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COVER: SCI BC peer, Riley Martin, poses in his race car.











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A Change in the Weather

hen the early 20th century French writer, Marcel Proust wrote, "A change in the weather is sufficient to recreate the world and ourselves" he was suggesting that changes in our environment, be they big or small, can influence the way we see both the world and ourselves. In other words, as circumstances change, so does our understanding of our world and ourselves. I think we can all relate to this in many ways.

I don't imagine Proust was thinking about the impact of spinal cord injury when he wrote this. I also don't imagine he contemplated the profound way our climate has been changing and just how much the resulting changes have been altering our world and our lives within it.

SCI BC has not been immune to the impact of climatic events over the past few years, which have forced us to adjust and adapt our services. Extreme heat, cold, flooding, and fires have prevented people from attending events, caused many event cancelations, and have significantly affected our Access BC fieldwork. To ensure the safety of our event participants and staff members, we recently purchased new equipment to mitigate the effect of heat at events and implemented a new policy to provide SCI BC staff guidance on how to respond to extreme weather alerts and warnings, and emergency orders.

But of much greater importance, these extreme weather events have seriously, and often disproportionately, impacted people with disabilities throughout the province. Evacuations, long periods of isolation, power outages, dangerous levels of heat in housing that lacks sufficient cooling, and other consequences of climatic events have threatened the safety, wellbeing, and independence of people with disabilities, who face unique barriers when it comes to responding to emergencies and the recovery that occurs after them.

I wrote about the need for emergency preparations and responses to be accessible and inclusive back in the Winter 2021 issue, so it is with guarded optimism that I recently received notice from Accessibility Standards Canada that they have released draft standards on emergency measures. The purpose of the Accessible Emergency Measures standard is to "reduce the impact of emergencies on people with disabilities and other vulnerable individuals and strengthen the ability of communities to recover after an event." The standard supports the goals of the Accessible Canada Act and efforts to create a Canada without barriers by 2040.

The importance of this standard has been underscored by the extreme climatic events we have endured in BC over the past couple of years. With climate models predicting a greater frequency of these events in the years to come, it is critical that our emergency response measures ensure no one is left behind. To help ensure this is the case, it is important for all of us to provide feedback on the

standard. After all, "nothing about us without us" applies to emergency response measures, too.

You can review and provide your feedback on the standard at accessible.canada.ca/can-asc-5-1 until December 13, 2023. I encourage you to do this.

-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 Selilwitulh (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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AIRPLANE SEAT FOR POWERED WHEELCHAIRS

Delta Flight Products (DFP) announced a ground-breaking debut of an airplane seat prototype that allows powered wheelchair users to remain in their own wheelchair for the entire flight. This invention was possible due to a partnership with a UK-based consortium that focuses on accessible air travel. A standard seat can be converted to fit a powered wheelchair and travellers can still experience a safe and comfortable journey with access to a headrest and adjustable tray tables. This offers an incredible new way for people with disabilities to travel and we can't wait to see this new seat design on aircrafts.

HP+

The HP+, designed by Quebec's Trackz Mobility, is an all-terrain wheelchair made for the outdoors. This wheelchair is ultra-resistant for all kinds of adventures outside your home. With the hand rims and fenders made with anodized aluminum, you can rest assured that this wheelchair can handle going off-road. The "push to lock" brakes ensure that you are free to enjoy the outdoors without worrying about safety. Along with the HP+ wheelchair, there are various additional wheelchair add-ons for both adults and children that provide more mobility freedom. Visit www. trackzmobility.com to learn more.





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The Bottle Opener, found in the Neil Squire Society's Makers Making Change assistive devices library, is a handy tool to help open and close bottles for people with limited mobility and dexterity. The device features a large, comfortable handle that makes drinking from bottles that much easier. Place the toothed gripping around the bottle cap, squeeze the handle to grip the cap and twist the device until the bottle is opened or closed. The adaptive tool comes in different sizes to fit bottle caps of all sizes. More assistive tools for daily living can be found at www.makersmakingchange.com.

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events



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Spinal Cord Injury BC

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Learn more about assistive tech. Find out how the WorkBC Assistive Technology Services program, operated by the Neil Squire Society, can benefit you. Learn about funding for assistive technologies in BC to overcome workplace barriers caused by a disability. Join Marketing Manager, Nate Toevs, on Wednesdays at 12:30 pm for a Zoom webinar on the following topics: workplace accommodations, ergonomics, product demonstrations, and more. Head over to www.neilsquire.ca/events to register.



Your next forum on healthcare.

On October 27, join ConnecTra Society's next Accessible Community Forum on Navigating the Healthcare System with a Disability from 1 - 3 pm over Zoom. This forum will address what is missing and ways to improve accessibility within the current healthcare system. ConnecTra Society will highlight organizations taking great strides to improve healthcare for Canadians with disabilities. Contact Emily at echambers@connectra.org to save your spot.

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peers

A highest-order shoutout to **PAUL GAUTHIER** for his appointment to the Order of Canada! Gauthier received this honour in recognition of his social entrepreneurship and advocacy of people living with disabilities in British Columbia. Some of you may remember Paul from his time with SCI BC (when it was BCPA) many years ago, but many more of you will know him for his leadership in founding the CSIL employers group and the Individualized Funding Resource Centre Society (IFRC), where he is the founding and current Executive Director. Gauthier has also been instrumental in establishing the Right Fit Program, a partnership between the IFRC and Disability Alliance BC that works hard to match wheelchair users with accessible housing in Metro Vancouver. We're sure Gauthier won't be resting on his OC laurels and will continue his welcomed leadership and advocacy for years to come.



A very quick shoutout to **KYLE GIENI** for earning a Guinness World Record for the fastest half-marathon in a non-racing wheelchair with poles! Gieni earned the title at the BMO Van-



couver Half-Marathon this past May, clocking the record time of 1 hour, 23 minutes and 15 seconds. "I used to do some cross-country skiing back in Regina back when I was a kid, so coming back here it just seems natural to hop on some and start grinding away," Gieni told CTV News after another race in Regina this summer. "Just to show people that it's possible, just to show people that anybody can do it, even if you're in a wheelchair, it doesn't matter, just get out there." Get out there he does, and for more than just record times: over the years, Gieni has used his races to raise funds for the BC Wheelchair Floorball Association, SportAbility, and SCI BC.



Shoutouts

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.

Congratulations to **MARY-JO FETTERLY** on the publication of her new book, *Where Science Meets Spirit – The Autobiography of a*

Paralyzed Yogi. As described on her website, the book is "an extraordinary memoir of unconventional approaches to life and paralysis, uncovering important knowledge about resilience, energy and embodiment, and our collective power from the limitless Life-Force Energy we are all made from." In addition to her career as a Yoga teacher and Best-Life and Mindfulness Coach, we are pleased to have Fetterly on board as member of SCI BC's new peer health coach team. As we went to print, her book was available for pre-order on her website: www.mary-jo.com.







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How one SCI BC peer's passion for race car driving continues a family legacy.

photo of SCI BC peer Riley Martin's late grandfather hangs in his kitchen. It's black and white, and tiny specks of dust and sunspots have appeared on the film over time causing a grainy effect to cover the image. In it, Martin's grandpa, Bill Martin, is behind the wheel of a 1950s race car with no bells or whistles, no roll cage, no flashy logos. Only his helmet-covered head and torso are visible as Bill is captured in the photo racing on a track somewhere in the Lower Mainland and rainwater sprays out behind his wheels (he is racing in the Lower Mainland, after all).

As *The Spin* talks with Martin; he holds up the photo and explains that his passion for racing is generational. "[My grandpa] built a race car with his friends and did some circuit racing in the 50s and then kind of passed that down to my Dad, who became a race mechanic during his undergrad in Vancouver in the 80s," he says. Now, Martin continues the tradition of race car enthusiasm as a competitive driver at Area 27 Motorsports Park in Oliver, BC.

