

the spin

SPINAL CORD INJURY BC

WINTER 2023



Changing the Game

The Neil Squire Society's adaptive gaming program, GAME Checkpoints, makes video gaming accessible for everyone



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GOT QUESTIONS?

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Spinal Cord Injury BC

COVER: GAME Checkpoints client plays Mario Kart 8 Deluxe at GF Strong Rehabilitation Centre.

Remembering Four Quiet Leaders

Through my work over the past three decades, I've had the privilege of meeting and working with many incredible people with SCI who have had a positive influence on my life and career. Some are well known—national heroes, Paralympic champions, elected officials, and the like. But many are less well known, people who have quietly been pioneering champions for change.

By nature, these quiet pioneers do their work out of the spotlight, and because of this, their contributions are not always fully recognized or remembered. Too often, it is not until they pass away that attention is drawn to the invaluable impacts they have had.

This past year saw the passing of four exceptional individuals with SCI who made enormous contributions to making BC more accessible and inclusive, to supporting SCI BC's mission, and, on a very personal note, to supporting me in the roles I've held in my career.

Terry Leblanc, Don Danbrook, Norman Haw, and Robb Dunfield will be familiar names to some, but unfamiliar ones to many more. All four broke down barriers, created rich networks of support, and effected change by leading by example. In their own ways, all were leaders and champions of the disability movement in this province. As I can only touch on their contributions in this editorial, I have posted a blog on the SCI BC website through which I share more about their contributions and the quiet impact they have had.

Terry and Don were long serving members of SCI BC's Board, providing invaluable insight into the importance of our peer support programs and helping guide the organization to where it is today. I'm certain this is true for the many organizations they supported. Both high level quads injured over forty years ago, they collectively served on boards within societies of the Disability Foundation, Lions Paralodge Society, Technology for Living, and the Neil Squire Society.

Norm Haw made his impact through several roles with SCI BC (BCPA back then), including a stint as its executive director. Norm's passion for helping people rebuild their lives was evident in all his work, but it is the role he played in the Creekview Project, a breakthrough for the independent living movement, that he considered his greatest accomplishment. Robb Dunfield was one of the five ventilator-dependent members with SCI who worked with Norm to be the first to bust out of the George Pearson Centre, described by Robb as a "warehouse for ventilator people," to live independently in the Creekview Co-op in 1985. Robb is also known for his career as a mouth painter and his role with Rick Hansen Foundation's Ambassador program.

It was a privilege for me to know and learn from these four quiet pillars of our community. Their insights and guidance have been immensely important in my efforts to serve SCI BC's mission, but it is their direct and indirect impact on the lives so many for which we can all be grateful. Legacies not to be forgotten.

—Chris McBride, PhD, Executive Director, SCI BC



thespin

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We acknowledge that *The Spin* is created on the traditional and ancestral territory of the Coast Salish peoples—Squamish, Musqueam, and Seilwiltulh (Tsleil-Waututh) Nations. Our provincial work takes place on the territories of Indigenous peoples who have lived on and cared for the land for time immemorial. We are grateful to work, share stories, and connect in these spaces.

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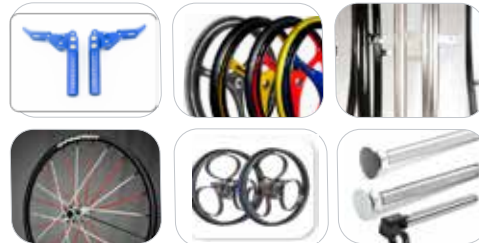
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Innovations

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ADAPTIVE BRAS AND PANTIES COLLECTION

Victoria's Secret launched its first-ever adaptive bras and panties collection this October. In partnership with GAMUT Management, a consulting company that collaborates with the disability community, this product line is specifically tailored for women with disabilities to feel confident and independent. The bra features front magnetic closures, front strap adjusters, sensory friendly fabric, and Memory Fit lining that conforms to your curves. The panty features the same fabric as the bra, along with magnetic side closures at the sides. Not only are these intimates functional, they also come in a variety of colours and sizes to suit your style. Shop the collection at victoriasecret.com.



SMART EARBUD

Keep a look out for Naqi Logix's earbud invention that could be a transformative breakthrough for the disability community. This Canadian technology, which made *Time* magazine's list of the 200 greatest inventions of 2023, gives you the power to control any electronic device, including powered wheelchairs, without the need for voice, touch, or screens. The earbud uses muscle and brainwave sensors to detect simple actions, such as a head tilt or a blink of an eye, which is then turned into commands for gadgets. Naqi Logix aims to get the earbuds on the market next year. More information can be found at naqilogix.com. You can also see a video of former Vancouver Mayor and peer, Sam Sullivan, trying it out on Global News.



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4shreads has got you covered for the winter with their ParaSHRED Leggy collection! Designed with wheelchair users in mind, the Leggy protects your legs and lower back from the cold with double layered fleece. It can be stretched to wrap around the seat of most wheelchairs and can even cover your shoes. You can get in and out of the Leggy without having to get off the wheelchair and it's designed so that there is no need to worry about the material getting caught in the wheels. The All Weather Leggy is wind and rain resistant and meant for those who are adventurous outdoors. You can count on the Leggy to keep you warm indoors and outdoors all winter long. Learn more at 4shreds.com.





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Learn more about SCI research.

SCI researchers from UBC Okanagan are coming to a Peer Program event near you! Catch a short and lively presentation about 10 SCI research studies that you can participate in. From physical activity to pain, be a part of a dialogue about SCI research over snacks and refreshments. The roadshow rolls through Prince George, Vancouver, Kelowna, Surrey and Vancouver Island in February and March 2024. Check out sci-bc.ca/events for more event details.



Join us for an SCI film screening.

"I feared that I would never feel like myself again... and that's changing for me now." While love is on our minds, join us on February 15 at the Blusson Spinal Cord Centre for a live screening of *Move Me*. Follow Kelsey Peterson's journey as a dancer while she continues to find and love herself in her recovery after a spinal cord injury. The documentary will be followed by a talkback with the filmmaker and SCI peers. For more information, email Ryan at rclarkson@sci-bc.ca.

HAPPY NEW YEAR!

Thank you for another fantastic year! Your support brings new connections, joy, and knowledge to many of our members. Help us spread SCI information across BC by supporting future *The Spin* issues with a donation.



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peers ■

A big cheer for **ROB GOSSE**, who made quite the splash at the 2023 IWWF World Disabled Waterski Championships in Elk Grove, California this past September. Competing in the multiple plegics double leg amputees (seated) MP5 over 35 M division, Gosse placed 9th in the Jump and Overall events. Incredibly, he cleared a distance of 14.4m (47ft) riding over a ski jump, which is nearly the length of a semi-trailer truck! If you're in the Lower Mainland, you may have met Gosse in his role as Mobility Sales Consultant for Sidewinder, a Chilliwack company specializing in lifts, wheelchair vans, and other mobility products. With his hard work and aptitude for water skiing, we can't think of a better person to advise peers on the best equipment to get around.



Peer Shoutouts



A big thanks and well-deserved shoutout to **RODNEY HODGINS** and his wife Deanna of Prince George for their willingness to make the most of a terrible air travel experience. You may have heard Hodgins' story in the news: On an Air Canada flight back from Las Vegas, he was forced to exit the plane by dragging himself through the aisle, rather than receiving assistance with the aisle chair. His wife helped him by moving his legs as he pulled himself forward. Hodgins' experience is unfortunately one of many experiences of indignity and violation of disability regulations for air travel. Hearing how Canada's Chief Accessibility Officer, Stephanie Cadieux's own wheelchair was lost by Air Canada, Hodgins decided to go public about his encounter. Hodgins shared with CBC News, "I didn't expect it to get this big. I just thought, 'Hey man, maybe we can make a change,'" after his story attracted national and international attention. Air Canada apologized to Hodgins and admitted it violated Canada disability legislation. Both the Ministry of Transportation and the Canadian Transportation Agency are launching official investigations into the matter. Hodgins says, "With all the reaction, with all the people all around the world, it gave me a little bit of faith in humanity."

Kudos to **TLELL LAROSE** of Nanaimo for her starring appearance in an Expedia commercial you may have seen on television. The ad shows a woman, Sonia (LaRose), in her wheelchair navigating gloomy weather and snowy streets with her dog, Bill. Once at home, Sonia decides to book a trip to Tepoztlán, Mexico with the help of Expedia and Chat GPT. The commercial ends with Sonia and Bill in the sunshine, smiling outside their hotel. The ad, shot in Toronto and Tepoztlán, follows past Expedia commercials featuring actors such as Rashida Jones, known for "Parks and Rec" and "The Office". We are always happy to see positive portrayals of disability and travel in the media and we can't wait to see where LaRose's next adventure takes her. You can watch the ad at ispot.tv/ad/1uFY/expedia-sonia-and-bill



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



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Changing the Game

The Neil Squire Society's adaptive gaming program, GAME Checkpoints, makes video gaming accessible for everyone.



“If you were an athlete before your injury, one of the first things a rehab therapist would think about is adaptive sports

or how to get back into that. But gaming doesn't have the same process,” says Tyler Fentie, Accessible Gaming Lead at the Neil Squire Society. “If gaming is suddenly not an option for people, or if that was the main way into their community, and it's just totally gone—that could be pretty devastating.” GAME Checkpoints is an initiative by the Neil Squire Society's Makers Making Change program that aims to address this issue by working with community partners across Canada to provide them with video gaming gear, resources, and training.

The origins of GAME Checkpoints (“GAME” stands for Gaming Accessibility Made for Everyone) was originally inspired by a Makers Making Change Access Makeathon in 2017. The Makeathon enlisted the help of inventors, creators, and hackers to build open source assistive technology, including a new Wii control for a youth with a disability. Since then, there has been continued interest in gaming solutions for people with disabilities and in 2023, Makers Making Change started the GAME Checkpoints program.

