

the spin

SPINAL CORD INJURY BC

WINTER 2024



SCI BC's Guide to Snowbirding

Lisa Franks and other SCI BC peers weigh in on what it means to escape BC's winter for warmer temperatures

“SpeediCath® Compact catheters give me the freedom to catheterize anywhere I go.”



Leanne, Paralympic Bronze Medallist
SpeediCath® Compact Female User

SpeediCath® Compact catheters are designed with you in mind! These discreet and convenient catheters feature our **Triple Action Coating Technology™**. The unique hydrophilic coating provides smooth and comfortable insertion and withdrawal during catheterization. The compact size lets you to carry, store, use and dispose discreetly.



Compact Female



Compact Female Plus



Compact Male

Request your FREE* SpeediCath® sample by scanning the QR Code below or visit:
[visit.coloplast.ca/SCIBC-Sample](https://www.coloplast.ca/SCIBC-Sample)



*Limitations apply

Leanne has received compensation from Coloplast to share her information. Each person's situation is unique so your experience may not be the same. Talk to your healthcare provider about whether this product is right for you.

SpeediCath® catheters may be prescribed for use by pediatric patients (children to age 21) and adults who require bladder drainage due to chronic urine retention or post void residual volume (PVR). Before use, carefully read all of the instructions. Call your doctor if you think you have a UTI or can't pass the catheter into the bladder. For more information regarding risks, potential complications and product support, call Coloplast Corp. at 1 (866) 293-6349 and/or consult the company website at www.coloplast.ca.

Coloplast Canada, Oakville, ON L6H 0H2/ 1-866-293-6349/ www.coloplast.ca

Coloplast and the Coloplast logo are trademarks of Coloplast A/S.

©2024-09 Coloplast A/S. All rights reserved.

SpeediCath®



contents

WINTER 2024

features

11 **Wheeling Forward Together: A New Chapter for Chair Stuff**

SCI BC peer Steve Milum is rolling into a new chapter of entrepreneurship alongside his new business partner, fellow peer, Sam Danniels.

14 **Cover Story**

Four SCI BC peers weigh in on what it means to escape BC's cold winter for warmer temperatures.

20 **Press Play on Aging with SCI**

SCI BC and SCIRE Community collaborated to fill the aging with SCI knowledge gap in a new video series.

22 **Access BC Adventures**

A snapshot of some of the latest projects SCI BC's Access BC team has been working on.

24 **Bowel Burdens**

New research deepens understanding of the burden of bowel care and what's needed to make a difference.

28 **BEAST Mode**

BCIT MAKE+ team strikes gold at the 2024 CYBATHLON, an international competition of assistive technologies.

departments

4 **editor's message**

Own it!

6 **gear & gadgets**

New products for daily living.

8 **events**

Important dates for your calendar.

9 **community highlights**

Shining a light on partner and staff achievements.

10 **peer shoutouts**

Giving credit where credit's due.

27 **ask InfoLine**

Drive wheel attachments for your handcycle.

32 **participate in research**

ICORD research projects that need your participation.

34 **last word**

Reflections from Kara Stanley and Simon Paradis on a year dedicated to tackling pain in their new book.

COVER: SCI BC peer, Lisa Franks, adventures out to the desert on one of her snowbirding trips.



GOT QUESTIONS?

How do I...



GET ANSWERS.

Visit our online SCI Info Database for more than 800 trusted resources.

 sci-bc.ca/info-database



Own It!

These days, it seems everyone wants your data. From social media giants to local retailers, from researchers to governments, our data is one of the world's hot new currencies. Whether or not we think about it or even realize it, we are constantly handing over our data in exchange for a service or convenience. In doing so, there are privacy and security related costs to us.

On the other side of the data exchange, businesses use our data to generate revenue through advertising, selling your data to others, or training new artificial intelligence products. This is why use of social media services, search engines, online shopping sites, AI apps, and loyalty programs are often free or relatively cheap: you pay with your data. Who benefits more from these exchanges is something we should think more about.

But here is something else we should think more about. In the examples listed above, you are the owner of your data and you make the decision who to provide access to it. However, curiously, when it comes to your medical records and health data, you are not the owner. More than curious, it often creates barriers to sharing our health and care information between health providers and services. These barriers arise through the requirements of the owners of these data to protect our privacy through the security of the different systems that collect and host our health data.

The complexities of these systems and the protections within and between them lead to gaps in communication and inefficiencies in delivering quality care. But what if we were the owners of our health data? Estonia's e-health system provides a glimpse into what an accessible and secure health information system where individuals control the use of their own health data could mean for us here in BC.

Estonia's health system has been fully digitized for the past 15 years, with citizens having the ability to not only access their own medical records through a highly secure online portal, but also to control who gets to look at their records. By having the ability to determine who has access to their health data, Estonians, not just health authorities or health services, can allow for communication between the different health professionals and services they engage with for their care.

This truly patient-centred system has created a more efficient health system and improved outcomes for those accessing it. Unfortunately, BC's painfully slow digital transformation of our health system is not so patient-centred and does not fully address the complex barriers multiple ownership of our data creates. If we are to truly transform the health system, we must change the the data ownership paradigm.

No system is perfect and there will always be issues of security and privacy to consider, but as the owners of ourselves, shouldn't we be the owners of our own health data?

—Chris McBride, PhD, Executive Director, SCI BC



The Spin is the quarterly magazine of Spinal Cord Injury BC. An online edition of *The Spin* is available on the SCI BC website (www.sci-bc.ca).

Executive EditorChris McBride
Assistant Editor/Designer.....Sophie Ni
Assistant EditorsAlison Brierley, Jocelyn Maffin,
Lydia Wood & Veronica Allan

SUBSCRIPTIONS

Free subscriptions are available for BC residents and health professionals:
T: 604.324.3611 TF: 1.877.324.3611 E: thespin@sci-bc.ca

ADVERTISING

Advertising rates and a publishing calendar for *The Spin* are available online at sci-bc.ca/thespin. You can also email thespin@sci-bc.ca or call 604.324.3611.

SUBMISSIONS

Submissions, suggestions and comments are greatly appreciated—please email these to thespin@sci-bc.ca or send by regular mail to:

Assistant Editor, *The Spin*
Spinal Cord Injury BC, 780 SW Marine Drive
Vancouver, British Columbia V6P 5Y7

COPYRIGHT

You are welcome to reproduce material from *The Spin* after gaining permission from the Executive Editor. All reproduced material must be appropriately acknowledged.

The opinions expressed in *The Spin* are not necessarily those of SCI BC. Also, SCI BC does not endorse nor is responsible for the products or services advertised within *The Spin*. The information contained within *The Spin* is presented for the purpose of educating people about spinal cord injury. Nothing contained in *The Spin* is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider.

Publications Mail Agreement #: 40684573

ISSN #: 1922-9445

Return undeliverable Canadian addresses to:

Spinal Cord Injury BC, 780 SW Marine Drive
Vancouver, British Columbia V6P 5Y7 T: 604.324.3611

To update/change delivery address, email thespin@sci-bc.ca or call 604.324.3611.

SCI BC HEAD OFFICE

780 SW Marine Drive, Vancouver, British Columbia V6P 5Y7
T: 604.324.3611 TF: 1.877.324.3611 F: 604.326.1229
E: info@sci-bc.ca

REGIONAL PEER CONTACTS

Greater Vancouver/Fraser Valley: Rod Bitz, Peer Program Coordinator
T: 604.500.2900 E: rbitz@sci-bc.ca

Kamloops/Okanagan: Tyler Tingle, Peer Program Coordinator
T: 604.326.1227 E: ttingle@sci-bc.ca

Okanagan: Sonja Gaudet, Provincial Peer Coordinator
T: 250-308-2983 E: sgaudet@sci-bc.ca

Okanagan: Scott James, Provincial Peer Coordinator
T: 250-308-1997 E: sjames@sci-bc.ca

Prince George: Brandy Stiles, Manager, Provincial Peer Coordinator
Program T: 250-563-6942 E: bstiles@sci-bc.ca

Northern BC: Caleb Brousseau, Peer Program Coordinator
T: 604.326.1216 E: cbrousseau@sci-bc.ca

Metro Vancouver: Teri Thorson, Manager, Peer Coaching and Outreach T: 604.714.4185 E: tthorson@sci-bc.ca

Metro Vancouver: Ryan Clarkson, Peer Program Coordinator
T: 604.714.4185 E: rclarkson@sci-bc.ca

Metro Vancouver/BC: Duncan Campbell, Aging with SCI Peer Coordinator T: 604.326.1215 E: dcampbell@sci-bc.ca

Nanaimo: Bert Abbott, Manager, Peer Mentor Program
T: 250.616.1186 E: babbott@sci-bc.ca

North Shore/Sea to Sky: Peter Chisholm, Peer Program Coordinator
T: 604.739.5913 E: pchisholm@sci-bc.ca

Victoria: Scott Heron, Peer Support Specialist
T: 250.812.0773 E: sheron@sci-bc.ca

SCI BC is grateful for the financial support of the BC Gaming Commission and the BC Paraplegic Foundation.

We acknowledge that *The Spin* is created on the traditional and ancestral territory of the Coast Salish peoples—Squamish, Musqueam, and Selilwitlh (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

WorkBC

Assistive Technology Services

Are you employed, self-employed, or seeking employment?

Funding is available now for hearing aids, vehicle modifications, ergonomics, and other assistive devices you may need for work!

1-844-453-5506
workbc-ats.ca

Canada



This program is funded by the Government of Canada and the Province of British Columbia.

TetraCon 2025

February 27, 2025
10 AM - 2 PM PT
Live on Zoom



Join the Tetra Society of North America's national community at the 5th annual virtual TetraCon on February 27th!

Presenters Include:



Ean Price
Technology For Independent Living
Tetra Society Board Member



Dr. Leonard Lye
Tetra Chapter Coordinator
Newfoundland



Tetra Society, No Limits, Endless Possibilities

Learn more at Tetrasociety.org



DRAG

Neil Squire's Makers Making Change contains an assistive device library that can help aid you with everyday tasks, including the DRAG Assistive Writing and Drawing Device. DRAG is perfect for anyone with hand mobility issues as it allows users to hold a pen or pencil without the need to form a tight, closed grip with your fingers. The device is easy to use as all you

need to do is place your hand on the device's body, press, and you are ready to start writing and drawing! The shape is symmetrical so that it is suited for both left- and right-hand users. More helpful tools for daily living can be found at makersmakingchange.com.



ORBITER MED

You may be familiar with Kalogan's Orbiter, a smart wheelchair cushion introduced in the Winter 2022 issue of *The Spin*. This year, Kalogan unveiled Orbiter Med, a cushion that combines the original's Advanced Pressure Managements (APM) system, along with customization for posture support and pressure management. The APM can intelligently redistribute weight based on personalized guidelines created by a clinician in the Kalogan App. Every cushion is custom-built for each person and their lifestyle based on details like clinical history and includes support for medial thigh, leg length discrepancies, and more. Its universal mounting design works with both manual and power chairs and the washable covers makes it easy to take care of. Orbiter Med is only sold through a seating specialist or clinician. Learn more at kalogan.com.

