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SPINAL CORD INJURY BC

SPRING 2025



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Spinal Cord Injury BC

Twenty Percent is Not Enough!

That we are in a housing crisis is not news. That we are in an even more acute accessible housing crisis is also not news, even if it's not in the news enough.

The massive investment all levels of government are making to address the critical housing shortages throughout the country represents a unique opportunity to seriously address the critical shortage of accessible housing that is forcing too many people with disabilities and their families into inappropriate or unsafe housing or homelessness.

Adaptable housing, also known as accessible-ready housing, is a rising trend that has been making its way into building codes across the country. The BC Building Code describes adaptable housing as "a dwelling unit designed and constructed with some accessible features, and which accommodates the future modification to provide more accessible features." In other words, it makes future accessibility-related renovations easier and far less expensive.

Some jurisdictions in Canada and around the world have been moving to require all new apartments/condos and lower density, ground-oriented housing to be adaptable. Anticipation has been building for changes to the BC Building Code that would apply such a requirement throughout the province.

Unfortunately, pressure from developers concerned about reduced profitability and the understandable economic uncertainty of the trade war started by the American government seem to have influenced the BC government's decision to, I suggest, miss the mark in only requiring twenty percent of new units to be adaptable.

While twenty percent is an improvement, it is hard to understand how this addresses the scope of the accessible housing issue now and in the future, and equity in accessing accessible and adaptable housing. It leaves many questions, like who gets access to these adaptable units? Which units will be the adaptable ones, the least valuable ones? If they are more in demand by folks who see the future need for accessible units, will people with disabilities who need accessible units now be shut out? Will the economics of supply and demand price these units out for far too many?

During this historic time of challenge and uncertainty, the adaptable housing provision in the BC Building Code could have introduced a much greater degree of certainty for everyone needing accessible housing now or in the future. It has failed to do so. However, the Code sets a minimum and there is no penalty for exceeding the Code, which means we must push for other ways that incentivize developers to build the maximum number of accessible and adaptable homes.

Am I optimistic that we'll see new developments exceed minimum adaptable housing requirements? Hmm, I don't know. Governments may be reducing the barriers for developers to build new housing but, simply put, they are putting profit over people and not doing enough to reduce the barriers faced by people with disabilities to access housing. Market demand may play a role but governments must do more. Twenty percent simply isn't enough.

—Chris McBride, PhD, Executive Director, SCI BC



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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.

SCI BC InfoLine: 1.800.689.2477



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JAR LID OPENER

Neil Squire's Makers Making Change has an abundance of assistive devices in their library to help people with disabilities live, work, and play with more independence. The Jar Lid Opener is one example of many tools to make daily living easier for anyone with limited hand motions. To open a jar, hook the opener under the lid and pull upwards or turn counterclockwise to take off the lid. For more information or for other everyday assistive technology, visit makersmakingchange.com.



ALL-TERRAIN WHEELCHAIR

The All-Terrain Wheelchair from Extreme Motus is a manual off-road wheelchair that tackles all sorts of outdoor environments, including grass, sand, rocks, mud, snow, and even water. The tires have enough air to make the chair float, and the design of the long wheelbase adds more stability over bumpy terrain.

The wheelchair can be conveniently tucked away into storage by removing two pins to fold the front wheels into the seat. This product comes in small (14.5" wide), medium (15.5" wide), or large (17.5" wide) and can be further personalized to your preference with various options, including different colours, add-ons like a camera mount, custom artwork on the seat cover, and more.

Start your outdoor adventure with the All-Terrain Wheelchair at extrememotus.com.

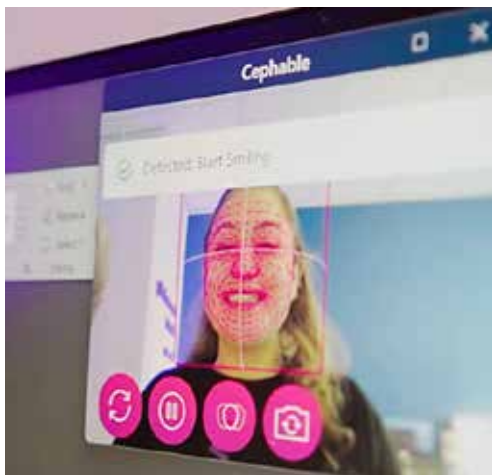


Innovations

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

CEPHABLE

Cephable is a free accessible control app for individuals with physical disabilities. The app's AI lets you control how you interact with your devices and includes features like adaptive voice controls, head motion detection, and facial expression on your computer. There are pre-built templates that you can start using right away for keyboard navigation, mouse controls, writing, and much more. The Cephable Companion App on your mobile lets you control your computer by adding virtual buttons to your control settings and using motion control such as tilting your phone to send commands to the computer. Cephable is available on PC and Mac for computers and Android and iOS for mobile devices. Add more control to your tech by downloading Cephable at cephable.com.



FLEXI PHONE HOLDER

The Flexi Phone Holder, created by England's Active Hands, is designed to attach your phone, tablet, or DSLR camera to your wheelchair hands-free. The design of the Fidlock Vacuum System securely holds your device in place with magnets and a vacuum seal. Tightening the clamp to your wheelchair is easy as it works like a sliding bar—perfect for anyone with reduced hand function. The flexible Loc-Line System is easily adjustable by removing or adding links to get the preferred height and angle. There are two different sizes to choose from to suit your needs: standard (16") and long (25"). Order the Flexi Phone Holder at activehands.com.



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Your next weekend getaway.

All of the best BC adaptive adventures are waiting for you in Whistler from July 25-27! Try outdoor activities like kayaking, paddleboarding, mountain biking, trail riding, and yoga. Food and accessible accommodation are included in this trip. If you have a recent SCI, or you haven't had a chance to experience our Whistler Adaptive Adrenaline Weekend, email Ryan to get on the RVSP list at rclarkson@sci-bc.ca or for more information.



Connect with your community.

ConnectTra Society's Abilities Expo brings together exhibitors, resources, and guest speakers to further enrich the disability community's connectedness. This year's theme is How to Thrive in 2025: Your Wellness, Your Way and features 50+ vendors from across the Lower Mainland. Join the rest of the disability community on June 5, 10 AM-4 PM in Vancouver. Ticket registration begins in April and for more details, visit connectra.org/abilities-expo.



BBQ season is coming.

Nothing brings us together like BBQ and sunshine! Join us across BC in communities like Surrey, Abbotsford, Coquitlam, North Vancouver, and Vancouver for food on the grill. Stay tuned for a special BBQ event at GF Strong on July 10! For more details about the Vancouver or GF Strong BBQs, contact Ryan at rclarkson@sci-bc.ca and keep a lookout for the nearest SCI BC BBQ in your area by signing up for our newsletter at sci-bc.ca/newsletter.

VANCOUVER MOUNTAIN FOUNDATION
Spinal Cord Injury BC

CHARITY CHALLENGE

Virtual Race: June 1 - 30 | In-Person Race: June 22

WALK, RUN OR WHEEL FOR TEAM SCI BC!

Connect with Krystyna at kpangilinan@sci-bc.ca to register. Visit sci-bc.ca/charity-challenge-2025 for more information.

HALL OF FAME LEGEND AWARDED MEDAL

Peter Webster has earned his place on the podium as a recipient of the King Charles III Coronation medal. Recognized for his contributions to sport, philanthropy, and community service, Webster's dedication spans over 50 years, including roles as Executive Director, Trustee, and Advisory Board Member at the BC Sports Hall of Fame. Inducted into the Hall himself in 2007, Webster co-founded the Canadian Association of Sports Heritage and was the first Canadian president of the Association of Sport Museums and Halls of Fame.

Through the R. Howard Webster Foundation, he has distributed nearly \$190 million to charities, and he continues to support the disability community as Chair of the BC Paraplegic Foundation and Board Member for SCI BC. Michelle Kitchen, BC Sports Hall of Fame CEO shares, "His legacy is deeply embedded in the history of British Columbia sport, and his tireless efforts have made a lasting impact on both the Hall of Fame and the broader sports community... When it comes to sport, philanthropy, and community service in our province, I can't think of a more worthy recipient."



