulin filaments that tricks bacteria into binding to it. But it’s not the only one.

“Thanks to our analyses, we now know that the bacterial pili recognize not only mannose but also other sugars present on uromodulin,” says Stanisich. “This might indicate that treatment with combined sugar supplements would be more effective. We do not fully understand how mannose or a cocktail of sugars would prove to be effective, but we could hypothesize that they add to the protective ability of uromodulin. We don’t think the sugars enhance uromodulin’s protective ability, but instead act as another line of defence that ‘trick’ the *E. coli* into binding to them instead of the host’s cells.”

Indeed, many previous research efforts have concluded that mannose extracts are somewhat effective for preventing and treating UTIs. This new research from Switzerland provides an even more compelling case to build on those findings. ■



PhD students Gregor Weiss and Jessica Stanisich are two of the study’s lead authors.



After his 2015 rodeo injury, Kevin Cunin didn't know if he'd ever be able to ride again. Thanks to his own perseverance and a little help from his friends, he's back in the saddle—and chasing down a career in cattle ranching.

It was supposed to be Kevin Cunin's last competitive ride of the year. When his horse bucked him right out of the chute, it turned out to be his last competitive ride ever, at least as a bareback bronc cowboy.

But it certainly wouldn't be his last time riding a horse, despite the extensive injuries he sustained in the accident, which happened during the 2015 Bulkley Valley Exhibition rodeo in Smithers.

"I have a T4 complete injury," explains Cunin, who lives in Prince George. "I also had a stable fracture at C7, as well as five broken ribs and a punctured lung. I have two rods holding my back together, anchored by eight vertebrae in total, both above and below my injury.

I was also diagnosed with permanent brain damage from the accident, but I never believed the doctors too much 'cause they didn't know how dumb I was before the wreck."

Cunin's sense of humour wasn't the only thing left intact after his accident. He still had his competitive spirit, a powerful work ethic, the perseverance that led to him becoming a rodeo cowboy in the first place, and a great love of horses and western life.

So it wasn't surprising that he began thinking about riding again shortly after his lengthy rehab—and then working toward that goal.

"The first time back was three years to the day after the accident," says Cunin,



who is now 30. "I drove to Quesnel where my dad lives. I didn't tell him what was going on; I just told him I was going to look at a horse. I actually went to a therapy horse ranch and rode for a while. It

was frustrating because I wasn't able to go ride like I wanted to. But it was also a great start and gave me a little confidence to believe I would again one day be back riding and rodeoing in the future."

It didn't take Cunin long to figure out that a regular saddle couldn't provide enough support to allow him to maintain his balance, let alone throw a rope or ride at speed. After failing to find a specialized saddle locally, he connected with another injured rodeo rider in Texas who had started a business crafting customized therapy saddles.

He experienced a little sticker shock when he discovered the custom saddles, being such a specialized item, are expensive—about four times the price of a regular saddle. But to his surprise and pleasure, a group of local businesses, rodeo clubs and individuals took up his cause and helped him buy the saddle: the Smithers Rodeo Club, Intercoast Construction Ltd., the Quesnel Rodeo

Club, Nomad Welding, Interlakes Rodeo Club and Clint Ellis.

"I had some amazing businesses come on board when I was looking for sponsorship to help make the saddle a reality, and they absolutely stepped up and were happy to help out," he says. "I wouldn't be where I am without their support."

Those who first saw the new saddle when it arrived in Prince George this past July were impressed to see the names of Cunin's sponsors etched into it, along with these words: "Winners never quit. Quitters never win."

"The saddle is similar to a regular saddle but it has a tall back on it with a large wide leather strap that goes around my stomach to hold me in and stop me from flopping around," explains Cunin.

The first time he tried it, three friends were at his side to keep him steady.

"The new saddle was also frustrating but rewarding," he says. "It's a completely different feeling from a regular saddle

because you can't roll your hips while riding. But knowing that the guy who built the saddle was also a paralyzed athlete and able to team rope competitively, I just had to believe in the saddle and that it would be able to get me back to where I want to be—rodeoing and having fun."

Since that first ride, he's persevered and has become more and more comfortable in the new saddle, to the point where he's able to ride and even rope independently.

"I have an absolutely amazing group of friends and supportive club members at the Prince George Rodeo Association that help me get on and off the horse," he says. "Eventually, with the right barn or arena set-up at home, I should be able to rig up a system to load independently, although I will probably not ride alone again just in case something happens to the horse. I could be in a really bad situation and, at least with someone riding with me, they could go get help."



Making the transition to the new saddle was made all the more easier by a new horse.

"I was able to get an older, bomb-proof rope horse out of Alberta that really takes care of me and knows his job. Horses are pretty special animals and they have a sense of what's going on. He acts differently when it's me riding him compared to someone else hopping on his back."

Throughout all of this, Cunin has been working full-time in the forestry industry. But he'd been dreaming about operating his own cattle ranch since his injury.

"After my wreck and getting out of the hospital, I moved back with my partner at the time to her parents' out in Vanderhoof," Cunin says. "They had some cattle, and I got into learning about ranching and cattle, because I didn't grow up around it. I needed to learn some basics with some more in-depth knowledge to see how I could make an operation work for me so I could still ranch and rodeo given the skills, as well as the restrictions, that I have."

So two years ago, he decided to enroll in the Applied Sustainable Ranching Program at Thompson Rivers University Williams Lake campus. He's currently in his final year of the program, taking classes remotely from Prince George while he continues to work. And he's also started work on his own ranch, on land he recently purchased outside of Prince George. With the help of business partners, he's already bought livestock and is forging ahead with his plan to build an energy and cost-efficient cattle operation.

"The eventual plan with the ranch is for it to be able to financially support myself so I can live the lifestyle I want and have the freedom to live a life I enjoy," says Cunin. "There are many different hurdles that are encountered on a daily basis. Some are simple and some are more complex. Most of the issues can be overcome when thought of in a different way than an able-bodied person looks at it. These hurdles are absolutely worth tackling so that one day I will be able to have the freedoms and lifestyle

that I want and am working towards."

Riding, roping, running a cattle ranch—these are all ambitious goals for anyone, let alone someone with an SCI. But Cunin is already back in the saddle, and given that, we have no doubt he'll complete his cowboy comeback.

"I have never been very naturally gifted with any God-given ability except being able to work hard and have some work ethics," he says. "I think I was lucky to be raised by two extremely hardworking parents who didn't just give my brothers or myself much in the way of a hand-outs—they showed us that anything is possible if you're willing to work for it. They gave us a great life, but showed us through their own work ethic that anything is possible. There's no doubt not all activities that a person did before their injury are possible or look the same, but new doors will open. There isn't a lot in life that a person can control except their attitude—it's the one thing they can control, and that can have the biggest impact on their life moving forward." ■



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PeerSAY!

Been tested yet?

With COVID-19 surging as we went to press, we realized that many readers may want or need to be tested this winter. We reached out to a few peers who have already been tested and asked them about their experiences. Note that all were tested using the swab-in-the-nose method; more and more testing centres are now using the new, less-invasive gargle test. Here are some facts about COVID-19 testing in BC:

- Testing is recommended for anyone with cold, influenza or COVID-19 symptoms. Testing is not recommended if you don't have symptoms. You can get a test from a physician, nurse practitioner, urgent and primary care centre, or at a COVID-19 test collection centre, (there are 104 throughout the province at the time of writing). You can call 8-1-1 to find the testing locations that suit you best (make sure you inquire about accessibility).
- The Northern Health Authority has an outreach testing program for people who have difficulty leaving their home. It's a fair assumption that other regional health authorities have a similar provision. If you can't get to the nearest COVID testing site or have concerns about accessibility, inquire about mobile testing.
- If you aren't sure you should be tested for COVID-19, you can use the BC COVID-19 Self-Assessment Tool to make a determination. The Self-Assessment Tool is available online or as an App for your mobile devices. Visit bc.thrive.health to see your options.
- Visit an emergency department ASAP if you're experiencing severe symptoms of COVID-19: difficulty breathing or shortness of breath, chest pain or pressure, and loss of speech or movement.

