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FALL 2024

Piersistance Wins in White Rock

New accessibility mat at the White Rock pier is a result of SCI BC peer's persistent advocacy and dedication



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Looking Forward as We're Looking Back

This year marks the 75th anniversary of the GF Strong Rehabilitation Centre. It's easy to take GF for granted. It seems like it's always been there and that there is an equivalent centre in many other parts of Canada and the world. But there isn't and it is regarded as a special institution for SCI rehab around the world.

We don't celebrate this enough. Nor do we take enough pride in the fact that, historically, Canada has been a world leader for specialized SCI rehab. In 1945, when many World War II veterans returned home with spinal cord injuries, advocates established the world's first specialized SCI rehab centre in Toronto, what is now Toronto Rehab's Lyndhurst Centre. For those veterans who returned to BC, an equivalent centre didn't exist.

That changed in 1949 when Dr. George Frederick Strong's daughter sustained an SCI. Working with what is now called SCI BC, Dr. Strong established the rehab centre that bears his name. GF Strong has gone through many changes over the last 75 years and increasingly, it is starting to show its age. While it has generally been held as beloved, almost sacred institution, I think it's fair to say that many folks have a complicated relationship with it. The complication of that relationship seems to be increasing these days.

The age of the building's infrastructure, strains on staffing, and ever shortening lengths of stay are changing people's experience at GF and leading for calls to create a new, modern rehab centre to better serve the rehab needs of all folks with SCI in the province. There's no question that new rehab infrastructure is needed.

But it isn't just the building that's made GF Strong a special place. First and foremost, it's the people working there that have done so. They created a positive culture that supported folks sticking around long enough to develop unique expertise in SCI rehab and all the benefits that has had for the SCI clients at the centre. However, changing times within and beyond the health system have meant more staff turnover, less development of SCI-specific expertise, and increasing pressure to rapidly move clients through to discharge. All this inevitably leads to less connection with the centre and its people—for staff and clients alike.

While the calls for a new or completely revamped building are justified, let's not lose sight of the fact that people are the key ingredient in making the infrastructure special. If we are to invest in a new building, we must invest in the people who provide the world class rehab services within it. As we look forward to modernize our rehab centre infrastructure, let's look back to what has made GF Strong such an influential place and invest in the people who provide the services and define the culture within it.

—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

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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.

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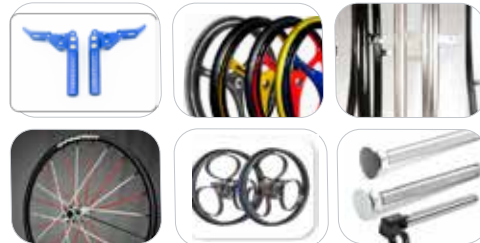
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SELF-DRIVING ROBOTIC POD

Vancouver's A&K Robotics has created Cruz, a self-driving pod to help move people. Cruz is currently being tested at the Vancouver International Airport (YVR) to help travellers with limited mobility get around, making this one push forward for

accessibility at YVR. The pod displays real-time mapping information that helps passengers navigate where they need to go, whether that's finding accessible bathrooms, restaurants, or the departure gate. Together with A&K Robotics, YVR, Innovations BC, and support from the provincial and federal governments, this project is expected to start trials with YVR employees, the accessibility community, and travellers to ensure the robotic pods are a safe integration into the airport. We are thrilled for a more inclusive airport experience in BC and will share any major updates in future issues.



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

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

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events ■



Learn more on jobs & disability. Neil Squire's Creative Employment Options webinar series is back for the fall of 2024. These free webinars are for job seekers with disabilities, injuries, or illnesses and people who face barriers and challenges to employment. The online sessions are now running every second Tuesday of the month at 10 AM until March 2025 and cover topics such as LinkedIn, AI, wellness, and more. Register for one or all of the webinars at neilsquire.ca/webinarseries.



The latest SCI care & health info. Join us for our next Ask an Expert webinar on October 16 at 5 PM with guest speakers, John Chernesky and Vanessa Noonan from Praxis Spinal Cord Institute to learn more about resources that are being developed by experts across Canada to improve SCI care. Topics will include the new Canadian SCI guidelines, data on how Canada compares to other countries, and resources for the community. Register at sci-bc.ca/event-dir/aae-sci-resources.



Join our online SCI community. Connect with your peers from all across BC in our ReachOut programming of online events—now including more dance classes! With a click of a button, you can meet new friends at a peer meetup, gain new knowledge at a webinar or stay active with a fitness class. And here's a fun fact: total attendance at our online events was over 2,700! Be a part of our online SCI community by heading over to sci-bc.ca/events for your next event.

A festive red banner for the SCI BC Online Holiday Auction. It features snowflakes, stars, a reindeer, and a circular photo of people in wheelchairs wearing holiday-themed clothing. The text includes "Spinal Cord Injury BC", "SHARE THE JOY OF GIVING", "Support SCI BC's Online Holiday Auction", and "November 18 – December 2, 2024". It also provides contact information for Krystyna at kpangilinan@sci-bc.ca.

Spinal Cord Injury BC

SHARE THE JOY OF GIVING

Support SCI BC's Online Holiday Auction

November 18 – December 2, 2024

If you are able to help us by donating an auction item, please contact Krystyna at kpangilinan@sci-bc.ca.



HONOURARY DEGREE RECIPIENT

Caps off to Rob Shaw for being awarded an honorary doctorate from his alma mater Nipissing University! Shaw was recognized for his many athletic, scholarly, and advocacy accomplishments. He is a professional wheelchair tennis player (including a two-time Paralympian who participated in this year's Games) and coach and sits on committees for organizations such as Wheelchair Tennis Canada and the International Tennis Federation. In his role as SCI BC's National Peer Program Lead, Shaw builds on his PhD research on the value of peer support for people living with SCI. Shaw told Nipissing University, "The hope for change is to have someone like myself, who receives such a prestigious award, not be a standout. I want that to become the norm. I want people with disabilities, whether it's physical or audiovisual or invisible disabilities, to have the opportunity to achieve what they can achieve." With Shaw as a role model and mentor, the future looks bright!



INTERNATIONAL RECOGNITION FOR PHYSICIAN RESEARCHERS

A scholarly shoutout to SCI physicians and ICORD researchers Dr. Stacy Elliott and Dr. Andrei Krassioukov for their recent research recognitions! Elliott was awarded the prestigious Academy of Spinal Cord Injury Professional's 2024 Donald Munro Lectureship Award for her clinical research and clinical practice in sexual health and fertility after SCI. Krassioukov was awarded the Senior International Scholar Award from Shanghai Jiao Tong University (SJTU). The SJTU School of Medicine is a highly ranked medical school in China known for collaborating with international scholars. While Krassioukov's research focuses on autonomic dysreflexia and cardiovascular health after SCI, Elliott and Krassioukov often collaborate, including work on the influence of neuromodulation on sex, bladder, and bowel function. These awards further cement Elliott and Krassioukov as leaders in their fields and reflect their commitment to impactful SCI research and evidence-based care.

ICORD'S NEW DIRECTOR

A cheerful congratulations to Dr. Brian Kwon for his appointment as the new director of the International Collaboration on Repair Discoveries (ICORD) in July. Kwon told Vancouver Coastal Health, "My vision for the coming five years is to establish ICORD as the global leader in spinal cord injury research, innovation, and care, leveraging the incredibly committed pool of scientists and clinicians at ICORD and the uniquely vibrant community of key spinal cord injury partnerships within Vancouver." And he's certainly the right man for job: Kwon started at ICORD back in 2000 as a PhD student and is now a surgeon-scientist at UBC, attending spine surgeon at VGH, The Canada Research Chair in Spinal Cord Injury, and Dvorak Chair in Spine Trauma. We are excited to work with Kwon and the amazing team at ICORD to investigate and share SCI research that is meaningful, relevant, and useful.



Community Highlights

An in the box shoutout to out of the box thinking peer **TANELLE BOLT** for the successful launch of the RAD Recreation Adapted Society's GearBox in Langford! Bolt is the founder of the RAD Society, a non-profit organization dedicated to making outdoor recreation accessible to individuals with mobility issues. The GearBox is a large storage container housing adapted outdoor recreation equipment available for low-cost rental fees. Bolt's strike of brilliance means more people with disabilities can enjoy the outdoors (and we all know how expensive adaptive equipment is!). Head to www.radsociety.ca to reserve equipment, including handcycles, sit skis, surfboards, mountain trike all-terrain bikes, ParaGolfers, and more. Next up for Bolt and the RAD Society? A partnership with Dr. William Miller to bring the GearBox to the University of British Columbia and explore how adaptive recreation access affects individuals and the community. Now that's rad!