Community Highlights

50 YEARS OF SEXUAL HEALTH REHAB

A cheeky congratulations to Vancouver Coastal Health's Sexual Health Rehabilitation Service (SHRS) who wrapped up their 50th anniversary celebration in February! Dr. George Szasz, who founded the SHRS in 1975, coined the saying "Sex is spoken here" to encourage open conversations about sexual health. The Rick Hansen Foundation's CEO, Doramy Ehling was on hand to present Dr. Szasz with a Rick Hansen Foundation Difference Maker Award for his dedication

to improving the lives of people with SCI and their partners. Today, the SHRS remains the only comprehensive sexual health and reproductive service of its kind in Canada. The team offers specialist clinical services at the GF Strong Rehabilitation Centre and Blusson Spinal Cord Centre, which anyone in BC/Yukon Territory with neurological impairments or illnesses can access. Over the past 18 years, more than 6,500 patients and their partners have received care from the SHRS, with over 125 babies brought into the world along the way! Recently, the SHRS partnered with BCIT to offer a micro credential in Sexual Health Rehabilitation for health care providers. Learn more about the SHRS at vch.ca/en/service/sexual-health-rehabilitation-service.



ADVANCING MEANINGFUL ENGAGEMENT IN RESEARCH

Our fabulous research partner Dr. Heather Gainforth has once again gained our admiration with her appointment as the Associate Director of Meaningful Engagement at the International Collaboration on Repair Discoveries (ICORD)! In this new role, Gainforth and ICORD Managing Director, Nancy Thorogood, serve as Co-Chairs of ICORD's new Meaningful Engagement Committee, which includes SCI BC's Chris McBride. The Committee's journey to deepen connections between research users and ICORD researchers began last October at the ICORD SCI Partnership Workshop in Kelowna, which brought together 70 people to explore better ways to include people with SCI in the research process and discuss the vision for the Meaningful Engagement Committee.

Gainforth is also an Associate Professor at the University of British Columbia Okanagan and heads the Applied Behaviour Change Lab. Her research is driven by the simple question, "How can I help?" With Gainforth's unwavering passion for creating partnerships that matter, she's sure to make waves and inspire change that sticks!



Parksville's **TREVOR HIRSCHFIELD** is leading by example as the next Head Coach of Wheelchair Rugby Canada (WRC)'s National Team! As an athlete and five-time Paralympian, Hirschfield tackled the wheelchair rugby world as co-captain of Team Canada, and one of the best low-point players in the world. His appointment as Head Coach is welcomed by WRC's High Performance Director, Jackie Patatas who says, "Trevor's journey from player to coach is exciting for him and for the sport. His deep understanding of the game, his passion, and his dedication to wheelchair rugby as an athlete for many years make him the right person to lead Team Canada forward." We'll be cheering on Hirschfield and the team at their future competitions!



A distinguished congratulations to **MONICA GARTNER** on her nomination for the 2025 Metro Vancouver YWCA Women of Distinction Award. Through every challenge, Gartner has shown unwavering strength, making her mark with public speaking, acting, peer mentoring, volunteering, and even writing her own book! She also founded the Canadian Assisted Travel Society to support travelers with disabilities. Gartner, winner of Coast Mental Health's 2024 Courage to Come Back award, told CityNews, "It's sad to see that some people, they go through a traumatic event, and they think it's the end of their life... At the end of the day, I take a deep breath and I go, 'Okay, well, what can we do to make things better? What can I do to move forward?'" The YWCA Women of Distinction Awards Gala takes place on April 28, 2025, and we wish Gartner the best of luck!

A round of applause (literally) for **AGASHA MUTESASIRA**, who sang the national anthems at the Vancouver Canucks vs. Detroit Red Wings game in February. Despite boos from the crowd during the "Star Spangled Banner" (which was followed by a raucous ovation for "Oh Canada"), Mutesasira delivered a top shelf performance for the Canucks' Black Excellence Night. She shared with CBC, "The Canucks production team did a good job of preparing me and letting me know, so it wasn't something that caught me off guard... I just acted like I was in my house singing it, and the rest was just background noise." Mutesasira's parents even travelled from Uganda to watch her perform! When she's not making music, Mutesasira can be found hosting peer events in the Tri-Cities as SCI BC's Service Delivery Coordinator!



Peer Shoutouts

CHLOË ANGUS is wired for success! Following her SCI in 2015, Angus helped found Vancouver-based Human in Motion Robotics (HMR). As HMR's Product Ambassador and Director of Lived Experience, Angus provided essential insights for the development of the XoMotion, the world's most advanced wearable robotic exoskeleton. The XoMotion helps individuals with mobility impairments stand and walk through self-balancing, hands-free functionality. It recently received Health Canada approval for sales in Canada. In January 2025, HMR showcased the XoMotion at the Consumer Electronics Show (CES), where USA Today named it the Top Robot at CES 2025! In addition, Angus also showcased the XoMotion exoskeleton during the official flag handover at the Invictus Games Closing Ceremony. Learn more about the XoMotion at humaninmotion.com.



Props to **ROBERT PULLEN** for pulling off a phenomenal performance at the Invictus Games Vancouver Whistler 2025! Founded by Prince Harry, the Invictus Games celebrate the resilience and determination of wounded, injured, and sick service members and veterans. Pullen, an Army Infantry Soldier, sustained his SCI while part of the United Nations Protection Force during the Croatian War of Independence. At the Games, he competed in alpine skiing, wheelchair basketball, and indoor rowing, winning bronze in the Indoor Rowing Men's IR2 One Minute Sprint. Pullen tells us, "The games were life changing. They literally opened my eyes to the fact that we have a lot more support than I thought was out there." He plans to volunteer at the 2027 Invictus Games in Birmingham, U.K.

ask the SPIN DOCTOR

Recently my doctor and I discussed medications for anxiety and depression, but I've heard some medications can make some of my SCI issues worse. What are they and can I do anything about it? —Nic in Nelson



To answer this question, we turned to Peter Ngsee, PharmD, B.Sc., Pharmacist at Vancouver General Hospital and G.F. Strong Rehabilitation Centre.

Given the impact spinal cord injury (SCI) has on mobility and function, being concerned about potential medical side effects is understandable. Depression and anxiety are more common in people with SCI, but good management of these conditions after an acute SCI can help with better rehabilitation outcomes and related functional recovery.

Medications are an important tool for managing SCI complications like pain, spasticity, and bladder dysfunction. As such, it is common for patients to be reluctant to add on another medication. As pharmacists, it is our role to help patients and families better understand and navigate the potential benefits and side effects with any new medication.

Treatment for anxiety and depression can range from medications, peer support, cognitive behavioral therapy, and more. Many people are reluctant to try medications for these conditions due to side effects and other risks, however it is important to also consider the potential benefits such as increased mood and reduced anxiety. These effects can improve a patient's ability to participate in rehabilitation and normal day-to-day activities.

The mainstay of treatment for these two conditions are selective serotonin reuptake inhibitors (SSRI), serotonin-norepinephrine reuptake inhibitors (SNRI), and tricyclic antidepressants (TCA). It can take up to four weeks after starting these types of medications to see an initial response to depression or anxiety, and up to 12 weeks to see whether the effects are appropriate or an adjustment is needed to get the desired result. Side effects usually occur within the first two weeks, so it is important to follow up with the prescribing physician to determine if changes are needed. There are also some additional benefits possible with these types of medications that might be helpful for some other chronic conditions, such as improvement in neuropathic pain and insomnia.

These classes of medications also have some uncommon side effects to consider. While they could happen to anyone, they may affect or complicate SCI related issues like spasticity and difficulty with temperature regulation. If your injury is T6 or above and you have noticed you don't sweat when you're hot, you may be experiencing how autonomic dysfunction affects your body's ability to regulate your temperature. Medications

like SNRIs, SSRIs, and TCAs may reduce your ability to sweat due to how they interfere with your body's control of secretions, especially if combined with other medications like oxybutynin that have similar effects. Due to this decreased ability to sweat, your body may not be able to cool itself down, which could lower your heat tolerance and increase your risk of heat stroke. In this situation, it's important to take steps to stay cool and avoid heat stress, like seeking out shade especially during peak times, staying hydrated, and using a fan or spray bottle.

A rare but known risk of these medications is serotonin syndrome, a collection of symptoms that include fever, muscle rigidity, muscle twitching, and high blood pressure that can happen to anyone but may complicate, worsen, or appear to mimic common SCI complications. People with SCI may already have muscle spasms secondary to their injury, which may increase their sensitivity to similar symptoms of serotonin syndrome. Unfortunately, there are not many direct studies of antidepressants comparing people with SCI to those without SCI to confirm whether there is an increased risk.

Serotonin syndrome can arise from an increase in activity in the central nervous system related to prescription and over the counter medications, herbal products, and medication interactions. It is important to always review and discuss any changes with a healthcare practitioner. To help prevent side effects, it is common for clinicians to start with increasing the dose slowly over a few weeks or months. Similarly, if stopping or switching medications, we typically taper them over a few weeks to avoid withdrawal side effects.

