

the spin

SPINAL CORD INJURY BC

WINTER 2019



In Pursuit of the Perfect Fit

Kevin Priebe gave up a career in the film industry to pursue his dream of creating customized wheelchairs and seating for his fellow SCI BC Peers



WorkBC Assistive Technology Services

Assistive Technology Services are available to individuals who have a work related barrier due to a disability or functional limitation. Learn about how this service can benefit you by attending a Lunch and Learn or Webinar.

Topics include:

- Workplace accommodations
- Available resources
- Community supports programs
- Funding options
- Assistive technology demonstration

Lunch and Learns take place at the Assistive Technology Services Lab, 400 – 3999 Henning Drive, Burnaby, BC V5C 6P9, on the 3rd Thursday of every month from 11:50am to 1:00pm. Lunch is provided.

Webinars take place online on the 3rd Wednesday of every month from 12:30pm to 1:00pm.

**For more information or to register, please contact Marketing Manager, Nate Toevs:
604-473-9363 ext. 122 or natet@neilsquire.ca
For more information: workbc-ats.ca**



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

contents

WINTER 2019

features

11 What's in your wallet?

Why SCI BC Peers should get and carry our new UTI wallet card.

12 Reversal

New findings by BC researchers suggest that lidocaine is only making things worse when it comes to your bowel routine.

14 Destination: Desolation Sound

Two intrepid SCI BC Peers sail their pocket yacht into BC's coastal wilderness.

18 Cover Story

SCI BC Peer Kevin Priebe left a successful career in the movie industry to customize your next wheelchair.

22 A New Option on the Island

Vancouver Island is home to a new clinic that offers SCI BC Peers the most innovative and effective treatments to restore hand function and ease spasticity.

26 Overreaction

A crackdown on opioids has left some people with SCI who live with severe neuropathic pain caught in the crossfire.

30 New and Improved

The *Physical Activity Guidelines for Adults with SCI* now spells out just how much exercise you need to improve your fitness—and reduce your risk for cardiometabolic disorders.

departments

4 editor's message

Skills training isn't enough to boost employment for people with disabilities.

6 gear & gadgets

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

8 events

Important dates for your calendar.

10 peer shoutouts

Giving credit where credit's due.

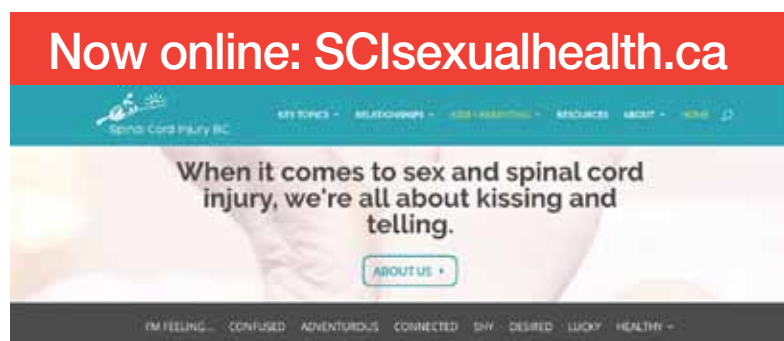
32 participate in research

ICORD research projects that need your participation.

34 last word

SCI BC Peer Program Coordinators Sonja Gaudet and Josh Dueck are honoured with hall of fame inductions.

Cover photo credit: Alison Brierley



Hard Work

As a society, we are obsessed with employment, and understandably so. Employment, or a lack of it, often defines us—it determines our relative well-being, our status, our life satisfaction, our ability to make choices about how we live. From a government perspective, employment is critical for productivity, economic growth, and stability. It allows people to be contributing, tax-paying participants in society.

It's no wonder then that governments pour money into social development programs and services aimed at increasing the number of people who are employed, including people with disabilities.

So why, then, has the employment rate for people with disabilities remained so far below that of the general population, and relatively unchanged for so long?

The simple answer is that increasing employment of persons with disabilities is not that simple. Most employment programs focus on skills training, coaching, and work experience. These types of programs often lead to successful outcomes for many people, but have limited success for people with disabilities because they fail to consider or address the myriad of barriers to employment they face: lack of access to worksite supports, accessible transportation, accessibility in the built environment, home care support and supports for daily living, affordable accessible housing, and flexible and informed employers.

The simple approach is not enough; supports for people with disabilities that extend well beyond those directly related to employment are required. This was underscored recently during the community consultations on the provincial government's accessibility legislation that SCI BC held with our BC SCI Network partners. The input about employment was clear—for employment to be a realistic outcome (even contemplated as one) for many people with disabilities, a wide range of supports need to be in place that are far greater in scope than those that simply focus on the ability of the person to do the actual work.

And it's not just people with disabilities that need to be the focus. Participants at our consultations were clear that one of the stickiest hurdles to overcome is that many employers have poor awareness and education about disability. Clearly, employer perceptions and attitudes need to change, and efforts are needed to dispel myths about hiring people with disabilities.

A recent study by Canadian researchers affiliated with the Canadian Disability Participation Project used an evidence-based approach to challenge 11 concerns employers held about employing people with disabilities at each stage of the employment cycle (recruitment, hiring, workplace integration, and performance management). The results of their research (published in the *Journal of Business and Psychology*) dispel detrimental myths: people with disabilities don't want to work, a disabled employee wouldn't fit in with a company's workforce, and employees with disabilities are less productive/more inclined to be absent/more likely to leave the job. In other words, employees with disabilities make for great employees. They also add to the diversity of workforces in positive ways.

If increasing employment rates for people with disabilities truly is a priority for governments, then they must recognize the complexity of the challenge and invest in a much broader approach to supporting both individuals with disabilities and potential employers so that they are prepared to gain and provide employment, respectively. Unless we move beyond traditional employment programs, employment rates for people with disabilities will remain woefully low, and a large pool of potential employees will remain unavailable to sectors currently experiencing labour shortages.

None of this is easy. It requires commitment and hard work. Time to roll up our sleeves and get at it.

—Chris McBride, PhD, Executive Director, SCI BC



thespin

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

Executive Editor Chris McBride
Managing Editor Cliff Bridges
Assistant Editor Alison Brierley
Design Cliff Bridges
Administration Maureen Brownlee

SUBSCRIPTIONS

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

ADVERTISING

Advertising rates and a publishing calendar for *The Spin* are available online at sci-bc.ca/stories/spin-magazine. You can also contact Terry Chen at tchen@sci-bc.ca or 604.326.1212.

SUBMISSIONS

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

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

COPYRIGHT

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

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

Publications Mail Agreement #: 40684573
ISSN #: 1922-9445

Return undeliverable Canadian addresses to:
Spinal Cord Injury BC, 780 SW Marine Drive
Vancouver, British Columbia V6P 5Y7 T: 604.324.3611

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

SCI BC HEAD OFFICE

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

REGIONAL PEER CONTACTS

Fort St. John: Lori Slater, Peer Program Coordinator
T: 250.787.1912 E: peervolunteerfsj@sci-bc.ca
Kelowna: Scott James, Peer Program Coordinator
T: 250.308.1997 E: sjames@sci-bc.ca
Nanaimo: Bert Abbott, Peer Program Coordinator
T: 250.616.1186 E: babbott@sci-bc.ca
Prince George: Brandy Stiles, Peer Program Coordinator
T: 250.563.6942 E: bstiles@sci-bc.ca
Quesnel: Alison Duddy, Peer Program Coordinator
E: peervolunteerq@sci-bc.ca
Metro Vancouver: Teri Thorson, Virtual Peer Program Coordinator
T: 604.714.4185 E: tthorson@sci-bc.ca
Metro Vancouver: Ryan Clarkson, Peer Program Coordinator
T: 604.714.4185 E: rclarkson@sci-bc.ca
Vernon: Sonja Gaudet, Peer Program Coordinator
E: sgaudet@sci-bc.ca
Kamloops/Kootenays: Joshua Dueck, Peer Program Coordinator
T: 250.306.7061 E: jdueck@sci-bc.ca
Victoria: Scott Heron, Peer Support Specialist
T: 250.812.0773 E: sheron@sci-bc.ca

SCI BC acknowledges the financial support of the BC Gaming Commission, the Rick Hansen Institute, and the BC Paraplegic Foundation.

SCI BC Info Line: 1.800.689.2477



Making it easier to get back on track



Concerned about UTIs? You're not alone.

