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## Making Waves

How the Kamloops Adaptive Waterskiing Club is making a splash with SCI BC peers

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1. IC user survey (Countries; US, UK, DE, ML, FR, IT), Jan 2016 (n=2942)

2. Clean Intermittent Urethral Catheterization in Adults – Canadian Best Practice Recommendations for Nurses. Developed by Nurses Specialized in Wound, ostomy and Continence Canada, Canadian Nurse Continence Advisors, Urology Nurses of Canada, and Infection Prevention and Control. 1st Ed. 2020.

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## GOT QUESTIONS?

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**COVER:** SCI BC Peer Coordinator, Tyler Tingle, enjoys a water skiing adventure. Photo by Kamloops Waterski Club.

# IT'S UP TO US

The origin of “Nothing about us without us” can be traced back to the sixteenth century, but it is its recent and highly effective use by the disability rights movement that we are most familiar with. It is a principle that underpinned the development and ongoing implementation of the Accessible Canada Act and Accessible BC Act and is increasingly being used by researchers to guide how they conduct their research.

The concept is simple: people with disabilities and disability organizations should be engaged in the development of laws, policies, programs, and research that impacts them. But what is not so simple is how to go about doing this. And, it comes at a cost in terms of time and individual effort.

“Us” is the trickiest part of the equation. Avoiding a deep dive into what is meant by “us”, engaging the full range of diversity of folks with disabilities is no small task. But it is critical to understand and learn from the full diversity of lived experience because we run the risk of basing laws, policies, and evidence-based decision making on biased input from a select few.

I see genuine effort by our provincial government and research agencies to support engagement with people who do not normally engage in consultation and research. They are providing dedicated resources and partnering with organizations like SCI BC to do so. The trouble is, hard to reach folks are hard to reach and there is a widespread feeling of engagement fatigue that has been exacerbated by the pandemic.

The engagement fatigue is understandable. After being largely ignored for decades, there has been an enormous surge in demand for engagement of people with disabilities in government consultations and research. “Us” only has so much time and patience. Time and patience, however, are exactly what “nothing about us without us” requires. We all complain that change can't come soon enough and that governments and research progress are too slow, but engaging with the full diversity of experience takes time, and it is time well spent. It is particularly well spent when the focus is on insights into solutions as opposed to barriers, which are now widely known.

Engagement also takes effort and sustained effort can lead to fatigue, especially when the pace of change is so slow. But we must continue to participate in the processes that will have direct impact on us because we want those impacts to be meaningfully positive for us. This doesn't mean that we all have to engage in everything — it means that more of us need to engage in everything that is for us, so that folks can take turns subbing out as others sub in.

For all the weirdness that is happening in the world these days, there has never been such an opportunity to advance accessibility and inclusion and meaningful research that is useful and useable. “Nothing about us without us” has led to this opportunity and if we are to capitalize on it, we must all do our part to ensure the “us” is clearly reflected in what is about us.

—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 Sellilwiltulh (Tsleil-Waututh) Nations. Our provincial work takes place on the territories of Indigenous peoples who have lived on and cared for the land for time immemorial. We are grateful to work, share stories, and connect in these spaces.

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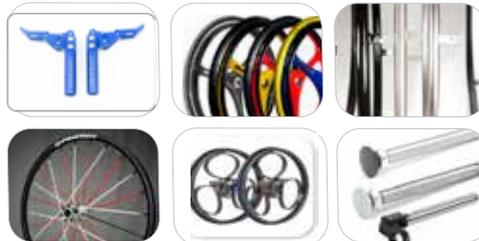
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## gear & gadgets ■

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# Innovations

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**Explore Whistler with SCI BC.**

You're invited to join SCI BC and Whistler Adaptive Sports for our annual Whistler Adrenaline Weekend! Come join the fun from August 18-20 and take part in an action-packed weekend with different adaptive sports, like mountain biking, kayaking, outdoor rock climbing, and so much more! The trip costs \$100 but it covers accommodation, food, and activities for the whole weekend. To register and for more details, connect with Avery at [aalbrecht@sci-bc.ca](mailto:aalbrecht@sci-bc.ca).



**Try adaptive cycling this summer.**

Cycle parks and trails this summer and get a taste of adaptive cycling with our Adaptive Cycling Program! The Program runs until October and offers new riders a chance to learn the basics and get fitted for the right handcycle in an Adaptive Bike Clinic & Ride (ABC+). Our Bring Your Own Bike (BYOB) group rides give you the opportunity to explore neighbourhood trails and connect with other adaptive cyclist enthusiasts. Visit [www.sci-bc.ca/cycling](http://www.sci-bc.ca/cycling) for more information.

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## peers ■

A beat-dropping kudos to Nanaimo DJ **MAT THE ALIEN**, who recently received a Creative BC grant to put out a new EP. An iconic DJ on the electronic music scene, people have been grooving to his beats at venues and festivals around the world for years. In 2020, an SCI from a mountain biking accident changed Mat's life but not his passion for making music. As stated on his website, "Some of the best art is born in the throes of struggle and Mat has solidified the power of that." Press play for Mat the Alien at [www.matthealien.org](http://www.matthealien.org).

# Peer 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](mailto:thespin@sci-bc.ca).



A page-turning shoutout to **DR. JON BREEN** on the publication of his new book, *Disability in the Workplace: The Politics of Difference*. Jon recently obtained his PhD in Social Work at UBC and is currently a postdoctoral fellow with the co-author of the book, ICORD investigator and Head of UBC's Department of Occupational Science and Occupational Therapy, Dr. Susan Forwell. Building on his research on the theoretical and practical understandings of disability, particularly as these apply in the workplace, the book introduces the difference model of disability. As described by the publisher, "Framed within an affect-based understanding of the relationships between those living with impairments and others, this new model offers a reconsideration of the construct of disability itself. Disability is flexible, relational, and perceived through an acognitive lens." The book is available in print and e-formats at Amazon, Indigo, Routledge, and other vendors and libraries.

A high impact cheer for Canada's first-ever Women's Cup Wheelchair Rugby team, which made its international debut at the 2023 Women's Cup in Paris this past March. The team, which included BC's **JESSICA KRUGER, TIANA HESMERT, AND JULIA HANES** and was coached by **KENDRA TODD** and our very own **TERI THORSON**, got off to a shaky start but pulled it together to take the tournament's bronze medal. As Todd told CBC, "I think it's often that women are not always viewed as just as athletically capable as men, especially in a co-ed sport. I think women having the opportunity to be leaders and show just how athletically capable they are, and how dedicated and fierce and how strong of a competitor they are, I'd like to say it's about time." About time it is!

