

# the spin

SPINAL CORD INJURY BC

WINTER 2022

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Spinal Cord Injury BC

**COVER:** West Kelowna's Anand Kannan enjoys his workout at UBC Okanagan's excellent accessible gym. In 2020, Kannan became one of the EPIC-SCI trial's first participants, and he continues his love of exercise to this day. Photo by Kenedy Olsen, SCI Action Canada.

# Great Advice From a Plumber

A good friend who builds houses once passed along some insight about how to tackle a problem for which a solution is not obvious. He learned it when contemplating a particularly daunting challenge with framing in a shower. His plumber noticed him agonizing over his options, and simply said, "Sometimes, the hardest part is the looking at it." My friend then proceeded to open up his toolbox and get to work on the problem, and as he did, the best way forward became apparent.

The current state of our health system seems a little bit like that construction conundrum. For too long, we've been looking at the problems without really rolling up our sleeves and getting to work. In some ways, COVID-19 has played the role of my friend's plumber, kickstarting actions that are beginning to address some of the issues we all face in accessing the health system. Recently-announced changes to the fee structure for family doctors is one example. In the short term, these changes will allow primary care doctors to spend more time with patients—a very positive change. In the longer term, it's hoped that the changes will help us retain and attract more family doctors so that we all have better access to the type of primary care that will keep us healthy and out of hospital.

Of course, primary care and emergency rooms are front and center in most discussions of our health care crisis. But inequitable and poor access to specialized health services for physical rehabilitation, psychosocial adjustment, mental health and wellness, and other neurorehabilitation-focused services in the hospital and community are just as in need of attention. It's been obvious for decades that we need a better system for rehabilitation and specialized health services required by people with SCI and other conditions and disorders. Now is the time to finally stop looking at the problem—we need act to improve equitable access to rehab and specialized care throughout the province.

In support of such changes, SCI BC is currently engaged in five different ideal patient pathway and models of care initiatives. Some are provincial; some are national. Some are specific to SCI while some also involve stroke and traumatic brain injury (TBI). While some are just getting under way, others are in the process of releasing their initial findings.

What all of these initiatives have in common is that they involve people with SCI, clinicians, health services administrators, researchers, and SCI organizations. And what's being heard in each of them is remarkably similar. For example, we need better health services navigation, increased access to health services online, and peer support throughout the continuum of services.

For these initiatives to succeed, we need to begin with implementing systemic changes. To do this, government and health authorities must take four critical steps: make rehabilitation a priority; recognize that SCI (and stroke and TBI) require proactive, specialized health services through an individual's lifetime; remove the artificial barriers created by the way our province's health authorities are funded and operated; and take a coordinated provincial approach to rehab to allow equitable access to specialized care throughout the province.

When it comes to changing rehab in this province, the hardest part is the looking at it. We've been looking long and hard at it for a long time. Now is the time to shift our collective focus to doing something about it.

—Chris McBride, PhD, Executive Director, SCI BC



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

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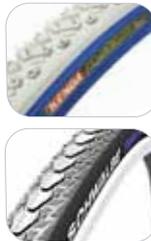
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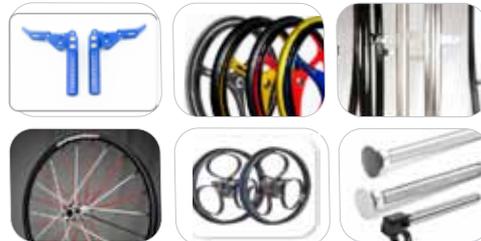
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# Innovations

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

### IPHONE CHARGING CABLE ADAPTER

Abilitease Adaptive, a California company created and operated by C6 quadriplegic inventor Mark Fuglevand, has created a lightweight iPhone charging cable adapter that makes charging a phone much simpler for anyone with limited hand strength or dexterity. It's essentially an enclosure that snaps



over the iPhone charging cable end. Once in place, the user grabs either the square or the loop to plug or unplug their charging cable independently. The design also includes offset tabs, which make it easier to open the enclosure to remove the cable. Visit [abiliteaseadaptive.com](http://abiliteaseadaptive.com) to get more details.

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### Cheer on your favorite team.

The Vancouver Invitational Wheelchair Rugby Tournament is one of the most exciting tournaments in the Pacific Northwest. For fans, it's one of the few opportunities to see some of the best quad athletes in the world. The tournament takes place from March 30 to April 2 at the Richmond Olympic Oval, and admission is by donation. For more information, visit wcrugby.com.



### This holiday, stay connected.

When the days get darker and colder, connect with others from the comfort of your own home through our online events. No matter where you live in BC, you can join us for coffee groups, games night, book club, adaptive boxing and so much more with a click of a button. The easiest way to stay informed about dates and times is to bookmark [sci-bc.ca/events](http://sci-bc.ca/events). We hope to see you online soon!

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This program is funded by the Government of Canada  
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## peers ■

A round of applause for Vancouver's **JEFF STANDFIELD**, who was recently selected as one of 11 recipients of the 2022 Danny Awards that recognize the musical talents of people with disabilities around world. According to Holly Edwards, Disability Awareness Outreach Manager of the New York-based Daniel's Music Foundation, Jeff was selected because of his "musical talent, passion and creative expression, and his memorable, compelling work that celebrates the musical talents of individuals with disabilities."

Jeff received a prize package that includes a weekend in The Big Apple and a workshop at the Orchard—a music distribution company and member of Sony Music Entertainment. And he also got to share his musical talents with the world during the actual show, which was held on Saturday, November 12 and livestreamed globally.

"I'm honoured to be selected as an award recipient for the 3rd Annual Danny Awards, and look forward to performing my original song *Rainbow Through at the Rain* at the awards ceremony in New York," said Jeff when we spoke with him early in November.

To learn more about Daniel's Music Foundation and its mission to support musicians with disabilities, visit [danielsmusic.org](http://danielsmusic.org). To learn more about Jeff and his music, visit [jeffstandfield.com](http://jeffstandfield.com).



# Peer Shoutouts

A caring shoutout to Victoria's **RON BRODA** for his efforts to develop a new online platform to connect SCI peers and other people with disabilities with caregivers. Ron created Your Choice Homecare Solutions because on his own dissatisfaction with the caregiver support he has received since becoming a paraplegic in April 2021.

"In my first nine months home from hospital, six different home care companies had some involvement in my care," says Ron. "I have learned that most, if not all, home care companies are run purely as a business focused on profits with little regard to care—and that the private home care industry is completely unregulated and unmonitored by governments. For these reasons, I decided to form Your Choice Homecare Solutions."

The site allows for clients with disabilities and caregivers to post their profiles. Clients can then seek matches and hire them directly.

"Our mission is to put you in control of your own home care," says Ron. "Through our portal you will have access to qualified independent care providers and negotiate with them directly in order to select your ideal personal care team." Learn more at [homecaresolved.ca](http://homecaresolved.ca).



A big shiny shoutout to Fort St. John's **LORI SLATER** for being awarded with a Queen's Platinum Jubilee medallion in recognition of her contributions to her community. Lori received the award in August from MP Bob Zimmer to mark the 70-year reign of Queen Elizabeth II, who passed away early in September.

In addition to being a Peer Coordinator for SCI BC, Lori is a member of our Access BC team, and works with Northern BC Tourism as the Access and Inclusion Liaison. She has been chair of the Fort St. John's Mayor's Disability Advisory Committee, a Rick Hansen Foundation ambassador, and a volunteer with Toastmaster and BC Games. She was singled out for the award because of her extensive work in disability inclusion.

"The support that I have had in all of the years, all of the work that I have done, is just part of who I am," Lori said when she received the award. "Having that lived experience and being able to support others in what they do means so much to me. I am so humbled because I don't do this alone. I've got my family, and a number of colleagues all over the province that support me in what I do."

*Are you an SCI BC peer with something to shout about? Or do you know a peer who has recently achieved something noteworthy? Send the details to [thespin@sci-bc.ca](mailto:thespin@sci-bc.ca).*





Shown here: All-wheel-drive full floor side entry from VMI on 2022 Toyota Sienna Hybrid



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# Switch it Up!

Tired of the same old exercise routine? A team of ICORD researchers has been working overtime to move the revolutionary aROW and aSKI cardio exercisers out of the lab and into our communities and homes.





*FACING PAGE: Kyle Gieni enjoys working up a sweat on the aSKI. LEFT: Brad Skeats puts in some time on the aROW. Both photos were taken at PARC, located on the ground level of the Blusson Spinal Cord Centre. (Photos courtesy of Cheryl Niamath, ICORD)*

In the summer 2021 issue of *The Spin*, we told you about the impressive work that a cross-disciplinary team of ICORD researchers have done to create the aROW and aSKI—two revolutionary adaptations for the very popular, commercially-available Concept2 rowing and ski ergometers that allow them to be used by people with disabilities without leaving their wheelchairs.

For decades, the only readily-available indoor cardio workout option for wheelchair users has been the hand-cycle ergometer. The aROW and aSKI offer long-needed alternatives—they're safer from a repetitive injury standpoint, they're a lot more interesting and engaging to use, and they offer a superior workout, which is born out by research (see bottom sidebar on the next page).