“Gaming has always been a big part of Makers Making Change... our flagship device, the Lipsync Joystick was one of the first gaming variations we did,” explains Fentie. “Around that time, the Xbox adaptive controller came out too, which was great, but you need accessories to work with it and it gets expensive fast. Folks were looking for options, alternatives, and customized equipment. The motivation grew from that.”

The GAME Checkpoints program now has seven locations across Canada, including two at the Neil Squire Society offices in Burnaby and Calgary, one at Eidos-Montreal, a gaming studio in Montreal, and one at each of the following rehabilitation centres: GF Strong Rehabilitation Centre in Vancouver, the Stan Cassidy Centre for Rehabilitation in Fredericton, and the West Park Healthcare Centre in



Toronto. When community partners join the GAME Checkpoints program, they work closely with Makers Making Change staff to determine what video games and gear would work best for their location and participate in training that covers the basics of video gaming, how to use adaptive video game equipment, and how to evaluate gaming needs.

In this way, GAME Checkpoints helps broaden traditional support systems such as occupational therapy or recreational therapy to include gaming assistance for people of all abilities. “Clinicians have been reaching out to us for years because a lot of clinical centres or libraries or wherever had bought an adaptive Xbox controller or other gaming stuff and it's just been sitting in the closet collecting dust because they don't know how to implement it,” Fentie says. “Creating best practices and having a whole day worth of training with the clinical centres where they can get hands on experience connecting these devices and playing games is important.”

Chad Leaman, Director of Innovation at the Neil Squire Society, underscores this importance, noting that abandonment rates for assistive technology are historically quite high. “How do you know it's going to work until you try it? Having a spot where people can come in to try games so they're not buying some \$500 setup that doesn't work is a great opportunity,” he says. In Vancouver, GF Strong clients can connect

with the GAME Checkpoints centre located in Assistive Technology Services and demo an adapted gaming station to see what fits their needs. GF Strong currently has a variety of consoles (Xbox Series, Nintendo Switch, a PC, etc.), controllers (Xbox wireless, Switch pro, Joycon grip, Playstation 4 and 5, etc.), games (Brawhalla, Celeste, FIFA, Mario Kart, Minecraft, etc.), and a multitude of Makers Making Change assistive switches, mounts, joysticks, controller modifications, and more that can be customized for your needs.

“We've also just started releasing some new OpenAT Joystick solutions,” Leaman adds. “At one of our last events, someone was using their chin as a joystick, so different sizes and different 3D printed add-ons make more things possible. We'd love for people to test these new devices and tell us what's the good, the bad, the ugly.” The OpenAT Joysticks are available for borrowing at GF Strong, and the Neil Squire Society's head offices, or can be sent to people as needed. They can be used for mouse control as well as adaptive gaming and are a cost-effective solution in comparison to commercially available equipment. “I think that's what makes us unique,” Leaman says. “We have the ability to manufacture something on hardware at a much lower cost with [3D printing, open source plans, and a national network]. Our ability to make things affordably certainly helps

get these solutions to people at a much cheaper cost.”

Although cost savings is a huge factor in the appeal of GAME Checkpoints, the impact of the program is more far-reaching than any dollar amount could account for. To see someone light up when they find their new favourite game or reconnect with a forgotten pastime is immeasurable.

“About a year before we did the training with GF Strong they had a client who was interested in gaming but at that time they only had standard controllers,” Fentie explains. “He had been playing games his whole life. His friends and him had been playing since Atari and they loved it—that was their main way of connecting after they all moved after university. They’d been playing weekly up until this client had a stroke and then he was limited to a really small number of games that he could play with only one hand...within 45 minutes of him coming back to GF [after our training] we got a solution set up for him using a 3D printed modification that was mounted on his controller so he would be comfortable playing for long periods of time and with different games. It’s one of those things where there is a

simple solution but without the training in context to that, they weren’t able to provide a solution for him previously.”

The solutions provided by GAME Checkpoints aren’t limited to experienced gamers only. Both Fentie and Leaman explain that many of the people that come to them don’t have any previous gaming experience or interest, but they want to give it a try. “Someone’s ability to play doesn’t equal the experience that they want to have when they’re playing,” Fentie says. For example, someone who may never have played video games before their injury might be curious about gaming to engage in competition against others, to express creativity, to solve a cognitive puzzle, or to have an adrenaline-filled experience. “Everyone who comes in is going to have a different perspective. Just like you know, movies, DVDs or books, those kind of things, gaming is so diverse. [The] genres of games and the player experience is definitely something that we want to hit home a lot.”

Once you know what kind of game you’d like to try, often the best place to start is with the system you already have. For most people, this means investigating

what already exists on their smartphone or tablet and then seeing how GAME Checkpoints and Makers Making Change can help provide assistive technology to enhance compatibility.

Currently, there aren’t industry-wide accessibility standards for video games, but GAME Checkpoints sees potential for change. “Accessibility features should be by design there to help promote the game experience, instead of just being there for the sake of it,” Fentie says. “I would love if every game had controller remapping or had blind accessibility or things like that. If there was this kind of curiosity to see how we can push this forward and how we can make this a creative element of our game. There’s no limit in where it can go.”

If you’re interested in gaming but not sure where to begin, GAME Checkpoints is more than happy to help you get started! You can reach out directly to Tyler Fentie at tylerf@neilsquire.ca or check out an extensive array of online resources at makersmakingchange.com/s/adaptive-gaming. We’ve also created an infographic to spark some inspiration. Happy gaming! ■



The GAME Checkpoints Program at GF Strong Rehabilitation Centre.

What Kind Of Adaptive Gaming Equipment Do I Need To Start Playing?

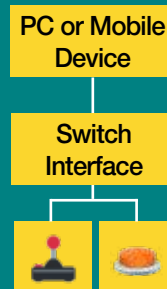


Game Genres:

- **Racing:** The focus of the game is to participate in a racing competition.
- **Sports:** The focus of the game is to simulate the practice of playing sports.
- **Puzzle:** The focus of the game is figuring out a puzzle or completing a cognitive task.
- **Competitive:** The focus of the game is to beat others.
- **Action:** The focus of the game is excitement, fast-paced, and action-oriented.
- **Adventure:** The focus of the game is to explore the video game's world and navigate through a series of storylines as a character(s).

Adaptive Gaming Equipment

Assistive switches are buttons that will work for your adaptive gaming equipment needs. All assistive switches can be used for gaming but require a switch interface. A switch interface acts as an adapter, allowing you to connect the switches to your computer, tablet, or smartphone using USB or Bluetooth. The type of switch interface required depends on what type of gaming device you are using. Makers Making Change can help you determine what technology is needed and what will work best for you!



Current adaptive gaming equipment products available by Makers Making Change:

Assistive Switches

- 1 Assistive Switches Kit (Most popular! This package includes: 1 Raindrop Switch, 1 Light Touch Switch, 1 Interact Switch, 2 MMC 60 Switch)
2. Single Message Playback Switch
- 3 Foot Pedal Switch
- 4 Siff and Puff Switch Analog
5. Rocket Switch Interface

Assistive Joysticks

- 6 Oak Compact Joystick
- 7 Spruce Mini Joystick
8. Ivy Nunchuck Joystick Adapter
9. Cedar Integrated Joystick
- 10 Birch Mini Joystick
11. Wheelchair Bluetooth Joystick Adapter

Switch Interfaces

12. FAIO Multiplexer
- 13 FAIO Multiplexer Wireless
14. Enabled-Controller
- 15 Enabled-Controller-Mini
- 16 Rocket Switch Interface
17. Forest Joystick Mouse Hub



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- Steve Saylor – youtube.com/@SteveSaylor
- MikeTheQuad – youtube.com/@MikeTheQuad
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Step Together

A mobile app developed by researchers at UBC Okanagan is helping people with SCI who walk get active.

When Dr. Sarah Lawrason found out that her brother, Peter, had been in a motorcycle accident, she didn't know very much about SCI. She had just started working on her master's degree in sport psychology at Queen's University in Kingston, Ontario, where she was studying coaching and leadership. She quickly learned that his life was about to change—a lot. But what she didn't anticipate is how much it would change the direction of her life too.

Peter sustained an incomplete SCI. Within six months of his accident, he was able to walk. “And when he walked, you know, all the doctors said, ‘This is amazing. I’ve never seen anyone like this. I’ve never met anyone or treated anyone who’s walked after an injury,’” recalls Lawrason.

But while the positive developments in Peter's recovery were welcome news to Sarah and her family, Peter's ability to walk led to new challenges—a “mixed blessing” as some might put it.

“It's a very lonely experience because you don't actually fit into any of the groups that you're supposed to fit into,” says Lawrason, reflecting on her brother's experience. “You don't look like you have a spinal cord injury, but you also are clearly not able-bodied.”

Here at *The Spin*, we've heard similar sentiments from our readers. In our Fall 2014 and Summer 2020 issues, we featured the stories of several peers with incomplete SCI. Although it's not an exact science, about half of all people with SCI have incomplete injuries, and between 25 percent and 50 percent of people with incomplete

injuries may have some capacity to walk, says Lawrason. That means that as many as one in four people with SCI can walk, but very few resources or programs exist to support this often-overlooked group of people.

It was this gap in programming that led Lawrason to the University of British Columbia Okanagan in 2018, where she began working on a PhD with Dr. Kathleen Martin Ginis, a pioneering leader in SCI and physical activity research.

“When I met with [Martin Ginis], we talked about how there's really no research at all on people with SCI who can walk on a regular basis, even though it's actually a growing population,” says Lawrason. “It's such a personal connection for me. And if we can create a resource for people with SCI who walk where they feel less isolated, that was my goal.”

Over the course of her doctoral work, Lawrason conducted a series of studies focused on better understanding the physical activity experiences of people with SCI who walk. What she learned from these studies culminated in the development of a mobile app to help people with SCI who walk get more physically active and have better quality physical activity experiences.