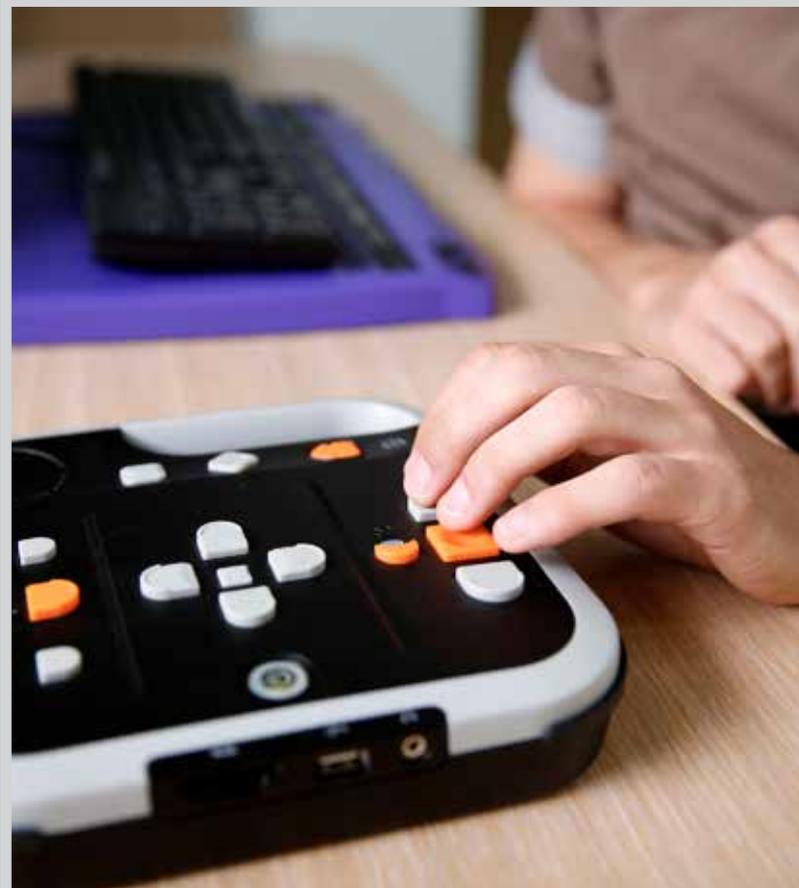




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# Making Waves

How the Kamloops Adaptive Waterskiing Club is making a splash with SCI BC peers.

**R**esourcefulness is something SCI BC Peers know a thing or two about. How can I find a way to reach that top shelf? How could I improve the fit of my chair? How can I modify my car to start driving again? After an SCI, being resourceful almost becomes second nature. Whether it's to solve everyday problems, get back to something you love, or try something new - the ability to adjust to any situation is crucial. According to Paul Dixon, President of the Kamloops Waterskiing Club (KWSC), the same is true for waterskiing. "Adaptive waterskiing is all about

resourcefulness [and] each participant has different needs that have to be considered and accounted for," says Paul. And that's exactly what KWSC aims to do for every participant that wants to give waterskiing a try.

Established in 1982, KWSC has grown from humble beginnings with a few members skiing on the Thompson River to hosting the 1993 Canada Summer Games, and eventually establishing a permanent facility on Shumway Lake. Ten years ago, KWSC evolved again to incorporate adaptive waterskiing into their regular portfolio of offerings and

began hosting clinics for interested participants. "The very first skier we got up and out of the water and skiing on their own was amazing and really set the tone for the clinic and the resulting success we have had," Paul recounts. Since then, the Club has facilitated annual summer clinics for people with all types of physical or intellectual disabilities. For people with SCI, Paul notes that a range of beginner to advanced skis are available, with beginner skis offering more balance and stability while advanced skis cater to speed and more aggressive turns.

Each ski comes equipped with a seating frame (also known as a cage) that allows skiers to be supported while moving across the water. These cages vary in size and height to accommodate people's needs and every clinic starts with an orientation session to get familiar with the equipment and find the proper fit. Once you've found the perfect ride and appropriate life jacket, your turn behind the boat is accompanied by an able-bodied side skier from KWSC, who will instruct you with the basics, and an NCCP certified SkiAbility coach will also be in the boat to ensure that participants have the best chance of success as possible. In addition, there are often a number of former national team Para athletes on hand for further guidance. "The participants' experience can be tailored to what they are comfortable with. They can be fully supported the entire time or they can choose to be let go so they can try on their own and practice turning," Paul explains. "It's one of the few sports that you can judge how well you are doing versus the week, month, or year prior." As participants build confidence in

their skills, there are opportunities to advance beyond recreation.

Rob Gosse, an SCI BC peer who first took to the water in 2007 knows firsthand what it's like to try the sport and advance to the next level. After a spinal cord injury in 2006, Rob was determined to get back to his active lifestyle and take part in the activities his children loved. This desire led him first to para-alpine skiing, where he competed provincially and on the North American circuit, and eventually transitioned to adaptive waterskiing. "My first experience waterskiing ... we had two pulls around the bay on a beautiful summer day—sun was shining, I was in my glory," Rob recalls. "[Since then] I had always wanted to figure out a way to get more days out on the water and to be able to do it more than once a year. In 2009 I bought my boat, had bought a slalom ski, and I found some friends to be able to pull me behind my boat to be able to go for a ski whenever I wanted." His passion and skill for the sport quickly grew and Rob made the Canadian National team in 2014 where he competed for three years in slalom,

trick, and jump events. "My favourite event is slalom," he says. "I competed in the Worlds for disabled waterskiing in 2017 in Australia and it was such an incredible experience for me!"

Nowadays, Rob focuses less on maneuvering through buoys at impressive speeds and more on giving back to the waterskiing community that helped him experience so many things. "It means a lot for me to not only coach the athletes [but also] to be able to coach the coaches to be able to teach adaptive waterskiing. I recognized a lot of holes in the system from the grassroots to the podium and want to help bridge that gap for the athletes coming through and wanting to help them succeed in their own goals. If it is just to go for a pull around the lake, or to be able to compete and represent Canada in the Worlds," he says.

Some of the gaps that Rob refers to include inaccessible locations and a lack of awareness. "Most waterski sites are not accessible. Kamloops is one of the few that is fully accessible. Any site I attend, I always bring my freewheel to make the experience easiest possible for me... Waterskiing isn't well known for





Paul Dixon, President of the KWSC

the adaptive community, for one reason or another,” he says. Similarly, Paul also hopes that the profile of the sport will grow along with participation. He notes that additional programs at other locations would help increase the access and visibility of the sport and highlights sessions running in Vancouver, Prince George, Alberta, and Saskatchewan. Above all, he just wants people to have the chance to experience the feeling of being out on the water. “Getting first

timers up and behind the boat and on their own if capable is truly rewarding. The grins and smiles of the participants say it all.”

