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thespin

SPINAL CORD INJURY BC

SUMMER 2021

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COVER PHOTO: SCI BC peer Derek Lunden works out on PARC's aSKI fitness machine. (Photo courtesy Cheryl Niamath, ICORD)


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editor's message

Accessibility legislation is inspirational, even when it isn't

When the federal government passed into law Bill C-81, the *Accessible Canada Act*, the mainstream media heralded this historic event with resounding silence. So it shouldn't have come as a surprise that no members of the fifth estate turned up at an online media event to celebrate the introduction of BC's long-awaited accessibility legislation—Bill 6, the *Accessible BC Act*.

Given how transformative these pieces of legislation are intended to be, why do they attract so little media attention? Is it because the media doesn't know how to talk about disability, doesn't know which questions to ask, or are scared to say the wrong thing? Is it because they don't think enough people are interested in issues concerning accessibility? Do they not understand what the impact of accessibility legislation can be?

Maybe it's all these things. And maybe it's also because legislation, in isolation, isn't particularly inspiring. After all, legislation like this is written in highly technical English with every single word scrutinized to ensure it's legally sound and, in the case of the *Accessible BC Act*, to ensure it's as broadly inclusive as it needs to be. Not many of us are fluent in legalese, and not many of us read the laws that govern our lives. The written words of legislation are rarely inspirational. This is true of the *Accessible BC Act* which, on its own, is a rather sterile document.

The fact that the *Accessible BC Act* is enabling legislation may further diminish its appeal to the media. This type of legislation is devoid of the types of specifics that would likely help the media understand the magnitude of change the Act is intended to achieve. It's intentionally written this way, as the standards and regulations that will affect the real changes in access and inclusion in this province will be developed over time.

So perhaps the *Accessible BC Act* doesn't appear to be inspirational at first glance. But it's not the legislation itself that provides the inspiration—it's what it represents and what it sets in motion that truly is inspirational.

By the time you read this, the *Accessible BC Act* should be enacted as a law and will have started the long, involved process of gradually removing barriers to access and inclusion, bringing about change that, for decades, SCI BC and so many other organizations and individuals have been advocating for.

All this requires a level of faith that government will carry out the plan as promised. Having served on two of the Minister of Social Development and Poverty Reduction's advisory committees, I have seen firsthand the sincere engagement of people with disabilities throughout the consultation process that led to the *Accessible BC Act*, and I know that people with disabilities will be at the centre of establishing priorities for the accessibility standards and regulations that will move us toward full access and inclusion. The process will be slower than any of us will like, but it's critical that it be done right if it's to succeed. Still, we must hold government to account on making progress sooner than later.

People with disabilities inspired the creation of the *Accessible BC Act*, and while it may not be an inspirational read, it is a historic piece of legislation that's the foundation for the movement to make BC accessible and inclusive for all. To me, that's inspirational, and when achieved, the media should think so, too.

CBM

—Chris McBride, PhD, Executive Director, SCI BC

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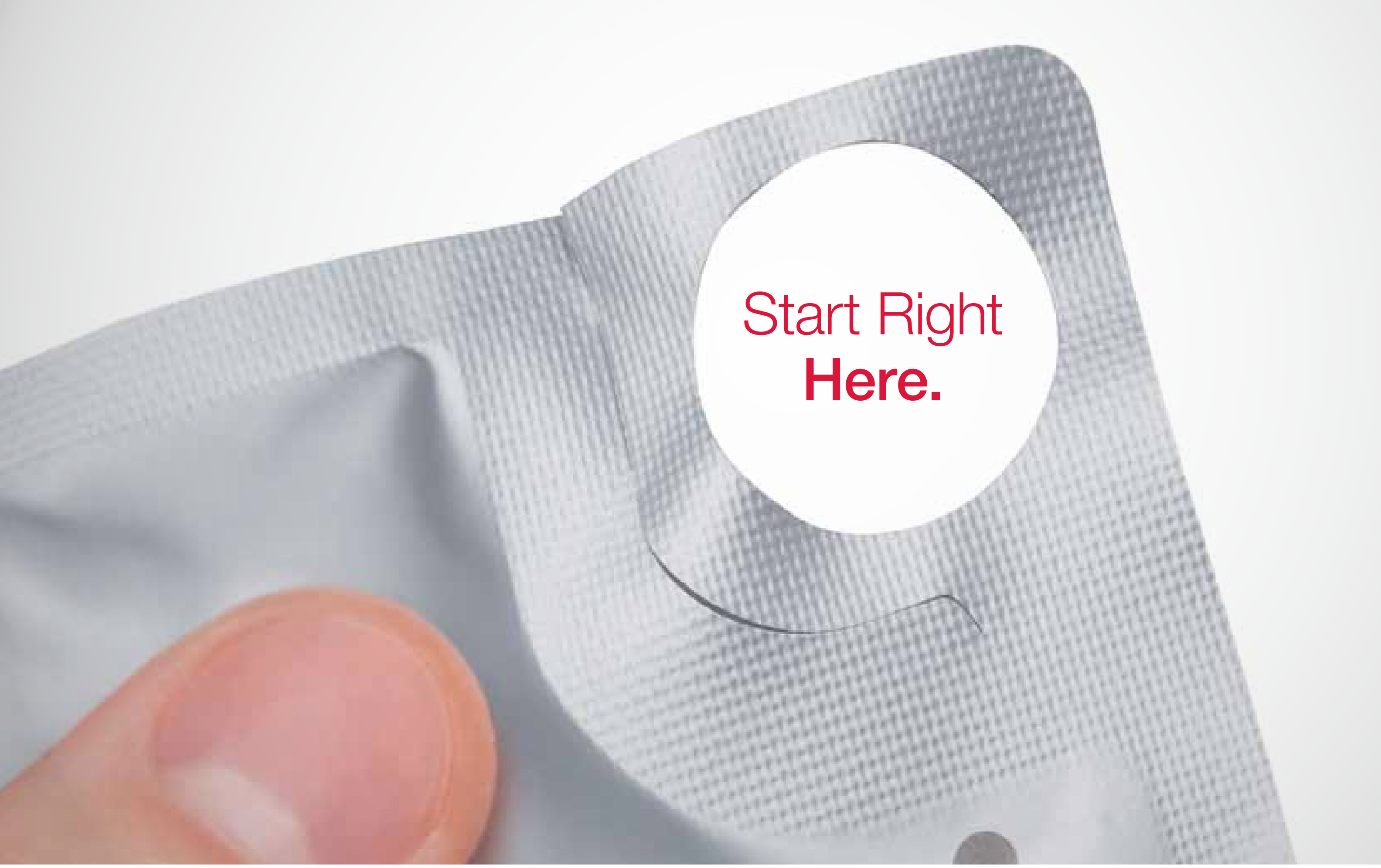
We acknowledge that *The Spin* is created on the traditional and ancestral territory of the Coast Salish peoples—Squamish), Musqueam, and Selilwitulh (Tsleil-Waututh) Nations. Our provincial work takes place on the territories of Indigenous peoples who have lived on and cared for the land for time immemorial. We are grateful to work, share stories, and connect in these spaces.

SCI BC InfoLine: 1.800.689.2477

Spinal Cord Injury BC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VERSA PADDLE

The Versa Paddle is an adaptive kayak paddle that's ideal for paddlers with disabilities. The paddle has a centralized, rotating support mount, which stabilizes and holds the weight of the paddle, while allowing it to pivot in every direction. This results in a smaller range of motion and less stress on your shoulders, back and joints. You can use it angled or straight, and it can also be used independent of the mount. Versa Paddle comes with one of three support mounts that attach to most single and tandem sit-in kayaks, and also some sit-on-top kayaks. Visit angleoar.com/versa-kayak-paddle to see video of the Versa Paddle in action.

RETYRE TRACTION

Norway's reTyre has teamed up with wheelchair manufacturer Panthera AB to create the TRACTION, a detachable tire tread skin for wheelchairs. The skins, which users can easily attach or detach themselves over their existing tires in a matter of seconds without any tools, provide a stable grip on sand, gravel, snow, and any soft, wet, and slippery surface. They stay firmly in place thanks to Velcro tabs, are easily cleaned, and fold to a compact size for storage. The reTyre Traction is currently available for all 24 inch rear wheels. You can learn more at retyre.co/traction.

THE JOËLETTE

Similar to BCMOS's TrailRider, the Joëlette is an all-terrain chair that allows people with disabilities to explore the great outdoors. Made by French company Ferriol-Matrat, the device is operated by two or more guides, with the rear guide providing balance and propulsion, and the front guide controlling traction and direction. There are several versions available. The single wheel classic model is ideal for the most rugged terrain, while an electric version provides guides with assistance for heavier passengers or longer journeys. A double-wheeled model offers more stability, is easier to guide, and is more suitable for less severe terrain such as park trails. And the Joëlette Kid is ideal to get kids with disabilities outside for hikes—its two wheel design makes it easy to handle and requires only a single guide. You can visit joeletteandco.com to see photos and video.