These clever adaptations are the result of a team effort by like-minded ICORD researchers—Dr. Carolyn Sparrey, Dr. Jaimie Borisoff, Dr. Bonita Sawatzky, Dr. Ben Mortenson, Dr. Andrea Bundon, Dr. James Laskin, and Johanne Mattie. The devices on their own are amazing enough (you can learn more about them in the sidebar at the top of page 15). But what's also incredible is that the research team has done much more than simply invent—they've been steadfastly committed from the outset to get SCI BC peers (and wheelchair users around the world) using them in their own communities and even their homes.

### FROM HUMBLE BEGINNINGS

"This has really been an evolving project," explains Sparrey, an engineer and associate professor at SFU's

*Dr. Carolyn Sparrey*

School of Mechatronic Systems Engineering who really got the ball rolling a few years ago. "It was initially driven by a request from Trevor Greene, an injured Canadian forces veteran, for an adaptive rowing solution—he was a high performance rower before his injury and wanted to have the chance to row again. With a student engineering club at SFU, we turned Trevor's ask into a student design competition. More than 80 students from across the lower mainland participated. It really highlighted the drive that many engineers have to impact the world and make things better, and made me realize this could be bigger than a solution for just one person."

But that revelation also made it clear to Sparrey that it would take a team effort to make it a reality.

"Through my decades of ICORD research seminars and activities, I had heard experts like Jaimie, Bonnie and Ben talk about user experience, barriers to participation, and the need for accessible exercise," she says. "I had previously worked with Jaimie on other projects, and Bonnie and I share an office at ICORD, so we started having conversations and ended up finding like-minded and passionate people through our network of ICORD collaborators to make this possible. I think as a team we saw a need and opportunity and realized that together we could actually have impact, which is exciting, rewarding and why most of us go into research in the first place—to answer interesting questions that matter in the real world."

With the collaboration of like-minded researchers established and committed to the concept, the team got to work re-



fining the initial aROW prototype. Over the last couple of years, aROW improvements have included a gas spring lock to improve securement and release of the lap pad, a new handle design to increase row stroke range of motion, removal of the Concept2 foot pads so the user is closer to the control screen and positioning is more intuitive, a modified chest pad arm and linkage to improve fit and usability, an improved chest pad with a pivoting attachment for increased comfort and usability, and a shortened wooden base with a tapered edge for easier access.

Meanwhile, the team was busy transferring the entire concept from aROW to the aSKI, which has enjoyed many of the same improvements during the refinement process.

Crucial to the refinement process was consumer engagement and feedback from SCI BC peers.

“A key part of the success of this project was the willingness of people with

SCI to engage with us and really share their experiences and opinions, and be open to trying new things—even the first prototypes,” says Sparrey. “While we have people on the research team with lived experience, the needs of people with different stages and severity of injury vary. Having input from a diverse group of people has been essential to the evolution of these designs to make sure they are as broadly usable as possible.”

Sparrey says refinement of both models continues today, but adds the team is close to finalizing the designs.

## FROM LAB TO REAL LIFE

As impressive as the aROW and aSKI are, the willingness of Sparrey and her collaborators to take on the considerable challenge of actually making them available for people to use is perhaps even more laudable. Throughout the history of invention, so many innovations have fallen by the wayside because of a lack

of a champion—consider, for example, the electric car, which played second fiddle to combustion engine cars for more than a century before Elon Musk brought them to the forefront through sheer tenacity.

From the outset, all of the design team’s efforts and funding requests emphasized that moving the aROW and aSKI out of the lab into real life use was a high priority. The effort has paid off: at the time of writing, the team has built 18 of each machine, which have been donated to 14 community facilities, including nine community gym facilities in BC.

“We’re planning to deploy two more aROW and aSKI systems, including hopefully a set out to collaborators in Nova Scotia,” says Sparrey. “Here in BC, with most facilities back to regular operations after a few years of pandemic closures, it’s likely that many of the BC SCI community can now actually access one of our machines.”

## aROW: Research is Confirming the Benefits

Since the aROW adaptation for the commercially-available Concept2 rowing machine was created a few years ago, a steady progression of fitness-minded SCI BC peers have tried it at PARC and other community gyms—and have raved about the workout it provides. Among their observations is that they believe it provides a superior cardio workout to more traditional workout machines like handcycle ergometers, and that it’s a lot more enjoyable to use as well.

Now, the researchers involved in developing the aROW are starting to confirm these benefits through rigorous scientific studies.

Earlier this year, ICORD researchers Drs. Bonnie Sawatzky, Ben Mortenson, Jaimie Borisoff and Carolyn Sparrey, along with Dr. James Laskin of the University of Montana and UBC medical students Brandon Herrington and Kevin Choi, published a study titled *Acute physiological comparison of sub-maximal exercise on a novel adapted rowing machine and arm crank ergometry in people with a spinal cord injury* in the journal *Spinal Cord*.

The primary goal of this study was to compare VO2 max in people with SCI during exercise using the aROW and the handcycle ergometer. VO2 max refers to the maximum amount of oxygen that an individual can utilize during intense or maximal exercise. The higher the VO2 values, the more intense exercise is in terms of challenging one’s heart, lungs, and metabolism.

“We wanted to see if our approach to allowing a different style of exercise also gives a good cardio workout,” says Sawatzky, an ICORD principal investigator and UBC associate professor who is the study’s lead investigator.

Fourteen adults with SCI took part in the study. The aROW, with its adjustable frame and support pads for thighs and chest, can be used by power and manual chair users, so participants with varying levels of SCI and trunk stability were recruited. After an orientation session, participants were tested on the arm ergometer and the aROW on two separate days. On each day, participants began with a warm-up on the selected machine, and then exercised for five minutes each at self-selected low and moderate workloads. Metabolic data, such as VO2 and heart rate, along with perceived physical exertion (how hard you feel like your body is working), were recorded during each session.

The most important finding of the study was that participants reached a much higher VO2 using the aROW than they did on the handcycle ergometer.

“The main takeaway was that rowing does give as good as a workout and actually increases the energy output,” says Sawatzky. She and her colleagues believe that the reason for this is that rowing relies heavily on the larger, posterior shoulder muscles.

“When you use larger muscles, you require a greater oxygen load to use these muscle groups,” she explains. “Thus, this exercise pumps more oxygen through your system and may potentially allow an equal workout, cardiovascularly-speaking, with a shorter duration than what might be required on another piece of equipment.”

Participants also reported that exercising on the aROW felt harder than exercising on the handcycle ergometer—but that was viewed positively rather than negatively.



The aROW (left) is an adaptation for the popular Concept2 rowing ergometer. The arm provides adjustable chest and lap supports to stabilize users while exercising from a wheelchair. The user wheels onto the base platform and secures the wheelchair brakes. The lap pad is slid into position and lowered until it comfortably restrains the upper thighs. At this point, anyone with full trunk strength can begin exercising. If your injury is higher level, you would attach the optional chest pad to the lap pad assembly, and adjust the height as required before beginning your workout.

The aSKI (right) is an adaptation for the popular Concept2 ski ergometer. The lap pad can be adjusted to stabilize wheelchair users no matter how tall they sit in their chair, or the size of their chair, allowing them to optimize their workout. The user wheels into position and sets the wheelchair locks. The aSKI lap pad is then swung into position and lowered until it comfortably restrains the upper thighs. At this point, the user can begin to exercise with the cross country motion.



Additionally, both designs have been made open source so that individuals could build their own, or have one built for them. You can see the plans and other resources at the project website (<http://tiny.cc/ly61vz>).

“Making an aROW or aSKI requires a workshop and a bit of skill, but it’s

something that a local tech college or a group like Tetra could do,” says Sparrey. “However, we’re realizing that many people would like to just be able to buy a complete system instead of trying to find people to build it for them. So we’re exploring partnerships and collaborations that could help make that happen.

Neil Squire, Tetra and others have been approached to hopefully find a way to make transition this to a sustainable and broadly available solution, although we don’t have any formal agreements yet.”

Naturally, achieving the momentum to see these devices find a way into SCI peers homes or community gyms across

“We were surprised how many of the participants enjoyed the increased workout and just doing a different motion,” says Sawatzky.

She adds that the study had limitations. The sample size was relatively small, and the participants were likely more active than the general population of people with SCI. Participants exercised on each machine for only five minutes in order to prevent potential overuse injuries, including skin shearing. These limitations mean that more research is needed to confirm the benefits.

“We need to do an exercise intervention study over time to see if it actually does improve fitness more than other methods,” says Sawatzky. “For the moment, we’re currently doing an intervention study where the participant gets an aROW combined with a smaller, less expensive commercial rowing machine (Sunny Health & Fitness Rowing Machine) in their home to use as often as they wish, without going to a gym for eight weeks. Then they get a pass to a gym for eight weeks to use a Concept2 aROW, plus all the other gym equipment. We’re comparing the enjoyability and feasibility of doing it at home versus going to a gym. We’re also measuring cardio fitness and muscle strength plus a few other quality of life measures.”