JESSICA VLEGENTHART, T8 Paraplegic, Kamloops

I had a bad cold and made the decision to get tested. I drove myself to the test location, the Public Health Unit in Kamloops—they have a little portable out back of the main building set up for COVID testing. I had no issues with access. There was a ramp that was to code. They didn't require me to transfer into another chair. The nurse just placed her hand on the back of my head to prevent recoil, I tipped my head back, and she did the swab. It's horrifying in the moment, but you forget about it quickly if that makes sense. It's five seconds of your mind screaming, "be cool, be cool, be cool" at your body, and then it's done. I gagged and had reflexive tears when they took it out, and the nurse said, "That's how we know we hit the right spot." Also, my teeth on the right side (where they shoved the swab up) weirdly ached for a few hours. Overall, it was more irritating than anything. I've been telling people it's a pretty similar experience to a Pap smear—not something you're pumped about, but over soon enough. Results came in 48 hours. If I had to get another test today, I'd be irritated but not freaked out.



HAL BENNETT, Double amputee, Chemainus, BC

I had symptoms suggesting I had been infected despite isolating, possibly from a roommate before they went back home for quarantine. Here on the Island, you had to call in order to get a location and time for a test. They said I could go in that day since my symptoms seemed to be getting worse. I drove myself to the Cowichan District Hospital in Duncan late in the evening. First I went through the nurse greeting station where they gave me a mask and told me where to go. Next was check in; this included more questions about my symptoms. A doctor eventually saw me and also needed the quick notes version of my story, then asked some contact tracing questions. After a few minutes, the nurse came to take the test. Preemptively, I rolled back into a wall. The nurse saw what I was doing and began to apologize for what he was going to do. With all the symptoms



and a really long wooden Q-tip swirling around behind my eyeball, I began to feel like everything was spinning out of my chair. I held onto my wheels and waited till he was done—it was quite quick—and then I was able to rub my nose and eyes to try and stop the itch. It was the exact same feel as pulling out a bunch of nose hairs. It took me a few minutes to trust my inner ears so I could get the heck out of there. The doctor told me to expect the results in

couple of days. The test came back negative. The wait for the result is the worst part. Everything gets put on hold; even those within your safe circle are kept out and/or have to go through the experience you just went through.

PETE FROESE, T8 Paraplegic, Fraser Valley

What started out as a scratchy throat developed into a full-blown cold, with a persistent cough and stuffed sinuses. Although I assumed I had simply a common cold, every cough or sneeze these days is suspect, so at the insistence of my wife I went



to get tested at the Chilliwack Public Health Unit's COVID-19 Assessment Centre near the Chilliwack General Hospital. As the earliest opening for an appointment was four days away, I chose to give the walk-in a try. When I arrived, it seemed as though the walk-in line wasn't any longer than the line for appointments. As I waited, a staff member came out to prescreen me with the usual COVID-19 questions. After about 40 minutes, I made it to door, where I entered another short line of people waiting for an open screening booth. I showed my Medicare ID and received a detailed check-list to complete. When a station opened up, a medical tech came to guide me to the station and described the procedure for me. Then I was instructed to tilt my head back and she proceeded to massage my eye sockets through my choice of nasal canals! Seriously, it was a bit of discomfort for three or four seconds, and then it was all over. I was tempted to ask for another one in my other nostril to clear both sides but didn't think it was the right occasion for humour. I was told to self-isolate until I got the results of my test, but was very pleasantly surprised when I got my results texted to me the next day. The test was negative and I could now go on with confidence that I just had a cold.



NEIL SQUIRE SOCIETY

This winter, Neil Squire Society will be offering a number of webinars and Lunch & Learns, as well as their usual fantastic programming. If you're looking for a job, need assistive technology for your home office, or want help connecting with others through email or social media, Neil Squire has you covered.

- Digital Jumpstart will help you improve your digital literacy so you have the confidence to take your next steps. You'll work one-on-one with an instructor in a virtual classroom and cover topics based on your needs. Resources are available for basic digital literacy hardware, software, and training supports.
- The Working Together webinar series continues this winter. Join Neil Squire Society staff and presenters as they explore a variety of topics in online sessions designed to support job seekers with disabilities and eliminate barriers to employment, and learn about businesses interested in hiring or supporting employees with disabilities.
- WorkBC Assistive Technology Services provides support to people with a disability, chronic pain, or old injury that impacts their employment or self-employment activities. Funding is available for assistive technology, ergonomics, communication and hearing devices, vehicle modifications, and more. Join WorkBC Assistive Technology Services and Neil Squire for an informative webinar or a Lunch & Learn—lunch voucher provided!

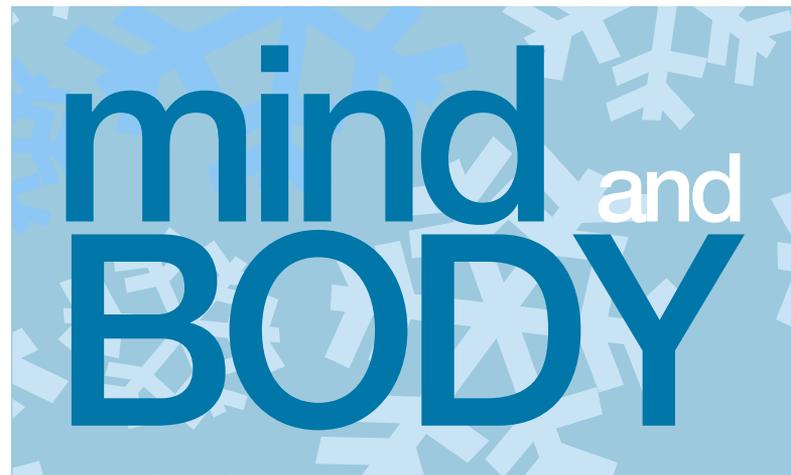
For more information or to attend an informative webinar, contact Neil Squire Society—email info@neilsquire.ca, call 1.877.673.4636, or visit the website (neilsquire.ca).

TECHNOLOGY FOR LIVING (TIL)

TIL is operating its usual programming aimed at keeping your tech skills sharply honed. Check out these popular group meetings and online education series to keep you at the top of your game.

- The Pathways to Independence Peer Group Meeting is run in partnership with the Individualized Funding Resource Centre (IFRC) and facilitated by Paul Gauthier. TIL technicians provide individual technology support for peers during the meeting if needed. This popular monthly Zoom meeting is usually 75 to 130 people strong. The next instalment takes place on January 27.
- WE Talk Tech is offered by TIL technical staff members Wayne and Ean. The duo provide an online discussion and education series to explain the assistive technology available from TIL for peers. These easy-going experts will offer their advice and opinions in engaging seven-minute episodes.
- Peers on Pages (POP!) Creative Writing Workshops provide an opportunity for you to share your writing and receive peer encouragement, feedback, writing tips and guidance. If needed, facilitators are available to support and assist you. This popular workshop will be running over the winter, but keep in mind that space is limited.

For more information about these programs, contact TIL by email at info@technologyforliving.org, call 1.866.326.1245 or 604.326.0175, or visit the website (technologyforliving.org).



THE DISABILITY FOUNDATION

The Disability Foundation will continue to host fun and diverse programming this winter. Here's what the foundation and its affiliates are offering this winter:

- Disabled Independent Gardeners Association (DIGA) will offer GrowABLE, an online adaptation of in-person workshops to help you prepare your garden for spring. This program, scheduled for January, will educate and inspire people during this challenging time, and grow your social connections. To learn more or to register, email Sheryl at snewman@disabilityfoundation.org, call 604.688.6464 ext. 117, or visit the DIGA website (digabc.org/events/category/growable).
- ConneTra will continue hosting its series of free virtual community gatherings every weekday. You can join on Zoom or Facebook for livestreams of meditation, chair yoga, adaptive fitness, and more. Email info@connectra.org, call 604.688.6464, or visit the ConneTra website (connectra.org/connecttogether).