Innovations

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

THE HANDI PAC

Developed by Ontario-based Advanced Freedom, The Handi Pac is a front-facing, two-part, secured and accessible wheelchair bag that's large enough to carry a variety of goods and designed so that you can keep a close eye on whatever you need to carry. The compartmentalized lap bag is great for valuables and technology, while a vertical piece is ideal for larger items and can be worn at the front or behind the chair. Oversized zippers, O-rings and magnet closures allow wheelchair users with limited hand strength to easily open and close the bag. Constructed of Cordura nylon, The Handi Pac is durable and water-resistant. The system is entirely compliant with carry-on baggage rules, and is capable of holding seven kilograms. To learn more, visit advancedfreedom.com.

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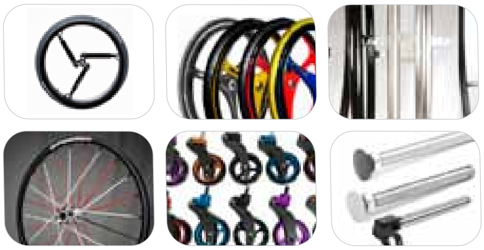

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Activate your advocacy skills.

You're invited to take part in our two-day advocacy webinar. Join special guests to learn all about advocating for yourself, and others. Our featured experts will teach you how to effectively advocate in areas of self-care and health. Plus, there'll be fun online activities and a chance to check out our new advocacy guide. This event, which takes place online September 24 and 25, is ideal for peers and their families. Please register for one or both days by emailing jwright@sci-bc.ca.

Prevent pressure sores.

The COVID-19 pandemic has had many of us glued to our computers for work, school, entertainment and socializing. Unfortunately, along with this increased computer time, comes a greater risk of a pressure sore. In our upcoming Ask an Expert session, GF Strong physiotherapists Regina and Shannon share ways to prevent pressure sores and techniques for treatment. The event takes place online June 30 at 5 PM. To register, please email jwright@sci-bc.ca.

Don't stop racing just yet.

Throughout BC, peers, friends and family raced in this year's Scotiabank Charity Challenge to raise funds and transform lives. We saw wheelers, runners, handcyclists, walkers and rowers dedicating their efforts to honour a special person in their lives. The race for donations isn't over yet—you can still celebrate someone special with your contribution to Spinal Cord Injury BC! Who are you racing for? Visit bit.ly/teamscibc-2021 to make your donation.

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Alliance Mobility has stepped up to help six-year-old Emiliano by donating a Dodge Grand Caravan with rear entry conversion to the Hernandez Family.

"Thank **YOU** for this generous donation! this is life-changing for us"
- Diana (Emiliano's mom)

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Congrats to Vancouver's **TREVOR FLYNN**, who is making his dreams of working in healthcare come to life. Trevor, who has spina bifida, recently landed a six-month contract position as a mental health personal support worker at Vancouver General Hospital's Willow Pavilion, and he says there's a good chance it will lead to a permanent position. "I'm working with clients who are accessing the long term mental health inpatient treatment program," he explains. "When I ended up in a wheelchair, I honestly thought I would never have a career. I've proved myself wrong through hard work and resilience. This is just the start of what I know will be an amazing next life chapter!"

A soulful shoutout to **KRISTINA SHELDEN** for the release of her new single, *Dancing With The Flames*, on May 29th. "I wrote *Dancing With The Flames* because there is a lot of 'you can get through this' mentality out there," says Shelden. "But for many of us, there are permanent issues that we won't get through, we simply have to live with them the best we can, no matter how much it hurts. We have to learn to dance with the flames. That's the idea behind this song."

Funding for the production was provided through a grant from Creative BC. "I am so grateful for this grant and my incredible team who helped develop a song that I hope others with chronic issues might identify with—the feeling that even when they're down, it's okay, we're just recharging until we rise back up for the next round. It's a dance song with an ebb and flow. I've found that when I'm with great people and doing something that I love, even when I'm in pain, I can feel awesome, which is a sentiment I put into the song as well."

The song is now on all major streaming platforms including Spotify. It will also be available for purchase through Shelden's website (kristinasheldenmusic.com).

Peer Shoutouts

A big-time, small town shoutout to **BRONWYN BERG** and **HAL BENNETT**, who recently opened an inclusive new business in Chemainus on Vancouver Island. Berg, 50 and Bennett, 48, both use wheelchairs--Berg sustained a brain injury six years ago, while Bennett is a double leg amputee. A few years ago, while living in Kelowna, the couple discovered Chemainus, located just south of Nanaimo, during a road trip to Vancouver Island. They marvelled at its accessibility—so much so that they moved there last August and opened up Clover Clothing Co in the fully accessible Chemainus Public Market, where they offer customers a carefully curated collection of new and consignment clothing,

The Chemainus Public Market has good accessibility features, including a flat entrance, automatic door openers and an accessible bathroom. Berg and Bennett only needed to add an accessible fitting room to ensure peers can have a full shopping experience in their store.

If you're planning a post-lockdown island road trip this summer, Chemainus is a great destination to add to your iternary—it's a charming and quaint community that's long been a tourist favourite. If you go, be sure to drop in and do a little shopping at Clover Clothing Co.

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.

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Keep It Clean

New ICORD research sheds light on the safest and most effective ways to clean catheters for reuse.

In a perfect world, people with SCI wouldn't have to pay for the privilege to pee—and government programs would provide single-use intermittent catheters as part of basic health coverage. Sadly, that's not the case, and with our current patchwork of coverage, peers are too often forced to finds ways of reusing catheters (even single use catheters which are approved for just one catherization) to keep their out-of-pocket costs in check.

The business case for comprehensive catheter coverage is obvious: reusing catheters significantly raises the risk of UTIs, and UTIs are tremendously expensive for our healthcare system (not to mention tremendously costly in so many ways for those who experience them). Here at SCI BC, we're working with several partners to change our current reality and convince policy makers that expanding catheter coverage and extending it to more people just makes good sense. But in the interim, it also makes sense to pass along any information to peers that can help them clean and sterilize their catheters to the best extent possible.

Recently, at the annual ICORD research meeting (held online for the second straight year due to the pandemic), we were pleased to see a comprehensive poster presentation reviewing the effectiveness of various catheter cleaning strategies. The poster, titled *The microbiological and physical properties of intermittent catheters: A systematic review on the impact of re-use and various cleaning methods*, was researched and created by Mark Grasdal, a UBC medical student in Dr. Andrei Krassioukov's ICORD lab, with assistance from Dr. Matthias Walter and Krassioukov himself.

"Current safety concerns about cleaning and reuse of catheters include increased risk of urinary tract infection due to remaining bacterial colonization on the catheter, and evidence suggesting that structural damage of the catheter itself from cleaning could put users at risk of contracting UTIs by their reuse due to an increased risk of urethral and bladder trauma," explains Grasdal. "Given this, we decided to undertake this review to determine if there was a catheter cleaning method reported that both eliminated bacterial colonization as well as preserved the physical structure of the catheter."

Grasdal began the project with an exhaustive search of the global scientific literature to identify credible studies of the effectiveness and safety of various approaches to cleaning and sterilizing intermittent catheters for reuse. In the end, any study that failed to assess bacteria levels or damage to the catheter after cleaning were excluded. And that left just 12 studies that were determined to be of high enough quality to include in the systematic review.

The cleaning/sterilizing methods analyzed in these

studies included heat-based sterilization, chemical cleaning solutions, mechanical scrubbing, photocatalytic sterilization (using light), and combined methods.

When the dust settled, it turned out that most of the methods studied just didn't cut it.

"Only two cleaning methods—less than ten percent of published proposed cleaning methods—eliminated all bacteria and did not cause damage to the catheter," says Grasdal.

The first method involved soaking catheters in a 70% alcohol solution for five minutes. The other, dubbed the "Milton method", used a combination approach consisting of a detergent wash followed by soaking in Milton sterilizing fluid—a solution containing sodium hypochlorite and sodium chloride that's produced by Procter & Gamble and mainly used in a diluted form to sterilize baby bottles.

Both methods left virtually no bacteria on the clean catheters, and neither did any physical damage to the catheters.

In contrast, heat-based sterilization and mechanical abrasion methods were either ineffective or damaged the catheters analyzed. In fact, all other cleaning methods were either non-bactericidal or caused gross visual or microscopic damage to the catheters, making them unsafe for reuse.

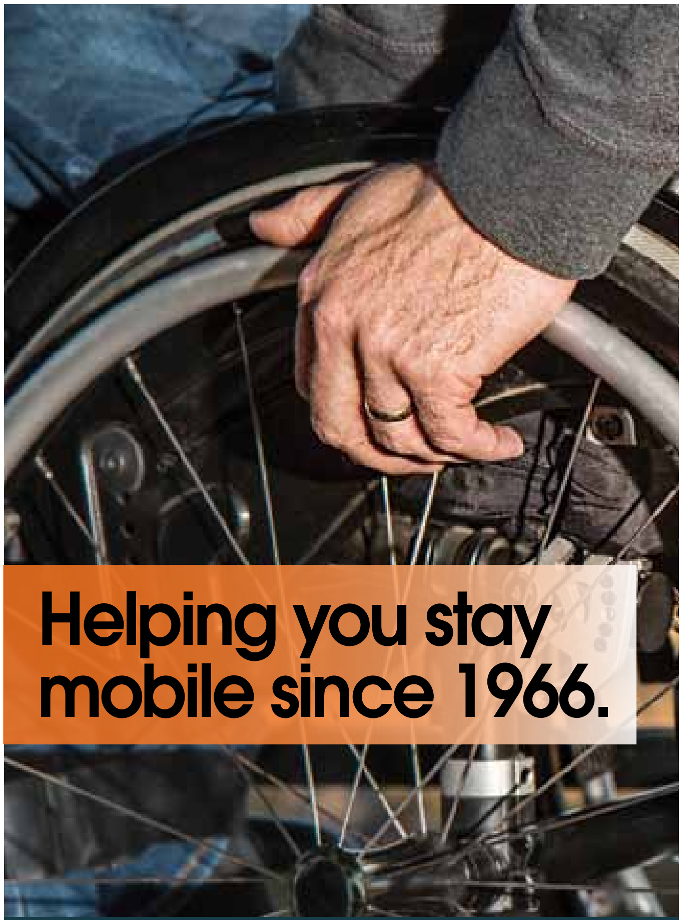
The take-home message for readers is that, if you have to reuse for financial or other reasons, then it seems logical to employ either of the two methods that Grasdal and his collaborators found to be effective. However, Krassioukov offers some cautionary advice.