With these medications, side effects are often reversible and manageable if identified early. It is important to have a frank discussion with your healthcare provider about concerns related to the medications or your other conditions. Doing this will help us create a personalized medication and treatment plan, including what medications we can try, what to monitor for, and when to follow up to re-evaluate. There are a number of treatment options available and your healthcare team can create a plan to meet your end goals.

Remember that you may not need to take these medications forever. They are meant to help improve your current health and wellbeing to a level you are comfortable with. Communicate with your healthcare team throughout the process to determine if or when it's appropriate for you to stop. ■

Know Your Rights:

How WorkSafeBC is Supporting Workers with Disabilities

Members of the BC SCI Network and WorkSafeBC are teaming up to help address employment-related safety challenges facing people with disabilities.

In 2017, the Government of Canada reported that just 59% of individuals with disabilities aged 25 to 64 were employed. By 2022, spurred forward in part by the enactment of the Accessible Canada Act, employment rates rose to 62%. This increase indicates progress towards the Accessible Canada Act's goal of a barrier-free Canada by 2040, but it doesn't represent the full picture.

Occupational health and safety (OHS) research by Curtis Breslin, a professor at Toronto's Seneca College, revealed that workers with disabilities are more likely to experience OHS vulnerability. Specifically, Breslin found that "a disability at work was significantly associated with greater hazard exposure." The study, published in *Disability and Rehabilitation* and supported by Toronto's Institute for Work and Health, also noted that people with disabilities were more likely to be employed in conditions where hazard exposure was combined with inadequate policies and procedures or inadequate empowerment. In this way, people with disabilities experience both a lower rate of employment (compared to the 78% national average for people without disabilities), and if employed, a higher likelihood of unsafe working conditions and feelings of disempowerment.

"We know from research that people with disabilities are perhaps more reluctant to speak up and ask for what they need, and that they face more safety

challenges," says Helen Chandler, an Industry Specialist from WorkSafeBC.

For over 100 years, WorkSafeBC has played a pivotal role in supporting workers and establishing a no-fault insurance system that provides fair compensation. Chandler, whose role encompasses developing and implementing programs that improve workplace health and safety, has recently expanded her focus to include building relationships with the BC disability community to address inequality issues highlighted in employment research. "We're trying to make connections with different groups [and] make sure that people with any kind of challenges know what they can ask for, what they should be asking for, and what their employer should be providing for them," she says.

In October 2024, Chandler presented at the annual BC SCI Network meeting to staff representing all five of the Network organizations (Spinal Cord Injury BC, Neil Squire Society, Disability Foundation, BC Wheelchair Basketball, and BC Wheelchair Sports). Her presentation focused on the rights of workers and the resources available to support them. "In BC, all workers have three basic rights," Chandler explains. "They have the right to know what hazards are and how to control the risks. This could be very specific for somebody who, for example, is in a wheelchair. Let's say they're working near a conveyor belt or a dip in the



ground; those are areas where their wheels might get caught, and the employer needs to think about these things and respond to them. They should be asking, what are the particular hazards for that particular person and how can we mitigate them? Workers also have the right to refuse unsafe work and the right to participate—which means the right to speak up or ask questions."

However, as Breslin's research indicates, invoking these rights is easier said than done. Out of nearly 2,000 research participants, those who self-identified as having a disability were almost twice as likely as those without a disability to report workplace vulnerability due to exposure to hazards and a lack of empowerment. It's an unfortunate chicken-and-egg dilemma that employees with disabilities can't avoid. Does having a disability lead to feelings of disempowerment and vulnerability, which increase hazard exposure? Or does the increased exposure to hazards in relation to having a disability result in disempowerment?

"It's definitely a balance," Chandler acknowledges. "I once had someone in a wheelchair tell me that she got a job when she was younger and didn't want to speak up because she didn't feel like she 'earned' it in some ways and knew she already stood out from [her co-workers]. She felt grateful to even have a job and didn't want to make waves... our education sessions are all about trying to make sure people know their rights so they can act confidently."

The Neil Squire Society is familiar with the complicated dilemma facing people with disabilities seeking employment or presently employed. Their programs, such as Creative Employment Options, Solutions, Computer Comfort, and Distance Computer Comfort aim to empower people with disabilities and build the skills needed to secure and excel in employment. Their newest program, Empower3D, launched in February 2025, provides youth with disabilities with the opportunity to develop transferable skills and gain valuable work experience in the manufacturing sector. Over the next two years, 10 groups of participants will participate in a 14-week skills-based training program and a 12-week full-time paid work experience.

"The curriculum covers soft skills. We talk about communication, teamwork, and we also teach them professional practice. On the technical side, the program teaches specific skills that are needed in manufacturing roles," explains



Helen Chandler presenting at the BC SCI Network meeting.

Kristina Mok, Program Manager at Neil Squire. Additionally, the Empower3D program will feature a guest presentation from Chandler about workers' rights, with a focus on increasing confidence in new employees. "I love to see young, new workers with disabilities on a joint health and safety committee," Chandler says. "That really gives them a voice and a chance to speak up about their particular safety needs," adding, "one of the things we usually suggest to anybody who's a little hesitant to speak up is to talk with your co-workers. They may have experienced the same thing, and if you can approach your supervisor with the support of other people, that's always helpful. A good employer will want you to bring things forward. They'll want to help—it's a win-win for them."

To be eligible for Empower3D, participants must have a self-declared disability and be between the ages of 15 and 30. Work environments are

dependent on the hiring needs of employers during the cohorts' placement. Therefore, due to the dynamic nature of these environments and the specific requirements of manufacturing facilities, wheelchair accessibility cannot be fully guaranteed at this time. However, Neil Squire hopes this won't discourage interested participants from contacting them and expressing their interest. "This is a big priority for us right now. We have meetings coming up with our partners and employers, and it's helpful to know the level of interest from participants who would need wheelchair accessible placements. If that's something you need, we will find a way to make it happen," Mok says.

Like Neil Squire, WorkSafeBC encourages people to get in touch with their questions or concerns. "I would love to hear from [SCI BC] members about their experiences on the job. I'd love to hear stories about something they helped fix at work, or maybe something that never got fixed," says Chandler. "Rights are the same for everybody in BC, but maybe there needs to be some resources specific to people with disabilities, and we want to help create those. It's corny to say, but safety is good business."

Review your workers' rights and find resources at worksafebc.com/for-workers. Connect with Helen Chandler at helen.chandler@worksafebc.com.

Learn more about Neil Squire's Empower3D program at neilsquire.ca/empower3d or email the team at empower3d@neilsquire.ca. ■



Empower3D Workplace experience.

Failing Forward

A conversation with UBC and ICORD researchers Kip Kramer and Paulina Scheuren about the opportunities, solutions, and lessons learned from the “failures” of SCI clinical trials.

Here at *The Spin*, it’s a priority for us to keep our readers up to speed on the latest advances in SCI research. From promising new treatments and care options for neuropathic pain, pressure ulcers, and bladder and bowel dysfunction, to innovations in technology that make it easier for you to take care of yourself, exercise, and get out and about in your community, we know that good-quality evidence plays an important role in helping you to find solutions that will benefit your life. But while we often focus our attention on the treatments and innovations that we know you’ll be excited to hear about, we don’t often take the time to reflect on the science that allows these game-changing advancements to happen.

That’s where Dr. John “Kip” Kramer, a UBC and ICORD researcher who studies the relationships between SCI and neuropathic pain, and Dr. Paulina Scheuren, a postdoctoral fellow in Kramer’s lab, have something to say. In a November 2024 article published in *eBioMedicine*, Kramer and Scheuren reviewed more than 400 clinical trials focused on SCI. Based on their review, they argue that recent “next generation” (or “next gen”) clinical trials that represent unsuccessful attempts to restore neurological function after SCI are a critical source of learnings for SCI researchers. By finding creative solutions to common challenges in SCI research, next gen clinical trials have the potential to unlock major breakthroughs, making way for the treatments and innovations that could make your life better.

In the form of a thought-provoking Q&A with Kramer and Scheuren, we bring you some of their key insights and lessons learned for the future of SCI research.



Left to right: Dr. John Kramer and Dr. Paulina Scheuren

In your own words, what is a “next gen” clinical trial?

Scheuren: The main point here is that we wanted to highlight trials that have been using newer approaches or focusing on different areas in terms of, for example, trial design. We wanted to highlight novel, innovative approaches that are being integrated into SCI clinical trials.

Kramer: We were really trying to emphasize that these aren’t your grandparent’s clinical trials anymore. These are the evolution of those trials and what we’ve learned from them, or what we’ve learned from past “failures” in the field. What we wanted to communicate is that they’re really not failures in many ways.