Innovations

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



GRIP GLOVE

The Grip Glove is an adaptive exercise glove made for quads or anyone who needs extra grip while working. Designed by Jason Ayler, a C5-6 quadriplegic, the glove provides wrist and forearm support by including a detachable bar for those with limited wrist movements. It also has heavy-duty straps that wrap around the wrist and forearm for additional support and D-Rings along the forearm for easy attachment to resistance bands

and pulley systems. The Grip Glove comes in small and large sizes and is available through Innovative Adaptations LLC for purchase. Head over to gripgloveusa.com to give your work outs more support.



GRIP-FREE GRABBER

The Grip-Free Grabber from KFK Designs is designed for people with limited hand function to grab day-to-day objects. Simply push down on the loop end of the stick to open the grippers and pull to grip an item. The handle is adjustable by sliding it up or down the pole or rotated until the desired position is achieved. The gripper ends even include magnets to make grasping magnetic objects easier. The Grip-Free Grabber comes in three different sizes of Long (48") for power wheelchair users, Standard (36") for manual wheelchair users, and Youth (30"). Visit kfkdesigns.com to grab your own Grip-Free Grabber.

90% of users rated GentleCath Glide™ with FeelClean Technology™ better than their usual catheter for comfort.¹

GentleCath Glide™
with FeelClean Technology™

Life is full of sticky situations

Thanks to GentleCath Glide™ with FeelClean Technology™, your catheter won't be one of them.

As coated catheters dry they can stick², and this makes removal uncomfortable. Stickiness and messy residue caused by PVP-based coatings* can all contribute to this lack of comfort.



Discover the relief that makes all the difference. Scan the QR code to request your free samples.

Always read the label and follow directions for use.

*PVP is used in glue and is what makes catheters sticky when they dry.

1. A Multi-Centre Clinical Investigation to Assess the Performance of GentleCath™ Glide intermittent catheters. Study U378 GentleCath™ Glide Final Report. July 2018. In vitro data on file. Convatec Inc.

2. Pollard D, Allen D, Irwin N J, Moore J V, McClelland N, McCoy C P. Evaluation of an Integrated Amphiphilic Surfactant as an Alternative to Traditional Polyvinylpyrrolidone Coatings for Hydrophilic Intermittent Urinary Catheters. Biotribology. 2022;32(Dec 2022):100223.

™ indicates a trademark of Convatec Inc. © 2023 Convatec Inc. AP-59949-CAN-ENG-v1 (v1.0)



 **convatec**
— forever caring —



Don't miss the action.

The Invictus Games are coming to Vancouver and Whistler from February 8-16, 2025! You will have a chance to catch 500 athletes from over 20 countries compete in adaptive sports. Come cheer on Team Canada at Whistler where outdoor sport events with ample capacity are free of charge, or in Vancouver, where sport events with limited capacity will require paid tickets. Be a part of the excitement by visiting invictusgames2025.ca for more details.



Research meets real life.

Join us February 19-20, 2025 for a two-day forum on the current state and developments in neuromodulation, including promising areas of research and treatment that are offering new ways to address secondary complications of SCI and return function. We'll be joined by a panel of researchers in the field and hear from peers with personal experience. For more information and to register, visit sci-bc.ca/stim to save your spot.



Our next SCI Forum is coming.

Join us on February 27, 2025 from 6-8 PM at the Blusson Spinal Cord Centre in Vancouver for the next SCI Forum: *Thriving for the Long Haul*. Come expand your knowledge about staying healthy and resilient throughout your SCI journey—no matter where you're starting from. We'll share practical information from clinicians, researchers, and peers for staying healthy and preventing injuries. Register today to Avery at aalbrecht@sci-bc.ca.

HAPPY NEW YEAR



We are incredibly grateful to our donors and supporters for another great year. Your support allows us to bring new connections, joy, and knowledge to our members all over BC. Help us spread SCI information across the province by supporting future *The Spin* issues with a donation.

DONATE TODAY:



LIFETIME ACHIEVEMENT AWARD FOR DR. K

A round of applause for Dr. Andrei Krassioukov (better known as Dr. K) for receiving the 2025 American Spinal Injury Association (ASIA) Lifetime Achievement Award! The highest honour bestowed by ASIA, the Lifetime Achievement Award is awarded based on career dedication, peer recognition, professional competence, and recognized achievement. Dr. K is a leading SCI researcher at ICORD and physiatrist at GF Strong, with 350 manuscripts and over 23,000 citations to his name. According to ASIA, Dr. K is, “internationally known for his pioneering and seminal work investigating the impact of SCI on autonomic nervous system. His research has resulted in a paradigm shift in the care of individuals with SCI around the world and improving education of medical professionals.” From 2018-2022, Dr. K served as the President of ASIA. Beyond his research, Dr. K is known for his excellent clinical care, mentorship, and advocacy. Dr. K will be presented with the Lifetime Achievement Award at the ASIA 2025 Annual Scientific Meeting on June 2, 2025 in Scottsdale, Arizona.



Community Highlights

NEW EXECUTIVE DIRECTOR OF THE DISABILITY FOUNDATION

A pitch-perfect congratulations to Graeme Wyman on his recent appointment as the Executive Director of the Disability Foundation! His education at the prestigious Berklee College of Music led Wyman to the Vancouver Adapted Music Society (VAMS), one of the six societies supported by the Disability Foundation. As an Audio Engineer and Program Coordinator, Wyman supported thousands of hours a year of lessons and recordings and was instrumental in growing VAMS’ programs. Over the past four years, Wyman has shown leadership and excellence as the Disability Foundation’s Program Manager for VAMS, the ConnecTra Society, and the Disabled Independent Gardeners Association. We can’t wait to see Wyman’s symphony of success in his new role!



FAMILIAR FACES JOIN SCI BC’S BOARD OF DIRECTORS

All aboard! We are proud to welcome our friends and peers Susan Bains and Steve Milum to the SCI BC Board of Directors! You may recognize Bains from the last issue of *The Spin*, where she shared her journey

successfully advocating for an accessibility mat on the famous White Rock Pier. A passionate member of SCI BC, South Fraser Active Living, and the Equal Access Collective, Bains lives by the principle “Nothing about us without us.” She also helps advance accessibility initiatives with the Surrey Accessibility Leadership Team. Bains comes to her role with over 20 years of experience in progressive HR and a passion for accessibility and inclusion.

Milum is well known as the founder of the medical supply business Chair Stuff. For over 23 years, Milum and his team have ensured peers in BC and beyond have access to the right bladder and bowel products when and where they need them. What started with a makeshift warehouse in his home is now a large warehouse that delivers thousands of products. Milum brings his business expertise, caring spirit, and knowledge of the community to his new role on the Board. As one of SCI BC’s longest corporate sponsors, Chair Stuff makes possible peer events across the province. This past year, Milum captained Team Spare & Chair Stuff in the Charity Challenge, raising over \$10,000 for SCI BC.



Welcome to the team!





An elect-ifying congratulations to SCI peer and politician **DANA LAJEUNESSE!** Following his provincial election win as the MLA for the Juan de Fuca-Malahat riding (former BC Premier John Horgan’s riding), Lajeunesse was appointed the NDP’s Parliamentary Secretary for Accessibility. Born and raised on southern Vancouver Island, Lajeunesse worked in mechanical engineering following an SCI over three decades ago. His move to politics began five years ago as a dedicated District of Sooke councillor, where he served on various committees. Lajeunesse shared with *Island Social Trends*, “I like to listen to people and address the issues that they have.” We are heartened to see people with disabilities, like Lajeunesse, at the forefront of our provincial government and we are excited to see his impact on accessibility in BC.

A latte of love and gratitude goes out to **TERRY LANDRY** for his decades of peer support and community-building on Vancouver Island! For 25 years, Landry has organized Peer Meetups with SCI BC, affectionately nicknamed “Coffee Clutches”, brewing a welcoming community for peers on the island. What originally started with a coffee group in Victoria expanded to meetups in the Cowichan Valley and Parksville at restaurants and peer’s homes, as well as holiday parties and group trips to Salt Spring Island. Further, after joining SCI BC’s Bert Abbott and Scott Heron on the SCI BC (known back then as the BC Paraplegic Association) Victoria Advisory Committee, Landry served as the Chairperson on our Board of Directors from 2002-2004. As well, Landry has been the Secretary of the Cowichan Valley Shrine Club since 1992. He shares, “[Our Coffee Clutches] continue to meet at the Duncan Casino banquet room every other month. We are always looking for new faces and welcome anyone that would like to join us.”



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.

Take note of the new and returning Rick Hansen Foundation (RHF) Ambassadors! Through the RHF School program, Ambassadors engage with students at all grade levels about their personal experiences living with a disability. BC-based peers returning as Ambassadors include wheelchair basketball star **CAMERON GELOWITZ**, athlete **PAULO GUERRERO**, social worker and para powerlifter **JENNA REED-CÔTÉ**, and students **MIHAI COVASER** and **MAGGIE MANNING**. Covaser and Manning also advocate for youth with disabilities in their roles on the RHF



Top row, left to right: Maggie Manning, Megan Smith, Jessica Kruger, and Jenna Reed-Côté
Bottom row, left to right: Cameron Gelowitz, Gina Martin, Paulo Guerrero, and Mihai Covaser



School Program Youth Leadership Committee. In addition, baker and wheelchair rugby player **JESSICA KRUGER**, disability awareness educator **GINA MARTIN**, as well as kinesiology student and wheelchair basketball player **MEGAN SMITH** join the RHF School program as new Ambassadors for the 2024/25 school year. These Ambassadors’ admirable advocacy and awareness efforts have certainly earned them an A+!



Wheeling Forward Together:

A New Chapter for Chair Stuff

After 23 years of being the sole owner and operator of Chair Stuff, a medical supply company, SCI BC peer Steve Milum is rolling into a new chapter of entrepreneurship alongside his business partner, Sam Danniels.

On the surface, it's clear that Steve Milum and Sam Danniels have a lot in common. Both Milum and Danniels are originally from Ontario, both have a background in athletics, and both have a spinal cord injury (SCI). The apparent similarities between Milum and Danniels, however, go much deeper, with both men sharing a desire for entrepreneurship that helps members of the SCI community and supports their families. "The reason I started [Chair Stuff] is two-fold," Milum says. "The first reason is that I had a bladder surgery around that time and the service out there was terrible. The second was that I had a two-year-old son, and I had a corporate job with a high demand, so I was never at home... [Chair Stuff] was a way to be there and be a better Dad."