"Although our review did identify two potentially promising methods of cleaning catheters for re-use, we still do not have any data confirming that the re-use of catheters with these methods actually do not result in UTI," he says. "This question has to be answered before anyone can make a final conclusion that these methods of cleaning are safe and we should change policies."

In other words, more research is desperately needed before any person or clinical guidelines can state with confidence that reusing single-use catheters is risk-free. The fact that there is such a void of quality research into this area was a real eye-opener for Grasdal.

"Initially, I was surprised by the lack of research done on this topic, given the large portion of individuals who reportedly reuse intermittent catheters," he says. "We hope that the results of this manuscript spark further investigation into this topic." ■

UBC medical student Mark Grasdal



PAD Your Ride

If you're thinking about adding a power assist device to your manual wheelchair, new findings recently published by BC researchers provide good insight into the choices available to you, along with their pros and cons.

In the past two decades, an exciting new mobility product has emerged—the power assist device, or PAD. PADs have built-in electric motors and rechargeable batteries. They're intended to be easily attached to and detached from a manual wheelchair, and to provide some of the benefits of a power wheelchair while still allowing the user to enjoy the light weight, manoeuvrability, portability, and exercise potential of their manual ride.

PADs have become an attractive mobility option for several reasons. First and foremost are shoulder and wrist overuse injuries that, unfortunately, have emerged to become a big problem for manual wheelchair users—particularly for those who have a lifetime of manual wheeling and transferring. It's no surprise that PADs have become an option for those already dealing with these types of very-difficult-to-fix injuries, as well as those who are prevention-minded. Also, those seeking to expand their range, get out in their communities more, and simply avoid being exhausted when they arrive at their destination have turned to PADs. And some types of PADs even make it that much more possible to get off the beaten (or paved) path.

Recently, a group of UBC, ICORD and BCIT researchers working in the fields of biomedical engineering and occupational therapy decided to take a deep dive into the world of PADs. The researchers—Mahsa Khalili, Angela Eugenio, Allison Wood, Dr. Machiel Van der Loos, Dr. Ben Mortenson and Dr. Jaimie Borisoff—wanted to better understand the devices' mobility benefits for users, compare perceptions about the three different types of PADs, and identify the features and design characteristics of PADs that users most appreciate.

The approach they decided on was to rely on the expertise and observations of manual wheelchair users themselves. They recruited 16 peers aged 31 or older who had been using a manual wheelchair for at least two and a half years, and had either purchased or tested at least one of the three types of PAD (see sidebar). Most participants had an SCI. Each participant completed a semi-structured interview, and the results of their experiences and wisdom were summarized in a research paper titled *Perceptions of power-assist devices: interviews with manual wheelchair users*, which was published on April 21 in the journal *Disability and Rehabilitation: Assistive Technology*.

TWO MAIN THEMES

The first of the two themes that emerged from the study was positive—for the most part, participants believed that PADs are (or could be) a benefit in their lives in three specific ways. The first was that they boost autonomy, independence and sense of belonging, primarily by making the task of getting to a destination less of a challenge. Second, PADs allow users to access and explore new environments—they can be relied on to travel longer distances and traverse more difficult terrain (for example, side slopes, inclines, and softer and rougher surfaces). And finally, they agreed that PADs are ideal for maintaining physical health—by conserving energy, and preventing and managing overuse injuries.

The second major theme wasn't as positive. Participants expressed frustration with their perceived shortcomings of PADs. Some of the drawbacks they identified included difficulty controlling the devices, less than ideal safety, too much weight and size, and financial barriers associated with purchasing one. Specific concerns included unexpected acceleration, unpredictability on uneven surfaces, unreliable battery life, difficulty attaching or detaching the devices, and high cost coupled with lack of funding assistance within existing government programs for mobility devices.

However, none of these perceived drawbacks outweighed the perceived benefits, and participants all expressed hope that any outstanding issues could be ironed out in the PADs of the future.

THREE TYPES OF DEVICES

Participants went on to describe what they perceived to be the strengths and limitations of the three different types of PADs—front-mounted attachments, rear-mounted attachments, and powered wheels (see sidebar for descriptions).

Front-mounted PADs were viewed as being the most ideal for anyone interested in extending their range and capability to negotiate difficult terrain in the outdoors. But participants also pointed out that, because of their size and how far they extend from the front of the wheelchair, these types of PADs were less than ideal for indoor use, accessing narrow spaces, and transitioning from outdoor to indoor spaces.

Conversely, participants perceived that rear-mounted PADs were a much better choice for confined spaces and indoor use, given their lighter weight, smaller footprint, and tighter turning radius. Those advantages indoors, however, were seen as being at the expense of outdoor performance— participants reported these types of PADs were only appropriate for smooth, flat surfaces. They also perceived rear-mounted PADs as being generally more difficult to control and somewhat less safe than the alternatives.

Finally, the powered wheels were perceived by participants as being the best all around practical solution. They noted that these types of PADs looked and operated much like a manual wheelchair, with virtually no addition to the footprint of their chair. While participants said they aren't as useful as front-mounted PADs in more difficult terrain outside, they felt powered wheels were safer and more reliable outdoors than the rear-mounted devices.

The researchers suggest that people interested in obtaining a PAD, along with clinicians who guide them, to carefully weigh their needs and intended uses of the device in order to make a decision about which type best suits them.

PADS OF THE FUTURE

While all participants identified what they believe were limitations or drawbacks of all three types of PAD, they also expressed hope, along with the researchers, that their input and that of other potential end users would be

Breaking Down the Three Types of PAD

1 A front-mounted PAD is attached to the front of a manual wheelchair frame. It lifts the front casters off the ground, resulting in a mobility device that looks a lot like a three-wheeled scooter. There are versions of this type of PAD that incorporate a manual hand bike with a power assist motor. Examples of these types of add-ons include devices from the Batec (shown) and Rio Mobility.

2 A rear-mounted PAD is a motorized wheel that is mounted to the wheelchair's rear axle. These devices are typically controlled with a frame-mounted joystick or, like The SmartDrive (shown), wirelessly via a wristband. These devices are the easiest to lift and transport.

3 Powered wheels are the final type of PAD and replace the conventional wheels of a manual wheelchair. These devices can be controlled either by a joystick, or by direct pushrim interactions—built-in force sensors detect the user's input force to the pushrims (this specific type of powered wheel is known as pushrim-activated power-assisted wheels, or PAPAWs). PAPAWs' in-hub motors provide propulsion assistance that is proportional to the user input force—push harder, and it pushes harder. The Alber e-motion and Yamaha NAVIONE (shown) are examples of PAPAW powered wheels.

incorporated in new PADs or revisions to existing PADs.

The most common suggestions revolved around improving the battery life to limit the possibility of being stranded, as well as addressing issues about safety and poor control.

Another area of concern was universal compatibility with all types of manual wheelchairs. Users spoke of frustrations with needing special brackets, and even the need to change their wheelchair frame entirely in order to be compatible with the PAD.

Size and weight was also identified as an area needing improvement, with participants saying that future designs should be smaller and lighter in order to improve portability and the ability to attach and remove independently.

Finally, although not a comment on design, participants spoke of the desire to see prices come down on PADs—and the need for government funding programs to consider PADs as essential equipment and widely eligible for funding.

NEXT STEPS

Borisoff, who is a co-supervisor of the study, says he and his collaborators have plans to extend this line of research.

"Power assist devices for manual wheelchairs are perhaps the most exciting area of growing innovation in our (mobility) industry," says Borisoff, ICORD principle investigator, and Director of BCIT's Rehabilitation Engineering Design Lab. "PAPAWs have been around for quite some time and most people understand their strengths and weaknesses. But rear-attachments and front-attachments are relatively new, with several new products entering the market very recently. Right now it can be confusing to end users and therapists about which device is most suited for a particular person, or environment, activity, etc. Couple that with limited resources of clients and their funding sources, and it becomes clear that there is some pressure in making purchase decisions. And there is relatively little information to guide this process. More research is needed."

He explains that this study's first author, UBC biomedical engineering PhD candidate Mahsa Khalili, is currently completing a large survey that's similar to this one. He also says that the collaboration is in the process of creating a framework for evaluating different PADs and comparing them in indoor and outdoor situations. And he also says his own lab will continue to research and develop new PAD technology.