Area 27 is a training facility and racing circuit with a 4.83 kilometer course fea-

turing 16 unique turns and 109-metre elevation. "When Area 27 came to Oliver, we got a membership before it was even built," Martin says. "When it was open we started lapping and then just last year, we started actually racing."

As someone with an SCI, the first step in pursuing racing was to connect with the Area 27 team and explore car options. "I don't want to say I'm surprised, because I never really expected anyone to be against me competing or anything, but it's been great to see the support. It's been extremely positive for me... and really cool how much of a non-issue it was for the race track and the administration," says Martin. The facilities at the track are all accessible and include a clubhouse with level entrances, accessible washrooms, and spectating locations for people of all abilities.

For Bill Drossos, President of Area 27 there weren't any concerns regarding Martin's driving ability, but some measures were implemented for increased safety. "What we have done from a safety aspect is improve the response time around the circuit in case of an incident like a vehicle fire. In Motorsports there can be challenging situations when extracting a driver from a damaged vehicle. At Area 27 we want to make the racing as safe as possible," Drossos says.

This means that extra considerations were taken when building and equipping Martin's car. For example, if a fire occurs while driving, he can pull a cord from inside the cockpit that starts a fire extinguisher in the engine and in the interior of the car. A tube is within reaching distance that can be controlled to direct the flow of extinguisher exhaust towards him. When purchasing the car, Martin and his Dad knew that hand controls were necessary, and that the transmission needed to be automatic - as Martin's T3 SCI doesn't allow him to switch between gears manually with a foot clutch. They ultimately decided on a 2004 Audi TT with a 3.2L VR6 Engine and all-wheel drive. "It took about 8 months altogether between sourcing the parts and getting certain things installed because we had to buy the car and then rip out all of the interior to make it really light," Martin says, adding, "it was a really good experience with Dad, and I know that he absolutely loves to have this project with me."





When it came to learning how to drive the car at speeds reaching up to 190 kilometers per hour and managing the resulting extreme g-force levels, Martin recounts three steps in the process. "The first is just learning how to drive the car fast and then two [is] learning how to drive the car fast against other people trying to do the same thing." These steps were accomplished through a three-day driving academy at Area 27 with professional racing instructors guiding him and the other attendees through a series of practice sessions and tests.

Once successful, the third step is learning how to relay information about the car back to your team while racing. In Martin's case, this means his Dad. "It's incredibly exciting, there's nothing else like it," he says. "You start racing at the back of the pack so you're learning how to race against other people trying to go as fast as I am ... and that's where communication comes into play. I have to let my Dad know what's going right or wrong so he can keep improving [the car]." After successfully finishing five races, Martin moved into the middle of the group and continues progressing towards the front based on race results.

"I don't feel disadvantaged out on the road because of the spinal cord injury," he says. Martin's T3 level injury means that he has no core or leg function, but has retained full hand function that he uses for driving. "Sometimes my hands get super tired because I use them to twist the throttle and push for the brake. I'm constantly twisting as hard as I can, and by the end of the race my arm is just dead and cramping. But, I mean, it's also hard work for others with their feet and legs running the manual transmissions. I don't think it's a disadvantage necessarily, but it's definitely a different aspect for me," he says.

Martin's racing techniques may be different, but he's not the first to implement them. "It's true that it's not common to see someone with a spinal cord injury in a race car," explains Drossos. "Having said that, there have been some extremely amazing exceptions, including Alex Zanardi and Robert Wickens. Both drivers lost the use of their legs due to horrible accidents in Indycar. Both drivers recovered and came back to race again and ... [exhibited] incredible determination, and perseverance, in the face of enormous adversity. At Area 27, Martin is the guy who exemplifies those same attributes."

This sense of determination propelled Martin to compete in his first GT 27 Continental Cup at Area 27 Motorsports Park in 2022. The Cup series consisted of 10 races between a pool of competitive novice racers with a variety of cars. Last year, he placed 16th out of 30 overall and received the



Lucas Van Herk and Riley Martin in the race car.

Rookie of the Year award. This year, "I'm trying to improve more and more and get into the top ten and then hopefully as close to the podium as we can get," he says. In addition, Martin and his Dad plan to continue to elevate the family tradition of racing by making incremental changes to the car. "Dad and I still have a bunch of, like, really small things that we can continually improve on the car. And we'll do those together."

Most recently, the Martin family's passion for racing has extended to another SCI BC peer. Lucas Van Herk, who lives in Chilliwack, BC showed interest in the sport and was invited out to Area 27 by Martin to take a ride in the car. "He absolutely loved it out there and I don't doubt he caught a bit of a racing bug," Martin says.

Catching the 'bug' for the sport is crucial, but Martin recognizes that it's only one piece of the puzzle when it comes to making the transition from fan to participant. Another significant factor for people considering getting into racing, especially for those with an SCI, is cost. Racing is one of the most expensive sports to pursue and personally financing a track's membership as well as purchasing, upgrading, and maintaining a car is nearly impossible. For Martin, the ability to race comes back to the sense of legacy and community that got him into racing in the first place. "For Dad and me to save a lot on shop labor, he did the labor himself, and we were able to pick up a few sponsors in the meantime," he says. "Our main sponsor is KSW Lawyers. They represented me after my motor vehicle accident and my injury so there's the connection there," Martin explains. "I've also got my realtor as a sponsor. His Dad sponsored a car back in the Netherlands where he's from, so that's also a personal connection for him, to continue to do that here. And Alliance Mobility Solutions gave us our hand controls and some funding because I've had them do stuff on my cars in the past... it's a collective effort and it absolutely makes a difference on our ability to be able to do this project."

Overall, for Martin, the price tag of racing is worth the reward. "I've been watching races for like the past 15 years. I love it and its always just kind of been something that's been passed down," he says. Through racing, he hopes to continue sharing this enthusiasm with others. "I know a lot of spinal cord injuries come from adrenaline related accidents, so for others to see that there is a way to get back to experiencing those things or something you enjoy... I know it's something I definitely would've liked to have seen for sure." Undoubtedly, this commitment to bolstering the sport and broadening its accessibility is something that Martin's late grandfather would have been proud to race towards.

If you want to learn more about Martin's racing pursuit, you can visit the Martin Racing team website at www. rileym.ca or catch one of his races at Area 27 Motorsports Park in Oliver, BC. You can also learn more about Area 27 at www.area27.ca.

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Walk It Off, Virtually!

Preliminary research showed that a virtual walking simulation game could reduce neuropathic pain in people with SCI. A clinical trial is underway to find out how.

hen most people think about virtual reality, or VR, they think about video games. They imagine someone with machine-like goggles strapped to the front of their face, making sudden and strange movements as they respond to what's happening in the virtual world in front of them. From enjoying a round of golf to playing the guitar, or perhaps engaging in an epic quest to find hidden treasure while outsmarting enemy treasure-hunters along the way, we think about VR as a form of entertainment. What we don't often think about, and what researchers around the world have been investigating, is how VR might be an effective way of alleviating neuropathic pain.

As a common experience for people with SCI, we know neuropathic pain—and effective ways of treating it—are top of mind for our readers. And while we can't always promise concrete solutions, we do



our best to bring you the latest developments in pain management research. For example, in the Spring 2013 issue of The Spin, we reported on how a group of researchers in England had stumbled on a way to reduce arthritis pain through video illusions ("The Power of Illusion"). This research, and a mounting body of evidence collected over the past decade, suggests that the key to relieving neuropathic pain resides in the brain, and that by correcting the brain's ability to interpret and respond to incoming signals from the rest of the body, we have an opportunity to reduce (or possibly eliminate) chronic pain associated with SCI.