The app, SCI Step Together, offers physical activity-focused education, peer support, goal setting, and activity tracking—all easily accessible on your mobile phone. “You have access to weekly education modules and a health coach who checks in with you once a week to talk about your barriers and goals related to physical activity, or even other health-related



Dr. Sarah Lawrason and her brother, Peter.

goals,” says Lawrason. “You can also connect with other peers in the program, and then finally, you can track your physical activity—or other metrics like mood, pain, and nutrition—on a daily basis.”

Lawrason and her colleagues partnered with Curatio (now RxPx Inc.), a tech company dedicated to connecting people with support, information and tools that will promote their health, to develop the app. Hosted on Curatio's Stronger Together platform, SCI Step Together is based on the best research evidence specifically for people with SCI who walk. The team responsible for developing the app included scientific research experts, individuals with lived experience, an SCI community organization, and RxPx Inc.

Beyond filling a gap in existing research and programming, the decision to create a mobile app for people with SCI who walk was grounded in a desire to help users connect with one another and feel less isolated while also improving their health through regular physical activity.

“There are very few people with SCI, just in general, and there are even less who walk. They can live all over Canada and the US, and may feel really isolated as a result,” explains Lawrason. “One

of the ways to kind of bring people together is through their phone, and that's one of the reasons we wanted to do an app. Another reason is that there's a big community of people on Instagram who are following each other's rehab journeys and finding support in that way, so we knew that it was going to be a relatively feasible way to connect people."

The physical activity guidelines for adults with SCI recommend at least 20 minutes of aerobic exercise at a moderate or high intensity twice a week as well as resistance or weight training (3 sets of 10 reps for each major muscle group) twice a week to achieve basic cardiovascular and muscle strength benefits.

Development of the app began with a review of the literature focused on physical activity for people with SCI who walk. The findings of the review confirmed that very few studies exist, and pointed to the need for new research investigating the quantity and quality of physical activity among people with SCI who walk, as well as what influences their physical activity behaviours. So, Lawrason conducted a mixed-methods study to do just that.

"The first part [of the study] was analyzing people's determinants of physical activity and their physical activity levels using the Physical Activity Recall Assessment for individuals with SCI (PARA-SCI) questionnaire. We had over 40 participants for that study, and it informed the types of behavior change techniques we would use in the intervention," says Lawrason. "The second part was doing interviews. We interviewed 23 participants to understand the quality of their physical activity, and what factors informed the quality of those experiences. Like, why were those experiences good or why were they bad? And we included all that information in the app itself."

An important aspect of the process was engaging people with SCI who walk as partners in the development of the app. Three people with SCI who walk reviewed the Stronger Together platform and the preliminary content of the app. They then participated in interviews with Lawrason to provide recommendations for the format and general content of the SCI Step Together program.

The next step involved evaluating the app. Specifically, Lawrason and her partners were interested in testing the

feasibility, acceptability, and engagement of the SCI Step Together app for people with SCI who walk. "We wanted to see if the app is actually practical for users. For example, does it require a lot of time to do? Is it really costly? Do people, you know, actually engage with the app and do they like it?" explains Lawrason.

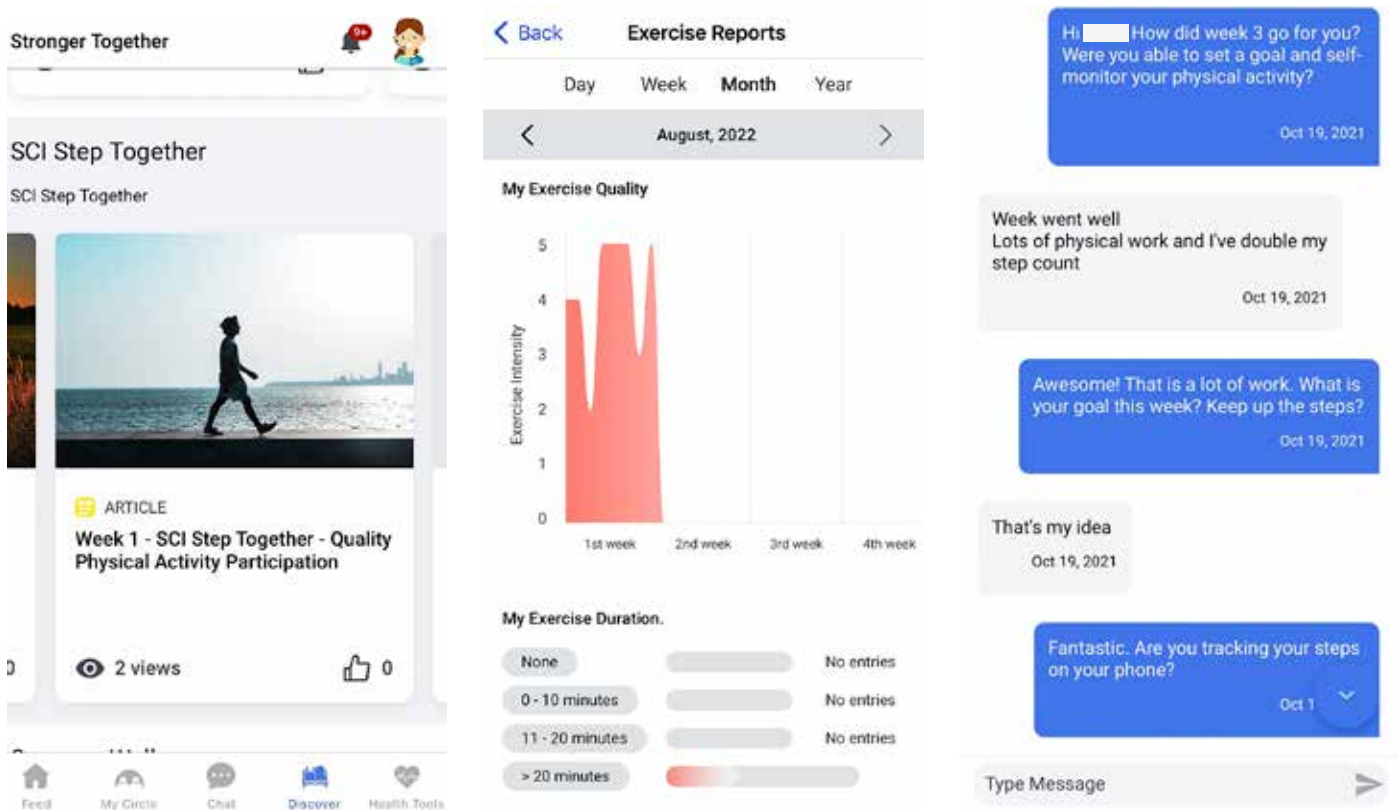
To this end, the researchers conducted a randomized controlled trial with 20 people with SCI who walk. About half of the participants used the app over an eight-week period, while the other half were asked to continue with their normal daily activity without starting any new physical activity programs. Participants completed questionnaires assessing the factors that influenced their physical activity and the outcomes of their physical activity, including its quantity and quality, at the beginning, middle, and end of the eight-week period. In addition, six participants from the group that used the app participated in interviews where they discussed their satisfaction with the app, as well as its usability and recommendations for improvement. At the end of the trial, participants in the control group were invited to use the app as well.

Although the researchers didn't see any improvements in physical activity as a result of the app, they did find that use of the app came with several other benefits. "Participants who used the app reported better basic psychological needs for their physical activity, meaning they felt more supported, had more autonomy, and felt more competent," says Lawrason. "They also had more knowledge on physical activity. And I think that was really due to the inclusion of the *Physical Activity Guidelines for People with SCI*." Lawrason also noted that because several participants in the study were already physically active before using the app, there may have been a "ceiling effect" for changes in physical activity levels.

The trial also showed that the SCI Step Together program demonstrated good feasibility, acceptability, and en-



Action Canada Lab, including Dr. Sarah Lawrason (top row, centre), Dr. Martin Ginis (top row, far right) and Dr. Rob Shaw (now with SCI BC; bottom row, centre left).



Left to right: educational module and exercise graph from SCI Step Together mobile app, and health coach support.

gagement. “When you do anything in partnership, it’s just generally more feasible because you have more human resources to work with,” explains Lawrason. “[The program] was totally safe. People were compliant. And the adherence was quite good, although it did wane over time. So, I think in the future, a four- or six-week program might be a better option rather than eight weeks. But overall, people tended to use the app pretty well.”

On the whole, people who have used the app had a positive experience using it. “They were so thankful to finally have a tailored resource for people who walk with SCI,” says Lawrason. “But there were some recommendations too.” For example, while users really liked tracking their physical activity through the app, they would like it to better integrate with the technology they are already using, such as an Apple Watch or Strava.

The app will likely produce the most benefit for people who want to be more physically active, but aren’t sure how

to get started, says Lawrason. Even so, she encourages everyone with an SCI who walks to try it. “The more people who use it, the more comfortable people are to connect with each other on the app,” she says. She also recommends that anyone who uses the app focuses on the quality of their physical activity experiences, rather than the quantity.

“Focus on knowing your body and what activities that you’d like to do, rather than needing to achieve every single exercise out there on the planet, and just getting really overwhelmed by all the other people on Instagram that you see that are doing rehab exercises,” she recommends. “Everyone is their own individual, so focus on what works for you.”

You can access SCI Step Together by downloading and creating an account on the Curatio: Stronger Together app, which is available on the Apple App Store and Google Play. Once you’ve created your account, select the SCI Step Together program option. The educational modules are also published on

the Canadian Disability Participation Project website at cdpp.ca.

SCI BC’s Ryan Clarkson also hosts an online Ambulatory Peer Group for those who have some form of ambulation (walking) after a spinal cord injury. The group is open to peers who are walking full time, and others who still mostly depend on a mobility device to get around. The group meets online near the beginning of the month—have a look at the events listings on SCI BC’s website for when the next ones are happening. ■



Ryan Clarkson, host of SCI BC’s online Ambulatory Peer Group.

Your Priorities for SCI BC's Aging with SCI Program



When SCI BC's Duncan Campbell asked about your priorities for his new Aging with SCI peer support program, you answered.