Peer Shoutouts

A big round of applause for the 126 athletes who proudly represented Canada at the Paris 2024 Paralympic Games! **TEAM CANADA** finished strong with 29 medals overall (10 gold, 9 silver, and 10 bronze). 22 athletes celebrated their first-ever Paralympic medals. The **WOMEN'S SITTING VOLLEYBALL TEAM** achieved a historic bronze, defeating Brazil 3-0 in their final match. They are the first Canadian team to win a medal in a team sport since the 2012 Paralympics! Team Captain **DANIELLE ELLIS** from White Rock told CBC, "I know how hard every athlete and every staff member and all of our family back home have worked for this moment. It's been years and years and years in the making, our third Paralympic Games, and we knew we wanted to be there."

Ellis was joined by peers **FELICIA VOSS-SHAFIQ** from Burnaby and **JENNIFER MCCREESH** from Smithers.

Canada excelled in the Para Athletics events as well. Victoria's **CODY FOURNIE** raced to first place in the Men's 100m and 200m wheelchair races. Fournie shared with CBC, "What was the most difficult part about racing was getting this chair figured out. With not having any stomach muscles, I had to use my head to change the direction of the chair and that took quite a while to figure out." Fellow Victoria athlete **NATE RIECH** earned silver in the Para Athletics T38 1500m race, while Kamloops' **GREG STEWART** took home gold in shot put. In para cycling, Victoria's **MELISSA PEMBLE** and West Vancouver's **NATHAN CLEMENT** competed fiercely. Clement earned his first-ever silver medal, completing the 14.1-kilometre course in 22 minutes and 53.36 seconds!

Swimmer **NICHOLAS BENNETT** from Parksville shined in the pool, winning two golds and one silver medal. Bennett and para canoeist **BRIANNA HENNESSY** were selected as flag-bearers for the closing ceremonies. He told CBC, "Being able to hold the flag and represent all the athletes that have competed is just another level of amazement for me that I have been able to achieve at these Paralympics."

Other highlights of the games included the **WOMEN'S WHEELCHAIR BASKETBALL TEAM** (including peers **KADY DANDENEAU** and **TARA LLANES**) reaching the semi-finals for the first time in 20 years! **BO HEDGES** and the **MEN'S WHEELCHAIR BASKETBALL TEAM**



Greg Stewart



Womens Sitting Volleyball Team

Photo Credit: Graham Denholm/Getty Images



Closing Ceremony

placed 4th as well. Peers **JOEL EWERT**, **BYRON GREEN**, **TREVOR HIRSCHFIELD**, **RIO KANDA KOVAC**, and **TRAVIS MURAI** fought hard to finish in 6th place for Men's Wheelchair Rugby. BC's delegation of amazing athletes also included **AUSTEN BURNS** (Para Equestrian), **YUKA CHOKYU** (Para Badminton), **PETER ISHERWOOD** (Para Table Tennis), **MARYAM SALEHIZADEH** (Goalball), and **ROB SHAW** (Wheelchair Tennis). The Paralympic Games are not only a celebration of hard work and dedication, but also a chance to progress in one's sport and serve as an inspiration to the next generation of para athletes.



A BIG thank you goes out to our Charity Challenge supporters...

133 members joined Team SCI BC and together, we raised over \$75,000 for people with SCI and related disabilities—we passed our fundraising goal! Not only did we blow past our target, we got the number three spot for top fundraising charity out of all of the other organizations this year. Our members joined us from all across the province and we hosted six regional Charity Challenge events in the Fraser Valley, North Shore, Vancouver Island, Okanagan, Northern BC, and the Lower Mainland. This is an incredible achievement and we could not have done it without people like you!

Special thanks to the corporate teams who participated...



Persistence Wins in White Rock

New accessibility mat at the White Rock pier is a result of SCI BC peer's persistent advocacy and dedication.

On August 31, 2024, SCI BC's peer Susan Bains used the White Rock pier for the first time in seven years. She didn't have to worry about looking down, getting stuck in her wheelchair, or anticipating painful spasms from bumpy surfaces. She simply went for a wheel. Accompanied by her daughter, Bains attended the ribbon-cutting ceremony for the opening of a new accessible mat on the White Rock pier and took the inaugural wheel. The installation of the mat, a five-foot-wide non-slip mat that extends the length of the 470-metre-long wooden pier, was a direct result of Bains' advocacy and persistence.

"I've always been the type of person to say something if it feels like it needs to be said," she explains. With a background in human resources, entrepreneurship, and fitness instruction, Bains has never been one to sit on the sidelines. Even when an idiosyncratic spinal cord digression in 2016 challenged her mobility and eventually led to leg paralysis in 2021, Bains remained determined to engage with others and adapt to change. "There was a lot happening when I came out of GF Strong," she says. "I was learning to live life in a wheelchair. I moved into a new house, I was in a new setting, and renovations were happening all the time to make it accessible. My mom also moved in with us and I had a young daughter and husband to navigate through all these changes with. It was a lot going on at once."

Despite everything, Bains recognized the need to get back to the things she loved and reached out to SCI BC to attend

our annual Whistler Adrenaline Weekend. As a first-time participant she tried paddleboarding, rock climbing, and hiking with a TrailRider. "It was going from nothing to, boom, trying everything at once. I was still in a very different mindset at that time, and it was hard for me to talk about my own situation with others. I didn't want to explain things or have small talk," she says. "But it was great in the fact that I got to try and was able to do so many more things than I expected. I got to see that it was possible."

When it came to accessing recreation opportunities closer to home, though, Bains struggled with access to the pier near her home in White Rock. "I was able to walk as much as I could at the beginning of my loss progression, but eventually, I couldn't do it. When I got into the new house, I had my power chair and tried using the pier but I was so uncomfortable and it triggered spasms," she says. "The first time I tried to use my manual chair on the pier was actually this year and I fell. I had one hand down on the ground and one of [the people I was with] had to push my shoulders back."

Knowing that change needed to happen, Bains wrote a letter to White Rock's municipal engineering department in August 2021. In this letter, she highlighted accessibility issues such as uneven surfaces, gaps in the wooden planking, and slippery conditions. "With my background in human resources, I always tackle things not just by complaining, but also giving solutions," Bains says. "I took pictures and suggested how things could be improved. I researched mat options and provided examples from other



places. I guess you would call it advocacy, but at the time I didn't even think of it that way. It was just an ask."

In the year that followed, Bains' ask circulated among City Council and various departments trying to gain traction. However, the main source of support came from her own community. "I was doing research and came across a news clip of [another SCI BC member] showing how they get their manual wheelchair stuck going sideways on the pier and I was like, 'Oh wow, I'm not the only person'," she says. "Through conversations with other people I would get little snippets of information, and I connected with other self-advocates. I started a lot of stuff all on my own, but it was great to have that support and know people would show up." Backing from the City of White Rock was slower to come.

In July 2023, Bains revisited her discussion with the engineering department and was told the main challenges to moving forward with the purchase and installation of an accessibility mat were tripping hazards, maintenance costs, and installation costs. "When I saw those three points, I had to see if that really was the case. I knew I had to do more."

Bains contacted Mobi-Mat, a Canadian-owned accessibility mat manufacturing company, and AccessRec, an alternative option, and compared costs, installation time, and maintenance details. Moreover, Bains started a letters of support campaign and connected with organizations who believed in the accessibility mat and the benefit it would provide to everyone using the pier. At the end of year, she attended a tree lighting ceremony at the pier with Equal Access Collective, a group of organized self-advocates. "We are all striving for the same individual goal of equal access and universal spaces, but our approach is to work collaboratively and come up with solutions while educating others about their obligations," Bains explains. Together, they applied public pressure and were invited to speak to Council and the City's Accessibility Committee to move forward with a solution.



Susan Bains high-fives councillors after the June Council meeting.

At the Council meeting in January 2024, Bains emphasized the legal obligation of the City to provide access under the Accessibility Act BC and the BC Human Rights Code. "I learned a lot about the legislation piece and what started out as a personal ask... really blew up over the years and it's a right, it's not an ask. It's a human right," she says. "That really shifted things for me. Once you bring that forward you can exercise those rights and knowledge is power." Along with legal knowledge, Bains shared extensive information and research about the proposed AccessMat from AccessRec.

The AccessMat is made of UV stabilized polyester material that had been tested as rot and rust proof. It can be attached to the wooden pier with aluminum mating connectors that adhere smoothly and is available in multiple colours. Overall, the total cost of the mat and installation would be approximately \$100,000. "At that point it should have been an acknow-

ledgement that the pier isn't accessible and proceed with a plan, but it wasn't." What followed was six more months of trial and tribulations, including a decision to move the accessibility mat item to a budget issue in 2025.