UTIs are a common issue for many catheter users. If you have worries, or feel uncertain about how to reduce your risk of UTIs, you're not alone. Indeed, with many catheter users experiencing two or more UTIs every year¹, they represent a significant source of concern.

Understanding Urinary Tract Infections is a free guide that provides helpful advice for catheter users on keeping their bladder health on track.

¹Source: IC user survey (Countries: US, UK, DE, NL, FR, IT), January 2016 (n=2942)

Request your **free** copy of
Understanding Urinary Tract Infections



Coloplast Consumer Support
1-866-293-6349



www.coloplast.ca/utibook



Making life easier

Ostomy Care, Continence Care, Wound & Skin Care and Interventional Urology

The Coloplast logo is a registered trademark of Coloplast A/S. © 2019-10 All rights reserved Coloplast A/S, 3050 Humlebaek, Denmark.
Coloplast Canada, A205-2401 Bristol Circle, Oakville, ON www.coloplast.ca

 **Coloplast**

PM-09171

FFORA

FFORA products are designed for wheelchair users seeking functional, adaptive accessories without compromising fashion. At the heart of the system is a proprietary attachment, which is essentially a dock or holster for attaching the company's other accessories to the customer's wheelchair. The attachment system is compatible with 21 manual wheelchair brands and more than 170 wheelchair models. Currently, there are three accessories that attach to the system—a cup holder and two different sizes of leather bag. Other pieces will be developed as needs and designs are identified. See more at ffora.com.



users stay cool. It consists of an ergonomic backrest cushion with a built-in fan that provides instant cooling. It works by dispersing air evenly across your back to lower your core temperature and keep your skin dry and clean. Power is provided by a rechargeable battery, with up to 20 hours of operating time on the lowest of its four cooling levels. Currently, the system is designed to fit all manual lightweight wheelchairs; the company intends to develop a version for power chairs. The cushion is composed of high quality memory foam, which also offers extra support while seated. More details at wheelair.co.uk.



PHASE 2 HYBRID FORKS

Frog Legs has been building shock-absorbing front forks and casters for wheelchairs for decades. The company's new Phase 2 Hybrid Forks take the concept to a new level. They feature an aluminum top with a high-strength, lightweight, curved carbon fibre swing arm and a wedge-shaped polymer shock absorber, all of which the company says combine to give the Phase 2 Hybrid Forks a faster quicker response to bumps and a smoother, vibration-free ride. The wedge shape also creates a progressive response — it becomes stiffer as more force, such as from cracks and bumps, is put on it. This prevents bottoming out, creates a smoother ride, and makes it easier to roll over small obstacles like curb cuts, sidewalk cracks and door thresholds. The Phase 2 Hybrid Forks are intended for users weighing up to 118 kilograms, and with any caster between three and six inches. Visit froglegsinc.com for more information.



Innovations

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

WHEELAIR

The WheelAir system is designed to help manual wheelchair



GRIPBEATS

Developed by a collaboration of designers, engineers and musicians, GripBeats is a wearable device that turns your hand into a musical instrument. It allows you to create music in any style, sound or instrument, using your hand's movements in three dimensions, along with touch. The device connects to your phone, tablet or computer wirelessly using Bluetooth, and is fully compatible with apps such as Garageband and Ableton. It can be laid flat on a surface and played by touching its 32 pressure sensors, or worn on your wrist like a watch. Suggested applications include triggering samples and playing arpeggios, virtual drums, melodies, bass lines, chords and sound effects. To fully understand how it works and its potential, visit gripbeats.com and watch the many videos available.



WE ARE BESPOKE

NOUS SOMMES SUR MESURE

WHEELCHAIRS | FAUTEUILS ROULANTS



BATEC MOBILITY



BATEC MOBILITY



BENOIT SYSTEMES



VARILITE CUSHIONS & BACKS



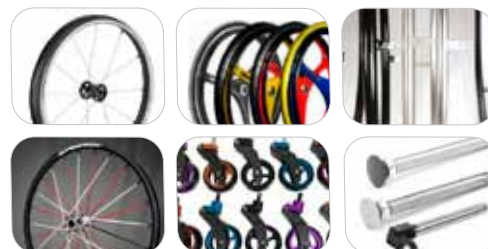
AELITE CRUTCHES



TIRES



WHEELS, SUSPENSION, PUSH RIMS & AXLES



ACCESSORIES



OFFERING A FULL PRODUCT LINE !

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

OFFRANT TOUTE UNE GAMME DE PRODUITS !

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



51 Caldari Rd, Units 6-7B
Concord, ON, L4K 4G3



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

49 **BESPOKE.COM**



Take the fastest way down.

If you're an intermediate skier or snowboarder, The Adaptive Snow Sports All Mountain Camp is ideal for you. It will provide four days of instruction, with a mix of race and all-mountain skill development, with both alpine and snowboarding drills. You'll build confidence, work on your technique and socialize with old and new friends! It takes place Jan 23 to 26, 2020 at Sun Peaks Resort. Visit bcadaptive.com for more details.



Discover your inner artist.

Our upcoming art class in Nanaimo will give Peers the chance to explore their creative side alongside their Peer community in a supportive environment. No skills or experience are necessary; just a willingness to have fun and try something new. All painting supplies are provided. The event takes place February 13, 2020 at the Nanaimo Aquatic Centre. For more information or to RSVP, contact Bert Abbott (babbott@sci-bc.ca; 250.616.1186).



Get into the groove.

Interested in checking out Nordic sit-skiing? Join Vancouver area Peers and our friends at Whistler Adaptive Sports Program (WASP) for an exciting day on the trails of Callaghan Country, south of Whistler. This free event takes place March 7 and is open to Peers regardless of experience. All equipment will be provided by WASP—just bring your smile and warm clothes! RSVP to Jenna Wright (jwright@sci-bc.ca; 604.326.1210).

Give a Gift That Lasts All Year

Give the gift of confidence, independence and community.

Become a monthly donor with Spinal Cord Injury BC and help British Columbians with SCI and their families adapt, adjust, and thrive.

VISIT sci-bc.ca/monthlygiving
EMAIL smilstein@sci-bc.ca



Spinal Cord Injury BC

Become a Monthly Donor



Supporting Chairstuff Supports SCI BC!



SCI BC is proud to announce a new, long-term sponsorship agreement with Chairstuff.

GREATER REACH & BETTER SERVICE

Chairstuff has your back ...

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

Intermittent Catheters

Bowel Products

External Catheters

Foley Catheters

Drainage Bags

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

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

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

— Crystle

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

– Kevin

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

STEVE MILUM

Founder & CEO
Chairstuff



1-866-363-0025 | 604-876-4133

info@chairstuff.com

chairstuff.com



peers

A sweet shoutout to Vancouver's **JESS KRUGER** for launching The Stubborn Baker, which offers custom cakes, cookies, and much more for any occasion. A recipient of the GRAGOPEAN Scholarship Trust (a scholastic award distributed by SCI BC and The Vancouver Foundation) and a graduate of Vancouver Community College's Baking and Pastry Arts program, Kruger is passionate about spreading joy through her love of baking and decorating.

"I chose to start my own business for a couple of reasons," she says. "One, because I've always dreamed of having my own bakery and this seemed like the next logical step in achieving that; and two, the pastry industry is a tough gig for someone in a chair, and I wanted to create an environment that was going to allow me to thrive."

So far, she's been overwhelmed by the support she's received.

"The best part about this business is getting to make something beautiful and delicious that will hopefully brighten someone's day. I started cake decorating when I had my SCI because I was desperately looking to find new hobbies to fill the void of the ones I had lost. In many ways, it has helped pull me out of a difficult time in my own life, in that it allowed me to bring joy in some small way to the people I cared about."

Place your order at thestubbornbaker.com.



A massive pedal-powered shoutout to **LEO SAMMARELLI** for taming the gruelling Gran Fondo on his handcycle.

The September 7th event, which this year celebrated its 10 year anniversary, saw thousands of cyclists tackle a 123-kilometre route from the Lion's Gate Bridge, up the Sea to Sky Highway, and to the conclusion in Whistler. Along the way, participants pedalled up almost two kilometres of elevation.

