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COVER PHOTO: Ed Milligan, Chairperson of SCI BC's Board of Directors (left), and Walid Qamishlo, SCI BC peer, take a spin together during one of our recent Adaptive Cycling Program workshops.



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GOT QUESTIONS?

How do I...



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Spinal Cord Injury BC

Paying for the Privilege of Peeing

To pee or not to pee? It's a question too many people in our province have to ask themselves on a daily basis.

This past May, I was pleased to see the provincial government's funding announcement about ending period poverty—the lack of access to menstrual products due to financial barriers. The funding will support a task force that will look into the factors that contribute to period poverty. It will also support continued delivery of free period products to those who need them.

I was pleased with the announcement for two reasons. One, obviously, is that this addresses a real need for many people in this province who struggle to afford period products and must make decisions about paying for these essential products or paying for other essential expenses, like food or rent.

The other is that the rationale for addressing period poverty is essentially the same one that needs to be made for ending a form of poverty related to another biological function—pee poverty.

Like menstruation, urination is not optional, but I suspect that most of the population assumes that, for everyone, the act itself is performed for free (except, perhaps, people who have travelled to some European cities and have been surprised that they need to pay to access a public toilet). However, as readers of this magazine are all too aware, those who rely on intermittent catheters do not pee for free.

As we have covered in many issues of *The Spin*, including this issue, the cost of catheters imposes yet another financial barrier and forces some difficult decisions for those who do not have adequate third-party coverage. One of those decisions is to re-use catheters that are designed for single use only. This decision comes with significant risks of urinary tract infections (UTIs) and possibly bladder cancer. Not only do UTIs negatively impact people's participation in daily life, they represent a heavy expense for our health system.

Is a task force on pee poverty needed? It couldn't hurt, but there's more than enough evidence being generated to support the need for equitable coverage and policies that address the inequities and barriers that the costs of catheters impose on people with SCI and others who are dependent on them to perform the most basic of biological functions. SCI BC is contributing to this evidence through collaborations with Canadian researchers and our provincial SCI Canada federation partners to understand the disparity in provincial policies for funding catheters and other essential supplies—and to support the case for removing pee poverty.

However, even without the evidence we are collecting, the case for providing equitable catheter coverage is intuitively obvious. After all, imagine how the public would react if they woke up one morning to a new fee that charged them \$3, \$5, \$10, or more every time they peed. And what they would have to give up or risk in order to afford to do so?



—Chris McBride, PhD, Executive Director, SCI BC



thespin

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Executive Editor..... Chris McBride
Managing Editor/Designer Cliff Bridges
Assistant Editor Alison Brierley
Editorial Support..... Sophie Ni
Administration..... Penaz Sidhu

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

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

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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

Fort St. John: Lori Slater, Peer Program Coordinator
T: 250.787.1912 E: lslater@sci-bc.ca
Greater Vancouver/Fraser Valley: Rod Bitz, Peer Program Coordinator
T: 604.500.2900 E: rbitz@sci-bc.ca
Metro Vancouver: Teri Thorson, Peer Program Coordinator
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
Nanaimo: Bert Abbott, Peer Program Coordinator
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
Prince George: Brandy Stiles, Peer Program Coordinator
T: 250.563.6942 E: bstiles@sci-bc.ca
Quesnel: Alison Duddy, Peer Program Coordinator
E: aduddy@sci-bc.ca
Victoria: Scott Heron, Peer Support Specialist
T: 250.812.0773 E: sheron@sci-bc.ca

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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 Selilwiltulh (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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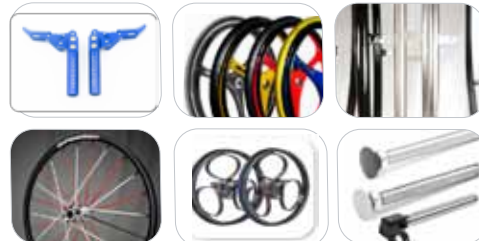
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SOREL EXPLORER BOOTS

SOREL has partnered with Zappos Adaptive to develop easy-on versions of three of its most popular boots. The SOREL Explorer Boot Dual Zip for men and Explorer II Joan Dual Zip for women offer a new adaptive double zipper design and an easy-to-grasp large loop on the heel that combine to make them easier to get them on and off for people with limited hand and arm strength. Meanwhile, the ankle-high SOREL Emelie II Chelsea Heel Zip features a single zipper and enlarged pull tab in the back that offer the same benefits. The SOREL Explorer Boot Dual Zip is available in men's sizes 7 to 15, while the Explorer II Joan Dual Zip and the SOREL Emelie II Chelsea Heel Zip are available in women's sizes 5 to 12. They're available exclusively at Zappos Adaptive—see zappos.com/e/adaptive for details.



WHILL MODEL FI

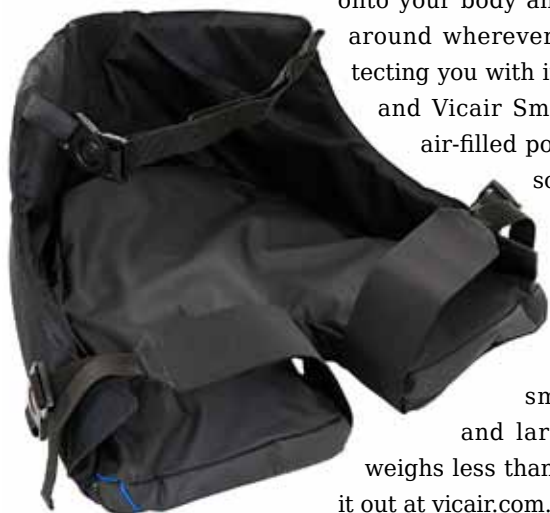
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Innovations

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

VICAIR ALLROUNDER O2

The Allrounder O2, made by Dutch wheelchair cushion manufacturer Vicair, has been around for a few years. But for those readers who are planning on another summer exploring our province, the Allrounder might be a timely piece of kit. It's ideal for those times when you want to get down to ground level (think camping or sports) and be active without risking a pressure ulcer-inducing bump or bruise. It's easily buckled onto your body and follows you around wherever you go, protecting you with its tough cover and Vicair SmartCells—tiny air-filled pockets that absorb shocks. To clean, simply throw it in the washing machine. It's available in small, medium and large sizes, and weighs less than a kilo. Check it out at vicair.com.



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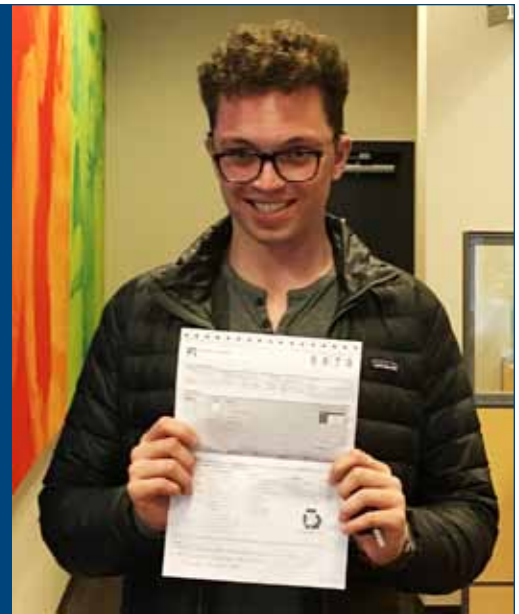
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When it comes to sex and spinal cord injury, we're all about kissing and telling.



SCIsexualhealth.ca

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

You can access the Sexual Health Rehab team online at **SCIsexualhealth.ca** or by phone at **604-875-4111 ext 69850**.



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Canada



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

A rugged shoutout to SCI BC's **ROD BITZ**, along with the rest of **BC'S DIVISION 2 WHEELCHAIR RUGBY SQUAD**, which recently won the divisional title at the Canadian national championships held in Montreal. In the title game, Team BC edged out a 41-38 victory over the Ontario Storm.

At 60, Bitz was the oldest player on the team. His teammates were **WILLIAM MCCREIGHT** and **JOSH HOLTON** of Kelowna, **TIANA HESMERT** of Richmond, and **ANDREW DAVIS, NATHAN BRAGG, JESSICA KRUGER** and **JULIA HANES** of Vancouver. The team was coached by ICORD doctoral student, Dr. Kendra Todd.

"The win in the final against Ontario can be chalked up to several factors," says Bitz, who lives in Burnaby and works as one of SCI BC's Lower Mainland Peer Program Coordinators. "We had a great game plan, great coaching and execution from the complete team. We were able to use the bench to either keep or regain a lead, and we had superb teamwork."

As for being the senior member of the team? "Fortunately, the aches and pains weren't too bad," says Bitz. "However, it takes a lot of rugby-specific training to keep up the speed and conditioning. Maintaining a certain level of fitness helps. It was an exciting tournament to have participated in for an old-timer!"



Peer Shoutouts

Shouting out respect to **STEPHANIE CADIEUX**, who resigned her position as a BC MLA in May to begin a four-year appointment as Canada's first Chief Accessibility Officer. In her new position, Cadieux will serve as an independent special advisor to Canada's Minister of Employment, Workforce Development and Disability Inclusion, and will provide advice on a wide range of accessibility issues, including continuing implementation of the Accessible Canada Act.

"I am honoured to become the first Chief Accessibility Officer today, and be part of the effort to create a barrier-free Canada," says Cadieux. "As an independent advisor, I will have a vital duty to provide a clear and candid view of the government's commitment to the inclusion of persons with disabilities. I am fully committed to support the meaningful change needed to achieve the full and equal participation of persons with disabilities in Canada."

We're proud to say that Cadieux started her career right here at SCI BC, where she co-founded our Peer Program and served us well as

Director of Marketing and Development. In an upcoming issue of *The Spin*, we hope to bring you an interview with Cadieux—we'll look for her reflections of her 13 years spent in public office as an MLA and a Minister, along with her thoughts on her new position and the challenges and opportunities it presents.

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.

A hi-tech shoutout to SCI researcher and peer **DR. JAIMIE BORISOFF**, who was just appointed Director of BCIT's MAKE+ research team—a multi-disciplinary research group that strives to support the creation of innovative technologies that contribute to BC's global competitiveness.

Borisoff certainly has the credentials for the position—he's both a neuroscientist and engineer, and is a Research Director at BCIT, the Canada Research Chair in Rehabilitation Engineering Design, a Principal Investigator at ICORD, and an Adjunct Professor at UBC's Department of Occupational Science and Occupational Therapy. He's well-known to our readers for innovations like the Elevation wheelchair and the AROW adapted rowing ergometer—and also for representing Canada for 13 years on the international stage as an all-star world champion and double gold medallist in Paralympic wheelchair basketball.