The team is also planning to include aSKI, the system that adapts the Concept2 ski machine for people with SCI.

“We want to study all these styles of adapted ergometers to see which ones will have more uptake,” says Sawatzky. “The size and space issues are important. A qualitative study is being done to include perceptions of the aSKI and aROW.”

Here at SCI BC, we’re following this line of research closely—more

effective and enjoyable exercise options for home and the gym can only be good news for SCI BC peers, particularly at a time when other research is making it clear how important exercise is for health and quality of life. For help getting more fit, see the *Evidence-Based Physical Activity Guidelines for Adults with SCI* ([sciguidelines.ubc.ca](http://sciguidelines.ubc.ca)).

*Study participant Richard Peter takes a turn on the handcycling ergometer while Dr. James Laskin and students Tom Li and Rebecca Wong monitor his metabolic data. (Photo by Dr. Bonnie Sawatzky)*



Canada and even around the world requires more than simply making or promoting them.

“We’re always eager to make more systems, but we’re also looking at how to make this a sustainable venture—making systems as part of a research study is different than being able to sustain and support systems longer term,” explains Sparrey. “What happens when a system needs a replacement part, or there are new users that need an orientation to the machines? We’re getting inquiries from people around the world on accessing these systems and building their own. We’re exploring different ways to enhance accessibility and sustainability, such as commercialization or engaging non-profit partners, but we also want to stick to the spirit of the project and make sure that these systems are available broadly. Moving out of the research and development space brings new complexity to the project, including things like product liability that we’re starting to explore. We’re also now working on home versions of the system that have a lower cost and are smaller. Finally, we’re looking at whether similar approaches to adaptive exercise could be used for older adults with mobility limitations. In conclusion, lots more work to do.”

It’s quite extraordinary, and even more so when you consider that the design team members are simultaneously working on research that quantifies the benefits of these machines (not to mention other research streams).

“We’re starting to scheme about the next phase of this research to measure benefits over a longer term trial, but we’re waiting to finalize the home aROW design so that we can include an aspect of assessing the community gym participation versus home exercise in the outcome measures,” says Sparrey. “We certainly want to be looking at muscle mass, trunk stability and cardiovascular health as part of this larger study, as there’s lots of evidence that higher intensity (HIT) exercise like that afforded by the aROW and aSKI can have benefits above baseline cardio exercise. Also, the community gym versus home rower will help us look at how exercise and community engagement affect mental health and wellbeing of people with SCI.”

### CREDIT WHERE CREDIT’S DUE

As explained above, Sparrey is grateful for the ongoing involvement of SCI BC peers for their efforts to bring the aROW and aSKI to the place they’re now at. However, she adds, none of it would have happened without the exceptional financial support provided by US-based Craig H. Neilsen Foundation (which, we’ll add, has also supported SCI BC’s efforts during the COVID-19 pandemic).

Founded by the late Craig Neilsen, an American entrepreneur who became a quadriplegic as the result of a car crash, the Foundation is the largest private funder of SCI research, rehabilitation, clinical training, and programmatic support in the U.S. and Canada.

“The Craig H. Neilsen Foundation has been a huge supporter of this project and has now supported another team in the US to build and deploy aROWs in South Carolina,” says Sparrey. “I think the foundation has found a great balance in their funding programs between supporting fundamental research and activities that directly impact the community. With our project, we have benefited from the foundation’s Creating Opportunity and Independence grants, which has allowed us to both conduct research and get systems into the community.”

Sparrey is also grateful for ICORD Seed Grants, which are supported by the Rick Hansen Foundation. “These have been essential for us to come together as a team and get early results to show Craig H. Neilsen Foundation that our proposed projects are feasible,” she says.

She also acknowledges the efforts of the many UBC OT students, biomedical engineering students, medical students, and ICORD Indigenous summer students who have contributed. “The students’ input, ability to work directly with participants, and unique perspectives on barriers and opportunities has expanded the project to be richer and more focused on the end user experience.”

She saves her final thanks for her colleagues for sharing her passion.

“We have such a fantastic and brilliant team of collaborators who really like working together, and value and respect the range of knowledge each team member brings to the project.” ■



## Where to Find and Use the aROW or aSKI in British Columbia

- Grandview Community Centre, Surrey
- Newton Recreation Centre, Surrey
- Champlain Heights Community Centre, Vancouver
- Creekside Fitness Centre, Vancouver
- Delbrook Community Recreations Centre, North Vancouver
- MOVE Adapted Fitness and Rehabilitation Society, Victoria
- Parkinson Recreation Centre, Kelowna
- Physical Activity Research Centre (PARC), Vancouver
- Raincity Boxing Studio, Richmond

# Raw Deal

A recently published research report lays bare, province by province, how our country's universal health care program is failing people with SCI—and how the situation in BC is among the worst in Canada.

Two issues ago, we published a feature about the unfair and often dangerous lack of funding for urinary catheter supplies that peers with SCI, here in BC and in other provinces, continually deal with (*Fee to Pee*, Summer 2022). You might recall that the story explained how there seems to be growing awareness of the problem of peers who rely on these essential supplies being forced to pay for them out of pocket, and how those who simply can't afford to do this often resort to using—and more alarmingly, reusing—inferior products and techniques despite the risk of dangerous UTIs and other complications such as autonomic dysreflexia (AD).

Part of that feature focused on how University of Manitoba researcher Dr. Kristine Cowley was leading a team working on a research report that would attempt to confirm the disparities between provinces when it comes to funding urinary supplies, along with other essential supports and services such as mobility devices and attendant services. In October, that report was completed and published. Disappointingly, but unsurprisingly, it paints a damning picture of how our well-intentioned universal health care system is failing SCI peers in every province—and how BC is among the most problematic.

The report is titled *Identifying Jurisdictional Gaps in Providing Essential Attendant Services, Medical Supplies, and Assistive Devices Needed by Canadians Living with Spinal Cord Injury*.

Cowley, who is herself an SCI peer, co-authored the report with four collaborators: University of Manitoba associate professor and OT Dr. Jacquie Ripat, SCI Ontario Director of Public Policy Peter Athanasopoulos, medical writer and consultant John Gregory, and University of Manitoba grad student Peter Warkentin. Funding was provided by the University of Manitoba and SCI Ontario.

The report is a highly detailed analysis of how each provincial government health ministry provides—or fails to provide—funding that addresses the essential needs of people with SCI in three key areas: attendant services, medical supplies for neurogenic bladder and bowel, and mobility equipment, including wheelchairs, seating, and lift and transfer devices. At 91 pages, it might sound like a lengthy read, but it's safe to say that most readers can find what they need in the report's executive summary and in the sections that outline what's available or not available in their own province.

At first glance, readers will quickly discover how bluntly and unapologetically it describes the critical nature of the services, supports and supplies it deals with. Here at SCI BC, it sometimes seems to us that, over the years, Canadians with SCI have had to resign themselves to having to practically beg (unsuccessfully, for the most part) for meaningful levels of govern-

ment assistance when it comes to these supports—and being quietly grateful when a bone is tossed their way. This report bluntly rejects this mindset, beginning on the first page of the executive summary with this statement: “In this report, essential needs are defined as medical services, supplies or equipment that, if withheld, could result in death of a person with SCI within days or weeks.” It's a clear and bold reminder that these supports are not luxuries or wish list options—they are, in fact, medical necessities that are absolutely critical for people with SCI to stay healthy and alive, and that the original intent of our universal health care system was to provide them as required.

On the same pages, the authors also succinctly spell out what they believe to be the primary reason for the problem: the devolution of decision-making to the provinces. “Today...there are limited processes in place to systematically identify ‘essential, publicly-fundable’ services and supplies between provinces/territories,” wrote the authors. “Thus, although universal health care is federally-mandated and transfer payments are provided to each province/territory, there is quite a bit of autonomy in determining health



care delivery levels and financial coverage of medical services and supplies within each jurisdiction.”

The executive summary also condenses the report’s findings into six main points, which are contained in the sidebar to the right (note that, in order to save space, they have been slightly altered where we felt it was possible without changing the intent or meaning). But the researchers didn’t stop with simply pointing out the problems—the executive summary also contains five recommendations for change, which again are in the sidebar to the right, and which have also been slightly condensed where we felt it was possible.

After the executive summary, the report then presents the situation in each province in detail, beginning with BC (the provincial breakdowns are ordered from west to east coast). For our province, the key takeaways, reprinted verbatim from the report, are as follows:

- There is a lack of health care workers, especially in remote areas.
- Lack of health support workers leads to increased reliance on family and friends as well as moves to institutional care facilities, even when inappropriate.
- Home support scheduling is viewed as too rigid; and assessments often viewed as prescribing inadequate care hours.
- Provision and approval of care at a regional health authority restricts ability to move from one health authority to another.
- Public provision of neurogenic bladder and bowel management supplies and wheelchairs is limited only to those receiving Employment and Assistance for Persons with Disabilities (EAPD). Funding model inadvertently encourages people to stay on disability or income assistance to retain coverage.
- Coverage for catheters goes against the Canadian Urological Association’s recommendation of single-use coated catheters for management of neurogenic bladder function (Campeau et al, 2020).
- Lack of affordable housing compounds all these issues.