In the last issue of *The Spin*, we introduced you to Duncan Campbell and the Aging with SCI peer support program he is developing. In that article, Duncan invited you to participate in a survey about aging with SCI. We checked in with Duncan to find out what many of you told us, and how your input is shaping our Aging with SCI program.

The overwhelming response to the survey clearly indicates that aging with SCI is a topic of great interest and concern. Within a week of opening the survey, 117 people had completed the survey and by the time the survey was closed, 132 surveys had been completed. In the world of SCI surveys, this is a remarkable response.

We sent out this survey to all SCI BC peers who are 40 years or older and shared the survey link in our newsletter and *The Spin*. The vast majority of responses came from older peers who are more than fifteen years post injury, and who use a wheelchair. Understandably, most (56 percent) responses came from peers who were already of retirement age. However, with 40 percent of responses coming from peers 50-59 years of age, we expect that this project is of interest to younger peers who may already be starting to experience early issues related to aging with an SCI.

Here's what we learned:

Three of the top five topics felt to be the most relevant to aging with SCI were related to health issues. Bowel and bladder issues were identified as the highest priority topics, with shoulder and pain issues coming in at number three and four, respectively.

"I thought that these common SCI complications had probably been addressed enough in the past, but as we get older we experience a lot of changes that prompt us to review how we manage these systems—including learning about new options available that could help address these changes," says Campbell.

Physical activity and fitness was the second priority, which resonates for Campbell, "I am a firm believer that exercise and activity are important parts of healthy living, and that not everyone has the knowledge and opportunities available to be active. The Aging with SCI program will share guidelines around how much exercise is enough to provide benefits, and options for getting more in your routine."

Care options rounded out the top five priorities. As we age, there is an increasing likelihood that we'll need home care support and many of us have not planned for the costs that can be associated with it. Accessing and advocating for home care supports is on our list for the Aging with SCI program to address.

While financial concerns were in the middle of the priority topics identified, the comments revealed a range of very different financial situations aging peers are dealing with. "It is pretty clear that as a person with a disability ages there are many, many financial implications, some to maintain our health, some to maintain our independence, and many of these are not covered or supported in any way. The variety of financial situations will need a few sessions to discuss, as well as ways to advocate for better support," says Campbell.

Campbell acknowledges that many comments said all of the topics were important,

noting that the rankings have given us a better idea of where to start.

"This project will have its own page on the SCI BC website featuring Ask an Expert and Aging with SCI videos, SCI BC resources, as well as links to external resources and research articles. We are also developing a calendar of sessions starting in January that will be available on the Aging webpage after each session," says Campbell. Education-related sessions will include professional experts and peers, which were important components to the majority of survey respondents.

Campbell is very pleased and appreciative of the response to the survey, "I want to, again, thank all of you who did the survey. The results have definitely helped to set priorities for development of this program." ■

As the Aging with SCI program continues to be developed, here's what is happening next:

Two online sessions per month will start in January, with the first two being:

- an Aging with SCI Education Session series with clinician and peer experts and a Q&A
- an Aging Discussion Group to discuss and share information and support around aging with SCI.

Keep your eyes open for the launch of the Aging with SCI webpage to collect videos and links to important resources from SCI BC and elsewhere.

Conceiving a New Treatment for Male SCI Infertility

A new clinical trial is examining the use of an inexpensive oral medication to treat an infertility issue experienced by most men with SCI.

The cold, grey months of Canadian winter aren't typically a time of year when birds and bees are active in the garden. But it is the time of year when "the birds and the bees" become more active in Canadian homes (yes, we're talking about sex and reproduction). It's during those cold, grey winter months that most babies born in Canada are conceived.

The question of whether or not to start a family one day likely isn't top of mind in those first few months, or even years, after sustaining an SCI. But that doesn't mean it won't be a priority one day. For example, in our Fall 2016 issue, we answered a reader named Bob in "Ask the Spin Doctor." He wrote, "Back in rehab, I never gave much thought to the idea of being a father... it just didn't seem like it was in the cards, and so I didn't really absorb much information about the subject when it was presented to me. Well, things have changed—and now I need to figure out what my options are. Can you help?"

Since then, we've covered how sexual rehabilitation and neurostimulation can improve sexual pleasure and function. But we haven't had any notable advancements in fertility research to share with you—until now.

Dr. Emad Ibrahim, Director of the Male Fertility Research Program at The Miami Project to Cure Paralysis and an Assistant Professor of Clinical Urology and Neurological Surgery at the University of Miami's Miller School of Medicine, has been awarded \$3.25

million US dollars (approximately \$4.47 million Canadian) by the US Department of Defense for a clinical trial examining the use of Probenecid—an inexpensive oral medication—to treat an infertility issue that affects most men with SCI. If successful, it would be the first ever trial to show that an oral medication can be used to improve sperm quality.

There are three issues that most men with SCI face if they would like to have a biological child. The first is erectile dysfunction, or the inability to get and keep an erection. The second, affecting at least nine in 10 men with SCI, is the inability to ejaculate. The third issue—and the focus of the trial—is poor sperm quality. According to Ibrahim, when compared to healthy, fertile men without an SCI, men with SCI typically have a similar number of sperm, but the sperm are less motile (meaning that the sperm do not move or "swim" well) and less viable (meaning that fewer sperm are alive).

"The issue comes with motility and viability—they are drastically low. So, if we say that the 'normal' motility is 40 percent, men with SCI would sometimes have 1-3 percent, maybe 10 percent tops. Viability tends to be higher, because the sperm can be alive even if it's not moving, but the percentage is still low," explains Ibrahim. "This is a very unique issue in male fertility, because most men with fertility problems in the able-bodied population would have low sperm counts with low motility. But normal counts and low motility? It's very, very unique and it's not very common with any other male fertility factors."

To produce a pregnancy, a partner contributes sperm in the form of semen, and there needs to be enough "good swimmers" in the semen to reach and fertilize a partner's egg during a period of ovulation. The male partner's contribution of semen is generally achieved through ejaculation. For the more than 90 percent of men with SCI that cannot ejaculate on their own, there are several sperm retrieval options, including penile vibratory stimulation, electroejaculation, and surgical sperm retrieval.

"Penile vibratory stimulation, which is the gold standard and the treatment of choice, is less invasive, inexpensive, and relatively safe if we manage autonomic dysreflexia. We can train the patient and make sure that it's safe for them to do on their own at home," explains Ibrahim. "If we can't get a sample by penile vibratory stimulation, then we resort to electroejaculation, which is a little bit more invasive, required to be done by a trained physician [at a clinic], and the cost of equipment is a lot higher."



Dr. Emad Ibrahim

Electroejaculation is commonly needed for men with SCI below T10. If ejaculation cannot be achieved through either penile vibratory stimulation or electroejaculation, then sperm can be retrieved surgically as a final resort.

“So, let’s say we manage erectile dysfunction, and we manage the ejaculation. Now we have an ejaculate. We’re talking about the third obstacle, which is the sperm quality, and that’s where the grant comes into the picture,” says Ibrahim.

Sperm quality, and motility in particular, plays an important role in egg fertilization. If a couple can’t conceive a child naturally, there are three main methods of artificial insemination to fertilize an egg, says Ibrahim.

The first is intravaginal insemination (IVI), which can be done at home. It involves inserting the partner’s sperm into the partner’s vagina using a syringe without a needle. “This is the simplest, cheapest method, but it requires over 20 million total motile sperm count,” says Ibrahim. In other words, a lot of good swimmers are needed for it to work.

The second option is intrauterine insemination (IUI), which is performed by a physician in a clinic and requires a total motile sperm count of at least 5 million. “In this case, we take the semen, we clean it up, and we get only the good motile sperm. Then, using a special catheter, we put it through the cervix and into the uterus,” explains Ibrahim.

If the total motile sperm count is less than 5 million, then in vitro fertilization (IVF) and intracytoplasmic sperm injection (ICSI) are the couple’s best chance to conceive a child. During conventional IVF, mature eggs are collected from the female partner’s ovaries and the male partner’s sperm is placed next to an egg on a laboratory dish. The first sperm to reach the egg produces an embryo, which is then implanted in the female partner’s uterus. ICSI follows the same process as IVF, except that a single sperm is selected and injected into the egg to encourage fertilization.

Treatments to improve sperm quality afford couples who are experiencing infertility more options in the treatments available to them. With a higher total motile sperm count, couples may be able to produce a pregnancy in the privacy of their own home or through IUI, which is less invasive and cheaper than IVF—especially for couples who are navigating infertility through the American healthcare system, like the ones in Ibrahim’s clinic.

“The difference in the price between the IUI and IVF is basically around \$2,000 USD for IUI compared to \$15-20,000 USD for IVF, so that’s a huge difference,” says Ibrahim. “The goal of our research is to move the couples that have total motile sperm count less than 5 million to at least 5 million so that they can have an IUI. It will save them money, they will have a more natural type of pregnancy, and it will be easier for them.”

Men with SCI and their partners in Canada would benefit too. “Improvement in semen quality could reduce the number of couples requiring assisted reproductive technology, allowing them to produce a pregnancy at home or with IUI alone, reducing waitlists, travel time, and costs to larger centers in BC to access IVF treatment,” says Dr. Stacy Elliott, the Medical Director of the BC Centre for Sexual Medicine, Co-Director of the Vancouver Sperm Retrieval Clinic, and ICORD Principal Investigator.

With these benefits in mind, Ibrahim and his colleagues pioneered research that explains why men with SCI experience poor sperm quality. And it’s this understanding of why men with SCI experience poor sperm quality that led them to Probenecid, an inexpensive oral medication used to treat gout, as a way to improve it. To understand why they decided to test Probenecid, let’s start at the beginning.

As mentioned, men with SCI have a similar number of sperm, but the sperm move less—a key factor in male infertility—than in men without SCI. To understand why the sperm of men with

SCI are less motile, the researchers took a closer look at their semen.