"I'm excited for the challenge, but at the same time cognizant of the expanded role and need to wear multiple hats, so to speak," says Borisoff. "Fortunately, I know we have a great team and I look forward to directing more projects that place the end-user at the centre of the innovation process."



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Free to Pee

A combination of research, advocacy and growing public awareness is helping to build the momentum needed to change inequitable funding and health practices for urinary catheter supplies across Canada.

If you ask most Canadians with SCI, along with others who rely on intermittent catheters for one of the most basic of human needs, they'll tell you that funding for them in most parts of Canada is unfair and short-sighted. But it's safe to say that the Canadian public, which takes for granted the privilege of peeing for free, has been in the dark when it comes to struggles endured by those who need to use catheters daily.

That may be changing. In late March, CBC News published and aired a comprehensive story about Chris Stigas, a Toronto quadriplegic who really took one for the team. He revealed deeply personal aspects of his life to veteran CBC reporter Rosa Marchitelli, explaining

how he can't afford the steep out-of-pocket costs for his catheters and collection bags, and so reuses them despite the fact that doing so puts his health in jeopardy.

The segment, part of the popular CBC News Go Public series, appeared on *The National* and was viewed (and read online) by audiences across Canada. The story pulled no punches and clearly spelled out the dilemma faced by Stigas and others with SCI—struggles to pay for safe supplies, intentional dehydration to avoid peeing, using cheap and unsafe equipment, and attempting to disinfect supplies over and over, all of which dramatically raise the threat of urinary tract infections, or UTIs.

This is likely the first time this issue has been publicized so widely to the Canadian public. We believe it won't be the last time. Through a combination of research and advocacy, we think this issue is gaining traction, and that Health Canada and their provincial counterparts are beginning to take notice.

NOT SO UNIVERSAL COVERAGE

The crux of the problem is this: SCI and its secondary complications, including urinary incontinence, are health issues and clearly fall under the domain of the Canada Health Act and Medicare, Canada's publicly-funded health care system. The Government of Canada, on its website, asserts that the basic premise of our

health care system is “universal coverage for medically necessary health care services provided on the basis of need, rather than the ability to pay.” But when it comes to funding catheters and other urinary supplies, coverage is anything but universal across Canada.

While the overarching responsibility for our universal health care belongs to the federal government, health care is administered by provincial and territorial governments. And they are certainly not on the same page when it comes to catheters and urinary supplies.

Just one province in Canada has close to ideal coverage, and that’s Saskatchewan (coincidentally, the home of our universal health care system). There, medical supply companies provide people with SCI with the high-quality supplies they need, and bill the government directly.

In other provinces, it’s a convoluted mishmash of coverage. In Ontario and Manitoba, for example, only people relying on social assistance have coverage

available. The situation is marginally better in other provinces such as Alberta and New Brunswick.

The situation here in BC is among the worst in Canada. If you were injured on the job, you get a free pass: Worksafe BC will cover all costs for urinary supplies. Other possible funding options include Veterans Affairs, ICBC, and private insurance. If you’re in a low income category or receiving social assistance, you may be eligible for some limited support. However, as many readers know, far too many people who need catheters here in BC have to foot some or all of the bill themselves. In other words, they have to shoulder the financial burden of what is a crippling fee to pee.

RESEARCH TO THE RESCUE

One likely reason that this situation has been allowed to persist for so long is that these differences in coverage from province to province are poorly understood. At the University of Manitoba, Dr. Kris Cowley is leading a project that

she hopes will shine a spotlight on the problem.

“We’re working on a policy-based and key informant interview-based assessment of the most important SCI-specific essential health needs across the country,” says Cowley, who is Director of the Spinal Cord Research Centre at the University of Manitoba and the Canada Research Chair in Function and Health After Spinal Cord Injury. “In addition to urinary supplies and coverage, we’re also trying to understand the differences between provincial coverage for neurogenic bowel supplies, wheelchairs, and home care for activities of daily living. We’ve done the policy review piece and the interviews, and have completed a preliminary report, which we’re distributing for feedback to SCI BC and its counterparts in other provinces.”

Cowley, who brings the added experience of living with an SCI to her positions, says the bottom line is that there are clearly glaring discrepancies in coverage across the country—but a



TAKING ONE FOR THE TEAM: SCI Ontario peer Chris Stigas revealed deeply personal aspects of his life with SCI to CBC News and the Canadian public from coast to coast in order to make his point about lack of funding for catheters. “Just imagine having to negotiate how many times you go to the bathroom based on how many catheters you have. Imagine having a urinary infection where the solution is that you have to drink a lot of water, but having to negotiate how many cups you can have because you don’t have enough catheters and you can’t afford what you need.”



Dr. Kristine Cowley, Director of the Spinal Cord Research Centre at the University of Manitoba

complete and accurate understanding of them is necessary in order to begin the process of pressing for change.

We'll get back to Cowley's research later in the story, but it's also important to note that a wealth of research concludes that single-use, hydrophilic (pre-lubricated) catheters are by far the safest option available, providing they are used as prescribed—in other words, just once, and never reused. In 2020, when the *Clean Intermittent Urethral Catheterization in Adults—Canadian Best Practice Recommendations for Nurses* was published, the authors (Nurses Specialized in Wound, Ostomy and Continence Canada; Canadian Nurse Continence Advisors; Urology Nurses of Canada; and Infection Prevention and Control Canada) considered this wealth of research and concluded, "A single-use, pre-lubricated catheter should be recommended for patients, especially those with repeated, symptomatic UTIs."

In Canada, no researcher has done more to promote the use of single-use, pre-lubricated catheters as a gold standard than ICORD Principal Investigator Dr. Andrei Krassioukov. In 2014, when the highly-respected journal *Cochrane Reviews* concluded that there was no disadvantage to re-using catheters, Krassioukov took exception. While work-

ing at the 2012 summer Paralympics in London, Krassioukov had observed that athletes who used catheters only once experienced three to four times fewer UTIs than those who reused catheters. Based on that and his own extensive clinical experience as a physiatrist, he assembled a team of international experts that reexamined the evidence and concluded that Cochrane was in error. Cochrane agreed—and subsequently retracted its analysis.

The Krassioukov lab continues its work in this area. In fact, it just completed a case study series to assess the damage to catheters after just three days of use. Not surprisingly, catheters showed damage and bacterial buildup, despite a relatively short amount of time and efforts to sterilize them after each use. You can read more in the sidebar on the facing page.

COSTS VS. SAVINGS

To summarize, single-use hydrophilic catheters are being increasingly accepted by clinicians as the gold standard, here in Canada and around the world. In France, for example, the health care system pays for all citizen's to use single use catheters—officials did the modelling and math and concluded that it was cheaper to implement and fund a single use catheter policy rather than pay the costs of

not doing so. So why aren't provincial health ministries in Canada taking steps to recognize this—and fund their use?

The obvious answer is cost. Most people who use catheters do so about five to six times a day. Single use catheters range from \$5 to \$30. So it's easy to see how governments are reluctant to add to already overburdened provincial health budgets. But their reluctance is shifting an incredibly unfair burden onto people with SCI and other conditions, many of whom are economically disadvantaged by virtue of their disability. The inequities here should be enough to prompt change. But there's a more powerful argument, which is simply this: reusing catheters leads to far more UTIs, and UTIs are incredibly expensive to treat—particularly more complex, recurring UTIs which require hospitalization and which people with SCI are prone to.

The exact cost of treating these types of UTIs is hard to pinpoint; one study we found was conducted in 20 hospitals in eight countries (Bulgaria, Greece, Hungary, Israel, Italy, Romania, Spain and Turkey) and involved 644 patients. The mean treatment cost per case was €5700, or roughly \$7,700. Even treating less complex cases of UTIs can cost as much as \$1,000. But this is probably too simplistic when it comes to UTIs in people with SCI, because they are often triggers for even more serious health complications. Consider, for example, that UTIs are one of the most common triggers of serious bouts of autonomic dysreflexia or AD, which can be life-threatening and require sometimes lengthy and costly hospital stays. As well, there's a well-researched correlation between recurring UTIs and the onset of bladder cancer.

There is no conclusive data to show how much money could be saved by our provincial health care systems if they were all to universally adopt a preventative approach of funding single-use, pre-lubricated catheters to everyone who needs them. But at the very least, it seems likely that this approach would significantly offset the cost, and perhaps even result in a break even of costs.

MAINTAINING MOMENTUM

Our hope is that increased public awareness, combined with more research that further underscores the dangers of reusing catheters and other urinary supplies, presents an opportunity for change. Dr. Cowley's study at the University of Manitoba, which will bring clarity to the disparities between provinces when it comes to funding this essential health equipment, may be the catalyst we need to begin the conversation in earnest.

"Education will be key to levelling what currently is a very uneven playing field across Canada," says SCI BC Executive Director Chris McBride, who, as Chair of SCI Canada's Executive Directors Council, is working with SCI BC's counterparts in other provinces to shed more light on and bring resolution to the situation. "All provincial members of the SCI Canada federation are pleased to be working with Dr. Cowley's team to ensure the final report is accurate and comprehensive. And when it's completed later this year, we look forward to helping ensure it gets the publicity and consideration it deserves, particularly from the federal and provincial governments."

Additionally, says McBride, SCI Canada and its members will collaborate with other organizations representing other users of urinary incontinence supplies, with the goal of furthering momentum.

"People with SCI are just one group of people whose basic health care needs are not being met by the current situation," he says. "For example, it's been estimated that a quarter of people who have MS rely on catheters. So we'll be exploring ways that we can share the workload of publicizing and distributing the completed report—and working with our health care authorities to bring some fairness to the existing situation."

Naturally, we'll be bringing readers more news on the report and our efforts to level the playing field in the months ahead—in fact, your voices and concerns may be vital at some point in the process, as Ontario's Chris Stigas has made abundantly clear. ■

Why does reusing catheters lead to UTIs?

There's no shortage of research that implicates intermittent catheter reuse as a cause of UTIs for people with SCI. For the most part, these are results-based studies—that is, they've compared incidence of UTIs experienced by people who have properly relied on single-use, pre-lubricated catheters with the incidence of those who reuse catheters, and it's the latter who are clearly more at risk. But this raises the question: why is this the case? What's the mechanism behind this elevated risk?

Recently, Dr. Andrei Krassioukov and members of his ICORD lab completed work on an interesting case study involving three SCI BC peers. The results have not yet been published, but were presented during the recent ICORD research meeting in the form of a poster titled *Short-term reuse of catheters is associated with microbiological and structural burden: a prospective pilot case series*.