These key takeaways are explained in detail in the following pages of the report. Together, it all paints a picture of a frustratingly overly-complex mishmash of rules, regulations, inadequate funding, and often grossly unfair discrepancies in supply and services provision based on individual circumstances rather than basic human need.

While no province comes anywhere close to providing a perfect situation for people with SCI, it’s interesting to note that BC can only be seen as close to the bottom of the heap. Consider, for instance, the arcane practice of means testing as a way of restricting access to these critical, life-sustaining services and supports. There are just two provinces that use means testing for all three categories of attendant care, neurogenic bladder and bowel supplies, and mobility devices: BC and Newfoundland.

That’s not to suggest that there are any provinces or territories that can claim significantly better approaches. For example, only the province of Saskatchewan provides intermittent catheters free of charge to people with SCI. Even then, only four per day are provided as opposed to the six to eight recommended by the Canadian Urological Society (CUA)—and those catheters are among the least expensive available.

In its conclusion, the document’s authors again pull no punches. “This research demonstrates the stark reality that, for the most part, the ten provinces expect Canadians with spinal cord injury to pay out of pocket for essential health services, supplies and equipment,” they wrote. “Citizens are means tested to determine co-payments. These findings call into question whether our provincial and federal governments are meeting the tenets of the Canada Health Act and the Convention on the Rights of Persons with Disabilities in Canada.”

The question now is what will happen to this report.

Dr. Chris McBride, Executive Director of SCI BC, believes the report is well-researched and written, and he’s working with SCI BC’s provincial counterparts,

including report co-sponsor SCI Ontario, to develop a plan for all members of the SCI Canada federation to promote it and leverage it for change.

“For anyone familiar with the issue or who lives with the challenges our systems impose, there will be no surprises in this report,” McBride says. “We’ve known for decades that these funding inadequacies and discrepancies exist. But what this document does so well is remove the ambiguities and unknowns, and pinpoint for the first time the specific nature of the problems in every jurisdiction, BC included. The document now becomes a starting point for engaging our partners and stakeholders in a specific conversation about how we can work together to effect the much needed changes to the supports provided for these essential services, supplies, and devices.

“Here in BC, we have seen the provincial government make progressive changes to supports for other essential supplies, such as the recent announcement about removing the financial barriers to accessing menstrual supplies as part of its poverty reduction strategy. Working with our members and partners, we will encourage the government to apply the same logical thinking to covering the essential core services, supplies, and devices outlined in the report, for not only would equitable coverage support the province’s poverty reduction strategy, it will also support the goals of the *Accessible BC Act*. Most importantly, we are talking about people and we must make sure everyone knows that we are talking about supports for things that are essential for people with SCI to live: essential to stay alive and essential to live as healthy and active participants in civil society. Yes, there is a cost to this, but the investment required will ultimately lead to a reduced burden on the health system and to economic benefits through participation in the labour force and the economy as a whole.”

We’ll publish any developments with this report in future issues of *The Spin*. In the interim, readers can email our office to request an electronic copy. ■

# Identifying Jurisdictional Gaps in Providing Essential Attendant Services, Medical Supplies, and Assistive Devices Needed by Canadians Living with Spinal Cord Injury

## OVERALL FINDINGS

1. There are significant disparities and inequalities between provinces for each domain of essential need.
2. Essential services and supplies are often difficult to access or request, involving complicated financial and functional assessments performed only by designated personnel.
3. Despite having a great deal of expertise regarding their needs and a time horizon of decades of continual need for these services and supplies, those with SCI are relegated to passive recipient roles and subjected to repeat assessments of financial and functional status to receive minimal and often inadequate essential health care services, supplies or equipment. Furthermore, the allowance for earned income is too low to be able to afford these essential services, supplies and equipment. This leads to inappropriate reuse of supplies and creates strong disincentives to leave income assistance realms and enter the paid workforce.
4. There are substantial inequities and shortages in essential attendant services. Means testing exists for attendant services/home care for activities of daily living (ADL) in 5/10 provinces... with many charging an individual with SCI thousands of dollars per year once the person earns income above the poverty line... Generally, provinces restrict services to 'in home only' or have severe scheduling restrictions that make outside employment or training difficult or impossible to maintain. Also, substantial shortages in health care workers are reported...Scheduling and lack of access to services is exacerbated for those living in rural or Indigenous settings, which is further complicated by a lack of accessible housing. This often forces those with SCI to relocate to urban locations to obtain needed attendant services for ADL. Failure of community health care workers to make scheduled appointments in private home care provision settings places those with SCI at risk and puts unreasonable pressure on family and friends. Alternate delivery models exist (e.g., self-managed attendant care) which may alleviate scheduling or service location issues, but payment levels are inadequate, forcing service limitations that impair the health of those with SCI. Once care needs exceed a certain undefined 'threshold', those with SCI are often encouraged to seek life in institutions rather than remain active members of their communities.
5. Means testing exists for essential bladder and bowel management supplies in 9/10 provinces (all but SK). Supplies are often severely limited such that recommendations of the Canadian Urological Society (CUA) cannot be achieved. The CUA recommends single-use hydrophilic coated catheters for all person with neurogenic bladder dysfunction, necessitating 6-8 catheters per day...In contrast, provinces limit catheters to 1-4 per day of 'the most inexpensive option available'. Further, public provision of these essential supplies in many provinces are limited to those living under the poverty line or receiving some form of social assistance.
6. Means testing exists for provision of essential wheelchair, seating, and lift and transfer devices in 4/10 provinces...or is based on providing a piece of equipment from a loans inventory program in 6/10 provinces. Programs are administered by health authorities in 3/10 provinces...or relegated to charities in 3/10 provinces...

Wording in policy documents "most inexpensive suitable option" does not address the concept of a customized, functionally adequate wheelchair that considers the person's pre-injury level of activity, employment and education interests and functional status. Provision of wheelchairs appears to be determined by contracts negotiated with national suppliers or availability of items in a loaned equipment pool that do not meet the individualized functional needs of each person with SCI. Most programs provide only one or a few models of wheelchairs and do not appear to have mechanisms in place to update available technology based on medical advances.

## CONCLUSIONS AND RECOMMENDATIONS

1. Overall, because of the lack of clarity and discrepancies across and within provincial jurisdictions regarding these three domains, a nonpartisan, objective scientific review committee/body should determine definitions of essential health care in Canada and identify minimal acceptable standards of care and treatment options. Recommendations for an acceptable standard of care/service should be determined by research-based evidence and reflect evolving changes in technology and medical advances. This will help to level the playing field across the country such that a person living with SCI in one province/territory will have the same access to essential medical supplies and services regardless of income.
2. Attendant services for ADL are an essential health need and means testing-based provision of service in certain jurisdictions contravenes concepts of universality of health care in Canada. Current levels of attendant services are inadequate in many jurisdictions. Lack of access leaves those with SCI (and other disabilities) at significant risk and extremely limits their ability to remain active contributing members in Canadian society. Levels and quality of care need to increase.
3. Means testing and limitations to the availability and coverage of medically necessary bladder and bowel management supplies is dangerously shortsighted and can lead to substantial increases in long-term costs to society through secondary complications such as urinary tract infections (UTIs), pressure injuries, and skin tears. More importantly, it leads to increased related morbidities, negative health outcomes and a reduced quality of life for individuals living with SCI.
4. Power and manual wheelchairs for those unable to ambulate due to SCI are an essential need. Means testing and a lack of access to functionally appropriate equipment in a timely fashion exacerbates wait times for hospital discharge, and limits employment and educational opportunities and community participation of those with SCI. Provision of functionally appropriate wheelchairs should be introduced or improved in jurisdictions across Canada to meet the concept of universality of health care.
5. A basic minimum allowance for essential medical supplies and services should be considered for those living with SCI, and these persons should be given greater autonomy in determining the characteristics of the services and supplies that meet their needs. In other words, essential health care services and supplies should be defined by functional need rather than earned income.

# Research Reboot

**ICORD researchers are hoping to regain momentum for an important research project that's attempting to demonstrate the benefits of exercise for people with SCI who suffer from chronic pain.**

It's no surprise that the COVID-19 pandemic has negatively impacted the segment of the global scientific research community that's engaged in clinical trials. In the first year of the pandemic, enrolment in clinical trials (other than those for COVID-19 vaccines) plummeted as potential participants understandably shied away from risk and many researchers changed their focus. The number of studies also dipped dramatically—one analysis of US research studies from February to May 2020 found that the number of studies initiated was only 57 percent of what would have been expected had the pandemic not occurred.

One study here in BC that has seen enrolment issues is EPIC-SCI, which stands for Exercise Guidelines Promotion and Implementation in Chronic Spinal Cord Injury (EPIC-SCI): A Randomized Controlled Trial.

The study was spearheaded by ICORD and UBC Okanagan researcher Dr. Kathleen Martin Ginis. She and her team at the Kelowna-based SCI Action Canada Lab set out to evaluate improvements in SCI-related chronic pain in participants who volunteered to follow the Inter-

national SCI Exercise Guidelines for six months. Here at SCI BC, we were pleased to be consulted during the design of this study, because we know how many peers are severely impacted by chronic pain—and just how few effective treatments there are for it.