Why is it important to understand the “failures” in SCI clinical trials?

Kramer: There are a lot of reasons why clinical trials fail. It’s possible to say, ‘It failed because the science is bad’ or ‘The drugs or treatments didn’t work because SCI is complicated,’ but we also need to be ready to capture the subtlest of changes—because these initial changes are what will eventually lead to major breakthroughs. For example, we can’t expect to make people with SCI walk (as was often the case in early clinical trials), but we can try to achieve small effects on things like bowel and bladder function, or sensory and motor function. That’s why understanding the history of clinical trials and adapting them moving forward becomes really important, because if we keep trying to “hit a home run” with the outcomes we choose, we’re likely to miss the treatments that might actually be effective.

Scheuren: And even though clinical trials might not always show positive effects of the treatments they’re investigating, they add value in terms of understanding what doesn’t work or uncovering new possibilities for future research. Understanding how the trial was designed, which participants were included, and why certain findings weren’t achieved is important so we don’t make the same “mistakes” again. This is why we can’t only publish positive findings and transparency is encouraged. We need to report on and understand what didn’t work too.

Clinical Trials 101: A Brief Explainer and Key Terms

What is a clinical trial?

A clinical trial is a research study involving human participants that evaluates the safety or effects of one or more interventions on health outcomes. Now, you might be wondering what we mean by “intervention.” An intervention is a treatment, activity, or therapy that researchers give to participants in an experiment to see how it affects them. For example, in recent issues of *The Spin*, we’ve covered clinical trials looking at the effects of interventions like cannabis and “virtual walking” (using virtual reality) as treatments for neuropathic pain. There are many different types of interventions, including but not limited to drugs, vaccines, surgeries, medical devices, educational programs, manual therapies, and psychotherapies.

How do clinical trials determine if an intervention works?

In clinical trials, study participants are often divided into groups to compare the effects of one or more interventions against one another, as well as a control group. In general, the control group does not receive the intervention being studied—providing a baseline against which the intervention (or treatment) groups can be compared. In some cases, the control group will receive the “standard treatment” for the condition being studied. The control group could also receive a placebo, which is a fake treatment that looks and feels like a real treatment (such as a “sugar pill” in place of medication with an active ingredient). Differences in the outcomes being measured in the control group and the treatment group are referred to as “treatment effects.”

What is a sample?

The sample in a clinical trial refers to the study participants. The sample is a subset of individuals from a larger population, such as people with SCI, that the researchers would like to draw conclusions about. In relation to the sample, you may hear terms like “sample size,” “sample heterogeneity,” and “sample homogeneity.” While sample size refers to the number of participants in the trial, sample heterogeneity and homogeneity refer to the characteristics of the participants in the sample. A heterogenous sample includes participants with a wide variety of characteristics. In contrast, a homogenous sample includes participants who are relatively similar in nature. Samples of participants with SCI tend to be heterogeneous due to the variability in the types and levels of injuries that can occur.

What is involved in the design of a clinical trial?

The design of the clinical trial is the planned approach to carrying out the research, including who the participants are, how they will be selected, what interventions or groups they will be placed in, what outcomes will be measured, and how the data will be collected and analyzed.

Blinding and randomization are common strategies used to minimize bias in the design of clinical trials. Blinding involves concealing which treatment group a participant is assigned to. Participants, study staff, and researchers can all be blinded in a clinical trial. Randomization is the process of assigning participants to different treatment groups by chance to ensure that the groups are as similar as possible. This means that neither the researcher nor the participant chooses which treatment group they will be in.

In this article, we also talk about “adaptive designs.” Adaptive designs make clinical trials more flexible by pre-defining rules for how and when the trial can be modified based on how the trial is progressing. The flexibility of adaptive designs can benefit both the researchers and the participants in terms of minimizing the resources required or the burden placed on participants.

What are some of the key challenges that SCI researchers face when conducting clinical trials?

Scheuren: One of the biggest challenges relates to the nature of SCI and the heterogeneity, or diversity, of injuries and responses to treatment. You might have two people that have similar injuries at the beginning, but their recovery is completely different. This ultimately affects recruitment for clinical trials and whether or not the resulting sample size is large enough to accurately detect a treatment effect.

Kramer: All of it comes down to the fact that most SCI research is done with small sample sizes. This is the challenge we’re trying to overcome. That’s where I think these next gen clinical trials are trying to tackle some of these issues.

What solutions are next gen clinical trials using to tackle issues related to the small size and diversity of samples in SCI research?

Kramer: Biomarkers can be used in clinical trials to understand how well the body responds to a treatment

for a disease or condition, or why one person responds to an intervention when someone else didn't. A biomarker is a biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. We know from other fields that a validated biomarker—one that has required significant energy, time, and money—results in greater clinical trial success. This is partly because in the early phases of the clinical trial you have a more reliable and robust assessment of whether there was a treatment effect, which provides confidence going into larger and more resource-intensive phases of the clinical trial. We're starting to learn more about biomarkers that tell us about SCI, but it really hasn't taken off yet.

There's also been a lot of effort put into understanding how people recover from SCI, and we can actually deploy that knowledge in clinical trials to inform whether or not we have a treatment effect. Historically, treatment effects are determined on the basis of a comparison to a placebo-controlled condition. And that's nice, but when there's a lot of diversity in the sample, sometimes the placebo group does far worse or far better than you thought they were going to do. And it's this movement of the placebo group that can actually dictate whether or not a therapy is beneficial or not. For example, if a therapy does nothing but the placebo group does worse, you now have the emergence of what looks like a treatment effect. And this is where you can bring in large, historical datasets to look at how well your treatment group did compared to other groups from previous research.

Scheuren: Other examples include using so called "adaptive designs" that allow researchers to make adjustments as the study progresses. These types of approaches can help researchers to figure out which participant is more likely to benefit from a specific intervention compared to another, or tailor trials to specific subgroups of people with SCI instead of applying the same approach to everyone.

Another problem when doing research on a small population of people, like people with SCI, is participant burden—which can include things like the time commitment, travel, discomfort from procedures, or psychological strain associated with participating in the research. How can adaptive designs be used to relieve the burden placed on people with SCI in clinical trials?

Scheuren: Some clinical trials are using what's called a seamless design. The researchers enroll participants in the first phase of the trial and then use the same group of participants for the second phase of the trial. While

this approach comes with some limitations, it ultimately reduces participant burden.

Kramer: Another simple example is interim analysis, which is when you analyze the data before the planned data collection is complete. Let's say you wanted to collect data from 300 people, but you stop at 150 and take a look at the data. If you realize that the treatment is having no effect at that point, then you can stop the trial. It's not a big scientific advancement but it's about relieving the burden on the folks who are participating in the trial.

Clinical trials eat up a significant number of resources, including time, money, and personnel. What are some ways that next gen clinical trials are making SCI research more efficient?

Kramer: One thing that the COVID-19 pandemic taught us about clinical trials is that we need to be fast and flexible and try new things. We need to be able to anticipate when a treatment is or isn't working so that if we need to, we can change gears and try something else. We are at a moment in time where a lot of time and energy goes into setting up infrastructure for clinical trials, which can be redundant and expensive. These adaptive designs are helping to overcome some of those resource issues.

Scheuren: A lot of time goes into it for the people who are participating in the trial as well. So, figuring out where to best allocate resources and when to apply which resources is important. Instead of enrolling participants into a trial where you already know that the treatment might not work based on your interim analysis, they can then have the opportunity to participate in a different trial, for example, accelerating the whole process.

Kramer: But there are still challenges with a more fast-paced approach. Safety should always be the number one consideration—you don't want to be whipping in and out of treatments that are not safe. If it's too high risk or there are too many unknowns, these adaptive designs might not be the best approach.

Are there any other key learnings from the next gen clinical trials that you'd like to highlight?

Kramer: Historically what we've done is study the biology of SCI in animals, usually rodents (like mice or rats), and then transfer that knowledge into treatments that we administer in humans. And there are a number of issues with that approach. Specifically, in the case of SCI, we know that there are some major differences in terms of the biology and response to injury between humans and rodents. But now there's an opportunity to learn in

humans and adjust what we do based on our understanding of the human experience. And with this knowledge, we can go back to the animal studies knowing which processes or links we need to understand and target to best understand how the treatment will work in humans.

Scheuren: Standardizing rehabilitation is something else that we're starting to see more and more. As your readers will know, rehabilitation is a big factor after SCI, so trying to standardize the approach to rehabilitation at least within a given trial could be very beneficial in terms of reducing the heterogeneity that we're already dealing with just based on SCI itself.

What role might artificial intelligence (AI) play in the future of SCI clinical trials?