The three participants (two women and one man who had lived with SCI from 24 to 48 years) were asked to clean and re-use polyvinyl chloride catheters for three days. Urine and catheter swab samples were collected on each day for microbiological analysis, and after the third day, all reused catheters as well as one new unused control catheter were analyzed via electron microscopy.

"Perhaps most surprising were the electron microscopy results, which showed structural damage to the biofilm of the catheter, and contamination by debris and bacterial growth, after just three days of re-use," says Dr. Tiev Miller, a postdoctoral fellow working in the Krassioukov lab who is coordinating this work as it moves forward. "This was an important finding, and suggests that damage to the catheter surface, accumulation of debris, and microbial growth may have progressively increased over the course of this relatively short trial—despite efforts to sterilize and handle the catheters carefully after each use."

In other words, even with the best attempts to maintain the integrity and cleanliness of catheters, they are quickly damaged and compromised.

Analysis of the swabs of the used catheters revealed that only about half were contaminated with colony-forming bacteria, and urine analysis did not find any elevated bacteria levels in the participants. But Miller believes this might be because of the short three day duration of the trial—which is why he and Krassioukov are seeking to run a larger trial with a longer duration.

"At the moment, we're trying to re-run this study with a group of 10 participants," says Miller. "But it has been challenging to move this portion of the project forward as it's quite difficult to find people with SCI who want to re-use the same catheter for three or more days, which is understandable. We are not endorsing catheter re-use either. On the one hand, it's good that the word is getting out about potential health risks associated with catheter re-use and that people are finding ways to adopt a 'one and done' self-catheterization practice. On the other hand, the only way to gain a clear understanding of the microbial burden associated with catheter re-use is to do a study like this."

If you have any interest in seeing this line of research explored more fully, Miller urges you to get in touch with the Krassioukov lab (see website info below).

"We're working hard to crack this case. We appreciate the support of the SCI community in helping to bring this project, and countless others, to fruition. It may seem like a small contribution, but every hour our participants dedicate to the research we conduct at ICORD brings us another step closer to changing health care policies that will improve peoples lives. Our evidence is only as strong as our numbers. The more participants we have, the stronger our evidence will be."

You can stay abreast of developments in Dr. Krassioukov's work, and express your interest in participating in this study or another of his lab's current studies, by visiting his website (icord.org/researchers/dr-andrei-krassioukov).

Stimulating Pleasure

Over the past five years, research has demonstrated that neurostimulation can lead to a number of important quality of life improvements for people with SCI, including better bowel and bladder function, arm and hand function, and cardiovascular function. Now it appears you can add sexual function to the list.

While the media continues to fixate on the ability of neurostimulation to restore some ability to walk after SCI, we've always chosen to write about its emerging promise to provide improvements in areas of daily living that people with SCI have long identified as their highest priorities—for example, the ability to use the bathroom in a more normal and healthier way, and the ability to grip and lift. Now, there's some good news about neurostimulation's benefits in another area of post-SCI life that we know is a high priority for readers—the ability to enjoy more normal sexual arousal and orgasm.

Despite the fact that, in survey after survey, people with SCI have repeatedly said that sexual function is among the highest of priorities, little research has been done in the area, and few therapies have been developed. One solution may have arrived in the form of neurostimulation.

Results from the E-STAND trial, an extensive, ongoing international project being led by Dr. David Darrow at the University of Minnesota, suggest that epidural spinal cord stimulation (ESCS) can improve the ability to experience genital arousal and orgasm in both men and women with SCI.

E-STAND, by the way, is an acronym for Epidural Stimulation After Neurologic Damage. Please remember that epidural stimulation is invasive and requires surgical implantation of an array of electrodes on the spinal cord, unlike transcutaneous stimulation, which is non-invasive and involves electrodes placed on the skin to target specific functions, spinal pathways, or organs.

E-STAND is attempting to determine benefits of ESCS in many aspects of SCI, but for the purposes of this story, we're concerned with a subset of 15 of the project's participants. Five women and ten men with complete thoracic injuries were implanted with a 16-contact stimulator at T11-T12. Over the course of 13 months, they underwent a regime of neurostimulation and reported their improvements in sexual functioning.

Preliminary results show that the treatment led to a better arousal response and orgasm ability for all participants, improved erectile dysfunction in most male participants, and reduced sexual distress by 40 percent in female participants (sexual distress is essentially described as frustration, anxiety, and worry regarding one's sexual activity).

A detailed analysis of the results from these 15 patients has now been started, led by ICORD Principal Investigator Dr. Andrei Krassioukov, an internationally-recognized expert in autonomic function after SCI, and a collaborator on the E-STAND trial from the outset. Assisting with this analysis is SCI sexual health expert Dr. Stacy Elliott, along with many members of Krassioukov's ICORD lab.

According to Dr. Claire Shackleton, a UBC postdoctoral research fellow who is coordinating this analysis at Krassioukov's lab, all the results are very encouraging—but perhaps none more so than the improvements experienced by the five women in the study.

"Not only is this work presenting novel findings on the effects of ESCS on sexual function in all people with SCI, but it's also highlighting sexual outcomes in an under-researched population—women with SCI," says Shackleton. "Despite rela-

tively promising treatments for men with SCI, there are limited treatment options for female dysfunction and a scarcity of research in this area, and women's sexual needs tend to be under-prioritized. Therefore, our team has recently analyzed the available data and completed a brief report on three female participants from the E-STAND trial. This report presents novel preliminary findings on the benefits of ESCS on sexual function and sexual distress in women with SCI. We're excited to be submitting this manuscript to a high-impact scientific journal in the upcoming weeks. And we look forward to analyzing the sexuality-specific data from E-STAND for all 15 participants on completion of the trial."

While the results are significant, Shackleton points out that the study is limited because of its relatively small number of participants.

"Additional large-scale investigations into sexuality and neuromodulation are warranted," she says. And she adds that expanding the scope of research to see if the same results might be obtained with transcutaneous neurostimulation is highly likely—which would make it easier to pursue larger studies.

"Currently, ESCS is an approved medical treatment (FDA and Health Canada) for pain management," she explains. "However, this is a costly option that also requires invasive surgery and highly-specialized technology to be implanted

into the individual. Presently, research is shifting more focus to non-invasive methods of spinal cord stimulation, including transcutaneous. There are advantages of transcutaneous stimulation—for example, it doesn't require invasive and costly surgery. Also, the electrodes can be freely moved to target different areas of the spinal cord. Several studies have shown that spinal circuits that are modulated by ESCS can also be modulated by transcutaneous stimulation. We also know that several studies on ESCS have shown improvements in bladder and bowel function—and the neural pathways that modulate these functions are in close proximity to those that control sexual organs. Therefore, it's likely that transcutaneous stimulation may too restore neural control related to genital arousal and orgasm in people with SCI; we suspect that the effects of transcutaneous stimulation on sexual function will mimic those of the ESCS."

The ultimate goal, says Shackleton, is to demonstrate the ability of neurostimulation to be used as a safe, widely-used treatment to improve a vital function in people's post-injury lives.

"Sexuality is recognized as essential to living a fulfilled life and one of the highest priorities for recovery after SCI. Therefore, developing therapeutic interventions for sexual function is one of the most meaningful recovery targets for people with SCI. Neuromodulation is a promising modality to treat sexual dysfunctions in people with SCI, and especially in women."

She cautions, however, that neurostimulation will likely be just one of many strategies required to make a meaningful difference in the sexual lives of women with SCI. "The complexity of female sexual function and the multiple influencing factors of sexuality will require a holistic approach to treatment involving a multidisciplinary team and complementary treatment such as cognitive training in mindfulness," she says.

We'll look forward to writing more about this promising avenue of research as developments occur. ■



Dr. Claire Shackleton

What's in your toybox?

Introducing some clever new sex toys designed to help people with disabilities maximize their pleasure

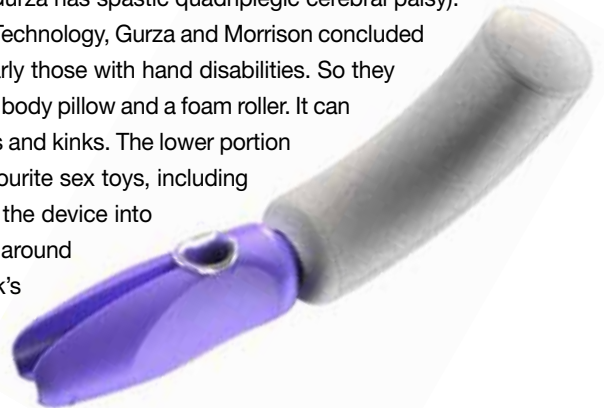
It's a promising sign that people with disabilities are increasingly being seen as sexual beings.

Sex toys have always been somewhat inaccessible for people with SCI and other disabilities—particularly those who lack arm and hand dexterity and strength. In the past few years, that situation has changed as more companies develop and market sex toys specifically for people with disabilities, many of which have been designed by people with disabilities themselves. And we're not just talking about vibrators like Ferticare that are typically employed as a clinical way to extract sperm from would-be fathers. We're talking about toys designed to, well, play with. Whether used solo or with a partner, these toys might just be your ticket to new levels of pleasure.

"Sexual devices to some might be an uncomfortable or overwhelming topic," says Shea Hocaloski, Sexual Health Clinician at Vancouver Coastal Health's Sexual Health Rehabilitation

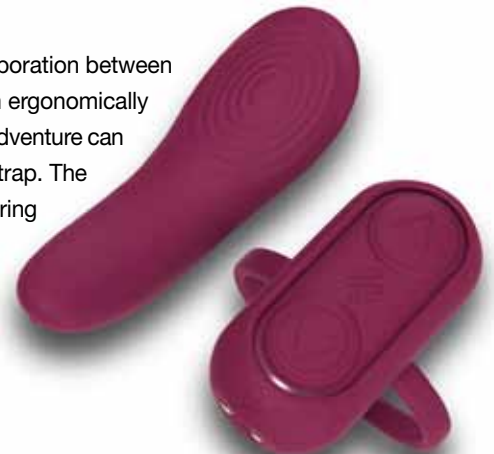
THE BUMP'N JOYSTICK, which was expected to be available as this issue was going to press, was designed specifically for people with limited mobility by Toronto-based siblings Andrew Gurza and Heather Morrison (Gurza has spastic quadriplegic cerebral palsy).