ICORD/PARC

ICORD's Physical Activity Research Centre (PARC) recently announced it's getting a new piece of equipment. This revolutionary adapted rowing machine will provide PARC users with a fully accessible cardio/strength workout to all PARC users. The new addition to the PARC facility was funded by the Craig H. Nielsen Foundation. Call 604.675.8800 or visit the website (icord.org/parc).



BC WHEELCHAIR SPORTS ASSOCIATION (BCWSA)

BCWSA will continue to work through its Return to Sport plans this winter. Over the past few months, BCWSA has overseen a gradual return of some of its sport programs, with limited attendance and increased health and safety protocols in accordance with viaSport BC and public health recommendations.

- Some of wheelchair tennis and athletics programs have resumed.
- Staff and volunteers are continuing to work with wheelchair rugby clubs to get those programs back and running with strict adherence to the province's health guidelines.
- BCWSA has also launched a weekly Virtual Junior Wheelchair Sports program. This includes a range of sports and activities for youth with disabilities looking to stay active from home. It's an excellent addition to the Association's Virtual Girls Only – Go time Program.

As the COVID-19 situation and its impact on sport is constantly evolving, BCWSA couldn't offer set dates for the start of their Winter Programming in 2021 at the time of writing this. To stay up-to-date, visit their website (bcwheelchairsports.com) or email Nathan at communications@bcwheelchairsports.com to join the BCWSA mailing list.

During this season of partial lockdowns, new and changing orders and guidelines, and modified social interactions, many of us are looking to the great outdoors, or to new online activities, in the hopes of adding a little excitement to the cold season. We're happy to announce that many of our community partners will be offering online and safe in-person events to keep us busy and engaged. We connected with our partner organizations to find out what winter activities they'll have to offer in the months ahead.



CRIS ADAPTIVE ADVENTURES

CRIS Adaptive is still open and offering supported hikes and overnight trips, as well as limited equipment rentals. Upcoming winter programs include Nordic skiing and snowshoeing. CRIS Adaptive is based out of the Okanagan, but staff are happy to travel around the province to help you bring your adventure to life. Email admin@adaptiveadventures.ca, call 250.979.3941, or visit their website (adaptiveadventures.ca).

WHISTLER ADAPTIVE SPORTS

Whistler Adaptive Sports is offering Para-Nordic programming starting in January 2021. Its number one priority is to keep athletes, participants, volunteers and coaches healthy and safe, so staff will be diligent in respecting all provincial and regional health mandates and protocols as well as viaSport COVID-19 Safe Sport Guidelines. For questions or registration details, email info@whistleradaptive.com, call 604.905.4493, or visit the website (whistleradaptive.com).



Pressure Relief

Could an innocuous white powder revolutionize pressure ulcer treatment?

What if we told you that a daily sprinkling of a fine white powder on your open pressure ulcer might cut the healing time in half, or even more?

If you think we've lost the plot or have joined Gwyneth Paltrow in the snake oil business, we wouldn't blame you. In fact, we'd be happy if this was your reaction, since we believe in science here at SCI BC—and the basis for all good science is healthy skepticism.

But we're keeping an open mind about Amicapsil, a compound developed in the UK that's based on something called MPPT, short for micropore particle technology. You may want to do the same. Amicapsil has a growing number of highly-satisfied end users with SCI, mainly in the UK. Yes, it's true that anecdotes do not constitute conclusive proof. But there's also a growing amount of scientific evidence to support Amicapsil—enough to suggest that there may be something to it, and that, given the enormous implications of pressure ulcers, it needs to be investigated fully.

Staggering Costs, No Treatments

People with SCI aren't the only ones prone to pressure ulcers, but we think it's probable that no one is impacted more by them. Lack of muscle mass below injury means people with SCI lack "padding" to prevent pressure ulcers. Lack of sensation means those with SCI often don't know they've injured themselves or that a pressure ulcer is getting more serious. And it's recognized that people with SCI have compromised immune systems that makes it easier for pressure ulcers to become serious.

The costs of pressure ulcers are enormous—to individuals, and to society. On an individual level, a serious pressure ulcer can stop us in our tracks, with the only remedy being weeks, months or even years of bedrest. The combined costs to our healthcare system are even more jaw-dropping. There's no current estimate of the economic burden of treating pressure ulcers in Canada, but extrapolating the results of a recent study in the UK suggests the annual cost to our healthcare system is a

whopping \$490 million per year. And that's not even considering the byproducts of this treatment: tons of non-recyclable plastic waste, and tons of antibiotics released into the environment.

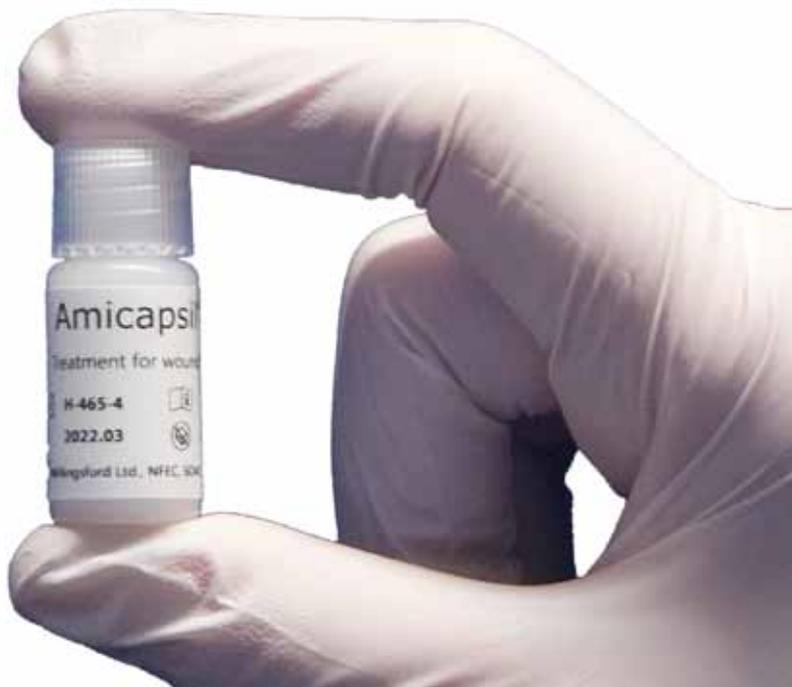
Despite this, it might surprise you to learn that there's no gold standard for treating pressure ulcers—particularly deeper wounds that refuse to close and heal. Nor has there ever been any game-changing research or treatment breakthroughs. Strategies once hailed as promising have since been determined to be ineffective at best, and harmful at worst. These include a wide range of antimicrobials, including antibiotics, natural ingredients like honey that have antimicrobial properties, and antiseptics.

What we've known for some time is that, once infected, pressure ulcers become difficult to close and heal. Not surprisingly, health professionals have looked to antibiotics and antiseptics to stem infections, and still do. But several recent summaries of existing research have raised serious doubts about these approaches. One, published in 2016 by the highly skeptical Cochrane Library, concluded that, "There was no consistent evidence of a benefit to using any particular antimicrobial treatment for pressure ulcers." In the USA, the FDA concluded in 2016 that there is no evidence that antibiotics or antiseptics have any effect on wound infection or support healing. In the UK, the National Institute for Health and Care Excellence (NICE), in its guidance on pressure ulcers, specifically states that antibiotics and antiseptics should not be used for treatment.

Bacteria: Friend or Foe?