What they found was that the semen of men with SCI has a lot of white blood cells called T-cells. T-cells produce cytotoxic chemicals called cytokines. In men with SCI, the researchers found very high levels of three particular cytotoxic cytokines: IL-6, IL-1 beta, and TNF alpha. “These are, in our opinion, what causes the damage to the sperm motility,” says Ibrahim.

“So, what’s wrong? What happens to cause this? We examined it a lot. And we found that these [cytotoxic] cytokines are the problem,” says Dr. Ibrahim.

Sperm coming out of testes in men with SCI tends to have good motility. It’s when sperm mixes with the fluid that forms semen once it leaves the testes that the sperm is damaged.

The next step in their research was to test what would happen to sperm motility if the cytotoxic cytokines in the seminal fluid could be neutralized. They performed a number of experiments using immunotherapies, such as monoclonal antibodies and receptor interference agents, to inhibit the cytokines. What they found was that when all three cytotoxic cytokines (IL-6, IL-1 beta, and TNF alpha) were neutralized, sperm motility improved.

“So, we said, ‘Okay, if that’s the case, then we have to try to find something that would manipulate the cytokines up the stream, before the sperm is mixed with the seminal fluid,’” says Ibrahim. “So, we worked with the neuroscientists in our institution and in the Miami Project to try to find a molecule that is causing these cytokines to be active. And we found a complex that is called inflammasome.”

Inflammasomes are large multi-protein complexes that assemble in the body in response to infection or stress. When activated, inflammasomes produce a chemical reaction that causes cytokines, including IL-1 beta and IL-18, to become active. This in turn leads



Dr. Emad Ibrahim explains results to his patient and his wife.

to the release of the cytotoxic cytokines that damage sperm motility.

What triggers the activation of the inflammasome complex in men with SCI? According to Ibrahim, “It’s due to the inflammatory process that happens with the [spinal cord] injury. It’s a generalized inflammatory reaction in the body, and it’s concentrating in the glands that produce seminal fluid. So, there’s a lot of inflammation going around that causes all these cytokines and all these toxic elements to be in present. Nobody knows for sure, but that’s the most reasonable explanation to what we see.”

The next challenge that the researchers at the Miami Project faced was finding a drug, ideally one that’s already on the market, that would block the activation of the inflammasome complex and in turn minimize the effect of the cytokines that are damaging sperm motility downstream. That’s when they found Probenecid.

Probenecid, originally developed to treat gout, has been on the market for years. It’s taken by mouth, it’s cheap, and it has very few side effects. It also happens to block the activation of the inflammasome complex.

“So, we did a pilot study on 18 men with SCI,” explains Ibrahim. “We gave them Probenecid in a standard dose that is used for gout for four weeks. We took a semen sample from each patient be-

fore they started the Probenecid, when they completed the treatment, and then four weeks after as a follow-up. And we found that the motility improved in all the patients that we studied.”

The pilot study, published in the *Journal of Spinal Cord Medicine*, served as the impetus for the four-year grant funded by the US Department of Defense. The grant will fund a double-blinded, placebo-controlled randomized controlled trial comparing the effects of Probenecid in different doses on sperm quality among men with SCI—a first of its kind in male infertility research.

“Our pilot study was the first ever to report oral medication that will improve [sperm] motility. And this is the first large double-blinded, placebo-controlled study for an oral medication.”

—Dr. Emad Ibrahim

Participants in the trial will be randomly placed into one of three groups, and neither the participants nor the researchers will know who has been selected to each group. In one group, participants will take a full dose of Probenecid. In another group, participants will take a half dose. And in the third group, participants will take a placebo, or sugar pill. Participants in each group will take the pills for three months.

“The reason we’re doing the three arms (treatment groups) is first to see if participants taking the full dose or half dose benefit when compared to the placebo, and second to see if we can find the same effect of the medication at a half dose instead of a full dose. If we can get the same effect from a half dose, then we can minimize the side effects,” says Ibrahim.

Like in the pilot study, the researchers will take semen samples from participants before and after the treatment period. They’ll take another sample six months after the treatment ends. At each timepoint, they’ll examine indicators of sperm quality, including concentration and motility. They’ll also do a unique test to see if the DNA in the sperm is intact.

The Probenecid trial will get underway early in 2024, and Ibrahim expects results to be available in about three years’ time. The researchers are aiming to recruit about 90 participants for the trial, 30 per treatment arm. The trial is based in Miami, but the grant includes a budget to cover travel and accommodations for 10 participants from outside of the Miami area. “We are open for anyone [who meets the inclusion criteria] that is willing to participate and willing to make the travel [to Miami],” says Ibrahim.

To learn more about the study or find out if you’re eligible, go to clinicaltrials.gov and search “Spinal Cord Injury” (condition/disease), “Infertility” (other terms), and Probenecid (intervention/treatment). You can also point your browser to themiamiproject.org for more information about the Male Fertility Research Program at The Miami Project to Cure Paralysis.

In the meantime, we’ll keep tabs on how the study progresses and report back when the results are in. While we wait, SCI BC and Vancouver Coastal Health’s Sexual Health Rehabilitation Service have an online resource where you can learn more about fertility, sexuality, relationships, parenting, and much more. Check it out at scisexualhealth.ca. ■



TEACHER OF THE YEAR

A tip of the cap to our friend and research partner at the University of Northern British Columbia (UNBC), Dr. Mark Groulx, who was recently honoured with UNBC's 2023 Excellence in Teaching Award, an award he was nominated for by his students. According to UNBC, Groulx has designed experiential and student-led inquiry-based courses that go beyond having a meaningful impact on students, to influencing planning and design projects, as well as the community as a whole. An Associate Professor in UNBC's School of Planning and Sustainability, Groulx has partnered with SCI BC's Access BC team on a number of accessibility projects over the years. Currently, Groulx is working with our Access BC team and UNBC's BERG Lab to co-create a standards-based accessibility assessment and reporting app that has a unique focus on the accessibility of outdoor recreation and tourism spaces. Knowing Groulx as an amazing researcher and collaborator, it comes as no surprise to us that he is also a superstar teacher, and we are pleased his commitment to innovation, sharing knowledge, and fostering relationships is being recognized by the UNBC community. Learn more about Access BC and Dr. Groulx's work at sci-bc.ca/access-bc.

Community Highlights

NON-PROFIT OF THE YEAR

A most outstanding congratulations to our excellent BC SCI Network partner, the Neil Squire Society, for being named the City of Burnaby and the Burnaby Board of Trade's Not-For-Profit Organization of the Year. The award, which they received at the 24th annual Burnaby Business Excellence Awards in November, goes to, "a Not-For-Profit organization that has made an outstanding contribution to the Burnaby community and its citizens, and in doing so has made Burnaby a better place to live, work and play." As a member of the BC Spinal Cord Injury Network, The Neil Squire Society helps make BC the best place for people with physical disabilities to live, work, and participate in the community. We applaud our friends at the Neil Squire Society for the amazing work they do not only in Burnaby, but throughout BC.



SILVER MEDALLIST AND FLAG BEARER

We're waving the flag for our very own Rob Shaw, who was selected as one of Canada's flag bearers for the opening ceremonies of the 2023 Parapan Am Games in Santiago, Chile. In addition to his role with SCI BC, Rob is a decorated Canadian Wheelchair Tennis athlete and went into this year's Games as the defending gold medal champion and the first Canadian tennis player to win a multi-sport medal in singles competition—with this year's silver medal win, he's now accomplished that feat twice! Upon finding out the news that he would be a leading Team Canada into the opening ceremonies, Shaw told CBC News, "Still in a bit of shock after finding out I would be one of Canada's flag bearers. It's one of the greatest honours an athlete can be given and something you never think will happen to you. I can't wait to mingle with all the incredible athletes, support them in their disciplines, and lead them into that arena as one unified team." And that he did. Canada finished the 2023 Parapan Am Games with a total of 52 medals.



Fire and Rain

When it comes to the most catastrophic ramifications of climate change, BC is emerging as Canada's most vulnerable province. With the situation predicted to only worsen in coming years, more and more people will be forced to evacuate. Are you prepared?

As evidenced by this year's wildfires, no area of Canada is immune from the ravages of drought. Areas of all 13 provinces and territories were charred in 2023, with Quebec, Ontario, Nova Scotia and the NWT experiencing major fires beginning as early as March. But late into the fall, as is almost always the case, wildfires in BC became the country's most deadliest and dangerous. Of the record 185,000 square kilometres of Canada that burned this year, some 25,000 square kilometres were in BC.

Of course, the potential for disaster doesn't end with autumn, nor is it limited to wildfire. BC is increasingly enduring catastrophic atmospheric rivers and flooding. The threat became abundantly clear in November of 2021, when a series of atmospheric rivers resulted in destroyed homes and sections of important infrastructure including the Coquihalla Highway—something that no one thought possible up until then.

The reason for these weather extremes? According to the U.S. National Oceanic and Atmospheric Administration (NOAA), the underlying mechanism for our province's vulnerability is a rapidly-warming Pacific Ocean—particularly the waters of the western Pacific.

On its website, NOAA explains that the Pacific Ocean is like a swimming pool with its heater turned on—the

areas of water closest to the heater increase faster. "If one thinks of the Pacific as a very large pool, the western Pacific's temperatures have risen over the past few decades as compared to the eastern Pacific, creating a strong temperature gradient, or pressure differences that drive wind, across the entire ocean in winter," the agency says. "In a process known as convection, the gradient causes more warm air, heated by the ocean surface, to rise over the western Pacific, and decreases convection over the central and eastern Pacific. As prevailing winds move the hot air east, the northern shifts of the jet stream trap the air and move it toward land, where it sinks, resulting in heat waves."

Meanwhile, in the cooler months, this overall warming trend creates opportunities for more powerful and drenching storms of the type that washed out portions of the Coquihalla in 2021. To a large extent, it's all about thermodynamics and how much moisture can remain aloft in the atmosphere. In the 19th century, two researchers, Germany's Rudolf Clausius and France's Benoît Paul Émile Clapeyron, proved that, for every one degree Celsius of temperature rise, the amount of water that can be held by the atmosphere increases by seven percent.