In response, Bains, the Equal Access Collective, and other supporters hosted an event at the pier to protest the delay. "Because of how all of this happened, they're forgetting the role that they support people. It was like we had to prove why we needed this over and over," Bains says. "I didn't back down because the support I had just kept me pushing. I just knew it was right." The choice to move the accessibility mat item to the 2025 budget was reversed and in June 2024 the decision to move forward with purchasing and installing an accessibility mat was finalized. The last hurdle to overcome was the City's insistence that donations be sourced to cover part of the cost, despite a pre-approval in the

amount of \$18,000 to support the project. In the end, the Self-Advocates of Semiahmoo (an independent organization mainly funded by Semiahmoo House Society and The Semiahmoo Foundation) donated \$5,750 and the Soroptimist International of White Rock (a local volunteer organization focused on helping women and girls) donated \$2,000. A grant from SPARC BC covered \$25,000 of the bill and the City paid the remaining costs. In total, the final purchase of the mat was \$81,796 (excluding GST) and installation by GDM Civil Ltd was \$8,280 (excluding GST).

In August 2024, over three years after Bains sent her initial letter to the engineering department, the accessibility mat was installed, and she took the first wheel alongside her daughter. "It's a great feeling to be supporting so many people, because what started out as a request for me in a wheelchair became something for everybody and that means a lot," Bains says. "It [was] a constant uphill battle. You have to adapt, adapt, adapt, and when we're pushing that idea to the City it feels uncomfortable. But that's life for us too—adapting."

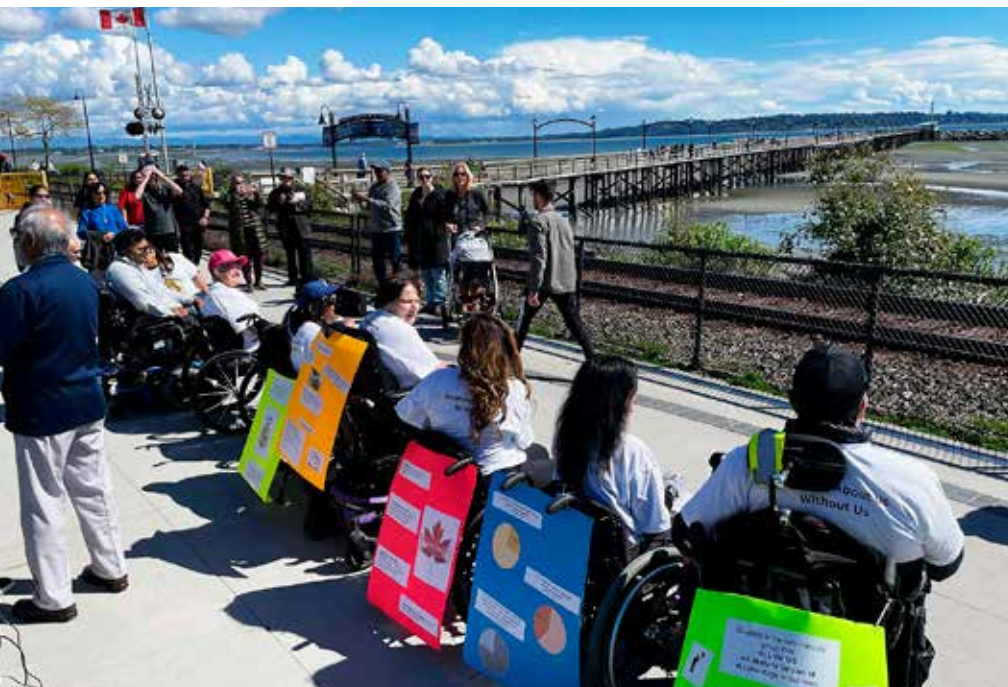
As important as the end result was for everyone involved, the journey to get

there was equally as meaningful to Bains. "My first [news] interview about the pier I was actually shaking, I was so nervous. My husband asked if I was okay, and I didn't know if I could do it. At that point it felt like ripping a band aid off. Everybody was going to see me, and I felt really exposed," she says. Going from her initial experience at SCI BC's Whistler Adrenaline Weekend, where she wasn't even comfortable talking to other peers, to being put in front of a camera was a big step, and a leap of faith in herself. "Finding your voice and finding connections and having support gave me more and more confidence throughout this whole thing."

It has encouraged Bains to continue advocating for herself and her community. She has already set her sights on improving access along the portion of the White Rock promenade that crosses train tracks and has been in meetings with TransLink regarding their new Surrey and Langley SkyTrain stations. "I want to be able to make a change and make a difference," she says. "This has fueled me to do more projects and to speak to these things because I have no problem bringing it forward and being persistent. That's the key, being persistent." ■



Top and bottom: Susan Bains and her daughter



Susan Bains and the Equal Access Collective team display accessibility facts on their wheelchairs to protest the delay of the mat installation.



Ask InfoLine: Answering Your SCI FAQs

What I'm experiencing as I approach mid-life seems different from what my friends talk about. It feels like a merry-go-round—are my UTI and vaginal symptoms gynecological, urological, or neurological? My doctors are eager to blame perimenopause but nobody's really certain what to do about it. How do I navigate this? —Deanna in Duncan



Left to right: Heather Lamb, MSW, RSW, InfoLine Service Lead; Teri Thorson, Peer Coaching and Outreach Manager; and Margaret Conquest, MSc

Questions about menopause are common these days on the InfoLine, and not a topic that most GPs are informed about in the SCI context. To answer this question, we looked to *Life After Tampons*, an online peer education series on menopause and SCI created by SCI BC and presented by Margaret Conquest, a tetraplegic peer and a health promotion advocate who brought together menopause research and peer experience on menopause to help peers equip themselves and their healthcare teams for the journey.

The menopausal transition (or perimenopause) is a time of decline in estrogen leading up to 12 months after a woman's last period (menopause). For women with SCI, it can increase already vulnerable SCI health risks. "Symptoms I think that women with SCI should pay more attention to in mid-life include vasomotor symptoms (i.e., hot flashes) if you usually get autonomic dysreflexia (AD), Genitourinary Syndrome of Menopause (GSM), skin health, balance issues, body composition changes, cardiovascular health, and bone health." Learning about how symptoms of perimenopause affect women with SCI differently can help you work with your healthcare providers to figure out if treating menopause symptoms might help you.

Is it my neurogenic bladder or is it aging? "It could also be GSM, one of the most underdiagnosed changes of menopause but I believe most impactful on women's lives." When estrogen declines, the vulva and vaginal structures that have the most estrogen receptors, such as the bladder, urinary tract, pelvic muscles, etc., don't work as well. Pelvic floor muscles weaken and tissues get thinner, making it hard to hold urine or causing a more overactive bladder. These changes can also make penetration or routine contact to this area, such as for transfers, more sensitive or painful. It can be awkward to share, Conquest notes, but urges women not to ignore these symptoms. It's important to review your bladder management with a urologist or continence nurse if the frequency of infections or leaks increases, and don't be afraid to talk to your primary care doctor or a gynecologist about treatments, like topical or systemic estrogen, for the symptoms of GSM.

Changing body composition can affect mobility: You may experience bigger shifts in body composition during menopause than your non-disabled friends: decreased muscle mass, weight gain, and heightened insulin resistance, posing unique risks for women with SCI. The big concern here for women with SCI is how these chan-

ges can affect transfers, mobility and wheelchair fit. Conquest emphasizes "simple, consistent, unsexy strategies" focusing on protein and fibre for diet change, and strength exercises to maintain mobility and independence—including daily tasks such as transfers, dressing, and bathing.

Movement of any kind is beneficial, notes Conquest, and regular exercise also helps many menopausal symptoms like hot flashes, sleep, and stress. It can also help maintain bone, muscle, and heart health, which are all at increased risk related to both menopause and SCI. Consider trying a new activity or exercising with others for extra motivation.

Be open to changing how you do things: Many women with SCI already experience fatigue and balance issues, which can worsen to the point that they may affect mobility or transfers. Reducing stress and improving your sleep routines is the most common advice, but also be open to changing your equipment: a power assist on your wheelchair or a lift in your vehicle are good ways to save your physical energy for other tasks. It's okay to consider home support if you're struggling! Declining bone density and drier, less resilient skin are also problems in perimenopause, so changes to make your transfers safer and easier can also help protect you from falls or injuries.

