ORTHOTICS FOR HEALING | THE PAIN/ANXIETY CYCLE | GRIP-ENHANCING GLOVE

thespin

SPINAL CORD INJURY BC

SUMMER 2020

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Assistive Technology Services are available to individuals who have a work related barrier due to a disability or functional limitation. Learn about how this service can benefit you by attending a Webinar.

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Canada BRITISH COLUMBIA

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BC's Response: Blueprint for a Pandemic?

It's a strange business, this novel coronavirus. In many ways it's similar to the invisible conditions so many of you are all too aware of—neuropathic pain, depression, anxiety. Because people can't see it, they have a hard time believing it's real. But when you're experiencing it or someone close to you is, the intangible quickly becomes very tangible.

From the onset, I never doubted the threat of COVID-19, but I'll concede that it became *very* real when someone close to me contracted it. Someone close to my age, in good health, who had a long nip-and-tuck go of it before recovering.

Thankfully, under the exceptional guidance of our Provincial Health Officer and provincial government, the vast majority of people throughout BC haven't had to witness the struggles of a friend or family member with COVID-19 in order to comprehend that the threat of COVID-19 is real. Collectively, we have modified our behaviours in order to flatten the curve and keep as many of us safe as possible.

Indeed, BC's response has been exemplary. Through my role as Chair of Spinal Cord Injury Canada's Executive Directors Council, I have heard repeated praise for how our province has responded to the pandemic, including the attention and consideration given to people with disabilities in this province.

One reason for this is the government's engagement with disability-focused organizations early on in the pandemic. I'm particularly appreciative of the extent to which the Minister of Social Development and Poverty Reduction and his staff have asked for input from the disability community, and provided clear and timely information about the emergency benefits and policy and service adjustments the government was making.

In April, Minister Simpson created the COVID-19 Disability Working Group. I was honoured to be named co-chair of this body, which has been providing advice and guidance to government about how people with disabilities are being impacted by COVID-19 and helping to identify solutions, increasing awareness within the disability community of available supports, and helping share important information about COVID-19 to the disability community. We are also advising on what measures have been working and what positive changes should be kept after the pandemic is over.

All of the early measures and the cooperation of British Columbians have allowed the province to move to new phases of recovery from the pandemic. In many ways, this is encouraging as we are all keen to return to some sense of normal life.

But we know that many of you are feeling uneasy about the easing of restrictions and the increased risk of COVID-19 that goes along with it. We get it, and it's why SCI BC will continue to provide all the online services we have been offering over the past three months to keep you informed and socially connected during the pandemic.

As proud as I am of our province's response to COVID-19, I am equally so of the team here at SCI BC, which responded to the pandemic so quickly and has continued to work so hard to ensure continued support through our Information and Peer services. Like the Province of BC, SCI BC's response has been exemplary. We are still here to help.

CBM

—Chris McBride, PhD, Executive Director, SCI BC

thespin

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SCI BC InfoLine: 1.800.689.2477

Spinal Cord Injury BC

At a Glance: SCI BC & COVID-19

How has SCI BC changed its services during the pandemic? We have made many programming changes since the onset of the COVID-19 public health crisis. Essentially, we have suspended all services that take place in public spaces. We have transitioned to offering a number of online events and meetups. Specific changes include the following:

- We have increased our capacity to meet an elevated demand of calls to our toll-free, staffed InfoLine service (1.800.689.2477).
- We have postponed or cancelled all in-person Peer events for the summer, and will continue to monitor the situation to see when small Peer group activites might resume (acknowledging that many of our members are uneasy about the relaxing of restrictions).
- We have transitioned to offering online events and meetups throughout the province. You can stay abreast of these events by visiting our online event calendar (sci-bc.ca/online).
- We remain committed to providing you with accurate, relevant information through all of our various channels, including our website, our social media pages, e-newsletters, and *The Spin* magazine.

How is SCI BC working to ensure the concerns and priorities of people with SCI are heard at the government level during this pandemic? We are committed to ensuring your voice is heard at all levels of government. Specifically:

- Our Executive Director, Dr. Chris McBride, is co-chairing our province's COVID-19 Disability Working Group.
- We are working with SCI Canada to inform the federal government on the impact of COVID and COVID restrictions on people with SCI and to advocate for support for people with disabilities in Canada.
- SCI Canada continues to work with other partners on a federal task force and its pandemic disability advisory group (bit.ly/disability-pandemic-advisory).

How is SCI BC working with its partners to ensure basic levels of service remain available to our Peers? As a member of the BC SCI Services Network, we are working daily with our partners (BC Wheelchair Basketball, BC Wheelchair Sports Association, Neil Squire Society and the Disability Foundation) to coordinate services, share information about what services we each have available, and collectively try to minimize the impact of the pandemic for all of the people we serve. You can stay abreast of all of our partners' service changes and updates by visiting sci-bc.ca/bc-sci-network-covid19.

Things continue to change rapidly during the pandemic, so we urge you to regularly visit our website (sci-bc.ca) and follow us on our social media pages (including Facebook, Instagram and Twitter) to get the latest news, information and event updates.

JOIN TEAM SCI BC!

Race in the first-ever VIRTUAL Scotiabank Charity Challenge!

GIVE to a good cause.

GO wheel, walk or run.

GET more events, support, and adventure from SCI BC!

How does it work? Set a fitness goal of 5, 10 or 21 km, then join Peers across the province and race throughout the month of July. Raise money for SCI BC, win prizes, and celebrate at an online race party on July 30!

SIGN UP:
Email Shelley at smilstein@sci-bc.ca

LEARN MORE:
www.sci-bc.ca/scc-2020

> *"This event is truly close to my heart … I got the support [from SCI BC] when I was first injured so to be able to give that support now is pretty awesome."*
>
> **- Kristen McBride**
> SCI BC Peer & five-time racer.

Innovations

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

SLICK SKIS

Slick Skis are caster attachments designed to make both sand and snow easier to navigate by wheelchair users. Once attached, they allow the front of your wheelchair to float on top of sand or snow and glide with ease. Essentially lightweight plastic paddles, Slick Skis attach easily—you slide your casters into brackets and then pull the straps tight to lock them into place. Slick Skis also help to protect your bearings from becoming packed with sand and snow. See product details at livingspinal.com.

CHEELCARE COMPANION

The Companion, made by Canadian company Cheelcare, is a power assist add-on suitable for most rigid manual wheelchairs. It connects and disconnects in just ten seconds, and since it weighs less than ten kilograms, it's easy to take along on a car trip or a longer voyage. The eight-inch wheels turn in place, providing outstanding manoeuvrability and the ability to negotiate narrow spaces. The motor is smooth, powerful and fast, with three different speeds to choose from. Range is up to 25 kilometres, and the battery charges in three hours. A hand-operated drum brake provides excellent stopping ability. The device is reported to be stable, safe and secure. Visit cheelcare.com to learn more.

LIGNORIM

The makers of Lignorim wooden push rims tell us that their products stay much warmer than metal rims during winter months, and that they provide better grip as well—particularly in wet conditions. They're reported to be extremely strong and lightweight, with a set adding under a kilogram of weight to your ride (that's about the same as carbon fibre push rims). Being laminated, they are guaranteed not to splinter, nor will they degrade in high humidity or when in contact with snow or rain. They're made in Austria from locally sourced spruce, birch and ash—see lignorim.com for more details.

VITAGLIDE

The newly-redesigned Vitaglide is a fitness machine that can be used independently in your home to give you a great cardiovascular workout while strengthening the arms, shoulders, back, chest and core. Like the original version, which was developed almost 20 years ago, the new Vitaglide allows users a way to perform a cross-country skiing motion while seated. However, it offers many significant improvements such as the addition of a rowing motion. As well, a touchscreen attached to the frame provides control of all features—resistance, duration and intensity of workout—and allows users to set workout goals and monitor their performance and energy expenditure. And unlike the original version, the arms move independently of each other and offer resistance going forward and backward, resulting in a more balanced workout for both arms. Resistance can also be adjusted for each arm in order to accommodate strength differences. The machine can be raised or lowered to accommodate any type or size of wheelchair. Learn more at vitaglide.com.

Supporting Chairstuff Supports SCI BC!

Spinal Cord Injury BC

CHAIRstuff

SCI BC is proud to announce a new, long-term sponsorship agreement with Chairstuff.

GREATER REACH & BETTER SERVICE

Chairstuff has your back ...

And your front! We *really* understand bowel and bladder issues. Over the years, our staff has been made up of people living with different disabilities, and we regularly mesh with the local SCI peer community. Combine this with our legendary efficiency, wide range of products, and competitive prices, and you have a winning team in your corner. Our products include:

- **Intermittent Catheters**
- **Bowel Products**
- **External Catheters**
- **Foley Catheters**
- **Drainage Bags**

Contact us for free product samples or to chat about your specific needs!

A supply company by people with SCI—for people with SCI

> *I have been ordering my colostomy supplies, catheters, and leg bags through Chairstuff since 2001. My stuff is always on time and that's pretty great considering I live 900 kms away from where they do business."*
>
> **— Crystle**

> *I switched over to Chairstuff from one of the bigger companies, which was more expensive. I like dealing with Steve because he's a dude in a chair who's got his own business. Anytime I need supplies, they're delivered to my door."*
>
> **- Kevin**

"We're here for you 24/7. We mean it."

STEVE MILUM
Founder & CEO
Chairstuff

CHAIRstuff

1-866-363-0025 | 604-876-4133
info@chairstuff.com
chairstuff.com

Join our VIRTUAL team.

Team SCI BC is going virtual! This year's Scotiabank Charity Challenge will be held on sidewalks, tracks, trails and living rooms around BC as we practise social distancing and raise critical funds for SCI BC. It's a different look, but the fun will remain the same. No matter where you live, now is your chance to join the team and get in on the action, and help us reach our fundraising goal of $50,000. Learn more by contacting Shelley (smilstein@sci-bc.ca) or visiting sci-bc.ca/scc-2020.

Stay connected—have fun.

In light of the COVID-19 pandemic, SCI BC has suspended all services that take place in public spaces. But fear not—we have an amazing array of online events happening every week. From movie nights, trivia and adaptive boxing, to virtual coffee groups, cooking classes and book clubs, there's something for everyone! Connect with one easy click, or dial-in and join the fun via phone. Visit sci-bc.ca/online or call our toll-free InfoLine (1.800.689.2477) to find out how to dial in.

Connect with our partners.

SCI BC is a member of the BC SCI Community Services Network. Like us, our partners at BC Wheelchair Basketball, BC Wheelchair Sports Association, Neil Squire Society and the Disability Foundation are all still here for you during this challenging time and look forward to connecting with you in new ways. To learn more about our partners' service updates, check out their individual websites, or take a look at our website where you'll find a list of their service updates: sci-bc.ca/bc-sci-network-covid19.