Through research conducted in 2018 with Australia's Royal Melbourne Institute of Technology, Gurza and Morrison concluded that few sex devices on the market meet the needs of disabled people—particularly those with hand disabilities. So they decided to develop the Bump'n Joystick, which they describe as the love child of a body pillow and a foam roller. It can be bent and flexed for different positions, genders, body types, preferences, needs and kinks. The lower portion has a variety of different sized and angled holes which will securely hold your favourite sex toys, including vibrators, dildos, wands and sleeves. With your favourite toy in place, you nudge the device into your ideal position with your arms and legs, and then cuddle into or wrap yourself around the top pillow portion. Once you've reached your hands-free conclusion, the Joystick's two halves can be taken apart for easy cleaning and storage. The Joystick adapter is roughly one meter in length and 30 centimetres in diameter. Visit getbumpn.com to learn more about this innovative sexual aid.



THE HANDY is a hands-free stroking device for men made by Sweet Tech AS of Norway. It's about the size of a standard flashlight, and has a powerful motor that moves an external sleeve up and down. Though the Handy isn't marketed specifically for people with disabilities, Sweet Tech says that it has developed The Handy with accessibility in mind, and the company's founders say they employ testers with disabilities. You (or your partner or personal care provider) insert your penis into the external sleeve with water-based lubricant, turn it on, and let the fun begin. The device's speed can be adjusted up to ten strokes per second, and stroke length can easily be adjusted to match the user. It fits all sizes, thanks to its unique TrueGrip system which can be adjusted to provide a firm grip, a soft touch, or to whatever feels right for you. A rechargeable battery provides power, and the device can also be controlled using Bluetooth and WiFi (that's right—even if your favourite partner isn't present, he or she can control your pleasure online). More details can be found at thehandy.com.

THE ADVENTURE PANTY VIBRATOR is part of the Quest product line, conceived by a collaboration between disability advocacy group Enhance the UK and British sex toy manufacturer Rocks-Off. It's an ergonomically designed rechargeable vibrator that fits against your body when placed inside your underwear. Adventure can be used independently or with the accompanying remote control that connects to a silicone strap. The control buttons on the vibrator and remote control are large and engraved into the surface, ensuring that they are easy to identify and navigate. Adventure offers 10 sensual settings combining both constant and pulsating vibrations, and its soft-touch silicone is body-safe and phthalate-free. The device is charged via USB with a magnetic snap contact. The Adventure, as with all Quest products, comes in sustainable, easily-opened packaging. This brand new toy is scheduled to be released in August—visit rocks-off.com for more information.



Service. “Although there is certainly no pressure to add them into your sexual life, they can be useful tools. They can add extra stimulation when sensation is decreased or absent. They can be used with or without a partner, and there are so many options on the market these days to suit your personal preferences. Sexual pleasure can potentially improve mood and pain tolerance as well as decrease spasms. Remember, however, that not everyone has the same experiences and that there are so many unique variables that can influence sexual pleasure.”

The toys on this spread don’t represent every accessible toy that’s available; we haven’t done an exhaustive search. But these toys, which have all been fairly recently developed and have been featured in the news, should give you an idea of how this market is slowly changing to meet your needs and desires, along with a few ideas of how to add some spice to your life.

Remember—if you’ve got questions about your sexuality or

need some help exploring it, help is readily available. Online, you can check out the scisexualhealth.ca website that our staff developed in collaboration with Vancouver Coastal Health’s Sexual Health Rehabilitation Service. And if you need more assistance exploring your sexuality as a person with SCI, the service’s highly specialized sexual health clinicians are readily available to you, or you and your partner. In a private appointment, you can ask questions, get information, and address sexual health concerns.

“To use these devices, an open mind and a sense of curiosity is necessary,” says Hocaloski. “If you’re interested in exploring this area a bit more, the Sexual Health Rehabilitation Service is a great resource to get you started.”

Appointments are available at either GF Strong or the Blusson Spinal Cord Centre. Getting a referral to the service is as easy as contacting the staff via the scisexualhealth.ca website.



Another offering from the Quest product line, the **ODYSSEY** has two components—the powerful Cookie Bean bullet vibrator, and a silicone accessory that allows it to be mounted on a finger and put to work without needing to grip it.

The Cookie Bean is for external use only, and will stimulate the most intimate areas of the female and male body—and can also be used to massage aching muscles. It offers ten sensual settings combining both constant and pulsating vibrations. The large control button makes the vibrator easy to operate, but the Odyssey includes a remote control to make the device even more accessible. It’s charged via USB with a magnetic snap contact lead, and is made from soft body-safe silicone. Like the Adventure, it’s expected to be available at rocks-off.com in August. Visit rocks-off.com for more information.

The U.K.’s Hot Octopuss created its line of Pulse male vibrators several years ago. Its latest version, the **PULSE SOLO INTERACTIVE**, was designed with input from disabled users. It’s unique in that you can use it with or without an erection, and with or without hands (which makes it ideal for men with quadriplegia). The flexible “wings” can be adjusted to accommodate a range of penis sizes, and to provide your desired grip strength. Once in place, the device’s raised, soft, coin-sized area oscillates your frenulum (the extra-sensitive spot on the underside of the head of your penis) at a variety of user-controlled speeds. You simply stay still, and let the intense oscillations do their thing. Power is provided by a rechargeable battery. As the name suggests, the Pulse Solo Interactive can be controlled by Bluetooth and WiFi. See the entire range of Pulse “guybators” at hotoctopuss.com.



Scottish sex-tech designer Tabitha Rayne didn’t create the first version of the Ruby Glow vibrator with accessibility in mind, but when she learned that it was being enjoyed by women with mobility impairments, she incorporated the input of disabled testers in her latest version, the **RUBY GLOW DUSK**. Like the first version, the device is a portable, saddle-style, ride-on sex toy that can be used hands-free.

With its saddle-style design, it stimulates the entire vulva and vaginal area, from clitoris to perineum (it’s for external use only). Two independent vibrating pads are operated by front-mounted controls, and power is provided from a rechargeable battery. Users can rock against the device, or enjoy without moving at all. This latest version also has a remote control with buttons of different sizes, making it easier to differentiate their functions by touch. Learn more at therubyglow.com.





The Fine Print

Just like SCI stem cell research a few years ago, there's a lot of hype surrounding neurostimulation. Now there's some concern that the complete story isn't being told—particularly when it comes to the online description and promotion of epidural spinal cord stimulation.

It's long been said that the devil is in the details. But sometimes, it's the lack of details that proves to be devilish.

At the recent 2022 ICORD research meeting in Vancouver, one of the poster presentations that caught our eye was titled *Getting lost in the sauce: A scoping review of publicly accessible web-based information on spinal cord stimulation*. It made a convincing case that many websites offering infor-

mation about neurostimulation aren't exactly being forthcoming when it comes to the potential pitfalls.

Neurostimulation (which is also known as neuromodulation, spinal cord stimulation, or SCS) is showing tremendous promise as a therapy to improve functional impairments associated with chronic disease and disability, including SCI. And while we're far from seeing widespread and approved use of different forms of neurostimulation as a treatment in SCI,

its promise is resulting in growing demand for information about it, not to mention growing public demand for the procedure itself.

The problem, says Dr. Tiev Miller, a postdoctoral fellow in Dr. Andrei Krassioukov's Autonomic Research Laboratory at ICORD and author of the poster, is that many online sources of information about neurostimulation are downplaying the risks involved—particularly with epidural spinal cord stimulation, which requires

invasive surgery to implant electrodes directly on the spinal cord.

"This review was conceived and initiated by Dr. Krassioukov and Dr. Rahul Sachdeva, who is a Research Associate in our lab, as a way of understanding what kind of information the general public is being exposed to with regard to the current use and application of spinal cord stimulation—transcutaneous, epidural, magnetic or others," explains Miller. "Ali Hosseinzadeh, a student at UBC, and I have been trying to extract and synthesize this information to see how comprehensive or fundamentally lacking it is overall. We're also trying to get an accurate appraisal of overall information quality—for example, whether or not the information is evidence-based—and find out what kinds of clinics, organizations, institutions and/or groups/individuals are authoring sites with SCS-related content."

The duo started the review by using Google Trends to identify the top search queries used world-wide in the last ten years. It turned out that "spinal stimulator" was identified as the top search term. Miller and Hosseinzadeh then used that term in the four most widely-used search engines (Google, Baidu, Yahoo, and Bing). This resulted in identification of 46 unique primary sites. Five were

What types of problems has the review discovered?

Dr. Tiev Miller says that, on the surface, there's nothing blatantly or overtly wrong with any of the sites he and his colleagues encountered in their online search and review.

"It's when we scratch a bit deeper that we see more of a subtle omission of critical information or the provision of potentially misleading information regarding the harms and hazards of these procedures," explains Miller, who provided us with a couple of examples to illustrate his concerns.

The first is nuraclinics.com. "This is a private clinic in St. Paul, Minnesota which offers ESCS and other implantation procedures, mostly for treating chronic pain," says Miller. "At the beginning of the neurostimulation page, implantation of the epidural stimulator is described as being similar to a cardiac pacemaker, which is misleading. The stimulation parameters and the target organs/tissues involved are very different. The aims and outcomes of these treatments are also different. If you look at the 'End of Procedure' section on this page, the last line states that 'After surgery, patients may experience mild discomfort and swelling at the incision sites for several days.' Here, the site authors are providing a mild post-surgical scenario while omitting all others—for example, bleeding, clotting, infection, dural puncture, spinal cord trauma, and others. The healing time is also vague: 'Wound healing may take up to several weeks or longer in some cases.' If this was meant to serve as a disclaimer, it should be more comprehensive. My intuition is that the authors don't want to deter potential clientele."

A second example is, surprisingly, a site hosted by a major US university—the University of Pittsburgh's Department of Neurosurgery (upmc.com/services/neurosurgery/spine/treatment/pain-management/stimulation). "This is another example of a site with vague or over-generalized descriptions regarding post-surgical considerations," says Miller. "What's surprising about this site is not that it's misleading, but rather that there is so little information provided."