The study got underway in 2020, just before the seriousness of COVID-19 became apparent. It has an ambitious goal of recruiting 86 participants from either the Okanagan or Vancouver, who will be randomly allocated to one of two groups.



Participants in one group will be asked to immediately follow an exercise program for six months. Participants in the other group (the control group) will be asked not to change their daily lifestyle for six months, and then begin the six-month exercise program. Regardless of when they start, each participant will be given access to a personal trainer to help them set up their exercise program, consisting of two to three hours of exercise per week at home or in a local fitness facility.

Over the course of their six month exercise program, each participant will be required to make three visits to the testing sites (UBC Okanagan in Kelowna or Blusson Spinal Cord Centre in Vancouver), where they would be asked to provide blood samples, complete fitness tests, and take a brief test to see how the body responds to pressure and cold stimuli applied to the arm. In addition, the researchers will contact the participants by phone each week to provide them with motivational support and advice to help them stay on track with their exercise program.

“We initially recruited nine people before the pandemic started, so we really started off with a bang those first three months,” says Martin Ginis. “But we were quickly put on pause due to the COVID-19 pandemic. We have been actively up and running again since this



*Principal investigator Dr. Kathleen Martin Ginis (left) and Clinical Research Coordinator Kenedy Olsen*



SCI BC peer William McCreight has his oxygen consumption evaluated while working out on an arm ergometer during his baseline fitness testing in Dr. Martin Ginis' UBC Okanagan laboratory.

past March, but we've struggled to regain the level of interest. Across both the Okanagan and Vancouver sites, we have now had around 26 participants consent to participate in the trial. Of these, 11 participants are currently participating in the intervention, and the remainder have completed their time in the study."

"We have heard anecdotally that it's been challenging to recruit participants for other studies as well, but this study has been especially challenging," says Kenedy Olsen, a recent graduate of UBC Okanagan's Bachelor of Human Kinetics Program who is Clinical Research Coordinator in Martin Ginis' lab. "Initially, we believe there was hesitancy to participate in research post-pandemic due to the uncertainty of the risks. We would like to reassure people that we have extensive safety precautions in place for in-person visits to protect against COVID-19, and the majority of involvement in this study can be completed remotely as well. If anyone is hesitant to participate because of the risk of COVID-19, we are able to provide PPE as well as ensure our entire staff is wearing it as well during visits. We want to

ensure all participants and staff members are kept safe during this process."

But Olsen admits that there are other obstacles discouraging would-be participants from signing on.

"One of the biggest issues we're now facing is that individuals are viewing the six-month time commitment as a challenge," she says. "However, realistically, we only need participants to come to the lab three times. All exercise programs and counselling can be done from home, so if individuals are planning travel or other ventures, this hopefully shouldn't be a barrier to participating."

While Martin Ginis concedes that low enrolment has been disheartening, she remains optimistic that more volunteers will come forward—particularly if they understand that their participation is a potential opportunity to be a part of meaningful change.

"We designed this project to create a place for individuals with SCI to become more physically active and we are here to help them do so," she says. "We want to do this study for the SCI community, and the science and results we get out of it is just a bonus in our eyes.

This research project was designed with the input of over 250 people living with SCI and SCI clinicians. This is research designed by people with SCI for people with SCI. We take pride in being a lab that works with the community to ensure the projects we are completing will have meaningful results and actually impact the lives of the people they're designed to help."

Additionally, says Olsen, there are perks for individual participants.

"Benefits include receiving a personalized exercise program and two visits with a personal trainer," she says. "If you live in Vancouver, you can use PARC, and in Kelowna, the UBCO adaptive exercise gym is available to participants as well. However, if you are beyond the distance of these sites, our personal trainer will visit your home or gym with you to ensure you are safely and effectively able to complete your exercise program. You'll also receive individualized weekly exercise coaching sessions to help keep you on track. We cover gas costs for travelling to and from the testing site, and we also provide a gift card honorarium at the end of the study."

She adds that participants can learn a lot about their bodies and pain from participating, gain insight about their overall fitness levels, and see what it's like to go through exercise fitness testing.

"Lastly," she says, "we hope that anyone who participates in our study will be set up for a lifetime of physical activity participation with all the support we provide during this intervention. We have heard from our participants how they are having some of the best workouts of their life based on the program our trainer makes for them. Many of our participants appear to have greater confidence in the gym and exercise setting after completing this study as well."

We wanted to hear the thoughts of some SCI BC peers who have signed up to participate in the study. Vancouver's Jessica Kruger and Kamloops' William McCreight agreed.

"I finished the study in October," says Kruger, an incomplete quadriplegic who, as a member of BC's quad rugby development team, is always physically active. "I'm always keen to participate with studies when time allows for the advancement of knowledge surrounding SCI, and this one just so happened to align pretty nicely with my upcoming wedding, so the added accountability aspect definitely appealed to me. It was definitely a good experience. I felt like, being an active and athletic person, there wasn't a ton of new knowledge, but the accountability aspect was huge to get me going to the gym more regularly, especially after COVID—if I skip the gym and only I know, not a big deal, but if I skip it and I'm messing up a research study, there are higher stakes."

McCreight, who is also quadriplegic, was randomly placed in the control group. After no changes in his routine for six months, he's just started the six month exercise component.

"I liked the idea of helping students with their studies," he says. "I saw the ad for the study and wanted to take advantage of having a workout routine that was set up specially for myself by a personal trainer. I wanted to train hard for the upcoming wheelchair rugby season. The experience on the control side was okay—I was trying hard to not change my daily routine



Jessica Kruger and William McCreight

because of my commitment to the study. Now that I'm done the first half of the study things are going well. I'm enjoying the change in my routine and look forward to my workouts."

Would Kruger and McCreight recommend participating in EPIC-SCI to other peers? "Definitely," Kruger says. "It would be especially beneficial to people who are a bit uncertain about what sort of exercises and workouts they should do at the gym."

McCreight agrees. "If someone has the interest and time, I would recommend this study to them. Just remember you may be on the control side to start. It's a great group of people and it is a fun atmosphere. The adaptive equipment is great to work with—even for individuals with hand impairment. They'll adjust your workout routine accordingly to your function."

Martin Ginis and Olsen are optimistic that peer endorsements like this will help bring about a successful conclusion to the study. "We're hopeful that, by the end of 2023, we'll meet our goal of 86 participants, but we want to be realistic as well. When creating research proposals, we factor in potentially having participants drop out or recruiting issues, so we make our expectations a bit more fitting. At the bare minimum, we still need around 65 participants in this study."

If you're interested, you can learn more about EPIC-SCI and determine if you're eligible to participate by visiting [icord.org/studies/2021/11/epic-sci](https://icord.org/studies/2021/11/epic-sci). You can also contact Bobo Tong by email ([bobo.tong@ubc.ca](mailto:bobo.tong@ubc.ca)) or phone (778.581.6487). ■

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

# LivingwithSCI.ca





Spinal Cord Injury BC

Help us give the gift of information across BC. Support future issues of *The Spin* by donating today.



[sci-bc.ca/donate](https://sci-bc.ca/donate)

# HAPPY HOLIDAYS

Your support brings new friendships, joy and knowledge to many of our members this holiday season. Individuals with spinal cord injuries can get the help they need and continue to stay informed and connected within the community. **Thank you so much for your generosity** and we look forward to seeing you in the new year!

–Spinal Cord Injury BC team

# ask the SPIN DOCTOR

"I feel like I've gained weight over the last few years, and I'm struggling with my transfers," says Gio in Abbotsford. "I think it's time to think more seriously about my weight. I used to think it was just part of having an SCI. Are there any treatments that could help me get to a healthy weight?" To answer this issue's question, we turned to Dr. Ian Rigby, an emergency room physician at Calgary's Foothills Medical Centre, a consultant with the Alberta Obesity Centre, and a certified American Board of Obesity Medicine diplomate. Dr. Rigby also lives with an SCI, and is the board chair of the Praxis Spinal Cord Institute. PLEASE NOTE: this column does not discuss the unique needs and concerns of people living with or in recovery from eating disorders. Please take care and consult your own healthcare team for more specific advice.



**G**io, you're not alone. It can be particularly hard to get information on weight management that is informed by the particular risks and needs of people with SCI.

I don't use the term obesity when talking with patients, but it has a medical definition that helps us understand who is most at risk and can help identify treatment options. Medical thinking has changed in the last decade to recognize obesity as a chronic disease of excess body weight that impairs health, with complex contributing factors that are much more than just how or what we eat.

As clinicians, our goal is to support health and prevent and minimize the risks of long term complications. With medical weight management, we think about treatments that help our patients address current health conditions or prevent future complications, especially for those who have complex health conditions affected by excess weight. After SCI, weight gain is common because our bodies are less effective at burning energy and we require less energy for day-to-day living. It can worsen many SCI complications such as edema, sleep apnea, and skin breakdown, and negatively impact the bone and joint health we rely on for mobility. We also see that people with SCI have more mobility and logistical barriers to regular physical activity and food preparation that can make weight management that much harder.