For our very own SCI BC Peer Program Coordinator, Tyler Tingle, getting out on the lake was all about experiencing this feeling of joy and sharing it with others. “The first clinic I went to was the first time I had water skied since before my SCI back in ‘89. I loved it and have attended all but one clinic since the inception,” he says. “I take a couple laps around the lake but love to help out someone new who hasn’t tried adaptive skiing before... We got 11 people out for the first one-day clinic,” Tyler recalls. “Everyone got up skiing that day, paras, quads, and amputees, as well as others.” This sense of accomplishment and fun led Tyler to pursue competitive waterskiing for a period and he sat on the board of KWSC while motivating others to get involved. During this time, he also attempted the mighty five-foot ski jump at KWSC clinics but after a femur break and some advice

from his doctor, he ultimately decided that his passion was better suited to trying to grow the sport through his connections with the community. Now, the Kamloops resident is a board member for the Kamloops Adaptive Sports Association (KASA) and Accessible Okanagan (AO), where he encourages peers without any background in water sports to come out and give it a try.

Paul and Rob both echo this encouragement. “I had a participant who expressed to me, as we were lowering him in the water, that this was the first time since his accident [more than two years prior] that he had been in a lake,” Paul says. For KWSC, creating memories like this is often more important than learning to ski. There’s something magical about spending a summer’s day on the water, and success isn’t measured by going faster or further, but by smiles. As Rob reiterates, “To anyone that has any interest in seeing it, come out and see how it goes! [You] don’t have to ski if you don’t want to but come out and enjoy the day!” ■

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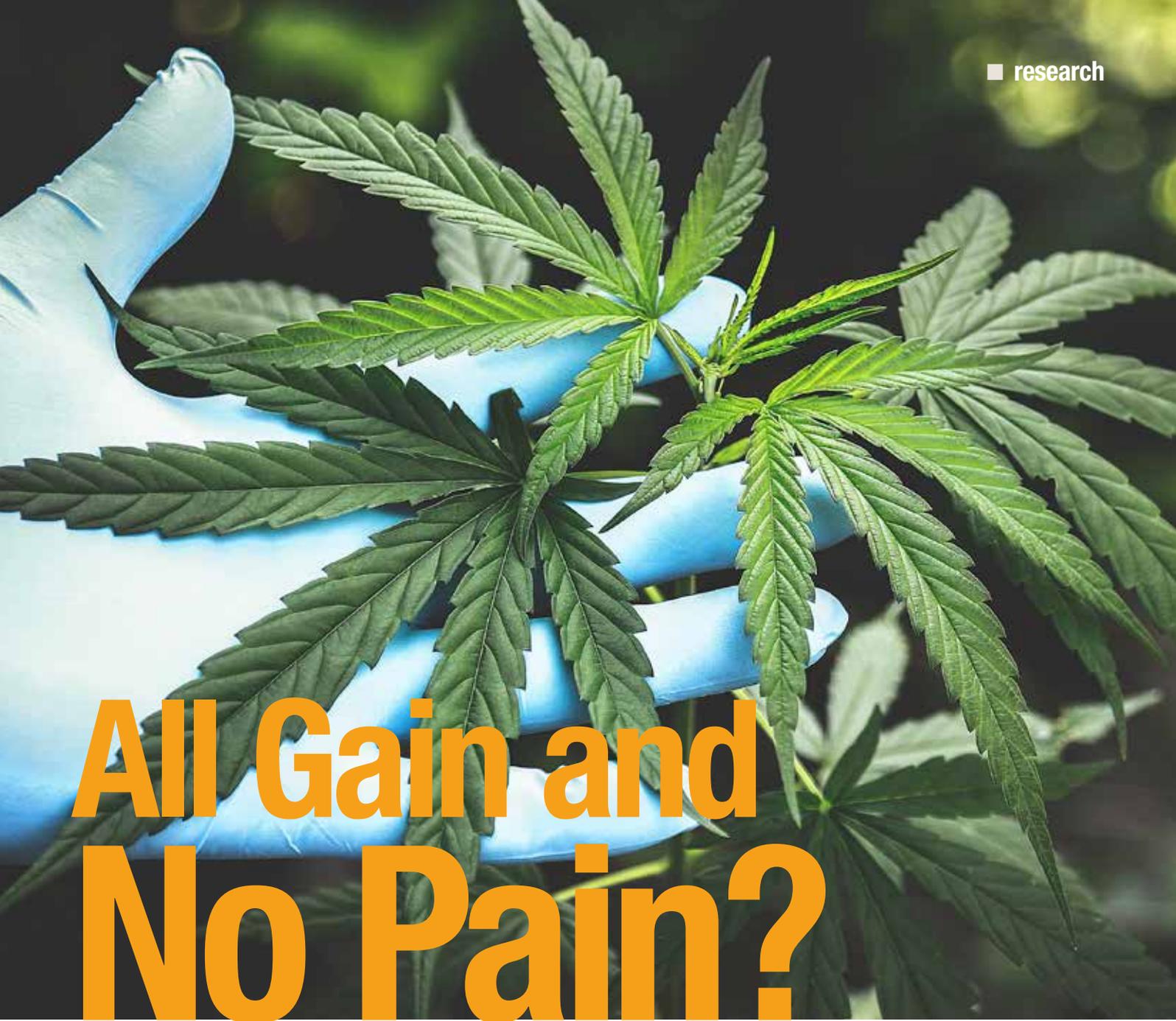
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# All Gain and No Pain?

Scientists at Australia's University of Sydney have been awarded \$1.7 million to find out if cannabis can effectively treat chronic pain in people with SCI.

**T**here are two reasons the headline of this article may have caught your attention. Either you're one of the estimated 53 percent of people with SCI who experience neuropathic pain, or you're one of a growing number of Canadians turning to cannabis as a prospective salve to improve sleep, reduce anxiety or, you guessed it, treat chronic pain.

If you fall into the first group—we know there are a lot of you out

there—and you're one of our dedicated readers, you probably already know that neuropathic pain is a frequent topic of conversation for us. We've covered everything, including cognitive therapies, physical exercise, skin creams and medications, all in our effort to support the SCI community with evidence-based solutions to the problem of chronic pain. While medications, including antiepileptics, antidepressants and opioids are the most common treatments for this prob-

lem, the potential for pain relief must often be balanced with a host of negative side effects, ranging from dizziness and drowsiness to drug dependence.

We also know that many of you fall into the second group. You've typed "cannabis and chronic pain" into the search bar of your web browser or talked to a friend who swears by cannabis for pain relief. Perhaps you've even used cannabis as a way to successfully manage your own pain.



*Luke Henderson analyzes MRI results.*

The problem is that (despite what the internet, your friend, and your personal experience might suggest) we don't have any consistent scientific evidence to show that cannabis is an effective treatment for neuropathic pain following SCI. And without a strong body of evidence, finding support for cannabis as a pain treatment—from medical prescriptions to insurance coverage—as well as guidance for a safe and effective dosage, can pose a significant challenge. But thanks to a new trial underway in Australia, we might have that evidence as early as 2024.