In Canada, from 1948 to 2022, it's estimated that the average temperature

has increased 1.9°C. So these days, any system moving into BC off the Pacific coast could be carrying almost 15 percent more rain than it did 75 years ago, and the situation will continue to worsen as global warming continues.

In practical terms, all of this means one thing: as a citizen of BC, your chances of having to evacuate your home are escalating.

Data showing just how many people are evacuated each year in BC, and for how long, is not readily available. Earlier this year, frustrated by this fact, the respected independent news website The Tyee worked with Vancouver data scientist Jens von Bergmann to get a handle on this by examining data and census information from the past six years.

"People in BC are being evacuated, on average, for approximately 22 days, according to figures over the last six years," wrote The Tyee reporter Francesca Fionda in April 2023 in an analysis of the findings. "Since 2017, there have been over 1,400 evacuation orders across the province and about 97 percent of those lasted over three days. Over that time, the BC government told us they spent over \$49 million to support approximately 113,453 evacuees through the Emergency Support Service program. The last fiscal year cost almost half of that funding at \$23 million."

Note that these figures don't include the estimated 35,000 British Columbians who were under evacuation order at some point in 2023 due to wildfires.

Fire and flooding are indiscriminate. Nobody gets a free pass from evacuation—and that certainly includes SCI BC peers or anyone who uses a wheelchair. We reached out to a trio of our peers who have been recently forced to evacuate, and they were willing to share their stories with the goals of giving readers some insight into their experiences, and providing them with information as they ponder the increasing probability of needing to evacuate as the climate situation worsens.

Rob Pullen



You might assume that anyone with military experience might be better prepared for an evacuation than most, and that's certainly the case with Kelowna's Rob Pullen.

During the 80s and 90s, Pullen spent eight years in the Canadian Army, serving a tour in Bosnia with our country's peacekeeping forces deployed in the Balkans. An SCI resulting in paraplegia ended his combat career, but Pullen has never stopped leaning on his training throughout his post-military life.

Today, Pullen is retired, making his home with his husband Warren and their two dogs in Kelowna's Wilden community. Life is usually peaceful for Pullen, who enjoys wheelchair curling, weight training, camping, sit-skiing, and just being outside. But on August 17th, things got a little hairy.

"We came home around 5 PM and noticed the large fire in Westbank," says Pullen. "By 6 PM, I felt that the fire would jump the lake, so I started packing essentials into our two SUVs."

Those essentials included medications, medical equipment, tools, emergency food supplies, legal documents, computers, medications, and Pullen's immediate equipment requirements.

Pullen's intuition paid off later that night. "We had finished eating dinner and I was planning to shower before bed in the event we were evacuated," he says. "That's when our neighbour banged on our door, telling us his friend's house up the street just caught fire. We had zero time—as we were

leaving the embers were flying down our street. There was never an order to evacuate, but we headed out and settled down close to city centre to figure out what we were going to do."

As a veteran, Pullen got word that the Legion was available for anyone needing short term refuge, and that's where they stayed that night. The next day, the couple decided to buy a new teardrop travel trailer for accommodation—it was a purchase they'd been planning for a while, as they wanted to join other SCI BC peers for some camping events.

"My concern as a person with SCI was comfort and security," explains Pullen. "I needed space to stretch out, and a location to shower and use the bathroom."

The Pullens initially set up camp at Prospera Centre's parking lot, where they had access to food, water, and accessible toilets. A day later, they found a better alternative.

"We eventually moved to Orchard Park Mall as I had a gym membership there and knew other businesses that would open up for showers and toilets," says Pullen. "We were also given the use of electricity by the mall manager. If we needed supplies, we went into the mall and spent our money there."

A week later, they were able to move back home. "Our house survived, but the forest around us was hit pretty bad," he says. "Our homes were built after the 2003 Kelowna fires, so they were built to withstand direct fires. If our home didn't survive, we had friends and family who offered places to stay."

Looking back, Pullen believes he was well-prepared despite the suddenness of the evacuation.

"As a military veteran, I have been trained to be ready 24/7 and taught that everything but life can be replaced," he says. "As for my head space at the time, I have military combat experience, and in short this was nothing worse. I was more concerned for other people with disabilities."

He concedes that, in hindsight, he and his husband could have done a few things better. "We should have bought the trailer prior to needing it for the evacuation. I also found that I was not completely prepared for one week, although my food and shelter was good. Medications and like supplies were where I failed by not having enough. I suggest a month supply for backup would be a good start."

He has some other great advice for SCI BC peers who might need to evacuate in the future due to emergency.

"Ensure that you have all absolute-ly necessary equipment and supplies that would be next to impossible to get in 24 hours," he says. "Ensure that you're prepared and have gone over your plans both verbally, and actually do a test run each year. I strongly suggest doing one or more practice evacuations each year with helpers and without—this way, if you find yourself alone, it would be no different. My advice would be plan well ahead as if you were going camping, keep those supplies needed for camping close by for your evacuation. I would also make a local list of wheelers who have space or may need space to stay during event. And everyone should carry no less than \$200 in small denomination bills."

More than anything, Pullen stresses that people need to be prepared to rely on themselves, both in preparation for an evacuation, and during one.

"Everyone needs to understand that, no matter their level of ability, they all need to have plans, and only focus on the minutes or hours in front of them. Have a few options for evacuation plans and multiple people they can utilize for their safety. Only depend on yourselves and a few people who can help you if needed. Many I found leaned on their living facility for guidance, but this is where everything usually fails. Do not lean on any government agency for assistance, as I found many barriers with accessing assistance."

Ryan Yeadon



For the two other peers we spoke to for this story, evacuation was forced by fire. But for 47-year-old paraplegic Ryan Yeadon, evacuation was the result of catastrophic flooding.

Yeadon was born and grew up in Merritt, BC. He moved to Alberta in the early 2000s. After recovering from a mountain biking accident in 2004, he enjoyed a successful career working with the City of Calgary, before moving on to the airline industry in 2010. Unfortunately, in 2020, Yeadon lost his job and his home due to the pandemic, and a seven-year relationship was also a casualty.

He decided to move back to Merritt, seeking a fresh start and a reconnection with old friends and family.

Everything changed in November 2021, when Merritt and several other BC communities were struck with a catastrophic triple atmospheric river event. In the early morning of November 15, the Coldwater River swelled to a level two and a half times greater than any engineering studies had predicted, easily breaching its muddy banks and overcoming dikes that had been prepared. Within hours, much of the town was under water. All 7,000 residents of the town were forced to evacuate, including Yeadon, whose house was positioned just a hundred metres from the river that carved six foot deep channels through yards, shifting houses off foundations.

"The police knocked on the door around 4:30 AM that morning," recalls Yeadon.

"We spent some time gathering any important documents, securing my pet, and locating medical supplies I would need for life during and after the evacuation. Within 20 minutes, it was already too late to safely leave the home in my chair, and it then basically just turned into getting as many possessions up off the floor and out of the crawlspace while we waited for the fire department to bring in their boat to get my senior mother and myself out of the house."

They were rescued by the fire department at 6 AM, just as the entire first floor of the house became submerged, and taken by boat to a dry road where they were picked up by a friend.

The Yeadons, along with other members of their community, were given surprisingly little time to prepare for the flood—in fact, British Columbia's River Forecast Centre (RFC) only issued its first warning at 5:30 PM on November 14. Despite that, Yeadon says he was prepared.

"I can't really say there is anything I would have done differently," he says. "Working for the airlines, I did a lot of travelling, so I pretty much just prepared like I was taking a normal trip away from home. I left with my wheelchair, an extra pair of pants and underwear, my commode chair, baby wipes, catheters and gel, my cat, and some food and a litter box for him. The biggest issue that I dealt with was simple basic needs like using a toilet. My number one concern that morning was making sure my commode chair was brought with me—there was zero chance I was gonna put myself in a position where I had to rely on Red Cross (or whoever) to try and find acceptable medical equipment for me to keep my dignity."

Strangely, Yeadon doesn't remember being overly stressed that morning—something he credits his cat for. "For me," he says, "having my pet with me helped me block out a lot of stuff—it really allowed me to just focus on what was right in front of me."

Yeadon had no choice but to live in hotels during the following months. Over the next two years, the home was re-

paired and renovated, but by that time, Yeadon was long gone—before the flood, he'd already been having doubts about staying in Merritt.

"The night before the flood came through town I realized that Merritt was not a healthy place for me," he says. "I went to bed trying to figure out what was gonna be my next step. Waking up to water completely surrounding the house—and eventually my bed—made it pretty simple to accept that that my life in Merritt was done."

And so, after five and a half months of hotel life, Yeadon came to the heartbreaking realization that, for his own mental health, he could no longer stay there and returned to Alberta.

"My advice to anyone with an SCI is to always be ready to go," says Yeadon, who now lives in Grande Prairie. "Have your supplies topped up, know where they are, and keep a mental note of what you use daily and what you can't get through a single day without."

William McCreight



Unlike the other two paraplegic peers who are sharing their evacuation stories, William McCreight's perspective comes from the position of being an incomplete quadriplegic.

Originally from Merritt, McCreight lived in Kamloops for about ten years before moving to Kelowna with his girlfriend, Emily, this past August. The couple's newly-purchased West Kelowna home wasn't threatened by this year's wildfires, but if it had been, McCreight would have relied on the hard-won experi-

ence he gained when he had to evacuate his Kamloops home two years earlier.

Ironically, McCreight had been packing his van to go camping for the July 2021 long weekend when the need to evacuate became paramount.

"I was at my house and I got a phone call from a friend," says McCreight. "He said, 'Hey, you better look out your window. There's a big fire that's burning between Valleyview and Juniper Ridge.' I was like, 'Okay, well I better roll outside and go have a look to see how this is.' I went about 300 yards to the corner of the street. And that's when I saw this massive fire that was working its way closer towards where I live."