Is it me or is it AD? Vasomotor symptoms (hot flashes or sweating) are well known during perimenopause but can be confusing if you are prone to AD. If you're getting AD more often it might be due to menopause symptoms, including hot flashes! For some women, profuse sweating is also a symptom despite not being able to sweat for most of their post-SCI life. Conquest encourages women to discuss these symptoms with a doctor because of their profound impact on sleep and wellbeing.

As Conquest cautions, "there is no magic bullet for menopause," and you need a personalized strategy for your situation and symptoms. Be patient with yourself as change can take time and it's a lot to deal with at once. The good news? This transition will end, and most women report that mental health improves afterwards. Don't tough it out or ignore it—see your doctor!

The InfoLine team is here to help, including finding accessible scales, adaptive equipment, funding supports, home support, and finding an OT for help to find the right equipment for safe transfers as your body changes.

To watch the *Life After Tampons* series videos and get an invite to our new bi-monthly Women Aging With SCI group starting in January 2025, check out www.sci-bc.ca/aging.

SCI BC's InfoLine provides information and support by phone or email on any topic relating to living with physical disabilities in BC. Contact InfoLine at 1-800-689-2477 or info@sci-bc.ca.



Adventure

Awaits

SCI BC peer, Jason Nelson, shares how his passion for travel has led him to conquering 114 km of the Camino de Santiago, a journey across northern Spain.

Jason Nelson and his wife, Lesley, love travelling. Their adventures together include hiking the Inca Trail to Machu Picchu, snorkeling with turtles and sea lions in the Galapagos Islands, and hiking into the Indonesian jungle to see orangutans. But after Nelson sustained a C6 incomplete SCI, the thought of travelling became more daunting, and even scary, to consider. SCI BC caught up with Nelson, who uses a wheelchair and is able to walk short distances

with poles or a walker, to hear how his SCI didn't dampen his enthusiasm for travel in his latest trip to Spain and what he learned about himself along the way. Here's what he shared with us.

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Last summer, we were ready to explore the world again but unsure of where to go and how to do it. The universe sometimes works in interesting ways—a friend loaned me a book that changed everything. I'll Push You is about two best friends, embarking on the Camino de Santiago, across northern Spain. One friend pushing the other in an off-road wheelchair, along the full 800 km. After that journey, the authors Justin Skeesuck and Patrick Gray established a Camino tour for wheelchair users.

Lesley was excited about this opportunity, so we applied for the 2024 excursion and got accepted! Woohoo! We're going to travel 114 km in six days, over rocky trails, cobblestone pathways, and over many hills and obstacles. This was exactly what we were searching for and I had a combined

sense of excitement and nervousness. I used to love the adventure of landing in a new country, finding suitable accommodation, and stumbling over a foreign language. Was I ready to do this again? This time I'd have extra equipment (wheelchair, walking poles, etc.), and likely face many physical obstacles, such as stairs, curbs, uneven pathways, to name a few. And that was before we tackled 114 km of uneven ground on the Camino. Thankfully, Lesley's sister, Michele, decided to join us on this crazy adventure.

The tour included an online training module to help us physically prepare for this task over the next seven months. The module included equipment recommendations and after a conversation with Justin, I decided to take my existing wheelchair and purchase off-road tires, a freewheel (to attach to my footplate to lift the caster wheels), straps to pull my wheelchair, and longer push canes for my helpers. Let the training begin.

Those seven months flew by, and suddenly we were boarding our first plane from Comox, BC. After 20 hours of travel and limited sleep, we were finally in Madrid. We had a couple days to recharge, before taking a train to Santiago de Compostela, to meet up with our tour group. Our group was made up of 50 people, which included seven wheelchair users, one person with a visual impairment, four guides, two videographers and a lot of helpers. Members of the group were from Brazil, Australia, France, Canada, and the US. These people would be our companions for the next eight days and in a short time, we would become close friends.

We loaded onto two buses, one with a lift for wheelchair users and one regular bus. Our destination was Lugo, which would be our home base for the first four nights while we travelled the Camino. Each day the buses would take us to our Camino start point, then back to the hotel after hiking the planned distance. The next morning they would take us to where we finished the previous day. Upon arrival in Lugo, we explored the ancient Roman wall that completely circles the old town

area. It was somewhat surreal being on this ancient wall that once protected the town and was now surrounded by a wall of modern buildings.

The first evening we had our welcome dinner hosted by Patrick and Justin. We met the full group and received some important details about our upcoming journey. Each day we'd be walking and rolling approximately 20 km and we were encouraged to join a different group over the next six days to get the most out of this experience. After dinner we received a scallop shell to attach to our daypacks (customary for the Camino), a Camino passport to collect stamps from vendors (minimum two per day), and our group shirts to wear on our final day. On the passport you had to indicate the method you were using for the Camino: walking, biking, horse, or wheelchair. I was amazed and impressed that they actually had a wheelchair choice! Time to get a good night sleep before our adventure begins.

Day 1: Sarria to Portomarin

After a group photo, our abilities were immediately tested as we travelled down a very long, steep "paved" slope—I was really leaning back in my wheelchair, to offset the steepness. As we got to the base of the slope, we encountered our next obstacle, a narrow wooden bridge just wide enough for a wheelchair, and with some rock steps to get onto it. Now it became evident why we needed so many helpers. Four people hoisted me in my chair onto the 20 foot bridge. On



the other side, we had a long, steep dirt slope to walk up. Time to get out our straps, attach them to the front of my wheelchair, and have the helpers begin pulling from the front and pushing from the back. Wow! This is just the beginning of six days! We finally got to a relatively flat section, where I grabbed my poles and walked a short distance.

One of my personal Camino goals was to walk a section each day. It wasn't long before each wheelchair group was spread out along the trail. Lesley, Michele, and I were now on our own, as we encountered a long, steep slope covered with small, loose rock. We had to stop every 20 feet to catch our breath and determine our next pathway. Halfway up the slope a tractor drove down towards us. Just what we needed! There was just enough room to hug the shoulder as he slowly went past us. After what seemed like an eternity, we arrived at the designated restaurant for lunch. At this point I was tired, hungry, frustrated, and angry that we didn't have more help over that difficult section.

As I waited for my lunch, I reflected on our recent experience, and wondered what we could have done differently. I realized there were four people a short distance behind us and we could have stopped to wait for them to catch up. With their help, that nasty terrain would have been much easier. It seems the Camino was already teaching me the value of accepting help from others, and even looking for help when faced with obstacles. With this newfound knowledge, I wouldn't make the same mistake twice. The first day was long, and we were thoroughly exhausted. After a quick group dinner at a nearby restaurant, we headed to bed.

Day 2: Portomarin to Palas de Rei

The weather forecast called for rain, so I wore my waterproof pants and had a rain jacket in my daypack. Thankfully we didn't get any rain, and the temperature was perfect for hiking. We started through the winding streets of Portomarin, over cobblestone, slate, and



Jason Nelson and his wife, Lesley.

pavement. Today we enlisted a few additional helpers. Yesterday we learned how much you can accomplish when you have help from others. It was already feeling easier than the first day. We travelled approximately 26 km, and a large portion was paved with fewer obstacles to avoid. I even got to wheel down some paved slopes on my own. Exhausted from another long day, we ate a group dinner at the hotel, and then off to bed.

Day 3: Palas de Rei to Melide

Our first obstacle was near the beginning of our trek through Palas de Rei. It was a steep roadway of large slate rock. By now our wheelie popping skills were proficient, so we made our way down the slope. Today we had a shorter distance to walk and roll, and we'd finish a bit earlier to give us time to pack our belongings. After our hike tomorrow, we'd transfer to a hotel in Santiago for the next four nights. Lesley joined another team, and we spent the next three days in different groups while on the trail. It was good for both of us. Lesley had the opportunity to allow others to help me and it gave me the experience of receiving help from others. We travelled through a lot of small forests, mostly trails that consisted of dirt and rocks, and constantly up and down slopes. The wheelchair

straps were a useful tool, helping us pull the wheelchair up long, steep slopes, and flipping it to the back of the chair to slow our descent down slopes. We had a late lunch at the end of our hike, to give us more time to pack. Even though the day was shorter, we were still tired.



The narrow rock bridge found on Day 4.

Day 4: Melide to Arzua

Around 10:30 AM we came to a large obstacle. There was a creek, 25 feet wide. We could either go through the water, or onto a narrow rock bridge (slightly wider than a wheelchair). Without hesitating, I asked my team which option was the best for them. I was putting my safety in the hands of people who I had just met five days ago, and I fully trusted their decision. They decided to carry me over the water, which was a success. Our whole group cheered on each team as they navigated this latest challenge. The rest of the day consisted of rocky dirt trails and constantly travelling up or down slopes. We started to feel more conditioned to this type of activity. At the end of the day, we headed to a hotel in Santiago, our new home base for the next four nights.