Kramer: Hard to say—the opportunities are pretty much endless at the moment. There is little doubt that in my lifetime, we will be testing a drug that was initially conceived by AI in people with SCI. This is an emerging field of research and investment, and it will evolve really quickly. Beyond this exciting capacity, AI will play a role in all facets of clinical trials from recruitment to assessment of participants and analysis. Eventually, it will also likely replace some amount of decision making. For example, AI will tell us what intervention or treatment has the most evidence to move forward into clinical trials.

I think this is really important because we need to coordinate our clinical trials. It makes very little sense to do one trial here and another there, both too small to have a meaningful conclusion. The historical problem has always been that we have humans deciding and this creates bias. With AI, we can just ask it, based on the available evidence, how should we prioritize our investment in clinical trials. For me, this is very exciting and resolves a longstanding problem.

What's one piece of advice or key message that you'd like to leave with our readers?

Kramer: I think it has to be one of patience and optimism. There will unquestionably be more failures ahead. There will be things that we think work now that won't work when we go onto the clinical trials, and those will be viewed as big disappointments. But I do think that as we learn more and more about SCI, more opportunities will come. We are making progress even though sometimes it doesn't necessarily feel that way.

Scheuren: I fully agree with what Kip said, and I would add that increased collaboration across different disciplines is needed to better understand SCI in humans and move the field of SCI research forward. Every trial, every study, and every effort teaches us something valuable, and your involvement is a vital part of that journey. ■

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Cringe and Tell

Sometimes the only way to survive embarrassment is to share it.

We've all had those cringe-worthy moments we wish we could erase from memory. Living with a disability comes with its own set of awkward situations no one prepares you for. A few brave peers are sharing their embarrassing stories to prove that sometimes all you can do is laugh.



“Years ago, I flew into Kosovo for a service project. Kosovo only had a military airstrip, so passengers deplaned via steep narrow staircases. Two airport staff carried me off the plane, and after a three hour flight without an aisle chair, all I cared about was reaching the toilet. Then I realized I was sliding out of my insulated pants with every step they took! It was -20°C and I held onto their shoulders for my life while waiting for my wheelchair. It wasn't until I got into my chair that I saw my pants were barely hanging on and realized I had mooned all the aircraft passengers as they deplaned. Not the first impression I'd been hoping to make! —JM”

“I went to use the restroom and found the door to the wheelchair stall was opened inwards and I couldn't get access! Thinking this was totally unacceptable, I grabbed a staff member. A polite young man dutifully followed me into the restroom and I showed him, with some indignation, the problem. He stepped forward, pulling the door open externally. Lots of room to get in now. I smiled sheepishly and said “hmmm, I didn't think to try that.” He was very gracious, and I was very embarrassed! —PC”

“I was crossing the road at a busy intersection during rush hour when my caster caught the lip of the curb. I went flying Superman style out of my wheelchair to face plant on the concrete. My friend, a fellow wheelchair user, thought it was hilarious! The karma gods were swift though. When he pushed my chair over to me, he somehow managed to tip over backwards. We made such a spectacle that dozens of people raced out of their vehicles to rescue us. This left traffic at a complete standstill and motorists were honking at us. I also remember being embarrassed when I had a tire blow out in a bar and people were scared by the noise and screamed! —BS”

“I travelled with my girlfriend to a conference where I was giving a keynote to over 300 people. We woke up at 5 AM to do the necessary bowel routine before my keynote at 8:30 AM. My girlfriend helped me set up in the bathroom with my tea and speech notes before leaving to grab breakfast. At 7:30 AM, she realized she had forgotten the keys inside the room and tried climbing through the ground floor window to no avail. Meanwhile, I'm helpless in the bathroom. After much excited conversation through two heavy wooden doors, she ran to get an extra key. We scrambled like humans on jet fuel to get dressed, switch the chairs, and wheel over to the conference hall. At 8:31 AM, I pulled up onto stage and acted as if nothing had happened! —MJF”

“My buddy and I crossed the border into Mexico, where a border patrol agent detained us and had a dog sniff us. I ran my mouth (maybe not the best idea) and he let us go an hour and a half later. A week later, I'm crossing back by myself. I was wheeling down a path with a pretty good decline when an elderly man bumped into me. My front casters hooked on an uneven stone, and I flew out of my chair like Superman! As he apologized, the same border agent from the week before approached. I'm thinking things are gonna go sideways. To my surprise, he lifted me up and threw me into my chair! You would not believe how grateful I was. When I crossed the border, I did not say a peep, only yes or no to their questions. —Big T”

Have an embarrassing story of your own you'd like to share? Email thespin@sci-bc.ca with your story.



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Breastfeeding Basics

New clinical practice guidelines and a consumer guide for mothers offer evidence-based recommendations for breastfeeding after SCI.



When Karen Hodge decided to start a family in 2009, like many women, she had a lot of questions about becoming a mother—her first question was, “Is pregnancy even possible for me?”

Hodge, who developed a permanent SCI as the result of abnormal blood vessels in her spinal column at the age of 15, knew little about pregnancy or breastfeeding after SCI in those early days of contemplating family life. Now, more than 15 years later, she is a busy mother of two and a passionate advocate for care of expecting and new mothers with SCI, all on top of a fulfilling career as a social worker.

One topic the Lower Mainland BC resident has been especially passionate about since her days as a new mom is lactation and breastfeeding. When she first became pregnant, she had a strong desire to breastfeed, in part due to the “breast is best” messaging that was consistently being promoted by experts, health care providers, and the mainstream media, but she was met with several challenges on her breastfeeding journey.

“When I was hoping to get pregnant, there was very little information about pregnancy or breastfeeding after SCI

available online or even in the health care realm,” she explains.

Recognizing that other women with SCI may be facing the same challenges or limited access to resources on their own motherhood journeys, Hodge took action. “I reached out to a group of providers I had met and found helpful during my first pregnancy and asked if there was a way we could work together to make information more readily accessible to persons exploring their pregnancy options and to their health care providers,” she says.

Together, they created the SCI Pregnancy and Perinatal Interest Group—a group of health care professionals, researchers, and SCI support groups, including SCI BC, working together to raise awareness, create resources, and educate people with SCI and health care providers on the topic of pregnancy, lactation, parenthood, and women’s health after SCI.

The group’s most recent contribution—led by Dr. Andrei Krassioukov, a physiatrist and scientist at the International Collaboration on Repair Discoveries (ICORD), GF Strong Rehabilitation Centre, and the University of British Columbia—is the publication of new clinical practice

guidelines for health care professionals who work with expecting and new mothers with SCI. Complemented by a plain-language consumer guide for mothers with SCI, the guidelines provide evidence-based recommendations for breastfeeding after SCI.

Why Breast Might Not Always Be Best

After giving birth to her first child, a son, in 2009, Hodge was encouraged to breastfeed.

“I met with health care providers and a lactation consultant prior to discharge and was told repeatedly that there was no reason why I could not breastfeed,” says Hodge in a video describing her postpartum experience.

But when she got home, she struggled to make it work. Her son was losing weight even though she was frequently placing him at her breast to feed. She was also experiencing regular episodes of autonomic dysreflexia (AD) when attempting to breastfeed, which many of our readers will recognize as uncontrolled spikes in blood pressure caused by painful or non-painful below the level of injury.

“I don’t have sensation in my nipples, so I couldn’t tell when he had a good latch

and when he didn't. My nipples quickly became bruised and then cracked and damaged," she explains in the video.

Despite these challenges, what Hodge took away from early conversations with her family doctor was that breastfeeding was best for her child, and she needed to try to find a way to make it work.

"Looking back, I think very likely [my family doctor] was also at an almost total loss as to what information to provide or how best to help. There was little information available to her; there were no clear answers in the literature or online about breastfeeding after SCI," says Hodge. "In many ways, we both felt it was important to keep trying to breastfeed as so much of our culture currently says breastfeeding is key to health. I desperately wanted to breastfeed even though it was clear it wasn't working. Both my child and I were struggling, physically and emotionally."

She eventually needed to introduce formula feeding due to her son's weight loss, but she continued to place him at her breast, to pump, and to hand express with each feed with little to no breastmilk occurring despite these consistent efforts. "It was totally exhausting," she says, reflecting on the experience.

While the SCI Pregnancy and Perinatal Interest Group has created several pregnancy-focused resources over the years, Hodge's experience with breastfeeding highlights an important gap in information focused on lactation and other postpartum considerations—a gap that had also been identified through survey research focused on women's experiences of motherhood after SCI. The new clinical practice guidelines and consumer guide focused on breastfeeding with SCI are intended to fill that gap.