Recently, there's been some research findings that are changing our understanding of how pressure ulcers and other wounds heal—and the use of Amicapsil builds on these findings.

At the heart of this is a growing realization of the importance of our skin's microbiome—an ecosystem of bacteria, fungi, viruses, and mites. When balanced, it's an integral part of our body's defence against infections. That's right—when it comes to our skin, a healthy microbiome of bacteria and fungi, working in concert with our bodies' immune system, is actually what



prevents dangerous bacterial infections by ensuring no single species of bacteria can become dominant.

In a serious pressure ulcer, the skin's microbiome can be compromised, allowing one or a few bacterial species to take over. This constitutes an infection, which slows or even stops healing. Our immune system tries to prevent this, but rampant bacteria secrete toxins and enzymes to thwart immune cells and attack other beneficial types of bacteria. And the infectious bacteria also secrete a biofilm that creates a slime wall "fortress" around themselves that our body's immune cells can't penetrate to do their job.

Simply put, attempting to "carpet bomb" the infection in and around a pressure ulcer with a topical broad-spectrum antibiotic or antiseptic might kill the culprit bacteria—but also all the other tiny living things essential for healing that make up our skin microbiome. In the case of antiseptics, even new cells at the wound site can be killed. There's also growing concern about drug-resistant bacteria. Today, most of us are carrying at least one resistant strain of bacteria on our skin. The risk is that, with antimicrobial treatment, the resistant type will not be harmed, but the non-resistant types will be killed. So antimicrobial treatment can actually provide the resistant bacteria with ideal conditions to aggressively multiply and infect the wound.

Rebalancing the Microbiome

All of this suggests that a better approach to healing difficult pressure ulcers would be supporting the immune system as it attempts to regain some balance in the microbiome at the wound site. This is exactly what MPPT does, according to the company that developed it, the UK's Willingsford Healthcare. The company describes MPPT and its MPPT product, Amicapsil, as "passive immunotherapy that disrupts the weaponry bacteria and fungi use to inhibit the immune system, allowing the immune system to recover."

According to Dr. Frank Sams-Dodd, co-founder of Willingsford Healthcare with his wife Jeannette, Amicapsil is

composed of "fine, highly porous particles that absorb wound exudate into a micropore structure." He says that the micropores act as pumps, which are powered by evaporation—the exudate, or pus, which contains the toxins and enzymes secreted by infectious bacteria as weapons against the immune system, is drawn from inside the wound to the surface, where it evaporates. The removal of these toxins and enzymes allows the immune system to recover and regain control to balance the microbiome—necessary for healing. He adds that Amicapsil also has the ability to create holes in the biofilm protection erected by dangerous bacteria, allowing immune cells to penetrate and do their job. All of this is achieved with mechanical action rather than antimicrobial action.

"Amicapsil was part of a 10-year early research effort specifically aimed at identifying improved treatments for wounds, followed by 10 years of development," says Sams-Dodd, a neuroscientist with 25 years of experience in the pharmaceutical and medical device industry. "The interest and idea came from the frustration of being unable to heal difficult wounds."

We pressed Sams-Dodd for some more details about the composition of Amicapsil, but his responses were a little vague—likely necessary to protect valuable intellectual property.

"Amicapsil is fully patented for use and composition," he offered. "Amicapsil does not contain any antimicrobials and is non-polluting. It consists exclusively of natural non-toxic ingredients. It is readily biodegradable and can go directly back into the biological cycle. Its manufacture is a complicated process."

Treatment consists of first rinsing the wound with tap water, in the shower or with a squeeze bottle. Once dry, Amicapsil is applied directly to the wound. Only clean procedures are required. The wound can be left uncovered, or covered with a piece of gauze, providing it's breathable to allow airflow and evaporation. The frequency of treatment depends on the severity of the pressure ulcer and the healing progress.



A pressure ulcer treated with Amicapsil

In 2016, Amicapsil was approved for use by professionals in the UK and throughout the European Union. In 2017, approval was extended for use by individuals. It has similar approvals in Australia and New Zealand. These approvals are for use as a medical device, not a pharmaceutical, and they don't extend to providing financial coverage for the powder—users must pay themselves (more on the cost later). There are no formal approvals in Canada or the US, but there's nothing to stop people in North America from importing it for personal use.

What the Science Says

There's a surprising amount of research evidence to support the use of MPPT and Amicapsil—in humans, and in animals (wound care is a big problem for veterinarians as well). Amicapsil has been evaluated in variety of wounds beyond pressure ulcers, including trauma and surgical wounds, diabetic foot ulcers, and venous leg ulcers.

In fact, there's way too much research to attempt to summarize it in detail here. But we'll provide a few highlights.

In a 266-patient randomized clinical trial in the UK, Amicapsil was compared to the antibiotic gentamicin and the common antiseptic iodine in abscesses, surgical wounds, venous leg ulcers and diabetic foot ulcers. The study showed that it removed wound infections 60 percent faster than both the antibiotic and the antiseptic, and reduced the number of hospitalization days by 31 percent.

In a clinical case-series performed at Bristol University Hospital in 2017, Amicapsil was able to advance the healing of infected surgical wounds to the same stage in four to five days that would have taken three or more weeks with the hospital's standard procedure of using vacuum assisted closure, or VAC.

Perhaps most relevant is a case-series study of 40 acute or chronic wounds and pressure ulcers in people with SCI that's taken place in the last couple of years in the UK.

According to Sams-Dodd, Amicapsil closed all the pressure ulcers, regardless of whether they contained resistant bacteria or not, as long as the person started treatment before the wound was two months old. The older the pressure ulcer was, and the more antimicrobial and antiseptic approaches that had already been tried, the longer healing took. In many wounds over six months old, the infection had spread to the bone, but even with these, Amicapsil was able to remove the infection in the soft tissue above.

We decided to take a deeper dive into the results from one of these case studies. We chose the most recent, which

was led by Dr. Oliver O'Sullivan at the Defence Medical Rehabilitation Centre (DMRC), the UK's national rehab facility for injured military personnel.

"We have found, similar to many other rehabilitation centres, that our management of chronic wounds has prevented optimal rehabilitation," says O'Sullivan. "So when we heard about MPPT, we felt it was worth trying."

O'Sullivan's case study subject, a service man in his 30s, had sustained a complete SCI in 2016. In early 2019, he developed an abscess. Despite several aggressive interventions including surgery, the abscess turned into a serious non-healing wound over the course of seven months. That, of course, took an enormous toll on the physical and mental health of the patient, who eagerly agreed to the Amicapsil treatment.

There was a dramatic improvement in the wound after one month—it no longer produced a foul odour, and it had reduced in size significantly. "We were surprised by the progress, especially at first," says O'Sullivan. "It was clearly making a difference. After a month, we, and the patient, really felt it was worth pursuing

as it was clearly improving this chronic wound, and enabling him to undergo more rehab and improve holistically."

Treatments were reduced from twice daily to once daily. After three months, only a small open area remained. And by six months, the wound had achieved almost full resolution.

The results of the case study were published in the August 4, 2020 issue of the journal *BMJ Military Health*. "Amicapsil has the potential to improve the management of chronic wounds at DMRC with its ability to heal wounds quicker," wrote O'Sullivan in the article's conclusion.

Amicapsil in the Real World

Amicapsil has been approved to purchase since 2017, so it's not surprising that many people with SCI have tried it and reported success.

One of them is 42-year-old Peter Hamilton, a software developer who lives in Salisbury in the southwest of England. Shortly after his C5/6 injury in 2011, he developed a pressure ulcer on his sacrum. It was the bane of his existence for years, with all conventional treatments including surgery failing to resolve it.

PRESSURE ULCERS: CARRY YOUR CARD!