Inspired by the female form
Can be opened and closed with one hand
Somewhere between Ballet Pink and Shell Pink
Beautiful pearlescent finish with a satin sheen
Hollister
Infyna Chic

Peer Shoutouts

A sunny Okanagan shoutout to SCI BC Peer **TYLER TINGLE** for his tireless commitment to volunteering and Peer mentoring.

"Tyler has long been a pillar in the wheelchair community here in the Okanagan," says Scott James, our Kelowna Peer Program Coordinator. "He travels all around and makes it to nearly every event. He's very giving of his time and will help out a friend anywhere. He also worked for SCI BC (as a Peer Counsellor in Kamloops in the 90s), and he started volunteering with us recently. He promotes and hosts coffee groups and is a contact for the Kamloops area."

"When I was first injured three decades ago, I was lucky that I already knew a couple guys who were paras," says Tingle. "Some gave advice to my parents, who were looking at the changes they would need to make to their home once I returned from GF Strong. As well, the people at BCPA helped with questions I had along the way...Long story longer, many people have helped me through my long journey in the SCI life; if I can give a little back and that can make a difference for someone, it's the least I can do."

Congratulations to North Vancouver's **TARA LLANES**, who was recently honoured with the BC Wheelchair Basketball Society's coveted MJ Boudreault True Sport Award.

Boudreault, who passed away in 2011, was an inspirational leader in our province's wheelchair basketball community. The award created in her memory is presented annually to an individual who displays Boudreault's tenacity, sportsmanship, competitive spirit and dedication to the sport.

Llanes definitely exhibits those traits. Originally a professional mountain biker who grew up in California, Llanes was injured during a 2007 competition in Colorado. She moved to Vancouver in 2010, and was playing competitive wheelchair tennis in 2016 when former Team Canada player Amanda Yan encouraged her to try wheelchair basketball. In just two short years, Llanes became a force to be reckoned with on the hardwood. Her aggressive style of play quickly led her to be invited to play on Canada's national team, where she is now a mainstay on the roster.

"I didn't know MJ Boudreault, but it's clear that she was a leader and had a strong competitive spirit, which makes me extremely proud to accept this award," says Llanes. "I take a lot of pride in pushing myself to be better as well as being there for my teammates. Thank you again to BCWBS for acknowledging the hard work these past few years and for their continuous support."

You can read more about Llanes on page 28 of this issue of *The Spin*, where we've profiled her and her business, Tara Llanes Industries, which sells adaptive mountain bikes, or aMTBs.

Usually, when we write about **DR. JAIMIE BORISOFF**, it's all about one of his innovative rehab engineering projects—as an ICORD Principle Investigator and the Canadian Research Chair in Rehabilitation Engineering Design at BCIT, he's the brains behind the Elevation wheelchair and the accessible rowing machine featured in our last issue. But in this issue, we're giving him a shoutout for his recent induction into the BC Wheelchair Basketball Hall of Fame.

Borisoff had an incredible career as a member of the BC Men's Wheelchair Basketball team (1991 to 2012) and Team Canada (1995 to 2008). He won numerous individual and team accolades, including two Paralympic Gold Medals and one World Championship. He was a natural leader on any team he played for, and was respected for playing as much with his mind as his body.

"It's quite an honour to be singled out like this for the Hall of Fame," says Borisoff. "My generation of athletes was really quite fortunate to have the infrastructure and resources in place already. And I was also quite fortunate to have the quantity and quality of local players to compete with. Past, current, and future national team members were regular teammates. So I always had plenty of opportunity to learn from the best. We really had a perfect storm of opportunity. I just had to show up!"

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.

Brace Yourself!

How do you heal an injured arm or shoulder when you have to rely on it daily for mobility? One solution might be an orthotic brace.

Arm and shoulder injuries are one thing for able-bodied people, who can immobilize and rest an arm during the healing process without compromising their ability to get around. But these types of injuries are an entirely different animal for manual wheelchair users. Completely resting an injured arm or shoulder in a sling or cast means almost a complete loss of mobility and independence—no wheeling, no ability to transfer. And failing to allow these types of injuries to heal completely often leads to chronic, life-long problems. Even if they do heal, they're not likely to heal the right way, so mobility can be forever compromised. (Younger readers take note: you're not immune. You might believe your youth and resilience make you invincible, but be warned that you have countless older Peers living with chronic injuries who once thought the same way you do.)

Could one answer be a brace or orthotic device? SCI BC Peer and Kelowna-based optometrist Dr. Paul Clark is a believer.

"My story is one of a partial triceps tear in the right arm which required full rest for six weeks that I never gave it," says Clark. "In the beginning, I did what I did when I was younger and simply exercised it. Not surprisingly, there was no improvement, so I just put up with it being weak. It affected my transfers, and even my ability to push doors open with the right arm. Worst of all, it destroyed my basketball shot. I couldn't even shoot the ball high enough to get it in the hoop if I was right under it!"

After a year of pain, Clark admitted defeat and approached his family physician with the problem. He was referred to Allan Blyt, a prosthetist and orthotist with Kelowna's Hager Orthopaedic Clinic Ltd.

The goal was to explore whether or not an orthotic brace could help.

Blyt confirmed that there was no suitable out-of-the-box brace available, but he was eager to take on the challenge of creating a custom solution unlike anything he'd ever built—an orthotic device that would allow the arm to heal but without completely compromising Clark's mobility and independence.

"At the initial assessment in my clinic, I heard from Paul how active he was, using his bike as his primary mode of transportation to and from his office daily," says Blyt. "He explained that the main issue was with transferring in and out of his chair and bike due to the permanent tear in his triceps muscle on his right arm. This did not allow him to maintain a straight elbow when weighted by his body as he attempted to transfer. I knew we could be of assistance because I had dealt with a similar issue across the knee joint of a patient who wanted to stand, but had quadriceps weakness due to illness. The concepts were the same and so it was just a matter of working across the elbow and not the knee."

"The brace was meant to take the weight off the tendon during transfers at that extreme flexed time," adds Clark. "It would lock to hold my weight without the tendon needing to be involved. Of course, Allan tried to make it lightweight, which meant I broke it in the first week. So a stronger joint was ordered; one that's normally used for knee braces. That turned out to be just the ticket."

HOW IT WORKS: When the arm is bent (left), the brace allows the elbow joint to operate through a normal range of motion. But when the arm is straightened (right), as it is during transfers and weight shifts, the mechanism ratchets up into a locked position, supporting the body weight and taking the pressure off the injured triceps tendon so that it can continue to heal.

Blyt explains that this is often the biggest challenge when creating a new orthosis—finding the right sized mechanical joints and upright bars to support the weight without being too bulky and heavy. But once he had resolved the

COVID-19, SCI and Vision

Since Dr. Paul Clark was willing to share his experiences with using a brace to heal his tricep, we thought we'd take advantage of his expertise as an optometrist and ask him for some specific information about vision care for people with SCI during the pandemic.

Can I still get an eye exam? As of May 19, BC optometrists resumed regular eye exams using elevated measures to reduce the spread of COVID-19—for example, patients will be required to wear masks and practise social distancing in waiting rooms. Optometrists are also continuing to offer virtual examinations for prescription refills and urgent concerns. You can call your optometrist for more details.

Should I switch from contact lenses to glasses during the COVID-19 pandemic? No. You should continue to wear your contact lenses, albeit with greater attention to hand washing. Having single use disposable contact lenses at this time is certainly safer than multi-use lenses, which involve more handling.

Are people who put glasses on to read at greater risk of infection because they're touching their face more? Yes, any time you might touch your face, whether it be to put glasses on or scratch your cheek, you need to be cautious and wash your hands frequently. There is greater risk for people with SCI who require someone else to put their glasses on for them—personal care assistants should be repeatedly washing their hands for this and other tasks.

I've heard you can get the virus through your eyes—is that true? Any virus can cause red eye, which is called conjunctivitis. Conjunctivitis has been seen in a small percentage of hospitalized patients—less than two percent of diagnosed COVID patients get conjunctivitis. It has never been shown that a patient acquired the virus though the eye. It is much more likely to get the virus by respiration or orally, so wash your hands. And if you get what you think is an eye infection, do not go to the emergency room—see your doctor instead.

Why have my eyes have been bothering me lately with dryness and and soreness? Online reading has increased during this pandemic by almost 50 percent! If your vision or the binocular balance of your eyes is not optimal, you may suffer from sore or dry eyes, along with headaches. When you read, not only do your eyes need to focus, they have to precisely turn inward. Many people have eyes that are slightly out of focus or suffer slight alignment problems, which is never an issue until they start doing more reading. Having glasses with the best focus can certainly help, as can making the print larger on digital devices. Dry eyes occurs because our blink rate reduces by half when we read and each blink restores the tear film. A good solution is just to stop reading and give your eyes and your brain a rest!
—Dr. Paul Clark is an SCI BC Peer and an optometrist with IRIS in Kelowna. You can reach his office at 250.861.5665.

sizing issue, he was confident that the device would be successful.

"We had several follow up appointments to fine-tune the orthosis—to trim the lines of the cuffs, make length changes to the straps, and flare the plastic cuff edges," says Blyt. "No major issues arose during those visits, so that meant the concept was working."

Clark wore the brace faithfully, despite never knowing if it would produce any result because he never had pain when it was on. His patience would eventually pay dividends.

"After six weeks of wearing it last summer, I stopped," says Clark. "The rest had done the trick, and while my arm was weak from lack of use, there was no pain. That allowed me to get back to exercising and strengthening the arm. It's still not quite where it was prior to injury—at that time, I could do triceps exercises with 20 pounds. I have improved from two to five pounds before resting the injury, to 12 pounds currently. And although my basketball shot is not back to what it once was—and many of my fellow players would say it never was that great—it's now so much better."

The result has also been gratifying for Blyt to see.

"It was a real pleasure getting to know and working with Paul," says Blyt. "It was rewarding to be able to solve his unique and interesting mobility challenge; it's why I enjoy my career so much!"

He adds that, if you've got a similar issue, consider getting a referral to his clinic if you're in the Okanagan area, or to your local orthotist if you live in another part of the province.

"What we do here at Hager Orthopaedic Clinics is primarily all custom work of this nature," he says. "We have a fully-equipped onsite fabrication laboratory with the equipment, materials, hand skills and knowledge to provide treatment options for almost any problem presented to us. We believe we can be of assistance to anyone's mobility issues provided they are willing to work with us and adapt to an orthosis being worn." ■

ask the SPIN DOCTOR

Jas on the Sunshine Coast asks, "As a person with SCI, I'm still confused about whether I'm considered high risk for COVID-19. Am I considered immunocompromised? If so, how do I explain this to people around me when I need to protect myself?"