"A few different areas are being researched," he says. "One is developing better control of PAPAWs. Another is developing more powerful PADs for difficult terrains—beaches and snow. A third area is improving safety and stability of manual wheelchairs with and without add-on devices, including PADs and passive devices like the Freewheel. We're also developing PADs that improve safety and stability. And finally, we're exploring add-ons that expand where a manual wheelchair can go—for example, up stairs."

You can stay abreast of Dr. Borisoff's research at commons.bcit.ca/redlab. ■

WHY I GIVE...

It all comes down to one person. Having one person to support you and encourage you. Nobody really gets it unless they've been there.

For me, that one person was my friend Kim. When I first met Kim, she didn't know anyone with an SCI and I was also very shy, so we helped each other and went to our first coffee group together. Before Kim, I never realized how much a one-hour coffee group could change my life, and the lives of so many others.

SCI BC is such a unique organization. Whether it's going to a coffee group, going up to Whistler, or even just talking on the phone. We're all social beings and we need that. There are so many things I wouldn't have done without SCI BC. That's why I'm a monthly donor.

I really like that my monthly donations are contributing to something bigger in some small way. I know if I donate even $10, it makes a difference. These donations add up. I've experienced the good that comes from them firsthand, and I know other people whose lives have changed as a result. Being a monthly donor makes me feel good.

Marney Smithies
SCI BC Peer, Volunteer & Monthly Donor

JOIN OUR FAMILY OF DONORS

VISIT sci-bc.ca/marney
CALL 604-326-1222

Spinal Cord Injury BC

PeerSAY

Brad Jacobsen

June 21, 1969 - February 17, 2021

We weren't surprised there was such an outpouring of grief from our community when Brad passed away. We could write so much about Brad and what he meant to us—about how he was instrumental in getting our Peer Program off the ground two decades ago, or how he inspired so many peers to look beyond the first days and weeks in rehab, or how he always had a smile on his face (and how he always was able to put one on ours). But we think it makes far more sense to publish what some of you said about Brad in the hours, days and weeks after he left us—and to remember him in photos. If you'd like to know more about Brad's story, please read his eulogy at bit.ly/BradJacobsen

Rest in peace, Brad. You were an inspiration and delight to be around, and a kind soul to everyone. Thank you for everything.

– ANGELA

Brad was a ray of positive light and helped me tremendously during my stay at GF Strong and beyond. I'm sure that he touched more people's lives than we could ever count. Rest in peace, Brad.

– WILL

I feel lucky to have known Brad for so long. My heartfelt condolences to his family. His light, positivity and smile, his deep thoughts will be missed by all of us. I will miss running into him on the seawall and chatting in the sun. Rest in peace, Brad.

– SHERRY

My husband met Brad in 2012 at GF Strong. My husband told me Brad was a peer support person who was there to talk to and answer all of your questions, and that Brad talked about going on adventures with friends. These stories inspired my husband (who at the time had recently become a paraplegic). My condolences to his family, friends, peers and everyone he gave hope and self confidence to.

– MELISSA

My sincere condolences to Brad's family and loved ones. He left such an imprint in our hearts and minds.

– LARA

So sorry to read this news. The few times I met Brad he was such a generous spirit, sharing his knowledge and experience. My condolences to his family and friends.

– RENUKA

I am so very sorry and sad to hear this. I met this wonderful soul in 2008 when I was in GF Strong recovering from a motor vehicle accident that left me a para. He helped me understand life was not over for me and showed me that I could carry on. Brad, I will never forget you. I thank you for everything you have helped throughout your life. Rest easy, brother, and prayers to family and friends.

– SCOTT

This is heartbreaking news. Brad was a rock-solid supporting pillar in the BC SCI community. He was compassionate, funny, informative and reassuring, and a never-ending inspiration. Thank you, Brad, for all you've done for so many of us. You will be missed good sir! Peace, brother.

– EDWARD

Brad was an amazing human. He was one of the people I could count on to talk about anything when I was in GF Strong. He will be missed.

– COLLEEN

Wow, this is such sad news. Brad was such a sweetheart and I always loved chatting with him at GF Strong. Heartfelt condolences to his many friends and family.

– MELANIE

Such a huge loss to anyone and everyone that was lucky enough to get to know him. He was one of the most positive and inspiring people I know. Will miss your smile and charisma, Brad. Be free my friend.

– MARGA

Heartbroken and stunned last night to learn of Brad's passing. He made my world, and that of all he touched, a better place. He was one of my best friends in my tenure at SCI BC. I am richer for having known him; poorer for his absence. I will miss how he and that infectious, amazing smile of his could brighten up any room the second he arrived.

– DAVID

Brad will be so deeply missed. It was a truly a privilege to know him. The world will not be the same without Brad in it. Much love to his family and the whole SCI community.

– JENNY

Such a great loss for the SCI community! You will be missed, my friend!

– ROB

I'm incredibly sad for the passing away of such a great guy. We will miss you, friend. Rest in peace and my deepest condolences to the family and friends.

– ISAAC

This is such sad news. Brad was always so happy to see us on trips to GF Strong. Condolences to his family. He will be missed.

– LORI

Brad was pure sunshine and the world feels a little less bright without him in it. But throughout his life, his light shone so brightly in so many people's lives that his legacy will live on in all of us—his light will continue to shine forever. I thank him every day for being a very bright light in my life. I miss you, my brother. Shine on.

– CORY

I'm so sorry to hear of Brad's passing. He's the person that you never forget.

– FRANCEEN

I learned so much from Brad. Such an inspiring person who touched so many lives and helped so many through their darkest days. He dedicated his life to helping others. What a gift he gave us all.

– KAILEY

Brad and I went through rehab at the same time. He was a few years older than me so I always looked up to him during that eight months. He was optimistic, funny, charismatic, and always stylish. This hurts.

– JASON

I'm so sorry to hear this. Brad was such a nice person and always warm to chat with at GF Strong.

– SUE

He was the first person I met walking into GF Strong and I will always remember the good times and laughs we had. He was amazing. Thinking of his family and friends.

– LORI

Sad indeed. A wonderful human being. We will miss him.

– PATRICK

So sad. He was such a friendly guy and always greeted you with a smile. Gone too young.

– MÍLDRED

A great man and mentor to so many—kind, caring and just an amazing person!

– SIAN

Stimulating Change

Dr. Andrei Krassioukov's ICORD lab has taken a lead role in the global research effort to investigate neuromodulation's potential to improve the quality of life of people with SCI

In the last two decades, neuromodulation (sometimes called neurostimulation) to reawaken neural circuitry damaged during SCI has become a popular focus for many in the global SCI research community. Originally, it was hyped as a way of restoring walking function, but gradually (and thankfully) interest has shifted to its potential to improve function in key quality-of-life areas—for example, restoring hand, bowel, bladder and sexual functioning.

Originally, Canada wasn't an active participant in this global neuromodulation research effort. But over the last few years, that's all changed, as Dr. Andrei Krassioukov's highly-regarded ICORD lab has become immersed in this rapidly growing, promising line of investigation.

Many SCI BC peers and readers of *The Spin* know Dr. K, as he's affectionately known, as he might have been one of their physiatrists during rehab at GF Strong. But what readers—particularly younger readers—might not be aware of is that Krassioukov is recognized as one of our planet's foremost experts on AD, or autonomic dysreflexia, and other aspects of blood pressure regulation and cardiovascular health after SCI. His reputation in the field recently led to him being appointed to the position of President of the American Spinal Cord Injury Association, or ASIA, regarded as a leader in advancing SCI care, education, and research.

That a significant part of his lab's research efforts has been deployed to better understanding the potential of neuromodulation shouldn't be a surprise, as evidence has grown to suggest that neuromodulation is a safe and effective treatment for resolving the often serious blood pressure regulation problems that go hand-in-hand with SCI.

You'll recall that, in our last issue, we told you about Calgary scientist Dr. Aaron Phillips and his work to demonstrate how neuromodulation can resolve episodes of orthostatic hypotension, or OH, which are dangerously low blood pressure events common in people with SCI. Through an animal study and one clinical case study of a person with quadriplegia, Phillips demonstrated how a short course of neuromodulation can "reset" the blood pressure in OH—which can be so severe that just elevating from a prone to sitting position can result in someone losing consciousness as their blood pressure plummets. The promise is that, in the future, those who suffer from severe OH may be able to get to back to living a normal life with the assistance of a daily dose of neuromodulation.

Phillips is a former member of Krassioukov's lab, and his work in Calgary was an extension of what he began as a post-doc fellow working under the supervision of Krassioukov here in BC.

Recently, a current member of Krassioukov's lab led another exciting project to understand the potential of using neuromodulation to resolve blood pressure regulation issues after SCI. But where Phillips focused on low blood pressure, Dr. Rahul Sachdeva, a post-doc fellow who joined the Krassioukov lab in 2016, has been working with his colleagues to explore the potential for neuromodulation to stop dangerously high blood pressure in its tracks.

We're referring to AD, which affects many people with injuries above T6, and is quite common since it can be triggered by what appear to be seemingly harmless events—for example, simply initiating a bowel routine, or bumping your leg during a transfer.