As someone with a C6-C7 injury, Milum has firsthand experience with the often slow, confusing, and impersonal medical equipment field and founded Chair Stuff in 2001 with the intent to provide a better medical supply service to those in need. "I enjoy the customers the most. The people—nurses, doctors, customers—the spine world is a pretty small world, and you get to know everyone really well and build those relationships," he says. Milum, who usually has a Bluetooth headset connected to one ear and a cell phone in his pocket, prioritized Chair Stuff's relationships and customer service from the beginning and has been at the helm of the business as it expanded.

"When I first started out, there were maybe three types of catheters and now there's over 100," he explains. "There's a lot of different products out there and there's a lot of different players that are all fighting for the same space. Knowing our customers and what it's like is what makes us different." Over the course of 23 years, Milum successfully navigated these industry changes and Chair Stuff has grown from a one-person operation running out of a makeshift warehouse in Milum's house

into a provincial provider delivering thousands of products from dozens of manufacturers. The business currently has four employees and operates out of a large warehouse in Vancouver. Moreover, Chair Stuff has built a close relationship with SCI BC and has been a long-term and ongoing supporter of our Peer Program since 2016.

This success has certainly not been without its ups and downs. "The most challenging thing is knowing that our products are needed. If you have a strike or any kind of disruption in service—it's stressful because you have to get that product to the person and you know how important it is," Milum says. The COVID-19 pandemic was especially difficult for Chair Stuff. Two employees became ill at the same time and Milum had to reach out to his kids (now fully grown and attending university) for help. "The stress level was getting too high. I was the only one here and I couldn't get sick, or things would stop, and our customers would be the ones paying for it."

Last year, Milum was approached by Sam Danniels, another SCI BC peer with a passion for business and family who was facing a similar dilemma Milum encountered over 20 years ago. "I reached out to Steve not with the intention of necessarily becoming involved in Chair Stuff as much as just being interested in the industry in general," Danniels explains. "I had been in residential real estate for almost a decade and had a bad injury a couple of years ago where I broke my shoulder, and it forced me to spend a lot of time on the couch. I was able to think about my next steps and I wasn't thrilled about the transition of becoming a parent and being in real estate... to put it bluntly, I felt like almost every day I had to decide—do I want to disappoint my family or my clients? There just wasn't enough of me to go around."

After their initial meeting in the summer of 2023, Milum and Danniels realized there may be a mutually bene-

ficial solution. Milum needed some stress relief and a shared workload and Danniels wanted a career shift that would allow him to have regular hours and more time with his young family (a situation all too familiar for Milum). "It took us awhile to figure out what made the most sense to each other as individuals, but also for the business," Danniels says. "But we kept coming back to this idea that together we'll be stronger and that'll be better for business overall." Danniels, who has a T4 injury, had been a Chair Stuff customer for about six years prior to meeting Milum and brought a wealth of personal experience and professional client-centered knowledge to the newly formed partnership.

"It's no secret amongst people with spinal cord injuries or who are in a similar situation that customer service isn't priority one for a lot of companies that deal in the sphere... Our goal here is to preserve what Steve's built with Chair Stuff, making sure we treat our customers like gold and that they come first."

As an accomplished athlete, Danniels competed professionally in three para-skiing disciplines and pursued cycling, snowmobiling, paragliding, and surfing. Through these endeavours he learned the value of connecting with and contributing to the SCI community. "I've thought a lot about my contribution to the community and being an athlete





Steve Milum's longtime support and active participation at SCI BC events over the years. Top, left to right: Handcycle Demo Day and Charity Challenge. Bottom, left to right: Multi Sports Day and Guy's Garage. Previous: Sam Danniels at Whistler during his racing days.

was a great way to be a role model, but it's a pretty narrow contribution," he says. "It's not quite the same as every day dedicating a part of yourself to making sure people in the community are living well. [Chair Stuff] has hundreds of customers who we contribute meaningfully to on a day-by-day basis. That's one of the boxes that I wanted to tick as I thought about a career change." As one of the prominent sponsors for SCI BC events like the Charity Challenge, Learn to Camp, Wellness Weekends, or our Adaptive Cycling program, Danniels and Chair Stuff will also undoubtedly give back in ways that go beyond ensuring peers have the medical supplies they need.

Milum and Danniels agreed on an official partnership as of September

2024, and are excited about what comes next. "It's about looking ahead," Milum says. "We've both put faith in each other and we're going to grow the business together and we're both going to succeed or not off those decisions together." For Milum, the year ahead will be about transitioning into shared responsibilities and for Danniels it will be all about industry learning and bringing a fresh perspective to processes and technology. "It's been impressive to get a 'look under the hood' and see how much Steve has done with such a lean team," Danniels says. "Going forward we want to offer more options for younger customers who might be more comfortable with online purchases... but we're not looking to become an e-commerce site. We just want to make

sure that as the world changes that Chair Stuff changes with it."

Above all, Milum and Danniels want to remain focused on the similarities that brought them together in the first place—a shared entrepreneurial spirit, family dedication, and commitment to customer care. "Having a disability of any kind is hard and there's a lot of baggage that comes along with it," Danniels says. "We want to make sure that people with disabilities are getting the supplies they need so they can go about their day feeling as comfortable as possible without adding to the complications of having a disability." Reflecting on the past two decades of business and thinking about the future, Milum adds, "That was always the goal, and it still is now." ■

SCI BC's Guide to Snowbirding

The appeal of escaping BC's cold winter season for warmer temperatures and an ocean breeze is tempting, but is it really worth the hype? Four SCI BC peers and friends weigh in on what it actually means to snowbird south for the winter as someone living with a disability. They share their experiences—the good, the bad, and everything in between.



ROB MABEY | Kelowna, BC
C5/C6 complete
23 years post-injury



Where do you go when the colder weather hits BC?

A little town close to the southern tip of the Baja Peninsula [in Mexico] called Los Barriles.

How long have you been snowbirding?

Since 2017... My kids got to university age and decided to attend the University of Calgary. I realized then that I didn't have to stay in Canada for the winter months that they were at school.

Why did you start travelling during the winter? What was the main reason?

The main reason for wanting warmer weather was the hassle of pushing

through snow and ice in a wheelchair. As a C5/C6 quadriplegic with no hand function, once you lose traction on your push rings when they get wet and cold you're pretty much dead in the water. Not to mention, having to bundle up with clothing just to keep warm... I figured pushing through sand in a cut off shirt and shorts is far better than pushing through snow and ice looking like the Michelin man!

How do you travel to your snowbird destination?

My preferred method of travel is driving. It gives me the freedom to enjoy the journey and explore on my way to the destination. My first [travel] vehicle was a Ford Flex with an adapted travel trailer. It was a 16-foot trailer that I had modified to go camping with my kids. I had to do some further modifications like putting a lift on the side to make it more independent.

The second iteration was a Sprinter van with custom building on the inside into a full motorhome. It has a lift in the side door, a full queen bed, shower, toilet, heater, hot water, and refrigerator. [It allows] my wheelchair to roll back-and-forth, turn around, and transfer from the bed to the toilet and shower. Because prebuilt motorhomes and Sprinter vans are very expensive (and I would have

to carve them up to accommodate the wheelchair anyway) I chose to custom build the van in my driveway. I pull a utility trailer behind the van to carry my front drive attachment, hand cycle, and various medical supplies. Typically, the van is fully equipped with all of my clothes and toiletries, food [and solar power], so it is self-sustaining.

How do you prepare for health-related issues, equipment needs, or medication requirements while you're away?

Because I drive, all my SCI related equipment and supplies are typically brought with me in the trailer. However, there is opportunity [in] the United States and Mexico to acquire most of the supplies [if you need to], it's just harder.

Health insurance is very important to travel with—especially through the States. A spinal cord injury is not considered a pre-existing condition, so you're not penalized for being in a wheelchair. [Receiving] healthcare in Mexico is much more affordable, especially for small ailments. I have direct experience with the Mexican medical process as I spent 16 days in a Mexican hospital last spring [and] was air-ambulanced out of Mexico back to Canada to spend another two and a half months in the hospital in Canada.

Have you encountered any unexpected challenges while snowbirding abroad? What has been your worst experience?

By far the most unexpected challenge was the medical event that led to my air ambulance evacuation back to Canada. [The second most unexpected thing happened] in Venice Beach—apparently, it's a thing there to grab people in wheelchairs and push them at high speeds along the boardwalk! When this happened to me, I was yelling at [the people] to stop and when they did—Newton's Law of 'things in motion tend to stay in motion, unless acted upon by an equal or opposite force' came into effect. I believe the teenagers [who pushed me] were [intoxicated], but nevertheless, when they stopped the chair, I flew forward about 10 or 15 feet [and landed] ragdoll on the pavement. They took off and some bystanders came to help me back into the chair. Luckily, upon doing a quick visual check that night, nothing was broken or damaged, just a few bruises.

In your opinion, what's the best part about being a snowbird?

The best part of spending time out of the winter is simply the warm weather. You tend to be more active and the extra vitamin D doesn't hurt! One of my mottos... is "move it or lose it." As a C5/C6 quadriplegic it's even more important as you have so little muscle to move your entire body. If you lose that, you become very dependent. [The warm weather] is simply a far more healthy environment in my opinion, both physically and mentally.

What is the biggest lesson you've learned since you started moving away for the winter?

My biggest takeaway from travelling is a faith in humanity. Ninety-nine percent of people out there are simply living their lives and aren't concerned about you or your stuff... Consistent with our current political environment there is a lot of misinformation out there. I have broken down various times in Mexico and people

are more than willing to help and go out of their way to make sure you're OK. I've been stuck on a sandy road with my attachment or front drive, and I've had truckloads of people hop out and push me up the sandy hill to get me on my way.

Do you have any tips or tricks you can share with others who are considering snowbirding for the first time?

The biggest tip or trick to travelling, especially the way I do it, is to simply not convince yourself out of travelling. Too often we are our own worst enemy by being fearful of the unknown. The unknown is exhilarating and nine times out of 10 it turns out to be very pleasurable.

LISA FRANKS | Moose Jaw, SK C5 incomplete 28 years post-injury



Where do you go when the colder weather hits BC?

Southern California, between LA and San Diego—there's a little beach town that I hang out in. If the weather isn't good there, I can be mobile—I go to the desert if it's raining on the coast or drive two hours inland and find sun... I keep coming back to California because I've met so many people here. It's a very accessible area of the U.S. and the weather is phenomenal—it's not too hot, not too cold.

When did you start snowbirding?

This will be my fifth winter overall going south... and it'll be three and a half winters staying down mostly full time throughout the year. The last few years I leave in October before there's any kind

of snow. It usually takes about four or five days of driving and I'll stay in Southern California until around April.

Why did you start travelling during the winter? What was the main reason?

I'm from Saskatchewan and our winters are so brutal. So, I just wanted to get away from snow and the -20°C weather... Saskatoon has been my home for the last 20 some years and I'm able to rent out my property while I live down [in California]—that's what provides me income to be able to do this.

How do you travel to your snowbird destination?

My first year in California was in my SUV... I had a little SUV and I had a platform bed and a cooler in it. I have a background in sports and I'm pretty social so I knew people I could stop and stay with along the way that first year. I was really relying on familiar faces to help support me, but now that's old news. I can figure things out on the road and adapt to whatever.