One way that researchers are testing this hypothesis is using VR to "trick" people into believing that they're using or feeling their legs. And while we've reported on this research in the past (see "Great Pains" in our Fall 2021 issue), a number of questions remain unanswered. More specifically, studies demonstrating the pain-relieving effects of VR for people with SCI have been conducted with small sample sizes, making the results inconclusive. And perhaps most notably, we still don't understand how VR interventions are causing or contributing to neuropathic pain relief. So, when we found out about a large-scale clinical trial that's testing how a virtual walking simulation game—called VRWalk—can reduce neuropathic pain among people with SCI, we were keen to learn more about it.

The VRWalk trial is an international collaboration between Immersive Experience Laboratories (a company that specializes in VR applications for clinical research), Virginia Commonwealth University, the University of Alabama at Birmingham, and the University of New South Wales. According to the study's primary investigator, Dr. Zina Trost, a clinical psychologist and health psychology researcher at Texas A&M University, the trial operates out of three sites at each partner university. Trost supervises the site at Virginia Commonwealth University, where she worked when the trial was funded.

VRWalk is based on mirror therapy, a technique used to treat phantom limb pain—a condition in which people with amputations perceive pain or discomfort in the body part that is no longer there. "We think neuropathic pain happens following the same processes that underpin phantom limb pain," explains Trost. "Specifically, your brain has a representation of your body, and even if you sustained an injury, like you lose an arm, your body still has representation of that arm. And it's the disconnect between the brain and the missing arm-a process called deafferentation-that creates a pain state. The same thing is essentially happening in SCI. The brain has lost contact, partially or fully, with a functioning part of the body."

Mirror therapy involves tricking the brain into thinking that the affected or missing limb is moving by using a mirror to create a reflection of the unaffected limb. For people with SCI, early research with this technique involved using a mirror to reflect the upper body on top of a projection of walking legs. "These people were looking at themselves walking toward themselves, and it actually helped. That was a pretty striking result," says Trost.

Building on research with mirror therapy, Trost and her co-investigators

wanted to take the approach one step further using VR. Working with Immersive Experience Laboratories, the trial's industry partner, and a group of stakeholders that included people with SCI, the team co-designed VR software that shows a first-person perspective of participants' hands and legs while they walk through different environments, such as a snowy village or a desert outpost.

"One of the big things that really informed the product design was realizing that we, as able-bodied people, had a different experience testing the virtual walking intervention then people with SCI did. When we imagine ourselves walking, we restrain our muscles from actually trying to walk. Whereas it seems that people with complete SCI do not, so they had a much stronger experience of walking," says Corey Shum, the Director of Immersive Experience Laboratories. "That was a discovery that really helped the whole process of product development and the study itself to know that there are neurological mechanisms there that we wouldn't have guessed if we didn't have people with SCI interacting with the product directly."

In a preliminary study of 27 people with complete paraplegia, Trost and her team found that participants who used VRWalk over a two-week period at home reported not only significant reductions in pain intensity, but also improvements in mood. "The responses were positive and pain improvement was observed. This is the preliminary data that helped us get the bigger funding," says Trost.

With funding from the United States Department of Defense, the VRWalk trial launched in 2020. The research team is aiming to recruit 188 people with SCI over a five-year period, and they are about one-third of the way towards that goal. According to Trost, the trial initially focused only on people with complete injuries,



First person views of virtual walking.

but earlier this year, the Department of Defense granted the research team with additional funding to include incomplete injuries in the trial as well.

The study involves playing the virtual walking game for 10 minutes, two times a day for 10 days. Participants also complete questionnaires before and after each virtual walking session, as well as 6 and 12 months later. The questionnaires assess self-rated pain and mood levels, as well as participants' experience of the game. To examine the mechanisms underpinning changes in pain levels as a result of the virtual walking sessions, participants that live near one of the three project sites are invited to participate in an MRI to assess changes in the brain. While the trial is focused on virtual walking, it's engaging lower body function more generally. "This is important because many folks [with SCI] don't have neuropathic pain in their legs directly but around the site of injury," says Trost.

A unique aspect of the trial is that the protocol can be completed remotely in participant's homes without the physical presence of a researcher. Although this wasn't the original plan, the arrival of the COVID-19 pandemic meant that for the study to continue, the plan needed to change. So, the research team began mailing kits with all of the VR equipment required for the study to participants' homes, and teaching participants how to use it over Zoom. With this approach, the team was able to increase the study's geographical reach beyond the planned project sites.

"We built out a system that hadn't existed before. And I was kind of expecting it to fall down around us, but it's worked surprisingly well," says Shum. "We ship it to them in a box. And then we give them a return label. When they're done, they slap it on the box, and a study coordinator helps schedule a postal worker to come pick it up. Then we clean the units, sanitize them, reset them and send them back out."

Participants are monitored remotely during the study to troubleshoot issues with the technology, and to make sure that the equipment is being used as intended. "We send a mobile hotspot out to everybody's house. So, we're in constant contact with their device," explains Shum. "We can update it, and the [study] coordinators can view recordings of exactly what the participant experienced, along with other metrics, and we can make adjustments to their systems on the fly."

Trost was initially concerned about the potential for people with SCI to experience negative psychological triggers while engaged in virtual walking. But none of the stakeholders with lived experience involved in the study design nor any of the trial participants have reported any negative experiences or concerns, says Trost. This could be due in part to the fact that the study only accepts participants who are at least one year post-injury, whose pain experience and medication regimen are more likely to have stabilized. "Although I do think that if we do this [intervention] early on, we can actually prevent development of neuropathic pain," says Trost.

An issue that the research team has experienced with the VR technology is 'simulation sickness.' "With the technology, our main barrier to use is nausea. This happens in about 10% of the people that we encounter," explains Trost. "So, we are trying, and experimenting, as we go with different ways to mitigate that nausea. You know, for example, creating different kinds of transitions from scene to scene."

"I think, as technology improves, and as our software mediations improve, we'll get better. But I don't think it will entirely go away. Some people are simply more sensitive than others," adds Shum.

Ensuring that the technology works well and can be adapted or custom-



Dr. Zina Trost

built for people with SCI has been both a challenge and a priority for the research team throughout the project. "We're constantly working to improve the technology overall, especially in response to the information we're getting out of all the stakeholders giving their qualitative assessment," says Shum.

"We have a stakeholder team—groups of people who are not necessarily scientists who are included in our design team-that can help us shape the product," explains Trost. In addition to the involvement of the stakeholder team, the study is co-led by Dr. Rachel Cowan, an Associate Professor at the University of Alabama at Birmingham who has both relevant research expertise and lived experience with SCI. "In the virtual walking study, we had a lot of ideas that were corrected by people with lived experience, which was incredibly helpful, and this is why I think we've seen so much success with people being able to use it," says Trost.

While the trial is ongoing, it has spurred additional lines of research centred on the virtual walking application. For example, building on research by VRWalk co-investigator Dr. Sylvia Gustin, Professor and Director of the NeuroRecovery Research Hub at Australia's University of New South Wales, they will be extending their line of research focused on neuropathic pain by using VRWalk "to retrain people from both a top-down and a bottom-up approach to perceive touch," says Trost. In addition to wearing the VR headset, participants in this study will place their feet on a device that provides touch-based stimulation while participating in the virtual walking game. The research team is also working on an exercise intervention using VRWalk. The goal of the intervention, says Trost, is to build an affordable, accessible means of exercise (at home) that would be tailormade for the SCI community.

Like the exercise intervention, what the research team hopes that the VRWalk trial will offer is an affordable, at-home therapy option that not only reduces chronic pain for people with SCI, but also provides an engaging experience. "What I would hope is that, basically, for people that have this kind of pain, we can just give them a little VR headset, right? That's not very expensive, and they could have it like an asthma inhaler that they could use every once in a while," says Trost.

According to Shum, the eventual goal is to have virtual walking software that could be used with any qualified VR hardware, whether it's created by Play-Station, Apple, or any other company. "I can very easily imagine this being just an app that you download," he says.

Findings of the VRWalk trial won't be available until at least 2025, but here at *The Spin*, we'll keep track of new developments and keep you in the loop. In the meantime, you could get the inside scoop by trying the technology for yourself!