In March, lead author Sachdeva, along with colleagues Tom Nightingale, Kiran Pawar, Tamila Kalimullina, Adam Mesa, Arshdeep Marwaha, Alison Williams, Tania Lam, and Krassioukov, published the results of their study in the journal *Neurotherapeutics*.

The essence of the paper, titled *Noninvasive neuroprosthesis promotes cardiovascular recovery after spinal cord injury*, is that episodes of AD can be completely resolved with a surprisingly simple treatment of transcutaneous stimulation, or TCS. Transcutaneous means that the electrical stimulation is delivered by electrodes placed over the skin, with no surgery is required. This is in contrast to Phillip's approach with OH, which relied on epidural stimulation in which the array of electrodes is surgically implanted on the spine.

Sachdeva and his colleagues reached their conclusions by first studying TCS in a rat model of SCI, and then following up with a single clinical case study of one person. Their goals were to demonstrate that TCS can prevent the onset of AD in the presence of the triggering event, interrupt and resolve AD that's already taking place, and, when used as long-term treatment, have a lasting benefit—in other words, a regimen of TCS will reduce the intensity or resolve AD even when the TCS is not being actively delivered.

"In rats with SCI, we show that TCS not only prevents the instigation of autonomic dysreflexia, but also mitigates its severity when delivered during an already-triggered episode," wrote Sachdeva and his colleagues. "Furthermore, when TCS was delivered as a multi-session therapy for six weeks post-SCI, the severity of autonomic dysreflexia was significantly reduced when tested in the absence of concurrent TCS. This treatment effect persisted for at least one week after the end of therapy."

The clinical case study portion of the paper describes how the team recruited a 37-year-old man with complete C4 quadriplegia to see if they could replicate the results of the animal study. Over the course of three sessions, the researchers carefully triggered a controlled, mild version of AD (safety was top of mind for the researchers) by stimulating the participant's rectum (digital anorectal stimulation, or DARS, is the most common way people with SCI initiate a bowel routine, but it's also one of the most common triggers of AD). As with the rats, one set of tests saw TCS delivered before the AD was triggered in order to see if it would prevent a bout, and another set of tests saw TCS delivered during a bout of AD to see if it would halt it.

In the first battery of tests, TCS delivered before the trigger event significantly reduced the severity of AD symptoms—for example, an 82 percent reduction in systolic blood pressure when compared to a bout of AD without TCS treatment beforehand. As well, when TCS was applied during an episode of AD, it reduced

PRESSURE POWDER

In the Winter 2020 issue of *The Spin*, we published a feature about Amicapsil—a naturally-sourced white powder that employs MPPT, short for micropore particle technology, to heal pressure sores. While we believe that Amicapsil, which was developed by the UK's Willingsford Healthcare, needs further scientific scrutiny, we opted to publish the story because the evidence to date suggests it can help peers resolve severe pressure sores that aren't responding to conventional treatment. Since we published the feature, we've heard from a couple of readers who have imported the product from the UK and have used it with impressive results. One reader says it has resolved a severe pressure sore that hadn't healed in two years. Have you tried Amicapsil? Did it work, or was it a waste of money? We'd love to hear from you. If we learn of a few more who have tried it, we'll publish a followup story in a future issue of *The Spin*. You can reach us at thespin@sci-bc.ca.

the severity by approximately 50 percent.

The ability of TCS to mitigate AD when used as a long-term "training" therapy was not tested in the clinical participant.

The takeaway message is that TCS was shown in this study to be really effective at preventing the onset of AD—and minimizing its severity when used to treat during an active episode of AD. This is remarkable in itself, but you can't help but feel even more optimistic about the prospects of TCS treatment for AD when you consider that it appears to be safe with no known serious side effects, unlike the various pharmaceutical treatments (which, based on these results, are also nowhere near as effective). And because it involves no surgery, it doesn't require the higher-risk surgical approach of epidural neuromodulation. Not only that, the prospect exists that a simple transcutaneous neuromodulation device could, in the future, be purchased by or provided to someone with SCI for a modest cost and used to treat AD—and perhaps a number of other SCI secondary complications like weak hand function and neurogenic bladder.

"We anticipate that TCS will offer significant therapeutic advantages, such as obviating the need for surgery resulting in reduced risk and medical expenses," wrote Sachdeva. "Furthermore, this study provides a framework for testing the potential of TCS in improving recovery of other autonomic functions such lower urinary tract, bowel, and sexual dysfunction following SCI."

And that's exactly what the Krassioukov lab are in the process of doing. Recently, in addition to new three-year funding to expand Sachdeva's TCS work in AD, it was awarded funding and received approval to begin three new clinical trials involving TCS. Krassioukov himself is the principal investigator of all three studies, and all three will take place at the Blusson Spinal Cord Centre.

The first is titled Below the Belt: Non-invasive Neuromodulation to Treat Bladder, Bowel, and Sexual Dysfunction Following Spinal Cord Injury. This study, which has been funded by the International Spinal Research Trust, is scheduled to begin this month. Approximately 40 participants will be recruited, with all work taking place at VGH and ICORD. The essence of this randomized study is that, following a regimen of TCS, improvements in the participants' bowel, bladder and sexual functions will be measured using a battery of industry-standard tests and questionnaires.

The second study, which is also underway, has a somewhat unwieldy name: Motor and Autonomic Concomitant Health Improvements With Neuromodulation and Exoskeleton Training: A RCT in Individuals With SCI (MACHINE). Funded by Praxis Spinal Cord Institute, this study, which is also randomized, involves using TCS and complementary activity-based therapy using a robotic exoskeleton to determine if the combination leads to improvements in standing and seated balance, as well as cardiovascular, bladder, bowel and sexual functioning. The study will recruit up to 12 participants, who will be tested to see if this therapeutic combination results in superior improvements.

The final study is industry-sponsored and will take place in many locations around the globe besides Vancouver. Titled Up-LIFT: Impact on upper extremities function, this study is funded by Swiss company ONWARD, makers of ARC Therapy neuromodulation systems.

The study's goal is to further evaluate the safety and effectiveness of ARC Therapy to improve arm and hand function in people with quadriplegia (several studies have already confirmed impressive benefits). It will seek to enrol 65 subjects at up to 15 sites in Canada, USA, UK, and Europe. About 10 will be recruited here, with recruitment scheduled to begin once UBC provides ethics approval.

What's interesting about this study is that, to ensure that the benefits observed in the study are directly attributable to TCS, all participants will first undergo a two month rehab program to regain and maximize their upper extremity function. Performance gains realized during this period provide a control that reflects the limits of conventional functional task practice without TCS. After that, a combination of rehab and ARC Therapy will then be administered over a period of approximately two months. At the end of the training period, improvements in function will be measured.

All three of these clinical studies provide a golden opportunity for qualifying readers of *The Spin* to contribute to this field via their participation (see page 32 for a recruitment notice for one of them). So it's not just BC-based researchers who are contributing to this local research effort—it's a great chance for SCI BC peers to get involved as well.

"Neuromodulation represents an exciting avenue for my patients with blood pressure dysfunction," says Krassioukov. "As a clinician, I am frustrated with the limited amount of pharmaceuticals that I can offer patients. Every single one of them has a lot of side effects. There have been no new drugs for 15 or 20 years. And it takes a long time to determine what the effects, positive or negative are. With neuromodulation, we get to see the results immediately. We can stop if there are side effects, and we can see very quickly how it is working or not working. With neuromodulation, there are less

The ARC EX nueromodulation system, developed by Swiss company ONWARD, will be evaluated by Dr. Krassioukov's lab to determine its effectivness for restoring arm and hand function in people with quadriplegia.

side effects and more benefits, and it is more controllable. So I will continue to do my best to attract funding here in BC for neuromodulation research."

But he adds a caveat—as promising as neuromodulation is, the results can't be rushed. Patient safety must not be compromised, particularly with neuromodulation that's using epidural stimulation and requires surgical implants.

"The problem I see right now is that some are claiming it's a panacea," he says, explaining that he knows of several Canadians with SCI who have travelled to other countries for spinal implants—and have since returned to Canada where our medical system is not able to offer the surgeries required (or fund them) when batteries need to be replaced or systems modified. "We need to support these patients, and that infrastructure is not in place at the moment."

These types of problems are one reason that all of Krassioukov's neuromodulation research will focus on non-surgical transcutaneous stimulation.

A great way to stay abreast of Krassioukov's work is to visit his ICORD lab web page (icord.org/researchers/dr-andrei-krassioukov). ■

ask the SPIN DOCTOR

Several peers have contacted us lately with questions about wrist pain and numbness resulting from carpal tunnel syndrome that have intensified as they age—and surgery to release it. We gleaned what we could from online sources and asked two of our peers who have also dealt with this to share their experiences.

Carpal tunnel syndrome, or CTS, is caused by pressure on the median nerve where it passes through the carpal tunnel, a narrow passageway in your hand. Symptoms can include pain, numbness, tingling and weakness in the hand and arm.

In the USA, research suggests that about five percent of the general population experience CTS. But for people with SCI (particularly paraplegia), it's a much bigger problem. Some studies say that up to 65 percent of people with paraplegia suffer from CTS. The reasons are thought to be repetitive motions of wheelchair use and frequent transfers.

To make a diagnosis, your healthcare team will rely on a physical examination, X-rays, and nerve conduction studies to see if nerve impulses are being slowed in the carpal tunnel.