In partnership with the Lambert Initiative for Cannabinoid Therapeutics, a group of researchers led by the University of Sydney's Professor Luke Henderson was awarded \$1.7 million Australian dollars (approximately \$1.5 million Canadian) from the New South Wales government to examine if cannabidiol (CBD), the non-intoxicating component of cannabis, is safe and effective for reducing neuropathic pain in people with SCI. The trial also aims to tease out the possible reasons why chronic pain develops, and the potential ways CBD might improve it.

"If effective, this trial will provide gold-standard evidence to support the use of CBD to patients with neuropathic pain following spinal cord injury," says Dr. Anastasia Suraev, the trial coordinator and a Research Fellow in the School of Medical Sciences at the University of Sydney. "It can also help to inform and ultimately change policy surrounding the prescription of medicinal cannabis for the treatment of neuropathic pain and improve patient access."

Globally, this trial is the first of its kind. While research indicates that CBD is a promising treatment option for neuropathic pain, the strength of the evidence to date is lacking.

For example, research with animals shows that CBD is an effective way to reduce pain hypersensitivity that develops during neuropathic pain. In addition, a recent trial suggests that nabiximols (sold under the brand name Sativex™), a mouth spray containing equal parts CBD and tetrahydrocannabinol (THC), the psychoactive component of cannabis that produces the "high" sensation, can reduce neuropathic pain compared to a placebo (a substance that does not contain the active ingredient, but appears identical to the active drug).

But when looking at CBD alone as a treatment for neuropathic pain in humans, Dr. Suraev warns that the findings of the research must be heeded with caution. While it's possible that CBD may be an effective way to reduce (and

possibly prevent, in the case of cancer patients going through chemotherapy) neuropathic pain, the way that existing research was designed and carried out increased the likelihood of bias and placebo effects. In other words, the effects of the CBD may have been due to the participant's belief in CBD as a treatment for neuropathic pain, rather than the CBD itself.

"In fact, no randomised, double-blind, placebo-controlled trial—the most rigorous way to test the potential benefit of a medication for a specific condition—has been conducted to-date exploring the efficacy and safety of oral CBD in the treatment of neuropathic pain, let alone neuropathic pain following SCI," says Dr. Suraev.

What this means is that neither the participants nor the researchers in the trial know who is getting a placebo and who is getting the active drug, and that participants are randomly assigned to a treatment group, limiting the influence of either the participant's or the researcher's belief about the treatment's effectiveness. The effectiveness of the treatment is then compared against the placebo to find out how well the treatment worked. This is the "gold standard" of evidence that the University of Sydney-based research team seeks to achieve.

According to Rebecca Robertson, a PhD Candidate in the School of Medical Sciences at the University of Sydney fo-



*Rebecca Robertson*



*Dr. Anastasia Suraev*



*Rebecca Robertson prepares a participant for an MRI scan.*

ocusing on the study of neuropathic pain following SCI, the trial began in June 2022 and it will run until mid-2024. Participants will get to trial both CBD and a placebo in random order over two six-week periods, and each period will be separated by a four-week “washout” to make sure the first treatment (CBD or placebo) is no longer in their system.

“During each treatment period, participants will be asked to rate their pain and wear a wrist-worn device that measures their sleep,” says Robertson. “Before and after each treatment period, participants will be asked to attend Neuroscience Research Australia (NeuRA), a leading medical research institute in brain and nervous system research, for a magnetic resonance imaging (MRI) and electroencephalogram (EEG) scan, questionnaires about their pain, sleep and mood, and a blood test.”

The research team will use the MRI and EEG scans to examine functional, structural and chemical changes in participants’ brains over the course of the trial. Likewise, they will use the blood tests to examine changes in participants’ blood after each treatment period. These measures will be combined with participants’ self-reported

pain, mental wellbeing, and sleep to assess if, how and why the CBD treatment works or doesn’t work when compared to the placebo, says Robertson.

“Together, these measures will allow us to build a holistic picture of the changes that may underly an effective chronic pain therapy, and why it is or isn’t effective—with the main goal being a reduction in pain during the CBD treatment,” she explains.

Because CBD is non-intoxicating and has relatively few side effects (even at high doses), it is considered an ideal long-term treatment, says Robertson. “The main concern related to CBD’s safety is the potential for drug-drug interactions that might occur when CBD is co-administered with standard treatments,” she explains. “However, this can be managed with slow increases in dosage and careful monitoring.”

Ultimately, the trial will aim to identify and understand mechanisms that lead to neuropathic pain after SCI and predict individual responses to CBD treatment. For example, the research team hopes to identify biomarkers that will indicate who is most likely to benefit from CBD treatment, says

Robertson. If the CBD treatment is effective, the trial has the potential to provide individualized, evidence-informed guidance around the dosage of CBD that can safely and effectively treat an individual’s neuropathic pain.

The trial could also lay the foundation for advancements in neuropathic pain research more broadly, claims Dr. Suraev. “The potential wider impact of this trial is a deeper understanding of the underlying causes of chronic neuropathic pain (with or without SCI) which could lead to even further refinement of therapy,” she explains. “Success of this trial would trailblaze future research on the benefits of CBD in other neuropathic pain conditions which, much like neuropathic pain following SCI, remain undertreated and misunderstood.”

Preliminary findings of the trial will be available in late 2024 or early 2025, says Robertson. Until then, we’ll have to wait for a better understanding of the role that CBD can play, if any, in neuropathic pain treatment. Stay tuned—we’ll keep tabs on how the study progresses and report back when the results are in. ■

# Rehab for Rehab

Our systems for hospital and community-based rehabilitation and recovery are in need of their own rehabilitation.

**W**e are fortunate in BC to have some of the best health care professionals and community service providers dedicated to supporting people with SCI, but the reality is that not everyone can access them when they need them. Our health systems are under immense stress and key infrastructure is aging and in need of renewal. Decades of budget belt tightening have disproportionately put the squeeze on rehabilitation and recovery care and services, resulting in inequitable access to care and services and a loss of true expertise in SCI. It may not be fair to say the system is broken, but it is obvious that it is severely challenged and that many people with SCI and other conditions are suffering unnecessarily as a result.

Times of challenge, however, present times of opportunity. And there is now an incredible opportunity to reshape

our system of rehabilitation and recovery. But how? This is the question two parallel, complementary, collaborative, community-centred initiatives set out to answer.

The BC Rehabilitation and Recovery Strategy and Advocacy Plan (the BC R&R Strategy) project is a collaboration between the Heart & Stroke Foundation, SCI BC, After Stroke BC / March of Dimes Canada, the BC Brain Injury Association and Brain Wellness Program, researchers, health professionals, and individuals with lived experience of SCI, stroke, and brain injury. Funded through a grant from the Vancouver Foundation and facilitated by the Emily Carr University Health Design Lab, the project examined post-hospital rehabilitation and recovery across SCI, stroke, and brain injury.