You've got your AD wallet card. You've got your UTI wallet card. Now you can add the pressure injury wallet card. As with all SCI BC wallet cards, the idea is to keep this resource in your wallet or purse. The card was developed as a collaboration with GF Strong clinicians Regina Colistro and Shannon Sproule with a specific use in mind: to alert your caregiver or healthcare professionals in the hopes that you can avoid a pressure injury completely. Print your own at sci-bc.ca/PressureCard, or contact InfoLine at info@sci-bc.ca or 1.800.689.2477 to get yours by mail.

Note for Patients

Give this card to your community health team, caregivers, nurses, physicians or ER team upon admittance.

Use the space below and the diagrams inside to communicate your history of pressure injuries. Share the information on this card with your health professionals.

Learn more about pressure injury and SCI from Spinal Cord Injury BC:

SCI BC InfoLine: 1-800-689-2477
Email: info@sci-bc.ca
Download an online version of this card:
sci-bc.ca/PressureCard

Note for Health Team

I have a history of pressure injuries.
 Location(s) and date of history: _____

I have an active pressure injury.



MEDICAL ALERT

PRESSURE INJURY PREVENTION

Please attach this card to my chart.

I have a spinal cord injury. I am at extremely high risk for developing an injury due to pressure, shear and/or insufficient mattress or positioning practices. This can quickly become life threatening. I require:

- skin check on admission
- priority use of a pressure redistribution mattress
- regular turns and repositioning
- head of bed no more than 30° to prevent shearing
- avoidance of sling left in place while sitting

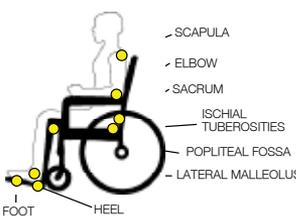
To obtain a pressure redistribution mattress in hospital, please contact the PCC/Charge Nurse.
Review this card for more details on pressure injury.

Produced in partnership with:

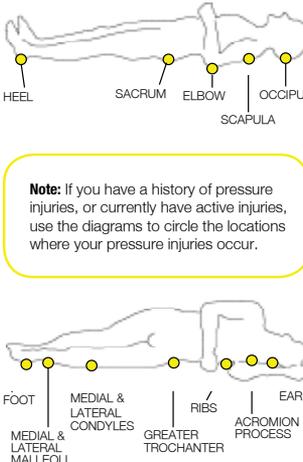
G.F. Strong Rehab Centre

Pressure Injury Information

Pressure injuries are common after SCI. They can affect as many as one third of people with SCI each year and almost every person with an SCI experiences at least one pressure injury in their lifetime. The risk of pressure injuries increases over time when living with an SCI long-term.



Common Locations of Pressure Injury



Note: If you have a history of pressure injuries, or currently have active injuries, use the diagrams to circle the locations where your pressure injuries occur.

More info on pressure injury:
scireproject.com/pressureinjurysummary
livingwithsci.ca/skin-health

Reprinting of this card funded by Spinal Cord Injury BC



Satisfied Amicapsil users Peter Hamilton and Raquel Siganporia

“The wound rarely stayed healed for more than six months at a time, and each time it broke down again it proved harder than the last to re-heal,” says Hamilton. “I’m a trustee of the Spinal Injuries Association (SIA), one of the national SCI charities here in the UK. One of the other trustees brought (Amicapsil) up at a board meeting, and having had a chronic pressure sore for the best part of four years, I figured I had little to lose.”

Hamilton purchased Amicapsil. Given his reduced hand function and the pressure ulcer location, he was unable to treat himself, but with daily consultations with Willingsford Healthcare, his wife and personal assistant were easily able to do the treatment. Over the course of several months, the wound closed to a tiny hairline opening—and finally resolved completely. Since then, Hamilton has successfully used Amicapsil for another pressure ulcer.

“Compared to anything else on the market, it is not far short of miraculous,” says Hamilton. “I have very sensitive skin and have always been at risk of skin breakdown elsewhere. Now I just don’t worry about it any more, because I know that with Amicapsil, a wound will just heal. Amicapsil has a refrigerated, unopened shelf-life of at least a year, so I can foresee me keeping some in my fridge for the next time my skin breaks down.”

Another satisfied user is 38-year-old Raquel Siganporia, a personal injury lawyer based in London who sustained a T6/7 injury 27 years ago.

She first used Amicapsil two years ago for a small, open breakdown in the IT

area (the two bones that are the lowest point of the pelvis when you’re sitting). Amicapsil helped this heal in 24 hours.

“However, the biggest test was a skin breakdown following a misjudged transfer where the skin on the back of my thigh broke,” says Siganporia. “The hospital advised treating with dressings, but I had an allergic reaction to the dressing and the wound then became infected. Within three weeks of using Amicapsil, the wound was no longer infected, and within four days of the eschar and slough both being removed, the wound had virtually healed. It took about another week for the wound to be strong enough to withstand me sitting up 16 hours on it. In total, it took six weeks for Amicapsil to fully heal the pressure ulcer, which was about five cm long and 2.5 cm wide. If I had been left to follow the NHS advice I would have been on bedrest for several months with it possibly worsening.”

Like Hamilton, Siganporia needed assistance from a family member to carry out the daily treatments, which were monitored by Sams-Dodd.

“I have no doubt that using Amicapsil sped up my recovery and substantially reduced the amount of time I had to spend on bedrest compared to how long it has taken for other skin breakdowns in the past,” she says. “Amicapsil is life-changing, and I now keep a bottle in my fridge for whenever I might need it.”

The Challenges Ahead

Will Amicapsil revolutionize the treatment of pressure ulcers? We think it’s too early to say. But if it’s to do so, we believe

there are three major hurdles that need to be addressed: no insurance coverage combined with what could be perceived as high cost, lack of awareness, and perhaps most importantly, the need for more research and conclusive evidence.

Let’s start with cost. At first glance, it is expensive—about \$100 for a 750 mg bottle. Sams-Dodd says that smaller wounds can be healed with one to three bottles, with more complex wounds needing more. For many, this might simply be too much. But conversely, for anyone who has ever experienced a non-healing wound and the weeks and months required to heal, the cost might not seem that high. Naturally, health care coverage would remove any hardship, and the company has applied for NHS coverage in the UK. Approval wouldn’t immediately help anyone living here in BC, but it would set an important precedent.

Then there’s the issue of lack of awareness globally about Amicapsil.

“It unfortunately always takes a long time for new treatments to be well introduced, particularly if it’s a fundamentally new way of treating a condition, and if you’re a small company with a limited marketing budget,” concedes Sams-Dodd.

The two end users we introduced you to above both believe that it’s successes like theirs that will turn the tide and lead to increased awareness and acceptance by national health programs.

“To my mind, this is an issue that will be driven by patients and results,” says Siganporia. “The proof will be in the pudding: if the product works, speeds up wound healing, reduces time spent on bed rest and reduces the financial spend and time spent in a hospital bed, then Amicapsil will become a no-brainer.”

“Although expensive, by healing wounds faster, Amicapsil may save money in the long run,” adds Hamilton. “The cost of conventional dressings and nurses’ time—especially on chronic, non-improving wounds—could be significantly reduced for the serious cases that can lead to expensive, repeat hospitalizations and surgical interventions over many years.”

We agree, but it also seems likely that the third challenge—completing more conclusive research—will be necessary for health policy-makers to get on board. O’Sullivan, the principal investigator of the most recent SCI case study of Amicapsil, agrees. “Whilst we have seen good effects in our handful of patients, and have seen a few papers describing its success elsewhere, I think that more evidence is required before the NHS can fund it,” he says. “I think further studies need to be done before it will be widely adopted, and we are at the early part of this new developments journey.”

One possible issue is that most of the research on Amicapsil to date has been funded and overseen by the company that makes it, Willingsford Healthcare. We’re not suggesting the research is flawed or compromised, but we do think more independent research may remove any suggestion of conflict of interest.