Treatment may be as simple as stopping problem activities, cold packs to reduce swelling, wrist splints, use of NSAIDs such as ibuprofen, and cortisone injections.

When these treatments don't work, carpal tunnel release (CTR) surgery is the remaining option. The goal is to relieve pressure by cutting the ligament pressing on the median nerve. This can be done in two ways—open surgery involves making an incision in your palm, while endoscopic surgery relies on tiny incisions to insert a tiny cutting tool and camera into the carpal tunnel. Both procedures have the same risks as any surgery (for example, infection), but the prospect of having their independence compromised severely during a lengthy healing period is what worries most people with SCI.

However, it should be noted that there's a fair amount of research to suggest that CTR is very effective for people with SCI. In February, a study was published in the journal *Nature* by Swiss researchers. They analyzed 77 surgeries completed in 55 patients with SCI (the majority were paraplegics). Of the 77, 66 resulted in total relief of symptoms.

"SCI patients with CTS respond well to surgical decompression of median nerve regardless of level and type of spinal cord lesion and risk factors," they concluded.

We asked two of our peers, Sherry Caves and Kirsten Sharp, to tell us about their experiences with CTR surgery.

"I was encouraged for a few years by my neurologist due to my ongoing symptoms but also as I was advised by her to prevent nerve damage, as that can't be undone," says Caves. "Once I was agreeable and over my hesitancy, it was a straightforward process. The surgery takes approx 10 minutes or so, and when the freezing came out, my symptoms were gone—no numbness or any symptoms pretty instantly."

Sharp, who had endured symptoms for two decades, believes her CTR was successful, although she hasn't had quite the same results as Caves. "The pain got to be too much, and the doctor said that I could start to lose function," she says. "It still hurts and it's been a year. Yes, some of the pain has decreased for sure! I really thought all the pain would go away, but obviously there are some other nerves blocked."

As for what to expect in the days and weeks after the surgery, both admit the procedure makes it difficult to maintain independence—but that some careful planning can help.

"I was able to go home right after the procedure—I didn't stay to get help, and my mom was able to assist," says Sharp. "I mostly did my own transfers. For bowel and bladder, ensure you have a way to do this—for me, transferring on the toilet was as simple as changing to my spare toilet so my left hand (that I wasn't getting surgery on) was the front facing hand for transferring. I had help, and needed someone there for a couple of weeks. I didn't shower for two weeks, took sponge baths, and then I rented a lift for the bath. Putting pressure on my hand to get in and out of the tub was not possible. Direct pressure wasn't possible for about six weeks. Direct pressure that felt pain-free—that likely took about seven months. So be prepared, though obviously you can get around."

Caves shared many of the same challenges as Sharp.

"The first couple of days were the ones that I had to rely on assistance to transfer," she says. "Shifting my weight and trying to do things with only one hand was tricky on the first couple of days. But within two weeks, I was back doing most everything. Ensure you do your routine the morning of your surgery so you have some downtime before doing it again. Prior to the surgery, pay attention to all those actions that enable your independence. Think about all the movements using your hands and arms for your bathroom routine, and getting dressed. I would recommend preparing meals for a few days before you have it done."

As always, keep in mind that everyone's situation is unique, and that any diagnosis and treatment of CTS begins with consulting your own doctor and healthcare team.

Exercising Options

A unique multi-institution research collaboration here in BC continues to expand peer options for new and better cardio equipment—in the home and the gym.

For decades, a small handful of companies have been building and marketing arm ergometers. Until relatively recently, they've been about the only way people with SCI have been able to get a good indoor cardio workout. But let's face it—cranking an arm erg isn't the most exciting way to stay in shape.

A couple of years ago, four ICORD researchers, Drs Carolyn Sparrey, Bonnie Sawatzky, Ben Mortensen and Jaimie Borisoff, collaborated to develop the aROW—an adapted, wheelchair-accessible version of the popular, commercially-available Concept 2 rowing machine. The retrofit consists of a sup-

LEFT: SCI BC peer Derek Lunden enjoys the workout on PARC's aSKI. RIGHT: SCI BC peer Leo Sammarelli demonstrates the aROW. Both machines are based on popular and commercially-available Concept 2 fitness machines. (Photo credit: Cheryl Niamith, ICORD)

port arm with adjustable chest and lap supports, which is mounted to the front end the rowing machine, and removal of the original sliding seat so that a wheelchair user can simply wheel into place, set their brakes, and start working out.

Readers might remember that we first told you about the aROW in our Winter 2019 episode. Since then, it's been installed and tested in a number of settings, including PARC at Blusson Spinal Cord Centre. Anecdotally, users have reported that it's fun to use, and that it provides a more effective workout than an arm ergometer because it engages different muscle groups (including the trunk muscles, at whatever level the user has available) beyond just their arm muscles, which are often already overworked for those who use manual wheelchairs.

But anecdotes are hardly scientific. That's why the original team, along with student researchers from UBC and Dr. James Laskin from the University of Montana, decided to team up and attempt to quantify users' experiences scientifically via a formal comparison of working out on the rowing ergometer versus working out on a standard arm ergometer. Their work was summarized in the paper *Exploring exercise participation and the usability of the adaptive rower and arm crank ergometer through wheelchair users' perspectives*, which was recently published in the journal *Disability & Rehabilitation*.

Fourteen participants with SCI were recruited. They first completed a five minute workout on each machine. They then completed a semi-structured interview and a usability questionnaire. Participants were asked about their experiences using both exercise machines, as well as their general exercise participation.

The essence of the findings is this: while both machines were viewed as being highly usable, the rowing machine was perceived as being more enjoyable—and more effective for cardiovascular exercise. As for participants' exercise participation habits, all prioritized exercise as important for improved physical and mental health, as well as for functional independence and community participation, but a lack of accessible equipment was identified by all as a prominent barrier.

We asked Borisoff if there were any surprises in the results, or, given three or more decades of wheelchair users complaining about how boring arm ergs are, if the results were predictable.

"I think you're correct—any alternative to wheeling and arm cycles is a welcome change," he says. "Just think about the choices that able-bodied people have with ellipticals, steppers, bikes, treadmills, etcetera. But I was surprised at how difficult rowing is perceived to be compared to arm cycling. So hopefully it will be a more effective cardio exercise device, not to mention safer, being that the aROW requires the opposite motion of the overused motions of wheeling."

So now wheelchair users finally have a second option for indoor cardio exercise, after years of gruelling workouts on arm ergometers, right? Not so fast, because a third option has emerged as perhaps an even more intriguing and easily adapted form of cardio exercise. We're talking about the ski ergometer, which simulates the poling actions of cross country skiing—an activity that's recognized as one of the most complete workouts in existence.

In particular, the same company that makes the easily-adapted rowing ergometer, Concept 2, makes a ski ergometer that is remarkably easy to adapt for a

BCIT/ICORD researcher Dr. Jaimie Borisoff wheelchair user—in fact, it's even easier to adapt than the rowing machine. And so Borisoff and his team decided to develop aSKI.

"The aSKI concept emerged rather organically," says Borisoff. "We noticed a bit of chatter about it, and it started showing up locally. PARC installed one. Actually, an SCI doc, Dr. Stacy Elliott, showed me one in her local gym a couple of years ago, before we started working in this area. Then, after our experience with our aROW, it was very clear the aSKI was a very nice complement that would be even easier to adapt. In fact, for many people, it can be used with no adaptations. But we think a few minor things that we've already done for the aROW can make it even more effective."

Depending on the user, the adaptations range from simply lengthening the cables so that the exercise can be done from a seated position, to widening the base to accommodate the width of a wheelchair.

"We're also adding a lap pad that holds the front of you and your chair down," explains Borisoff. "We think it allows for a more intense exercise capability—by holding the chair more still and preventing any tipping backwards, or, at the very least, offering more stability and the perception of being secure while exercising. A key feature is that the lap-pad mechanism is easily swung aside so if it's not wanted or needed, it doesn't affect general use by anyone else who doesn't need the adaptation. This makes it a little different from our aROW, which is a more adapted device for use in a wheelchair or stationary chair."

Unfortunately, the COVID 19 pandemic has made testing the aSKI difficult.

"An early version is at PARC," says Borisoff. "But very few have used it. So it's early days for our aSKI development still." He adds that two of their students have just started a study to evaluate the aSKI, with data collection scheduled to start in September.

Meanwhile, Borisoff and his team will continue to tweak the aROW and aSKI.

"These are mostly small design improvements based on user feedback. We're trying to make it all more user friendly—for example, making it easier to adjust independently and quickly. And a big part of this phase is also about training—making material that is intuitive for users to get setup as well as possible, and creating a training protocol for fitness trainers and volunteers who work in places like PARC, so they can provide info to users, and help them get setup."

The Concept 2 ski ergometer can be used out of the box by some people with SCI, but the aSKI modifications (such as the lap brace shown) make it even more accessible.

The training protocol is being led by new team member and PARC Faculty Advisor Dr. Andrea Bundon.

As COVID restrictions continue to be used, the team will also begin to get the word out and make the new exercise options available to readers—getting more installed in adapted gyms like PARC, but also in mainstream gyms in the community and people's homes.

"We plan to equip at no cost a total of 16 sites with both an aROW and aSKI device, thanks to our funding from the Craig H. Nielson Foundation," he says. "These will be a combination of PARC-like and community gyms."