As a member of the BC R&R Strategy steering committee, SCI BC helped co-design a series of twelve online workshops with health care profession-

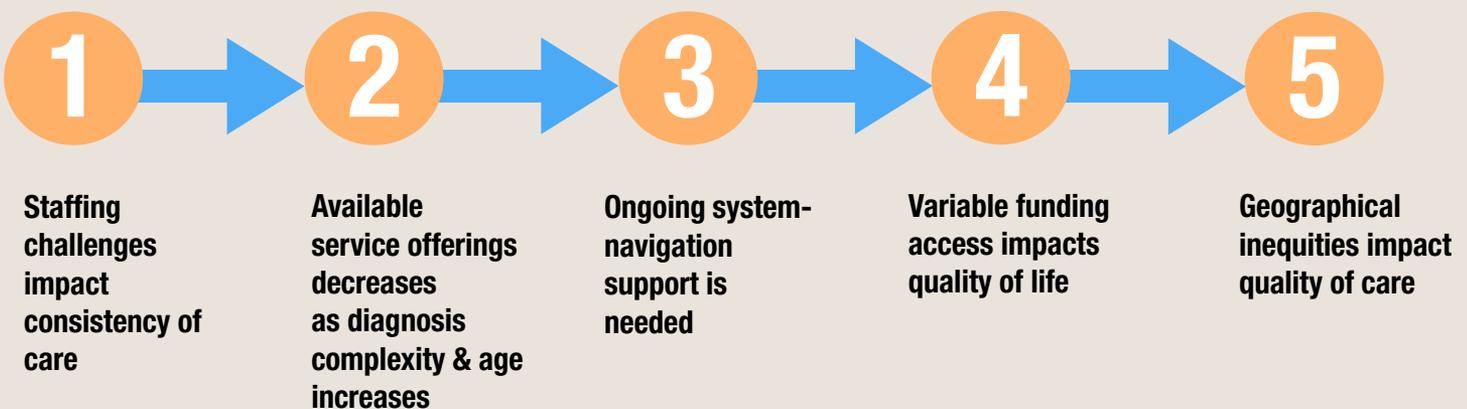
als and people with lived experience of SCI, stroke, and brain injury. Held in the spring of 2022, the workshops set out to understand the experience of people who both work and live with British Columbia's current system of rehabilitation and recovery for these three diagnoses and to learn about their ideas to improve that system.

In all, 49 people participated in the workshops, including 7 SCI peers and 11 health professionals and researchers from across the province.

The SCI Care Strategy is an SCI community-led initiative facilitated by the Rick Hansen Foundation that is engaging health authorities, practitioners, and researchers, and is closely informed by individuals with SCI. Whereas the BC R&R Strategy focussed on post-hospital rehab and recovery, the BC SCI Care Strategy focused on all aspects of care for traumatic and non-traumatic SCI - from the time of injury onward. As an actively engaged partner in both

## CURRENT EXPERIENCES OF REHAB & RECOVERY IN BC

(From findings from the BC Rehabilitation and Recovery Strategy)



## FUTURE CONSIDERATIONS

**1. How can we enhance provincial networks for professional support & learning?**

**2. How can we increase long-term support over the life span by investing in community-based programming & supports?**

**3. How can we formally integrate roles for people with lived experience through the recovery journey?**

**4. How can we enhance coordination of services and information across the continuum of care?**

## 9 PRIORITIES for improving BC's system of rehabilitation and recovery for SCI, stroke, and brain injury.

1. Create a BC-wide agency with responsibility for establishing a rehabilitation strategy and integrated care model.
2. Operationalize a hub-and-spoke network of practitioners and facilities, through training and mentoring, mobilization of specialist multidisciplinary clinics, and greater use of technology to extend patient reach, notably in rural and remote locations.
3. Expand acute care infrastructure to fulfil unmet and expected new demand, including facilities renewal and alignment of governance and funding at GF Strong as an anchor for broader system redesign.
4. Establish a program of trained navigators, with roles for peers with lived experience, to support patients and their families in making the transitions from acute care to the community and to facilitate connections with health, community care, and social services and programs.
5. Institute income support for those unable to work and not covered by WorkSafe or ICBC, in addition to non-means tested support to ensure access to essential care, equipment, and services.
6. Increase funding for physiatrists and allied health professions, as well as home service workers, and align post-secondary training accordingly, to help assure timely access to experienced health practitioners.
7. Formalize resourcing for the network of community groups operating in stroke, SCI, and brain injury, leveraging their autonomy and on-the-ground experience to enhance information and supports for people living with these and other chronic neurological diagnoses.
8. Create more transportation options for short- and long-distance patient transfers to strengthen patient experience and the ability to attend work and access health care and other services.
9. Consistent with the broader provincial housing agenda, develop more inclusive and accessible accommodation – from transitional housing post discharge to specialized long-term care to affordable homes – improving both patient lives and utilization of high-cost acute facilities.

initiatives, SCI BC has played a central role in coordinating communication between them.

Between the two initiatives, over 200 persons with lived experience, practitioners, researchers, and organizations shared their experiences within the system and insights on how to improve it. And while the two strategies used different approaches to gather this input, what was heard was so similar that it was possible for the two initiatives to develop a joint set of recommendations for advancing rehabilitation and SCI care in BC.

The joint recommendations will be made public soon, but in the meantime, we can provide you with a summary of what it will contain.

Currently, the system faces two core structural challenges. One is the barriers to provincial coordination of health and community services, a challenge reinforced by the artificial boundaries created by the way our health authorities are set up. This lack of provincial coordination compromises transitions during different phases of one's journey as a patient and com-

munity member. It also adds to the burden of navigating through different health systems and services. The other is a lack of capacity when it comes to appropriate health care infrastructure and rehab professionals with SCI expertise. This creates major hurdles and reinforces regional and social inequities to accessing care and services.

When it comes to imagining a new model of care in SCI, there first needs to be a recognition that SCI (and stroke and brain injury) is a lifelong condition that requires ongoing, specialized health and community services. A coordinated systemic approach to these services and information about and how to access them is required. For this to happen, rehabilitation must be viewed as a provincial priority, with more practitioners and providers, equipment and spaces, and research to better meet the needs of those impacted by these and other injuries. Having centralized SCI expertise and specialized centres is necessary, alongside regional capacity building and use of technology to sustain excellence and consistency in care across BC.

Along with these high-level recommendations, nine priorities the province should act on have been put forward. These priorities range from establishing a BC-wide agency responsible for a provincial rehab strategy and integrated care model to creating roles for peers in the system, to ensuring people with SCI, stroke, and brain injury have the financial supports, housing, and essential needs and services to maximize their health and quality of life. (See the list above and infographic on previous page).