Great question, Jas, and one we've heard from many Peers recently. To answer your question, we're drawing on the expert opinions shared in our Ask an Expert video series held last month (www.sci-bc.ca/askanexpert).

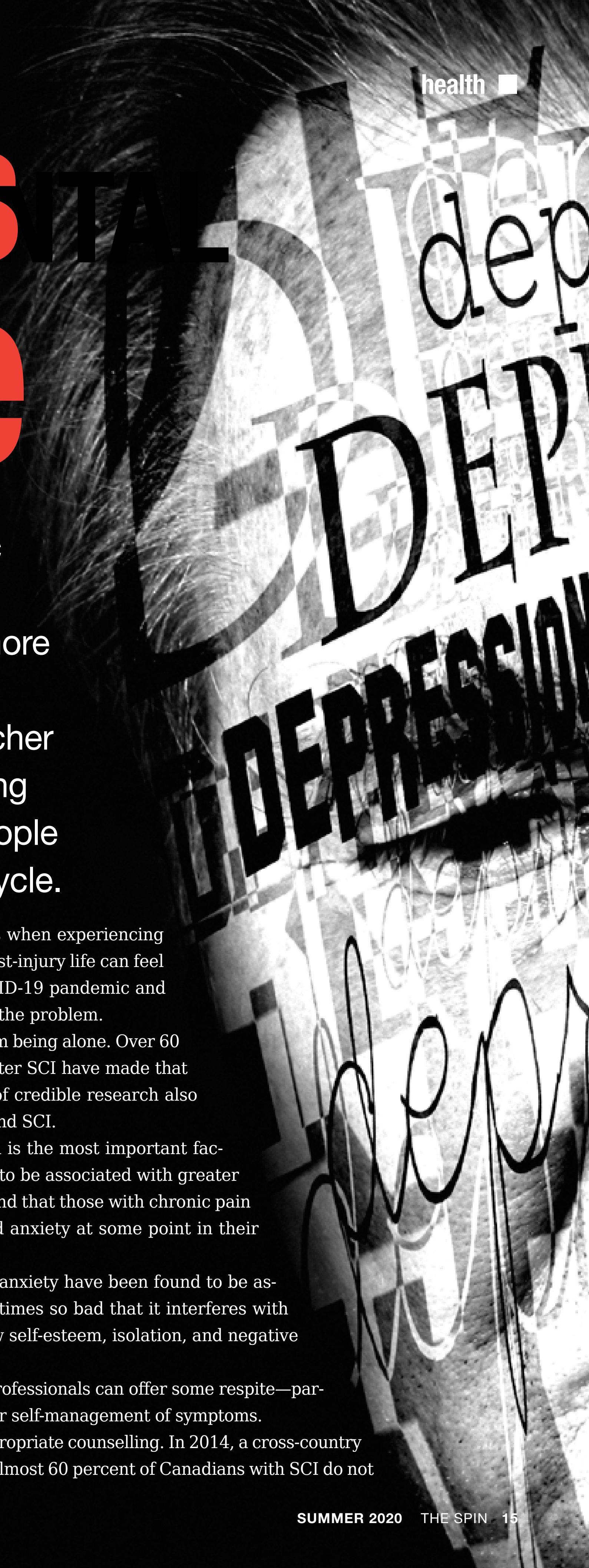
In their respective sessions, Dr. Jennifer Grant, an infectious diseases specialist at Richmond Hospital, and Dr. Andrei Krassioukov, GF Strong physiatrist, explained that many chronic complications of SCI elevate the risk for serious cases of COVID-19. While your SCI itself is not as much of a risk factor, certain complications of SCI may present bigger concerns. For example, respiratory compromise is common at higher injury levels, and weakened breathing muscles or an impaired cough affect how well your body is able to get rid of respiratory secretions—which is an important part of your body's ability to clear the virus. Additionally, people with SCI who use ventilators are at higher risk of pneumonia, which is a known feature of COVID-19. Early reports about COVID-19 patients with SCI also suggest there may be fewer early symptoms, or symptoms are obscured by SCI complications. For example, lack of a fever may be due to autonomic dysfunction, leading to missed or slower diagnosis.

But should people with SCI truly be considered immune compromised? It's a difficult question. Dr. Krassioukov stated that SCI does result in some degree of systemic immune suppression, although not to the level of serious immune deficiency syndromes like HIV/AIDS. However, SCI affects the nerve connections to important immune system organs like the spleen, bone marrow and liver, which produce immune cells that help the body fight off infections. People with higher levels of injury are likely to have higher degrees of immune suppression.

SCI may also pose some extra risks of exposure to the virus. Many people require caregivers from outside their household who are not able to self-isolate, yet must provide care at close quarters. Careful use of personal protective equipment (PPE) and regular proper handwashing for both caregiver and client are essential for this situation, stressed Dr. Grant. She also noted that some people find it difficult to effectively keep their hands clean because they touch their chair so much. She recommended washing your hands properly and wiping your wheelchair down with household detergent and water regularly, and that caregivers should clean any equipment they've touched before they finish. See the excellent SCI U graphic on handwashing on page 18.

Your last question is the trickiest. Many Peers are finding it hard to protect themselves from people around them who aren't taking precautions. First, talk to your doctor or a rehabilitation clinician about your specific risks. Realize that the most powerful actions you can take to protect yourself are personal: wash your hands properly and often, and keep your distance from those around you outside your household. Plan extra cleaning of high touch surfaces and provide PPE for yourself and caregivers or family who aren't able to physically distance outside your home. Have a direct conversation or write down your concerns for people in your life who aren't respecting your precautions. Reduce contact with things they touch like utensils or remote controls, and keep your distance. You can set up a handwashing station with hand sanitizer near your front door so it's convenient and hard to miss! If you need PPE or household cleaning support, or just want to talk through how to explain your needs to those around you, reach out to our InfoLine team: info@sci-bc.ca or 1.800.689.2477.

— Jocelyn Maffin, Manager, SCI BC Resource Centre



Vicious Circle

For many people with SCI, chronic pain leads to depression and anxiety—which, in turn, leads to more severe pain and other secondary complications. A Canadian researcher has developed an online counselling platform with the goal of giving people the tools they need to break this cycle.

Managing your emotional and physical symptoms when experiencing distress and chronic pain at any point in your post-injury life can feel isolating. No doubt, for many readers, the COVID-19 pandemic and its ensuing lockdown have greatly exacerbated the problem.

If this has been the case for you, you're far from being alone. Over 60 years of helping people adjust to and cope with chronic pain after SCI have made that clear to all of us here at Spinal Cord Injury BC. A great deal of credible research also confirms the link between chronic pain, mental health issues, and SCI.

In several surveys, people with SCI have reported that pain is the most important factor for decreasing their quality of life—in fact, pain was found to be associated with greater emotional distress than the SCI itself. Several studies have found that those with chronic pain often also experience significant symptoms of depression and anxiety at some point in their post-injury lives.

In a perverse negative feedback loop, more depression and anxiety have been found to be associated with reports of greater post-SCI pain severity—sometimes so bad that it interferes with activities of daily living. Other concerns such as feelings of low self-esteem, isolation, and negative body image are reported all too commonly.

So how do you spell relief? Counselling from mental health professionals can offer some respite—particularly when one of its goals is to help people develop skills for self-management of symptoms.

The problem, of course is that it's pretty difficult to access appropriate counselling. In 2014, a cross-country study led by Laval University's Dr. Luc Noreau concluded that almost 60 percent of Canadians with SCI do not have their emotional counselling needs met. The result is often a vicious circle of declining health, both mental and physical, according to Dr. Swati Mehta, a researcher at Lawson Health Research Institute in London, Ontario.

"These issues not only place an emotional burden on the individual, but can also influence management of other SCI secondary conditions," explains Mehta. "For example, chronic anxiety has been significantly correlated with other secondary conditions such as chronic pain and sleep interference. Increased distress has been shown to result in slower recovery during the rehabilitation process and greater rates of rehospitalizations."

Mehta believes that one way to improve access is an online service that provides mental health guidance and coaching. Through a patient-oriented approach, Mehta and her team created an SCI online program that was adapted from a similar, successful initiative in Australia. This course is intended to bypass one of the biggest hurdles people encounter when accessing traditional mental health services—simply the difficulty of getting to a physical location for face-to-face counselling. It's an obstacle for even those living in cities where such services exist, and one that is particularly magnified for those who live in small towns and rural settings.

> "Getting emails asking if we were okay, learning how to apply the skills in daily life, and being accountable to someone each week were really important."

"I think this solution offers a convenient option for people who might be experiencing barriers to accessing traditional mental health services," says Mehta. "Also, it allows people to work on their wellbeing at their own pace. Sometimes, when you access traditional services, you have to allocate one to two hours of your day to attend the session, and appointments may only be available during office hours, which might mean taking time off work. The internet-delivered option that we offer allows the individual to work at their own pace; they can break each week's lessons down to 10 minute intervals which are easier to digest and less of a daily burden."

The program was recently piloted among a small group of individuals across Canada. The study found significant improvements in pain interference, self-efficacy, symptoms of depression and anxiety, and quality of life among those with SCI.

Participants were interviewed about their experiences in the program. Several reported that having the program online allowed it to be more accessible and flexible. "For me, I'm sure for all SCI people too, driving is hard," reported one participant. "Having it online and being able to see if I even qualified online was really good."

Others mentioned that having weekly guidance from a trained clinician made it easier to engage in counselling and allowed them to stay motivated. Others reported that the program was a great resource for developing skills to manage not only their emotional symptoms, but also other secondary symptoms.

"Getting emails asking if we were okay, learning how to apply the skills in daily life, and being accountable to someone each week were really important," said one participant.

"I feel more capable," reported another. "I have more tools in my tool belt to deal with things that used to get me down. I am doing more planning. Just the way I look at possibilities now, it seems that there are more options."

Based on the results from the pilot study, Mehta and her team, in collaboration with the Online Therapy Unit at University of Regina, have obtained funding from the Craig H. Neilsen Foundation to conduct a larger three-year study to evaluate its effectiveness among a much larger group of people with SCI. The study is a randomized controlled trial which compares the effectiveness of the online program compared to an education-only group. The free eight-week online course is open to any Canadian with an SCI. Participants of the program will receive up to $50 in Amazon gift cards for participating.