Emily was visiting McCreight at the time. The couple raced back to the house and started to add some belongings to what they'd already packed for their camping trip. McCreight says his entire focus was on making sure he had his medical supplies and mobility equipment. He estimates they had about 15 to 20 minutes to evacuate. But despite the urgency, he remembers staying calm.

"I wasn't that worried, because I've lived and been around some forest fires when I was able-bodied," he says. "My girlfriend, Emily, was definitely more stressed. She was born and raised in the GTA, so she had never experienced anything like this before—it was very scary for her to go through."

The single road from McCreight's community was bottle-necked with traffic, which caused some confusion and concern. But eventually, the pair made it to a safe location on the side of the Trans Canada Highway. They watched the fire for a few hours, all the while receiving invitations for shelter from friends and family. Ultimately, they made their way to a fellow peer's accessible home, located in a safe part of Kamloops.

A few hours later, the grass fire had been largely contained, and they got notice that the house was safe and they could return home. The next day, they packed up the rest of their stuff, and left to go camping.

Looking back, McCreight says that, for the most part, he's happy with how the

evacuation went. But he concedes that it might have gone worse had he not been in the process of packing for a camping trip. And he recognizes that a power failure would have complicated things—for example, if he'd been by himself, he wouldn't have been able to manually open his garage door to get his van out. And he also says he was fortunate Emily was with him at the time.

"It's sometimes more difficult being in a chair. Just the fact that I can't quickly grab a whole bunch of items in my arms and sprint down the stairs and throw it in the vehicle and go. I can't just jump in the vehicle in five seconds and be out the driveway. It takes me time to transfer. There's all this stuff to keep in mind. For this example, it was fine, because I had Emily there to help me grab things. If it was just me, it would have been difficult to grab those items in that time. I would have had to decide how much time I needed to safely get as much as I could get, and I would have just had to hit the road."

There are other things he says he could have done better. "It wasn't until I left my house that I realized, wow, I left a lot of things behind that I wanted to go back for—I didn't even really put two and two together to grab stuff like my passport and personal belongings," he says. "When I got home and I saw all these things in my house, I wish that I had made a list when I was of sound mind." He recommends peers create a list like this.

"Put everything on there that's very important to you," he says. "Then at least you have your list at all times, somewhere safe, ready to go. And when you know it's getting bad or fires are kind of starting to get close, where you may have to be evacuated, that's when

I would pack up and have things ready at the door. So if you get a knock on the door, get your list, get your go-bag, and you're on your way."

Another thing he'll do in the future is grab all of his medications, and not just a week's supply.

"If you had to leave or go to a different town, it can just be a pain to try to get prescriptions filled and have to deal with that," he explains. He also would try to bring more items of sentimental value, although he concedes that they would take a back seat to essential items if the situation was really urgent.

"Actually, in summer, peak season, possibly pack a bag, so it's faster to grab on your way out the door," he recommends. "I think my go bag would basically just be three months of medical supplies, or something like that. Just bring three months of all of my medical supplies and have it convenient and ready to go. And then have that list of stuff to grab. And have that in a convenient spot. So when you're in a panic mode and you're told you've got to leave now, you have that list and you can quickly grab a couple of things."

He offers this final piece of advice to peers. "If it's fire season or there's a fire slowly getting close to where you live, always make sure you have a full tank of gas. The last thing you want to do is be in a big panic and rush to leave town and need gas—especially if you can't get out and you're gonna need someone to help you (pump gas) in a big panic and rush. That could be another scary challenge if the fire is getting closer to wherever you are and you're scared and need to get away; it's just gonna add extra stress and anxiety that you don't need put on you." ■

There are many excellent resources available online to help you prepare for an emergency evacuation. Excellent starting points include:

- **Canadian Red Cross:** bit.ly/canadian-red-cross-emergency
- **Government of Canada Emergency Preparedness Guide:** bit.ly/gc-getprepared
- **Government of British Columbia Public Emergency Preparation and Recovery:** www2.gov.bc.ca/preparedbc

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.

Priorities For Recovery Following SCI

Overview: Researchers in Dr. Andrei Krassioukov's lab are inviting individuals living with SCI, healthcare professionals/clinicians, and researchers/scientists to complete a survey. The goal is to assess the SCI community's priorities for recovery as well as to assess the understanding of recently developed technologies, in particular, spinal cord stimulation as a rehabilitation strategy. This survey will be released internationally to 18 countries to allow for cross-country comparisons and will also include comparisons between the opinions of individuals with lived experience, researchers, and clinicians.

What to expect: This study requires completion of one online survey. It will take approximately 15-20 minutes to complete and will be anonymous.

Who can participate: To participate, you must be aged 18 years or older, able to provide consent and answer questionnaires, and part of one of the following demographics: a person with a spinal cord injury, a scientist/researcher who is currently doing or has done research involving spinal cord injuries, and/or a clinician/health care professional who is currently/previously working in treating/addressing spinal cord injuries.

Why participate: This study will improve education and awareness about what people with SCI need and which health complications are most important for quality of life. The results of the study will be used to guide and improve treatment options/rehabilitation strategies and future research to better align with peoples' priorities for recovery following SCI.

Location: Online survey (links are provided on the study's webpage: icord.org/studies/2023/09/priorities)

For more information or to sign up: Please contact the study coordinator, Jennifer Phan, by email (anhduong.phan@ubc.ca) or call 604-675-8816.

Sex Differences In Cardiac Function In Individuals With High-Level SCI

Overview: Drs. Chris West and Alexandra Williams are investigating whether there are differences between the male and female heart in individuals with SCI between the C4 and T6 levels, in comparison to any sex-related differences that exist in uninjured individuals, and if the differences exist at rest and when your posture changes.

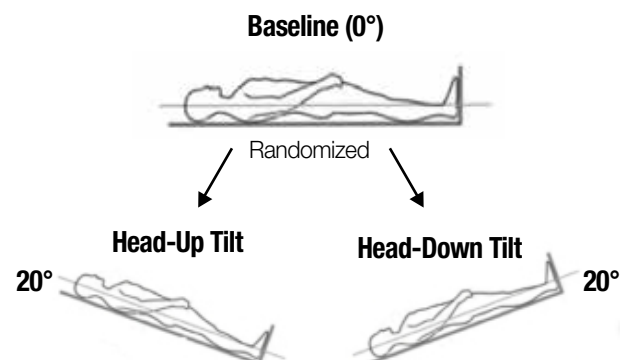
What to expect: A single visit to the laboratory at ICORD lasting 1.5-2 hours is required. The researchers will make sure they can get clear images of your heart with ultrasound, and if so, will collect ultrasound images of your heart and monitor your blood pressure while you are lying flat, and then during different postures on a tilt table.

Who can participate: You may be eligible to participate in this study if you are living with SCI or are uninjured, and are between the ages of 18-45. Individuals with motor-complete SCI (more than 1 year) will be included if they have a lesion between the C4 and T6 levels. See the study webpage for more information about eligibility.

Why participate: At the moment we don't know whether there are differences in the male and female hearts after SCI, so this study will be the first to look at whether those sex-related differences exist and how those related to blood pressure control. Compensation for participation is provided.

Location: Blusson Spinal Cord Centre (818 West 10th Avenue, Vancouver)

For more information or to sign up: Please contact the study coordinator, Alexandra Williams, by email (alex.williams@ubc.ca).



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

EXERCISE CAN BE A PAIN BUT WHAT IF IT COULD REDUCE YOUR CHRONIC PAIN?

That's the question the SCI Action Canada lab is trying to answer with their Exercise Guidelines Promotion and Implementation in Chronic Spinal Cord Injury (EPIC-SCI): A Randomized Controlled Trial study.

60% 
of people with SCI live in chronic pain

We think the EPIC-SCI study is a great opportunity because you get a...

- ★ personalized exercise program
- ★ trainer
- ★ health coach

Your weekly exercise can be completed from the comfort of your home or in a local fitness facility—your choice! Plus, even peers who are ambulatory, older adults, or those who have a non-traumatic SCI can participate.

Physical Activity
Guidelines for
Adults with SCI:



The EPIC-SCI study is currently recruiting participants from the Lower Mainland and the Okanagan (there may be opportunities if you are from outside of these regions, too). For more information, go to icord.org/studies/2021/11/epic-sci or email sharisse.lin@ubc.ca.



Addressing the Housing Needs of People with Spinal Cord Injury/Dysfunction

We are looking for people with spinal cord injury/dysfunction (SCI-D), family members & professionals involved in accessible housing to take part in a study exploring housing needs.

The study involves a 60 minute interview or focus group by phone or Zoom.

TO LEARN MORE, PLEASE CONTACT:

Kirstin Yuzwa, Research Associate
+1 (416) 226-6780 x 57605 or HousingStudy@sunnybrook.ca

Funding provided by the Craig H. Nielsen Foundation

PRINCIPAL INVESTIGATOR: Dr. Sander L. Hitzig, Senior Scientist

Phone: +1-416-226-6780 x 57177 Email: sander.hitzig@sunnybrook.ca

This study has received ethics approval from the Sunnybrook Health Sciences Centre.



 **Sunnybrook**
ST. JOHN'S REHAB

PeerSAY: Wheeling in Wet Weather

Don't let the rain put a damper on your plans! The hassle of wet clothes, squeaky wheels and slippery sidewalks is all too common for wheelchair users. Luckily, rain or shine, we've got you covered. We asked our SCI BC peer team how they modify, look fly, and stay dry!

BERT: The wind and rain combination leaves me soaking wet for the rest of the day until I can get home. I try to avoid cushions and backrests that are absorbent (made of foam or honeycomb) when it's wet to reduce my risk of pressure injuries and other skin issues. My wheelchair wheel rims are slippery when wet, so going down hills can be tricky. I slow down as much as I can or try to find a lower incline path. Also, wet wheels squeak loud on certain surfaces, so everyone turns and looks at you. Not a real big deal but I'm still looking for a solution!