We know the recommended changes cannot be made soon enough, but the reality is that there is much more work to do. The work done so far has set a general plan for the rehab and recovery system's own rehab and recovery journey. The next phase of the journey will require the development of a detailed operational case for change and political will to support it. This will take time, but some changes can be made sooner and more easily than others. With so many of us working together, the push for change is a strong one. We'll keep you posted on the progress we make. ■

# When it comes to sex and spinal cord injury, we're all about kissing and telling.



[SCIssexualhealth.ca](https://SCIssexualhealth.ca)

Questions about SCI and sexuality, fertility, relationships, and more? Spinal Cord Injury BC's SCI Sexual Health website has you covered. Created in partnership with The Sexual Health Rehabilitation Service in Vancouver, BC this website provides the answers you need.

You can access the Sexual Health Rehab team online at [SCIssexualhealth.ca](https://SCIssexualhealth.ca) or by phone at **604-875-4111 ext 69850**.

## Save energy & money

SCI BC is teaming up with FortisBC and BC Hydro to offer SCI BC members personalized advice and home installation of energy-saving products – at no cost to you.

Some households may even qualify for a new fridge, insulation, or a natural gas furnace.

**Call our InfoLine for more info:**

**1-800-689-2477**

This program is available to owners or renters living in single-family homes, townhouses, and duplexes.

We're working together to help B.C. save energy.



\*Products installed depend on the individual characteristics of the home and other program criteria. Only FortisBC natural gas heated, FortisBC electrically heated or BC Hydro electrically heated single family homes, townhouses and duplexes may be eligible for insulation upgrades. In addition, only FortisBC natural gas heated homes may be eligible for furnace replacement. Other program criteria apply. Apartment units and mobile homes are not eligible for insulation or furnaces. Offer subject to change.



## DR. K PROVIDING SCI CARE IN UKRAINE

Well known to readers of *The Spin* as a leading SCI researcher at ICORD and physiatrist at GF Strong, Dr. Andrei Krassioukov (better known as Dr. K) recently travelled to Ukraine as part of a World Health Organization team of SCI experts to set up a new national SCI rehabilitation centre for military personnel injured during the war. On returning from his first trip, Dr. K asked SCI BC to produce Ukrainian language versions of our health info wallet cards (available upon request by contacting [info@sci-bc.ca](mailto:info@sci-bc.ca)). We obliged and are pleased to hear they have been appreciated by those who have received them. Although many of Dr. K's experiences in providing care at the Ukraine centre have been similar to those here in BC, he notes some stark differences. As he stated in a story by ICORD, "These are young men who don't have homes. Their homes are under siege or have been totally destroyed. This is one of the most challenging and heart-breaking situations I have faced. I can give recommendations for how to manage some physical challenges, but how will they get adjusted to their community? I don't know. This uncertainty adds a whole extra layer of complication on top of physical rehabilitation."



## HEATHER LAMB'S SOCIAL WORK AWARD

If you've ever called SCI BC's InfoLine, there's a good chance you spoke with InfoLine Services Lead and Information Resource Specialist, Heather Lamb. And if you did, there's an even better chance you valued the excellent service she provided, an excellence that has not gone unnoticed by her peers. In March, Heather was honoured by her social work colleagues with the Canadian Association of Social Workers (BC) Distinguished Service Award. The selection was made by the Board of the BC Association of Social Workers and awarded during National Social Work Month and BC Social Work Week. She received the award from social work colleague Beth Quesnel and Minister of Children and Family Development Mitzi Dean via a ceremony on Zoom. This is not the first time Heather has been recognized for her outstanding service. In 2016, Heather received the Bridget Moran Award, which is presented annually by the BC Association of Social Workers, Northern Branch (BCASW) to a northern social worker who has made significant contributions to social work and Northern BC.

# Community Highlights

## RESEARCHERS OF THE YEAR

SCI BC is proud to partner with some of the best SCI researchers around. And when we say the best, we mean it. Take for example, Dr. Heather Gainforth and Dr. Femke Hoekstra, who were recognized for their excellence by receiving two of UBC Okanagan's most prestigious awards. Gainforth, an ICORD Investigator who leads the Applied Behaviour Change Lab, was honoured with the 2023 Researcher of the Year for health research. Hoekstra, who conducts her research with Gainforth and Dr. Kathleen Martin Ginis, received the inaugural Postdoctoral Fellow Researcher of the Year. Gainforth and Hoekstra have partnered with SCI BC on a wide range of research studies over the past several years. They take an integrated knowledge translation approach that fully embraces the principle of nothing about us without us, which they know is key to producing research that is relevant, useful, and useable. You may have seen Gainforth at our recent Ask an Expert: How to use science to change your behaviour session, which you can check out at [www.youtube.com/spinalcordinjurybc](http://www.youtube.com/spinalcordinjurybc).



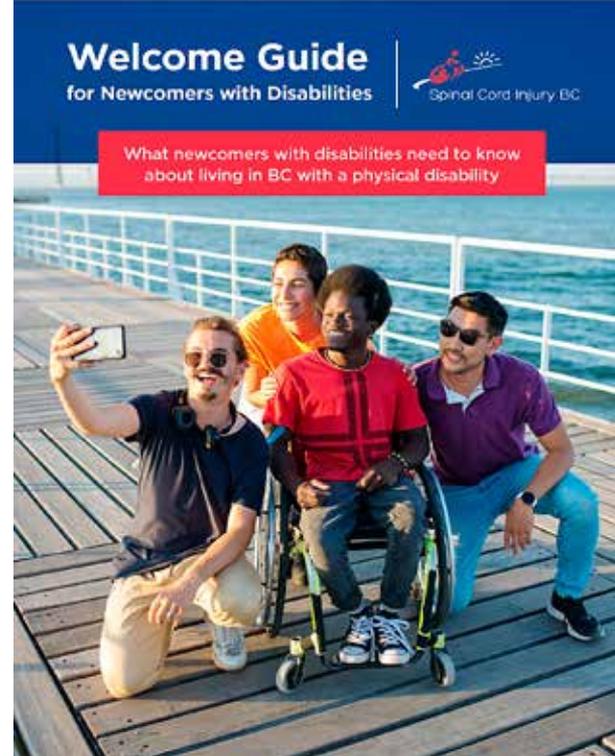
Dr. Femke Hoekstra (left) and Dr. Heather Gainforth (right).