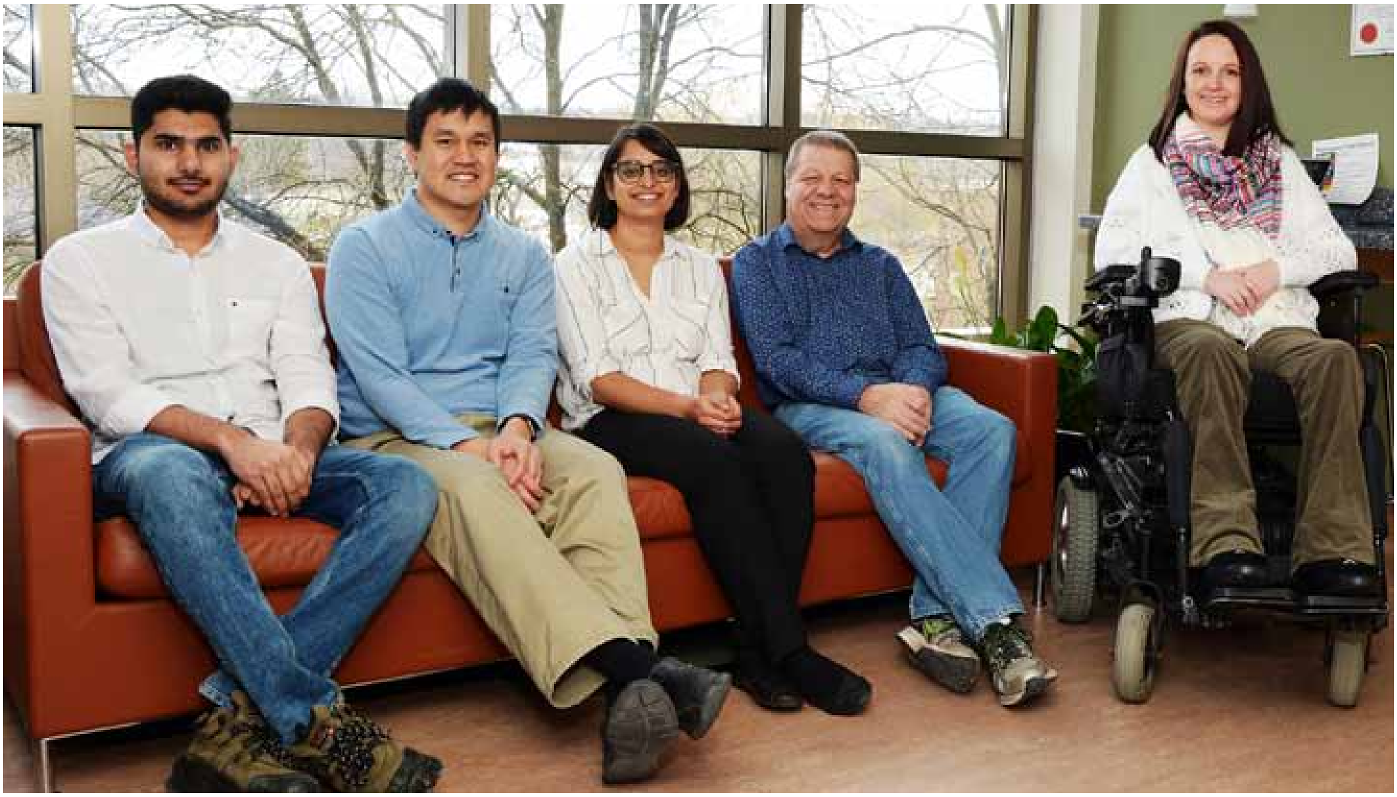
At the heart of the program is cognitive behaviour therapy, or CBT. CBT is an evidence-based program that has been shown to be a powerful tool to help some people manage their anxiety, depression, and chronic pain by changing the way they think and behave. CBT aims to help people recognize when they make negative interpretations of events and situations in their lives and behavioural patterns that reinforce their distorted thinking, and then develop strategies to avoid these negative thoughts.

"It's an eight-week program that aims to provide skills for managing emotional wellbeing after SCI," Mehta explains. "The guided course consists of five lessons, do-it-yourself activities, and case vignettes based on experiences of real people with SCI. The lessons cover information about symptoms of chronic pain, depression, anxiety, unhelpful thoughts and practical strategies to manage them, evaluating physical symptoms of how anxiety and depression manifest, practical skills for overcoming some of the behavioural aspects, and how to improve motivation and get more involved."

Along with the online lessons, course participants have the option of participating in weekly check-ins with a trained clinician via email or telephone.

The course also provides guidance and resources on other essential skills for persons with SCI, including effectively communicating with health care professionals, assertiveness training, and improving sleep hygiene. Mehta says some of the most powerful components of the course are the vignettes or stories from people with SCI, which make it easier for course participants to challenge their own depression-skewed views.

"You don't have to have clinically significant symptoms of depression or anxiety to feel under pressure from the stressors in everyday life. The program is there to help participants learn skills that can be used in normal every-



The people behind the research (left to right): Mitesh Chaudhary, Dr. Eldon Loh, Dr. Swati Mehta, Dr. Dalton Wolfe, and Julie Watson.

day situations. For example, one of our participants commented that, since his injury, he sometimes feels badly that he hasn't been able to take his kids out to some activities they previously did as a family. And these passing thoughts can make him feel isolated and decrease his self-worth. But through the program, he was able to see that there are other new activities they're able to engage in together, and though his wife might take the kids to some of the activities alone, he still feels fulfilled and connected."

The biggest challenge for Mehta at the moment is to get the word out to people who might benefit from the course, and make the course even more effective by providing their feedback.

"Anyone in Canada that has sustained an SCI, both traumatic and non-traumatic, is able to participate," she says. "It's meant for everyone, not just those that are experiencing symptoms of depression and anxiety." She also encourages people with SCI to get in touch with her even if they don't want to formally participate.

"Everyone is in a different stage of life, and some lack time or have other priorities. But I would really appreciate any feedback so that I can figure out how I can make the program more accessible. All feedback, even negative, is important in the process of making improvements that may end up helping others."She adds that spouses or caregivers can also take part to give their perspective on how their lives have changed.

"I think the biggest reason people should get involved in the study is to become empowered and improve their ability to exercise control over meeting their care needs in a way traditional services can't allow," says Mehta. "Another reason is to help us contribute to the understanding of wellbeing among all people with SCI. Everyone has different experiences and needs in their life. Participating in the study can help bring about changes and improve the system for other people in the future."

She estimates it takes about 20 minutes to complete the initial survey, and then about an hour a week to do the lessons. At the end of the course, participants complete a 40-minute post-treatment assessment. Additionally, there is a three month and one year follow-up. Participants receive a $25 Amazon gift card when they complete each follow-up questionnaire.

Initially, the service is being offered and evaluated as a research project—Mehta hopes to publish the data and, if successful, hold workshops to help other clinicians understand the power and potential of the online intervention.

"We will anonymize the information we collect to ensure confidentiality, and pool the data to examine if the intervention helps to improve participants' outcomes," she says. "Also, we hope to examine which individuals are likely to benefit from this, and why. We do need to confirm that this is a program that will be helpful and acceptable for people with SCI."

Given positive results, Mehta says the ultimate goal will be to create a permanent home for the program, as well as expand into other settings across Canada.

"For our next step, our team would like to work with SCI clinicians, administrators, and persons with lived experiences to figure out a way we can implement this program in SCI rehabilitation programs and the community," she says.

For more details or to sign up, visit www.onlinetherapyuser.ca/sci. ■

HAND HYGIENE FOR PEOPLE WITH SPINAL CORD INJURY

PREVENTING COVID-19

1

HAND HYGIENE BASICS

- Soap and warm water: **20 seconds, all parts of hand** (front & back, under nails, between fingers, wrists), or
- Sanitizer (60% alcohol): cover **all parts of hand** (front & back, under nails, between fingers, wrists).
- Take care when you dry your hands; use single-use paper towels in a public place or a clean towel at home.
- **Avoid touching your face**; keep track of where you put your hands and clean those items/surfaces regularly.

The coronavirus (that causes COVID-19) can live for **hours or even days** on a variety of materials; be especially careful of **surfaces in public areas** that are touched by many people (elevator/door buttons, keypads, handrails, touchscreens, etc.).

2a

MANUAL WHEELCHAIR USER

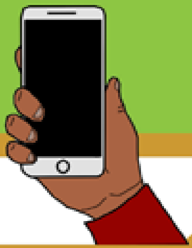
- **Wash your hands** frequently and whenever you enter your living space.
- Remove **gloves** first and clean them with a non-damaging cleaning product.
- After you wash your hands, be **careful about touching your tires**; if you need to transfer, you may want to use paper towels or cloths to cover your tires.
- Clean your **pushrims** as well, since you're constantly touching them… anything that gets on your pushrims is very likely to get on your hands.
- Clean your **brake handles, push handles** and any other parts of your wheelchair that anyone touches with their hands.
- Clean your tires regularly, and try to **avoid making contact** between your hands and your tires when you're pushing.

2b

POWER WHEELCHAIR USER

- **Wash your hands** frequently and whenever you enter your living space.
- If you're not able to wash your hands, get **someone to help you** clean them with soap and water or sanitizer.
- Clean your **joystick** and any other **controls** (while taking care not to damage the electronics)
- Clean your **armrests, tray,** and any other parts of the wheelchair that your hands touch.

This advice is meant to address the COVID-19 pandemic. Certain supplies may be limited but you can still protect yourself and prevent infection using the cleaning products you have; soap and water is always better than nothing.



3

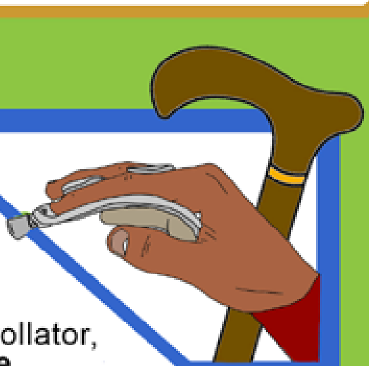
EVERYONE

- Clean your **cell phone** or other mobile device, and any parts of a **bag or backpack** that you touch.
- Clean your **keys**, **wallet**, and any **cards** you use in public places.

4

OTHER ASSISTIVE DEVICES

- Clean all parts of any **splints, cuffs, braces,** or **reachers,** or any other assistive device, that you touch with your hands.
- Clean the handles of your **cane or crutches.**
- Clean the **handgrips** and **brakes** of your walker or rollator, and any other part that you touch (such as a **storage compartment**).



5

USING YOUR MOUTH

- If you have limited hand function, you may typically use your **mouth** to grasp and hold all kinds of things. Although it may be more difficult, it's a good idea to find **other strategies** (including **asking for help** if necessary) so you can avoid using your mouth, ESPECIALLY with any object that **someone else** may have touched.