The research team is actively recruiting participants to take part in the VRWalk trial. Canadians with a complete or incomplete SCI who experience neuropathic pain are eligible to participate in the US-based trial, as long as the VR equipment can be shipped to their home address. To participate, you must be 18 years of age or older, use a wheelchair, and be able to use both arms at least a little bit. If you are interested in learning more, please call or text 1(804) 569-5965 or email sci@vrwalk.org. You can also visit sci. vrwalk.org/home.

Accessibility Update: Tse'K'wa **National Historic Site**

With guidance from SCI BC's Access BC team, the Tse'K'wa Heritage Society has made transformational improvements to its site.



n 2022. SCI BC's Access BC team visited the Tse'K'wa National Historic Site, formerly known as the Charlie Lake Cave, just outside Fort St. John in Northern BC. The importance of the site goes back more than 13,000 years, when a massive boulder broke off from the surrounding sandstone and revealed a small cave while creating a 12-meter-long gully on the hill. Over time, Dane-zaa ancestors made use of the cave and, as the gully filled with layers of soil, they left behind a wealth of artifacts, including a 10,500-year-old stone bead, spear and arrow points, harpoon heads, and bones from various animals. The excavation of these artifacts between 1974 and 1991 reinforced the

spiritual and historical significance of the area to the Dane-zaa people of that region and are some of the most important archaeological findings in North America. Three First Nations jointly purchased the property in 2012 and established the Tse'K'wa Heritage Society. In 2019, the cave was officially designated a national historic site by Parks Canada.



Amphitheater for cultural events and community gatherings.

The purpose during Access BC's visit last year was to provide an accessibility assessment of the site for the Tse'K'wa Heritage Society using an auditing app currently in development through a partnership between the University of Northern BC and SCI BC. The app enables users to capture accessibility data for outdoor and recreational environments based on a set of recognized standards in Canada, such as height, building dimensions, surface grades, and more. When completed, Access BC's Tse'K'wa assessment included best practice recommendations for entrance and exit routes, accessible bathrooms, parking improvements and more.



Accessible washrooms.

"Access BC's accessibility assessment has served as our roadmap for inclusive improvements to our site. Having a list of recommended priorities has allowed us to focus our efforts on the improvements that will have the greatest, immediate impact," says Alysa Currie, Executive Director of Tse'K'wa Heritage Society. Using the guidance provided by Access BC, Tse'K'wa has installed two accessible parking spots, a patio ramp, two universally designed outhouses, two accessible picnic spaces, a universally designed trail connecting parking and outhouses, a low-mobility access trail and entry to an archaeology dome, and a low-mobility trail to a hands-on teaching old camp known as kwâzâa watsáádzé? in Dane-zaa Záágé? language. The changes made to the site are nothing short of transformative. "We did the original consultation when there wasn't much [infrastructure] there... they needed to build and start some places from the ground up," explains Nancy Harris, SCI BC's Regional Development Liaison and lead of its Access BC team. "They really have embraced this and have done a lot of improvement."

One of the most exciting improvements is an amphitheater that will host cultural events and provide a much-needed space for community gatherings. "Accessibility is a spectrum, not all-or-nothing," Currie says. "Access BC has been incredibly encouraging as we work towards creating a site that is as inclusive as possible ... Lori Slater, Access BC team member and Access and Inclusion Liaison for the Northern BC Tourism Association, has been particularly helpful as she has visited our site multiple times to provide input and support throughout the construction process."

Slater, who has been involved since day one with the project at Tse'K'wa, previously wasn't able to explore some parts of the site due to uneven ground or inclines. Now, she can access the information and cultural programming provided in the dome feature and learn more about the archaeological site and Indigenous knowledge. In this way, the experience of incorporating accessibility has been mutually beneficial - the Tse'K'wa Heritage Society has learned more about universal design, and Access BC has learned more about the geographical, cultural, and historical importance of the location. As Currie notes, "[The Access BC assessment] has also been a powerful conversation starter, giving us the appropriate language to discuss access and inclusion on our site."

This process has not been without its challenges, however. There have been various financial, geographical and logistical hurdles to overcome when trying to create a universally accessible site. For example, the entrance to the cave is located on the side of a hillside with a steep, naturally formed pathway through trees. Although the simplest solution would be to redirect the path or alter the location, that wasn't possible. "The biggest challenge we have faced so far has been balancing the need for accessible infrastructure and the preservation of a known archaeological site," Currie says. "Tse'K'wa [is] protected under the Heritage Conservation Act. As a result, all infrastructure



LEFT: Lori Slater tries out the accessible path into the Tse'K'wa archaeological dome. RIGHT: Rest area and educational point of interest.

has to be built while minimizing ground disturbance and ensuring any impacts are monitored and documented by our archaeologists. It has been pleasantly surprising to see the creative problem solving that has resulted from bringing together our accessibility experts, archaeologists, and external contractors."

As upgrades continue to move forward, Access BC will remain in contact with the Tse'K'wa Heritage Society and will revisit the site as the accessibility app evolves. Ultimately, the goal is to return to Tse'K'wa when accessibility updates are complete, and the fully developed app can be used to reassess the location and gather data. "Inclusive design benefits everyone," Currie says. "It has been interesting to see how accessible infrastructure improves everyone's experience of the site, not just visitors with disabilities. This work has prompted a lot of quality conversations about what it means to be a welcoming, inclusive space." Access BC looks forward to continuing to be a driving force behind this conversation and action.

Learn more about Access BC at www.sci-bc.ca/access-bc or reach out to Nancy at nharris@sci-bc.ca.

Contact the Tse'K'wa Heritage Society at tsekwaheritage@gmail.com, (250) 224-7906 or www.treaty8.bc.ca/ tsekwa to find out more about the Society and the archaeological site.

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Ganding for Health

New studies show playing video games can provide health benefits for people with SCI.

e're all well aware of the health benefits of being physically active. And most of our readers are also well aware of how challenging it can be to find accessible, affordable physical activity options for people with SCI. So, it's no surprise that here at *The Spin* we spend so much time covering innovations in equipment and technology that can help you experience the benefits of exercise without the hassle.

Most recently in the Switch It Up article from the Winter 2022 issue of *The Spin*, we told you about how a team of ICORD researchers has been working overtime to move the revolutionary aROW and aSKI cardio exercisers—rowing and skiing ergometers that have been adapted for use by people with disabilities without leaving their wheelchairs—out of the lab and into our communities and homes. But while some of us can't go a day without a long wheel, ride, row or ski, not everyone enjoys long bouts of repetitive aerobic exercise. Most of us, however, do enjoy a good game. And for those of you that prefer video games to the gym, the good news is that two new studies suggest that gaming can be an accessible way to improve health.

Games That Move You

A new study published in the journal *Spinal Cord* shows that 'exergaming' can be used for exercise at a level that provides health benefits for people with SCI.

Exergaming refers to digital games that require moving the body to play, delivering an active gaming experience. They involve the use of digital devices, such as computers or game consoles, and their accessories, like hand-held controllers or virtual reality goggles. Examples of exergames include boxing or bowling games using a system like Nintendo Wii.

The study was a collaboration between a group of researchers at the Sunnaas Rehabilitation Hospital in Norway and the Centre for Health and Technology at the University of South-Eastern Norway. The researchers were interested in finding out if exergaming, as a commercially available, affordable and engaging activity that can be enjoyed at home, could be a suitable alternative to other forms of aerobic exercise.

"We see a lot of people with SCI [at our hospital] and a lot of them find it challenging to keep in shape. It's especially challenging to find types of exercise that are motivating to do over time. And when you're in a wheelchair, you are quite restricted in the type of exercise you can perform... So, we need to find other motivating types of exercise," says Dr. Matthijs Ferdinand Wouda, the lead researcher and Head of the Clinical Physiological Laboratory at Sunnaas Rehabilitation Hospital.