"It was a tough challenge doing it at race speed," says 25-year-old Sammarelli, a former Canadian boxing champion who was injured in a North Vancouver shooting two years ago. "My arms felt like I'd gone 15 rounds with Mike Tyson when I finished."

And finish he did, in a time of just over eight hours.

Sammarelli has embraced handcycling and virtually every other sport possible as a means of adjusting to his post-injury life.

"It all reverts to sports," he says. "I was able to immerse myself in sports, and that really helped with the pain, the emotional, physical and psychological pain that I was dealing with. Rehab doesn't stop after you leave GF Strong; there's always more you can do."



Peer Shoutouts

A huge forehand shoutout to Kelowna's **ROB SHAW**, who recently captured the gold

medal in singles quad tennis at the Parapan American Games in Lima, Peru. In doing so, he became the first Canadian tennis player to win a singles medal at a multi-sport games.

"This is definitely the biggest win so far of my career if you consider the magnitude of the stage and the number of fans in the crowd," says Shaw, a doctoral student in UBC Okanagan's Faculty of Health and Social Development. "There's a really big tennis wave going through the country right now and it's just nice to contribute a little ripple."

Shaw is ranked ninth in the world and is the reigning four-time national quad singles champion. His two immediate goals are to qualify

for the Tokyo 2020 Paralympics and complete his PhD—as a doctoral student, he works in professor Kathleen Martin Ginis' SCI research group, which focuses on improving the health and well-being of Canadians living with SCI. In particular, Shaw is investigating the impact of peer mentorship for people with SCI in both hospital and community settings.



A big literary shoutout to longtime SCI BC Peer and well-known Comox folk musician **JUDY**

NORBURY, who recently published a travel memoir titled *Sometimes I Kiss My Feet: Wheelchair Adventures in Pakistan and India*.

Norbury was born in the foothills of the Himalayas to a Canadian fashion-model mother and a British father. She spent four years there, until she contracted polio and her family relocated to Vancouver.

The autobiographical book explores her early memories in India, where she was beloved by the villagers and neighbours, her return to India 43 years later, and her experiences on a more recent return visit, when, in addition to visiting India, she spent some time in Pakistan visiting a fellow polio survivor.

"In Pakistan my husband and I were guests of people who were activists in the disabled community, and it was a remarkable experience," says Norbury.

Her book is available on Amazon as both a paperback and a Kindle e-book.



Are you an SCI BC Peer who has something to shout about? Or do you know a Peer who has recently achieved something noteworthy? Send the details to thespin@sci-bc.ca.

What's in Your Wallet?

A collaboration between GF Strong clinicians and SCI BC leads to development of an important new resource for our readers

At GF Strong, physiatrist Dr. Viet Vu and Outpatient Nurse Bonnie Nybo routinely ask spinal cord injured patients to provide a urine sample when a UTI is suspected. But when they began noticing patients drawing samples from their existing Foley or SP catheter without changing to a fresh one, they became concerned. Samples from a used catheter almost always have high levels of bacteria, and the result is often a false positive—samples show signs of infection when there isn't one and, in turn, patients are prescribed antibiotics when they're not needed.



Jocelyn Maffin

Given that antibiotic overuse leads to bacteria becoming resistant, Vu, Nybo and Rehabilitation Consultant Karen Anzai approached SCI BC Resource Centre Manager Jocelyn Maffin with an idea for a resource that would help prevent this.

"At the same time, on InfoLine and as part of development of the LivingWithSCI.ca online resource, I was starting to see that many Peers didn't have a good understanding of what the signs of UTIs were and when they should seek treatment for them," says Maffin. "I think the same week they came to see me about this resource, I was working with several Peers who were dealing with UTIs on both ends of the spectrum—some on endless rounds of antibiotics, and some uncertain about when to go to the doctor despite serious symptoms of kidney infection."

Together, they agreed that a wallet card Peer resource would be a perfect way to address this knowledge gap.

"A wallet card format was just right for this, because it lets us put the best practice evidence in the hands of the Peer for their own information but also to support discussions with their physicians," says Maffin. "I was seeing that Peers needed something that helped them understand how and when to seek treatment for UTI symptoms, and the clinicians at GF Strong wanted Peers to know exactly how to produce a proper urine specimen so that their physicians had an accurate picture to base treatment decisions on."

The new card, which debuted in October, was carefully and collaboratively developed by Maffin and the clinicians, with best practice evidence gleaned from the SCIRE (Spinal Cord Injury Rehabilitation Evidence) resource.

Maffin believes that the card is relevant to anyone with SCI who is a catheter user, but especially valuable for those with recent injuries who are returning home and will be looking after their ongoing care with their family doctor.

"Their doctor may not have any other SCI patients, and may not specify that a specimen needs to come out of a clean catheter," she says. "The wallet card would serve as a reminder to the Peer about what their specific needs are related to being a catheter user who has a risk of UTIs, and as a way to share that information with their physician in the event of a UTI."

It borrows some features from the autonomic dysreflexia (AD) wallet card that are intended to give it some extra weight during conversations with physicians.

"For example," says Maffin, "there's a space for the SCI specialist clinician to sign and add their information when they give the card to the Peer, which we hope emphasizes its credibility when it's shared with another physician. We also added a special link to SCIRE so that a physician or ER clinician could look up that evidence if needed."

The UTI wallet card is still a brand new resource, and we'll strive to improve it over time.

"Ultimately, we want these cards to not just inform Peers, but equip them to have informed conversations with their physicians and enable them to get the best care for their SCI and its complications," says Maffin.

Printed copies of the new UTI wallet card can be picked up at GF Strong (either from the clinician you're seeing or from our own SCI Resource Centre on the ground floor), or the urology clinic at Blusson Spinal Cord Centre. Anyone outside of Vancouver can simply email info@sci-bc.ca or call our Infoline to request a card be sent to them by mail. Yet another option is to download the digital file (www.sci-bc.ca/UTIcard) and print it at home. Note that the image below only represents one side of the UTI wallet card. ■

Note for Clinicians

It is recommended to start empiric antibiotics if:

1. Fever is above 38° C
2. Leukocytes are elevated (or leukocyte esterase is positive)
3. Nitrites are positive
4. Increased spasticity from baseline
5. Other symptoms: bypassing urine, autonomic dysreflexia, malaise or chills are present

Otherwise, please wait until the results of the culture are available. A positive culture is >100m/cfu. Do not use Nitrofurantoin (Macrobid) unless no other options are available, as this is less effective for complicated UTIs with underlying neurogenic bladder.

More info: scireproject.com/UTI

Referring Physician

x

Physician Stamp/Number

SPINAL CORD INJURY AND NEUROGENIC BLADDER

Information on Symptoms and Treatment

In partnership with:

Vancouver Coastal Health
G.F. Strong Rehab Centre

SCI BC Infoline: 1-800-689-2477
Connect: info@sci-bc.ca
More: livingwithsci.ca/bladder

Reversal

Is lidocaine part of your bowel program? New findings by ICORD researchers strongly suggest it's probably doing more harm than good.

Dr. Victoria Claydon has long been intrigued by how SCI disrupts cardiovascular function. As an ICORD scientist and Professor in the Department of Biomedical Physiology and Kinesiology at Simon Fraser University, much of her work focuses on autonomic dysreflexia, or AD, the dangerous increase in blood pressure that's a reality for many of our readers.

In 2018, two of her grad students—Vera-Ellen Lucci and Jessica Inskip—conducted a survey about bowel care. One of the key findings was that bowel care was a key factor that impacted quality of life, and that for many individuals, AD provoked by bowel care was particularly problematic. So Claydon, Lucci and Inskip, along with three other collaborators, decided to investigate further.

"There were hints from a previous study that anaesthetic lubricants, like those containing lidocaine, might improve AD during in-hospital, nurse-led bowel care by blocking the sensory stimulus that triggers the high blood pressure," says Claydon. "So we decided to test if this was true in a real-world community setting. We were hopeful that lidocaine would be an effective means to minimize AD for affected individuals, because the theoretical rationale for its use was compelling."

The team designed a study, and then worked with SCI BC and ICORD to recruit participants.

"Partnership with SCI BC was critical for this work—the nature of the research is inherently personal and having links with a trusted organization like SCI BC was important to help our participants feel comfortable," says Claydon.