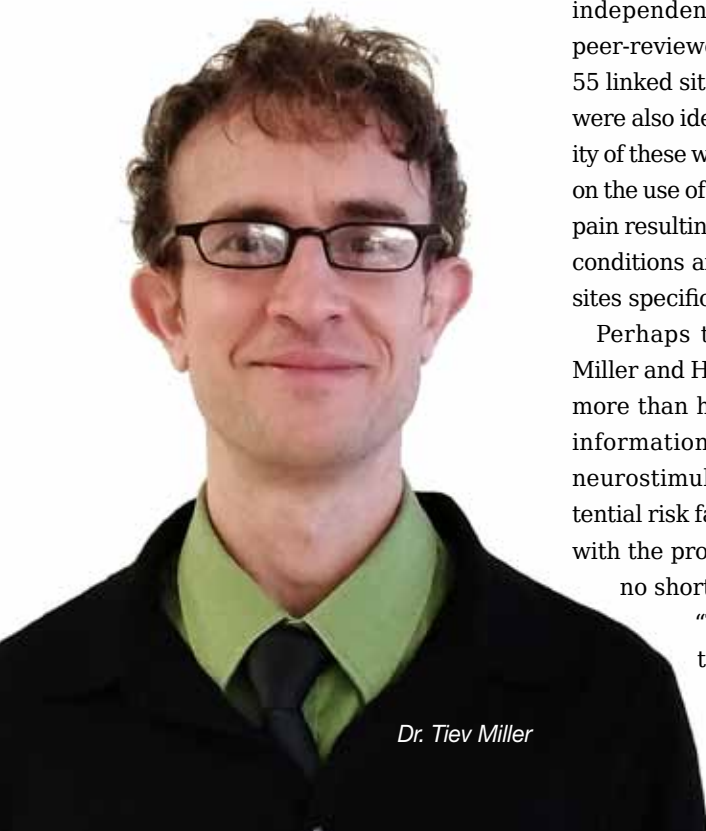
scientific resources, eight were non-profit sites, 17 were for-profit sites, three were news/media sites, and three were independent/blog sites, and ten were peer-reviewed journal articles. As well, 55 linked sites with additional resources were also identified. Note that the majority of these websites provided information on the use of neurostimulation for chronic pain resulting from a number of different conditions and diseases; there were few sites specific to SCI.

Perhaps the most disturbing trend Miller and Hosseinzadeh found was that more than half of all websites curating information on epidural, or invasive, neurostimulation did not describe potential risk factors and harms associated with the procedure—of which there are no shortage.

"There are a number of risks to consider with epidural stimulation," says Miller.

"Some issues are related to the surgery itself—for example, infection, trauma to the spinal cord or other tissues, bleeding, clotting, and wound healing. Others are device-related issues that may occur at the time of implantation or in the immediate post-op recovery phase—there could be damage, malfunction and failure. And long-term management after implantation is another important consideration. What is the likelihood, frequency, and severity of adverse side effects? What are the restrictions in daily life—for example, showering or certain types of physical activity? What's the battery life, rechargeability, required maintenance schedule, etcetera? Finally, is the implantation procedure, device maintenance, and long-term follow-up care affordable, covered by insurance or at least partially billable?"

While we haven't dug deep enough to be absolutely sure, we believe the an-



Dr. Tiev Miller

swer to this last question is, for the moment, no—at least for the vast majority of people.

All of this suggests that the public is likely to be exposed to incomplete or potentially misleading information about neurostimulation and, in particular, epidural stimulation, at a time when it's getting a lot of publicity. This raises fears of a rise of unscrupulous actors preying on people, evoking memories of the well-documented issues with stem cell tourism.

"This is a bit beyond the scope of our review but an important question nonetheless," says Miller. "It's important that members of the SCI community remain vigilant about the immediate and long-term issues they might face when returning from abroad. These clinics are out there and are just a few key strokes away. Take this site for example—veritaneuro.com/thailand-bangkok. It's published by a hospital in Thailand which offers ESCS implantation. If you look beyond the clean layout of this site and the eye-catching images, you'll find issues. SCI is lumped together with other conditions such as stroke, and there is no information about the potential harms of the procedures being offered. There's nothing cautioning people about the lack of support back here in Canada once the procedure has been done. Medical tourism is big business. Once the procedure is done, offshore providers are no longer liable for anything that happens to patients afterwards."

All of this begs the question: what's the best way to resolve this problem?

"I think it would be difficult, if not impossible, to regulate or restrict clinics from posting and curating misleading information—especially when there is big money to be made in selling epidural stimulation procedures abroad," says Miller. "As Bill Clinton once said back in the early 2000s, controlling the internet is like trying to nail jello to a wall and expecting it to stick. However, one way to circumvent 'bad' sites is by optimizing institutional and non-profit/advocacy organization sites that curate high-quality, evidence-based information. Putting more money into search engine optimization ensures that the 'good' sites will reach the top of the search engines' lists of hits."

As an example, Miller points to SCIRE (scireproject.com), which is led and managed by ICORD and UBC researchers, and was developed specifically to inform the SCI community—clinicians and researchers, as well as people living with SCI.

"Sites like these feature high-quality, evidence-based information on topics like neurostimulation," says Miller. "This site, and others like it, should be optimized so that they arrive at the top of the search results list. Of course, this requires extra funding and expertise in search engine optimization techniques. I think what is important, and something worth fighting for right now, is making sure the public has access to high-quality, evidence-based information on this topic."

The review of online information resources about neurostimulation continues, but Miller and Hosseinzadeh are hoping to wrap it up and submit it for publication later this year. ■



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Sticking close to home this summer? A healthy way to explore your community and province is adaptive cycling, which is why we've geared up our efforts to introduce you to the sport via our new Adaptive Cycling Program.

One of the lessons we've learned in the past two years is that, if we're forced to stay close to home because of high travel costs or the difficulties of traveling safely during a pandemic, embracing that big beautiful BC outdoors can help us stay mentally and physically healthy. And one of the best ways we've found to do just that is to explore the world of adaptive cycling, or handcycling.

Many peers have discovered that an adaptive bike that fits right and is well-maintained can provide years of exercise, adventure and enjoyment, with few additional costs beyond your initial outlay. And as a sport or recreational pursuit, it's one of few that lets you enjoy the outdoors alongside family and friends. And of course, cycling has no rules or schedules, and you can ride just about anywhere, from city streets in your neighbourhood

to wilderness trail networks in virtually every corner of our province.

But despite these benefits, we've heard loud and clear how hard it's hard to break into adaptive cycling. The equipment is expensive or not sold in local stores, and there's no place to rent or test drive an adaptive cycle, despite the increasing variety on the market. The result is often a poorly-planned purchase that gathers dust in a corner because the owner had no opportunity to try it or be properly assessed by someone knowledgeable.

For the average able-bodied person, finding a bike is pretty straightforward: visit a bike shop, where there's typically so much choice (and assistance) that they can quickly figure out what works. But for people with SCI, it's not that easy. What's the level and completeness of your injury, and how does that affect your purchase? Do you need adaptations like specialized

hand grips? How can you figure out what works for you when you can't just go and see what's available in one convenient location? What do you need to learn to ride the darn thing safely, and who can you ride with?

This year, we made a decision to get serious about breaking down that barrier. In the past, we've offered informal events to allow peers to give it a go. But we've taken that up a few notches with our new Adaptive Cycling Program.

"Adaptive cycling has been at the centre of a passionate conversation for many SCI BC peers, employees and board members for a long time," explains Jenna Wright, our Provincial Peer Program Lead and coordinator of the new program. "The pandemic seemed to free up some time to explore these conversations in more depth, and soon we found our Executive Director and our board of directors excited at the possibilities presented by a program like this. We got the green light to proceed, and we've been working very hard this past year—from email exchanges with similar programs in America, to partnerships created with community organizations—to create a program that really meets the needs of our SCI community."

That program is now up and running. Throughout the summer, it will offer numerous opportunities for peers to dial in a bike that works for them, learn to cycle, improve their skills, and join group rides with other cycling-savvy peers.

The program has two main components. The first involves finding an adaptive cycle that works for you. It begins with a fitting/assessment—a one-on-one meeting with a trained adaptive cycling instructor to help you explore the models and various options.

"Unfortunately, despite Vancouver being a bike-centric city, there just aren't adaptive bikes in the windows at the local bike shops," says Wright. "That's where this program comes in—our focus is to remove the barrier and allow opportu-

ities for people to test out a bike or two, be properly fitted to them, and receive instruction in skill development so that they can take that information and make a more accurate decision when it comes time to purchase their very own. Instead of going unprepared into such a big purchase, we're encouraging people to sign up for our program so they can get the feel of what bike they like, the set-up they like, what accommodations are needed for their level of injury, and whether they want the extra power from an e-assist."

Currently, we have a fleet of six bikes (see the models on the next page). "All the bikes have recently been fully serviced and three have been retrofitted with e-assist, which is a game changer for many," says Wright. "We're excited to be adding a Freedom Ryder and a Top End Force 3 into our fleet in the near future."

During your fitting/assessment, you'll dial in a ride, and explore the need for any adaptive equipment you need, like quad grips, pads to prevent injury, and straps to keep you stable and secure. Once you're comfortable with your cycle, you'll be able to try it out during a clinic. You'll ride in a safe, off-street area, where you'll practise pedalling, shifting, braking and using e-assist (if applicable). You'll also have the chance to learn from other more experienced cyclists.

At that point, you're free to move on to the second component of the program—

getting out on the trails in organized group rides. We offer several ability levels of rides at different times, so there's something suitable for every type of rider. Group rides will take place on off-street, protected bike trails with minimal traffic to contend with.

Peers with their own adapted cycles are welcome to join.

"We encourage veteran adaptive cyclists to join our clinics and group rides to share their experiences with adaptive cycles, how they made the decision to purchase, and tips and tricks that they've found most useful," says Wright.

This year, most fittings and clinics will take place at the Trout Lake Community Centre in Vancouver's Trout Lake (John Hendry) Park, located at Victoria Drive and East 15th Avenue. Trout Lake Community Centre has ample accessible parking off of Victoria Drive, and accessible washrooms are available during our fitting and assessment and cycling clinic sessions. As for group rides, they'll also be held at Trout Lake Park, although we have a couple of dates planned in Burnaby and Surrey, at the Central Valley Greenway and other locations. You can choose group rides that match your interest, location, and proficiency.

"We're essentially piloting the program in the Lower Mainland this spring and summer," explains Wright. "I think next summer, after we've fully vetted the pro-

gram and have it dialed in, we'll explore bringing our bike fleet to other areas of the province and offer the same programming to other SCI BC peers and family. But meanwhile, if you're a peer from anywhere else in BC, and you're interested in travelling to the Vancouver area to take part, we'll work with you on an individual basis to find and coordinate times that work for your schedule."

As for who can participate, if you have elbow function and can transfer with minimal assistance, we're ready for you. Some limited assistance will be available, and we'll also provide any equipment you'll need, including helmets, transfer lift seats, sliding boards, straps, pads, and brake and crank grip adaptations, including active hands gear.

You can start by registering for events at sci-bc.ca/cycling. There's a \$5 fee required to register for an event—this offsets our expenses for staff, volunteers, vehicles, community space and insurance, and reduces the possibility of no-shows. We'll be pleased to refund half of your registration upon request after you show up for your session.