These measures may seem difficult and time-consuming, but it is **EXTREMELY IMPORTANT** for people living with SCI to prevent infection by the coronavirus. During the current emergency, taking **every possible measure** to protect yourself will help you stay healthy.

More information on COVID-19 and people living with SCI:
www.sciontario.org/covid-19-update

SCI&U
FOR HEALTHY LIVING

A Research Project of:
Physical Therapy
UNIVERSITY OF TORONTO

SHAWN FERREIRA
DESIGNS

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

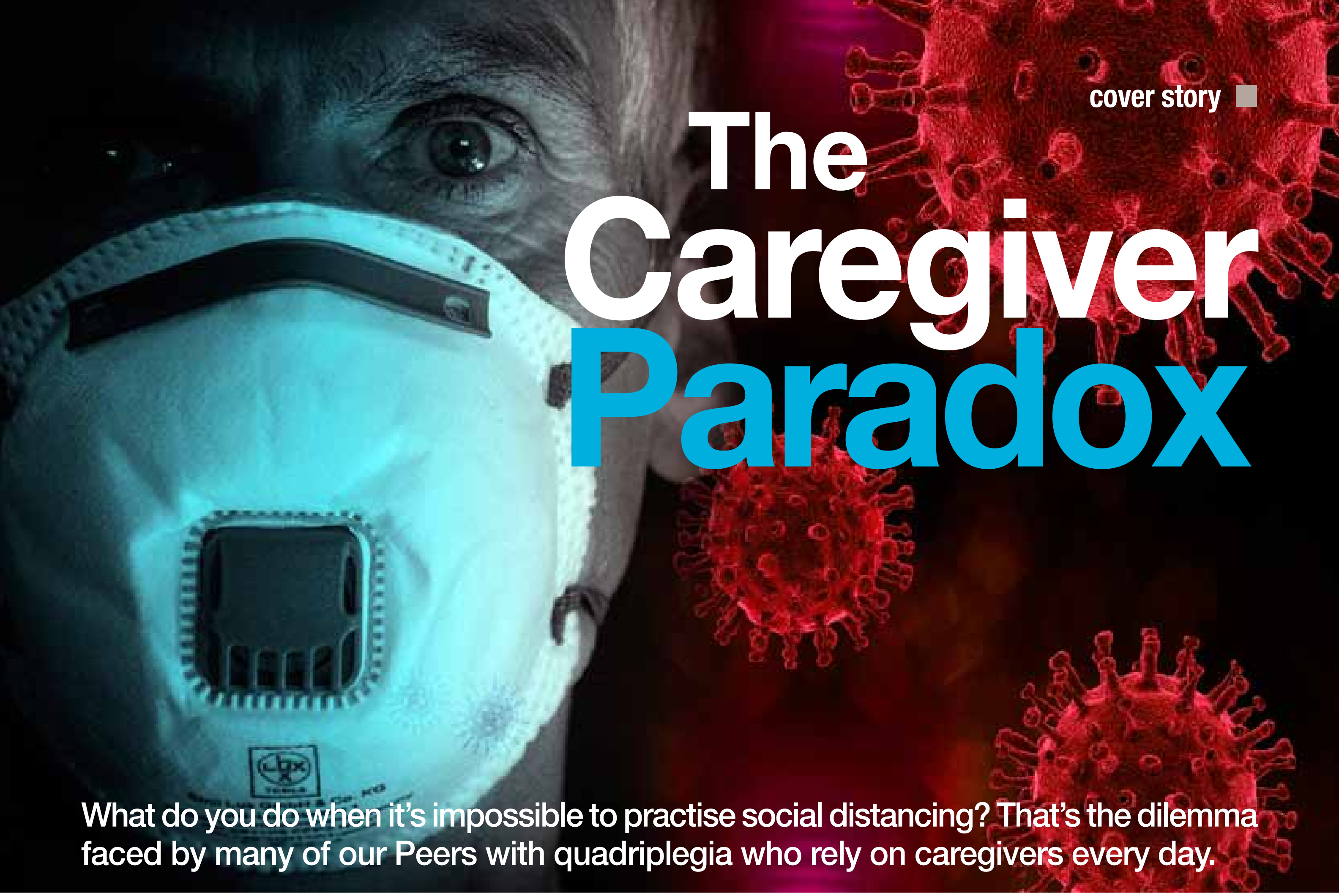
The Physical Activity Guidelines are based on the best scientific evidence available and have two levels. If you're just beginning an exercise regimen, consider incorporating the recommendations included in the STARTING LEVEL. If you're already physically active, you might want to begin using the ADVANCED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

START **MEET** **EXCEED**

The starting level is the minimum level of activity needed to achieve fitness benefits.

The advanced level will give you additional fitness and health benefits, such as lowering your risk of developing Type 2 diabetes and heart disease.

LEARN MORE AT:
www.sciguidelines.com



The Caregiver Paradox

What do you do when it's impossible to practise social distancing? That's the dilemma faced by many of our Peers with quadriplegia who rely on caregivers every day.

Nearly four months into the COVID-19 pandemic, there are countless questions that remain unanswered. But one fact is indisputable: social distancing and isolation, along with strict hygienic practices, can lower the risk of contracting or spreading the virus.

That's reasssuring for the majority of individuals and families. But what about people who are absolutely reliant on daily support from caregivers for the most basic of needs? That's the reality for many readers—people with higher levels of quadriplegia who face the double jeopardy of being potentially exposed because of their reliance on caregivers, and being at high risk for serious COVID complications because of their compromised immune and respiratory functions and other health issues related to their SCI.

We suspect this dilemma has elevated the anxiety levels of most SCI BC Peers who rely on caregivers—particularly after reaching out to three of them who fall into this category. Vancouver's Barry Araña, and Victoria's Joe Coughlin and Chris Marks, all agreed to share their experiences navigating the pandemic up to this point. We wanted to know if they managed to stay healthy, what their fear factor was, what steps they took to mitigate the risk, and how they're preparing for a possible (perhaps even probable) second wave this fall and winter.

The good news is that all three have stayed infection-free—at least, to the best of their knowledge. The bad news is that they've all found the experience extremely frightening, and although they've been doing the best they could, they've all felt a loss of control, relying on improvisation rather than a firm plan. Not only that, they've all felt unsupported by government and our health care system. And despite the fact that all are doing what they can this summer to prepare for a second wave, they're all dreading that possibility.

"I may be doing my part staying at home at all times, but my exposure is high because of my home support workers," says Araña, a C-5/6 quadriplegic who receives about four hours of assistance daily from three different workers via Vancouver Coastal Health. "They visit multiple patients per day in the community; they take public transportation. There was an outbreak at Haro Park where over 20 home support workers tested positive for COVID. Learning this created paranoia for me. There's no doubt that I was panicking about getting the virus from a home care support worker. But I have no choice but to continue using home support from VCH. I cannot function normally without the help of home support."

Coughlin, also a C-5/6 quadriplegic, agrees the pandemic has been incredibly stressful.

SAFE AND SOUND UP TO THIS POINT; WORRIED ABOUT THE FUTURE: *From left to right, Joe Coughlin, Chris Marks and Barry Araña*

"My anxiety level has increased tenfold, but whose hasn't?" muses Coughlin, who self-manages his own seven hours of daily care via the CSIL program. "I've been flying by the seat of my pants. If anyone tells you that they were completely prepared for a global pandemic, they're flinging bullshit. I laid off all my part-time staff back in late March, when the Medical Health Officer declared that HCAs could only work for one facility—my part-time staff fell under that declaration. My live-in worker stepped up to the plate and got me through this pandemic. She hasn't had a break and is looking forward to some well-deserved rest. Both of us were very concerned about infection spread from part-time workers who served a multitude of clients during their full-time duties."

Like Araña, Coughlin is only now beginning to relax a little. At the time of writing this (first week in June), he was just considering the idea of bringing back one part-time worker, primarily so he could give his primary caregiver some much-needed respite.

Marks, who is also a CSIL client and, as a C-5 quadriplegic, relies on the same approximate amount of care as Coughlin, also reports experiencing high levels of stress and the need for creative problem-solving to make it through the worst of the pandemic.

"I had been watching the news and seeing China welding doors shut for entire apartment complexes, and Italy, Spain and France getting hit, and the USA denying it would be an issue," says Marks. "There were definitely some times I was concerned. I slept with a thermometer and pulse oximeter beside my bed, and still do. On a scale of one to ten, I felt like (my stress) went from a three up to a seven or eight as far as increased risk."

At the start of the restrictions, Marks had two roommates.

"One left about March 12th to isolate with their family, and the other one isolated with me as a caregiver back in the beginning, but that only lasted about ten or 12 days before they also went to go isolate with family," he says. "Luckily, two of my longer-term caregivers came back to help, and another friend helped out with some shifts—which paradoxically was great but also increased my risk of exposure to COVID-19. I needed all three to fill in the shifts for the week, but by any math that multiplied my risk of exposure coming into my house many times."

All three were never in doubt of the threat, and did their best to minimize the risk.

"For the first month or six weeks, caregivers would come in and remove their shoes, wash their hands really well, and put on a mask," says Marks. "We would both wear masks for the shift except for eating, brushing teeth, and showering, where I would remove mine briefly." He adds that he started to relax the protocols gradually beginning in mid-May, when it started to become clear that BC—and Vancouver Island in particular—had managed to avoid much of the community spread that had become so disastrous in other provinces. Coughlin and Araña also began to breathe a little easier and relax their protocols around the same time, although both are still instructing their staff to practice superb hygiene and use personal protective equipment, or PPE.

"I'll insist that the part-time staff mask and glove up, at least until we get a vaccine," says Coughlin.

"All my home support workers continue to wash their hands as soon as they arrive and use PPE at all times," adds Araña.

Disturbingly, the trio have been left with the impression that they've been dealing with the crisis largely on their

own, with little or no support from their local regional health authority or any other government body.

"I was extremely frustrated and disappointed with VCH," says Araña. "They never communicated with us, their patients, about what they were going to do to protect workers and patients. They never contacted or sent us any communication about any new policies or procedures that they were going to create and implement during these difficult times dealing with the COVID pandemic. I feel strongly that they needed to do more to protect the home support workers in order to protect and keep us, the patients, safe and healthy."

In Coughlin's case, his concern was about not being recognized as being a priority when it came to getting the supplies he needed.

"I had very little supply of PPE when the public health emergency was declared," he says. "The usual sources for this supply dried up completely. I tried to get some from the health authority. They told me their supply was for the front-line workers. I contacted Safe Care BC and they were able to secure a donation of about two months' supply of PPE for me."