In total, 13 people took part. They all had high level injuries, a history of AD, and a consistent bowel program. All were asked to complete their bowel care in the same way on two days, in the setting of their choice, while the researchers measured their blood pressure and heartbeat. On one day, they were randomly chosen to use the medicated lidocaine lubricant, and on the other day they used a placebo lubricant that looked identical but didn't contain any medication.

In addition to monitoring blood pressure and heart beat, the researchers measured the length of time it took to complete bowel care on each day.

When testing was complete, the researchers compared the results—and ended up being quite surprised.

When using the lidocaine lubricant, bowel care took about 20 minutes longer to complete than with the placebo lubricant. Not only that, the lidocaine lubricant clearly resulted in elevated AD levels. While all participants experienced significant AD on both test days, their blood pressure rose to a higher level, and stayed elevated for longer, with the lidocaine lubricant. Additionally, the researchers noted that, while cardiac arrhythmia (irregular heart rhythms) was common on both days, there were more arrhythmia incidents with the lidocaine lubricant.

Many said they felt as though their bowel care was worse on the day they used the lidocaine lubricant—they felt it took them longer to initiate their normal bowel movement, and that their bowel care took longer and was more difficult than usual on the lidocaine day.

"Prior to the testing, we did consider that lidocaine might impair reflex bowel emptying, which is why we included metrics designed to capture the impact of the medication on bowel emptying, like the time it took participants to complete their bowel care," says Claydon. "However, we always expected lidocaine would improve AD—we certainly didn't expect it to make the severity of AD

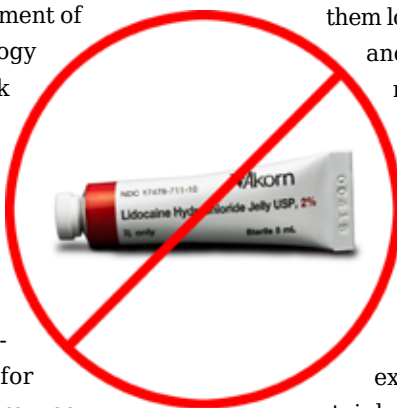
worse and exacerbate the cardiac problems."

Claydon and her team suspect the lidocaine lubricant impairs reflex defecation by blocking the sensory signals (like digital stimulation or suppository use) that are typically used to initiate a bowel movement by people with SCI.

"This means that it's harder to empty the bowels, and bowel care takes longer," says Claydon. "We think this more difficult, and longer bowel care increases the trigger for and duration of AD, resulting in blood pressure rising to higher levels for longer periods of time, and provoking irregular heart beats."

So now what, given that lidocaine lubricant is widely used by people with SCI for their bowel care, and recommended by medical professionals and institutions for this purpose?

"Based on our results, we have questioned the current clinical guidelines that recommend use of lidocaine lubrication to



Dr. Victoria Claydon (left) and Vera-Ellen Lucci, the study's lead author

reduce the severity of AD elicited during bowel care,” says Claydon. “This is something we thought very carefully about, because our study sample size was quite small, and in science in general it can be hard to make a case for modification of guidelines based on the experiences of a relatively small group. In this case, we decided to suggest the guidelines be reconsidered, despite the relatively small sample, for a number of reasons.”

The first, she explains, is that theirs is the only study that has looked at the real life experiences of individuals with SCI when using lidocaine during their typical at-home care; all three previous studies examined bowel care in the hospital or performed by a nurse. Second, although the sample size was small, Claydon says it was the *right* sample.

“We tested individuals most likely to use lidocaine to help manage AD during bowel care—those with high level injuries and known and quite severe AD, with a regular and predictable bowel routine. Accordingly, our data better reflects the

realities of bowel care for the target population.”

Third, Claydon says the team was careful to measure the true severity of AD elicited during bowel care by measuring blood pressure continuously throughout participants’ bowel program (the previous studies only measured it intermittently). Additionally, no other studies examined the impact of lidocaine on the time to complete bowel care, nor did they study cardiac function.

The bottom line, says Claydon, is that the team’s results with even a small sample were so significant that failing to question existing practice would be unethical, as would expanding testing to include more participants.

“In our case, we didn’t feel it was ethically responsible to continue testing more people when we already had compelling evidence that the lidocaine intervention was making things so much worse—we would be exposing these new participants to the intervention with little expectation of benefit, and perhaps

some risk to them given that we now knew that the lidocaine wasn’t working. So for ethical reasons as well as scientific ones, we stopped the trial and questioned the recommendations for use of lidocaine during at-home bowel care.”

Claydon and her colleagues will now focus on making sure that the results are widely publicized so that people with SCI, along with clinicians and caregivers, can change their practices.

Claydon also acknowledges that this research offers an important cautionary tale for her and other researchers.

“When conducting scientific research, we need to be aware that results in a controlled laboratory setting may not always equate in a predictable way to responses in real life, and it’s vital to work with individuals with SCI to examine how clinical interventions work for them in the real world,” she concludes.

The research was funded by the Craig H Nielsen Foundation and ICORD. The results were published last month in the journal *Spinal Cord*. ■



Alliance Mobility Solutions

info@amsvans.ca

www.amsvans.ca



BraunAbility
Life is a Moving Experience



VMI
imagine possibilities

Wheelchair Vans & Adaptations • Braun & VMI Vans • Vehicle Lifts • Driving Aids

Richmond Office: #110 – 12211 Vulcan Way | 604-370-7004

NEW! Kelowna Office: 1075 McCurdy Rd | 236-420-1400



Destination: Desolation Sound

When my husband and I decided to sail our 19-foot pocket yacht into the heart of the BC coast's pristine wilderness, we knew we had friends and family members secretly doubting our sanity. The reality, however, is that we knew our little boat was perfectly suited for two adventure-craving sailors who both have an SCI. – *by Shira Standfield*

“We should sail to Desolation Sound!”

And so began a conversation my husband Jeff and I had this past spring. It was an exhilarating adventure to dream about. But it was also one that appeared a little daunting, since we would be sailing more than 160 kilometres north of Vancouver in our modest 19-foot sailboat—and Jeff and I don't exactly fit the traditional definition of able-bodied seamen.

In the end, the prospect of an amazing trip and confidence in our pocket yacht outweighed our fears.

Once the decision was made, Jeff began creating our trip plan and I began figuring out a food menu for 21 days, the majority of which would be just us together on the boat.

We'd long known that *Chateau*, our little Horizon Cat made by Com-Pac yachts in Florida, works perfectly for us. She can be sailed from the cockpit without the need to climb up front. She has a trusty inboard diesel engine and a surprisingly comfortable interior despite her tiny size. We have everything we need on board to “glamp” comfortably. People always ask if the boat has

been adapted for us, given our limited mobility. The fact is, *Chateau* is just well designed and we had no need to make any changes to her.

There are some challenges with long trips, however, including limited storage space, no refrigeration, no flush toilet, and living in a very small space with another person for weeks at a time. We've managed to work out most of these issues by bringing just the essentials, dehydrating all of our food, using a camping toilet, and being very organized. We do make space for all of the essentials, though, including a guitar, ukulele, iPad, plush

duvet, a slingshot, two inflatable kayaks and paddles, scrabble, excellent coffee, Jeff's crutches and my wheelchair. Anything that doesn't spark joy or have a purpose is left behind.

We decided that we would need to be self-sufficient for 17 of the 21 days. We weren't sure we would find fresh produce and wheelchair accessible shops along the way, so we cooked and dehydrated food for our entire trip. I spent three weeks prepping and ended up with four shopping bags of food, including snacks. We had delicious meals including ratatouille, lentil dahl, stews, veggie chili, lemon citrus salad, scrambled eggs, oatmeal, and brownies for dessert.

From a practical sailing point of view, Jeff and I are a team, and together, we have all boating departments covered. He's the engine mechanic, trip planner, anchor and dock lines guy. I'm the cook, sailor, perfect anchoring spot finder, and VHF radio gal. We both work together to make trip decisions based on the weather forecast, tides and currents. Jeff is able to stand and climb up front to drop and lift anchor as well as flake the sail and tie it down. By necessity, he has become skilled at docking the boat, so there's no need for either of us to jump off when we approach a dock. We do get funny looks when we pull up to a fuel dock at a marina and don't stand up. There's usually a look of confusion at the fuel dock



SMOOTH SAILING: Jeff and I usually take turns at the helm.

when we ask the attendant if it would be OK for us to pay without getting off the boat. We always wink at each other when we see the confused look, and we also smile when we get our bill for a bit of diesel fuel, usually around \$6. It amazes me that some power boaters pay many hundreds of dollars each time they fuel up.