One final note: the Adaptive Cycling Program is a team effort, and we'd like to thank our program partners at Hub Cycling, Cycling BC, and Chairstuff.

"HUB Cycling is a non-profit organization that strives to remove barriers to cycling in Metro Vancouver—what a perfect fit!" says Wright. "They've been interested in learning more about adaptive bikes, so our partnership includes helping them develop more accessible programming. As well, we discovered that getting insurance is a challenge of every adaptive cycling program, ours included. We were able to solve that problem by becoming Cycling BC's first recreational adaptive cycling club. And we're extremely grateful to Steve Milum, owner of Chairstuff and enthusiastic adaptive cyclist. Chairstuff has donated the majority of the adaptive bikes in our fleet, and we couldn't have done it without them." ■

sci-bc.ca/cycling



Our Adaptive Cycles

Our bikes include a variety of road/recreational handcycles and adaptive bikes to suit peers with a range of abilities and interests. Take a look at some of the models below.

1. GREENSPEED HAND MAGNUM

This recumbent handcycle has a fold-away crank boom, which aids to an easier transfer from your wheelchair. It has a tighter turning radius and an adjustable seat. Our Hand Magnum has been equipped with a 300W mid-drive electric assist. Learn more at greenspeed-trikes.com.

2. INVACARE TOP END EXCELERATOR

This trike is designed for the beginner recreational handcyclist. It's best suited for riders needing a level transfer from a wheelchair and higher visibility on the road, as well as riders with long legs or leg/joint flexibility issues. Learn more at invacare.ca.

3. INVACARE TOP END XLT

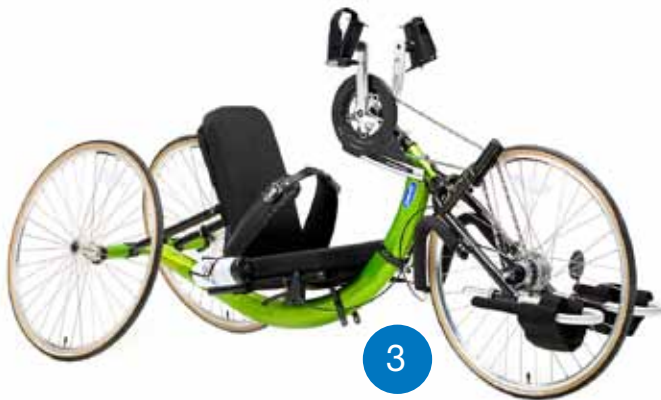
This upright trike is great for paved trails and touring. It has an intermediate seat height, and is very stable for riders with less abdominal control. We retrofitted it with electric assist with a coaster brake for easier control for quads. The XLT is faster than the Excelerator. Learn more at invacare.ca.

4. JEDD HANDCYCLE

This fun entry-level handcycle is best suited for the new, recreational rider with some trunk balance. This bike has lots of room for adjustment. Learn more from prairievelo.ca.

5. SUNSEEKER ECOTAD

The ecoTAD is a recumbent, foot-powered trike that's best suited for riders with adequate hip and knee function, such as those with incomplete SCI or MS. Our ecoTAD model has been equipped with 300W mid-drive electronic assist. Learn more at sunseeker.bike.





Accessing History

A partnership between SCI BC's Access BC and the Tse'K'wa Heritage Society is helping to ensure that the Tse'K'wa National Historic Site will be accessible for all.



The Tse'K'wa National Historic Site, formerly known as the Charlie Lake Cave archaeological site, is located in the Peace River basin, just outside Fort St. John in Northern BC. More than 13,000 years ago, a huge boulder broke off from a hill at the site, revealing a small cave and creating a 12-meter-long gully in front of it. Since then, the gully has been filled with layers of soil containing a wealth of indigenous artifacts, including a 10,500-year-old stone bead—the oldest example of human adornment in North America—along with spear and arrow points, harpoon heads, and bones from various animals, including bison and raven.

Despite its modest size, the cave and gully are considered one of the most

significant archaeological discoveries in North America, and Parks Canada designated it national historic site in 2019.

The site is a deeply significant cultural and spiritual place for the Dane-zaa people. Today, the site is managed by the Tse'K'wa Heritage Society—a unique collaboration of three Dane-zaa First Nations: Doig River, Prophet River, and West Moberly—and provides an opportunity for visitors to step into the past and learn more about its rich history, its importance to the area's First Nations, and its archaeological significance.

But there's one major problem—lack of accessibility.

Enter SCI BC's Access BC program, which aims to create inclusive and accessible spaces through universal design training, accessibility assessments, educational workshops, and key partnerships with tourism and government agencies throughout the province. When the Tse'K'wa Heritage Society began to consider infrastructure updates and renovations, they reached out to Access BC, in the hopes it could help ensure the site becomes truly accessible to all.

"We're finding this project a very unique opportunity because it's mostly a blank slate," says Nancy Harris, Regional Development Liaison for Spinal Cord Injury BC and the Access BC Lead.

Harris and several other members of the Access BC team visited the Tse'K'wa site in April, and have since provided recommendations to the Society on how to improve accessibility in ongoing infrastructure updates to the current building and surrounding land.

"We were given a broad overview of the areas they wanted to work on," Harris says. "There's so much that can be done from the ground up when it comes to accessibility. It's a really exciting project."

"The partnership with SCI BC and Access BC is an excellent opportunity to draw on the expertise of the people who know this subject best," says Alyssa Currie, Executive Director of the Tse'K'wa Heritage Society. "Their accessibility assessment is a great first step as part of that, and we're thankful to have the

funding in place to take this step."

Access BC's assessment is conducted using an auditing tool developed in partnership with the University of Northern BC. The final report includes best practices for entrance and exit routes, bathroom design, parking and more.

But Lori Slater, Access BC Team member and Access and Inclusion Liaison for the Northern BC Tourism Association, makes it clear that the accessibility assessment is not intended to dictate what happens next.

"We're not coming in and saying this has to be this way," explains Slater. "What will come from the report is best practices and recommendations with reasoning as to why we're making those recommendations. Making people aware and educating is important."

Slater and Harris are both quick to point out that education goes both ways—as visitors on the Tse'K'wa site, Access BC is learning about the geographical, cultural, and historical importance of the location, from past to present.

"We're learning about the value of the land and how it's so important, and the cultural part of importance," says Slater. "For me, it's a learning experience."

Perhaps most importantly, this unique collaboration offers a valuable example for others to follow.

"As a society, we really are looking more at access and inclusion, but people don't know where to start," says Harris. "The Tse'K'wa Heritage Society is looking at access and inclusion throughout this project and right from the start. So it will provide a great example of how other organizations and projects can move forward based on what's happening here."

Harris concedes that financial restrictions, community concerns and geography are all challenges when it comes to improving accessibility in some places, but says that recognizing

the importance of making accessible and inclusive spaces is the initial step.

"We will follow up for as long as we're needed to move things forward," she says. Currie adds that she couldn't be happier with the partnership and what it will bring to the site as work continues.

"We really feel this was of value—not only for us, but for the Fort St John community as a whole and the broader Treaty 8 region," she says. "We've started implementing several of the recommendations made by SCI BC in our infrastructure upgrades. Most notably, the board has approved an expansion on the first-floor bathroom renovations to ensure that this space is as inclusive as possible. We are also exploring grant opportunities to implement other recommendations made during the assessment process."

The Society hopes that renovations will be complete by 2024. We'll share updates on the work as it progresses. ■

Please visit treaty8.bc.ca/tsekwa or call 250.224.7906 to learn more the Tse'K'wa Heritage Society. For more information about Access BC, head over to our new Access BC webpages on the SCI BC website, where you can learn more about accessible recreation and travel in our province, take virtual tours, see photos and videos, and read highlights of Access BC's work over the past 15 years. Visit sci-bc.ca/access-bc.



LEFT TO RIGHT: Dr. Mark Groulx of the University of Northern British Columbia, Alyssa Currie of the Tse'K'wa Heritage Society, and Heather Lamb, team member of Access BC.

Reconstruction Zone

What can you expect as you recover from shoulder reconstruction surgery? We asked two SCI BC peers to share their experiences.

For wheelchair users, shoulders become the workhorses of mobility. It's a job they weren't exactly designed to do, as many peers have found out later in life when their well-used—and often overused—shoulders sustain painful, mobility-compromising injuries that require surgery.

The good news is that rotator cuff repair surgery is readily available in our health care system. Not only that, surgical techniques have greatly evolved over the past couple of decades—injuries once thought to be inoperable because of their severity are now routinely repaired with good rates of success.

There are, of course, many different types of injuries and many creative ways of repairing them—far too many to describe here. But they all have one thing in common: recovery is a long, painful process that requires approximately one year from start to finish. It starts with patients being virtually helpless from a mobility perspective. For the first six weeks, their arm must be completely immobilized in a sling with an abduction pillow. Gentle range of motion exercises are typically introduced after that, and gentle strengthening exercises follow. But patients remain restricted from doing any weight bearing activities for at least 10 weeks, and often as long as six months. That means zero transfers; zero pushing or wheeling. In essence, patients are one-handed for months.

After that, gruelling rehab sessions become the order of the day. Not only do patients have to build strength and range of motion in their reconstructed shoulder, they have to rebuild muscles that have greatly atrophied because of lack of use in the initial post-surgery rest period.

The bottom line is that surgery is the easy part of the process. However, beyond the pain and compromised ability of recovery lies gratification—patients typically report high levels of satisfaction as they regain the ability to use their shoulders without the debilitating pain that they often lived with for years prior to their decision to have surgery.

We know that many peers are considering this surgery, or are already on the list to have shoulder reconstruction. And so for this issue of PeerSay, we reached out to two peers who have had their shoulders recently reconstructed, and asked them about their experiences preparing for and enduring the lengthy recovery and rehab process. It's unlikely that their specific surgeries will be exactly like yours, but it's our hope that their accounts will give you some idea of what to prepare for. Our thanks to Debbie Richardson and Marnie Abbott for graciously sharing their stories.

DEBBIE RICHARDSON

Debbie Richardson is well known to many peers—she's active in our Lower Mainland community, and is the creator of the B.C. Paraplegic & Quadriplegics group on Facebook. Now 67, Richardson is an incomplete paraplegic who was injured in 1981.

She's had two shoulder surgeries. The first, which took place in 2008, was relatively straightforward and only took about eight weeks to heal completely. She spent the entire eight weeks in hospital, where she had all the assistance she needed during the time she was immobilized. The surgery was a success, and when she was discharged, she was able to quickly get back to her life.