While all three are happy to be through what appears to be the worst part of the pandemic, none are relaxing this summer. Instead, all three are putting their faith in the best scientific and expert advice—all of which suggests that a second wave is possible, and that it may be even more catastrophic in the absence of a viable vaccine or therapeutic treatment.

"I'll be trying to secure more PPE, if and when it's available," says Coughlin. "I'll also be looking to hire more part time staff."

Marks is going a few steps further.

"I have masks and hand sanitizer ready, and other PPE too. I also built a greenhouse and planted a garden, and a friend is helping me build a chicken coop and I'm getting some chickens. So that's my plan for the next six months. The chicken coop, greenhouse and garden I've been thinking about for years, but finally started making it happen at the end of March. On the island, we only have three days to a week of food and supplies in case of a natural disaster, and we just had a reminder of that during the early days of the pandemic. I think growing a few veggies and having some chickens, and supporting local businesses and food production, is smart and necessary. I have no idea what I'm doing but I'm doing it anyway."

Despite their preparations, all three aren't exactly confident as they contemplate the possibility of a second wave. However, they all have some advice to offer other Peers in the same boat.

"I have a great relationship with all my home support workers, so I'm able to communicate how imperative it is to follow the instructions from (BC Provincial Health Officer) Dr. Bonnie Henry about ways to protect ourselves during the pandemic," says Araña. "Advocate for yourself. Don't be afraid to express your concerns. Be assertive. We must do everything we can in order to keep safe and healthy."

"Plant a garden if you can; stock up on PPE for the fall," says Marks. "Now is the time to press for a universal basic income that adds to disability supports and does not penalize us."

Marks also suggests keeping an open mind and taking the initiative to look beyond our borders where other countries have had success with different approaches.

"The Japanese guidelines are to pay attention to closed spaces, crowded spaces, and close contact," he says. "Minimize those times, ventilate and provide airflow through indoor spaces where possible, and wear masks when you can't maintain distance if you have to go out in public."

Marks also has some words of wisdom about how you treat your caregivers. "Remember, don't make it too stressful for your caregivers because it's already stressful enough. Look for ways you can appreciate them; I was fortunate to be able to get three of mine health and dental coverage for a year along with a small raise."

The last word goes to Coughlin.

"Be prepared, be prepared, be prepared," he says. "I never planned for this kind of disaster. I'm prepared for an earthquake or another kind of disaster, and the officials say that we should be able to survive on our own for 72 hours. Three months is pushing that somewhat. When I worked with the BC Office for Disability Issues, our staff developed a Disability Lens—a guide for policy developers. Clearly it was not used in the response to this global pandemic. My hope is that, in future disaster planning, folks like me will be considered. It sure didn't happen this time. I was on my own." ■

SCI BC will be working over the summer months to improve the support for all of our Peers, particularly those who rely on caregivers, in the event of a second wave of COVID-19. We're making our concerns and recommendations known through a number of channels, including the BC government's COVID-19 Disability Working Group, of which our Executive Director, Dr. Chris McBride, is a co-chair.

Grasping the Subject

Three Kelowna post-secondary students take full advantage of a class project to create a glove that enhances the grasping ability of people with quadriplegia.

Earlier this year, when second year Okanagan College students Tenley Csolle and Zoe Dack teamed up to work together on their final term project of their Therapist Assistant Diploma (TAD) program, they agreed they wanted to develop something that would benefit quadriplegics.

"I became quite interested in adaptive devices through my program and was always thinking of ways to better what was out there," says Csolle. "Wanting to help someone with SCI came about because our class was introduced to a friend of one of our professors who had sustained an SCI. He came to speak to our class about his daily life as a quadriplegic and how he performs daily tasks to help us understand better how to work with future SCI clients in their rehabilitation process."

In particular, Csolle and Dack were intrigued as they witnessed the guest speaker making use of tenodenis grasp—a technique that most, if not all—quadriplegics are familiar with. It allows them to pick up and hold objects despite the fact that they have little or no control of their fingers, and works by bending or extending the wrist, which causes the fingers to curl or grip. Relaxing the wrist then releases the grip.

"I was already familiar with tenodenis grasp and the concept behind it, but seeing our guest use the technique made me start to think," says Csolle. "I wanted to come up with something that would make picking up objects a whole lot easier for someone with an SCI without the use of any kind of cuff."

The approach the duo settled on was to modify a glove into an aid that would amplify the wearer's tenodenis grip. But they weren't sure how to make it a reality, so Csolle approached her boyfriend, Spencer Bell, who is in his second year of mechanical engineering at UBC Okanagan's Applied Science program.

Bell came up with the idea of adding high-tension cords to a standard work glove purchased at Rona. They first attached special pads to the glove's fingertips, thumb and palm that provide more friction for gripping. But the special sauce was a set of low-friction cords attached to the fingertips and thumb, which then run down the hand and connect to a device on the wrist.

"The actual mechanism on the wrist is really just composed of a 'tuning key' of sorts that the cords are attached to," says Csolle. "When turned, the cords are tightened. A small ramp increases tension on the cords when the wrist is brought back into extension. The effect is a mimicking of what happens to the tendons in your fingers during tenodenis grasp. In short, the actual enhancing of grasp comes from the cords just acting as much tighter artificial tendons."

Tenley Csolle and Spencer Bell plan to continue work on the T-Glove

She notes that the wearer must have sufficient strength in wrist extensor muscles to make the device, which they dubbed the T-Glove, work.

Bell reproduced the idea in 3D CAD software, and after iterating a few changes with Csolle and Dack, was able to 3D print a plastic device that would provide tension control.

The trio completed a promising functioning prototype—but it's never really been tested on a suitable candidate.

"Unfortunately, we weren't able to test the glove on someone with quadriplegia because our professor's friend who agreed to test it was on vacation when we were finishing up the project," says Csolle. "Then COVID-19 complicated the situation. Not being able to test it really just came down to the fact that we had a fairly short timeline to finish it for school."

After finishing the prototype for their school presentation, the trio had no intentions of taking the design any further because they had no idea there would be so much interest from the public and the SCI community. Of course, restoration of hand function has long been a top priority for people with quadriplegia—a fact made clear in countless surveys. There have been numerous research projects aimed at improving grasping in people with quadriplegia, and several powered glove devices and surgical procedures (for example, nerve and tendon transplantation) have been developed over the years. More recently, transcutaneous stimulation of the spinal cord has also offered some promise. But there's never been any solution developed that's quite so simple and inexpensive as the T-Glove.

"After a story about our project was published in a local media outlet, a representative from Praxis Spinal Cord Institute reached out to us," explains Csolle. "He urged me to gather my colleagues again and pitch the idea to their accelerator group to see how they may be able to help the product go to market."

Dack has moved onto to other interests and priorities, but Csolle and Bell are now enthused to focus their efforts on moving the T-Glove forward.

"We have quite a few people with SCI who have volunteered to test the glove so we can develop it further," says Csolle. "In fact, we're planning on creating a whole new glove to pitch to the (Praxis) accelerator group—it will have a lot more ease-of-use and is more polished."

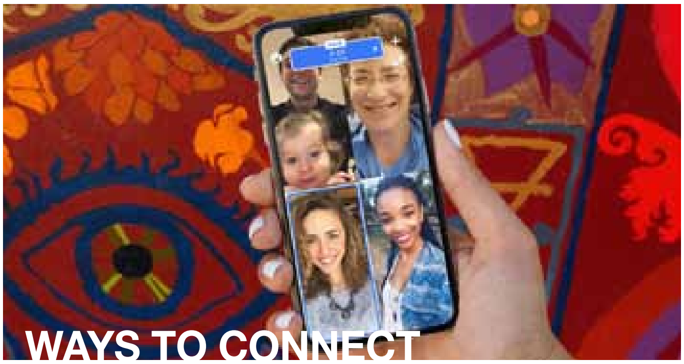
For Csolle and Bell, the entire experience has been remarkably formative at this point early in their careers.

"I've been keen on working with those who require rehab after SCI for a while now, but this innovation will definitely help me to gain valuable connections with professionals in the field which may help further my career in the future. As for Spencer, he's had intentions of working in biomedical engineering and design for quite some time. This opportunity is exactly what he would like to be doing with his life, and he hopes to make a career out of it."

Keep in mind that the T-Glove is currently a prototype that will require considerable work to determine if it is viable commecially. We'll follow the progress in future issues. ■

CONNECT with Tech

At the time of writing, social distancing guidelines were slowly being relaxed here in BC. But many of us still find ourselves separated from friends, family and routine, and it seems like a possibility that guidelines may be reintroduced if the contagion reemerges in the months ahead. As many of us have discovered, technology offers some relief, so we scoured the web and asked SCI BC Peers for the best online resources, apps, and sites they've been using to stay safe and sane during COVID-19. The result is a list of essentials to get you through this difficult time. So, power up, plug in and peruse!



WAYS TO CONNECT

HOUSE PARTY is the "ultimate chilling with friends at home" app. It comes with fun, quick games and features. *houseparty.com*

DISCORD offers free voice and text chat for gamers, but is growing more popular among other audiences too. *discord.com*

QUARANTINE TOGETHER is a new dating app specifically created for what we're going through right now. *quarantinetogether.com*

CREATIVE MORNINGS offers various inspiring and creative online sessions with guest speakers—connect with a community that resonates with you. *creativemornings.com*

NEXTDOOR helps you stay informed about what's going on in your neighbourhood. *ca.nextdoor.com*

QUARANTINE CHAT is a voice-chat app for serendipitous connections with people around the world affected by the pandemic. Meet new people and share stories. *quarantinechat.com*

CREATIVITY & CULTURE

LINE OF ACTION, QUICKPOSES, PROKO, AND SKETCH DAILY are fantastic drawing sites that make it easy to practice daily. Each site offers something a little different—tutorials, prompts, timed drawing sessions, and more. *line-of-action.com, quickposes.com, proko.com, reference.sketchdaily.net*

VIRTUAL MUSEUM TOURS give you an opportunity to explore some of the world's most renowned museums or art exhibits. Google is an easy way to find your favourites.