The reality is, fuelling up and going ashore aside, *Chateau* gives me a liberating opportunity to stow my wheelchair for several weeks and enjoy daily life without being "disabled" by barriers. I feel connected to my whole body while I'm on

the boat, as my legs follow me as I move around. There's no need to stand and, in fact, standing is awkward on a tiny boat. With a few extra pieces of adaptive equipment—a gel cushion with straps for moving around without a wheelchair, a grabber for reaching things without having to go below, and an inflatable cushion to protect my skin while transferring out of the kayak onto the boat—I've dialed in what's needed to make my cruising adventure comfortable and safe.

Jeff sailed solo for the first four days, leaving Vancouver on July 15 and mak-

About Desolation Sound

Desolation Sound is a deep water sound at the northern end of the Sunshine Coast in British Columbia, Canada. Flanked by Cortes Island and West Redonda Island, its spectacular fjords, mountains and wildlife make it a global boating and sea kayaking destination.

The Government of British Columbia created Desolation Sound Provincial Marine Park in 1973, under the advocacy of MLA Don Lockstead and the NDP government, out of an area comprising 8,449 hectares and over 60 kilometres of shoreline. Its many inlets, islets, coves and bays attract many pleasure craft each summer, when it is not uncommon for a hundred boats to share a small anchorage. The sound is home to a wide variety of wildlife and still relatively free from development, although some areas, such as Theodesia Inlet, show signs of clear-cut logging.

Desolation Sound was inhabited by tribes of the Mainland Comox prior to the arrival of Europeans. In the summer of 1792, two expeditions led by Captains George Vancouver, Dionisio Alcalá Galiano and Cayetano Valdés y Flores arrived and cooperated in mapping the sound. Vancouver named it Desolation Sound, cryptically claiming that "there was not a single prospect that was pleasing to the eye." - Wikipedia





ABOVE: Jeff enjoying the view as we approach a moorage. BELOW: Chateau looks a little diminutive at the dock. LEFT: Our tiny but functional galley.



ing his way up the Sunshine Coast. This gave him the opportunity to visit with family and have a few days to himself on the boat. Four days later, on the 19th, I joined him. I took the ferry and then bus up to Madeira Park and we started our trip together from Pender Harbour.

I'll concede it was a bit of shaky start. Low tide made for a very steep and sketchy ramp down to the dock. We had to do a bit of problem solving in order for me to get my wheelchair down to the boat without an incident that would have quickly ended our trip.

Safely aboard, we spent the afternoon anchored in beautiful Pender Harbour and paddling our inflatable kayaks to some intriguing sites.

The next day we were off on our adventure, making our way up the coast. Over the next few days, we fell into our routine: morning coffee, oatmeal, check the weather, clean up, get organized, lift anchor and head off.

Our goal was to arrive at our next anchor spot by around 3 PM, so we'd have enough time to inflate the kayaks, paddle, swim, explore the bay, dry off, have dinner, and perhaps enjoy a game of scrabble before planning our next day. The beauty of cruising is in its simplicity—experiencing the elements, enjoying the scenery and wildlife, listening to the water and wind, having time to think, having few responsibilities and limited screen time.

We spent the first days making our way up to the town of Lund, located at the end of the Sunshine Coast Highway. We were able to squeeze into a tiny spot at the marina, and dig out my wheelchair and Jeff's crutches. We certainly got a few surprised looks from people as we made our way up the ramp toward the marina office.

That night we had a lovely dinner at a little restaurant with a deck overlooking the marina, and a shower in an almost-

accessible public facility—a pleasant and welcome surprise.

The next day, we rounded the point to finally enter Desolation Sound. That's when we were treated with the money shot—the view of the sound with stunning mountains in the background; the same view that's shown front and centre on most guidebooks to the area. It was spectacular. We savoured the view and the feeling of accomplishment as we reached our destination. We found a little bay, anchored and had a lovely paddle that evening, checking out the little islands around us. Our chili dinner that night tasted especially good.

The next few days were spent meeting up with friends on another boat in Prideaux Haven. Together, we paddled, swam and enjoyed the view of the gorgeous cliffs at Tenedos Bay. Although there were quite a few large and even enormous yachts in some of the bays, little Chateau only draws 2.5 feet, so we were able to tuck into shallow and private areas and avoid the fray.

There were so many amazing days, but my favourite was our visit to the waterfall in Teakerne Arm. The wind was strong that day, so we had an exciting sail. Spotting a humpback whale feeding added to the day's magic.

The falls are situated in a horseshoe-shaped cliff. We were able to get fairly close to them in the boat. They were quite simply spectacular.

The wind picked up even more on our sail back to Refuge Cove, and we had some excitement in hoisting the sail and setting our course in the strong wind. Just as we were nearing our anchorage, we spotted another humpback whale breaching off in the distance. It got closer to us, all the while putting on a spectacular display jumping and splashing down into the water. Jeff was able to capture it on video and we were able to share our experience with family and friends. It was incredible to witness a whale while being under sail in such a beautiful place.

That evening, we found a private little bay in Refuge Cove and had a lovely late evening paddle, exploring the area.

There was a restaurant in the Cove, but there was a long staircase up to the building, so we feasted on a delicious meal of lentil dahl on the boat instead. We ended off the evening with a quick swim and wash in the bay.

With our last day in Desolation quickly approaching, we were excited to be meeting up with friends in their 41 foot yacht in Grace Harbour. They were just starting their own Desolation Sound trip as we were finishing. They were already anchored when we pulled up beside them and tied up to their boat. We felt so tiny compared to them—we couldn't even see up and into their boat! I wasn't able to transfer up the four feet to get up and into their boat, so all three of them climbed down and dined with us on Chateau. It was so crowded that I had to sit down in the cabin to make room, but we had lots of fun and stayed up until the mosquitoes ended our evening. Jeff and I seem to think Chateau is bigger than she is until we see her next to other bigger boats. But that's also what we love

about her—that she's tiny enough to get us into the best spots and anchorages, while being tough and stable enough to take us where everyone else gets to go.

After two weeks on the boat, it was time to say goodbye to Desolation Sound and make our way back to Vancouver. We treated ourselves to shore leave in Lund as well as at Grief Point near Powell River. Laundry, showers and meals on land were a treat.

Our second to last day was exciting as we rounded Gower Point on our way into Gibsons Landing Harbour. The wind had picked up and our last hour of sailing was quite epic for us. Chateau was fighting the gusts and we both had our hands on the wheel to keep her headed downwind. Jeff's uncle and aunt saw us heading for shore in front of their place, unaware that we were struggling to keep her heading through the channel and not up on the beach. After an exhausting hour, we managed to round the next point and, with some shelter from the wind, lower the sail and head in.

Our sail back to Vancouver from Gibsons Landing the next day was equally exciting with us surfing large waves from Point Atkinson all the way back to Kits beach. When we finally pulled into False Creek that afternoon, we were exhilarated—and incredibly proud of ourselves that we had such an incredible, independent adventure together, on our 19 foot pocket yacht.

You probably won't be surprised to learn that we'll be spending a lot of time this Christmas holiday talking about where to sail this coming summer! ■

Shira and Jeff Standfield are both long-time SCI BC Peers and former Paralympic rowers who have competed for Canada in wheelchair basketball and swimming respectively. Jeff is also a musician and has been involved with VAMS for many years. Our thanks to Shira for penning this feature story for The Spin. Our hope is that it inspires other SCI BC Peers to pursue their adventure dreams—whatever they are.



- driver adaptation & transfer seating
- accessible vehicles
- experienced, professional staff
- extensive inventory

 **Silver Cross**
 AUTOMOTIVE
silvercrossauto.com
1.877.215.7609





The Perfect Fit

SCI BC Peer Kevin Priebe believes there's no fit like a custom-fit. His new business, Society Wheelchairs, offers a customized experience to anyone seeking the perfect fit.

It was a full house at Vancouver's Andina Brewing Company during our annual Guys' Garage earlier this summer. Despite the crowd, Robert Smeltzer, an incomplete paraplegic, stood out from his Peers because of how tall he is in his chair. He was literally head and shoulders above the crowd.