Day 5: Arzua to A Rua

Our day began with two members sharing a story about The Red Glasses Movement. Their relative, Audrey, was only five years old when she passed away in 2018. She was born with Down's syndrome and a heart defect. Audrey was defined by her bright red glasses, her contagious smile, and her lack of inhibitions. She loved indiscriminately and without restrictions. The Red Glasses Movement is Audrey's living legacy. Their mission is to inspire the world to live boldly, love big, and pass it on. We each received a pair of red glasses to wear on this day, to help us see through Audrey's eyes. It was definitely an emotional start to our morning. I'm honoured to hear about Audrey's story and I'll do my best to live boldly and love big.

While waiting at one of our rest stops, one of the group members taught me how to wheelie. In the past I've spent so much time improving my walking, that I haven't focused on wheelchair skills like wheelies. My instructor, Robert, had me in a wheelie within 15 minutes. It's amazing how quickly a new skill can be learned when you receive good instruction. I'll need more practice before attempting some of Robert's crazy routes. After going through the streets of Arzua, we enter the countryside, passing through many forests, and once again travelling up or down slopes. After another long day of travel, we head to a nearby restaurant for a group dinner and then bedtime.

Day 6: A Rua to Santiago

Our final day on the Camino had arrived. I felt some sadness knowing that we would soon reach our goal and that this adventure would be over. Throughout the past six days, we became a tight knit family. We quickly passed through the streets of A Rua and entered the forests. We'd conquered so many obstacles that the terrain didn't phase us. I'm proud of accomplishing my goal to walk a section of the Camino each day. Initially I was worried about the prospect of walking, when the trail seemed to always be on a steep slope.

Passing through some eucalyptus forests, we encountered a person playing bagpipes for us pilgrims. The music provided some extra energy for today. After our lunch break, we stopped at a viewpoint of Santiago de Compostela, and we saw the cathedral, our final destination. Our guides collected our passports to hand in, so that we can receive a Compostela Certificate for completing the last 100 km of the Camino. By 3 PM we reached the outskirts of Santiago, and gradually made our way through the streets to the cathedral. We entered the old town, and our whole group collected together just outside the cathedral square. Three of us wheelchair users decided to walk into the square, and our group carried on at our pace. As we got close to the square, the sound of bagpipes could be heard from the cathedral and as we entered the square, it erupted





Final Camino de Santiago group photo in front of the cathedral.

with the sounds of cheering and clapping for our group. Such an amazing experience! I can still feel that magical moment.

The next day we had our final group dinner at the Parador, a luxurious restaurant in the cathedral square. After some amazing food, we received our Compostela Certificates, with our names written in Latin. We had time to share our experiences or learnings from the past seven days and it was a very emotional night, filled with laughter and tears. It was bittersweet spending those last moments with our Camino family and I'm

grateful for the time spent with these amazing people. I didn't want it to end but I knew we had forged some lifelong friendships. Buen Camino! (That's Spanish for Happy Trails!)

Final Thoughts

The greatest lesson that I learned was the value of accepting help from others and expanding my support network beyond my wife, Lesley. Previously, I thought accepting help meant I was a burden to others. Now I realize that most people want to help and when they provide it, they receive a full-

filling sense of purpose. When you work as a team, you can accomplish great things—I just travelled 114 km of the Camino using a wheelchair! Armed with this experience, Lesley and I are ready to travel again. Look out world, here we come.

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 Captivated by Nelson's sense of adventure? Get the confidence you need for your next trip with accessible travel tips, extra peer travel stories, and more at sci-bc.ca/travel. To learn more about *I'll Push You* and the Camino de Santiago, visit illpushyou.com. ■



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Fight or Flight?

Coinciding with Canada's first National Air Accessibility Summit, a new study highlights the challenges of air travel for wheelchair users with SCI—and how to make it better.

“We’ve all heard the downright atrocious, inhumane experiences people with disabilities have endured during air travel, some resulting in serious injury, all causing deep emotional harm. We are talking about nothing less than the human dignity of each passenger.”

These are the words of Stephanie Cadieux, Canada’s Chief Accessibility Officer, while speaking at Canada’s first ever National Air Accessibility Summit in Ottawa on May 9, 2024. Cadieux, a wheelchair user and former employee of SCI BC, first spoke out about the “dehumanizing” treatment of people with disabilities during air travel after Air Canada left her wheelchair behind on a flight from Toronto to Vancouver six months earlier.

In her statement, Cadieux described the emotional frustration and loss of independence she experienced when she learned her wheelchair had not made the trip to Vancouver with her—a feeling our readers with SCI are likely to know all too well.

“Over the past six months, I have seen this issue catch fire in a way I don’t think it ever has before,” remarked Cadieux. “This is a global issue. In some areas, Canada is leading the way, and we should be proud of that, but we should be much farther ahead.”

Similar sentiments are shared in a new study published in the journal *Spinal Cord Case Series* earlier this year. The US-based study is one of the first to explore the experiences of wheelchair users with SCI during air travel.

The lead author, Julie Pfeiffer, is a physical therapist and a PhD Candidate in the College of Education at the University of Kentucky. Through Pfeiffer’s early experiences working in SCI research and rehabilitation, she was exposed to the realities of air travel for people who use wheelchairs.

“I heard stories from individuals who had their wheelchairs damaged or had been personally injured while flying. These individuals experienced significant impacts on their quality of life including decreased independence with performing transfers, missing therapy sessions because they were unable to leave their house, and even episodes of hospitalization,” says Pfeiffer.

These experiences are what sparked her passion for improving air travel accessibility, especially among wheelchair users. What quickly became clear, however, is that the anecdotal stories she was hearing needed to be backed up with scientific evidence.

“When I began exploring this line of inquiry as part of my PhD studies, it became obvious that US legislation designed to

protect individuals with disabilities against discrimination during air travel was not achieving its goal,” explains Pfeiffer. “Not only had there been a steady increase in disability-related complaints filed against airlines by wheelchair users [in the US] over the past decade, but progress towards developing solutions appeared to have stalled.”

To get the evidence she was after, Pfeiffer interviewed six people with SCI or related disabilities who use a wheelchair full-time about their air travel experiences.

“We purposefully selected individuals who not only had significant experience travelling by air as wheelchair users but also had a variety of characteristics that could impact their experiences,” says Pfeiffer. “We interviewed manual and power wheelchair users, and individuals with tetraplegia and paraplegia. Some participants were able to transfer from their wheelchair to the airplane seat independently while others required a two-person assist.”

In addition to their air travel history, the research team asked participants about their pre-flight, in-flight, and post-flight experiences, as well as suggestions to improve their air travel experiences. Only one participant identified as a woman, which limited the researchers’ ability to discuss the air travel experiences of women living with SCI.



According to Pfeiffer, a significant finding of the study is that the most challenging barriers to air travel occur when the wheelchair user interacts with the airplane and airline personnel—not the airport. In fact, participants reported that barriers to airport accessibility were minimal and no different than barriers experienced at other public accommodations or services.

When interacting with the airplane, challenges most frequently arose during boarding and deplaning and accessing the onboard bathrooms. “The most humiliating times of flight are getting on and off the plane,” stated one study participant.

For example, participants reported that the equipment used to access the plane is not well designed and often in poor working condition. The most common concern was that the design of the aisle chair increased the risk of serious injury, such as feet slipping off the footrest and being dragged on the floor or pressure injuries resulting from minimal seat padding.

Inability to access the onboard bathrooms also led to embarrassment and concerns about medical complications. Anticipating that they wouldn’t be able to access the onboard bathrooms, some participants described restricting food and fluid intake for several hours before the flight, increasing the risk of dehydration and urinary tract infection.

But it was the risk of something happening to their wheelchairs, not to them, that ultimately caused the greatest concern for the participants in this study. In fact, all participants reported having their wheelchairs returned to them damaged—ranging from scratches and dents to broken joysticks, wheels, and actuators—following a flight.

“The participants in our study reported that damage to their wheelchairs was the greatest obstacle to flying,” explains Pfeiffer. “Participants discussed the significant impact that damage to their wheelchair

during flight had on their independence, even months after returning home.”

As a result, the participants described making choices that adversely impacted themselves to avoid damage to their wheelchairs, such as avoiding layovers, driving to a larger airport, or using an old wheelchair for travel.

According to Dr. Walt Bower, the Preservice Training Coordinator for the Human Development Institute at the University of Kentucky and a coauthor on Pfeiffer’s study, the study’s findings point to the need for major changes in how the airline industry accommodates people with disabilities, especially wheelchair users, during air travel.