I've also designed a van that I stay in that's all accessible for me... I ordered a blank cargo van that came with two front seats and the rest of the back was empty. I have a surfboard and a mountain bike so I designed the van to fit those things and made sure the living area had enough room for my wheelchair to maneuver around and that I could reach everything. I also had a wheelchair lift installed. The biggest challenge was that my bike is so high. I ended up making my





bed high enough, so it fits under it and then I have a bench next to my bed with a lift that raises up to the height of the bed... A lot of thought went into it.

How do you prepare for health-related issues, equipment needs, or medication requirements while you're away?

Before I leave, I forward my mail and purchase travel insurance. I get all of my prescriptions ahead of time and I get about six weeks' worth of catheters and other medical supplies... I have a bit of an extra challenge when it comes to [supplies] because I don't have a fixed address when I snowbird. I'm always kind of planning out my route and making sure that as my supplies are getting low, I know where I'm going to next and where I can get them sent to a general post office.

Because I've made the trip a few times now I also know where there are places that I can stop to find the accessible bathroom or refill my water tank in the RV at an accessible stop... there's also tools like the Overlander app that I use. It tells you things like pullouts that are good for sleeping at night or where you can shower. It's a crowdsourced app and other travellers have inputted information you can view or add to.

Have you encountered any unexpected challenges while snowbirding abroad? What has been your worst experience?

I've had minor things. I tore a ligament in my hand once and waited about 10 days or so before crossing the border back to Canada because it was my first year and I bought the cheap insurance where you had to pay a deductible. So, I waited that time, but I decided that I did not want to be in that situation ever again of having to weigh out whether I should go get looked at or not. From then on I always chose the zero deductible travel insurance.

I also remember my first night where I wasn't in an established campground or at a friend's house and I slept in a Home Depot parking lot or something like that... I didn't get a wink of sleep because I was so anxious all night. But now? I just put my ear plugs in and crash.

In your opinion, what's the best part about being a snowbird?

I think the freedom to go wherever. The van is so mobile—if someone says oh, we're going to go to the desert tomorrow I just need to put in the GPS coordinates and go. I don't have to pack anything. I can be spontaneous and take on whatever opportunities come my way... Before this, I had a nine to five job, and I was always structured and scheduled. I didn't have any free time, so I'm taking full advantage of it now.

At one point I also thought I was the only person out there with a high-level injury doing this nomad life but there are so many people. I have a YouTube channel (@KeepinItWheel306) and through likes and comments I know there's a lot of wheelchair users and people out there doing this type of thing.

What is the biggest lesson you've learned since you started moving away for the winter?

Before I started out, the biggest concern from my family and friends was, what happens if you break down or

something? But I've had breakdowns and I've been able to work through it on my own. The more you do that, the more confidence you have that you can tackle whatever's next. I've also got quite a community now since I started my YouTube channel showcasing my lifestyle... it's been really neat to see that community and get positive feedback. It's really motivated me to keep going and is a good reminder that there's good people out there.

Do you have any tips or tricks you can share with others who are considering snowbirding for the first time?

I would say you could start by doing some research online. I researched destinations based on weather or accessibility and access to interesting activities. Maybe start with a destination that you know you want to go to and build off of that. Doing the research to begin with is a big kind of peace of mind thing, just to have of a plan when you're not experienced... and then being open to experiencing things from there.

Follow along with Lisa's adventures on her YouTube channel Keepin It Wheel 306 or on Instagram @keepinitwheel306!

LISA SCHULTZ | Vernon, BC C6/C7 incomplete 36 years post-injury



Where do you go when the colder weather hits BC?

Yuma, Arizona. I'm a C6/C7 incomplete Quadriplegic... [and] have the most incredible husband who takes care of me [and] allows me to be a snowbird.

How long have you been snowbirding?

For the past 13 winters we have been lucky enough to winter in Arizona!

Why did you start travelling during the winter? What was the main reason?

My parents were snowbirds for three years in Yuma before we started going there. After many phone calls hearing about the warm, sunny weather, it was a no-brainer compared to living on Vancouver Island in the damp, rainy, dreary, sometimes snowy winters. My husband also has rheumatoid arthritis and so the main reason was to go to a warm, dry climate for both of us.

How do you travel to your snowbird destination?

Our first two years we hauled our 30-foot travel trailer pulled by our full size wheelchair accessible van. My husband had built a lift so that I could independently get myself in and out of the trailer. We stayed in Yuma for six weeks the first year (2012) and 12 weeks the second (2013). We decided we'd like to spend the maximum time allowed for Canadians to be in the USA (182 days) so... we chose a small resort park in Yuma where annual park fees were affordable for us... [and] in 2014 we ordered a 400 square foot park van model. We had to adapt the design for wider hallways, wider door frames, and a roll-in shower. My chair raises so I'm able to cook and reach the sinks in the kitchen without having to lower the counters. We chose a small resort park in Yuma where annual park fees were affordable for us.

How do you prepare for health-related issues, equipment needs, or medication requirements while you're away?

I order enough medications and medical supplies for the six months along with purchasing emergency medical insurance. I recommend that you shop around to several brokers and your bank [for insurance], as I've experienced significant



savings for the exact same insurance company and policy.

We have a portable patient lift system which comes apart and my husband loads it in the van. We set it up over the bed and he uses it to put me in my shower chair and eventually, when I can no longer transfer into my chair, we'll use it for that as well.

Once the lift, supplies, medication, and suitcases are in the mini-van we're ready to go. We usually spend three nights in a wheelchair accessible motel room and arrive in Yuma on the fourth day.

Have you encountered any unexpected challenges while snowbirding abroad? What has been your worst experience?

We haven't experienced any problems travelling abroad but we are very aware that we're in a country that allows people to carry guns. We don't go anywhere that is questionable and if I'm shopping after dark, I ask for an escort to the van.

In your opinion, what's the best part about being a snowbird?

The best part about being a snowbird is finding the OG RV Resort Park in Yuma. We have made a host of lifelong friendships. People from all over Canada and the United States bend over backwards to include me and my disability. [They] have

built ramps to allow me to wheel onto the shuffleboard court and included me in beanbag games (allowing me to wheel closer to the box so I can throw the bags in the holes easier). The park has a portable lift allowing me to use the pool and hot tub, a clubhouse with a daily schedule of activities, events, and games as well as dinners and dances. To me, it's an adult playground. We love it!

Do you have any tips or tricks you can share with others who are considering snowbirding for the first time?

The only tips I can offer anyone who wants to experience being a snowbird is choose a destination and book an accessible hotel for a week or two. Look around the area [and] drive through the hundreds of parks to find the one that best fits your needs and interests. And don't wait until your age and health becomes an issue for higher medical insurance rates.

TYLER TINGLE | Kamloops, BC T4 complete 35 years post-injury



Where do you go when the colder weather hits BC?

Mexico.

When did you start snowbirding?

I don't know if I qualify yet as an "official" snowbird but I've been to Mexico [approximately] eight times. I think the first trip was in the late 90s... Last winter I was there for a month and this year we are set [to stay] for January and February. I've been looking at buying a space and that's in the works



now. [It] will be a bare lot [that I build on]. There will be a large palapa roof and walls on three sides but open to the drive aisle.

Why did you start travelling during the winter? What was the main reason?

Originally, it was to take a holiday away from work and have a break from winter.

How do you travel to your snowbird destination?

I fly, but in the future, I'll drive down in [my] bus. I purchased the bus be-

cause I wanted a small motorhome with a diesel engine to tow an enclosed trailer to haul a side by side. The small motorhomes usually have a smaller gasoline engine and towing an enclosed trailer of this size is very hard on the engine and the fuel economy is horrible. The drive down will be part of the holiday where I can see different things each time I head down or home.

How do you prepare for health-related issues, equipment needs, or medication requirements while you're away?

The bus will be self-sufficient and can be restocked along the way. As a paraplegic, a trip that is six months long will require packing more than enough supplies for that time frame... six months for me means about 1,000 catheters, 100 rubber gloves, a few tubes of lube. In case of a bladder infection I would bring a half dozen indwelling catheters, 40 leg bags

(that would be enough for constant use over the six months as I've been dealing with reoccurring infections this past year). I would also bring at least one extra wheel for the chair and a set of tires and tubes. An extra cushion for the chair, and a power front wheel assist unit.

In your opinion, what's the best part about being a snowbird?

There was a time when dealing with winter was offset by my winter activities of snowmobiling and wheelchair basketball. Winter for a guy on wheels in Kamloops, is wet, dirty, and cold. There's a lot of work snow blowing my large driveway. You are stuck indoors much of the time. Thinking about the coming winter is depressing but the thought of running the side by side up an arroyo, pedaling a handcycle down the beach as the tide goes out, or snacking on a churro after pickle ball in the sun puts a smile on my face. ■



no limits



get ready for winter
let it snow, let it snow



accessible vehicles | adaptations | service | silvercrossauto.com

1.877.215.7609



WE ARE BESPOKE

NOUS SOMMES SUR MESURE

WHEELCHAIRS



BATEC MOBILITY



PAWS



TRACK WHEEL



VARILITE CUSHIONS & BACK



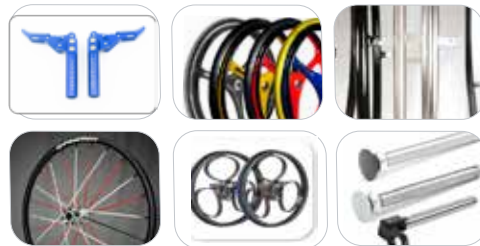
LIGNORIM



TIRES



LOCKS, WHEELS, PUSHRIMS & AXLES



ACCESSORIES



OFFERING A FULL PRODUCT LINE !

...and a host of other products from fine manufacturers around the world.

OFFRANT TOUTE UNE GAMME DE PRODUITS !

...et toute une gamme de produits additionnels de première qualité.



137 Buttermill Ave
Concord, ON L4K 3X5

t. (416) 661-4499
e. 49@49bespoke.com

49 BESPOKE.COM

Press Play on Aging with SCI

SCI BC and SCIRE Community collaborated to fill the aging with SCI knowledge gap and bring you a bite-sized video series.



“We’re the first generation of people with spinal cord injuries that have had enough options in our lives to keep ourselves healthy,” explains Duncan Campbell, SCI BC’s Peer Support Specialist. His own experience of aging with SCI inspired him to create the Aging with SCI Program. Launched in 2024, the program explores a new topic each month, with a peer discussion group followed two weeks later by an expert-led session addressing the group’s questions.

Jocelyn Maffin, SCI BC’s Associate Director of Service Delivery shares, “We heard over and over how experienced clinicians didn’t want to be called an ‘expert’ in this area when they did a presentation because there’s so little published research or best practices



Dr. Dominik Zbogor

available to be an expert on aging and SCI. Peer experiences are particularly powerful in situations like this, where they have this outsized ability to tell the story of what we know and what to expect and communicate to peers that they aren’t alone.”