SMULE is a social singing app with more than 10 million songs to karaoke by yourself or with friends. *smule.com*

SIDEDOOR was created by BC musician Dan Mangan and delivers online interactive concerts featuring a variety of Canadian musicians. Tickets are affordable and all proceeds support musicians. *sidedooraccess.com*

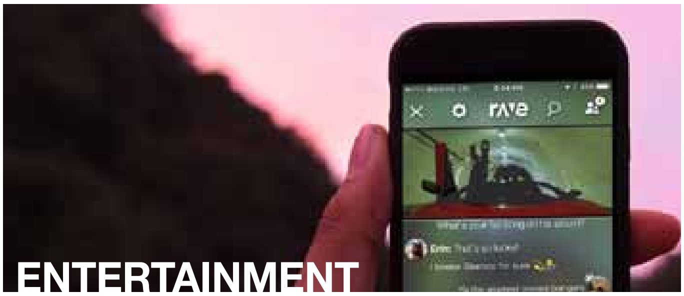
NANOWRIMO is an online platform that provides the tools to reach your writing goals—track progress, set milestones, and be part of an online writing community. *nanowrimo.org*

CANON OUTSIDE OF AUTO is a website that allows you to learn and practice photography skills online from the safety of your own home. No camera required! *canonoutsideofauto.ca/play*

DUOLINGO is an easy-to-use app that can help you learn a new language with a few minutes of practice each day. *duolingo.com*

OVERDRIVE makes it easy to track down your next read in the form of an audio book from your regional library. *overdrive.com*

CRASH COURSE is a YouTube channel that's ideal for those into history and psychology. *youtube.com/user/crashcourse*



ENTERTAINMENT

CROWDPURR TRIVIA allows you to make your own trivia game and play online with friends. The site keeps score for you and shows real time answers and rankings. *crowdpurr.com*

JACKBOX GAMES is a "box" of fun online games that are fast-paced, easy to learn, and perfect for a group game night. *jackboxgames.com*

AIR CONSOLE has more than 130 multiplayer games available to play online. Connect via your web browser and use your smartphone as a game controller. *airconsole.com*

ANIMAL CROSSING allows you to create your own unique world and befriend cute animals. A Nintendo Switch console is needed for this hugely popular game. *animal-crossing.com*

TWITCH is for the real gamers out there. Watch, chat and connect with millions of users around the world on this video game livestreaming platform. *twitch.tv*

JUST DANCE 2020 (for PC, Xbox, Xbox One, Playstation 4, Switch, Wii, Google Stadia) is a great way to keep active and have fun, and only requires shoulder and elbow mobility.

RAVE markets itself as a new way to watch videos and listen to music in perfect sync with friends, and includes DJ mashups. Perfect for your next Friday night in! *rave.io*

NETFLIX PARTY allows you to watch a movie with your friends despite social distancing. Stream a movie of your choosing and live chat with friends—don't forget the popcorn! *netflixparty.com*

THE INTERNET ARCADE is a web-based library of vintage arcade games. Take your pick (Astro Blasters, anyone?), insert your "coins" and play via your web browser. *archive.org/details/internetarcade*

HEALTH & WELLBEING

SCI & U MINDFULNESS SESSIONS, offered by our friends at SCI & U, offer weekly online mindfulness sessions facilitated by SCI BC Peer and certified yoga instructor Mary-Jo Fetterly. No experience required! *sci-and-u.ca/basic_pages/34*

EVERY BODY FITNESS is a great website for exercise resources that meet your needs. *scitotalfitness.com*

SCI ACTION CANADA gives you the tools you need to maintain your physical and mental health. Use the Canadian Physical Activities Guidelines for Adults with SCI as a starting point to plan your exercise routine. *sciactioncanada.ok.ubc.ca*

GET IN MOTION is a free, telephone-based physical activity coaching service from the Canadian Disability Participation Project (CDPP) that will be available until the pandemic is over. *cdpp.ca/get-involved*

HEADSPACE is an easy-to-use mindfulness app with guided meditations and sleep training. Free two-week trial. *headspace.com*

MINDSHIFT is an app developed by Anxiety Canada. It has a ton of useful resources based on cognitive behavioural therapy (CBT) and is completely free. *anxietycanada.com/resources/mindshift-cbt*

DAYLIO is a daily diary app you can use to track your moods and activity. Select goals and habits or create your own and see at a glance what's working and what's not. *daylio.webflow.io*

WOEBOT is an automated chatbot app that checks in on you and asks you about your day, mood, etc. Easy to use, super cute and interactive. *woebot.io*

MOMENT can help track your smartphone usage and provide daily exercises to make sure you're using your phone in a healthy way. *inthemoment.io*

WORKING FROM HOME

ZOOM is multi-person video conferencing on steroids. *zoom.us*

SLACK offers instant messaging and more. *slack.com*

TRELLO is a superb list-making app. *trello.com*

TOMATO TIMERS is a break reminder app intended to make you work more efficiently and effectively. Set automatic break reminders or try the Pomodoro method with increments of focused work. *tomatotimers.com*

LOOM allows you to send video messages and screen recordings. *loom.com*

WETRANSFER is a large file transfer website, with no account required. *wetransfer.com*

DROPBOX is another large file transfer website—an account is required, but it offers bigger "free" file transfer capacity. *dropbox.com*

WRITEROOM is perfect for creating a distraction-free writing setting. It's simple, uncluttered, and has no email or notification distractions. At the moment, it's only available for Mac users. *hogbaysoftware.com/products/writeroom*

OMMWRITER is similar to WriteRoom. This distraction-free writing site provides nature soundscapes, simple typeface and soft backgrounds to keep you focused and inspired. *ommwriter.com*

TOGGL tracks your work progress, break times, time spent online, and more. A great tool for people who are self-employed and need to track and report project hours. *toggl.com*

PADLET helps you organize your education, career and almost all important aspects of your life. *padlet.com*

DOODLE POLLS is a voting system for meetings that makes scheduling a breeze. Type in some options for dates and times and have your co-workers vote for the best one. It's an easy way to make plans with family and friends too. *doodle.com* ■

Born to Ride


Niall Pinder Photo

It's been quite a life journey for SCI BC Peer Tara Llanes, but the one constant throughout it all has been a passion for mountain biking—a sport which she loves sharing with others.

Tara Llanes believes that a perfect antidote for pandemic-induced stress is to get outside.

"A lot of us can feel cooped up right now, and having the opportunity to get outside and get some exercise, while keeping some social distance, is awesome," says Llanes, a transplanted Californian who now calls North Vancouver home. "Especially with the weather starting to turn, it's important to keep our mental health in a good place."

In particular, she believes that adaptive mountain biking is tough to beat as a great way for other Peers to safely experience the outdoors.

Of course, Llanes (pronounced *yawness*, not *lanes*) may be just a little biased, having been a mountain biker for most of her life—before and after being injured. Originally a BMX rider (she started at the age of 11), she graduated to mountain biking in 1993 and spent the next 15 years travelling the world and competing as a professional mountain biker. Her accolades include an X-Games Gold, two Silvers, and a Bronze.

All that changed in a split second during a 2007 competition in Colorado. She hit an obstacle the wrong way and was thrown over the handlebars. The crash left her an L1 paraplegic.

During her recovery, an unexpected romance with a fellow mountain biker altered her life path.

"I met Elladee when I was 17 years old while we were both racing mountain bikes on the pro circuit in the US and Europe," says Llanes. "After she retired, we had lost touch for about 11 years, but we bumped into each other a year after I broke my back. I was living in California and we'd started a long-distance relationship. After flying back and forth, I made the decision to move to Vancouver. It was actually a very easy decision. It wasn't like I toiled over it. It was more, 'Let's really do this. I'll come to you.'"

The couple have been together since, and Llanes became a citizen shortly after she obtained her residency status.

"I couldn't be prouder," she says. "I was born and raised in the US, but there is just something about Canada. The pace of everything just feels right. And now that I've been here over 10 years, things seem much more polarizing south of the border, which makes me appreciate life here even more."

Shortly after starting her new life in Canada, many doors started to open for Llanes—including an opportunity to get back in the saddle.

"When I first got hurt in 2007, the only thing I could think about was being able to rail on a bike again," she says. "I wasn't interested in just cruising. I wanted to have a piece of equipment that would allow me to pin it down a mountain. It was a couple years after I moved to BC, around 2012, when some friends of mine found this awesome aMTB. They did a fundraiser and surprised me with it—a new Sport-On Explorer. It had full suspension; you sat in more of an attack position. It was the first aMTB I'd ever seen that looked like it could handle the types of trails I wanted to ride."

But the Explorer did more than just get Llanes back on the mountain—it ended up being the catalyst for a new career.

"The thought of having my own business had never crossed my mind," she explains. "It wasn't until I had my Explorer, and had so many people ask me about it while on the trails, that it even occurred to me. BC is the mecca of mountain biking and it made me wonder why there were no reps here. I contacted the owner of Sport-On, Jaroslaw Rola, a double-amputee who originally started designing and manufacturing the bikes in Poland because people saw the bike he'd made for himself. I let him know I had a background in mountain biking, loved the bike, and felt there was a market out here. From there I think it accidentally turned into a business."

Today, as the owner of Tara Llanes Industries, Llanes represents the Sport-On aMTBs across Canada.

"It's taken some time to evolve and honestly, I knew absolutely nothing about running my own business," she admits. "It was a lot of trial and error. A lot! In the beginning I wasn't sure what I was getting myself into. Being self-employed, there is so much uncertainty as to what your salary will be, and not having any sort of pension is a bummer. However, the pros are that I can make my own hours, I'm my own boss, and I can run things the way I think will help grow the sport. I knew that mountain biking had a rich history here in BC and I felt like adaptive mountain biking finally had equipment that was capable. It was a great opportunity to give people a chance to be out in the mountains during summer months."

We asked her to explain her company's business model.

"I am not a distributor, meaning that I don't have a warehouse with tons of bikes. We don't have office space simply because it would cost us too much here in BC. Instead, I like to focus on working with adaptive organizations such as Whistler Adaptive, Kootenay Adaptive, and others. If potential customers want to demo the bikes, they get in touch with these organizations. This way, it promotes the adaptive organization, the bike and the sport, while keeping costs down for both myself and ultimately the customer."

She adds that she creates awareness of the Sport-On bikes via social media, word of mouth, and good customer service. But she thinks the most effective way of spreading the word is having the bikes at camps held by adaptive sport and recreation organizations.

"Whistler Adaptive has hosted an aMTB camp for the past four years, and it's a great way to get people set up on the bikes, answer questions, and have their knowledgeable staff and volunteers take us out on the trails. I've also headed out to GF Strong a few times to show the bikes to people who are newly injured."

If you've never seen the Sport-On line, Llanes would love for you to check them out—she says there are models for just about every type of use and user.

Elladee Brown Photo

"When I first got hurt in 2007, the only thing I could think about was being able to rail on a bike again. I wasn't interested in just cruising. I wanted to have a piece of equipment that would allow me to pin it down a mountain." – Tara Llanes

The aMTB that started it all: the revolutionary Sport-On Explorer.