# PeerSAY

Navigating spinal cord injury can be a bumpy road, but for newcomers to Canada with SCI, it's part of a much bigger journey – just ask SCI BC peers Walid, Maha, and Agasha. After arriving in Canada they each had to find their way through complex education, social service, and settlement services. They weren't alone. Coinciding with numerous global events, SCI BC's InfoLine team noticed an increase in requests to InfoLine from newcomers with SCI looking for help with accessible housing, healthcare, and medical equipment. Around the same time, newcomer and SCI peer mentor Jana Husseini saw the chance for SCI BC's peer support community to fill the void with just the kind of useful information needed to adjust, adapt, and thrive in BC with a disability.

Husseini worked with SCI BC's Jocelyn Maffin and Heather Lamb, along with the input of settlement workers and newcomers with disabilities, to create the *Welcome Guide for Newcomers with Disabilities*. As the Guide was being finalized, Husseini and Bahar Taberi of the BC Refugee Hub adapted key sections into a series of fact sheets and videos that could be easily translated, including interviews with two SCI BC peers, Walid Huseeni and Maha Al Sedawi.

We asked Walid, Maha and SCI BC staff member Agasha Mutesasira to share some of the obstacles they had when they first came to Canada.



You can find the Welcome Guide for Newcomers with Disabilities and links to the fact sheets and videos on our website: [www.sci-bc.ca/newcomers](http://www.sci-bc.ca/newcomers).

## WALID, 37, SYRIA



The first six months are a little difficult because we don't speak English. So, it's very difficult to go outside. Sometimes I took the bus, and the driver asked me, "Where are you going?" I couldn't answer because I didn't speak English. The first six months were so difficult but now every day I smile, go out, do a lot of things. Before, when I came [to BC], life was very difficult. The first six months were very difficult. I couldn't sleep well, my doctor had trouble understanding my disability. Now I'm better, every year I'm better.



## MAHA, 30, SYRIA



We didn't have an electric wheelchair. It was hard for us to go and come back [from school and home]. These were some of the difficulties we were facing when we first came. Transportation without an electric chair is difficult. You might miss some appointments because of it. We adapt but we keep asking for our needs because there is no other solution.

Going to school every day makes me feel much better than staying at home. I'm so proud of myself! While I have a disability and have difficulties with studying English, it's been very successful for me.



## AGASHA, 24, UGANDA



When I first moved to Canada there was quite a lot to process and navigate. In my first year, I needed to know where to find parts for my chair when my caster broke. My chair isn't sold in Canada.

Finding information that I needed was overwhelming and never all in one place. Over the years I have learnt to ask for help and look for information where needed but when I first got here it felt daunting to ask and somehow embarrassing that I did not know that information.

For my school program, I needed to get co-op work placement. I wish my university had more information on navigating the work scene with a disability.

I like to be active, but I didn't know that there were so many cool ways to do activities with a disability. If I hadn't made those connections that I did, I don't think I would have known or taken part in them.



# ask the SPIN DOCTOR

Q: “I’ve been dreading an upcoming colonoscopy because of how hard the preparation is. I’m afraid of getting a pressure sore from sitting on the toilet that long and I don’t have enough caregiver time to help me with it. Is it really necessary?” asks Simran in Kamloops. We asked Dr. Karen Smith, Physiatrist and Emeritus Professor in Physical Medicine and Rehabilitation at Queens University, and co-author of the *Actionable Nuggets* ([www.actionnuggets.ca](http://www.actionnuggets.ca)).



Simran, you are not alone in feeling this way as preparing for a colonoscopy can be challenging. It is important to discuss the medical reasons for colonoscopy with your physician and how bowel preparation could be adjusted to make it practical and safe for you.

There are some conditions where a colonoscopy for colon cancer screening might be unavoidable, such as a family history of colon cancer (cancer in a first-degree relative, such as a parent, brother, sister, or child), a personal history of precancerous polyps, or inflammatory bowel disease.

In our brief clinical guidance resource on primary care for people with SCI, the *Actionable Nuggets* (4th Ed.), we advised, “Initiate colorectal cancer screening for patients with SCI using the same principles as those for the general population.”

Colorectal cancer is about as common in individuals with SCI as the general population but harder to screen for and often diagnosed at a more advanced stage. Decreased sensation and mobility can prevent individuals with SCI from recognizing symptoms that would be evident to someone without SCI. Because symptoms of colorectal cancer relied on for screening, such as rectal bleeding, are seen more often in people living with SCI due to neurogenic bowel, routine screening for colorectal cancer is essential.

As with the general population, individuals with SCI between the ages of 50 and 74 years with no family history should be screened for colorectal cancer according to current Canadian guidelines, which have been updated with the availability of the fecal immunochemical (FIT) test.

People are considered to be at average risk of colorectal cancer if they are aged 50 to 74 years with no first-degree relatives who have been diagnosed with colorectal cancer, and who have no personal history of pre-cancerous colorectal polyps or inflammatory bowel disease.

People at average risk and asymptomatic for colorectal cancer should be screened with a FIT test every 2 years (abnormal FIT results should be followed up with colonoscopy within 8 weeks). Those who choose to be screened with flexible sigmoidoscopy (FS) rather than a FIT test should be screened every 10 years.

FIT tests are at-home test kits provided by a clinician that check stool for very small signs of blood and do not require any special bowel preparation. However, because rectal bleeding is both a symptom of colorectal cancer and very common after SCI, flexible sigmoidoscopy is the screening

test recommended for people with SCI if they have a history of rectal bleeding. Flexible sigmoidoscopy is performed by a trained medical professional who uses a narrow, flexible tube fitted with a light and camera to look inside the lower part of your colon. It is a less invasive test that involves less bowel preparation than a colonoscopy.

Colonoscopy is not recommended to screen for colorectal cancer in individuals at average risk. Preparation for colonoscopy, which permits direct visualization of the large bowel in its entirety, is a significant ordeal for someone with neurogenic bowel, to the extent that it is often incomplete and produces compromised results. It is recommended only in the case of a positive screening test. In some cases, colonoscopy for individuals with SCI is done in an inpatient setting; however, inpatient admission for elective procedures can be difficult to access. A consultation with a gastroenterologist may also be required, but this is often not available in many regions. Given this, a physiatrist can be a good starting point for planning the procedure.

When colonoscopy is recommended, how can it be accomplished with the least risk to skin and autonomic dysreflexia (AD), without increased caregiver support, and with the greatest chance of successful screening? Preparation for a colonoscopy typically involves changing to a clear liquid diet. However, alternatives suggested for colonoscopy bowel prep indicate that a more prolonged period of clear fluid diet of three days, in addition to magnesium citrate, polyethylene glycol (PEG) 3350 and/or electrolyte lavage solution orally had 89 percent adequate colon preparation. I recommend to my patients with SCI to prolong the period of clear fluid diet to three days but otherwise follow the recommendations of the colonoscopy unit, usually involving a combination of oral laxatives.