Screening tools are a first step clinicians use to determine who is most at risk of health complications and recommend treatments based on the patient's health goals and risks. After SCI, our bodies have a different composition of muscle and fat than the general population due to muscle atrophy and lower bone density, so we use waist circumference to screen patients for cardiometabolic risks associated with excess weight. It's just one part of a more detailed conversation about your health risks and concerns to guide treatment discussions.

As a physician, I know that even very modest changes can lead to very meaningful improvements in management of chronic diseases like high blood pressure and reduction of risks of cardiometabolic conditions. Most physicians will look to take a stepwise approach to considering treatment options based on screening results, health conditions and individual risk factors like family history, with the goal of treating health issues and reducing the chance of serious illness in the future.

The first cornerstone treatment step is lifestyle modifications: nutrition, physical activity, sleep, and behaviour change.

There are a multitude of good nutrition interventions like low-carbohydrate or Mediterranean diets that all have benefits, but the best nutrition approach is one you can stick with long term. Clinicians may make more specific recommendations if you have complications like diabetes, high cholesterol or hypertension. A dietitian can work with you to translate nutrition approaches to a daily menu that works for you.

For physical activity, any is better than none. The *Evidence-Based Physical Activity Guidelines for Adults with SCI* state that aerobic training should consist of at least 150 minutes per week of moderate physical activity or at least 75 minutes per week of vigorous intensity aerobic exercise. You also need to include strength training at least two times per week and emphasize training large muscle groups to increase lean body mass. Check it out at [scguidelines.ubc.ca](http://scguidelines.ubc.ca).

In our clinic, we spend a great deal of time on the behaviour change part more than any other because it's so fundamental to enabling any lifestyle change. We use a cognitive behavioural therapy approach involving setting goals, getting support, and problem-solving to overcome obstacles.

The next treatment step considered is prescriptive nutritional interventions such as replacement of one or two meals per day with a calorie-controlled but nutrient-dense shake or bar. Research tells us that these medically-supervised meal replacement approaches are an effective way to manage weight. The combination of dense nutrition and ease of preparation makes this option a popular one.

Medications are the next step, and are usually considered for patients who have more excess weight—especially if this is having negative health effects. The type of medication is chosen based on factors such as coexisting medical conditions. The goals are to decrease appetite, create a "full" feeling earlier, or reduce food cravings.

The last of the treatment options is weight loss surgery. These procedures offer the most benefit for patients who have serious health complications and for whom the benefits outweigh the risks of the surgery. These may be options for people with SCI who meet the criteria, but are better discussed with physicians after other steps are considered.

Remember that meaningful improvement in your current and future health can come with even relatively small changes. Start by talking with your doctor or physiatrist, and discussing the changes you can make to those four lifestyle factors: nutrition, physical activity, behaviour change, and sleep. ■

"My weight loss experience has been a long road. Here are some tips that I found helped me. Limit when, how much and where you eat—for example, I don't eat after 7 PM or within a few hours of going to bed. I made a choice to not eat in my bedroom, in the car, etc. I also cut out all junk food. I don't count calories, nor do I avoid sugar...just excess. It's important to also exercise. I like working out for an hour a day, mixing it up between yoga, dance, and weights, all on Zoom from the comfort of my own house, and I encourage everyone to join me anytime. Your friends might notice the weight loss before you do; it's hard in a chair to weigh ourselves often so you might also want to measure different areas and a month later measure again and so on. It does take time, so be patient. And if you notice you lost one pound—great! That is a success. Soon you will see your clothes are fitting better or looser, and that is a great feeling." – **MARNEY SMITHIES, Surrey**

"One of the most effective ways to help me manage my diet and still enjoy the pleasure of food is to eat slow and mindfully. This is especially important with treats—chocolate mousse tastes the same whether you eat it slowly or gobble it down. I drink water before and during my meal to feel fuller. Sometimes I drink flavoured carbonated beverages that have little to no sugar/calories. I try to have pre-made healthy snacks ready to eat, rather than grabbing processed and fast foods. Sometimes I have cravings, which are usually emotionally related. So if I want to feel better, I try to think about and do things that improve my mood, like a walk, going to a movie, or exercising. If I still have cravings, I try to have something that satisfies but is low in calories, like hard candy and Lifesavers. When you do treat yourself to cake, cookies and other desserts, take a smaller portion. If you eat slowly, you get just as much flavour and half the calories!" – **KIM EGGER, Surrey**



# PEERSAY

Recently, Dr. Ian Rigby presented much of the information on the facing page to attendees during our recent online weight loss symposium. We asked some of our peers who were in the audience to share some of their own weight loss and weight maintenance strategies with readers.



"My treat is yogurt—that's all the sugar I eat. I've gone from using a dinner plate to a lunch plate, which has helped me cut down on the amount of food I eat. I drink a lot of water every day, sometimes with a bit of soda water. I took cognitive behaviour therapy, and keep my brain active with my body. I eat much more slowly now, and with someone to help me be accountable. I am on a medication called Contrave, and this reduces my appetite—before that, I would have a heaping dinner plate, and now, with the medication, I am eating a small meal instead of huge amounts of food." – **JEFFREY GARTRELL, Vancouver**

"I've had many years of dieting, and it's very hard to keep the weight off as we can't exercise and we are aging. What I have learned over the years is no snacking at all after 7 PM. Cut back your portions. I use a smaller plate as we usually eat with our eyes. I stop half way through eating and go make a coffee or do something, and then go back to eating, as it takes 20 minutes to register you have eaten and I am full by the time I go back to my plate of food. I used to have a can of pop a day; I changed that to a bottle of vitamin water, as I hate drinking water. Water is good for us but I can't stand just water, so this way I get extra vitamins. I usually sip the vitamin water all day between my few coffees. I also added vitamin B-12 as I read it helps with weight loss because of its ability to boost metabolism and provide lasting energy." – **DEBBIE RICHARDSON, Vancouver**



# Fun With Three

Like other SCI BC peers, Simon Harrington has discovered the amazing Can-Am three wheelers and how they can open—or re-open—the door to experiencing the joys of motorcycling.

**D**uring this time of the year, winter can really start to lose its allure, and you can't blame any Canadian for dreaming of warmer weather. For Simon Harrington, when his mind wanders to thoughts of spring, it's all about being on the open road on one of his Can-Am three wheelers.

The Can-Am Spyder first came on the scene back in 2007. With its single rear drive wheel and two front wheels for steering, it was immediately hailed as revolutionary. It almost seemed like a snowmobile designed for the road, with wheels instead of skis and track. That's not surprising, given its pedigree—Can-Am is a division of Bombardier Recreational Products, a spin-off of Bombardier Inc., the Quebec company that is globally recognized as being the inventor of the snowmobile (company founder Joseph-Arman Bombardier debuted the first snowmobile in 1935).

It didn't take long for wheelchair users with a penchant for speed and tinkering to see the potential for the Spyder to be modified and provide a way to get into—or back into—motorcycling. Its three-wheeled stance offered great stability, and its reverse gear, anti-lock brakes, and traction and stability control provided reassurances of safety.

In the 15 years that have since elapsed, scores of wheelchair users across North America and around the globe have embraced the Spyder. We don't know how many Spyder riders with disabilities there are, but a quick online search will turn up hundreds of thousands of hits—images, videos, group postings, and more.

Harrington, who lives in Courtenay on Vancouver Island, joined the ranks of enthusiasts in 2016. Now 56, Harrington sustained a T12 incomplete injury while skiing in 1989. When he learned about the Spyder, he saw it as a way to rekindle an old passion.

"I got my first motorcycle when I was about 21 years old, just a year or two before my accident," says Harrington, who recently retired from a career with Worksafe BC. "I rode down to California with a bunch of friends on bikes. That was an amazing adventure. I still remember riding over the Golden Gate Bridge in San Francisco, feeling like I was in *Easy Rider*."

After he was injured, Harrington initially put motorcycling on the back burner. But as the years went by, he found himself dreaming of motorcycling again. In 2016, he decided to scratch the itch. He first considered the Ural, a Russian motorcycle and sidecar combination, but with its manual transmission, the modifications it would require presented a challenge. That's when he made the decision to go with the Can-Am Spyder.

"With the Can-Am, changing gears was already done with an electronic hand trigger shifter, so only the braking



# Wheels

system had to be modified,” he says. “I found a company in the USA that had developed a hand controlled braking system for the Spyder. This was a relatively easy do-it-yourself install. The system works excellent, providing normal braking power.”

Before he could enjoy his new bike, he had to have the adapted brake system approved by ICBC. “Essentially,” he explains, “once the modification has been completed, the vehicle needs to be inspected at a designated inspection facility to confirm a passed inspection. The vehicle is then registered as a modified vehicle with ICBC.”

With his inspection completed, Harrington still had to jump through another hurdle—getting his class 6 driver’s license, which was revoked after his injury, along with his standard class 5 license.