PETER: The rain accumulates and I end up with a lap full of water! Water also causes deterioration of castor stem bearings and I usually need to replace them once or twice per wet season. Lap covers and extra-long raincoats are essential. In a pinch, a dollar store poncho or shower curtain works well to cover the lap and legs from heavy rain. But these drag on the wheels when pushing for manual wheelchair users, so it's only a temporary option.

TERI: My big pet peeve is coming home from the rain and tracking all the dirt, mud, and water all over my floors. Tire marks everywhere! When I come inside, I use an absorbent hand towel to wipe my wheels. I keep the towel by my front door or under my seat if I'm out and about. Tire covers are also handy and reduce that wet tire squelching noise.

BRANDY: The wet pavement causes more reflection at night, which makes wheelchair users less visible to drivers. I make myself more noticeable by wearing reflective materials or lights on my clothing and chair. And I find that the cold and damp increase my pain and spasticity. I always have extra layers to keep warm, but it is harder to change out of wet clothing, especially in public.

RYAN: This time of year is terrible for wheeling. Leaves and snow piling up on the sidewalk do not help. I find I can deal with most rainy situations if my gloves have grip (like nubuck palms or silicone coating) and cover my fingers to keep them warm. Gorilla Grip gloves are my personal favourite. I order them in bulk on Amazon, so I always have a good pair to use when mine wear out!

HOW CAN COMMUNITIES HELP? Jocelyn recommends:

- Look to ensure puddles do not accumulate on ramps or crosswalks, and that nothing obstructs accessible parking spaces.
- Accessible cabs should be available for wheelchair users—don't call for one if you can take an alternative cab type.
- Keep accessible spaces clear on transit.
- Make room for wheelchair and scooter users in bus shelters, especially if you already have an umbrella covering you. And be careful that your umbrella doesn't drip on someone's head!

RAINGEAR RECOMMENDATIONS:

1. MEC's Greycoast Rain Jackets
2. Gorilla Grip's Slip Resistant All Purpose Work Gloves
3. IZ Adaptive Reversible's Water-Resistant Lap Blanket
4. RehaDesign's Wheelchair Slippers
5. Kinetic Balance's Raindek
6. Chloe Angus Design's Leg Jackets (coming soon at chloeangus.com)



ask the SPIN DOCTOR

Back in 2014, we had Dr. Jeremy Road respond to the following question from John in Surrey: “It seems like I haven’t had a good night’s sleep since my injury. My wife says my snoring is intolerable, and that I sometimes seem to stop breathing while asleep. Is it possible I have sleep apnea? What should I do about it?”

To update this 2014 Spin Doctor article, we turned to Dr. Aditi Shah, MD FRCPC, a Respiriologist specializing in sleep and neuromuscular disease at Vancouver General Hospital and the new Medical Advisor for the Provincial Respiratory Outreach Program (PROP).



Symptoms of daytime sleepiness, poor sleep quality, inattention, periods of not breathing, and waking up in the night suggest sleep apnea. These symptoms could have other causes, but their presence in someone with SCI is enough to warrant further assessment, especially since as many as 80 percent of people with SCI experience sleep apnea. It is particularly common among people with a cervical SCI and those who have co-existing conditions such as brain injury or use of medications that impact breathing control.

Your first step is to speak to your primary care doctor or nurse practitioner, who will in turn refer you to a specialist qualified to diagnose and treat respiratory sleep disorders, including sleep apnea. Your referral will include an overnight stay in a hospital or sleep clinic, where you’ll be assessed for sleep apnea using polysomnography, a test that records specific physical activities while you sleep. Your “sleepover” will be conducted in a natural, comfortable setting.

If you’re diagnosed with sleep apnea, the goal of treatment is to restore natural breathing throughout the night, resulting in a return of daytime energy and alertness. Treatment depends on the type of sleep apnea you are diagnosed with. If you’re diagnosed with obstructive sleep apnea (OSA) and weight is a factor, losing some weight can sometimes be enough to reduce apnea. As part of your body’s weight reduction, elimination of excess adipose tissue around the upper airway makes it that much easier to breathe while you’re asleep. Avoidance of medications and drugs, including alcohol, that relax the muscles in the upper airway can also be a simple solution. Failing that, an oral appliance custom-made by a specialist dentist can often reduce or eliminate mild to moderate OSA. These devices move the lower jaw forward during sleep, which prevents the tongue from falling into the airway.

For more severe cases of OSA the treatment is CPAP, or continuous positive airway pressure. With CPAP, a soft mask is worn during sleep, with positive air pressure delivered by a small, quiet machine. You may also be diagnosed with central sleep apnea (CSA), or a combination of CSA and OSA. People with quadriplegia are

at an increased risk for this type of apnea. There are a variety of bilevel positive airway pressure (or BiPAP) machines for treating this combination of OSA and CSA. These machines, which are more sophisticated (and more expensive) than CPAP, are designed to minimize hypoventilation, which can occur when breathing during sleep is not deep or regular enough. Hypoventilation is associated with an elevation of carbon dioxide levels in the blood, which can produce symptoms of headache and sleepiness in the morning. Like CPAP, BiPAP involves a mask and a machine to maintain air pressure. The “bilevel” component refers to the fact that there are two alternating pressures—higher pressure when you breathe in, and slightly lower pressure that allows you to breathe out.

In BC, sleep apnea assessment is covered by BC MSP. For people with respiratory muscle weakness (common for those with cervical SCI) who use BiPAP, the Provincial Respiratory Outreach Program (PROP) provides supplies and support free of charge. Unfortunately, CPAP is not covered by MSP, except for those with PWD medical coverage.

Because sleep apnea can be a serious condition, it is important to get assessed. The good news is, getting a diagnosis and starting treatment can improve cognitive symptoms, sleep/fatigue, and overall quality of life.

Aging with SCI Peer Support Specialist Duncan Campbell adds:

For me, sleep apnea was a sneak attack with symptoms I couldn’t detect, like snoring and talking in my sleep. I dismissed other symptoms like poor sleep and my daily nap as normal signs of aging. Even after I was tested for sleep apnea it didn’t seem that important. Meanwhile, it decreased oxygen to my brain and my cognitive abilities, making it harder to recognize the symptoms and pay attention. It was only when sleep apnea and pneumonia combined put me in hospital that I understood how important it needed to be. If you have any of these symptoms, it’s worth getting tested for sleep apnea. Best of all, it’s treatable and can keep the problem from becoming much worse.

Charges Pending

Electric vehicle charging stations are popping up around the province, but people with disabilities are being left out.

Have you thought about purchasing an electric vehicle (EV)? As of September 2023, there are more than 120,000 EVs and 153 public EV charging units at 84 sites in BC, according to BC Hydro. Over the next 10 years, the number of EVs in BC is expected to increase by up to eight times, with the installation of 3,000 additional units planned. In the last issue of *The Spin*, we shared tips from SCI peers on self-serve gas stations (PeerSAY: Self-Serve Gas Stations, Fall 2023). With the advent of EVs, we can't help but wonder about the accessibility of EVs and their corresponding charging stations.

SCI peer Jacques Courteau was one of the first advocates to raise concerns. "BC Hydro was making a presentation to [the Vancouver Electric Vehicle Association] on new charging stations that they had planned. On all of the slides that they showed, I would not have been able to charge at any of those chargers," Courteau told Electric Autonomy Canada.

When it comes to charging stations, there's two main things the user must be able to do: get to the station itself and plug in the charger. What Courteau and other EV users with disabilities have

found is that charging stations are built on curbs and with limited width to turn around in a wheelchair. Protective posts in front and elevated equipment and controls make it difficult or impossible to operate the charging station. And, people with (and without) disabilities who manage to get to the stations report that the charging cables are too heavy.

Unlike gas stations, there are no attendants at charging stations to offer assistance. Likewise, most charging stations are not covered, which for people with disabilities who may take more time to get to and operate the charger, means more time exposed to Canada's often unfriendly weather—no one wants to get drenched by rain or snow while they pump gas or charge their EV!

We turned to Nancy Harris, SCI BC's Access BC Lead, for input. "When it comes to something relatively new, such as electric vehicles, we have the opportunity to design for accessibility from the start. When I advise on accessible spaces, cost is one of the first concerns brought up, but it's much less costly to build something accessible from the start than fix it later," explains Harris. In fact, she recommends that all EV charging stations be accessible. This way, "anyone can use the charging stations," she says.

Indeed, this would solve another preventable conflict: the construction of EV parking spaces in spaces previously designated as accessible parking. Since charging stations need to be located near a power source, EV parking spaces are frequently built at the front of parking lots near buildings. What's more, despite replacing accessible parking spaces, the EV spaces are typically no longer the size of accessible parking spaces. As of 2018,



local governments in BC are responsible for parking standards, meaning accessible and EV parking varies widely across BC as it is dependent upon each local government's understanding, commitment, and investment in accessibility.

So, what happened with Jacques Courteau and BC Hydro? BC Hydro invited him to travel with their team to several charging stations. "Their reaction was amazing. They were so eager to do something about it," Courteau told BC Hydro. He worked with BC Hydro to revise their standards for new stations, including wider parking spaces, paved ground, posts that don't interfere with wheelchair access, lighter weight charging cables, and operating controls at a lower, more accessible height.

When the voices of people with disabilities are valued, listened to, and implemented, amazing things happen. Car manufacturers are working on innovations such as robots for hands-free charging and wireless charging pads for vehicles. There's even a new road being tested in Detroit that charges vehicles as they drive on it. SCI peers have floated the idea of EV charging stations being able to charge mobility devices, too. Imagine being able to charge your wheelchair battery while waiting for your electric vehicle to charge or while on a road trip. How great would that be?

To achieve Canada's goal of net-zero emissions by 2050, federal regulations require that at least 60 percent of new vehicles sold in Canada will be zero emission by 2030. Governments and manufacturers need to build trust and invest in accessibility now if they want buy in from the disability community, so we can all be included in the transition to EVs. ■



Jacques Courteau



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