And because the combined cost of both the commercially-available device and the modifications is modest (in the same range as reputable stair climbers, ellipticals and stationary bikes for able-bodied use), Borisoff sees incredible value in promoting the aROW and aSKI for home installation.

"We're still figuring this out," he says. "As you know, it's perhaps the hardest part of assistive technology—getting devices to people that need them. Some is just education—for example, many can use a ski erg with few mods right now, if they knew they could. But for those who need modifications, the plan now is to team up within a community partnership framework in order to provide them at little or no cost, using an open source approach with volunteer help."

If it sounds like we're talking about Neil Squire Society, we can tell you that Borisoff and his team are in discussions with the society's Makers Making Change program to see this happen.

While Borisoff and other members of the team have been working on these machines for a few years, their enthusiasm hasn't abated at all.

"The most exciting part of all of this, and one that's still being researched, is that we believe both the aROW and aSKI may be more effective for long term fitness and health than traditional exercise options for wheelchair users," says Borisoff. "We're talking about cardio health, but also shoulder and upper limb health. At the same time, we're asking other questions. Is there an efficiency angle here, too? Does more bang for your buck time-wise and a more interesting workout mean that these machines would be more likely to be used long term, and thus provide even greater and longer lasting fitness benefits? Does the fact that they use the opposite motion to wheeling translate into better muscle balancing? And will this in turn lead to better trunk stability and balance, and translate to easier and safer daily living activities such as transferring?"

We're looking forward to seeing these questions answered. ■

Tough Pants

We don't know what's cooler—two new options for protecting the lower body of climbers with disabilities, or the collaboration that resulted in their creation.

The popularity of adaptive climbing, or paraclimbing, continues to grow. Organizations and groups are springing up in different locations around the world, and the International Federation of Sport Climbing (IFSC) has stated its intention to promote paraclimbing as a Paralympic sport.

Here in our country, the Canadian Adaptive Climbing Society (CACS) has emerged to steward the sport's growth. To date, it has chapters in Vancouver and Toronto, with more planned.

As CACS quickly discovered, the sport had a lingering problem: how do you protect the lower limbs and skin of climbers with SCI, who are often not only unable to prevent scrapes and bruises, but also can't feel when they're actually happening? There's no off-the-shelf solution. For example, knee pads—even the full length versions used by mountain bikers—don't offer enough protection.

CACS Co-Executive Director Brent Goodman wracked his brain trying to come up with a solution. That's when he thought of chainsaw chaps. They were ugly, orange and grease stained—but they offered full leg protection, were easy for chair climbers to put on and take off, and could be used with knee pads.

While effective, the chaps were far from perfect. They didn't prevent the climbing harness from pulling pants down at the waist and up at the ankles. They didn't keep the knee pads in place. And they weren't exactly stylish.

Enter SCI BC peer and avid climber Kevin Priebe. You may recall we featured Priebe and his new custom mobility manufacturing business, Society Wheelchairs, in a recent issue (Winter 2019). Priebe volunteered his time to work with Goodman on a number of improvements: changing the fasteners so that the chaps could tighten around the leg and hip more securely, adding grab loops around the knee for quick repositioning, and a stirrup around the ankle to keep the climbing harness from pulling them up. Then he worked with CACS to transfer all of these design features onto material that was even more durable than what's used on chainsaw chaps, and added climbing rubber to the knee.

It was a big improvement, and since they were easily put on, they could be used by different climbers. Perhaps the only drawback was that they didn't really offer a personalized (and stylish) solution for more serious climbers.

Last August, in a stroke of serendipity, a student at Kwantlen Polytechnic University's School of Design, made contact with CACS. Hanae Yaskawa was searching for a meaningful capstone project to help her graduate from the school's Technical Apparel Program, and had actually thought of an adaptive climbing pant even before she learned about the work CACS and Priebe had already done with the chaps.

Goodman agreed that Yaskawa's idea was a perfect fit. An agreement was reached, and work began with Yaskawa visiting Priebe to see the progress to date with the chaps, and researching other solutions developed by climbers around the world. She then worked with Priebe to develop a prototype. Meanwhile, another willing collaborator signed on with an offer of design and financial support—Arc'teryx, the BC-based high performance outdoor clothing and equipment company known for leading innovations in climbing, skiing and alpine technologies.

Late last year, the collaboration's efforts came to fruition with a finished prototype, which was appropriately dubbed Resilience. Since then, it has passed testing with flying colours. The goal now is to continue to refine the prototype in order to maximize the design and function and ultimately, make it available to climbers on a bespoke basis.

Yaskawa, who is from California, is hoping to continue living in Vancouver and working on Resilience—and transferring the technology to other garments that meet the needs of others in the para sport community.

Meanwhile, the chaps and the Resilience pants offer two new great protective options for climbers with disabilities.

"The main difference between the Resilience pants and the chaps is that the pants are designed for an individual person, and are something that they can own and come climbing with that fits their body type," says Goodman. "The chaps are intended to be a little more universal, where they can be used by one person while they climb, and then quickly removed so that another person can use them. We see this being very useful as a tool that a climbing gym could just have at their facility, as well as for us during group climbing sessions where there are multiple people who have not ever climbed before."

Goodman adds that the entire collaborative process has been amazing.

"I'm grateful for Kevin's eye for detail," he says. "He was able to take my initial vision from just a standard set of chainsaw chaps to a functional climbing tool. It has climbing rubber in key locations, it has pull tabs that make it easy to position your legs quickly and easily, and it integrates well with the climbing harness. I really believe that adding Hanae in on this problem-solving has resulted in two distinct products that address the same issue in adaptive climbing—protecting the lower body during climbing. I'm grateful for the Wilson Design School and Kwantlen Polytechnic University for effectively supporting the parameters of the collaboration."

If you've been waiting for your chance to climb, it's hopefully coming soon.

"We've decided to wait a little longer before we start offering any climbing," says Goodman. "This activity is challenging to keep socially distant, and requires a large ratio of volunteers to climbers. We will continue waiting until the situation is more favourable for group gatherings. Besides, climbing is all about community, and this is what makes our days memorable and fun. It's the support, the encouragement, and the relationships that are key for a good day out in the vertical world." ■

Above: Kevin Priebe climbing with the modified chaps. Right: Paulo Guerrero climbing a wall at the Hive Northshore with the Resilience climbing pants. (Photos by Nic Vissers)

Freedom to Roam

If you're contemplating exploring our province this summer, you'll find more and more accessible attractions and destinations—and our Access BC program is one reason why.

When Nancy Harris was appointed Regional Development Liaison for our Access BC program in 2016, she wrote a wish list of things she believed she needed to accomplish in order to achieve the program's goal of building or expanding accessible recreation experiences in BC. Building relationships, providing universal design training, conducting site assessments—just to name a few—were all included. But she quickly found she was missing a boilerplate to start work.

"There was a gap of information when we first started," Harris says, adding that, at the time, there were no standards or best practices for assessing and recording accessible information of outdoor and recreation areas in the province.

"Access means something different to everyone, so we had to create a tool that took that into account," she says.

This accessibility assessment tool—a detailed checklist of over 200 minimum standards for everything from the height of grab bars in pit toilets to the slope of trails—was completed and was immediately put to use to assess outdoor tourism and recreation sites across BC.

Since its first use in 2016, Harris and the rest of the Access BC team have relied on it to assess the accessibility of more than 500 sites and areas. The tool, as well as the team that uses it, has continued to evolve.

"Sometimes there were just a few of us in the beginning," Harris says. "But now it's a real team effort. It's a whole group of people and everyone is involved."

Assessing accessibility is just part of the team's work. Development of partnerships with five regional tourism associations throughout BC has been vital to the program's success. Five team members (four of whom have an SCI) work with these associations. Lori Slater liaises with the Northern BC Tourism Association, Sonja Gaudet with the Thompson Okanagan Tourism Association, Agasha Mutesasira with the Kootenay Rocky Tourism Association, Alison Duddy with the Cariboo Chilcotin Coast Tourism Association, and Harris with Tourism Prince George.

As an aside, we're grateful to our BC SCI Network partner, Neil Squire Society and its Working Together Program, for funding two of our team members, Slater and Duddy.

Every role on the Access BC team is a little different, but the overall goal is the same: collaborate with tourism partners to create and expand accessible and inclusive opportunities.

"Tourism isn't just doing this for people with disabilities," Slater says. "It's an economic driver. When people with disabilities visit these places, they don't come alone. They bring family and friends. It's going to make it easier for everyone."

Mutesasira, who is currently studying Hospitality Management at Vancouver Island University, is also a big believer in the partnership approach. "Hospitality is a really broad industry, but it's all about building relationships," she says. "People with disabilities aren't always heard that well, so to be a part of this work and to be visible in these spaces or to share knowledge is really important."

Similarly, Gaudet, a former SCI BC Peer Program Coordinator and Paralympic champion who has been with Access BC since 2018, agrees.

"Meeting our stakeholders and creating relationships with them while breaking down stigmas that

exist around accessibility and inclusion is the most gratifying part of this work," she says, adding that making personal connections helps puts an end to misperceptions.

One of the most important connections realized through Access BC's work has been with the University of Northern BC's Dr. Mark Groulx. As an Associate Professor for the School of Planning and Sustainability, Groulx believes deeply that outdoor spaces should be accessible.