A chance encounter in late 2023 connected Campbell and Maffin with Spinal Cord Injury Research Evidence (SCIRE) Community, who had received funding from Praxis Spinal Cord Institute to produce a video series on SCI. The SCIRE Project, co-led by Dr. Janice Eng and Dr. Robert Teasell, is an international collaboration of scientists and health professionals that gathers SCI research evidence. SCIRE Community provides free information written in everyday language with peers and the public, whereas SCIRE Professional focuses on health professionals.

Campbell recalls, “I talked to the right person at the right time. Sometimes you just get lucky because you talk to people.” He connected with Dr. Dominik Zbogor, SCIRE Community’s Research Coordinator who explains, “It became clear that aging was a topic we wanted to cover. We know what changes with age in able-bodied people. But what happens when you layer on SCI? Sometimes it’s the same thing, but sometimes it’s not.”

What followed was a fruitful collaboration resulting in four bite-sized videos on aging and pain, physical activity, bladder management, and bowel management. The team decided on topics already deemed a priority from SCI BC’s Aging with SCI survey (Your Priorities for SCI BC’s Aging with SCI Program in *The Spin* Winter 2023 issue). Zbogor and SCIRE Community Research Assistant Kelsey Zhao joined the Aging with SCI discussion groups to gather feedback, which helped shape the videos. Peers were recruited by both organizations to share their stories on filming day.

Zbogor says, “I set things up and the videographer took over. We had a checklist to make sure the [peer volunteers] answered the questions that we were asking. Everybody was great.” Campbell, who shared his experience with deciding to get an ostomy in the Changes in Bowel Management video adds, “Filming was a breeze.” He was accompanied by nurse Bonnie Nybo who says, “Making changes as you age is when what you’re doing right now isn’t working for you.”

But don’t take our word for it—watch the videos yourself! Head to our Aging with SCI webpage (sci-bc.ca/aging), where you’ll also find recordings of past education sessions. In the Staying



Stills from the Aging with a Spinal Cord Injury video series featuring SCI BC peers (from left to right) Mary-Jo Fetterly, Brad Skeats, and Marney Smithies.

Active video, peers Marni Abbott and Marney Smithies discuss barriers and benefits of staying active, with insights from adaptive fitness coach, Megan Williamson. Abbott shares, "After I retired [from wheelchair basketball], I had a really hard time being motivated to be active."

In the Managing Pain video, GF Strong physician Dr. Andrea Townson discusses neuropathic and musculo-skeletal pain and changes with age, and peer Brad Skeats explains, "My pain with age has definitely increased." In the Taking Care of Your Bladder video, nurse Nybo describes challenges specific to men and women. Peers

Dr. Arun Verma and Mary-Jo Fetterly discuss their experiences with bladder issues and solutions. Verma shares, "Since I started the indwelling [catheter], it's made life much easier."

The videos were shared on SCIRE Community's YouTube channel in October 2024. Campbell says, "Overall, I appreciated the fact that the videos were short, but informative. I asked at the last discussion group, and everybody thought they were pretty good." Maffin adds, "We love working with the SCIRE team! Dominik and Kelsey really understood how valuable these videos would be in sharing clinical and peer experiences. They worked with us to sort through

what Duncan was hearing from peers in his program and had the experience to create a really professional product."

Zbogar agrees, "We worked well together, and we created something that we wouldn't have been able to create without each other. I'm eager and interested in looking for the next opportunity to work together. And we were able to take some of the content that we had created for the videos and update articles on the SCIRE Community website on those same topics." Learn more at community.scireproject.com.

What do you think of the Aging with SCI video series? Share your thoughts with Duncan at dcampbell@sci-bc.ca. ■

MOVING FORWARD Monthly Giving Club



In 2024, monthly donations have contributed to...

- ✓ 50 in-person events
- ✓ 130 peer meetups
- ✓ 180 virtual events
- ✓ 1,753 requests for info

Wow!! I had so much fun. I enjoyed meeting old friends and striking up friendships with new peers. It is always an inspiration to hear others' journey.



A monthly gift to SCI BC is one of the most impactful ways to support people living with SCI. JOIN OUR FAMILY OF DONORS TODAY:

Access BC Adventures

An inside look at how we are making accessibility a reality across BC.

Have you been wanting to explore the great outdoors but worried it won't be accessible? Or worried about accessibility issues at a hotel or tourism attraction? SCI BC's Access BC program was developed out of a need to improve accessible outdoor spaces and recreational and tourism opportunities in BC, and to help share information about them. The program aims to create inclusive spaces through educational workshops, universal design training, accessibility assessments, and key partnerships with tourism and government agencies throughout the province. Here's a snapshot of some of the latest projects from SCI BC's Access BC team:

Assessments and Virtual Tours

Ever wonder where to find accessible spots before heading out? Since 2007, SCI BC's Access BC team has been blazing trails to improve accessible outdoor spaces and recreational tourism opportunities in BC. We work closely with all tourism associations across the province.

We partnered with all six tourism regions and Destination BC to update hellobc.com, Destination BC's flagship website, with accessibility information on accommodations and attractions across BC. Our team has assessed over 400 sites, including Tsawaak RV Resort (4VI), Scout Island Nature Centre (Cariboo Chilcotin Coast), Mount 7 Lodges (Kootenay Rockies), the Great West Life Mobility Trail (Northern BC), Turtle Valley Donkey Refuge (Thompson Okanagan), and the Great Blue Heron Nature Reserve (Vancouver, Coast, and Mountains). Check out each location's Hello BC listing (hellobc.com) for details on accessible washrooms, slopes, doorway widths, and more! In collaboration with our tourism partners and Jody Wall Photography, we created over 60 accessibility-focused Google virtual tours at key tourism destinations across BC. Learn more at sci-bc.ca/access-bc.

Accessible Fishing in Northern BC

Hooked on accessibility? Reel North Adventures is a guide fishing business

that offers fishing trips around Terrace and Prince George. With Access BC's support, owner Jerry Daoust launched a 20-foot accessible flat bottom boat with a custom boarding ramp. Daoust told the Northern BC Tourism Association that the boat, "allow[s] our guests to get up onto the casting deck safely and experience multiple methods of fishing from trolling, casting, fly fishing, jigging, and more." Peer Pat Harris says, "This was a fantastic experience with Jerry, our gracious host. Not many outdoor adventure companies provide the level of accessibility as Reel North Adventures. You will catch fish!" The next project to tackle? Renovating cabins to make overnight stays just as accessible. Learn more at reelnorthadventures.com.

Training in Tofino for Indigenous Businesses

In celebration of Indigenous Disability Awareness Month, Access BC visited Tofino in November 2024. In partnership with Tourism Tofino, Tla-o-qui-aht Nation, and local Tribal Park Allies, the team provided training on sustainable best practices for collecting accessibility information. Access BC Coordinator Emily Wiebe shares, "Local businesses were engaged and enthusiastic to learn more about improving accessibility! We were encouraged by the number of business owners that were interested in having an assessment done. It was the perfect opportunity to provide hands-on training in tandem with the assessments." However, a bomb cyclone threw the Access BC team into the eye of community emergency preparations. Tourism Tofino stepped up, sheltering locals and tourists alike. When the generators ran out, hotel staff simply donned headlamps and continued looking after guests. In the end, breaks in the weather allowed the team to finish training and produce Google virtual tours, now available on Tourism Tofino's website.

For more Access BC highlights and accessible travel resources, head over to sci-bc.ca/travel for tips and tricks on your next adventure. ■

Affordable Adaptive Snowsports

Our Access BC team is dedicated to improving accessibility across the province. Happily, we're not alone! Take for example the Vancouver Island Society for Adaptive Snowsports (VISAS).

VISAS purchased the Twinrider, the world's first commercially available sit-down snowboard. VISAS' first adaptive snowboarding student just happened to be SCI BC peer Jason Nelson. Nelson is an avid snowboarder, with 25 years of experience before his C6 incomplete injury. He says, "After five lessons last season, I was boarding down the bunny hill independently... I'm so grateful to have the chance to snowboard again. It felt incredible to carve turns on the hill once more, just me and my board. One of the biggest challenges of a disability is losing the activities that previously brought you joy. Thankfully there's some amazing adaptive equipment out there to help us continue to have adventures."

Live on Vancouver Island? Connect with VISAS (visasweb.ca) to try snowboarding at Mount Washington Ski Resort. No nearby options? Show your local organization the Twinrider, available at prodaptive.nl.



Jason Nelson high-fives his adaptive snowboarding instructors.



Google virtual tour of outdoor accessible features across BC.

Bowel Burdens

We know that bowel care is an urgent priority for people with SCI. New research shows the extent of the problem, and what's needed to make a difference.



Whether or not you've been following Simon Fraser University and ICORD researcher Dr. Victoria Claydon's research on bowel care in *The Spin* for the last few years, if you live with SCI, you're likely familiar with the challenges of bowel dysfunction. For example, in our Winter 2017 issue of *The Spin*, we covered a survey of 287 people with SCI led by Claydon. An undeniable 78% of respondents reported that bowel management was a problem, revealing just how many of you are dissatisfied with your bowel care routine.

"[The survey] told us that bowel care was a huge priority for people living with SCI. It wasn't just an inconvenience or a frustration. It was a major priority, and it was having a major impact on quality of life and the ability to complete activities of daily living," says Claydon.

Respondents rated bowel management as one of the worst effects of living with SCI, citing how it's a drain on time and resources, interferes with personal relationships, and triggers autonomic dysreflexia as some of the key issues. But despite these concerns, 71% of respondents had not made any changes to their bowel care routine in the last five years.

"Most people said they hadn't changed a single aspect of their bowel care for more than five years," says Claydon. "And we really wanted to dig into that piece and see why this poor quality care was not being addressed for people with SCI."

These findings led Claydon and her research partners, including SCI BC, down two paths: First, they wanted to see if the broader scientific literature reflected the voices of people with SCI they heard in the survey. Second, they wanted to better understand why people with SCI weren't changing their bowel care routines if they were so frustrated and dissatisfied with them.

Why going number 2 is priority number 1

To see if the voices they were hearing from people with SCI in the survey were reflected in the broader scientific literature, Claydon worked with SCI BC and a team of researchers to conduct a systematic review and meta-analysis. Using this approach, they combined and analyzed the data from multiple published studies to draw conclusions based on the body of evidence as a whole.

The study, published in the journal *Spinal Cord* in the spring of 2024, evaluated the extent of bowel dys-

function after SCI and the impact of bowel dysfunction on quality of life. After searching five databases, the authors identified 39 research studies representing 4000 participants to review and analyze. The results not only validated the survey findings, but also highlighted important nuances concerning the impact of bowel dysfunction on quality of life.