“We need to rethink the assumptions about what accessible air travel involves for people with SCI in society,” says Bower. “Based on the recommendations of our study participants, an important and practical next step for the airline industry is to redesign an aircraft seat that enables a wheelchair user to take their wheelchair inside the cabin of the plane during the flight. Remaining in their own wheelchair would eliminate the dehumanizing transfer to an aisle chair and damage to their wheelchair during stowage in the cargo area of the airplane.”

On the ground in Canada, Cadieux has had conversations with airports, airlines, service providers, industry associations, and international leaders. While redesigning aircraft seating could take some time, her remarks at the National Air Accessibility Summit highlighted some of the changes that are already taking place.

“Airlines have been working on improvements, testing new ways of storing and securing wheelchairs, investing in more training for staff, and making commitments to do better,” she said in her statement.

At the Summit, the Government of Canada and the National Airlines Council of Canada announced a number of commitments to

improve air travel accessibility. These include developing a simplified approach for accommodation requests and accessibility documentation that can be shared between airlines so that passengers with disabilities will only have to tell airlines about their needs once, and proactively collecting and sharing data about the experiences of their passengers with disabilities. The Government of Canada has also committed to taking a leadership role with international partners to promote better passenger experiences for persons with disabilities.

In an update on August 20, which is National Accessible Air Travel Day in the US, Cadieux’s office reported that “work on these three items has been actioned quickly and is progressing.” To this end, Cadieux’s office reported that the Deputy Minister of Transport Canada has established working groups and drafted a workplan to provide accountability for these promised actions. In addition, the federal government is working to roll out information campaigns that clearly define the rights and responsibilities of airlines and passengers and ensure the development and implementation of accessibility features and infrastructure on airplanes.

Pfeiffer and Bower also have more work to do. “Down the road, we hope to develop a larger and more comprehensive study of the barriers to accessible air travel for passengers with disabilities, including individuals with SCI, that builds on the findings of our present study. We would also like this program of research to advance public policy and training to create more inclusive air travel for people with SCI, their families, and communities,” says Bower.

“Disability is a natural part of the human experience. That does not diminish a person’s right to participate in all aspects of life, including transportation and air travel,” he adds. ■

Better Bladder Care

An international team of multidisciplinary experts and disability organizations are advocating for universal access to single use catheters for bladder management.

If you're one of the more than 90% of people with SCI who have a neurogenic bladder, then you probably read the headline of this article and thought, "What took you so long?"

Neurogenic bladder is the term for what happens when your nervous system affects the way your bladder works. For people with SCI, having a neurogenic bladder usually means that your brain can't communicate with the parts of your body needed for voluntary bladder control.

Most people with neurogenic bladder rely on intermittent catheterization for bladder management. Intermittent catheterization, or self-catheterization, involves using a catheter to drain urine from your bladder at regular intervals throughout the day. It's a way to "manually" empty your bladder when the signals from your brain can't trigger your pelvic floor muscles to do it on their own.

Like many conditions associated with SCI, the costs of neurogenic bladder are significant. Neurogenic bladder impacts health-related quality of life and often limits the lifestyle choices of people with SCI. Limited space, unhygienic conditions, and inaccessible washrooms are just a few examples of the challenges that people who use intermittent catheters face. As a result, people who use intermittent



catheters for bladder management often avoid social situations in favour of staying home, contributing to social isolation and increasing risk of depression.

Complications of neurogenic bladder, such as urinary tract infections (UTIs), can also take a toll on patients' physical and mental health, while also resulting in significant economic costs.

"In Canada, it is estimated that the annual economic burden associated with care for people with SCI is about \$2.6 billion, and one of the most common complications of SCI is a neurogenic bladder and associated UTIs," explains Dr. Andrei Krassioukov, a clinician-scientist at the International Collaboration on Repair Discoveries (ICORD), GF Strong Rehabilitation Centre, and the Division of Physical Medicine and Rehabilitation at the University of British Columbia. "In fact, based on studies that my team conducted in BC, we estimated that an emergency room visit for a person with SCI with a UTI costs \$5000 to \$100,000, just for one visit."

Options for bladder management, such as the type of catheters available, can play a serious role in the size of these costs—for both the patient and the healthcare system.

Hydrophilic single use catheters are currently regarded as the "gold standard" of care for bladder management. Single use catheters, as the name implies, are

intended to be disposed of after each use. Compared to reusable catheters, which are cleaned and reused multiple times, single use catheters are associated with a lower risk of developing UTIs. But in many places, including parts of Canada, limited access to catheters or the financial cost of purchasing catheters for only one use means that, for some people, reuse is the only option.

The significant economic and health-related costs associated with neurogenic bladder and UTIs are what prompted Dr. Krassioukov and a team of international experts to work together on a solution. Their recently published position paper, 'Intermittent catheterization: individuals' rights, accessibility and environmental concerns,' reflects the culmination of their work.

The authors of the paper represent a Global Advisory Board focused on UTIs and catheterization for Coloplast, a company that develops ostomy, continence, urology, wound, and skin care products and services for people with intimate healthcare needs. The advisory board is made up of physicians with expertise in urology and physiatry (physical medicine and rehabilitation) from Canada, Belgium, Switzerland, France, South Africa, and the Netherlands. The group meets once or twice every year to provide advice to Coloplast.

Over the past year and a half, the group has been trying to answer some important questions, says Dr. Krassioukov. Questions like, 'why are some people with SCI coming back to the ER with UTIs multiple times per year?' And 'what can we do to ensure that single use catheters are made accessible to people who rely on intermittent catheterization around the world?'

"But we knew we couldn't rely solely on medical knowledge to answer these questions," explains Dr. Krassioukov. "We needed the perspectives of disability organizations and people with lived experience to better understand the reality of catheterization around the world, and what could be done to improve it."

So, with the support of Coloplast, the advisory board brought together representatives from SCI organizations, including SCI BC, SCI Ontario, and equivalent organizations in other countries, for a series of virtual meetings to discuss ways of improving bladder management on a global scale.

The position paper that resulted from these discussions highlights persisting barriers to the rights of people with neurogenic bladder to access the best evidence-based standard of care for bladder management, as well as their right to adequate and comfortable facilities when performing intermittent catheterization.

For example, some countries are legally obligated to provide the highest attainable standard of care for intermittent catheterization. Elsewhere, including here in BC, barriers related to funding limit the type and number of catheters available, and in some cases, mean that users cannot afford their preferred type of catheter. Policies around reimbursement for single use catheters can further compound the issue of affordability. Lack of education and awareness around the types of catheters and the risk of UTIs, as well as the requirements of intermittent catheterization, are contributors to these issues, particularly among healthcare professionals and reimbursement bodies (for example, government programs and insurance providers).

“Surprisingly, in Canada, we still don’t have unified implementation of single use catheterization,” says Dr. Krassioukov. “There are totally different rules and laws about single use catheters from province to province. For example, in Ontario, Manitoba, and British Columbia, there is no universal coverage for people with SCI. If you’re injured at work, WCB [Worker’s Compensation Board/Work-SafeBC] will cover all of your catheters. Or if you have third party health insurance, you might have coverage. But the majority of people, particularly people with low income, have no coverage. It’s a totally different situation in Saskatchewan, where all medical devices for

people with SCI, including catheters, are billed directly to the government.”

Another challenge for people who rely on single use catheters is the growing concern about the impact of single use plastics on the environment. This is a challenge that people with SCI are facing on multiple fronts, with plastic items that allow them to live safely and independently, from plastic straws to pre-packaged foods, on the chopping block.

“I do appreciate that medical devices such as catheters are made from materials which are not easily disintegrated in the environment. But I believe it’s a question to the industry: Can we design a catheter that will be environmentally friendly? Can we find materials that could be disintegrated easily, or could we have some kind of collecting system to reduce waste and reuse the materials for something else?” asks Dr. Krassioukov.

“The frequency of UTIs and cost of care for people with SCI to treat UTIs, in my opinion, totally overshadows our concerns about environment. We have to prioritize the health of the people, and evidence demonstrates that reusable catheters will increase frequency of UTIs,” he adds.

In addition to shining a spotlight on the barriers to optimal bladder care around the world, the position paper also calls out strategies to address them. For example, medical societies can strive to educate specialists by providing up-to-date information on current research focused on products and technologies used in bladder management. Likewise, interdisciplinary healthcare professionals can collaborate with reimbursement bodies to provide education around the challenges faced by individuals with neurogenic bladder dysfunction. Specialist nurses, who often have the most contact with people who experience neurogenic bladder, could also be the target of investments in training and education.