"The guidelines for breastfeeding stem from another project, initially looking at women with SCI in pregnancy. From this project it became apparent that more specific information was needed for women with SCI on their breastfeeding journey. Mothers expressed feeling the 'breast is



Shea Hocaloski

best' pressure to breastfeed, and were struggling when things weren't working. There was very little support for these women from their primary care providers as they were often told to keep trying," explains Shea Hocaloski, a Registered Nurse and Sexual Health Clinician with the Sexual Health Rehabilitation Service at the Blusson Spinal Cord Centre. Hocaloski is a member of the SCI Pregnancy and Perinatal Interest Group and a co-author of the guidelines. "From this, our team realized we needed to develop guidelines for health care professionals."

Impacts of SCI on Breastfeeding

The World Health Organization (WHO) recommends that children be breastfed exclusively for the first six months of age—and for good reason. Breastmilk provides an ideal (and free) source of nutrition for infants, as well as antibodies that help to protect against illness while a baby's immune system develops. Breastfeeding is also convenient, supports bonding, and lowers the mother's risk of breast and ovarian cancers in the future.

Many women with SCI are capable of breastfeeding, and face many of the same challenges as women without SCI. For example, the child may have difficulty latching due to a lip or tongue tie (a band of tissue underneath the infant's lip or tongue that can limit movement), or the mother may experience clogged ducts or inflammation in the breast tis-

sue that causes pain and limits the flow of breastmilk. However, women with SCI also face unique challenges that may impact their ability to breastfeed.

Because the nerves that allow communication between the spinal cord and the breasts are located between the first and fifth thoracic vertebrae (T1-T5), women with injuries above T5 may experience decreased (or loss of) nipple sensation and an impaired "let down" reflex—a physiological response that allows milk to flow out of the breast to the baby. These challenges are impacted by not only the level of injury, but the completeness of the injury as well.

In addition, about one-quarter of women with SCI, and up to 40% of women with cervical SCI, may also experience AD while breastfeeding—a sudden increase in blood pressure that may be accompanied by a headache, sweating, and flushed skin above the level of injury. AD typically occurs in people with SCI at or above T6 but has been seen in injuries above T10. AD during breastfeeding can result from the process of breastfeeding itself, or from other painful processes initiated through the breast (such as cracked nipples or clogged ducts), and can lead to potentially life-threatening consequences, such as seizures and stroke, if uncontrolled.

People with SCI can also experience periods of low blood pressure, which can impact the length of time a mother can hold and breastfeed her child before experiencing fatigue or possibly fainting. Another issue is that women with injuries above T1 may find it difficult to position their baby for breastfeeding due to reduced motor function in the arms and hands.

"So, the biggest question is typically whether or not [the woman with SCI] can breastfeed," says Hocaloski. "And our advice is typically to just give it a try... If it doesn't work for you, it doesn't mean that you are doing it wrong or that you are failing in any way. One of

the beautiful parts about being able to breastfeed is the bonding, and there's still lots of ways to do that through skin-to-skin contact even if breastfeeding isn't accessible to you."

The Clinical Practice Guidelines for Breastfeeding with SCI

The clinical practice guidelines were developed by a BC-led international team of health care providers, SCI researchers, and women with SCI, including Hodge and Hocaloski. They provide evidence-based recommendations for health care professionals—including but not limited to general practitioners, obstetricians, pediatricians, physiatrists, lactation consultants, nurses, midwives, occupational therapists, and physiotherapists—who work with expecting and new mothers with SCI.

The process for developing the guidelines began with an international survey of 52 mothers with SCI. With funding from the Craig H. Neilsen Foundation, the survey was later expanded to include 102 mothers with SCI and their breastfeeding experience. The surveys focused on identifying the women's biggest challenges and concerns related to breastfeeding. At the same time, the research team conducted an environmental scan to evaluate the extent to which existing postpartum guidelines could be applied to breastfeeding after SCI.

The guidelines were developed from the survey findings, gaps in the scientific literature, consultants' input, and results of the environmental scan, then reviewed by independent experts. Throughout this process, the benefits of breastfeeding were evaluated against the potential health risks specific to SCI. The guidelines will be reevaluated and updated every five years based on new research and experience.

The recently published guidelines cover six topics related to breastfeeding after SCI:

1. Lactation and breastfeeding: Information about the impact of SCI on lactation and breastfeeding, the need

for early identification of breastfeeding challenges, aids for milk production, and individualized care.

2. Mobility and activities of daily living: Information about how to position infants for good latching and aids that can be used when mobility is limited, as well as considerations for the mother's self-care routine and community accessibility.

3. Autonomic dysreflexia: Information about the prevalence and potential harms of AD while breastfeeding. This section calls out the limited availability of research to guide the management of AD in women with SCI who are breastfeeding.

4. Interdisciplinary knowledge and collaboration: Information about the importance of interdisciplinary care teams, who they should include, and what types of knowledge they should have.

5. Community support: Information focused on ensuring that breastfeeding mothers with SCI can live and access resources in their home communities, including accessible housing and transportation, as well as health care facilities and play spaces for children.

6. Psychosocial health: Information about the emotional highs and lows women may experience following childbirth and when attempting to breastfeed, infant bonding and attachment, fatigue and adjustments to parenthood, and risk for postpartum anxiety and depression.

In general, the recommendations in the guidelines are focused on patient counselling and education, anticipating and addressing breastfeeding challenges, and developing an interdisciplinary care plan with relevant health care professionals.

For Hodge, the guidelines are a game changer. "As a mom who very much tried everything in my power to breastfeed both of my children but with very little success, I felt so alone in my experience and like a failure both when I sought out support at the time and even when talking about it many years later. No one had any concrete answers to my questions and most friends and health care providers were at a loss as to how best to offer support," she explains. "I am

hopeful that these guidelines will provide an easy-to-find, go-to resource for health care providers... that will help to improve the quality of care that [women with SCI] receive."

Hocaloski agrees. "I'm pretty excited that [the guidelines] are out in the world now. It took many years of collaborative work, and it is a big step forward in improving care for mothers with SCI," she says.

The Consumer Guide for Mothers with SCI

Another important step in the development of the guidelines was the creation of a consumer guide for women with SCI who are planning on or currently breastfeeding. The plain language guide outlines the most common issues women with SCI experience during breastfeeding—from positioning, latching and milk supply to medications, mental health, and AD—while offering practical suggestions, recommendations, and resources to address them.

"We have the guidelines that are for medical professionals, but we've also done a supplementary guide for women because they are the ones typically looking for the information," says Hocaloski. "So, the idea is that we have these two companion pieces where women can get the information that they are looking for that is already researched and backed up by science, and their health care professionals have a resource to use to better support mothers with SCI."

The consumer guide is intended to empower women who are considering pregnancy, are pregnant, or are new parents with information about breastfeeding after SCI and the options available to support them.

"I think equipping mothers with SCI with knowledge is really important," says Hocaloski. "If mothers are aware of what experiences are common or may be expected then this can limit the pressure or anxiety they may feel if they face these challenges. Becoming a new mother is both exciting and nerve-

wracking. There are a lot of ‘what if’s,’ so to be equipped with information that you can quickly look up and say, ‘Okay, this is common, this is what I can do, or this is who I should speak to’—this can help reduce a mother’s anxiety and help them to feel less alone.”

Hodge offers a similar sentiment, “I am hopeful that these guidelines will... help raise awareness of the possibility that there might be challenges and breastfeeding might not always work out exactly as planned, but that support is available and that it is okay and actually really helpful to tell others when challenges arise.”

Planning for parenthood after SCI

Becoming a parent can be a time of intense joy, wonder, and gratitude paired with uncertainty, exhaustion, and frustration. New babies require around the clock attention and care. And for parents with SCI, the demands of a frequent daytime and nighttime feeds may add new challenges in addition to the time and energy routinely spent on personal care and other daily tasks. Planning ahead to anticipate possible challenges and the supports you might need throughout pregnancy and the postpartum period is a critical step to set yourself, and your baby, up for success in the early days.

“Have conversations with your partner, your support network, and your care providers during your pregnancy about your hopes, your wishes, and your plans, but also have discussions about what will be the initial clues and potential next steps if things aren’t working out,” suggests Hodge. “In my experience, there was a lot of planning for what needed to be in place during pregnancy, but less planning for where to seek out support once the baby arrived and we had returned home.”

For some people with SCI, parenthood can also involve the added pressure of feeling like you need to ‘prove yourself’ as a capable parent. These feelings can add to the overwhelming mix of fatigue

and emotions that every parent experiences, and even prevent some parents from seeking the help they need.