"In the survey we had almost 300 people and nearly 80% of them said that bowel care was a major concern for them. In our review of the published scientific literature, when we combined responses from all the papers and all of the people who had participated in all of those papers, we had just over 4000 people's voices reflected. And the people who felt bowel care was a major problem is about 75%. So that's a pretty strong parallel between the lived experience and what the data's telling us," says Claydon.

Across the literature, participants with SCI reported fecal incontinence, constipation, bowel-related autonomic dysreflexia, and prolonged bowel care routines as the most common problems with bowel dysfunction. As a result, more than half of participants (56%) reported moderate to severe deterioration in quality of life and nearly two-thirds (64%) reported that they fit

their lives around their bowel management a little or a lot.

“We saw those key priorities that impact care and quality of life are the long time to complete care, problems with incontinence, problems with constipation, problems with autonomic dysreflexia... but it was teasing out the particular impacts on the domains of quality of life that was interesting in the systematic review,” explains Claydon. “Emotional wellbeing, social engagement, relationships, ability to work... those were the key domains.”

Qualitative research included in the systematic review showed that impacts on physical health (including a lack of predictability, secondary complications such as fissures or rectal bleeding, and pain or discomfort), emotional wellbeing (including feelings of frustration, irritability and distress), and social life (including interference with relationships, lifestyle, and ability to work) are common and intricately connected consequences of bowel dysfunction.

“We decided to include any paper that addressed the subject, including qualitative research, meaning research involving interviews and surveys, as well as numerical data,” she explains. “I think it gave [the findings] new perspective that you can’t always capture in a number.”

For instance, the qualitative data showed how the fear of episodes of incontinence could be just as debilitating as experiencing an episode itself. “You might not be having very frequent incontinence concerns, but if you have them at all and you’re worried that you might get one, it impacts quality of life and it plays a role in your ability to fully participate in, for example, social activities or a work environment,” says Claydon.

Change takes a village

Another question that Claydon has been working to answer is why people with SCI aren’t changing their bowel care routine if they’re so dissatisfied with it.

Partnering with SCI BC and local SCI physicians and nurses, Claydon and a team of colleagues interviewed 13 people with SCI about the factors that make it easier and harder to change their bowel care routine. We covered the results of this study, which was published in the journal *Spinal Cord* in 2022, in the Spring 2022 edition of *The Spin*.

Seven Factors that Influenced Changes in Bowel Care

1. Workplace flexibility: When participants were engaged in a flexible and supportive work environment, they felt empowered to make changes.

2. Opportunity or circumstance: Sometimes optimizing another care routine like bladder care gave people the opportunity to now focus on their bowel care.

3. Access to resources: A lack of perceived support (physical and financial) was often cited as a barrier to change. When these resources were present, change was facilitated.

4. Beliefs about the consequences of change: Fear that changes might lead to accidents or loss of independence was another barrier to change.

5. Perceived support: Whether friends, partners or caregivers were supportive of changing care routines impacted decisions about making changes.

6. Peer mentorship: Peer mentors were regarded as highly influential when it came to making changes to care routines

7. Knowledge of options available: When people aren’t aware of the options, they don’t know what changes are possible. Knowledge of options was viewed as empowering.

“One of the key barriers and facilitators for people living with SCI was around knowledge of care options and knowledge of ability to change care. That was a key factor that predicted whether people would make changes [to their bowel care routine],” says Claydon. “And

for a lot of people, that knowledge piece comes from their healthcare provider.”

Because healthcare providers are often the ones making suggestions and discussing options for bowel management, talking to healthcare providers about the factors that influence how they support changes to bowel care for patients with SCI was a logical next step, according to Claydon. So, in continued partnership with SCI BC and local SCI clinicians, the research team interviewed 13 healthcare providers in BC who work with patients with SCI.

In the study, published in the journal *Disability and Rehabilitation* in November 2024, healthcare providers were defined as any professional directly involved as a member of a care team for an individual with SCI, including nurses, nurse continence advisors, physiatrists, dietitians, peer support workers, care aids, physiotherapists, and occupational therapists. Because SCI is a complex condition that requires an interdisciplinary care team, the research team felt a broad approach was needed to best understand the influence of healthcare providers on bowel care.

“One of our participants in one of the studies told us bowel care after SCI takes a village and I thought that was a really nice viewpoint,” says Claydon. “If you only go to, I don’t know, the experts, [like] the physiatrists, you might have missed a big chunk of that village, especially for people in more rural areas.”

The healthcare providers in the study expressed that being knowledgeable about bowel care and bowel management options was necessary to help patients with SCI change their care routines. They also stressed that time and teamwork were required to have conversations about changing bowel care, but that time was in short supply. Balancing competing tasks, attending to more pressing medical needs, and the nature of shiftwork are all challenges that healthcare providers face when it comes to having conversations about bowel care.

“Resources are short. Appointment times are short. The healthcare system is under pressure. And what that means is that the most urgent medical concern is understandably the priority in any health care visit... which often means that the bowel care quality of life piece can be neglected,” explains Claydon.

While time and resources may be limited, participants highlighted the important role that peer support from community members with SCI can play in supporting changes to bowel care routines. Claydon also pointed out that sometimes bowel care choices are simply based on an individual’s financial situation or health insurance.

“We’ve learned from our work that sometimes bowel care choices are made not based on what’s the optimal choice, but what’s covered by insurance. And that coverage is going to vary in different provinces, even, and certainly in different countries,” says Claydon.

Another key finding of the study was that the relationship dynamics between

the healthcare provider and the client can encourage or discourage conversations about changing bowel care. For example, if healthcare providers feel that having a conversation about bowel care will cause discomfort and negatively impact their relationship with their client, they may be less likely to engage in bowel care conversations. The social and cultural identities of both the healthcare provider and the client can play a role in shaping these dynamics.

Regardless, Claydon points to the importance of prioritizing and normalizing conversations about bowel care. “It’s important to have conversations about it regularly and to review it regularly so that when concerns come up, they can be addressed promptly and that burden on quality of life can be improved,” she says.

Moving forward, Claydon is working with SCI BC to develop and evaluate resources to increase knowledge around bowel care. “We don’t just want to put resources out there and hope they will help, but rather we want to really be

mindful to evaluate them,” she says. “Just because they’re well-intentioned doesn’t mean they’re going to land well or actually be helpful.”

But on the whole, she says, the research speaks for itself: “One of the key takeaways is that bowel care is a major priority for people with SCI, and if it’s a priority for people living with SCI, then it should be a priority for healthcare providers and researchers.”

You can follow Victoria Claydon’s lab for updates at x.com/VClaydonLab. ■



Dr. Victoria Claydon

Safe & Happy Holidays...



...From the staff of Access Driver Rehab!

Our Driver Rehabilitation Specialists provide the highest quality driver evaluation and rehab services—when you want, and where you want. We are the only program in BC that offers a mobile service throughout the province, as well as Alberta and the Pacific Northwest. We offer assessments, training, and driver rehabilitation in either a sedan or high tech (electronic controls) van.

Access Driver Rehab—your key to independence.



Phone: 604-263-5218
Email: AccessDriverRehab@gmail.com
www.accessdriverrehab.com

Ask InfoLine: Answering Your SCI FAQs

I want to get some regular exercise by handcycling, but I have no core and I struggle to transfer from my wheelchair. I've heard I can get one that attaches to my wheelchair—how do I get one? What do I need to know? —Sam in Smithers



Jocelyn Maffin, BSc, is Associate Director of Service Delivery at SCI BC. InfoLine provides information and support by phone or email on any topic relating to living with physical disabilities in BC.

In SCI BC's Adaptive Cycling Program we hear about the difficulty of transferring from wheelchair to handcycle all the time! An attachment is a great solution to your problem. You can add a front wheel, driveshaft, and either a classic handcycle crank-and-chain drive (manual), electric motor and battery (power), or a hybrid of both—we can refer to all of these as 'drive systems', as there's no agreed upon name for them yet. Some people also call them clip-ons because they attach to a wheelchair frame with clamps. Power only attachments are commonly called front drives in BC.

Avoiding that transfer means you can ride more independently, and use any specialized seating you have on your wheelchair already. These attachments also help extend the range of your manual wheelchair with manual, power, or hybrid drive systems. They enable you to keep your wheelchair with you while you're riding, making a mid-ride bathroom break, or even commuting to work. Riders cycling in the upright position in a wheelchair are also generally more visible to traffic, pedestrians, and other cyclists than in most handcycles.

Considerations

YOUR GOALS: If your ultimate goal is competing in handcycling, it's important to know that clip-on attachments are not competition legal and heavier than a road racing handcycle, so you'll need to plan to transition to a handcycle if your competition dreams come to life. If you want to ride with friends or family, consider a hybrid model so you can keep up.

YOUR WHEELCHAIR: If you use a folding wheelchair, your options are more limited. Under-mounted attachments like the Batec may not be suitable at all or may require additional equipment to properly mount. Ultra-light or carbon fibre frame wheelchairs are generally not suitable as they are not strong enough to withstand the forces applied to the wheelchair by the attachment clamps, particularly for hybrid and powered attachments. Check with your wheelchair vendor and the manufacturer of the handcycle attachment you want before you buy. Some attachments clamp on the frame, so it's essential to be sure your wheelchair frame has the space and rigidity required.

YOUR POSITIONING NEEDS: If you have a short reach you may find that operating or reaching the crank arms of the attachment is difficult for you. It helps if your chosen model of attachment has some adjustability, but these adjustments also affect the placement

of the front wheel—generally speaking, the traction is better the closer the front wheel is to your centre of gravity, the more weight is on that front wheel, and the larger the wheel is. These attachments are designed to raise your casters off the ground once attached, but this can also tilt your seat back and decrease stability overall. It's smart to review positioning of the attachment on your wheelchair with an OT and your vendor to make sure that docking on your wheelchair, positioning, and safety are all addressed.

THE WEIGHT/PORTABILITY TRADEOFF: The more features they have, the heavier these attachments get, which is great for traction but can make them very difficult to transport in a vehicle or by air. Do you want to use it while travelling, or in your own neighbourhood primarily? Heavier attachments are also easiest to use with a dock or stand for mounting and removing.

Drive Systems

MANUAL/CYCLE ONLY: Traditional handcycle crank-and-chain drive. **Advantages:** Great for people whose goal is handcycling or fitness and those who have limited storage for a handcycle or difficulty transferring. Lighter and simpler than a hybrid or powered attachment. **Limitations:** Hills and rough terrain. **Consider:** Get a larger wheel size and a model with some adjustment if it's your first attachment, and add weights over the front wheel for better traction.

HYBRID: Crank-and-chain drivetrain with e-assist motor and battery. **Advantages:** All of the advantages of the manual attachments such as exercise and easier storage, plus electric assist to help with grades/rough terrain and expand your cycling range. Excellent for commuting or riding with two-wheeled cyclists, and doesn't require as much strength to start. The battery and motor also add weight over the front wheel that increases traction. **Limitations:** Higher cost than other drive systems, more complex to maintain, and considerably heavier.