Another issue may be that the bulk of the research specific to SCI involves case studies. Approving bodies such as the UK’s NHS and the USA’s FDA may wish to see these case studies augmented by large-scale RCTs, or randomized clinical trials. RCTs compare the experimental treatment with another treatment or no treatment at all (placebo), with participants randomly selected to each group.

For his part, Sams-Dodd is aware of the need for more research—but he points out that RCTs are difficult to design for products like Amicapsil.

“We have discussed an RCT with the major SCI centre in the UK, but the choice of comparator has turned out to be the main challenge for everyone because it raises serious ethical questions,” he says. “In accordance with FDA guidance, an RCT only has a purpose if there is a gold standard treatment that is known to work, or you are able to include a placebo control group. You must then demonstrate superiority to this gold standard treatment or to the placebo treatment. The justification for an RCT is, however, highly questionable in the absence of an effective gold standard, and even more so when it is predictable that the patients

are highly likely to deteriorate if they use the common or standard approach.”

Sams-Dodd also thinks it would be difficult to find RCT participants. “In one treatment group, you have a product that has shown to have 100 percent efficacy in acute wounds, and in the comparator group you have something that has been shown to be ineffective and that everyone in the community knows this. Who would consent to participating?”

He also points out that the high costs of RCTs are often recouped by raising the cost of treatment.

For these reasons, Sams-Dodd says the company will continue to focus on systematic baseline studies for acute wounds, given that this is a scientifically-accepted method of evaluating new treatments in areas without a gold standard. “However,” he adds, “Amicapsil can also be used to control soft tissue infection and regenerate the tissue in chronic grade four ulcers prior to osteomyelitis surgery in order to improve the success rate, and here more traditional RCTs are appropriate. We are actively looking for collaborators for both.”

Getting Your Hands On It

No doubt, some of you have been reading this and thinking, “OK...I need to try some of this!” The good news is that you can reach out to the company, which would be happy to not only sell you some, but also consult with you about your treatment.

However, we know it’s likely that, if you’re suffering from a serious pressure ulcer, you’re working with your own medical team towards resolution, and you’ll want to ensure any treatments

are supported and approved by them. The problem is that it’s highly unlikely that more than a few health professionals here in BC have heard of Amicapsil, let alone any experience with it. So if you’re determined to try it within the context of your medical treatment and with your medical team’s blessing, you might have to take the lead in terms of encouraging members of your team to learn about Amicapsil.

If your team is reluctant to support it, you always have the option of trying it by yourself—remember, it’s considered a medical device, not a medicine; and to the best of our knowledge, it’s been found to be safe. If you move forward with this, Willingsford Healthcare is willing to review daily photos and offer guidance to you, or to your family member or carer who is handling the treatment, via e-mail.

“This has developed into a more formalized telemedicine approach, which we currently are pursuing, because it allows anyone to use Amicapsil independently of where they are in the world,” says Sams-Dodd. “This has gained extra relevance and attention during these COVID-19 times, where individuals even with severe wounds were left to mend for themselves. Everyone who has used the approach has been extremely positive because it allowed them to control when and where to do the treatment.”

Amicapsil can be purchased directly from Willingsford Healthcare. For more information, visit willingsford.com or email contact@willingsford.com.

A final request to readers: if you decide to try Amicapsil, please let us know about your experiences with it so that we, in turn, can let other peers know. ■

“If I knew then what I know now...”

What do you wish you’d done differently earlier in your post-SCI life? What do you realize now that you didn’t back then? In the spirit of peers supporting peers, we’d like to share your hard-won wisdom with more recently-injured readers in the next issue of *The Spin*. We’re not looking for a shopping list; we’re looking for THE ONE THING that you wish you would have known about or have done differently. Write us a short email, and describe the one thing you’d do differently if you had a time machine, and why. Please send your emails to Jocelyn Maffin, SCI BC Resource Centre Manager, at jmaffin@sci-bc.ca.

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Sweat Your Pain Away

It turns out that one of the best medicines for chronic pain might not be a medicine at all.

A new scoping review published recently by BC researchers in the journal *Spinal Cord* suggests that physicians treating chronic pain for patients with SCI should consider prescribing physical activity and exercise, along with medications.

Over the years, there's been some credible research that suggests exercise is a good way for some people to alleviate SCI-related chronic pain—both muscular pain and neuropathic pain. The scoping review, conducted at Dr. Kathleen Martin Ginis' SCI Action Canada Lab at UBC Okanagan and led by graduate student Kendra Todd, is the first time all of this research has been summarized. These combined results leave little doubt that exercise and physical activity can result in improvements in both chronic pain and overall well-being.

The review, titled *Physical activity interventions, chronic pain, and subjective well-being among persons with spinal cord injury: a systematic scoping review*, began with an exhaustive literature search to identify all relevant and credible studies from around the globe that have attempted to measure the effects of "leisure time physical activity interventions" on both chronic pain and

at least one measure of subjective well-being—for example, life satisfaction.

A total of 3,494 articles were screened. Of these, just 15 published articles, describing 12 different studies, met the review inclusion criteria.

"Of these 15 articles, 12 concluded that exercise led to reductions in pain and improvements in well-being for people with SCI," says Todd, a PhD student in UBC's School of Health & Exercise Sciences. "Interestingly, the exercise that was prescribed within these articles varied and included multiple types of aerobic and resistance training. Perhaps the most critical finding of this scoping review was that not one single study reported that participants experienced increased pain and worsened well-being as a result of exercise. Also, an important take-home from these studies was that exercise can improve multiple types of pain, including neuropathic or musculoskeletal—but the frequency and intensity of exercise matters."

Todd also adds that the review reveals the shortcomings of research done to date on the subject.

For one, the mechanisms behind these improvements are poorly understood. "Chronic pain is a complex biopsychosocial phenomenon with biological contributors such as tissue damage, psychological contributors including a person's level of coping skills, and social contributors like social relationships," says Todd. "Any combination of these components can impact a person's pain experience. One possible reason for exercise leading to improvements in chronic pain and well-being is that exercise can increase levels of serotonin, which is a mood stabilizing hormone and influences nervous system cell interaction. However, mechanistic causes of pain development vary between the

social phenomenon with biological contributors such as tissue damage, psychological contributors including a person's level of coping skills, and social contributors like social relationships," says Todd. "Any combination of these components can impact a person's pain experience. One possible reason for exercise leading to improvements in chronic pain and well-being is that exercise can increase levels of serotonin, which is a mood stabilizing hormone and influences nervous system cell interaction. However, mechanistic causes of pain development vary between the



Kendra Todd

different ‘types’ of pain—for example, neuropathic or musculoskeletal—and I would like to be cautious not to over-generalize.”

Another problem made clear by the scoping review is that researchers working in this field have never been on same page when it comes to using the same types of exercises for testing.

“These inconsistencies prevent researchers from identifying the appropriate frequency, intensity, time or type of exercise required to lead to the largest improvements in chronic pain and well-being among persons with SCI. Future research should use consistent exercise protocols—particularly protocols that adhere to the SCI Exercise Guidelines—in order to accurately compare results across studies. Furthermore, future research should continue to test the effects of exercise on both chronic pain and well-being using evidence-based theories, in order to identify mechanisms responsible for these effects.”

Regardless, Todd says that the review

concludes there is enough evidence to alter how physicians treat patients with SCI experiencing chronic pain.

“Currently in Canada, pharmaceuticals are the most commonly-prescribed treatment for neuropathic and musculoskeletal pain among persons with SCI,” she says. “One reason for this is that there is a lack of controlled research investigating alternative types of management options, which inhibits clinicians from prescribing anything other than medications. Based on the developing evidence, it appears that exercise could be incorporated into an individual’s pain management program because it may have positive impacts. At the very least, exercise should be considered by clinicians alongside currently prescribed pharmaceuticals such as gabapentin and baclofen. However, it’s important for people to monitor how new treatments, exercise included, impact their pain fluctuations, as any treatment is not a one-size fits all approach. As we know, everybody’s SCI

is different and therefore one person’s experience with exercise as a treatment for pain may vary from others.”