I encourage my patients to work with their care team to explore the possibility of additional care in the home, using measures to reduce the time needed on the commode, such as briefs or blue pads for the first few hours, or the possibility of respite care in your area. If you are at high risk of AD, I strongly recommend that you speak with your doctor or physiatrist about completing the later portions of the bowel preparation under some supervision or with a clear plan in the event you experience autonomic dysreflexia.

Everyone’s situation is unique but I hope this gives you some reassurance and information to work with your health-care provider to do what is best for you.

# 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.

## Physiological Impact of the AAPLEwalk Sit to Stand Exercise Machine

**Overview:** Through this study, Dr. Jaimie Borisoff aims to explore the usability and acute physiological potential of a new sit to stand exercise machine that is being developed at BCIT. To do this, researchers in the Borisoff lab will be engaging users who have mobility impairments to test their novel sit to stand exercise machine prototype and provide feedback on their experience.

**What to expect:** Participants will be asked to take part in up to 4 testing sessions (no more than 2 hours/session) exploring the fit and basic function of the prototype exercise machine and also of the NuStep exercise machine. During the testing sessions, participants will be asked to use the devices and provide input on design and use. Various physiological measures will also be collected.

**Who can participate:** You may be eligible to participate in this study if you are between 18 to 65 years of age; have a complete spinal cord injury below C6; are at least 2 years post-injury, for those with SCI; currently engage in moderate physical activity, a minimum of 30 minutes/day on 5 or more days/week; transfer with minimal assistance and tolerate supported standing with or without an assistive device for at least 5 minutes; are able to communicate effectively in English; and are fully vaccinated against COVID-19.

**Why participate:** The main benefit of this study is the potential to contribute to the development of a new exercise machine that may benefit people with mobility limitations. In the long term, these results could also contribute to better device solutions.

**Location:** Centre for Applied Research and Innovation at the BCIT Burnaby Campus (4355 Mathissi Place in Burnaby, BC)

**For more information or to sign up:** Please contact the study coordinator, Angie Wong, by email ([angie\\_wong@bcit.ca](mailto:angie_wong@bcit.ca)) or phone (604) 451-6934.



## Experiences of People with SCI Leaving Rehabilitation and Integrating into the Community

**Overview:** For many spinal cord injury (SCI) patients, rehabilitation to community transition can be challenging. According to a study, 17–25% of people with SCI experience physical and mental disorders after entering the community. However, most of these studies were done before the pandemic; there are concerns regarding rehabilitation services that can best meet the needs of people with SCI now. Researchers in Dr. Ben Mortenson's lab want to understand the perspectives and the challenges of patients with SCI regarding returning home after being discharged from rehabilitation facilities and identify solutions to facilitate the transition of patients with SCI back to the community.

**What to expect:** Participants will complete a brief survey on post-discharge needs and quality of life. The survey can be completed online or via phone. The time commitment is estimated to be 20 minutes.

**Who can participate:** You may be able to participate in this study if you have a spinal cord injury; have been discharged from GF Strong inpatient rehabilitation for a period of at least 6 months are able to provide your own consent; and are able to communicate in English.

**Why participate:** Findings from the study will inform changes to clinical practice at GF Strong, which will be transferable to other rehabilitation facilities in Canada and abroad. Ultimately this will improve the patients' transition into the community (e.g., reducing secondary complications and facilitating participation in meaningful activities), which will improve the quality of their lives. The findings will also inform changes to clinical practice in occupational therapy at GF Strong to improve discharge planning and preparedness.

**Location:** The study will take place online or by phone.

**For more information or to sign up:** Please contact the study coordinator Jodine Perkins by email ([mortenson.lab@ubc.ca](mailto: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 [www.icord.org/research/participate-in-a-study](http://www.icord.org/research/participate-in-a-study)

# 911: Calls for Change

The Neil Squire Society is helping to ensure new ways of contacting 911 will work for everyone.

In an emergency, we all know to call 911. Sometimes, we even call 911 when we didn't mean to (odds are, more than one of you has "butt-dialed" it at some point). But whether intentional or not, the only way to reach the 911 service has been to dial the number on your landline or mobile phone. Thanks to new technologies, new options for contacting emergency services are coming, but it is imperative that there are options that work for everyone.

This is why the Neil Squire Society undertook a project entitled, *Research to Inform Standards for Next Generation 911 Communications*. Funded by Accessibility Standards Canada, the project reached out to people from different disability groups to learn how new ways of communicating with 911 affected their ability to communicate with the emergency service.

Feedback was collected through focus groups and a national online survey. Participants were shown six new ways to communicate with 911 and were asked if they made it easier or harder to get help, to rate the new ways to get help, and which ones they liked the best and least. In all, 51 people took part in the focus groups and 493 people filled out the survey. Just over one third of the survey responders identified as having a mobility disability, the majority of which were considered severe impairments. The other disability groups included cognitive, hearing, vision, and deafblind.

The top three choices were Total Conversation, live video streaming, and the Help app. People liked Total Conversation best because they could choose to use voice, video, or text. Live video

## Six new proposed ways to improve 911

- **Text messaging with photo or video:** Lets users add sound, images and videos into text messages.
- **Live video streaming:** Lets users show someone with their phone camera what they are seeing in real time, but the user cannot see the other person like in a video call.
- **Real-time text messaging:** People can see the text message as it is being typed.
- **Total Conversation:** Lets users choose how they want to communicate. Users can make a call with video and live text at the same time.
- **Help app:** Allows a 911 phone call to have live video streaming. The app can send the user's medical information and can also speak a help message that's been recorded and put in the app.
- **Picture Help app:** Lets users choose pictures instead of typing words to make sentences and help users to describe their emergency. It will also send the user's location.

streaming was popular because it can be used right away and there was no need to install an app to use it. The Help app was the third pick as it allowed video information to be shared with a 911 operator during a call but it required the app to be installed in order to use it.

Text messaging with photo or video was not a top choice but people did like the option of including images or videos in a text. Live text messaging was also a less popular choice as seeing the text being typed in real time was not thought to be useful. Participants also noted these apps use voice dictation and screen readers, so can't be used silently in an emergency. The Picture Help app ranked the lowest as it takes longer to pick out icons to make sentences than it does to send photos.

Seven recommendations have come from the research: Total Conversation should be used by 911; everyone should be able to use text messaging with photo or video; people need to be trained to

use the options; emergency staff need to be trained to know how to use and support new ways of contacting 911; 911 systems need to be improved; people with disabilities need their information protected; and internet and video calls to 911 need to be free.

The next generation of 911 is coming. Thanks to the Neil Squire Society and those who participated in the study, it stands a better chance of being more accessible to all.

You can learn more about the project and its results at [bit.ly/911-study](https://bit.ly/911-study). ■





# Greater Reach & Better Service



Chairstuff is proud to continue our long-term sponsorship with SCI BC.



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## Chairstuff has your back...

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

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STEVE MILUM  
Founder & CEO  
Chairstuff



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