POWER ONLY (also known as a front-drive): Electric motor and battery only, more like an electric Razor scooter than a handcycle. **Advantages:** These models really shine when used to make everyday mobility easier and more fun. Generally good mobility on uneven terrain. The simplified drivetrain means these are smaller and available in more portable, lightweight or less expensive options. Some models can even fit in the overhead compartment on a plane. **Limitations:** No fitness or exercise benefit; some models prioritize portability over traction and power; some models and batteries can be costly.

Interested? Check out our list of attachment models on our blog at sci-bc.ca/handcycle-attachments.

BEAST Mode

BCIT MAKE+ team strikes gold at the 2024 CYBATHLON, an international competition of assistive technologies for people with disabilities.

Seated atop a three-wheeled chair with large, rugged tires, bicycle-style handlebars, and robotic footrests, wheelchair pilot Dr. Jaimie Borisoff waits patiently for the race to begin. Sporting a yellow helmet and supported by a team of coaches and spotters, he has eight minutes to complete 10 challenges that lie on the obstacle course ahead of him.

A clock next to the start line counts down the seconds until the race begins. “Five... four... three... two... one... GO!” calls out a race official, waving a green flag to start the race.

Borisoff expertly navigates the wheelchair, nicknamed the “BEAST” (BCIT Extending Articulating Wheelchair for Serious Terrains), up and down staircases, around tables and objects, and over uneven terrain and doorsteps. Along the way, he elevates the chair to reach an object

above sitting height, uses the chair to pick up a bottle off the ground and place it on a table, and opens, passes through, and closes a door with a different door handle on each side—without touching the door with his hands.

The stands erupt in applause as Borisoff crosses the finish line, having successfully completed all 10 challenges in a record six minutes and 17 seconds.

After nine months of rigorous engineering, testing, and training to develop a high performance wheelchair with advanced capabilities, Borisoff and the British Columbia Institute of Technology (BCIT) MAKE+ team travelled more than 8,300 km to compete in the wheelchair race at the 2024 CYBATHLON, an international competition that challenges participants to develop assistive technologies for people with disabilities. The competition took place from October 25-27, 2024 in Zurich, Switzerland.

Scoring a perfect 100 points, the BCIT MAKE+ team was the only Canadian team to secure a gold medal at the 2024 CYBATHLON.

“We were happy. Our goal was to do all 10 tasks under eight minutes, and we did that. Turns out that was a win, so that was exciting,” says Borisoff, who has been a wheelchair user since sustaining an SCI more than 30 years ago.

A Research Showcase and a Competition

Borisoff is the Director of BCIT MAKE+, a group of multidisciplinary researchers focused on product development, evaluation, applied research projects, and education. Borisoff is also the former Canada Research Chair in Rehabilitation Engineering Design, with an extensive program of research focused on how technology development can improve accessibility and mobility for people with SCI.

“It’s interesting when you go into it because... [the CYBATHLON] is a combination of a scientific conference plus the Paralympics,” explains Borisoff. “It has elements of both where you have people showcasing the research they’re doing and then it truly is a competition. So, it helps to go into it with a competitive mindset.”



As a four-time Paralympian and three-time Paralympic medallist who spent 13 years on Canada's national wheelchair basketball team, Borisoff is no stranger to the pressures of competition. But his first priority was to share some of the innovative wheelchair technologies that the MAKE+ team has been working on in recent years.

"One of the reasons we wanted to go to the CYBATHLON was to showcase the work we do at BCIT MAKE+," he says. "We have a long history in our lab of wheelchair research and development... [We are working on] how to get wheelchairs into trails and forests and on the beaches, working well in snow, and these sorts of things."

In fact, you may already be familiar with some of Borisoff's work. Borisoff developed the SWIVL, a front-wheel attachment like the FreeWheel that extends the wheelbase of the chair and lifts the castors off the ground, making it easier to navigate difficult terrain. Featured in the Winter 2021 edition of *The Spin*, the SWIVL can be folded up and stored between the front legs of the user when it's not in use—making it easier to use and store than products like the FreeWheel.

Now, with new funding from the Canadian Foundation for Innovation and the BC Knowledge Development Fund, Borisoff is leading a team of researchers and engineers focused on developing and testing advanced wheelchair technologies in efforts to improve the lives of people with disabilities. Together with Dr. Jacquie Ripat, a professor of occupational therapy who holds an Endowed Chair in Technology for Assisted Living at the University of Manitoba, Borisoff and the MAKE+ team are working to understand which products allow users to tackle more challenging surfaces or obstacles such as stairs, snow, and off-road trails.

Or what is more likely, according to Borisoff, they will create new devices to overcome these challenges, ideally as attachments that can modify a manual wheelchair "on the fly" for different environments. Examples include swapping



The 2024 CYBATHLON obstacle course. Previous: Borisoff's BCIT MAKE+ team celebrates CYBATHLON gold.

wheels to match the terrain and adding motors and other powered features.

Testing Solutions to Real-World Problems

The CYBATHLON—a non-profit initiative by ETH Zurich, a public research university in Zurich, Switzerland—presented a perfect opportunity to not only share, but also test, some of the most recent advancements in assistive technologies. The event takes place every four years, and since its inception in 2016, it has grown to include over 100 teams from more than 30 countries competing in eight categories. The categories include separate races for arm prosthetics, leg prosthetics, assistance robots, brain-computer interfaces, exoskeletons, functional electrical stimulation bikes, and wheelchairs.

For the wheelchair race, teams are required to develop a powered wheelchair that is capable of navigating complex, real-world obstacles. The wheelchair must be powered externally, not manually, and driven by a pilot with a severe walking disability.

The BCIT MAKE+ entry into the CYBATHLON wheelchair race, the BEAST, has a form loosely based on a manual "Elevation"-style wheelchair combined with a powered front-end attachment that turns the chair into a three-wheeled device. It also incorporates powerful rear wheels with an extending and retracting long wheelbase. It is highly maneuverable in tight spaces and can tackle a variety of terrains, featuring elevating seating and a "steer by wire" system that can be used with any kind of control, like a joystick or sip and puff, allowing the chair to be driven by users with diverse abilities.

According to Borisoff, the competition presented a unique opportunity to marry the research and development being done in the MAKE+ lab with the requirements of the CYBATHLON wheelchair race—10 tasks with a time limit for completion in a competition environment.

"We wanted to think about a wheelchair with different modular components, attachments, motors, wheels, other things," says Borisoff. "What can we attach to a manual wheelchair to tackle this CYBATHLON course?"

Two Steps Forward, One Step Back

While the BEAST produced a record-setting performance that placed the MAKE+ team on top of the podium, the team didn't originally set out expecting the win.

"We had challenges. I mean, you always do the entire way up to and including the final day [of competition]," says Borisoff. "We only started [working on the BEAST] in January... it's a relatively short time-frame, which meant we were kind of putting out fires all the time, we were just kind of triaging things we needed to do until the final day."

One of the first challenges that the team faced was in the functional design of the wheelchair. Originally designed as a manual-hybrid wheelchair with a powered front-end attachment, competition organizers warned the MAKE+ team that the BEAST wouldn't meet the requirements for the competition unless the steering could be externally powered. The team decided to stick with their original concept but created a new steering system to comply with the requirements.



Dr. Jaimie Borisoff navigates through the challenges at the 2024 CYBATHLON.

“So, you’ll see me in all the videos using something that looks like a bicycle handlebar with throttles and brake levers and all sorts of things. But the neat thing is there’s no mechanical connection between any of that with the wheels or the brakes. Everything is ‘steer by wire’ and ‘brake by wire.’ It’s all done with actuators and sensors and microelectronics,” explains Borisoff.

Several Wheelchairs in One

Overall, the development process involved creativity and experimentation, grounded in what the team had learned from their past work. For example, they knew that a three-wheel structure including two powerful rear wheels with fat tires and a single front wheel could “tackle trails really well and handle beaches and get on snow,” says Borisoff. They also knew that the BEAST needed to be very short and compact in order to maneuver easily in tight spaces, but that length would be important to handle steps and stairs.

“So, we put together a device that was very long with the same kind of front end and with rear wheels that are further back,” explains Borisoff. “We performed experiments to answer, ‘How long should it be? Where should the centre of gravity be? How much power do the rear wheels need?’”

To ensure the BEAST would have enough ground clearance to get over obstacles, the team drew inspiration from three-wheel handcycles. “[The BEAST] has the length of a hand cycle, and the legs are up, like you sit in a kind of recumbent style,” says

Borisoff. The articulating footrests allow the feet to be elevated to waist height, increasing the clearance beneath the chair.

But the real challenge, according to Borisoff, was managing all of these constraints in one wheelchair. “We want to be short. We want to be long. We need ground clearance. The feet have to get up, and the seat needs to rise up 30 cm. That gives us eight of the 10 [CYBATHLON] tasks, and the two that it doesn’t give us are the ones that require some kind of manipulation [like picking up a bottle or opening a door].”

Inspiration for the final two tasks came from Borisoff’s personal life. One day while going through the front door of his home with his powered front attachment, he realized that the front wheel could be used to open the door, as long he could get it open an inch or two first. To tackle this problem, the team added a gripper to each footrest, which—when elevated to gain ground clearance—could also be used as a tool to open the door handle or pick objects up off the ground.

“A lot of that went up right until, you know, we were in Switzerland. And we had a whole bunch of variations of the same part because we weren’t quite sure what the final size of the doorknob would be or the door handle,” says Borisoff.

The Winning Formula

In the end, the MAKE+ team accomplished what they set out to do: Complete all 10 tasks in under eight minutes. Winning the competition was simply “the icing on the cake,” Borisoff says.

He’s also quick to note that it wouldn’t have been possible without the team behind the BEAST. While Borisoff is the Director of MAKE+ and piloted the BEAST in competition, the team that developed the BEAST was led by MAKE+ research associate and BCIT alumnus, Garrett Kryt. The team also included mechanical designer Rory Dougall, who piloted the prototype while it was in development. “Rory is able-bodied and very athletic, a surfer and mountain biker. So, he would be able to use his legs to save himself if something went awry, which would happen all the time during testing,” says Borisoff. Other key team members included Joe Newton and co-op student, Ethan Stiller, as well as several other MAKE+ engineers that jumped in to help when needed.

In terms of what’s next for the BCIT MAKE+ team, they hope to research which of the BEAST’s features are most interesting and useful to wheelchair users’ everyday activities and then start developing modular components that could become products one day.

They also plan to defend the teams’ gold medal at the next CYBATHLON. “We plan to compete four years from now in another CYBATHLON. We have the funding to do that,” says Borisoff. “We won’t get started for a while because the course will change, the venue will change, the rules will change... but we’re definitely going to stay in that space and compete again.” ■



ALLIANCE Mobility
Freedom Through Mobility.

www.amsvans.ca

Sales | Service | Adaptations | Rentals



ALLIANCEMOBILITY



Lower Mainland
#110, 12211 Vulcan Way
Richmond, BC
T: 604-370-7004

Interior BC
1791 Baron Rd.
Kelowna, BC
T: 236-420-1400

Vancouver Island
2405 Douglas St
Victoria, BC
T: 250-940-2100



Free Employment Support for People with Disabilities

Neil Squire's **Creative Employment Options** program offers:

- Individualized career and personal development
- Job search support and virtual training
- Distance learning technologies
- Ergonomic and/or assistive technology solutions
- Potential wage subsidies

Contact us today!