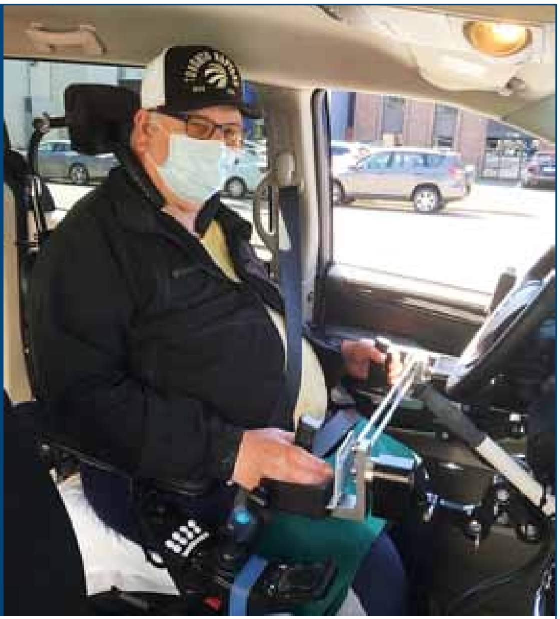
"One of the lessons we've learned during the COVID-19 pandemic is how important it is to have accessible outdoor spaces available to everyone," Groulx says. "Right now, persons with an impairment don't share equal access to these spaces."

Thanks to the Social Sciences and Humanities Research Council of Canada Partnership Development Grant worth $177,838 that was recently awarded to Dr. Groulx to support his research, this may change.

His research will involve working with Access BC to look at ways to synthesize Access BC's accessibility assessment tool into a standalone smartphone application and database that houses accessibility data for outdoor spaces. Operators of outdoor spaces, community groups or volunteers could use the app and database to identify what they need to measure and interpret the results. The data collected will be open for partner organizations to use and share with the public. With the introduction of the federal *Accessible Canada Act* in 2019 and the new *Accessible BC Act* that was introduced to legislature this spring, this work is more timely than ever.

"Seeing things come to fruition is so exciting," Harris says. "It means our work will be sustainable and embedded in communities. Strong communities are strong tourism, and communities start with relationships." ■

Sonja Gaudet, Access BC's Regional Development Liaison with the Thompson Okanagan Tourism Association, explores one of the tunnels on the accessible Kettle Valley Rail Trail.



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.

Exploration of Social Media Use Among Family Caregivers of Individuals with SCI

Overview: ICORD researcher Dr. William C. Miller, and his research team at UBC are exploring the main reasons for using social media among family caregivers of individuals with a SCI, and investigating the potential impacts of social media support and in-person social support on the well-being of family caregivers of individuals with SCI.

What to expect: The time commitment for the online survey is approximately 30 minutes, and the time for the optional phone interview is 45 to 60 minutes.

Who can participate: You may be able to participate in this study if you are a partner of family caregiver to an individual with a SCI; are able to speak and understand English; are living in Canada or the USA; are familiar with social media and have access to at least one social media platform; are caring for an individual who is 1.5 years post-SCI; and are caring for an individual who currently resides in the community (e.g., not a group home or assisted living centre).

Why participate: The findings from your participation in this study will contribute to the future development of resources to support caregivers' well-being. Individuals who participate in the online survey are given the option to put their contact information into a draw to win a $100 gift card. After the survey, individuals have the option to participate in the phone interview. Participants who choose to participate in the phone interview will receive a $30 token of gratitude for their time spent participating.

Location: The study will take place remotely (online survey/phone interview).

For more information or to sign up to participate: please contact the study coordinator, Somayyeh Mohammadi, by email (rehab.research@ubc.ca) or by phone at 604.734.1313 (extension 6292).

Motor and Autonomic Concomitant Health Improvements with Neuromodulation and Exoskeleton (MACHINE) training: A Randomized Controlled Trial in Individuals with SCI

Overview: Researchers in Dr. Krassioukov's lab are investigating the effects of activity-based therapy (ABT) with non-invasive (transcutaneous) spinal cord stimulation (TCSCS) on motor function, autonomic (cardiovascular, bladder, bowel, and sexual) function and quality of life in people with SCI.

What to expect: Individuals who are eligible to participate in the study will receive activity-based therapy and either (a) transcutaneous spinal cord stimulation (TCSCS) or (b) ineffective stimulation (SHAM) at three days/week for 12 weeks for a total of 36 treatment sessions. The study also involves six additional visits to conduct necessary screening and assessments. Overall the total duration of the participation is approximately 20 weeks.

Who can participate: ou may be eligible to participate if you are a BC resident with an active medical services plan, are 18 to 60 years old, have had a traumatic SCI for more than one year, have an SCI at or above T6 that is motor-complete (AIS A or B), weigh less than 300 lbs, measure between 5'2" and 6'2" tall, and have no clinically significant depression.

Why participate: By participating in this study, you will learn about various aspects of your health. The information we obtain from this study may improve our understanding of the effects of activity-based therapy and electrical spinal cord stimulation in individuals with SCI and lead to an alternative treatment for improving motor, cardiovascular, bowel, bladder, and sexual function. Participants in this study will receive compensation for their time and commitment.

Location: The study will take place at ICORD (Blusson Spinal Cord Centre), 818 West 10th Avenue, Vancouver

For more information or to sign up to participate: please contact Carolyn Barakso by email (barakso@icord.org) or phone 604.675.8856.

Learn more about what makes ICORD one of the biggest and best SCI research centres in the world, and the research they are doing, by visiting www.icord.org/research/participate-in-a-study

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The Final Frontier

Wanted: an astronaut with a disability

All humans who have ever broken free of Earth's gravity have had at least one thing in common: they have been able-bodied men and women in peak physical condition.

But as you read this issue of *The Spin*, a remarkable thing is happening: the European Space Agency (ESA) is screening applicants for the position of parastronaut.

Earlier this year, the ESA created quite a stir when it announced that, as part of a recruitment drive to fill four to six vacancies within the ranks of its astronaut corps, it would seek to ensure one individual would be someone who has a physical disability.

"In a first for ESA and human spaceflight worldwide, ESA is looking for individuals who are psychologically, cognitively, technically and professionally qualified to be an astronaut, but have a physical disability that would normally prevent them from being selected due to the requirements imposed by the use of current space hardware," reads a recruitment statement on the ESA website.

The rationale provided by ESA was that it sees direct benefits from introducing as much diversity as possible into its operations.

The recruitment process ran from March 1 to May 28, and the final selections will be announced October 2022.

"To be absolutely clear, we're not looking to hire a space tourist that happens also to have a disability," said Dr. David Parker, the Director of ESA's Robotics and Human Spaceflight Programme, during an event to announce the recruitment process. "To be very explicit, this individual would do a meaningful space mission. So, they would need to do the science; they would need to participate in all the normal operations of the International Space Station (ISS). This is not about tokenism. We have to be able to justify to all the people who fund us—which is everybody, including people who happen to be disabled—that what we're doing is somehow meaningful to everybody."

If this news has you polishing up your resume and dreaming of exploring the great beyond, keep in mind that the opportunity is only open to citizens of the member states of the EU. As well, the ESA's definition of an allowable physical disability seems to preclude people with SCI, although it's somewhat ambiguous. Here's what ESA's website states:

"The educational and psychological requirements for these candidates are the same as for the ESA astronaut selection. However, with respect to physical requirements, this feasibility project will allow the inclusion of candidates with the following disabilities:

- a lower limb deficiency, as follows:
  - single or double foot deficiency through ankle
  - single or double leg deficiency below the knee
- a pronounced leg length difference
- a short stature (<130 cm)"

You might also notice the words "feasibility project" in the above statement. And that's exactly what it is. At this stage, the selected individual would be part of a study intended to determine just what has to change in order to make space flight or a stay at the International Space Station (ISS) become a reality for a parastronaut. The project has a one million Euro budget, which the ESA will use to determine the logistics and adaptations to space vehicles and equipment, along with modifications to training and support programs, in order to ensure a parastronaut could safely and capably fulfill an actual mission.

So there is no guarantee that the recruited parastronaut would ever fly. But the ESA is adamant that this is not a PR exercise; that its ultimate goal is to see its chosen parastronaut carry out a mission.

Of course, ESA's primary partner is NASA, which has no immediate plans to follow suit with its own parastronaut recruitment drive. But recently, NASA provided this hopeful statement to CBC News: "NASA applauds ESA's emphasis on diversity and inclusion for its para-astronaut selection process and program. NASA shares a common goal with our commercial and international partnerships to make space fully accessible."

Besides having a suitable physical disability, candidates must be fluent in English with a good knowledge of a second language, and have a master's degree (or higher) in natural sciences, medicine, engineering, mathematics or computer sciences (or be qualified as an experimental test pilot).

The successful candidate will go into a reserve, with ESA then beginning work with its partners on the ISS to find the best way to fly a parastronaut.

"We did not evolve to go to space so when it comes to space travel, we are all disabled," says Samantha Cristoforetti, the ESA's only female astronaut and the current record-holder for the longest ISS stay by a European (199 days). "What brings us from being disabled to being able to go to space is just technology. This is a feasibility study and we're going to look into what exactly is needed, how much it will cost—but that's the goal." ■

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