"If you are in a wheelchair and especially if the weather is bad, then it's not that easy to go to the gym. Exergaming is easy, accessible, and you can perform it at home. You can do it on your own, or you can do it with others, people who have a disability or able-bodied people," explains Wouda. "So, our research question was 'can exergaming be performed at an exercise intensity level that can give health benefits?' And I think we have we found evidence for that." The study included 22 men and 2 women with complete and incomplete SCI (all wheelchair users) in inpatient rehabilitation at the Sunnaas Rehabilitation Hospital. The participants' injury level ranged from C5 to T12, and all participants were classified as having average, good or excellent levels of cardiorespiratory fitness.

After consenting to participate in the study, participants completed a 'pretest' to establish baseline measures of cardiovascular fitness. "Participants did a maximum arm cranking test. in which we measured VO2 max and their maximum heart rate. We needed these measurements to calculate their relative exercise intensity during exergaming," explains Wouda. By measuring relative exercise intensity, the researchers were able to assess participants' level of effort based on how hard they were working relative to their individual levels of fitness. This was important given the differences in participants' gender, level of injury and degree of cardiovascular fitness.

The next day, participants had a practice playing session with three different exergames: Fruit Ninja on Xbox Kinect, Wii Sports Boxing on Nintendo Wii, and Thrill of the Fight, a virtual reality boxing game, on VR Oculus Rift. While Fruit Ninja is controlled by body motions, which are picked up and analyzed by a camera, Wii Sports Boxing and Thrill of the Fight are played by imitating boxing movements while holding movement sensitive game controllers. To ensure that participants remained within operating distance of the game consoles and provide a safe gaming environment, participants' wheelchairs were strapped down on a platform in front of the game consoles to limit chair movement while the games were in play. In addition, some participants wore specialized gloves that helped them to grip the hand-held controllers.

The following day, participants played each exergame in a randomized order for 15 minutes, with a 5-minute rest between each. "Before they started, we told them, 'you have to remember that when playing these games, that they are a form of exercise, so don't hold back.' You know, so they were eager to play and to sweat," says Wouda.

In total, participants played the exergames for 45 minutes. While gaming, the research team measured participants VO2 (oxygen consumption) and heart rate. "And then we presented our results in percentage of their maximum heart rate and their VO2max," says Wouda, referring to participants' relative exercise intensity.

When considered in terms of the potential for health benefits, the results were compelling. Participants spent more than two-thirds of the 45 minutes they spent exergaming—about 31 minutes—at a moderate to high level of exercise intensity. The remaining time was spent at low intensity.

"What was interesting was that the people with higher-level injuries, they were at the same exercise intensity as the people with lower-level injuries," notes Wouda. There were no differences in how much time participants spent at low, moderate or high exercise intensities while exergaming. It didn't matter how fit the participant was coming into the study, or what level of injury they had.

The only difference the researchers observed was in the type of game console or exergame participants played. Participants spent slightly more time in the high intensity range while playing Oculus Rift compared to the other games.

But according to Wouda, all three games were hits with the study's participants, and that's what matters. "[The participants] were all very excited about all three games. There was only one person that did not want to play the virtual reality boxing. They found it too scary. But otherwise, we had a really nice mixture of people that had been playing before, but also those that had never played before. And they all liked it. And they were rather surprised at how exhausting it actually is," he explains.

Most importantly, the findings suggest that people with SCI who use a wheelchair can use exergaming as a way to achieve the health benefits of aerobic exercise. The physical activity guidelines for adults with SCI recommend 20 minutes of aerobic exercise at a moderate or high intensity, twice a week, for basic fitness benefits. For additional benefits, such as lowering your risk of developing Type 2 diabetes and heart disease, the guidelines recommend 30 minutes of aerobic exercise at a moderate or high intensity. three times per week. So, through 45 minutes of exergaming at least twice per week, you can achieve the aerobic activity component of the physical activity guidelines. Add in resistance or weight training twice a week (3 sets of 10 reps for each major muscle group) the strength training component of the guidelines—and you're set!

That said, we'd be remiss if we didn't acknowledge the limitations of this study. In particular, while this study demonstrates that exergaming can be performed at a sufficient in-

More research is needed before we really know the extent to which exergaming provides health benefits, but in the meantime, if you're looking for a fun, affordable form of exercise that you can do at home, alone or with friends, why not give exergaming a try? The researchers behind the study have a few tips to help you get started:

- Select games that you find interesting and engaging
- Ensure that the area where the game will be played is free from obstacles (anything that you might roll over or hit your head or arms on)
- Play for 45 minutes to get 30 minutes of moderate to high intensity exercise
- Try using a heart rate monitor to measure your exercise intensity
- Build up gradually over time to reduce injury risk if you are not currently active



Dr. Matthijs Wouda

tensity to achieve health benefits, it didn't measure whether health benefits actually occurred.

"This was a cross sectional study so, of course, we don't know if [exergaming] actually gives health benefits," says Wouda. "And now we have applied for funding to do the whole protocol in a follow-up study in which participants will borrow the equipment, and they can do the exergaming at home over 12 weeks, and we will measure changes before and after. That's the next step."

The research team is also interested in understanding how psychological factors, such as participants' interest and motivation, may influence their exercise intensity during exergaming, says Wouda. "In the longitudinal study that we are planning, we are also going to measure motivational aspects before, during and at the end of the intervention, because, of course, exergaming sounds much more interesting than arm cranking to most of us. But we are not sure how motivating it is after three weeks or six weeks, or if we should change the games during the intervention period," he explains.

"Most of us know somebody that has an Xbox or Playstation, so it's easy to give it a try. And if you have a heartrate monitor, put it on and see if you get out of breath," says Wouda. "There are many different types of games. Plus, it's cheap and it's easy. So, it's not the worst thing if you try it and don't like it."



Dr. Drew Redepenning

Breathe It Out

While exergames are a promising way to achieve the health benefits associated with exercise, other types of adaptive gaming technology may also have benefits for users' health. Preliminary findings from a study out of Albany Medical College in Upstate New York show how another type of gaming device, pneumatic sip-and-puff controllers, may have respiratory benefits for users with cervical-level SCI.

"There is a lot of data on the benefits of participating in adaptive sports for individuals with SCI, but there have been few studies analyzing the benefits of participation in adaptive video gaming," says Dr. Drew Redepenning, the study's lead researcher. Redepenning is a biomedical engineer and a certified assistive technology professional who is currently completing his residency in Physical Medicine and Rehabilitation at the University of Pittsburgh Medical Centre. Redepenning's current research is focused on investigating the benefits of adaptive video gaming with the goal of increasing its acceptance as an integral rehabilitation service, which is what he aimed to do with his research on sip-and-puff controllers.

Sip-and-puff devices allow users to take a "sip" or "blow a puff" of air into a wand that resembles a straw to create air pressure. This air pressure sends a signal to the device (in this case, a game console) and ignites certain commands that allow the user to navigate and play the game. In the Albany Medical College study, 124 people with high cervical-level SCI filled out a survey about their gaming habits, respiratory quality of life, and the impact of adaptive video gaming on their respiratory health. Nearly half of the participants 'agreed' or 'strongly agreed' that their breathing control improved after using their sip-and-puff gaming controller, and that their respiratory health has improved. Individuals who reported that adaptive video gaming has improved their breathing control also reported a significantly higher level of exertion while gaming compared to those who did not.

"It can be difficult to get started with adaptive video gaming using sip-and-puff controllers. However, with practice, adaptive controllers like the Quadstick can allow someone with SCI to play video games at a very high level just using their mouth," says Redepenning. "Users may have to start with easier games at first when getting used to the controller, but with practice there is no limit to which games they can play."

These findings indicate that the use of sipand-puff video game controllers may have respiratory benefits for people with high cervical-level SCI, but that the benefits appear to be dependent on the user's level of exertion while playing video games. These findings are significant because respiratory function is an important component to overall health and quality of life for people with cervical-level SCI.