At 6'2", Smeltzer (that's him on the right) is a tall man on his feet. In particular, his legs and arms are so long that he really has never been able to find a wheelchair that's high enough to be comfortable for him. Even his latest chair, an aluminum Ti Lite extra large with huge 26 inch wheels, forced him to bend radically at the waist in order to wheel.

"This was the case even though the extra large chair was fully adjusted to its top height," says Smeltzer. "Many inches of cushion and other materials were added and placed where necessary on the seat to mitigate this awkward positioning."

Last year, when he had the opportunity to have his ride customized by Kevin Priebe, a fellow SCI BC Peer, he jumped at the chance.

"I attended an SCI BC event at the Blusson Spinal Cord Centre, and it was impossible to miss Kevin's own extraordinary chair with its massive wheel customization and titanium frame," says Smeltzer. "Kevin quickly assessed that my extra large chair wasn't even close to being a workable fit, and determined that my leg/arm length was the equivalent to a person 6'6". So we loaded the chair into his van and the work began in his shop."

Priebe modified Smeltzer's frame by adding six inches of welded strut material to the brackets underneath the chair, which determine the height. He also modified the front tubes that join the foot platform to the rest of the frame. To properly balance the entire build, he added larger castor wheels.

"The end product was an increase of nine inches to the height of the chair and several inches to the wheelbase," says Smeltzer. "Not only is the entire ensemble now completely ergonomic, it is as smooth-operating as is possibly



imaginable, courtesy of artisan-calibre craftsmanship and the use of only top-end bearings and other materials. It's a pleasure to use."

Clearly, this wasn't Priebe's first kick at the can when it comes to customizing a mobility device.

A T3 paraplegic, he was injured 26 years ago when he was an 18-year-old living in Pitt Meadows. Like many Peers, he embraced sport as a way of dealing with his injury and rehabilitation. He first became a fierce competitor in sprint kayak and canoe, and then got hooked on cross-country skiing about ten years ago. Unsatisfied with the equipment he was using, he set out to build something better, using skills his father had taught him along with knowledge he'd acquired as a mechanical apprentice before his injury.

"I built my own seating, which led to a ski, then my own chair," says Priebe.

That was the beginning of Priebe's "hobby" as a custom mobility equipment fabricator. Since then, he's built his own wheelchairs and specialized sport seating, and taken on similar projects for a growing number of Peers. Along the way, he acquired more and more specialized equipment for his shop, along with new skills and even training at BCIT.

For years, he balanced fabrication with his job as a well-known special effects guru in the motion picture industry. It

was a job that he excelled at (among his achievements is a Leo Award, a provincial industry honour, for makeup and special effects in a Second World War film called *The Remembrance*). But at one point, he realized his true calling was custom mobility equipment fabrication.

"I needed a change of direction; to find a new path," says Priebe. "I loved the buzz being part of the film hubbub, but with all the hours on set I could see the end of my film career approaching."

In 2018, he took the first of several bold steps to make his dream a reality.

"It all started last year with putting pen to paper. I needed to somehow transform a hobby into a viable business and learn how to blaze a new trail. The first step was writing a business plan to test its viability on paper. I needed to review the existing market, find the actual numbers, and determine if they would work."

And that's where the Community Futures Entrepreneurs with Disabilities Program (EDP), which provides assistance to entrepreneurs with disabilities to start or grow their businesses, came to his assistance.

"It was no free ride," says Priebe. "We worked together for months. I can tell you this—I now know the market and my business!"

The next priority was finding funding, and stepping up to the plate was the Business Development Bank of Canada, or BDC. Priebe had made a decision to share a home in Maple Ridge with his aging parents, and make good use of the property's sizable shop. BDC provided funding for renovation, tools and equipment that Priebe needed to get his enterprise off the ground.

He also credits WorkBC Assistive Technology Services and the Neil Squire Society for their assistance with providing work place assessment and advice.

Following all of this, he made the bold move of incorporating Society Wheelchairs Limited—a company that specializes in building and modifying wheelchairs, seating and sports equipment, all customized to truly fit the size, shape and needs of its owners.



Kevin Priebe and his employee, Jazz Chew, focus on the exacting work of finishing a new custom sit-ski frame.

"We are all about fit, form and finish," says Priebe. "What that means is that our wheelchairs are an extension of who we are. It's important to us that our clients' lives are improved by making products that are designed to meet their needs and maximizing comfort through design; that our clients project

confidence and self esteem. Our goal is simply to improve quality of life through innovative wheelchair design."

Technology, he adds, is central to his vision of meeting clients' needs. He employs computer modelling, CAD and other technologies to arrive at designs that truly make a difference in peoples' lives.

"We are refining a process that is helping us to bridge the gap for the equipment fitting, using technology and ingenuity," he says. "We believe that, as we refine the process, it's going to become a game changer for our clients."

Already, Priebe's shop is crowded with projects. Yet hurdles remain. Foremost among them is cost.

"Titanium, carbon fibre and aluminum—making wheelchairs, custom seating and sports equipment requires a wide range of materials and equipment," he says. "Then throw into the mix the need to make the working environment accessible. We just picked up a CNC router for making fitted cushions, moulds and aluminum parts. We're stretching our budget; the equipment requires rebuilding and upgrading to do what we need. This is no easy task."

There's also the formidable task of going head-to-head with an established industry.

"We're challenging the normal in a mature market and that isn't easy," says Priebe. "Systems of manufacturing, supply and distribution are already well-established, and here I come with this novel idea of disrupting the market."

convenient & accessible

Welcoming the SCI community to this wheelchair accessible hotel on W. Broadway. Minutes to Blusson Spinal Cord Centre & VGH. Ask for Medical Rates.

Adding Color to LifeSM

parkinn.com/hotel-vancouverca

park inn
by Radisson & suites

Park Inn & Suites by Radisson Vancouver, BC
898 West Broadway, Vancouver, BC V5Z 1J8
T: +1 (604) 872-8661, F: +1 (604) 872-2270, pd_brbc@parkinn.com

(800) 670-7275
parkinn.com

One way that Priebe is meeting this challenge is by becoming a Community Contribution Company, or CCC, which is a hybrid corporate model established in BC in 2012 for businesses that bridge the gap between for-profit and non-profit. The CCC is the first hybrid business structure of its kind in Canada, and allows entrepreneurs in BC to pursue social goals through their businesses while generating a profit and providing investment opportunities to like-minded investors.

"Making use of this type of social enterprises business model will allow us to tap into programs and resources that we ordinarily couldn't," says Priebe.

Priebe's social business philosophy also extends to finding qualified employees who, like him, have an SCI or other physical disability. It's yet another reason why he's striving to make his shop and equipment universally accessible.

"We just were accepted into the New Ventures BC ISI grant program which is so amazing," he says. "It gives us the op-

portunity to hire students through both co-op and outside of programming. We will soon be eligible for Employer Training Programs. One of the biggest hurdles that I've struggled with in finding employment is getting accepted into certification programs. To become an employer that is able to offer training and certification in manufacturing... wow! I believe that we have a lot to offer. Building a skilled, dynamic, inclusive team, building what we know—now that's where it's at."

Building a socially-responsible business, being a trainer and employer, and getting the finished product to customers—it's clearly a huge undertaking. But Priebe is already demonstrating he's up to the challenge. One reason, he says, is that he continually focuses on time and energy management.

"I would say that everything takes 30 percent more time and energy with the everyday struggles of living with SCI," he says. "One key for me is simplifying and trusting the right people—I am so lucky to have this amazing network of people

working with me. The other big one is to reduce barriers and make those things that are really difficult to do a lot easier. Everything from making a specialized welding table that tilts and rotates, to the simple things like getting hoses, wires and plugins off the floor, made easily accessible for work efficiency."

We offered Priebe the final word.

"I'd like to give a shout out to my para athletes—swimmers, sprint kayakers, nordic racers, adaptive climbers, those participating in the new Para Boxing program. There have been so many people along the way that I have raced, trained and worked with, and they have all helped me get this business off the ground. Society Wheelchairs is an opportunity for me to take my talents to another level. I have always pushed myself to try different things and never just accept the status quo, and strive to improve things around me to make life better and more accessible for all of us."

For more information or to contact Priebe, visit societywheelchairs.ca. ■



PeerSAY!