“Even as a trained counsellor, I did not recognize for a long time that I was experiencing postpartum anxiety and depression. I was so in the thick of things that I couldn’t see my way through the fog. I was so exhausted and busy with baby care and my own personal care, that I didn’t reach out to friends... and I became quite isolated,” reflects Hodge on her own experience after the birth of her first child. “I so wanted to prove to everyone that I could do this and do it well. I didn’t initially realize that my level of daily worry and fear... was significant anxiety that was negatively impacting my daily life and not just normal ‘new mom’ worries.”

Women with SCI are at higher risk for postpartum depression and anxiety, and it’s important for new mothers and the people around them to recognize when feelings of sadness, worry, or fear extend beyond the typical ‘baby blues’ that last for a few days or up to a week or two.

Feeling sad, down, or crying easily, or feeling worried, agitated, anxious, or an overwhelming fear that something awful is about to happen, for more than a couple of weeks—especially if these feelings are impacting your ability to participate in day-to-day activities (such as caring for yourself and your baby)—are signs that you or someone you love may be experiencing postpartum depression or anxiety. Seeking help from a network of supportive people, including loved ones and care providers, and turning to resources like the clinical practice guidelines and consumer guide for mothers on breastfeeding after SCI, can be helpful tools to manage difficult feelings and ease the transition to motherhood.

“You have the capacity to be a great parent, and breastfeeding may be a possibility but it is also totally okay to reach out for support along the way,” says Hodge. “It is my heartfelt hope that the breastfeeding after SCI clinical and



Kate Hodge’s message to mothers with SCI.

consumer guidelines will now be easy to find, easy to read, and will provide parents and health care providers with the information they are seeking to help guide and support them on this journey into parenthood. ■

Where to Learn More

You can read and download the clinical practice guidelines online at: doi.org/10.46292/sci23-00079

You can read and download the consumer guide for mothers online at: community.scireproject.com/topic/breastfeeding

More resources on pregnancy, parenting and sexual health after SCI are available through SCI BC at scisexualhealth.ca and the SCIRE Project at scireproject.com under “Sexual and Reproductive Health.”

Smooth Sailing: Hullo Ferries’ Accessibility Journey

How the SCI BC community helped advocate for improved wheelchair accessibility aboard the new ferry service.

When Hullo Ferries launched their high-speed passenger ferry service between Nanaimo and Vancouver in August 2023, one of their main goals was to be the world’s friendliest ferry service. With an average sailing time of only 70 minutes, two brand new vessels, free Wi-Fi, and ferry terminals located near downtown public transit on either side of the Salish Sea, it appeared Hullo was on track to do just that. However, accessibility concerns were quickly raised by SCI BC peers, staff, and passengers with disabilities. Jocelyn Maffin, SCI BC’s Associate Director of Service Delivery and local Nanaimo resident, was one of the first wheelchair users to utilize the new ferries. Despite all of the positive aspects of her inaugural Hullo Ferries journey—a fast travel time, help-

ful staff, and a convenient location—the multitude of accessibility issues could not be ignored. “The ramp over the threshold into the main cabin was too narrow, and it was really hard to figure out how to get a wheelchair ticket on [the Hullo] website,” she says. The biggest concern was Hullo’s mandate that all passengers travel in a designated ferry seat. This meant wheelchair users were required to transfer to a seat upon boarding and then transfer back to their wheelchair to disembark. “Because I can transfer, I [was] able to use the service, but I know how many of our peer community members were upset that this brand new option was out of reach for them because of the requirement to transfer to the ferry seat provided,” Maffin says.

Hullo is the first operator in Canada to receive full approval under the High Speed

Craft Code and must adhere to stringent safety standards that exceed those of the other operators, such as BC Ferries and the Victoria Clipper. Being the first of its kind, Hullo proactively engaged with Transport Canada and Bureau Veritas to try and provide the best safety and service for all passengers, but guidelines were either not always clear or restrictive. The requirement for all wheelchair users to move to a fixed seat during the voyage is a particularly challenging example. “One of the most important things to remember is that because we travel at 40 knots, we have a completely different designation than other ferry systems in Canada... there are no vehicles, no outdoor seating or anything like that,” explains Xander France, Director of Marketing and Sales at Hullo Ferries. “Because our chairs on board were rated by Transport Canada as the safest option, we had to work within those guidelines. But as [SCI BC] knows, that’s not an option for everyone.”

Hullo responded to ongoing accessibility challenges by working within the policy they were given. They discounted ticket prices for wheelchair users travelling with a companion, installed a wider boarding ramp, and removed some of the interior tables for additional transfer space, but it didn’t address the issue at the heart of the matter. Moreover, due to Transport Canada policy, Hullo Ferries didn’t allow power wheelchairs on board because of concerns related to transporting lithium-ion batteries. “[Power wheelchair] users already face some of the biggest barriers to transportation like expensive modified vehicles and a lack of options,” says Maffin. “Most people I know with power



wheelchairs are safer in their own custom seating than in the airline-style seating on Hullo's ferries, let alone transferring... Hullo [didn't] require reserved seating for non-disabled passengers or force them to remain in their seats during the whole 70-minute journey, so why is that the case for wheelchair users?"

By the fall of 2023, it was clear a new approach was needed to address accessibility. Maffin contacted Canada's Chief Accessibility Officer and former SCI BC employee, Stephanie Cadieux, for help. Together, they reached out to Transport Canada and were told that many of the issues brought forward were at the discretion of the ship's captain. However, when Hullo Ferries' Captain Steven Carroll submitted a case to Transport Canada with passenger feedback, they received a reply reiterating the formal policy. Faced with a bureaucratic stalemate, efforts pivoted once again and looked to the SCI BC community for support.

In November 2023, a group of three SCI BC peers took part in a trial journey with newly installed tie-down straps for power wheelchairs. "Through [Maffin's] connections, we looked at some options on the Island and went with Mediquip. We were able to get our team to install the right restraints and the right tie-downs and... with that in place, we were able to get approval to try power wheelchairs," explains France.

As of March 2024, Hullo officially allowed power wheelchairs on board with the use of a tie-down system. Unfortunately, this small victory was overshadowed by the remaining fact that passengers still had to transfer out of their chairs—manual or power—into a ferry seat.



Xander France



Left to right: Jocelyn Maffin and Stephanie Cadieux.

"I would've complied if there was some common sense to it, but there was none," says Jamie Coleman, SCI BC peer and Duncan resident. Coleman first used Hullo Ferries in 2023 and had no issues. He wasn't asked to transfer and completed his trip in his own wheelchair.

In May 2024, though, Coleman was about to get on the ferry to Vancouver but was told he would have to transfer. "They said I had to get out of my chair, and if not, I couldn't get on the boat," says Coleman. "I said, 'Well, I can't get out by myself, and I can't self-transfer.' I was with my wife, and while she can physically get me from chair to chair if she really has to, it's a huge pain. At the end of the day, she managed to do it and we made it happen, but it was hard on her and embarrassing for me."

Coleman still isn't sure why the transfer policy was enforced on his second voyage and not his first, but the incident left him feeling frustrated and upset. "I'm much safer in my wheelchair," he says. "I have a [C5/C6] injury, and when they got me into the seat I wasn't stable. I have no function higher up, so I'm more dangerous in their chair compared to my own. Also, once they got me into a fixed chair, they tied down my wheelchair—so really, why don't you just let me sit in it?"

After his experience, Coleman immediately filed a human rights complaint and wrote to his MP, his local MLA, the CEO of Hullo Ferries, and several disability organizations, including SCI BC. As a practising lawyer, Coleman felt his professional skills could be put to use for

the benefit of others. "I don't consider myself to be an advocate. I'm a quadriplegic lawyer with twins. I'm busy with a bunch of my own stuff and I don't always have time for other things, but this issue really resonated with me, and I knew I had the tools to push the envelope a bit."

Hullo supported Coleman's initiative and encouraged him to communicate with the Ministry of Transport and Transport Canada. Coleman's MP wrote to the Minister of Transportation directly and the media was contacted to help amplify the call to action. "It's stressful when you're up against regulations that are clear in saying you can't do anything about them, but we all knew how important this was," France says. "With the larger group coming together, it was really quite impressive for us all to push to make this happen."

Ultimately, the combination of Coleman's advocacy, pressure from community members and disability organizations, media coverage, and Hullo's reception to change led to a positive outcome. "Jamie was one of the biggest champions... we were able to get an exemption to the High Speed Craft Code that [allowed] guests to stay in their wheelchair," says France. Transport Canada and the Marine Technical Review Board granted the exemption, confirming that Hullo's improved safety measures exceeded the requirements of the Code and effectively ensured passenger safety.