Given the size of the sample and the selfreported nature of the data, more research is needed to determine whether there is an objective improvement in respiratory health and quality of life after using a sip-and-puff video game controller. Redepenning is also interested in exploring whether participation in adaptive video gaming has other benefits for individuals with SCI.

"Adaptive video gaming equipment can also be used for activities such as computer access, so using it may increase overall daily independence and even help individuals with SCI with tasks for work or school," he says.

Until then, you can breathe easy knowing that new developments in research are on the way!

community

EXTENDED SUPPORT FOR THE BC SCI NET-WORK

In celebration of BC's sixth annual AccessAbility Week, the Ministry of Social Development and Poverty Reduction announced more than \$25 million in funding for a number of organizations to support expanded services and supports for people with disabilities. Amongst the recipients was the BC SCI Network, which received an additional \$2 million to support expand the coordinated and complimentary services of the five partner organizations. Along with SCI BC, the Network includes BC Wheelchair Sports, BC Wheelchair Basketball, the Disability Foundation, and the Neil Squire Society. The Network is now funded through to March 31, 2027.



ROYAL ASCENT

Some regal applause for UBC Okanagan and ICORD researcher, Dr. Kathleen Martin Ginis on her election to the Royal Society of Canada (RSC), one of the highest honours recognizing outstanding achievement in the Arts, Social Sciences, and Sciences. From the RSC's announcement, "Kathleen Martin Ginis is the international authority on physical activity behaviour-change interventions and psychosocial outcomes in people with disabilities. Her innovations in theory, measurement, intervention design and knowledge-translation are used worldwide. She has led international teams that have developed, tested, published and implemented hundreds of evidence-based tools and programs, while advancing scientific rigour and understanding of physical activity behaviour among people with disabilities."



Dr. Kathleen Martin Ginis (left) and Dr. Sarah Lawrason (right).



Rick Hansen (left), Dr. Wolfram Tetzlaff (centre) and Dr. Sasha Rabchevsky (right).

WOLF PACKS IT IN

A heartfelt congratulations and thank you to Dr. Wolfram (Wolf) Tetzlaff, who after ten years as ICORD's Director has stepped down and will now focus his passionate scientific energy on his SCI research. Tetzlaff has been a great friend to SCI BC and a champion for our longstanding partnership with ICORD. Through his leadership, ICORD continued to grow and develop world-leading research and researchers that are helping to make SCI preventable, livable, and curable. Congratulations too to Dr. John (Kip) Kramer, who is serving as Interim Director until a new Director is appointed.

Community Highlights

GOVERNOR GENERAL'S GOLD MEDAL

A cap toss for Dr. Sarah Lawrason, who was named UBC Okanagan's 2023 winner of the Governor General's Gold Medal. This

> prestigious award goes to the graduating PhD student with the most outstanding academic record. Those of you who participated in her studies on the health and wellbeing of people with SCI who can walk probably won't be surprised that she received this honour. As her PhD supervisor, Dr. Martin Ginis (she's on a roll!) describes, "Sarah has established an outstanding reputation for research leadership and conducted her PhD research with unwavering commitment to using community-engaged methods and improving the health of people with disabilities." Martin Ginis clearly has the magic touch – you may recall that another one of her students, Dr. Rob Shaw won this award last year!

To Pee, or Not to Pee, That is Not a Question

SCI BC teamed up with Coloplast to share a survey with catheter users about their catheter use and funding.

o pee or not to pee should never be a question, but when paying up to \$2,500 out of pocket every month for essential bladder supplies, it can become one every time you need to go. What can we do to change this? We need to start by asking some questions, which is why SCI BC teamed up with Coloplast to share their Catheter Use and Funding Survey.

Before we begin, we need to start with a disclosure. Although SCI BC didn't gain financially from sharing Coloplast's survey with our members, it is important for us to acknowledge that Coloplast, one of several continence care companies, is one of SCI BC's sponsors. Importantly, Coloplast did not have any input or influence on the writing or editing of this article.

Still, you may reasonably be asking why we are sharing the results of a Coloplast survey. There are two main reasons, one reason we are reporting on the survey is that many of you participated in it. The other is we believe that people with SCI (and others) who rely on intermittent catheters (ICs) should be able to pee for free and to not compromise their health by having to reuse them. In other words, there needs to be a case for provincial coverage of these essential supplies, and because that case is going to need a lot of evidence, we welcome any evidence that helps supports it.

Why the focus on catheter coverage? You may recall the Raw Deal article from the Winter 2022 issue of *The Spin* in which we explored a report led by Dr. Kris Cowley of the University of Manitoba titled, *Identifying Jurisdictional Gaps in Providing Essential Attendant* Services, Medical Supplies, and Assistive Devices Needed by Canadians Living with Spinal Cord Injury. In that report, essential needs are defined as "medical services, supplies or equipment that, if withheld, could result in death of a person with SCI within days or weeks." Catheters are one of those essential needs, and coverage for them in BC is amongst the worst in Canada.



This situation is creating an additional financial burden on those who already face many economic barriers. It is creating pee poverty in a way that is highly analogous to the period poverty that led to the provincial government's welcome decision to provide period products to those who need them. However, pee poverty is not just causing financial hardship, it is creating preventable health issues as many IC users are forced to reuse products that are only meant to be used once.

We've dedicated a number of pages to the inequities of catheter coverage and health issues relating to the reuse of ICs in recent issues of *The Spin*, so here we will focus on the results of the national Coloplast catheter survey. Specifically, we focus on the BC results from that survey.

The survey ran between May 9 and June 7, 2022. Catheter users were recruited by Coloplast directly through their database, and SCI organizations across the country shared the survey with their members. In total, 687 surveys were completed, including 209 from catheter users in BC. Of the people who participated in BC, well over half (57%) identified as having an SCI. 63 of the BC participants identified as male and 37 identified as female, and nearly two thirds were over the age of 50.83 participants indicated that they currently use ICs to manage their bladder, while 13 used indwelling/foley catheters and 10 used suprapubic catheters.

We know from recent research from Dr. Victoria Claydon's lab that many people with SCI are unsatisfied with the current bowel routine but haven't changed their routine from the one they were originally taught. Just as there is not one bowel management solution that works best for everyone, there is not a one-type fits all catheter solution. And yet, it seems that the majority of catheter users are sticking with the one they were originally introduced to - most commonly an uncoated catheter, and most commonly provided by a health care professional. There are likely many reasons for this, such as cost and lack of knowledge about alternatives. There is a need to dig deeper into this.

Almost all who reported using a different catheter to the one they were introduced to switched from an uncoated to a hydrophilic coated catheter. For many people, hydrophylic catheters offer a number of possible advantages over cheaper, uncoated alternatives, such as decreased risk of urethral trauma and infection: would more people switch to hydrophylic if they knew about them and could afford them? There is a need to dig deeper into this, too.

Most ICs are only meant to be used once, and there is growing consensus amongst health care professionals that single-use catheters should not be used more than once. However, there is also appreciation that for many catheter users, this is simply not financially feasible. In fact, in a separate survey of health professionals, they indicated that financial difficulty was the single greatest challenge faced by their patients who use ICs. This is likely one of the reasons that almost two thirds reported that their clinic or facility included information on how to wash and reuse ICs. Interestingly, 76% of respondents indicated that they would not teach their patients to reuse ICs if cost or funding was not an issue for them. That's telling.

Health professionals were one of the main sources of information on washing and reusing ICs but not the only one. 40 percent of the catheter users surveyed indicated that they received instruction on how to wash and reuse their catheters from their healthcare provider or healthcare facility. Instruction from retailers (2%), peers (7%), and online searches (5%) were some of the other sources of this information. Of some concern, almost half (47%) indicated that they figured out how to do it themselves.