But in 2018, she severely injured the same shoulder while transferring between toilet and chair.

"I could feel my left bicep and back of shoulder tear, and great pain like sharp knife tears—worst pain ever!" she says.

After two years of trying various therapies, she was examined by orthopaedic surgeon Dr. Farhad Moola, who booked her for shoulder reconstruction. That was in 2020.

This time, she didn't get off so lucky.

"The surgeon didn't know until the operation what he would find and have to repair," says Richardson. "It ended up being a far more complex surgery with many things needing to be repaired. He wanted me to stay in bed for five months. I didn't expect that—I thought it would be eight weeks like the first operation on my shoulder."

This time she wanted to recover at home, which her surgeon agreed to. She had prepared extensively for her recovery.

"I had two baskets on one side of my bed with extra pee bottles, leg bags, catheters, baby wipes, Kleenex, paper towel, blue pads, reading book, tablet, TV remote, tic tacs, cough candies, bag of chips, dry hair shampoo, pen, notepads, calendar, comb, brush, hand cream, bottle water, anything I use daily—was in my baskets so I didn't have to bother hubby for things all the time."

Despite her prep, Richardson says the recovery was gruelling, mainly because she had to stay in bed for five long months. But she says the situation was made worse because the home support she was counting in from Fraser Health home care was



substandard compared to her previous experiences. Workers failed to show up at scheduled times, or had little time when they did arrive. They didn't know how to assist with her bowel program or change her leg bag. And there was the ever-present threat of COVID-19.

"My husband was so upset with workers not listening to the care I needed that we cancelled after several weeks," she says. "My husband, who shouldn't have to, became my primary caregiver and even checked my bowels—not a great job for hubby."

Not surprisingly, Richardson recommends that, if you have the surgery and intend to recover at home, you need to check and double check that your home care supports are going to be adequate and in place.

"Make sure through your health unit that they know exactly what you need—particu-

MARNI ABBOTT-PETER

Marni Abbott-Peter is another well-known peer on the Lower Mainland. She's enjoyed an incredible career in wheelchair basketball, winning three Paralympic gold medals and four World Championship titles. She's lived with T4 paraplegia for 39 years.

Steadily worsening chronic pain in her left shoulder led her to seek medical advice.

"I actually think sports helped keep my shoulders healthy; it was when I retired from sport that I started experiencing problems," says Abbott-Peter, who is now 56. "MRI determined my shoulder joint had completely deteriorated due to osteoarthritis. The surgeon wanted to do the operation immediately, but I was afraid of the rehab and waited almost five years before finally agreeing to do it. I managed the pain with cortisone and

larly with bowel and bladder care," she says. "I set this all up before the operation, but the system failed me this time. Document everything that's been agreed to."

She concedes that some of the home care issues were likely due to the pandemic, and that her experiences with physio and occupational therapists were excellent.

"I had physio after eight weeks at home," she says. "Then I believe on the fourth month I started with occupational therapy, and started building the strength to start transfers, brushing teeth, washing up. I had to get stronger before starting to transfer to toilet and bathing. You will know when you feel safe to do those things. You will be weak, so have patience with yourself. The occupational therapist got us a portable lift so that my hubby could get me up three times a day, breakfast, lunch and dinner until I could stay up longer period of times."

Was it worth it? "Over all," she says, "yes, well worth it. Before you know it, you'll be back up and doing things again. My shoulder is good as new with no pain. I just have to be careful, which is hard sometimes; if you fall you automatically try to save yourself, thus tears happen then. If I ever think I have torn my shoulder again, because I am older, I would try to work with the pain if I could. But I would do another operation if it was painful like it was the last time, as you can't do much without it repaired."



Tylenol but it was getting increasingly worse, limiting my activity and making daily living a challenge."

Her surgeon, St. Paul Hospital's Dr. Jeff Pike, booked her in for surgery in September 2020. She knew exactly what her post-sur-

gery would entail. But her recovery plan was exactly opposite of Richardson's.

"I was adamant that I could not go home for rehab and had to advocate very, very hard, along with my GP and my surgeon, to get me into a facility post surgery," she says. "GF Strong would not take me as I was not acute, and there are very few options for people with SCI for post-surgical care or any other medical issues; they expected me to go home and there was no possible way that would work for me or for anyone else with an SCI. That was the biggest cause of stress throughout the whole thing—even going in on the day of the surgery, nothing had been decided, but my surgeon assured me they would keep me at St Paul's if need be."

Fortunately, she was admitted into Holy Family Hospital, a rehab facility for seniors.

"They had very little experience with SCI but were fully equipped for it," says Abbott-Peter. "I got excellent care there, I would not have managed without being there."

She says the first few days were an ordeal.

"I thought I was well prepared, but truly, it was like a hard punch in the gut," she says.

"In the first few days after the surgery, as I

was trying to manage with one limb, I was really regretting my decision. But my husband and my surgeon helped me through it, and once I got to Holy Family Hospital, I felt much more confident in everything."

That's not to suggest that the ensuing recovery and rehab weren't gruelling.

"It was a lot harder mentally than physically for me," she says. "With my background as an athlete, I was raring to go and had to really work hard to be patient and not do too much too soon. All of this was in the thick of COVID as well, but the docs, nurses and staff at Holy Family were amazing and so positive, it made it manageable. There wasn't much pain at all, the toughest part was the first week, once I was able to get up into a power chair and move around freely things were much better. I had to use a lift for all transfers and a power chair for three months. I was cleared to start using my day chair on after four months—that was a big transition and took some time to adjust to doing transfers with a sliding board. Once I mastered that, I was able to go home and continue my rehab there."

Her surgery was a complete success. "It was 100% worth it," she says. "I did not realize

the impact that daily chronic pain was having on my overall well-being. Surgery was tough, I admit, but certainly well worth it. I have one small scar across my pectoral and the front of my shoulder that is barely visible. My shoulder is strong and has full range of motion—it has no pain whatsoever and I am fully confident in using it. I am still gaining back my power and strength overall but there were a few factors unrelated to the surgery that impacted that, including getting a serious bout of the delta variant of COVID in 2021—which I still have some lingering effects from."

The single-most important piece of advice she has for peers considering shoulder surgery is fight for the right to do your first few months of recovery in a rehab setting.

"There is no possible way to do it successfully at home with home care or with a spouse or partner. That is completely unrealistic, and the surgery will be a waste of time. In fact, I believe that many surgeons will not even consider this type of surgery if you're a person with an SCI, mainly because of the poor rehab options available to them. This says a lot about some of the glaring holes in our medical system in BC and Canada." ■

Save energy & money

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

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

Call our InfoLine for more info:
1-800-689-2477

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

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



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



Striking a Balance

Challenging times are leading to mental health problems for some SCI BC peers. So how can you help yourself or someone you know? When do you know it's time to seek professional help, and where do you find it?

– Brad Hallam, Ph.D.

It's no secret that the past two years have been challenging for people living with SCI. In short, what's been good for controlling a pandemic—and staying infection-free—has not been good for mental health. Meanwhile, there's a lot of other bad news out there: climate change, mass shootings, war in Ukraine, inflation. Add your own personal struggles with relationships, family, health, function and finances, and life can feel overwhelming.

So, how do you know when feeling sad or anxious is part of the normal range of emotions, or if it might warrant clinical intervention?

Let's start by talking about the role of emotions in our lives. Rich neural pathways connect the emotional centre and the rational, planning parts of the brain—we're "hardwired" to integrate emotional information into decision-making. Feeling anxious alerts us to avoid danger; feeling sad alerts us to hurts or losses. We need these emotions to navigate the world. So, to be clear, the goal is not to eliminate anxiety or sadness. They are part of the full range of human emotions and function to keep us safe. Instead, the goal is to ensure they don't become overwhelming.

Humans have an amazing capacity to hold objects in mind, both for memory

and planning, and this is where things get complicated. Sometimes, we think about the world in exaggerated and unhelpful ways. Do you remember when you first heard the news that you had sustained an SCI? After the initial shock, your mind probably went in a thousand directions, from "I can beat this!" to "My life is over." Sometimes our minds can jump back and forth between extreme statements in a matter of seconds. These thoughts are like the string of a yo-yo attached to emotions that rise and fall. And from our thoughts come behaviour. When we think, "I can beat this", we choose behaviours like slamming a fist on a table, pushing beyond tolerance and hurting ourselves. And when we think, "My life is over", we choose behaviours like waving weakly with a passive, open hand, signifying that we feel resigned or defeated.

So again, the goal is to ensure your thoughts are calibrated to reality, and that they're balanced. Balanced thoughts don't involve seeing the glass half full (unrealistic positivity) or half empty (unrealistic negativity). Instead, they look at the whole glass. Returning to the original example, perhaps a balanced thought would be, "This injury has changed my life, and I'm going to work hard to move on and regain as much

function back as possible." The behaviours that flow from balanced thinking allow us to interact with the realities of our lives like a handshake. We take the challenge of our situation, both good and bad, and get to work.

MENTAL HEALTH CHECK-UP

If you visit a physician or psychologist to talk about mental health, chances are pretty good they will ask you to complete self-report screening measures. Search online for these measures and you'll easily find them for free on numerous mental health websites.

- PHQ-9 screening measure for depressive symptoms
- GAD-7 screening measure for anxiety symptoms

You can complete them at home as a mood check. Emotions cross the line into mental health conditions when symptoms from these measures are severe and prolonged. If your scores fall into the moderate and severe symptoms or if you have any indicators warning of self-harm, it's time to take active steps to work on your mental health.

HELPING YOURSELF

There are a lot of free, evidence-based "bibliotherapy" services available to help you manage your mental health. Some recommended sites include:

- Keltys's Key (keltyskey.com)
- Anxiety Canada (anxietycanada.com)
- CARMHA Antidepressant Skills Workbook (sfu.ca/carmha/publications/antidepressant-skills-workbook.html)
- CARMHA Positive Coping with Health Conditions (psychhealthandsafety.org/pcwhc)
- Centre for Clinical Intervention, Self Help for Mental Health Problems (cci.health.wa.gov.au/Resources/Looking-After-Yourself)

These resources are based on cognitive behavioural therapy, or CBT, which has a large body of evidence to support its use for treating depression and anxiety. The CARMHA resources can also be

downloaded as audio files, which might be helpful for individuals with limited hand function. However, if your mental health symptoms are severe, it can be hard to concentrate or find enough energy to effectively use self-directed, online resources. Instead, it might be time to reach out for help.