Given the evidence summarized in this review, and that exercise is generally accepted as safe, readers might consider making a decision to get on the exercise train without doctor’s orders. And remember that there’s a host of proven benefits of exercise above and beyond being an analgesic.

“In addition to pain relief, exercise participation may benefit a person’s health in other ways such as reducing the risk of cardiovascular disease, helping to control spasticity, decreasing incidence of pressure sores, and stabilizing blood sugar and insulin levels,” concludes Todd.

If you’d like to learn more about your options for exercise and physical activity, a great place to start is to learn more about the Physical Activity Guidelines for Adults with SCI—see the info graphic below, and visit at sciguideines.ubc.ca for more information and resources. ■

PHYSICAL ACTIVITY GUIDELINES

for Adults with Spinal Cord Injury



STARTING LEVEL

AEROBIC ACTIVITY

20 MINUTES **2x** A WEEK

of moderate to vigorous intensity

AND

STRENGTH-TRAINING ACTIVITY

3 SETS **10** REPS **2x** A WEEK

for each major muscle group

ADVANCED LEVEL

AEROBIC ACTIVITY

30 MINUTES **3x** A WEEK

of moderate to vigorous intensity

AND

STRENGTH-TRAINING ACTIVITY

3 SETS **10** REPS **2x** A WEEK

for each major muscle group

The Physical Activity Guidelines are based on the best scientific evidence available and have two levels. If you’re just beginning an exercise regimen, consider incorporating the recommendations included in the **STARTING LEVEL**. If you’re already physically active, you might want to begin using the **ADVANCED LEVEL** recommendations.

START

MEET

EXCEED

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WHY I GIVE...

I started working at SCI BC in 1979 as a receptionist. At the time I wanted to go into nursing, but I just loved the work so much. And then I met Ted, my husband, who also worked here, and I never did get to nursing! I had a bit of a detour, but I don't regret it. SCI BC has been a big part of my life.

I remember one time Ted, who had an SCI, visited a young guy at the Spinal Cord Injury Acute Unit and later at GF Strong. Ted wore this little bag with fringe on his chair—it was very stylish at the time! When Ted passed away in 2011, the guy wrote me a message about that visit from Ted, and how he thought at the time, "Oh man, so you can still be cool." That meant a lot to him.

These types of peer to peer encounters are so much more than little anecdotes. They open the door to important conversations and pave the way to acceptance of such big life changes. It was being a part of those little moments that made me want to stay and not work anywhere else.

About six years ago I became a monthly donor. I can't think of a better place to donate to or a better way to show my appreciation. I plan on retiring this year, but I know I won't be a stranger. I'll volunteer and I'll continue donating every month because it makes me feel good to help. I'd encourage everyone to become a monthly donor if they can.

Maureen Brownlee
SCI BC Staff, Volunteer and Donor

JOIN OUR FAMILY OF DONORS

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Opportunity Knocks

BC spine surgeon and ICORD principal investigator Dr. Brian Kwon has been tapped to co-lead a new multi-million dollar international research collaboration funded by the US Defence Advanced Research Project Agency, or DARPA.

We don't devote a lot of ink to SCI acute care research here in *The Spin*—our focus has always been on research that's intended to improve function and quality of life for those already well into their post-injury lives, as they make up the vast majority of our readers. But we're happy to make an exception and tell you about a new international collaboration focused on improving treatments and outcomes immediately following injury because it's being partially led by Dr. Brian Kwon, one of our province's most respected researcher/clinicians.

As one of VGH's small group of highly-respected spine surgeons, Kwon has personally operated on many of our readers following their injuries. But as most readers realize, Kwon is much more than a spine surgeon; he's also an internationally-renowned SCI researcher. In addition

to being associate director of clinical research at the International Collaboration on Repair Discoveries (ICORD), he's also the Canada Research Chair in Spinal Cord Injury, and a professor in the UBC Faculty of Medicine's Department of Orthopaedics.

Recently, Kwon added to his already impressive workload by accepting a new role: co-leading an international research project that's focused entirely on studying methods of improving SCI acute care treatments and, as a result, long term functional outcomes.

In October, the collaboration received a \$48 million grant (US\$36.5M) from the United States Defence Advanced Research Project Agency (DARPA) to conduct its research over a five year period.

"Never before has an agency committed funding of this magnitude for spinal cord injury and set such a high bar to demand not just incremental, but truly transformative solutions," says Kwon, the project's co-principal investigator, along with Dr. Karen Moxon at the University of California, Davis; Dr. Grégoire Courtine at École Polytechnique Fédérale de Lausanne, France; and Dr. Mark Tuszynski at the University of California, San Diego.

ICORD scientists Dr. Babak Shadgan, assistant professor in UBC's Department of Orthopaedics, and Dr. Chris West, assistant professor in UBC's Department of Cellular and Physiological Sciences, will also play key roles on Kwon's team.

The project's primary focus will be the stabilization of injury using revolutionary biologic and engineering techniques, and regenerating lost connections between

the patient's brain and spinal cord through the delivery of neural stem cells to the injury site through a 3D-printed biodegradable scaffold.

The UBC team will lead the project's acute injury stabilization efforts. The main thrust of their work will be developing and refining a fully implantable device that monitors the status of the injured spinal cord and feeds this information into an electrical stimulation system that will control a patient's blood pressure to optimize delivery of blood and oxygen to the damaged spinal cord tissue.

Their ambitious goal is to see this technology implanted into an acutely injured patient at Vancouver General Hospital by the final year of the DARPA grant.

Kwon and West recently published findings that will help form a basis for their work. The study, which appeared in the October issue of the journal *Nature Communications*, confirmed that, following high-thoracic SCI, the heart's ability to contract is impaired, leading to reduced spinal cord blood flow—a serious problem because lack of blood and oxygen lead to further damage and permanent loss of function. It also demonstrated the potential of a new experimental drug therapy targeting the heart to counteract the low blood pressure.

Up to this point, spine surgeons have attempted to maintain the flow of blood to the injury site using drugs that cause key blood vessels to constrict in order to increase blood pressure. In their study, which involved an animal model of SCI, Kwon and West used dobutamine, a medication that is sometimes used in



cardiac arrest patients. Dobutamine directly stimulates the heart to beat more powerfully, resulting in increased cardiac output and, leading to higher blood pressure and delivery of a higher volume of blood to the injury site.

“The key difference is that by targeting the heart, we increase blood pressure by increasing blood flow instead of by causing the blood vessels to narrow,” says West. “This is important because, by increasing blood flow, we can deliver more blood and oxygen to the spinal cord, which is expected to minimize the damage at the epicentre of the injury and therefore reduce injury severity and bleeding in the cord, both of which are expected to improve the chances of people with SCI retaining more function.”

“It is important to note that one of the only things we can currently do for acute SCI patients is to try to optimize the supply of blood and oxygen to the injured spinal cord to prevent further secondary injury,” adds Kwon. “We need to seek ways of delivering this care in the most effective manner possible, as any bit of spinal cord function that could be improved upon by novel approaches such as this would potentially be very impactful to a patient.”

Kwon says he’s a little awed by the responsibility of leading such a prestigious and important research project. But he’s looking forward to the challenge.

“Thanks to the rich multi-disciplinary research and clinical environment at UBC and VGH, we have a unique opportunity to bring scientific discovery to human application,” said Kwon. “We have our sights set high on making a real difference in the lives of those who have been severely affected by spinal cord injury.”