“The process consists of a motorcycle knowledge test and a skills test. The knowledge test is done at the driver’s licensing office. Most of the questions pertain to general driving knowledge and rules of the road; however, there are questions that relate specifically to motorcycles. Once the knowledge test is passed, you’re able to practice riding with a supervisor—this could be someone in a car who has a class 5, or a fellow motorcyclist with a valid class 6—at a 60km/hr speed limit.”

After two weeks of practice, Harrington was allowed to take the skills test.

“This is a two part test,” he says. “The first part is done in a parking lot and is to ensure you can control the bike at low speeds. The second part is a road test. The examiner follows behind in a car. You communicate with the instructor by a

headset intercom system. All in all, I didn’t find getting my license difficult.”

He adds that ICBC’s Learn to Ride Smart and Tuning Up for Riders guides provide riders of all abilities with all the knowledge they need to successfully pass the licensing process.

With license in wallet, Harrington was finally able to start enjoying his Spyder.

“Getting back to riding on the bike was great,” he says. “The best part was that I was able to join my friend, who is an avid motorcyclist, to go for rides together. Riding a motorcycle is so different than riding in an enclosed car—I suppose it’s the ‘openness’ of it.”

Soon, Harrington was going on longer and longer rides.

“The Spyder is like a Cadillac,” he says. “It loves the open highway, has a great sound system, and heated hand grips, which are a must for those chillier riding days. In 2019, I rode the Spyder to Winnipeg and back. I camped along the way. I carried all my camping gear, clothing, and food on the bike.”

He was having so much fun on the Spyder that, when Can-Am came out with a new three wheeler in 2019, he couldn’t resist.

“Of course, ask any motorcycle owner—you can’t have just one bike,” says Harrington. “So when Can-Am came out with the Ryker, this piqued my interest, because the bike was designed to have some off-road capabilities. As an ATV owner, I enjoy getting out into the bush on the quad, but the downside is you can’t go on the roads or highways with the quad. So I thought the Ryker would be the perfect fit to enable me to get out to the forest service roads without having to trailer the quad first to get there.”

In short order, he purchased a nearly-new Ryker, which was again modified with a hand braking system. He quickly fell in love with the new purchase.

“The Ryker is like a Baja rally car,” he says. “It does much better on the gravel roads than the Spyder. Unlike the Spyder, you’re able to turn off the stability control system, which is referred to in the Spyder community as ‘the Nanny’. This system ensures the bike’s traction is effective and helps control the bike in the turns. I’m happy to have the system on the Spyder when travelling on the highways; however, for the Ryker Rally, when I’m on the forest service roads, I like to be controlling the bike, as opposed to the bike controlling me. It’s great to get more onto the off-beaten track and it rides more like an adventure bike.”

Besides the braking systems, the only major modification Harrington needed for both bikes was a carrier system for his wheelchair. For the Spyder, he worked with a local metal fabricator to develop a system that’s secured onto the backrest and seat on the bike.

“This essentially holds the chair off the back of the bike,” he explains. “It even allows space for a passenger on the Spyder. Three quick-release mechanisms hold the chair securely in place. Of course, that’s when you remember to tie it down. One day I had placed the chair on the bike, got distracted, and

forgot to tie it down before I hit the road. Well, a few 90 degree turns later, I happened to look in my side-view mirror to see my chair hanging haphazardly off the side of my bike. Close call!”

With the Ryker, he developed a similar system, with the difference being it utilizes a top box on the bike of the bike. “I placed some ATV gun rack tie-downs on the top box to lock onto the wheelchair’s axle. I then just fabricated an extension out of aluminum to hold some of the remaining weight of the chair and stop it from hitting the top box. It also keeps the chair in good position, so the integrated top box lights can still be seen well from behind.”

With either bike, Harrington transfers aboard and then manually pulls his chair up in series of manoeuvres to get it into position on the carrier and locked in place.

“With the Spyder, the wheels stay on the chair, but with the Ryker I have to remove the wheels from the chair because it won’t fit due to the width of the top box,” he says. “I utilized some spare wheelchair axle receivers to use as holders for the wheels, one on each side of the bike, which I attached to the existing pannier racks.”

While his own wheelchair carrier designs work great, he thinks there are other options. “I’m sure there are other methods that could be utilized as well, such as using a folding wheelchair and having a carrier installed on one side of the bike. I think this would lessen the distance from the ground to the carrier, making it perhaps easier to get the chair onto the bike.”

His next challenge is to find a way of towing a small tent trailer which can be towed behind him. “I think this would be a great companion to the Spyder or Ryker for those longer trips. The Spyder already has the ability to add a tow hitch, complete with the necessary wiring. The Ryker doesn’t have any such set up. However, with a little ingenuity, anything is possible!”

Little wonder Harrington is dreaming of warmer weather.

“Both bike are amazing and provide me with a lot of enjoyment. I think the Can-Am bikes are a great choice for anyone who wants to ride, but may not be able to manage a two-wheeled motorcycle.” ■

Visit [can-am.brp.com](http://can-am.brp.com) to see the entire Can-Am lineup.



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# Relax the Risk

New research by Dr. Andrei Krassioukov's ICORD lab confirms the ability of fesoterodine to improve urinary function and reduce the risk of AD for people with SCI.

**N**eurogenic detrusor overactivity, or NDO, is a reality for the majority of people with SCI, with incidence estimates of up to 95 percent for those with injuries anywhere above the sacrum. At the very least, NDO (sometimes referred to as neurogenic or spastic bladder) increases the difficulty of managing your bladder routine—more UTIs, more accidents, less quality of life. But because it often compromises the coordination of the muscle of the bladder and the urethral sphincter, NDO can lead to an overfull bladder—one of the most common triggers to often-dangerous bouts of AD, or autonomic dysreflexia. So for people with SCI, treating NDO may have a greater benefit beyond reducing the misery of bladder incontinence.

For this reason, Dr. Andrei Krassioukov, ICORD principal investigator and one of the world's foremost experts on AD, has long made treatment of NDO a research priority in his lab. A few years ago, he and his colleagues demonstrated that Botox injections to relax the bladder can not only improve urinary function, they can also reduce the frequency and severity of AD in persons with SCI at or above T6.

The problem, however, is that Botox (which is the trade name for botulinum toxin type A) is a second-line treatment for NDO. The first-line treatment (the one clinical guidelines recommend first) is a class of pharmaceuticals known as antimuscarinics—a subtype of a class of drugs known as anticholinergics. These



drugs work by blocking nerve signals to the bladder. While not as robust, the relaxing effect in the bladder is very similar to that of Botox, and the advantages are that no invasive injections are required, and the cost is significantly lower.

Recently, Krassioukov and members of his lab received industry funding to see if, like Botox, a particular antimuscarinic drug known as fesoterodine might have the same ability to reduce the incidence and severity of AD. Fesoterodine has been approved in Canada to treat NDO since 2012, and its ability to do so is well-established through research around the world. But it's really never been evaluated to see if it's effective as an agent to prevent AD.

The study was led by Dr. Matthias Walter, a former post-doc in Krassioukov's lab who has since returned to his native Switzerland to take a post at University Hospital Basel. It involved a 12-week course of fesoterodine, followed by administration of standard urodynamic studies (UDS). No doubt, most readers are familiar with UDS—most SCI BC peers receive one annually. As UDS involves filling the bladder, it often triggers AD, and urologists administering the tests have to be vigilant for this.

Twelve participants were recruited—four women and eight men, with a median age of 42. All were injured for more than one year, and had injury levels of T6 or higher. Following their course of fesoterodine, they underwent UDS.

The study results, titled *Fesoterodine Ameliorates Autonomic Dysreflexia while Improving Lower Urinary Tract Function and Urinary Incontinence-Related Quality of Life in Individuals with Spinal Cord Injury: A Prospective Phase IIa Study*, were published in the October 25, 2022 issue of the journal *Neurotrauma*.

While the title of the study might seem unusually long and unwieldy, it does make it obvious at a glance that the results were, in fact, successful.

“With regard to our primary outcome, 10 (83%) and nine (75%) participants experienced a decrease in severity of AD during UDS and during daily life, respectively,” wrote Walter and his fellow researchers. “The majority of our cohort experienced a decrease in severity of AD during UDS and in daily life without any significant deterioration of cognitive or bowel function...In conclusion, fesoterodine reduces the magnitude and frequency of AD, while improving LUT (lower urinary tract) function and urinary incontinence-related QoL in indi-



Dr. Matthias Walter



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viduals with chronic SCI without negatively affecting cognitive or bowel function.”

Walter admits he and his colleagues were expecting positive results, but perhaps not the degree to which they were successful.

“To be honest, I was actually a bit surprised how efficacious fesoterodine is, even indirectly compared to the very potent second-line treatment option of Botox,” Walter says, adding that seven of the 12 participants didn’t show any signs of NDO during UDS, and none seemed to be suffering from any side effects that have been associated with fesoterodine in past studies, including cognitive or bowel dysfunction.

All in all, says Walter, the results suggest that SCI BC peers prone to NDO and AD should consider talking to their doctor or urologist about fesoterodine or another antimuscarinic, either as an ongoing treatment, or a short term treatment leading up to scheduled UDS (note that, while there are other types of antimuscarinics, fesoterodine is the only one that has been assessed for efficacy with AD specifically).