Collaboration with the SCI community, like the group that put forward the position paper, is also needed to ensure that



Dr. Andrei Krassioukov

solutions are realistic and relevant for the people that they will impact.

“There is a discrepancy in how physicians and scientists want to help people with SCI and what people with SCI are asking for. That’s why we need ongoing dialog and collaboration between clinician scientists and people with SCI,” reflects Dr. Krassioukov.

The paper concludes that “access to intermittent catheterization must not be limited to those who can afford it, and if reuse is the only option, we need reusable solutions that minimize negative effects on health and safety.”

But without a unified system to make single use catheters available to the people who need them, Canadians who live with neurogenic bladder do not always have this right.

“That’s why we need to push the Ministry of Health,” says Dr. Krassioukov. “We need to push government further and further and further with the evidence that we have.”

We agree, which is why we are collaborating with other organizations to build a case for full intermittent catheter coverage here in BC. In addition, we have started holding focus groups for SCI BC peers to share their challenges in accessing funding and the right catheters for them, and why and how the province should provide full coverage for catheters. A report on the first set of focus groups will be available soon and more sessions will be scheduled in the coming months. Stay tuned as your voices will be critical for the movement to end what amounts to an unfair taxation on urination. ■



The Full Spectrum

How one SCI BC peer's accidental foray into entrepreneurship is helping advance accessibility consulting.

Unknowingly, SCI BC peer Arnold Cheng has been preparing to be a business owner and accessibility consultant his whole life. “I grew up being surrounded by floor plans and subconsciously absorbing a lot,” he says. Cheng’s father is a retired property manager, his brother is an architect, and his sister is a former engineer. Cheng himself has a background in graphic design and over 10 years of lived experience as a person with a disability from non-traumatic spinal injury.

Despite this personal and professional background, Cheng never considered a career in accessibility consultation until an opportunity in 2018 led to the creation of Spectrum Ability. Despite this personal and professional background, Cheng never considered a career in accessibility consultation until an opportunity in 2018 led to the creation of Spectrum Ability.

“It was an accidental business idea,” he says. “I got a request from my old boss at the Rick Hansen Foundation to help them with their accessibility certification pilot program. They were having trouble getting enough buildings across the finish line to satisfy the government grant they received. So, I went in to help.”

The Certification program, known as the Rick Hansen Foundation Accessibility Certification (RHFAC), is a rating system that measures and certifies the level of access of buildings and spaces. Businesses, owners, and organizations can seek a Certification rating that, in turn, helps them understand the level of mobility, vision, and hearing accessibility in any given space and how to improve. Individuals from businesses, development companies, architects, or property managers can take the Certification training themselves to learn how the ratings work and how to make a space more accessible.

Cheng took the training as part of his contract work with the Rick Hansen Foundation when the program was just getting underway, and it is the basis upon which his accessibility evaluation knowledge and business grew. “I already had

a part-time job at the time and thought I would do it for a bit and then move on, [but] I didn't expect to like it so much," he says. "I didn't expect the clients to keep calling and it became very apparent within 24 hours of my first client calling that I couldn't keep this under wraps."

After the initial contract ended, Cheng decided to take the entrepreneurial plunge and founded Spectrum Ability. "We are an accessibility consulting firm based in Vancouver, but we've provided services all over BC and sometimes outside of BC as well," Cheng explains. "We look at buildings from a mobility, sight, and hearing perspective... and we give recommendations to the property owner or manager on how to improve their accessibility long term and short term, from high cost to low cost." To date, Spectrum Ability has provided recommendations to a variety of settings including the North Surrey Ice & Sport Complex, New Westminster's Ryall Park Community Garden, Destination Canada, the TELUS Garden office building, and The Station building at Waterfront Station in Vancouver.

The consultation process looks like this: Spectrum Ability conducts a site visit and reviews accessibility considerations from a multitude of perspectives using the Canadian Standards Association (CSA) guidelines and the RHFAC as evaluation tools and the principles of universal design as guidance. Buildings are required by law to meet the minimum standards laid out by building code, but

Spectrum Ability's goal is to help properties evolve beyond the minimum—in other words, move from a passing grade to an A-grade. After a site visit, Cheng and his team prepare a report for the property with recommendations on how best to improve accessibility for their user demographic. "The definition of universal design is not what most people think. People think it means it's accessible for everyone, but that's impossible because everyone has such different needs. Everyone's body is different. Everyone's preferences are different," Cheng says. "So, the definition of universal design we refer to talks about being as accessible to as many users as possible."

This is a fine balancing act. Providing optimal accessibility to one group in the form of installing tactile indicators on the ground, for instance, may create bumpy, uneven surfaces that aren't optimal for people who use mobility devices. "How do you balance those two?" Cheng comments. "I think the most important thing is to think about who your user profile is. Asking 'who' is the most important question. Who is using this building? Who is this being built for?" Spectrum Ability aims to provide recommendations that are feasible, sustainable, and based on expected users of a space. Oftentimes, the solution to an accessibility issue isn't the most expensive or the most innovative. "While there are certain capital projects that are going to cost

money, there are so many non-capital improvements that you can make. A lot of people think [that] because the accessibility symbol uses a wheelchair, that solutions and the impact you can have is limited," Cheng says. "But one solution could be as simple as a trip to Home Depot to buy some paint and add visual variation [for visual accessibility]."

As a business owner with a disability, Cheng recognizes his unique perspective in entrepreneurship. "A lot of people might have preconceived notions of what people with disabilities are capable of... Some people have [a preconceived] idea of what accessibility means or don't have any experience at all," he says. "But having a disability can be an advantage because you know that people learn in different ways... You can use your body to show why a kitchen counter isn't accessible, use your body to show why a heavy door won't work." The CSA guidelines and RHFAC program continue to change as new best practices are established.

For example, the CSA guideline for the optimal turning radius of a wheelchair in a room has been updated from 1500 millimetres to 2100 millimetres. Having lived experience with disability helps Cheng and his team recommend a realistic middle ground that would work for a majority while taking building restrictions and construction concerns into consideration.

Spectrum Ability's team currently consists of Cheng, founder and general manager, Natalie Imbeau, an accessibility assistant and fellow SCI BC peer, and



Left to right: The Station building at Waterfront Station, North Surrey Ice & Sport Complex, and TELUS Garden are three of many projects Spectrum Ability has worked on.

Henry Nguyen, a visuals and graphics specialist who brings a valuable neurodiverse perspective to the table. Notwithstanding this range of experience, Cheng believes the most important element when providing accessibility services is empathy. “It can be a misconception that because you’re in a wheelchair or have a disability that you’d automatically be a good consultant... I think being empathetic enables seeing accessibility from other people’s perspective and being willing to learn. That’s a key ingredient,” he says.

One of the biggest lessons Cheng has learned on his entrepreneurial journey is to have confidence and build trust. “[I try] to be easy going. People will make mistakes. Don’t let them worry about using the wrong word—for example, if they call you a ‘disabled person,’ just tell them what you prefer and know that you’re there to help them. It becomes more of a trust relationship.”

In general, Cheng has noticed that property management companies and commercial properties are enthusiastic

accessibility stakeholders, while residential property managers and developers struggle. He recommends a mixture of incentives and legal requirements to engage these groups and emphasizes a need for more education in the industry.

Looking ahead to 2025, Spectrum Ability will continue to provide accessibility consultations and recommendations to buildings and spaces in BC and beyond. They are also eager about the possibility of contributing expertise to accessible EV charging stations and helping businesses communicate their level of accessibility in a way that everyone can understand.

Perhaps the most exciting project on the horizon is Spectrum Ability’s recently awarded bid to consult on the new Scotia Place in Calgary, Alberta. Scotia Place will replace the City’s current Saddledome arena—home to the Calgary Flames and various concerts and touring events. It is the largest consultation to date for Spectrum Ability and Cheng, as an avid hockey fan and business owner,

is looking forward to contributing to the project. More than that, however, he is excited to foster more moments of realization and insight in others.

“The ‘aha moment’ that I see from clients is what I enjoy the most,” he says. “Sometimes the person who does the site walkthrough with me is the person who called me, and that’s easy. But sometimes... there’s an employee on the job who has no connection to the project or is less enthusiastic. They start to get on board and see things they haven’t even thought of before. By the end of it you can tell they’re really into it. That’s the most rewarding feeling in the world.”