In September, Kwon also made headlines when he was announced as one of three winners of the inaugural Craig H. Neilsen Visionary Prize. Kwon received the \$1M USD for his “distinctive contributions and demonstrated excellence in the world of SCI.” The award honours the late Craig H. Neilsen, an American entrepreneur who became quadriplegic in a car accident in 1985. ■

ask the SPIN DOCTOR

I was injured late last year and missed my period for several months. Now it’s back and it feels a lot more complicated to manage – got any tips? - Kelly from Chilliwack

As you’ve already experienced, most women who were of child bearing age at the time of their SCI miss their periods for as long as 12 months. While this is completely normal, for many women, it’s an inconvenient addition to an already steep post-SCI learning curve. With some time, practice, hormonal management, and menstrual products, you should be able to find a routine that works for you.

Once a menstrual cycle returns, many women find that SCI-related complications such as spasticity, pain, fatigue, swelling in the legs, and autonomic dysreflexia (AD) are worse during their period or the days leading up to it. Others aren’t aware of their period at all, and may have to use a calendar or app to keep track of their cycle to avoid surprises. Adding to this difficulty is that, depending on your age, your periods may come back in an irregular pattern that’s hard to keep track of.

The period basics you learned as a young person still apply post-injury, with some added importance: it’s essential to keep clean during your period to prevent UTIs and protect your skin, change pads and tampons frequently to prevent odour and leakage, and use soap and water or wipes to clean your vulva.

Your approach to managing your period might depend on your hand function, how you manage your bladder, and how much help you need or have available for your personal care.

Traditional menstrual pads are safe and easy to manage for many; however, if you pull your underwear on and off while managing your bladder, you might find pads can get twisted and end up stuck to your skin. It helps to check before you leave the bathroom that you have everything back in place. Sitting on a bunched up pad is not only bad for your skin, it’s a recipe for leakage! Because of this, many are turning to absorbent period panties like Thinx that can be a lot easier to get on and off than a pad stuck to your underwear, especially if you get dressed in your chair or have reduced hand function.

Tampons are a good and popular option for women with SCI to manage periods. Compared to using pads, they can make intermittent or indwelling catheterization a little cleaner during your period—there’s less leakage and clean up to do, which can help avoid UTIs. Just make sure you change your tampon around every four hours to prevent rare complications. Keep in mind that tampons can be harder for quads to manage (though there are gadgets to help with this!), and they’re pretty intimate if you rely on a caregiver for help with personal care. If you get AD during your period, make sure to check your tampon, as they can sometimes cause discomfort that triggers AD even if you can’t sense it.

Menstrual cups are a similar method to tampons, but involve a flexible silicone cup that is inserted into the vagina up around the cervix. It’s removed and emptied on the toilet, so may be more convenient for people with full hand function who drain their bladder into the toilet as well. This isn’t a great method if you catheterize from your chair because of the angle required to get the cup out (and risk of spilling).

Another way to manage your period is to not have one at all! Great, right?

Hormonal birth control (an oral contraceptive pill or vaginal ring used continually, a hormonal IUD, or an injection like Depo-Provera) can alleviate some of the unpleasant effects of your menstrual cycle and its effect on your SCI complications while reducing or stopping your period entirely. These methods can be managed by your primary care provider or at the Access Clinic at BC Women’s Hospital in Vancouver (www.sci-bc.ca/AccessClinicReferral).

Read scisexualhealth.ca/contraceptionPDF for more information on hormonal contraceptives and SCI.

— *Natasha Prodan-Bhalla, Nurse Practitioner, Access Clinic, BC Women’s Hospital (with contributions from the Women with SCI/D Facebook group)*

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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.

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).

COPE: Community-Health Outcomes and Personalized Education/Exercises for people with SCI

Overview: Researchers in Dr. Andrei Krassioukov's lab are investigating the most important medical care and rehabilitation needs after SCI and developing online modules for continuing care for people with SCI living in the community and their support networks. Content of the online modules will include videos demonstrating at-home exercises, adaptations for accessibility in the home and community, and mini articles on important aspects of SCI care (e.g., autonomic dysfunction/activities of daily living). These resources will aid people who have lived with SCI for years, those transitioning from an acute to chronic SCI, and all those who provide support to someone living with SCI.

What to expect: The study will be divided into two parts. The first part will involve a one-hour online survey. The second part involves testing of online web modules that the study team creates based on survey results. Testing and providing feedback will take around three hours and can be done at your own pace (i.e., you do not need to complete all modules in one day). Total time commitment is four hours.

Who can participate: You may be able to participate in this study if you are between 18 and 65 years of age, have a chronic (>1 year) traumatic SCI, are currently living at home in the community, and have good command of English. You may not be able to participate in this study if you have any documented traumatic brain injury or cognitive disorders.

Why participate: The findings from this study will directly lead to online resources for the SCI community, including people with SCI, family, caregivers, and support networks. Participating in this study will help ensure that these resources provide relevant and evidence-based guidance for continuing SCI care. Participants will receive a \$20 CAD a gift card upon completion of the study.

Location: Remotely (online survey/mail-in survey/phone survey).

For more information or to sign up to participate: contact Laura McCracken by email (laura.mccracken@alumni.ubc.ca) or call 604.675.8816.



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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Peer Power on the Big Screen

Chelsea McEvoy's new award-winning film offers powerful visual confirmation of SCI BC's six decade commitment to the concept of peer support.

In 2018, Kelowna's Chelsea McEvoy reaped praise for the short film *Wheel Love*, which chronicled the efforts of her and her partner, SCI BC peer and Accessible Okanagan president James Hektner, to start a family. Not one to rest on her accolades, McEvoy was soon back at work with her collaborator, fellow Okanagan filmmaker Ryan Tebbut. The duo recently put the wraps on a new documentary, *Re-Inventing The Wheel*. The hour-long film chronicles a unique community of Okanagan peers guiding and supporting a newly injured friend and his wife through his first year of life as a paraplegic.

In October, McEvoy and Tebbut were rewarded for their efforts when *Re-Inventing The Wheel* took top documentary honours at New York's annual (and appropriately named) Chelsea Film Festival.

"Originally, *Re-Inventing The Wheel* was supposed to be about the active wheelchair community in the Okanagan," says McEvoy. "Upon receiving the funding from TELUS STORYHIVE's program, we quickly learned about Dan McLean and his recent SCI. We thought, 'Wouldn't it be amazing to document the first year of life after injury and the integration of community and peer support?' We gathered the courage to call Dan and his wife and they were on board right away! It's a testament to Dan and Colleen and who they are as people. They could have told us to pound sand but even in the midst of their trauma and grief they were willing to educate and help people by sharing their story."

The goal for the duo was clear from the outset: to showcase the power of peer support. "No amount of research can capture the real life outcome of what a strong community can contribute to one's healing after an SCI," says McEvoy. "You can learn a lot from clinicians and medical professionals, but to get information and life experience from someone who understands and who speaks your language is an invaluable resource."

McEvoy hopes the film will encourage anybody with an SCI to seek out community. But she believes the concept of peer support can be applied in many other life situations. "If you're struggling," she says, "seek people who have been in your shoes because, at the end of the day, we are all in this together."

She also hopes that the film breaks stereotypes and further educates the public about SCI.

"Winning Best Documentary at the Chelsea Film Festival was very validating for the *Re-Inventing The Wheel* team. It



just reassured us that we have a really unique story to tell and people are excited to watch a 60-minute documentary on people with SCI. The vast majority are uneducated and, might I add, uninterested in stories about disability. For us, it's a major win to know people are watching and they like what they see."

If you're interested in seeing the documentary for yourself, we can only tell you that it will be aired in 2021. The exact date is TBA, so we'd suggest following the film's progress on Face-

book or Instagram (@reinventingthewheelmovie) where the duo will be sure to keep followers updated on a release date.

What's next for McEvoy and Tebbut?

"I think we have an excellent opportunity, following this film, to expand and tell more stories about the SCI community," says McEvoy. "We have some exciting things in the works and we can't wait to keep rolling on and creating content that makes people laugh, cry and change their way of thinking." ■



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