25% of catheter users reported reusing ICs:

- 35% reused 1-4 times
- 12% reused 5-9 times
- 30% reused 20+ times

Consistent with what healthcare professionals identified as the greatest challenge faced by their IC-using patients, 60 percent of IC users stated that cost savings was their main reason for their reuse of single-use ICs, and another 12 percent stated that lack of insurance/coverage was why they reused. Five percent stated they reused based on advice from a healthcare provider. 12 percent indicated that environmental concerns were the main reason they reused their ICs.



Clearly, catheter users experience a lot of urinary tract health issues, which in turn requires significant health system resources. A 2017 study in the Journal of Neurotrauma by researchers at the Rick Hansen Institute supports this. In 2017, the mean cost to treat a UTI in hospital was \$7,790. No doubt, that figure is much higher now. But any complication requiring the attention of a health professional is expensive and adds to the strain on the health care system. Surely, investment in prevention, such as providing universal coverage for the right catheter for those who need them will an investment well spent. A better understanding of the health economics of this will be critical for the case for catheter coverage.

When it comes to who pays for catheters now, there is great inequity in who is covered. More than a quarter of those who responded to the survey pay for them out of pocket because they do not have insurance support. Amongst the rest, half had partial coverage provided by their insurance and the other half had full insurance coverage. This means the majority of respondents are forced to pay for the essential biological function of urination.

Pee poverty is real, and so are its consequences on the health and financial wellbeing of individuals for whom catheters are an essential supply, and on the capacity and economic impacts on our health system. With the cost of everything rising and the amount of support not keeping pace, pressures continue to mount and the consequences of pee poverty will only get greater. We must work together to address the inequities of catheter coverage and remove the unfair burden of pee poverty that exists in this province.

Catheter manufacturers are not off the hook. Cost and environmental impact are concerns for many catheter users and the catheter industry must innovate to create affordable, easy to use products that can safely be reused.

This survey is but one part of what will need to be a coordinated effort amongst many partners to build a case for BC to conquer pee poverty and become the leading jurisdiction when it comes to catheter coverage. We are at the early stages of that effort and SCI BC is keen to build on the survey by convening workshops this fall to learn more from SCI BC peers about their experiences and challenges with respect to their catheter use and funding, and their ideas about what coverage in an ideal world would look like.



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Learn To Camp *Vict<u>oria, BC</u>*

Peer Kayaking Victoria, BC

Adaptive Cycling Program Vancouver, BC North Vancouver, BC

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Peer BBQ

Bowling Night Nanaimo, BC

A snapshot of our peers at our summer events



Adrenaline Weekend Whistler, BC

Summer Recap

Visit www.sci-bc. ca/events for a calendar of events Adaptive Mountain Biking Prince George, BC

PeerSAY: Self-Serve Gas Stations

Whether road tripping, evacuating or commuting, SCI BC peers have been on the road this summer. Here's what they shared with us about fueling up when venturing beyond the range of full serve gas stations.

Our peers love the fuelService app!



Download the app on the Apple Store for IOS and Google Play for Android users.

The disability fuelService app is great. It lists gas stations which will help and has a direct call and directions to them. Shell also has a pay app so you don't need to leave your car.

Andrew Peters, Okanagan

On the island, I go to either Petro Canada or Co-op gas stations. I have been told Shell and Chevron will [pump for you] as well. When you pull up to a pump, call them, tell them you are a wheelchair user and they will send someone out to pump your gas. They either tap your credit card or take it into the station to process and bring you the receipt. I have a credit card just for gas with a low limit in case I need to give them my password. I haven't had to yet.

I do pump my own gas occasionally. Just make sure you give yourself room to maneuver your wheelchair between the car and the pump. And make sure you don't park on the wrong side for the pump. Done that before and what a pain.

- Bert Abbott, Parksville

I have only once had to pump my own gas in the Fraser Canyon. If travelling to the BC Interior I plan out the "Super Save Gas Stations." They have been great for pumping gas even now they have started to have part self service. Plus I live in Coquitlam where all Gas Stations have full service by law.

- Martin Schikora, Coquitlam

whilst grumpily transfer out and do it myself whilst grumbling the whole time. I also make a mental note of where all Super Save stations are throughout the interior - they're full service.

- Jessica Vliegenthart, Kamloops

I try to pick the outside island if it's available so I can park with lots of space between the pump and my van for my wheelchair. I always pay ahead even if not required because many pumps are too high for me to use the pay at the pump screen.

- Jocelyn Maffin, Nanaimo

What I recommend to peers is to make a list of phone numbers before a trip (for those without data) and try to call the station a little bit before the expected arrival time, but to be aware that staff can only help with gas if there are at least two staff on duty, so there may be a delay or times of the day when it isn't possible.

- Heather Lamb, Prince George

I don't have any full service pumps in my neighborhood, but I normally just end up calling the gas station that I need to fuel up at and somebody comes out and helps me. If you explain your situation, I feel like they're always happy to help. in my experience people were always super friendly.

There's also an app that calls to gas stations that you're at for you, I used it a couple times, but I find just calling the station directly is a better way to go. Hope this helps!

- Olivia Rey, Whistler

- Scott James, Vernon

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.

eHealth Program to Support Family Caregivers of Individuals with SCI

Overview: Dr. Bill Miller and his research team are undertaking a multi-phase eHealth module development study. They have completed the first stage of co-creating the contents of the module from family caregivers and health-care professionals through numerous interviews. They have identified 9 main topics that may be included in the online module. They are now in the stages of prioritizing the main topics and the sub-topics from all the contributions through this survey.

What to expect: Participants will be asked to review each main topic and subtopics, and rank how important it is for the topic/sub-topics to be addressed and included in the online module. The time commitment is approximately 30 minutes.

Who can participate: You may be eligible to participate in this study if you are working with or worked with individuals with SCI and/or their family caregivers for at least five years or you are a caregiver of someone with SCI; are a resident of Canada or the United States; and can speak and understand spoken and written English. You will not be eligible to participate in this study if the individual with SCI you are caring for is considered to be palliative or you are a paid caregiver who is not related to the person with SCI.

Why participate: There may or may not be any benefit to participation in this study. Participation in this study may contribute to supporting family caregivers of individuals with spinal cord injury. All participants will be entered into a \$50 gift card raffle prize.

Location: This study will take place remotely (online survey/phone/video call)

For more information or to sign up: Please contact the study coordinator, Sarah Park, by email at sarah.park@ubc.ca or by phone at (604) 822-1718.

Pelvic Floor Muscle Activity During Exoskeleton Walking

Overview: Researchers in Dr. Tania Lam's laboratory are interested in understanding how the pelvic floor muscles respond to walking in different exoskeletons. The pelvic floor muscles (PFM) are crucial for bladder function, and training these muscles can improve bladder symptoms for many people. Previous research has shown that people classified as motor-complete SCI can still engage muscles below their level of injury during certain exercises. In this study, we want to explore if and how the PFM and other muscles are active in people with motor-complete SCI during exoskeleton walking.

What to expect: This study involves 2 visits, each of which is 4 hours in duration. On the first visit, participants will complete a series of questionnaires, get screened for exoskeleton use, and practice walking in exoskeletons. In the second visit, they will put special recording electrodes on participants to monitor activity from the pelvic floor, trunk, hip, and leg muscles during walking in the Lokomat and Ekso at different speeds.

Who can participate: You may be eligible to participate in this study if you are at least 19 years of age; have a non-progressive SCI that occurred at least 12 months ago and is at or above the L1 neurological level; have stable management of spinal cord related secondary health concerns (e.g., spasticity, neuropathic pain); and have no other neurological injury or diagnosis. For a full list of eligibility criteria, visit icord.org/studies/2023/06/exoskeleton.

Why participate: While participants may not experience direct therapeutic benefit from participating, the results from this study will help us better understand how the PFM work and inform bladder management options after SCI. Participants will receive an honorarium of \$50 to compensate for their time.