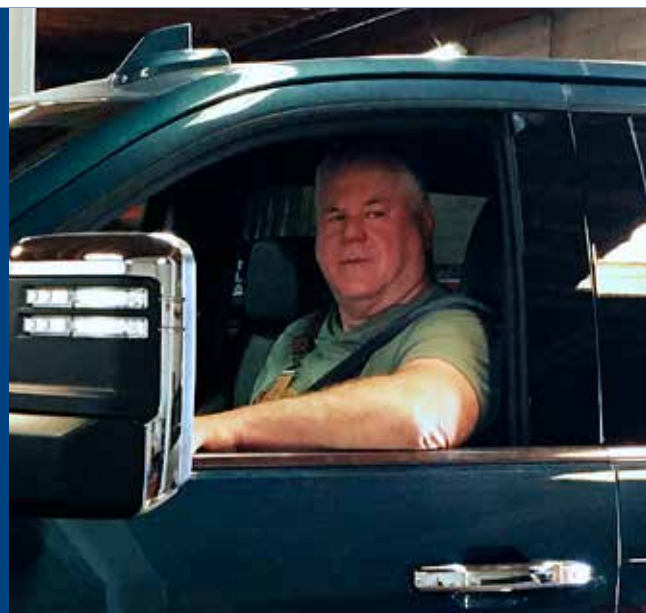
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SCI research is about much more than test tubes, stem cells, and a far-off cure.

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.

Co-developing a Novel Intervention to Promote Well-being of Family Caregivers and Individuals with Spinal Cord Injury

Overview: ICORD researcher Dr. William C. Miller and his research team at UBC are exploring the use of an eHealth tool developed to optimize the well-being of family caregivers of individuals with an SCI. They partnered with the co-founders of WAGS of SCI to develop this eHealth platform. The eHealth platform, called the Companion program, aims to provide an affordable, accessible resource for family caregivers to better support their family member(s) with SCI and themselves, and help decrease caregiver burden.

What to expect: The time commitment for the online survey is approximately 30-90 minutes and will be completed 3 times over a 6-month period. Participants in the intervention group will be invited to take part in an optional semi-structured interview at the end of the 6-month period, which will take between 45-60 minutes to complete. Participants will receive a \$50 CAD stipend after completion of each survey (i.e. a total of \$150 CAD for completing all 3 surveys throughout the study).

Who can participate: You may be eligible to participate in this study if you are a partner or family caregiver to an adult individual with an SCI; are more than 18 years old; are able to speak and understand spoken and written English; live with the individual with SCI in the community (e.g. not a group home or assisted living centre); and live in Canada or the United States. You may not be eligible to participate if you provide care for an individual with an SCI who is currently a patient in a rehabilitation facility, or you have a major medical or physical condition that requires routine visits to medical doctors.

Why participate: The findings from your participation in this study will contribute to the continued development of resources to support family caregivers' own well-being and the care they provide to their family member(s) with SCI.

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

For more information or to sign up: Please contact the study coordinator, Dr. Somayyeh Mohammadi by email (companion.study@ubc.ca) or by phone at 604-734-1313.

Sedentary Behaviour and People with Physical Disabilities Interview (SBriNT)

Overview: Researchers in the SCI Action Canada Lab are exploring how people with physical disabilities experience sedentary behaviour (i.e., sitting still for long periods of time). The results of this interview will be used to set up future lines of research investigating sedentary behaviour in people with physical disabilities as well as creation of a resource for appropriate sedentary behaviour language to be used in health messages for people with disabilities.

What to expect: Participants will be interviewed (~60 minutes) to explore what they know about sedentary behaviour and its effects on health and well-being as well as how they experience these behaviours on a regular basis. A \$50 Amazon gift card will be provided as compensation for participating.

Who can participate: You may be able to participate in this study if you have been diagnosed with a physical disability; are greater than one year post diagnosis; are 18 years of age or older; are able to read and speak English; currently live in Canada; use a manual wheelchair or power wheelchair as the primary mode of mobility in the community (i.e., when outside of the home). You will not be eligible to participate in this study if you primarily walk (unassisted or with gait aids) for mobility when outside the home. For more eligibility information, visit the study webpage provided below.

Why participate: You can share your experiences with sitting, your perceptions of how sitting impacts you, and contribute to products which will be designed to improve the way sitting is discussed in media and science following this study.

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

For more information or to sign up: Please contact the study coordinator, Nathan Adams by email (adamsmnt@student.ubc.ca) or call 253-363-1575, or visit icord.org/studies/2024/08/sbrint.



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That's the Spirit!

Meet Dan Duffy, the recipient of the 2024 Susan Marshall Fighting Spirit Award.

It takes a special kind of person to uplift those around you, while also dealing with your own daily challenges, adventures, and life hurdles. Susan Marshall was one of those people.

Following a motor vehicle crash in 1985, Marshall became a C5 quadriplegic. Despite constant pain and serious health issues, Marshall always managed to laugh, joke, and smile. Her main concern was always the well-being of the other people in her life. On numerous occasions, when the medical professionals were about to give up hope, she would bounce back against seemingly impossible odds. If you ever met Marshall, her "fighting spirit" was undeniable.

Following Marshall's death in 1999, her good friend Roger Jones established the Susan Marshall Fighting Spirit Award Fund within the BC Paraplegic Foundation (which provides essential financial support to SCI BC, formerly the BC Paraplegic Association). The award returned this year after a 15-year hiatus, continuing a legacy celebrated by previous winners such as Ted Brownlee, Robert Kay, Sherry Caves, Brad Jacobson, and Diana Dimitru.



Susan Marshall

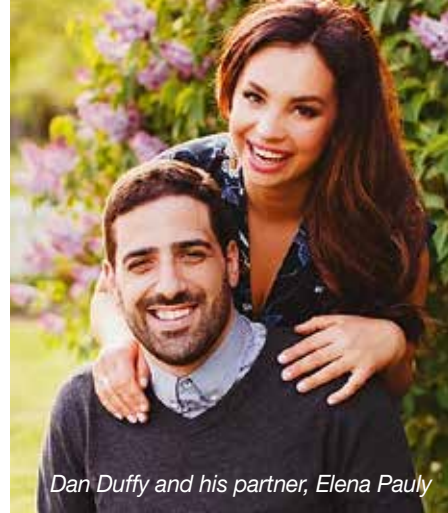
Now, meet the 2024 recipient of the Susan Marshall Fighting Spirit Award, Dan Duffy!

"Since his injury, I've watched Dan transform into someone I know he is proud of. He has never let SCI hold him back, despite all the daily challenges that accompany it. From the moment his wheels hit the floor, he's ready to start a new day with a smile on his face to help others... I am very proud of his determination to never give up and always show up," shares Elena Pauly, Duffy's nominator and partner.

Ryan Clarkson, SCI BC Peer Program Coordinator at GF Strong, agrees: "Dan has a natural gift of making peers comfortable, and he does an excellent job at showing recently injured members what is possible in the community."

Whether he is connecting with peers at SCI BC events, working out at ICORD's Physical Activity Research Centre (PARC), participating in a research study, or volunteering at GF Strong to support newly injured peers, Duffy is a generous and active member of the SCI community. During the COVID-19 pandemic, he even hosted engaging virtual cooking classes for peers (check him out on Instagram @quadchef). For the past 7 years, Duffy has been pursuing his Bachelor of Therapeutic Recreation at Douglas College. With support from the GRAGOPEAN Scholarship Trust, he is learning how to use leisure activities to improve the health, well-being, and quality of life for people living with disabilities.

"It's a privilege to win and to be nominated. It's nice to know that what you're doing after you have disability, your efforts are being recognized by the people around you. All that I have accomplished



Dan Duffy and his partner, Elena Pauly

since my injury would not be possible without the support of my partner Elena, or my family and friends. Quite often they are the ones who pick me up when I'm down and encourage me to continue on my journey. They are the reason I am the person I am," Duffy explains.

So, what does having a fighting spirit mean to Duffy? "It's having resilience and being able to go through hard times, persevere, and come out the other side as a stronger person. What I see as having that fighting spirit is not giving up. I try to live every day like it's a new one. Just keep on trying to move forward with whatever I'm doing."

Duffy recalls, "When I was early in my injury, [a coach from BC Wheelchair Sports] shared with me, 'A lot of doors have closed for you, but a lot of doors have opened as well.' I really took that advice to heart. Now I'm finishing my Recreation Therapy degree! I'm going to be able to use the knowledge that I've learned with my disability and my school to help others. One door closed, another one opened." At the time of publication, Duffy is completing his final practicum and plans to support people with SCI as a Certified Therapeutic Recreation Specialist. We can't think of anyone better for the job!

The next round of nominations for the Susan Marshall Fighting Spirit Award opens in early 2025. Duffy encourages, "If you think someone is deserving of the award, throw their name in the hat! It's a great honour. Even though you have a fighting spirit, there's down days, there's days that are hard. Receiving this award is a major morale booster." ■



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

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