Not every hotel room or vacation rental is perfectly accessible, so how do you deal with showers when you can't sit unsupported and there's no bench or shower chair? Answers came from several local Peers sharing their tips in the Women with SCI/D facebook group...

"A plastic raincoat from the dollar store can usually fit over your chair in a pinch." - Steph, C5-6 incomplete

"I had a waterproof cover made for my wheelchair so I can sit in it when I'm in the shower without it getting wet, or I can hold it on my lap and lean over the tub." - Teri, C6

"I always have a no-rinse body wash and do a basic wash up on the toilet, to let me reach everything. There is also dry hair shampoo you spray in and your hair which works great too." - Debbie, T11-T12

"I've almost always been able to find a plastic chair when there's no shower bench available. I travel with a small gel butt pad for stuff like this, or pile up towels to pad the chair or bench." - Jocelyn, T11 incomplete

"I use the bench in the shower with a towel on it. My husband straps me to the wall. If the hotel didn't have a bench, I swipe a plastic pool chair and return it after." - Patty, T3-4 complete

"I just use the shower bench in the hotel bathroom. I brought a cheap inflatable cushion to put on top of it since they are usually hard and my bony butt can feel it. If I end up in a regular room then I just use a regular chair to sit (in the shower)." - Cecilia, C8-T1

Have you ever wanted to find out how others tackle those everyday challenges of SCI life? Let us find you an answer from SCI BC's Peer community. Email your questions (and suggestions) to jmaffin@sci-bc.ca.

A New Option on the Island



Vancouver Island is home to a new clinic that offers SCI BC Peers the most innovative and effective treatments to restore hand function and ease spasticity.

We always think of the Lower Mainland as being our province's epicentre of specialized SCI medicine and treatment. That's not likely to change, but a new clinic on Vancouver Island may offer another option—or even a first option—for those seeking greater independence through restoration of hand function.

The Victoria Combined Peripheral Nerve and Spasticity Clinic also offers the latest treatments for severe spasticity resulting from a range of neurological conditions. It's the result of a collaboration that began three years ago between Dr. Paul Winston, a physiatrist who is Medical Director of Rehabilitation for Island Health, and Dr. Emily Krauss, a plastic and peripheral nerve surgeon. Krauss is one of the few specialists in Canada—and the world, for that matter—who has extensively studied nerve transfer techniques to restore hand function in people with quadriplegia. Winston's expertise lies in treating spasticity.

More recently, the team was expanded to include Dr. Daniel Vincent, an interventional anesthesiologist, and together they began offering the latest breakthroughs in nerve motor blocks to people with extreme spasticity.

"To the best of our knowledge, we are the only dedicated frequent clinic in Canada to offer this combination of treatments with plastic surgery, anaesthesia and physical medicine and rehabilitation," says Winston.

Now in its third year of operation, the clinic assesses and treats patients at Victoria General Hospital.

LEFT: Dr. Emily Krauss evaluates a potential nerve transfer surgery candidate at her clinic in Victoria. RIGHT: Dr. Paul Winston (left), Dr. Daniel Vincent, and Dr. Emily Krauss.

The team's work on treating spasticity is remarkable. It involves novel, cutting edge techniques to ease severe cramping and restore function. In fact, their work in this field is getting international attention. But it's only fair to point out that the majority of our readers, who are people with SCI, aren't ideal candidates for these treatments; they're primarily for people with neurological conditions such as cerebral palsy and multiple sclerosis.

The nerve transfer surgery, however, is a state-of-the-art, life-changing procedure intended exclusively for people with SCI.

You might recall that we've written about this surgery in previous issues (if you need a primer on what it involves, see the sidebar on page 25). The problem is that, up to this point, it just hasn't been readily available. There are very few surgeons who have completed the necessary specialized training, and consequently, there are few places in Canada where it's available. Here in BC, up until this point, it's been offered in Vancouver on a very limited basis. The only other location in Canada that we know about is the Ottawa General Hospital.

All that changed when Krauss teamed up with Winston. She's long had a spe-



cial interest in improving function after SCI, dating back to her graduate work in neurosciences at the University of Alberta. When she finished her residency in plastic surgery at Halifax's Dalhousie University in 2015, she knew she wanted to apply her skills to hand surgery. So she set her sights on learning from the best—Canadian-born surgeon Dr. Susan Mackinnon, who is acknowledged as the pioneer of nerve transfer surgery.

"In 2015, I went to Washington University in St. Louis and did a fellowship with Dr. Mackinnon to learn the surgery," she says. "Nerve transfers were first used in brachial plexus injuries, but Dr. Mackinnon had started doing them in SCI patients. I was able to participate and be a lead surgeon on a number of these transfers when I was in St. Louis."

Armed with new knowledge and skills, she relocated back to Canada and set up practice in Victoria, where she quickly teamed up with Winston with the goal of using her abilities to the greatest extent possible.

"We only began assessing patients in Victoria one year ago for nerve transfers in SCI," she says. "I have done one patient to restore hand function, elbow extension and wrist extension, and with another patient, I have restored their ability to extend their elbows. It's been some of the most life-changing and rewarding work I have ever participated in. There is nothing more amazing than seeing a video of a patient who could not use their hand when I met them, now holding a water bottle, using a fork, and using their hands. It brings tears to my eyes every time; it feels like a miracle."

Her goal now is nothing less than seeing this surgery offered to every British Columbian who could benefit.

"When we look at the population of patients with an SCI in British Columbia, it's possible that there might be up to 50 patients every year who would benefit from surgical treatment such as a nerve transfer to improve their ability to use their hands or extend their elbows," she says.

Now, thanks to a research initiative, she may get her wish. Under the um-

brella of the clinic, she has teamed up with Dr. Mike Berger, a physiatrist and ICORD principal investigator who is also based in Victoria. Recently, Berger obtained a research grant to test up to 50 patients with cervical SCI to see whether they are candidates for nerve transfers.

The duo will begin by testing patients on Vancouver Island who are interested in coming to Victoria to be assessed.

"We are incredibly excited that, beginning this winter, we will have a dedicated clinic and dedicated time to assess as many SCI patients as we can to see if they would benefit from nerve transfers to improve their hand function," says Krauss.

"The important thing with this operation is a complete assessment by a knowledgeable team—we only want people to have an operation if we know it will work. This is why Dr. Berger and I have set up the clinic. Patients will be seen by both me and Dr. Berger. We will do a complete examination to look at their hand function, and then patients will have electrodiagnostic testing to see if they are candidates for surgical treatment."

As for cost for the assessment and surgery, there is none.

"Canada is amazing in that we don't have to worry about private insurance to provide life-changing surgery," says Krauss. "These are all established techniques, they are not experimental, and MSP pays for them. Since working with physiatrists such as Paul and Mike, I've realized that we have a much better system in Canada to help treat these patients' medical conditions, and get them safely to the operating room so that they can have a life-changing surgery while minimizing potential complications."

Back to spasticity, which was the clinic's initial focus. For decades, spasticity has largely been treated with physiotherapy, bracing, and botulinum toxin injections (Botox). While these treatments have been shown to relax muscles and improve range of motion for some people, they're not always effective for everyone. Winston and Krauss wanted to do better, and they began exploring possible treatments, including cutting

tendons to open up contracted muscles, blocking or cutting nerves, or even freezing them—a technique known as cryoneurotomy.

The duo had witnessed how cryoneurotomy offered some impressive results—for some patients, it can restore function and motion in a matter of minutes. They realized they needed the skills of a skilled anesthesiologist, and that's when they recruited Vincent as the team's third member. Since then, they have pioneered and finetuned the procedure, and offered it to dozens of patients with extreme spasticity, and published a paper on their technique.

Vincent first identifies the problem nerve using ultrasound. He then uses a probe to freeze the nerve to minus 60 degrees Celsius, which degenerates the nerve and lets the muscles relax. The effect lasts until the nerve grows back, which can take a year or longer. It can then be repeated.

Select patients seeking more permanent treatment for severe spasticity (and who have no hope for functional recovery) have also been offered neurectomy surgery by Krauss. During the process, the problem nerve is identified and permanently cut to ease the cramping. By cutting nerves, she has been restoring active hand opening to patients with no hand function, or opening nonfunctional clenched fists with skin breakdown.