T 1 877 673 4636 E info@neilsquire.ca

www.neilsquire.ca/creativeemployment



Funded in part by the Government of Canada's Opportunities Fund for Persons with Disabilities



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.

At-Home Sleep Testing in Individuals with SCI

Overview: ICORD researcher Dr. Victoria Claydon and her research team at SFU are interested in characterizing a typical night of sleep for individuals with SCI, using non-invasive wearable equipment to determine the duration of sleep, sleep stages, and sleep breathing patterns.

What to expect: This study involves wearing a set of non-invasive wearable equipment (mesh shirt, headband, and watch) on two consecutive nights of sleep in your usual at-home sleep environment. Sleep equipment hand-off/return will be delivered via tracked pre-paid packages, or in-person delivery can be arranged if you reside in the Lower Mainland. They will arrange for a call to provide instructions for instrumentation, and you will also be asked to complete a short online questionnaire. When equipment has been returned, participants will receive a \$15 honorarium as a thank you for your time.

Who can participate: We invite you to participate if you have a chronic (≥ 1 year injured) SCI (inclusive of all SCI levels and severity), are ≥ 19 years old, and are able to understand instructions in English, or have help to do so. You may not participate in this study if you are using a ventilator to breathe or use a positive airway pressure (PAP) machine during sleep.

Why participate: Sleep health is emerging as a priority for people with SCI, but travel, financial, and accessibility concerns may be barriers to seeking in-lab sleep testing. Particularly as sleep apnea (breath holding during sleep) tends to be underrecognized among individuals with SCI, there is a need to investigate alternative methods of sleep testing. We hope that the results of this study will shed light on how SCI impacts sleep and test the utility of this system to detect sleep breathing patterns.

Location: Once the equipment is in your possession, sleep testing occurs on your own time, in your usual home sleep environment.

For more information or to sign up: Please contact the study coordinator Rebekah Lee by email (rebekah_lee@sfu.ca) or call 778-735-8235.

The Canadian SCI Pain Survey

Overview: The SCI Action Canada Lab, under the guidance of ICORD researcher, Dr. Kathleen Martin Ginis, invites adults with spinal cord injury (SCI) across Canada to take part in the Canadian SCI Pain Survey. This study is led by Robert Buren, a PhD student at the University of British Columbia, who has lived with neuropathic pain since sustaining a T7 SCI in 2008. This survey aims to assess the current state of pain intensity and pain treatment methods among Canadians living with SCI. In addition to pain, the survey will explore various factors that impact the pain experience, such as: emotions, personality traits, anxiety, depression, support systems, resilience, sleep, and exercise habits. The goal is to gather a wide range of experiences to help better understand and manage pain within the SCI community.

What to expect: The time commitment for this study is approximately 30 minutes. You do not need to currently experience pain to participate.

Who can participate: You may be eligible to participate in this study if you have an SCI from a traumatic or non-traumatic cause; are age 18 years or older; can read, speak, and understand English; and live in Canada.

Why participate: Chronic pain is one of the most difficult and life-altering challenges faced by individuals with SCI. By participating in this survey, you will help researchers uncover key insights into how pain is experienced and managed by people with SCI. The data collected will guide future treatments and interventions aimed at reducing or eliminating pain for the SCI community. A Canadian vendor gift card will be offered upon completion of the survey. A Canadian mailing address will be required to issue the gift card. A very short (5 minute) identity verification on Zoom and a short discussion on living with SCI may be required before the gift card is issued.

Location: Remotely (online survey/phone/video call).

For more information or to sign up: Please contact the study coordinator Robert Buren by email (robert.buren@ubc.ca) or by phone at 416-705-6111.



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.

More than just numbers.

"I strive to be both an accountant and a mentor. I can help navigate our tax and disability support systems with a combination of professional and personal experience."

- Walter Gagen
accountant & founder



We're the missing piece!
Our services include:

- CSIL bookkeeping
- Personal and corporate tax prep
- Custom services to meet your needs
- Pick-up and delivery available

www.gagen.ca

wgagen@telus.net

1-866-277-2745 | I'm Walter Gagen. Call me - I'm able. | 604-597-5100

POWER YOUR PUSH

Book A Free Trial!
236.309.3708



Macdonald's
HOME HEALTH CARE

On Sale Now!

25% Off
Demo Batec Handbikes

10% Off
Paws Rehasense City 14
Paws Rehasense Tourer 20
Permobil Smartdrive

www.macdonaldsHHC.com

VANCOUVER 148 West 6th Ave. PH: 604.872.5496

BURNABY 7640 Winston St. PH: 778.379.5496

Tackling Pain Together

Reflections from Kara Stanley and Simon Paradis on a year dedicated to tackling pain and their new book *The Pain Project*.

“Pain is something that we might know, but we don’t always understand it that well,” explains Kara Stanley, writer of *The Pain Project*. Ten years prior to writing *The Pain Project*, Stanley’s husband and lifelong best friend, Simon Paradis suffered a brain and spinal cord injury. His recovery and determination to return to work as a professional musician is detailed in Stanley’s first memoir *Fallen: A Trauma, a Marriage, and the Transformative Power of Music*.

Following his injury, Paradis faced unyielding chronic pain that resisted treatment—an experience familiar to many readers of *The Spin*. He says, “Your world gets small because you start to reserve your reaction to committing to things. You have this little voice of doubt in the back of your head like ‘Will you really be able to handle that on the day?’ So, you cocoon and realize as you cocoon that you’re not mortgaging the future against experiencing pain. The pain is still relentless and persistent as it always was. But now you don’t have the same enrichment of the usual day-to-day touchstones that build your quality of life.”

In 2018, the Sunshine Coast couple launched a year-long “Tackling Pain Project” to improve how they thought about pain. Stanley says, “There’s so much energy spent trying to run away, avoid, or distract yourself from pain. We thought, what if we took all that energy and really focused on it? We were not necessarily going to find solutions, but we could really work hard on asking better questions.”

In *The Pain Project*, Stanley and Paradis explore the nature of suffering and pain through extensive research, profound conversations with pain sufferers and experts,

and personal trials of new and old pain management approaches. From cannabis to mindfulness and a suspenseful nerve ablation procedure, Stanley’s writing walks you through their process of understanding pain. Their affectionate, witty banter lightens the heavy topic, drawing readers into the discussion.

Fellow SCI peer and author Bonnie Klein praises the book for its collaborative approach. “Simon and Kara tell their story together,” she notes, highlighting that the publisher included Paradis’ name on the cover. In Klein’s book review in *Herizons* magazine she states, “Thankfully, this memoir does not offer the typical ‘triumph over tragedy’ narrative. Rather, it is about the acceptance of human suffering and the ways in which caring for someone brings you together... Stanley and Paradis’ pain project is not ultimately triumphant with a capital T nor could it be. Brutally honest and vulnerable, their relationship prompts us to consider how we might respond to life’s inevitable challenges. Are we capable of similar grace, curiosity, and humour?”

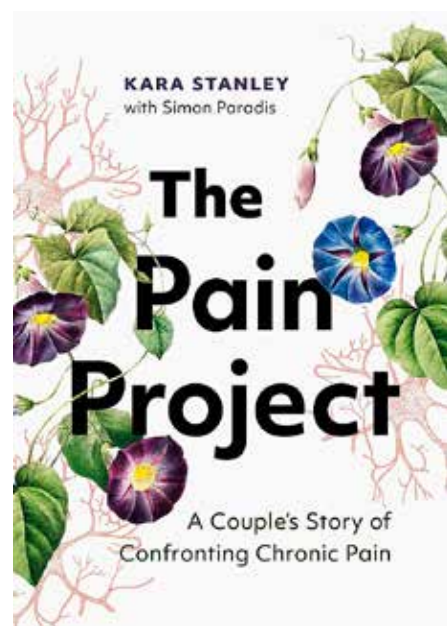
Ultimately, Stanley and Paradis hope readers come away from the book feeling less alone. “The book really is about my metamorphosing into someone that finds different ways of managing pain on a day-to-day basis, rather than trying to obliterate it,” explains Paradis. Stanley says, “Having fun is sometimes what we’re left with in terms of an intervention. Loving your life, loving each other, and building that capacity is our best intervention.”

We asked the couple how things have been going since the project concluded in 2019. With the COVID-19 pandemic halting Paradis’ music gigs, he had the time and space to fully taper off the opioids he was prescribed many years ago (Paradis’

efforts to reduce his dosage by half are detailed in the book). In addition, an article in the Fall 2023 issue of *The Spin* introduced Paradis and Stanley to a virtual reality (VR) walking simulation game for neuropathic pain, exactly the type of research they had sought during their project. They plan to travel to Texas A&M University to participate in VR research.

Pain remains a daily reality, but Paradis shares a recent triumph. “One of my biggest fears dealing with chronic pain and being a performing musician is to be in the middle of a song and have an attack on pain that derails the performance. Recently, I was performing with a band. Between songs I got hit with a really bad pain and I had to say, ‘I need a moment, folks.’ After two and a half minutes I said into the mic, ‘Thank you. We’re gonna go on to our next song.’” Stanley proudly adds, “There was a huge round of applause and then he leaned in and thanked the audience for making what could have been a really uncomfortable moment very beautiful.”

You can buy *The Pain Project* at Indigo, Amazon, and select bookstores. Learn more about the couple at karastanley.com and simon-paradis.com. ■





The catheter glides effortlessly for ease of use giving users confidence and more time for living.¹

Jonny uses VaPro™ catheters
Katie uses Infyna Chic™ catheters

Experience the ease of use² and comfort³ of our NEW HydraBalance™ Lubricating Technology

Made with naturally sourced ingredients, its unique combination of hydrophilic coating and hydration fluid creates a smoothly gliding hydrogel cushion that not only helps protect the urethra, but also provides smooth and effortless insertion and withdrawal for a more confident and natural catheter experience.^{4, 5}

Key features of our NEW HydraBalance™ Lubricating Technology:

- **Smooth and comfortable on catheter insertion and withdrawal.⁶**
- **Helps protect the urethra from potential micro trauma and Urinary Tract Infections.⁷**
- **Designed to capture the right balance of naturally sourced ingredients for as natural of an intermittent catheter experience as possible.⁸**

For more information, please call us at 1.800.263.7400 or visit us at www.hollister.com

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

Greater Reach & Better Service



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



When you support Chair Stuff, you support SCI BC.

Chair Stuff has your back...

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

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

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

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

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

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

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

STEVE MILUM
Founder & CEO
Chair Stuff



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