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

For more information or to sign up: Please contact the study coordinator, Alison Williams, by email at awilliams@icord.org or by phone at (604) 675-8815.





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**

ask the SPIN DOCTOR

I recently noticed I sit funny in my chair – one shoulder is always higher and I am always leaning to one side. My partner noticed my spine curves a bit. Should I be concerned, and can I do anything to keep it from getting worse? Could I have done anything to prevent this when I was first injured years ago? – Lia, Langley

To answer this question, we turned to Brittany Marcoux, Occupational Therapist, and Shannon Sproule, Physiotherapist, both from the Advanced Practice Spinal Cord Outpatient Program at GF Strong Rehabilitation Centre in Vancouver.



How you sit after spinal cord injury (SCI) is a complex combination of active function and resting posture. Posture is affected by your level of injury and how much balance and support you have in the seating system (your wheelchair cushion, back rest and other components), among other factors.

Postural issues can develop slowly and may not be noticed until they cause other problems such as neck, back, or shoulder pain, skin breakdown, changes in sitting balance or loss of function. Scoliosis is an abnormal curve of the spine when viewed from the front that is commonly seen after SCI due to muscle imbalances caused by paralysis, spasticity or surgical procedures.

Whenever possible, the goal is for a wheelchair user's seated posture to align most of their body weight over their ischial tuberosities (sit bones), with the pelvis in a neutral position that supports equal pressure between both sit bones. This alignment maintains the natural curves in the back.

It is rare that anyone sits with the "ideal" posture, as the ideal posture is not always the most functional, or comfortable. After SCI, paralysis in trunk and pelvis muscles may make the ideal posture very difficult to achieve, especially without proper support from the seating system or when doing activities with two hands. If prolonged, poor posture can contribute to persistent changes in the shape and posture of the spine, such as scoliosis.

After SCI, posture management is one of an overwhelming amount of education we offer to our clients. We encourage our clients to have an adequate seating system and prevent posture problems from developing. It's particularly important for clients with SCI to participate in wheelchair prescription, talk about how you feel in the wheelchair, how you'll use it, how to get in and out of it, assess how balanced and comfortable you feel, and to look in the mirror and take note of your posture in each set up. Even though not every goal can be achieved by each seating set up, you as the user you get to determine what's most important to you.

Spasticity, seating instability, habits such as hooking an arm around your back canes, loss of range at the hip, or other orthopedic issues are all known causes of posture deformity. Left unchecked, over time these causes can limit function, physical health, self-confidence and cause skin breakdown.

Our goal for our clients with scoliosis post-injury is to stabilize the curve and prevent it from progressing, which assists in maintaining or improving the individual's function while resolving any problems the current deformity is causing. There is often a fine balance between function, comfort and ideal posture. Decisions involve input from the client, therapist and vendor and are critical to find the optimum solution.

You can help keep an eye on your posture by viewing yourself in your wheelchair with your shirt off at least annually. Take photos from the front and side to help keep track of changes over time. Note if you are sitting symmetrically in your wheelchair. If you start to notice signs of changing posture including new skin breakdown, losing your balance more easily or if wheeling is getting more difficult, reach out to your local occupational or physical therapist to be re-assessed in your seating system.

These therapists can work with you to prevent and address postural changes that lead to scoliosis. Whether they creep up slowly or are evident from day one, we work together to prevent posture problems and keep them from getting worse. Regular self-assessment and then timely action to address any significant changes is the best approach to prevent significant postural issues and seating challenges. This includes:

- monitoring muscle imbalances and range of motion
- working on management of spasticity and abnormal tone
- managing pain
- keeping equipment in good repair and ensuring it is optimally setup
- managing your weight

If you notice abnormalities, get a referral to have a complete seating review, involving a review of your posture sitting in the wheelchair, detailed seating ROM while lying down, and a simulation of your seating sitting on a solid mat. This process helps to determine if the posture changes are flexible enough to correct.



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Aging with SCI: Be Prepared!



SCI BC's new Aging with SCI Peer Support Specialist, Duncan Campbell shares what's behind the new Peer Support Program he's creating and why he's doing it.

his past summer, SCI BC welcomed Duncan Campbell to the peer support team. Affectionately known as the Quadfather for his role in founding the sport of wheelchair rugby, Campbell is well known to many of us for his long career in therapeutic recreation and wheelchair sports. Campbell experienced first-hand many of the challenges of aging with SCI, and the relative lack of information and support related to it. Not one to rest on his laurels, Campbell has taken a break from retirement to start up the new Aging with SCI Peer Support Program at SCI BC. We sat down with Campbell to learn more about the program and his motivation for putting it all together.

"When I was injured in 1973, aging was the farthest thing from my mind. For one thing, I was 17, and back then nobody thought quads would live much past age 55. So I set my mind to getting fully independent," says Campbell.

"I threw myself into creating a whole new team sport for quads called wheelchair rugby, and learning how to ride a handcycle. When I was first injured there were no adapted bikes but as I got older they got better. Eventually I rode to and from work every day on my handcycle for almost 20 years."

Campbell remembers going to an SCI research conference 15 years ago and the topic of shortened expected lifespan for people with SCI was brought up a lot. "I was friends with tons of people with SCI through sport and it was obvious we were going to live past 55, but I don't think the health and social support systems ever expected we would get old," he says.

Campbell started to experience health issues as he got older, some were "self inflicted," some were aging related. "As aging related complications kept me from my lifelong activity levels. I only realized then how much it had kept me healthy."

But what really motivated Campbell to take these age-related changes seriously was an intense medical event. "I'd caught pneumonia and had sleep apnea at the same time. I was very close to not surviving. I realized I had to do something to get fit again. Now, I exercise every weekday at PARC."

Reflecting back, Campbell recalls that he wasn't well prepared for what can happen as you get older and experienced a whole bunch of unexpected expenses. "Luckily I had some [health] coverage through my wife. I want others to know this may happen and they need to plan ahead to make sure they can make it comfortably."

When SCI BC invited Campbell to join the team, he knew immediately that he wanted to make sure that other peers have the opportunity to be better prepared for aging than he was. "In my new role, I'm developing resources to assist other people with SCI to address all the changes that can come with aging."

"When I suggested it, I thought it was really concise project but as I go, it reaches further and gets broader. It's not just about how your health and SCI complications change as you age, and how important physical activity and mobility is. There're also the financial barriers as your resources change. The supports we need are means tested just like non-disabled people who are aging, but our expenses are far higher, with lower levels of employment. We can save for our retirement, but then not be able to afford the home support we've always relied on because of changes to the supports we once had or costs we now face."

"Peers out there may not have thought about preparing for aging or know how to adjust now that they are into their advanced years. Then there's those who have experienced issues and might want to talk about it and to share their experiences, and know they're not on their own."

The important lessons Campbell has learned is to keep exercising, and not be afraid to look at your finances early and regularly. "This Peer Support Program is all about sharing information so we can make the best choices we can and learn from each other how to navigate the challenges ahead." This fall you can share your experiences in the Aging with SCI survey at sci-bc.ca/ aging. If you want to learn more on the Aging with SCI Peer Support Program, connect with Campbell via email at dcampbell@sci-bc.ca. **90%** of users rated GentleCath™ Glide with FeelClean™ Technology better than their usual catheter for comfort.¹



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*PVP is used in glue and is what makes catheters sticky when they dry. 1. A Multi-Centre Clinical Investigation to Assess the Performance of GentleCath™ Glide intermittent catheters. Study U378 GentleCath™ Glide Final Report. July 2018. In vitro data on file. Convatec Inc. 2. Pollard D, Allen D, Irwin N J, Moore J V, McClelland N, McCoy C P. Evaluation of an Integrated Amphiphilic Surfactant as an Alternative to Traditional Polyvinylpyrrolidone Coatings for Hydrophilic Intermittent Urinary Catheters. Biotribology. 2022;32(Dec 2022):100223.



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