In October 2024, Coleman was the first passenger to officially travel in their wheelchair aboard Hullo Ferries and test



Jamie Coleman was the first passenger to travel on a Hullo ferry in his own wheelchair. Photo credits: NanaimoNewsNOW/Pattison Media

out the new process. “This time, I went with my son and everything aligned. We went over to Vancouver for a hockey game and everything was fine,” he says. More than a year after launching, Transport Canada granted a continuing exemption to Hullo Ferries that allows wheelchair users to remain in their chairs for the duration of their trip. The updated policy went into full effect by the end of 2024 and Hullo passengers can now expect

this standard to be upheld, along with a number of other adjustments to service.

“We now have a dedicated booking flow and an accessibility landing page on our website with information for passengers. When you arrive at the terminal, it’s also noted on that sailing if there’s someone travelling that needs extra assistance and our staff has been trained on how to support individuals,” says France. Going forward, Coleman

hopes that accessibility will be a priority and that concerns will be responded to with sincerity and attention. “This was clearly a discriminatory case and a justice issue. I try to let common sense prevail, but in this situation, there was no common sense to begin with. [The regulation] didn’t make things safer for anyone and it wasn’t beneficial,” he says. “In the end, I’m glad the red tape wasn’t too thick to stop us—but that needs to change.” ■

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Fear of Falling and Exercise Self-Efficacy in People with Neurological Disabilities Who Can Walk: Relationships Between Physical Functioning and Psychological Outcomes

Overview: The SCI Action Canada Lab, under the guidance of ICORD researcher Dr. Kathleen Martin Ginis, invites adults with spinal cord injury whose primary mode of mobility is walking to participate in a series of tests related to balance, sit to stand, and a hand grip strength test.

What to expect: The study involves one visit up to 2 hours in length. Prior to participating in the physical activity portion of the study, the research participants will complete questionnaires relating to: Sociodemographic, Falls Efficacy Scale, Exercise Self-efficacy Questionnaire, and the Leisure-Time Physical Activity Questionnaire for People with Disabilities (LTPAQ – D).

Who can participate: You may be eligible to participate in this study if you are age 18 or older, have been diagnosed with a spinal cord injury or multiple sclerosis, walk as your primary mode of mobility (independently or with walking aids, such as cane, crutches, etc.), and are available for attending one in-person visit at the UBC Okanagan campus in Kelowna.

Why participate: Study participants will receive an in-depth evaluation of their overall balance, handgrip strength, and physical function. Participation in this study will help the SCI Action Canada Lab to advance research on the association between physical abilities, fear of falling, and the confidence to exercise, which will inform the future design of more effective programs to prevent falls in people with neurological disabilities. Compensation for participation is \$25.

Location: This study will take place at the UBC Okanagan Campus, Kelowna.

For more information or to sign up: Please contact Matteo Ponzano by email (matteo.ponzano@ubc.ca) or by phone (226) 505-9470.

Integrating Patient-Centred Outcomes in Rehabilitation and Community Spinal Cord Injury Care

Overview: Patient-centred spinal cord injury care considers the needs, preferences, and values of patients. Completing self-assessment questionnaires at specific time points in treatment can help clinical teams better understand how individuals with a spinal cord injury feel and can function, and plan the next steps in treatment.

What to expect: If you choose to participate in this study, you will complete a short questionnaire and a 20-minute self-assessment on your computer or mobile device. You will be asked about areas such as self-care, resilience, mobility, and independence. You may also be asked to take part in a brief online interview to discuss your experience.

Who can participate: You may be eligible to participate in this study if you are 19 years of age or older, have a spinal cord injury of any type, have completed inpatient or outpatient rehabilitation for a spinal cord injury in Canada at any time in the past, and can read and write in English.

Why participate: You will not personally benefit from participating in this study. However, you might contribute to the advancement of science in the field of patient-centered care for people with a spinal cord injury. To thank you for your time, you will receive a \$20 e-gift card for the self-assessment and a \$25 e-gift card for the interview.

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

For more information or to sign up: Please contact the study coordinator, Jodine Perkins, by email (mortenson.lab@ubc.ca) or call (604) 737-6491.



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 icord.org/research/participate-in-a-study.

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Funding for this study is provided by the Craig H. Nielsen Foundation
This study has received ethics approval from the Sunnybrook Health Sciences Centre.



I Feel Like a Woman...

Women with SCI across the world are facing similar healthcare challenges, according to a new survey from the Global Women with SCI Movement.

Teri Thorson, SCI BC's Manager of Peer Coaching and Outreach, was curious whether other women with SCI shared her struggles. As it turns out, she wasn't alone.

"The idea [for the Global Women with SCI Movement] started from going to international conferences and really realizing there was not a lot of women-specific research. When speaking to other women with SCI, there wasn't anything addressing our unique challenges, specifically around accessing healthcare," says Thorson.

In January 2024, the Global Women with SCI Movement launched, bringing together women with SCI from Canada, the U.S., the U.K., Nigeria, and Uganda. The goal is to, "create a global understanding and awareness of the diverse experiences faced by women with SCI, fostering a world that acknowledges, empathizes with, and leverages these experiences to advance peer, medical, and scientific knowledge."

Their first step? An online survey to understand how women with SCI around the world experience healthcare. To date, 77 women from nine countries have shared their insights. Thorson says, "The biggest takeaway was that it didn't really matter where you lived, all the issues were still the same." Here's what they found:

Experiences of Women with SCI

Women with SCI reported gaps in healthcare and the need for advocacy and resilience. One U.S. woman shares, "I feel like an outsider, especially as the only mom in a wheelchair in my community."

In rehabilitation, women with SCI often deal with isolation, lack of peer

support, and inadequate care that dismisses their identity. Financial and structural barriers only compound these effects. A woman from the U.K. recalls, "Initially I was sent home with care in the community [and] very poor support from inexperienced professionals' knowledge. No advice given on what life will be and the effect on sexual function or mental health." Fortunately, some women have healthcare providers who make an effort to connect. A Canadian woman says, "I was lucky enough to have a few women near my age and ability level to share experiences with [and] to have a female physiatrist... who could relate to my experiences as a woman."

What Women with SCI Want Others to Know

Women with SCI are clear they want to be seen as individuals with rich identities. "We are women with [an] SCI and not spinal cord injured women. See the woman in me before you see the SCI and not the other way around," says a Swedish woman.

Intimacy and relationships also matter. "My value as a sensual woman extends far beyond my ability to use and feel my genitals. It is about my ability to connect physically, emotionally, spiritually, and intellectually with my partner," shares a South African woman.

Positive Healthcare Experiences

Compassionate, patient-centred care makes all the difference. One woman from South Africa remembers, "In rehab after my brace with the halo around my head was removed, they prepared a bubble bath with candles for me... I will never forget it!" Further, a woman from

Canada says, "My family doctor found me a gynecologist with an accessible exam table." When healthcare providers prioritize accessibility and empathy, it empowers women with SCI.

Negative Healthcare Experiences

Sadly, many women with SCI feel dismissed and their women-specific health needs go unaddressed. A Canadian woman shares, "Dealing with a breast cancer diagnosis, I felt that my quality of life was questioned, and I did not get the same amount of aftercare that other women did."

Women with SCI frequently face systemic barriers and must self-advocate for basic care. "I was turned away from appointments because I didn't have someone to assist on an inaccessible exam table," says one U.S. woman. A Nigerian woman describes healthcare providers using "gendered language, referring to me as 'sweetie' and 'honey', which felt condescending and unprofessional." What's more, many women face incorrect assumptions about motherhood and disability. One U.S. woman recalls, "Many nurses look surprised when they find out I am a mother since I'm in a wheelchair."

So, what's next for the Global Women with SCI Movement? Thorson says the group will focus on employment, exploring what services are available and what women with SCI are doing in the workforce across the world.

If you want to share your experiences, take the survey at sci-bc.ca/globalsciwomen. For more information, contact Teri Thorson at tthorson@sci-bc.ca. ■





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1. Hollister Clinical Study, CLR-00847, 2021 2. Hollister Clinical Study, CLR-00847, 2021 3. Hollister Data on File, TR-00643, 2023 4. European Association of Urology Nurses (EAUN), Evidence-based Guidelines for Best Practice in Urological Health Care – Catheterisation, Urethral Intermittent in Adults Dilatation, urethral intermittent in adults (2013), pages 25, 33, 47 5. Hollister Data on File, CL-001027 6. Hollister Data on File, CL-001015 7. European Association of Urology Nurses (EAUN), Evidence-based Guidelines for Best Practice in Urological Health Care –Catheterisation, Urethral Intermittent in Adults Dilatation, urethral intermittent in adults (2013), pages 25, 33, 47 8. Hollister Data on file, CL-001017



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