"Our XCR bike is our hardtail gravel grinder, double track type bike. It's front-wheel drive with your legs out front. It's perfect for green and blue circle types of trails. Our Explorer is our all-mountain bike with rear-wheel drive. It comes with full suspension, and you kneel in a more aggressive stance. It has two steering systems—one is the chest pad allowing you to lean on the pad while pedalling, and then you've got the handlebars for when you're ready to go downhill. The FAT Explorer is the same bike, but with a FAT tire option. Then we have the Jeetrike, which is our newest model. It's an amalgamation of the XCR and Explorer. It has full suspension and is rear-wheel drive, but your legs are out front like the XCR."

If you're interested in knowing more, Llanes recommends checking out her website and then getting in touch.

"If someone is interested in a bike, they can call or email me and I'm more than happy to answer questions they have about the bikes—which Sport-On models are best on which terrain, and what type of electric assist, drive train, and accessories we offer."

Of course, Llanes has interests beyond mountain biking, She's a gifted athlete and fierce competitor who isn't afraid of a new challenge, and that's what led her to take up wheelchair tennis shortly after arriving in Canada. She quickly excelled at it—she was a Singles and Doubles National Champion in 2017. In 2018, she was encouraged to try her hand at basketball, and once again, she quickly rose up the ranks—in just two short years, she's become a mainstay on Canada's National Team. But mountain biking is clearly going to stay a big part of her life.

"It's been exciting to be part of this sport for as many years as I have now. To see it grow, not only on the equipment and technology side, but also in terms of camps and programming through adaptive organizations, guidelines, and signage, is amazing. So is helping people that want to get outside in the woods with family and friends."

Looking back, Llanes says she has no regrets.

"A life journey is exactly what it's been! Every once and a while I miss riding my mountain bike and hiking the way I used to, but not so much that I would change anything. This injury had me hit rock bottom before I started to figure it out. It forced me to reinvent myself and figure out who I wanted to become. Life has a way of working itself out and I'm enjoying it every step of the way."

You can learn more at tarallanesindustries.com. ■

Get in Motion: It's Back!

For many people, staying active during COVID-19 isolation can be a struggle. More so for people living with SCI and other disabilities, says Dr. Kathleen Martin Ginis, professor at UBC Okanagan's School of Health and Exercise Sciences, and director of the Canadian Disability Participation Project (CDPP)—a group that recently revived a service called Get in Motion to help people with disabilities get regular physical activity.

Some readers might recall that Get in Motion was a phone-in coaching service developed by Martin Ginis's lab, but put on hold a few years ago. Martin Ginis and her CDPP colleagues from Queen's University, Dr. Amy Latimer-Cheung and Dr. Jennifer Tomasone, reintroduced the service with a team of other volunteers.

"People with a disability are at increased risk for social isolation under usual circumstances, but especially so during the COVID outbreak," says Martin Ginis. "They also face unique barriers and challenges to physical activity. With the closure of adapted physical activity and recreation programs, we are very concerned about the health and well-being of Canadians with disabilities. We are offering the Get in Motion service as a way to manage some of the psychosocial and physical health risks of being inactive at home."

Martin Ginis explains the idea came up after she and her colleagues had discussions with their community partners that offer adapted sport and exercise programs (for example, PARC at ICORD), which have been closed across the country because of COVID-19.

"We were all feeling upset about the impact these closures will have on community members with disabilities," she says. "We were all thinking 'I wish we still had Get in Motion' and then Amy Latimer-Cheung started the ball rolling—and got the service back up and running."

Based virtually out of Latimer-Cheung and Tomasone's lab at Queen's, Get in Motion is available for all Canadians with physical disabilities, as well as for Special Olympics athletes. Participants can connect with a volunteer physical activity coach via phone or online conferencing. The volunteer then guides that person through an at-home physical activity program.

The service is entirely flexible. Some participants might want to speak to a coach just once—for example, about how to do strength-training at home without specialized equipment. Others might want regular phone contact with a coach in order to receive ongoing support for physical activity goal setting, planning and scheduling physical activity, developing plans to overcome barriers, or finding resources.

"With Get in Motion, we are striving to provide that sense of belonging through phone calls with trained volunteers who have experience with adapted sport and exercise," says Martin Ginis.

For more information about the Get in Motion, or to enrol in the program, visit cdpp.ca/get-involved.


future
work
family
home

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.

COVID-19 Disability Survey

Overview: The Canadian Disability Participation Project (which is led by ICORD researcher Dr. Kathleen Martin Ginis, and of which SCI BC is a community partner) and the Abilities Centre are collaborating on this special initiative to record the experiences, concerns and needs of people with disabilities during the COVID-19 outbreak and recovery period. After a successful launch in Ontario, the partners are now starting a national version of the survey to ensure the experiences, concerns, and needs of people with disabilities throughout Canada are recorded. The purpose of the survey is to generate data that will be used by non-government and government organizations to address the needs of Canadians with disabilities in the coming months and years.

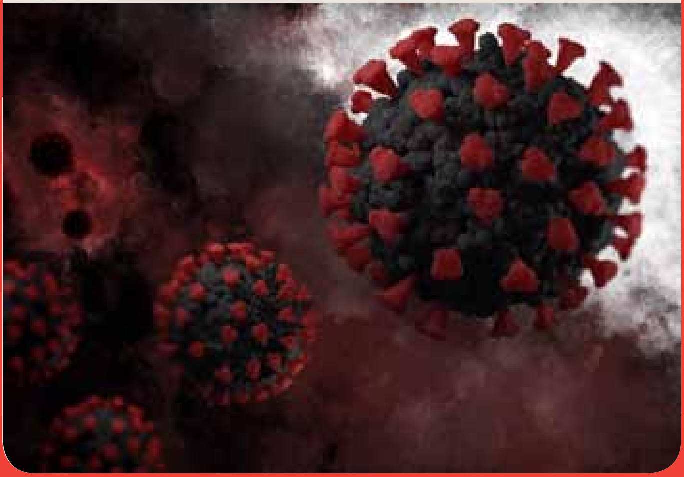
What to expect: This online survey is designed to be accessible to all and should take approximately 20 minutes to complete. New surveys will be sent approximately every two weeks for participants to provide real-time updates on their needs and experiences.

Who can participate: Adults who identify as having a disability (or having a child or family member living with a disability in your household) may sign up to participate in a 20-minute survey to voice the unique experiences, concerns and needs of navigating the COVID-19 pandemic while living with a disability (such as a physical, cognitive, or sensory disability).

Why participate: The survey's findings will provide important information to help communities across Canada ensure that COVID-19 response strategies meet the needs of people of all abilities. Survey findings will be posted on the survey website to help support government, community organizations, and service providers responding to the needs.

Location: Online at abilitiescentre.org/disabilitysurvey.

For more information or to sign up to participate: Please call Meagan O'Neill at 1.866.639.1858 or email disabilitysurvey@abilitiescentre.org.



Supporting Snowsports Leisure Opportunities for PEople with disabilities (SSLOPE)

Overview: ICORD researchers Dr. William C. Miller and Dr Andrea Bundon are calling on all past participants of adaptive snow sports programs. If you have previously participated in adaptive snow sports programs, but no longer do, you're invited to participate in this research study to learn more about your experiences. The purpose of this study is to better understand the quality of participation for people living with disabilities engaged in adaptive snow sports, including those offered by the British Columbia Adaptive Snowsports (BCAS).

What to expect: The study involves one phone interview, lasting approximately 45 minutes.

Who can participate: You may be able to participate in this study if you are 14 years of age or older, are able to communicate in English, are a person with a disability or are a representative of a person with a disability who has participated in adaptive snow sports in the past but no longer chooses to participate.

Why participate: The findings from your participation in this study will be translated into resources to improve the experiences of people with disabilities in adaptive snow sports programs.

Location: The study will take place over the phone.

For more information or to sign up to participate: Please contact Staci Mannella by email (staci.mannella@alumni.ubc.ca) or call 201.317.1903.

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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email Dr. Swati Mehta, swati.mehta@sjhc.london.on.ca
visit: www.onlinetherapyuser.ca/sci

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last word

“What did you do during the COVID-19 pandemic?”

That’s the question we’ll all be asking each other at some point in the future. For the fun of it, we recently asked Peers and staff what they’ve been doing up this point, telling them to think of the request as an adult version of “How I spent my summer vacation.” We were surprised and amused by the various ways they kept their sanity during this time of self-isolating and social distancing. Here’s a look at some of their responses.

1. “I’ve been driving deep into the woods and enjoying the outdoors.” —*Mohee Matee, New Westminster*
2. “During the first couple of weeks, I completed my first puzzle in 30 years. I enjoyed it—I’m now on my third one!” —*Bert Abbott, Nanaimo*
3. “We picked up a used Nintendo WiiU system to help fill some time with fun. We’ve been enjoying the curling game actually, it’s pretty cool!” —*Alexis Chicoine, North Vancouver*
4. “Sending big love to show appreciation for all essential service workers out there keeping us safe.” —*Tracy Boyd*, Vancouver
5. “I’ve been colouring and thinking about loved ones.” —*Marni Abbot-Peter, Vancouver*
6. “Gotta get out for a bit of sunshine, a cruise and a bike ride. And we’ve been making pancakes and doing puzzles.” —*Richard Peter, Vancouver*
7. “I’m finally finishing Shelley Milstein’s Xmas gift! Actually, what’s keeping me busy is starting all the projects. It’s a bit of a problem. —*Jocelyn Maffin, Nanaimo*
8. “I’ve been going on early morning walks with my kids. We discovered this beautiful chalk artwork in one of the laneways in the neighbourhood.” —*Karen Meadows, Lower Mainland*
9. “Made this, then ate it!” —*Cameron Rankin, Vancouver*


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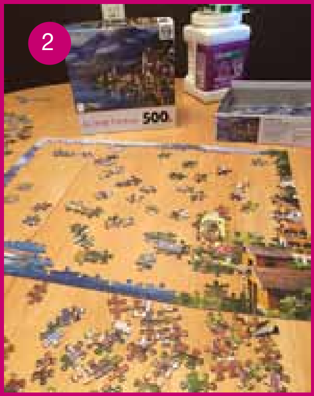
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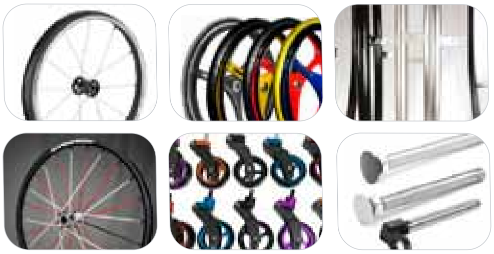

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