“Experiencing AD during UDS is just one possibility; however, it gives you an idea how persons with SCI might experience NDO-related AD during daily life,” he says. “So if one person under treatment with fesoterodine has less frequent or less severe AD during UDS, this person will likely have less frequent or less severe AD during daily life, as we saw in our study using Botox. Fesoterodine, as well as other antimuscarinics, is not

only a first-line treatment option, but for some individuals, is the only option covered by their healthcare insurance. For example, Canadian provincial healthcare coverage often does not include second-line treatments, such as Botox, thus presenting significant economic burden.”

Walter points out that the study had several limitations, including lack of a control or placebo group, and limited number of participants. For these reasons, he and his colleagues are now hoping to conduct a larger, randomized, double-blinded, placebo-controlled study to confirm the benefits. ■

## The BC Government Wants Your Feedback

The BC Government’s Accessibility Feedback Tool, part of its ongoing work to implement the *Accessible BC Act*, is now online for people to share their experiences when it comes to accessing provincial government services. The tool will support the government’s ongoing efforts to identify, remove, and prevent barriers that impede the full and equal participation of everyone in BC. Barriers include anything that hinders you from easily accessing or taking part in something fully and equally, and include physical barriers such as lack of wheelchair ramps, and communication barriers that restrict access to information. In addition to submitting your experiences online with the tool, you can also provide your feedback by phone, email or regular mail. Learn more and share your feedback: <http://ow.ly/BNSN50Lqcy6>

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

# 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.

## Sex Differences in Cardiac Function After SCI

**Overview:** ICORD researchers Drs. Chris West and Alexandra Williams are investigating whether or not there are differences between the male and female heart in individuals with SCI, and comparing those differences to any sex-related differences that exist in uninjured individuals.

**What to expect:** What to expect: This study requires one visit of 1.5 to 2 hours. The research team will collect ultrasound images of your heart and monitor your blood pressure while you are lying flat, and then during different postures on a tilt table (tilting upwards and downwards).

**Who can participate:** Individuals living with SCI between the ages of 18-45 may be eligible to participate if they have had a motor-complete SCI between the C4 and T6 levels for more than a year. Uninjured individuals between the ages of 18-45 may also be eligible to participate. Please see the study listing on the ICORD website for the full list of eligibility criteria.

**Why participate:** At the moment we don't know whether there are differences in the male and female hearts after SCI, so this study will be the first to look at whether or not those sex-related differences exist and how they relate to blood pressure control. Participants will receive an honorarium upon completion of the study.

**Location:** This study is taking place at Blusson Spinal Cord Centre.

**For more information or to sign up:** Please contact the study coordinator, Alexandra Williams, by email at alex.williams@ubc.ca.

## Using Near Infrared Spectroscopy (NIRS) On the Bladder

**Overview:** ICORD researcher and urologist Dr. Lynn Stothers is assessing a device that uses light to determine how the bladder muscle uses oxygen. The aim of this study is to develop safe and non-invasive techniques for studying bladder function without the use of catheters in people with SCI and other neurological injuries or disorders. Currently, all tests related to the function of the bladder require that a catheter be in place.

**What to expect:** This non-invasive research study will be done during a urodynamics study (UDS). You can expect UDS to take about 15 minutes during the one-hour time requirement.

**Who can participate:** You may be eligible to participate in the study if you have an SCI or other injury or disorder related to nerves, spinal cord, or brain; are aged 19 years or older; and require examination and measurement of bladder pressure using UDS.

**Why participate:** It is hoped that the information learned from this study can be used in the future to benefit other men and women with bladder symptoms due to a nervous system problem. A \$50 honorarium will be granted to you to account for your time and involvement in the study.

**Location:** This study is taking place at Blusson Spinal Cord Centre.

**For more information or to sign up to participate:** Contact the study coordinator, Kennedy Cresswell, by email at bladder.research@ubc.ca or phone at 604.675.8881.



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

# Gyne Rights

Spring Hawes believes BC women with SCI are being overlooked when it comes to an essential health service.

**S**pring Hawes, an SCI BC peer and staff member who calls Kelowna home, is on a mission to right a wrong—for herself, and for all women with SCI or those who use a wheelchair.

“The issue is that some disabled women have difficulty accessing gynecological care—or don’t receive any at all,” says Hawes, who is SCI BC’s Peer Program Coordinator for the Okanagan, a board director for the Interior Health Authority, and co-chair of BC’s Provincial Accessibility Committee. “This may be because there is an assumption that they don’t need it, their doctor doesn’t know how to provide it, they don’t have a doctor, their doctor’s clinic is inaccessible, the exam room or OBGYN exam table is inaccessible, or ultimately, there is no accessible clinic in their community.”

To illustrate the problem, Hawes, who has a complete C7 injury, points to her own situation in Kelowna.

“My gyno has an accessible office, with an OBGYN exam table that lowers, so some disabled people can transfer onto it,” she explains. “However, some people like me can’t self-transfer, and require physical help or a ceiling lift, which no private gyno anywhere in BC has, at least that I’m aware of. Also, paralyzed people and others need leg supports, which regular exam tables don’t have.”

The result, Hawes says, is that for women who use wheelchairs, or even many women who are elderly, lack of access too often leads to people skipping important, necessary exams.

“It affects me personally because I have a cervix and a uterus that require checkups, just like everyone else with



Spring Hawes

those body parts. But additionally, as a paralyzed woman who can’t see or feel important parts of me, it’s extra important to have regular examinations.”

Hawes has a long history of advocating and is a firm believer in equity in healthcare. And so she’s taken it upon herself to advocate for accessible gynecological care everywhere in BC.

“I’ve talked about it to everyone I can,” she says. “I have brought it up in my role as a board director for my health authority. I’ve spoken about it to researchers. I have collaborated with my gynecologist. I talked to my colleagues at SCI BC. I’ve

talked about it on social media, and I’m talking to *The Spin* now.

“At a minimum, I would like to see the regular provision of accessible gynecological care be a requirement for every Patient Care Network established in our province. This is something the Ministry of Health could mandate and fund. It should be a deliverable, in my opinion.”

She believes that her efforts are important, but adds she can’t achieve what needs to be done without help—particularly from other peers.

“Talk about it!” she says. “Share your experiences. Talk to your healthcare provider. Have a meeting with your MLA. SCI BC can amplify these messages on behalf of our membership.”

She also hopes that the research community will take up the challenge as well, starting with efforts to better understand the problem, and the risks that lack of access bring with it.

“Health research rarely focuses on disabled people, so there is a lack of data about our health, as a demographic,” she says. “There are a few studies that show that disabled people do not access preventative health services like mammograms or pelvic exams to the same degree as able-bodied people, but I have not been able to find any research about how that affects us as a population. Do more of us die of cervical cancer? Logically that would be true, but there doesn’t appear to be studies that have attempted to determine this.”

Meanwhile, Hawes urges anyone willing to take up the cause alongside her to get in touch with her via email ([shawes@sci-bc.ca](mailto:shawes@sci-bc.ca)). ■

## Accessible Gynecological Care: Take the Survey!

Here at SCI BC, access to gynecological care is an issue that we deeply care about. We completely agree with Hawes and applaud her efforts, and that’s why we’re working with her and some research partners to find ways of making change. You can help! If you have a uterus or a cervix, take our Gynecological Care Access Survey and tell us where you’ve experienced gaps when attempting to access this care, or share an accessible clinic or experience with us so we can refer other peers there. You can find the survey online at [sci-bc.ca/gynccare](https://sci-bc.ca/gynccare). It only takes a few minutes to share your thoughts and make a difference.



# RICHARD PETER

## MEET THE NEW **INDIGENOUS** **LIAISON FOR BC SCI NETWORK!**

The BC SCI Network is pleased to welcome Richard as its Indigenous Liaison. In this new role, Richard will support the Network's actions on advancing reconciliation, connecting Indigenous people with disabilities to our services, and making connections to co-develop new, culturally relevant services. Richard also continues in his full-time roll with the Praxis Spinal Cord Institute.

A proud member of the Cowichan Tribes, Richard Peter is a respected leader, mentor and ambassador within SCI, Indigenous and Parasport communities.

A five-time Paralympian and a three-time gold medalist in wheelchair basketball, Richard is one of Canada's most decorated Paralympic athletes. In addition to his sporting background, Richard brings a wealth of experience to the role thanks to his current work as an ambassador for BC Wheelchair Sports Association's Indigenous Bridging the Gap program and previous experience as a Peer Mentor with Spinal Cord Injury BC, helping people with SCIs adapt and thrive.

This new position is made possible, in part, thanks to the support by the BC Government and viaSport BC's Team UP Grant. The BC SCI Network would like to recognize and thank the provincial government for its support of the network and its organization's initiatives that help people with disabilities live, work and play across the province.

**About the BC SCI Network:** Formed in 2010, the BC Spinal Cord Injury Network (BC SCI Network) is comprised of five disability organizations working together to help make BC the best place for people with physical disabilities to live, work, and participate in the community.



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