GETTING PROFESSIONAL HELP

You can start a conversation about mental health with any physician. Be intentional about adding mental health to the agenda for your physician appointments. You may be a candidate for medications, talk therapy or both. To find a psychologist or counsellor, you can ask your physician for recommendations or use a search engine like psychologists.bc.ca/find_psychologist, or counsellingbc.com.

The good news is that many mental health clinicians now offer telehealth sessions. The bad news is that there will likely be a wait time due to the toll of the pandemic on everyone's mental health.

More options for mental health clinicians in your area can be found at sci-bc.ca/counselling (our thanks to Willow Tree Counselling).

For some advice about how to critically evaluate the credentials of mental health clinicians, you can read this article: healthydebate.ca/2020/05/topic/talk-therapy.

Don't be shy about asking clinicians about their approach to treatment, whether they're part of a regulated college, about their experience working with clients with SCI or other chronic health conditions, and whether they offer a sliding fee scale based on income. It's worth the time and energy to find a safe and qualified partner for your mental health recovery.

HELPING OTHERS

Research coming out of Dr. David Klonsky's lab at UBC has highlighted the importance of social connectedness to emotional well-being and suicide risk. His laboratory has proposed that when physical and/or emotional pain exceeds social connection, individuals are at

greater risk for depression and suicide. Furthermore, rates of depression in SCI are correlated with the number of hours spent outside the home. Perhaps the take home message here is "get out and get connected." Recognizing that there can be many barriers to this "simple" equation when it comes to SCI, one good approach is to work with your SCI BC community to see if they can help remove barriers preventing people you're concerned about from getting connected.

Now that public health orders have loosened, and we're finding a rhythm with a new normal, it's time to take stock of your SCI peers. Is there someone you haven't seen in a while? Do you know someone who is isolated or dealing with severe, chronic pain? A first step in getting them out and connected may be checking in over Zoom, phone or text. Remember that social withdrawal is a symptom of depression and anxiety. Some people may not be reaching out because they are struggling emotionally, not because they don't care about you.

WHAT ABOUT A CRISIS?

If a friend's words or actions suggest they intend to end their life, it's time to get help. Here are a few things to keep in mind if this is the case:

- Don't be afraid to talk about it with your friend. Talking about suicide does not increase the risk. If anything, it helps reduce the isolation the person is feeling.
- Don't agree to keep secrets. It raises the anxiety of the secret keeper and it is an unfair burden.
- Share the worry with a physician, psychologist or qualified mental health clinician who can assess the person's risk and connect them to appropriate intervention services.

An excellent resource for a suicidal person or their support person is the SAFER program—a free time-limited counselling service offered at Mental Health and Substance Use Outpatient Services at Vancouver General Hospital. Call the Access and Assessment Centre at 604.675.3700 to connect with SAFER.

Additionally, the Access and Assessment Centre, located in the Segal Building at Vancouver General Hospital, will accept self-referred patients and see them the same day. The Centre can also speak to concerned family members or friends to provide guidance about whether the person would be better assessed by their clinic or the emergency room. Ideally, all of this would be done with your friend's knowledge and cooperation, but if they're resistant and you feel the risk is imminent, you can take your friend to the emergency room or dial 911 to request an emergency mental health evaluation.

Remember, you can call 911 anywhere in the province, at any time of the day or night. Another province-wide option is calling 1-800-SUICIDE (800.784.2433) to speak with a trained crisis line worker. This 24-hour service is provided by the Crisis Line Association of BC, which also offers non-crisis information and support—call 310-6789 to reach the Mental Health and Information and Support Line, from anywhere in the province. You will receive emotional support, and information on appropriate referral options to address mental health concerns.

Finally, you can also call HealthLink BC toll free at 811 if you need non-emergency mental health information or advice. This is available 24 hours a day. ■

Dr. Brad Hallam is a registered psychologist, a board-certified neuropsychologist, and a Clinical Assistant Professor at UBC's Division of Physical Medicine & Rehabilitation



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.

EPIC-SCI: A Randomized Controlled Trial

Overview: ICORD researcher Dr. Kathleen Martin Ginis is evaluating the effects of following the *International SCI Exercise Guidelines* over the course of a six month period. Participants will be randomly allocated to one of two groups. One of the groups will follow an exercise program. The other group (the control group) will be asked not to change their daily lifestyle. After six months, the control group will have the opportunity to enjoy the exercise program.

What to expect: The exercise program consists of two to three hours of exercise per week, at home or in a local fitness facility. The study involves three visits to the testing site as well as questionnaires that will be filled out online or over the phone. During each visit, participants will be asked to complete fitness tests, participate in a brief test to see how the body responds to pressure and cold stimuli applied to the arm, and provide blood samples.

Who can participate: You may be eligible to participate in this study if you are 18 or older, have been fully vaccinated against COVID-19, have been diagnosed with an SCI more than one year ago, have an injury level at C3 or below, experience chronic pain, participate in less than 40 minutes per week of structured, moderate intensity, aerobic exercise AND less than two bouts per week of strength training, and have no medical contra-indications.

Why participate: Through participation in the study you will learn what your peak oxygen uptake is, in addition to your current levels of muscular strength for major muscle functioning groups. Although there are no other guaranteed benefits, you may get fitness and cardiometabolic health improvements associated with exercise, which may lead to sustained exercise adherence. You will be compensated a flat rate for travel to the testing site.

Location: The study will take place in the Okanagan and Vancouver, but is currently recruiting at the Blusson Spinal Cord Centre site in Vancouver only.

For more information or to sign up: contact Bobo Tong at bobo.tong@ubc.ca or 778.581.6487, or visit icord.org/studies/2021/11/epic-sci.



How do wheelchair platform lifts work for you?

Overview: ICORD researcher Dr. Jaimie Borisoff and his team at the British Columbia Institute of Technology have created an online survey to get feedback about your experiences using stair lifts, enclosed lifts and unenclosed lifts in Canada. As a part of the survey, you'll have an opportunity to submit videos or photos of you using a lift to help us better understand the issues you describe in the survey.

What to expect: The online survey will take 10 to 15 minutes to complete.

Who can participate: You are invited to participate in this online survey if you use a wheelchair or scooter as a means of mobility AND have experience using platform lifts in Canada (note that this does not include elevators or lifts in vehicles).

Why participate: Your contribution will be summarized in a report to the Canadian Standards Association (CSA) with recommendations for improvements to the standard (B355), which controls how wheelchair lifts are designed, installed, and maintained. We anticipate this will lead to some positive changes in the accessibility and usability of these devices. As a thank you for participation, we will enter your name in a draw for one of three \$100.00 pre-paid Visa gift cards.

Location: Online survey can be completed by anyone with a qualifying mobility disability living anywhere in Canada.

For more information or to sign up to participate: please visit the survey website (ca.research.net/r/bcitiifts), or contact the study coordinator, Angie Wong, by email at Angie_Wong@bcit.ca or phone (604.451.6934). Further details are also available at icord.org/studies/2022/04/platform-lifts.



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

Words Matter

Have you ever wanted to explore writing in a safe, supportive and non-judgmental environment? SCI BC's Virtual Writing Group might be just what you're looking for.

— Lisa Hislop

Have you ever been around something for so long that you no longer see it? For me, that something was editing. I spent my childhood laying waste to shelf after shelf of books, grew up to major in literature, and then went on to write for non-profits, which often involved editing other people's work. But editor as a job title or career flew under my radar.

In fact, it wasn't until I was in the midst of a late-in-life career change that I noticed the role of the editor in literature making, and that I could become that editor. After a bit of research, I learned there isn't even a degree program for editing, just an unassuming Continuing Studies certificate at SFU. Literature, language, and rules attracted me to the field, but the mystique of invisibility sealed the deal. I had found my forever job!

It took me just over a year to devour two years of coursework, and another year and a half to find my footing as



a freelancer. Today, I'm a professional editor specializing in short stories, collections and anthologies. And I also have a secret editing life in which I use my skills to help disabled self-advocates tell their stories.

This last venture is thanks to SCI BC and COVID-19. As a fairly introverted autistic person, I was quite at home with my dictionaries and style guides in quarantine. But when SCI BC announced

its online programming early in the pandemic, I couldn't resist the allure of the online book club. So I joined. And when they needed a volunteer to keep the group going, I was nominated.

Here I am, a year and a half later, hosting not only the online book club, but also a recently-formed monthly virtual writing group.

You heard it. A writing group. We're just three meetings in, but already we're a small, thriving collective of aspiring writers who share our works-in-progress and give supportive feedback to each other every first Wednesday of the month, all via Zoom. We encourage each other to write more, and—gulp—send our writing out into the wild world of magazines and literary journals.

Have you ever thought about writing? What would convince you to try? It might help to know that publishers are very interested in hearing under-represented voices right now. Readers are craving better representation in the industry and in literature. Now is a very good time to put pen to paper (or Dragon Dictate to screen). Even if you've never written anything or have nary the spark of an idea, come hang out in our monthly group. Listen to us read and talk about how to strengthen our writing. You'll leave with a dose of our complementary post-writing-group inspiration and perhaps an urge to return next month with your very own piece to read to your new literary-minded friends. ■

Your guide to spinal cord injury from the people who've been there...

LivingwithSCI.ca





BC SCI NETWORK

The BC Spinal Cord Injury Network helps make BC the best place for people with physical disabilities to live, work, and be active.

Ean's Journey

As a successful entrepreneur and all-around active guy, Ean Price requires a ventilator to breathe and has limited mobility that requires extra support. "I only have the use of my thumbs. And that's how I control my wheelchair and my computer," he explains.

Seeking resources to help him with these aspects of living with a disability, he learned about the BC SCI Network and is now a regular participant, partner, and volunteer with programs led by the Neil Squire Society, the Disability Foundation, and Spinal Cord Injury BC.

Through the Tetra Society of North America, an affiliated society of the Disability Foundation, Ean has been the recipient of a number of innovative products. "The shower chair that I use when traveling was built by Tetra volunteers ... I wouldn't have the confidence in the equipment that I'm bringing [without Tetra]," he says. In addition, Ean often works with Neil Squire's Makers Making Change program team to test out new devices like the LipSync, a mouth-operated computer joystick that allowed him to get back to work quickly and connect with friends and family after an arm injury.

As a volunteer with SCI BC, Ean hosts an online group for peers with disabilities. "We talk about real life problems; good things, bad things, and simply talk about life. And the objective is to help create a safe space where people can talk about anything and share their stories, experiences and help one another," he explains. He adds that the Network is "a strong component of a bigger picture of the entire network of services available for people with disabilities ... without these five [organizations] that would be a huge piece of the puzzle missing."

sci-bc.ca/BCSCINetwork



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— Crystle

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— Kevin

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STEVE MILUM
Founder & CEO
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