Again, we have to note that very few patients receiving these novel spasticity treatments have been people with SCI. Most have been people with MS, stroke and cerebral palsy seeking long-term or permanent solutions for severe spasticity in order to relieve painful cramping and improve function—for example, people with cerebral palsy whose hands are often cramped into painful positions. Of course, this is not the type of spasticity typically associated with SCI.

"One must be very careful in addressing spasticity in SCI as you are dealing with very weak muscles, and relieving spasticity can result in loss of strength," says Winston. But he believes that cryoneurotomy (the technique involving

freezing of the nerves) will increasingly become an option for people with SCI.

Nuerectomy (the actual cutting of a nerve) will likely never be a widescale option for patients with SCI, says Krauss.

“So far, there are only a few patients with SCI that I have done this surgery on because it’s permanent, and I don’t want any patient to lose function,” adds Krauss. “In SCI, every function a patient has is so critically important. Probably the best candidate in SCI for neuerectomy surgery would be patients with spasticity of the muscles bringing the legs together, but only if those muscles aren’t used for support in transferring or walking.”

So, for the moment, traditional treatments remain the primary spasticity treatments for people with SCI.

In the space of two short years, the Victoria Combined Peripheral Nerve and Spasticity Clinic has emerged to be an excellent option for SCI BC Peers, along with others with a range of neurological disorders. Island Health, the Vancouver Island regional health authority, can be acknowledged with encouraging and supporting the initiative. But we think the lion’s share of the credit has to be given to Winston and Krauss, who got the ball rolling three years ago.

“Our success is based on a profound love of anatomy and finding ways to restore function and ability,” says Winston. “The key is the joy of working together to share our skills and knowledge. To be honest, we hug, laugh and stare in disbelief at what we have done. We speak every day, and are pushing the boundaries on what we were trained to do. We urgently see each others’ cases. We learn so much from each other. Our outcomes have surpassed anything we have been trained to do. Seeing someone use their hand for the first time since they were a child, or regain functional hand use, is an extraordinary feeling.” ■

Patients from anywhere in British Columbia can be referred to the Victoria Combined Peripheral Nerve and Spasticity Clinic through a family doctor or physician at a walk-in clinic.



What is Nerve Transfer Surgery?

Dr. Emily Krauss describes nerve transfer surgery as “an operation that can restore someone’s ability to use their muscle by ‘re-routing’ the wiring from another muscle.”

With SCI, the specific intent of the surgery is to improve hand function in people with quadriplegia. It involves splicing a functionally intact nerve from one area of the arm onto a nerve that, prior to injury, controlled hand function but, because it’s routed through the spinal cord at or below the level of injury, is no longer able to receive a signal of intent from the brain. When function begins to return (a process that typically takes up to a year or longer to finish), the patient is trained to “think” about moving the original muscle controlled by the donor nerve in order to achieve the desired movement—for example, grasping an object.

Krauss explains that those with C5 and C6 injuries are by far the most likely to benefit from nerve transfer surgery.

“The optimal candidates,” she says, “are those with no active ability to grasp or bend their fingers, or no active ability to extend their elbows.”

She adds that there are currently three types of nerve transfers primarily being used to treat SCI patients: reassigning a nerve to one of the elbow flexors (responsible for bending the elbow) to the finger flexors to give the patient the ability to pinch or grasp; reassigning a nerve to a muscle called the supinator on the back of the forearm to the finger extensors to improve hand opening; and reassigning a branch of the axillary nerve at the back of the shoulder muscle to the triceps radial nerve branch to give elbow extension (and hopefully the ability of the patient to push and shift their weight in their chair).

“The ideal time to do these operations, we believe, is around one year after injury, but many patients have had their operations up to 14 years after injury and have gained the ability to use their hands,” says Krauss. “The first ability to move the fingers or elbow usually appears around seven months at the earliest. The recovery takes a long time—up to three years—and the strength in the hands will never be normal. But even these small gains in strength have resulted in a huge improvement in what tasks a patient can do on their own.”

As we told you in the main story, Krauss recently teamed up with Victoria physiatrist Dr. Mike Berger to assess as many people as possible. As such, she would love to hear from you if you’re someone with poor hand function due to an SCI at C5 or C6.

She says that, at best, you could be determined to be an ideal candidate for nerve transfer surgery. If not, your clinical assessment will help her figure out if there are other interventions that can improve your function, and will also support research aimed at developing international guidelines for which patients would benefit from surgery.

SCI BC Peers interested in being assessed can have their family physician make a referral to either Dr. Berger’s office at CBI Health Centre in Victoria (1.800.897.9640) or to Dr. Krauss’s office at RebalanceMD in Victoria (250.940.4444). Assessment and nerve testing will be performed at the Victoria General Hospital, likely on Fridays.



Overreaction?

North America is in the midst of a war on opioid addiction. But recent prescribing changes for BC doctors has left people with SCI living with neuropathic pain caught in the crossfire.

For many reasons—including proliferation of illegal opioids, overzealous promotion by pharmaceutical companies, lack of oversight, and increasingly liberal prescription by physicians—opioid addiction and overdose has become a multi-headed monster over the last two decades. This crisis led to well-meaning regulatory efforts in BC and elsewhere to reign in prescription of opioids. However, it now seems that the crackdown in BC has been somewhat of an overreaction, and that many people with SCI, who have a long history of safely and responsibly relying on drugs such as Oxycontin to manage severe neuropathic pain, are now paying a heavy price.

Jocelyn Maffin, Manager of SCI BC's Resource Centre, is among those who believe there's ample evidence of this.

"The real struggle here, as I've seen it in my own situation and in the lives of a wide group of Peers we talk with at Peer events or on our InfoLine, is that these changes are being forced upon many individuals who have a long history of responsibly using opioids as one weapon in their arsenal of therapies used to deal with what is often excruciating pain," she says. "At the same time, there aren't any new resources for physicians to work with patients with neuropathic pain from SCI, and existing low abuse risk alternatives—for example, the intrathecal

pump—are now unavailable in BC for chronic non-cancer pain, or CNCP. This has left our population with no real options, and the risk doctors see from prescribing opioids now has caused frequent incidents of criminalizing patients who have used opioids successfully for years, or being forced off of those meds without a plan for their pain and level of function. This is one of those situations where we see our members falling through huge cracks and experiencing considerable suffering as a result."

SCI BC's Information Resource Specialist Heather Lamb, who speaks daily with people from across BC, agrees.

"I've actually heard virtually the same story from people in several parts of the province, so it's definitely a widespread issue," she says. "Many of these people have been using the same prescription for many years without concerns."

For some answers, we turned to Dr. Michael Negraeff, an anesthesiologist and pain specialist who is an associate member at ICORD and Head of Pain Management in the Department of Anesthesiology, Pharmacology & Therapeutics at UBC. He's also a founding member and the past chair of Pain BC, a non-profit organization established in 2008 to improve the lives of pain sufferers through education, empowerment and innovation. And if these credentials aren't enough, Negraeff also lives with

an SCI and suffers from chronic pain as a result.

He believes that context and history are necessary to understand the problem and find solutions.

"The climate for prescribing opioids for CNCP was already cooling off significantly at the same time that increasing numbers of people began dying of opioid overdoses across the country," he explains. "But this failed to prevent a broad assumption from being made in our society—that prescribing opioids for CNCP was causing opioid deaths. In reality, the conflation of the two stories of liberal use of prescription opioids for CNCP and many people dying from opioid overdoses was unfortunate, as it later became clear that the vast majority of people dying from opioid overdoses were not from a legal prescription supply, but from an illegal supply that had become contaminated with very strong opioids like fentanyl and carfentanyl."

These largely unsubstantiated fears, explains Negraeff, led to some hasty policy reactions by regulatory bodies that served to increase the fear of opioids drastically and suddenly reduce the willingness of physicians to prescribe opioids. In turn, this resulted in the stranding of many patients who were not having problems with opioids, but instead reported to be benefiting from them—for example, many SCI BC Peers.

In our province, the College of Physicians and Surgeons of BC is the regulatory body that controls opioid prescription. One of its first reactions to the crisis was to work with other Canadian regulatory bodies to develop the Canadian Guideline for the Safe and Effective Use of Opioids for Chronic Non-Cancer Pain, which would address concerns about opioid misuse and safety, and provide guidance to physicians and policy-makers regarding opioid use in CNCP based on best evidence.

The guidelines, which were released in 2017, make a weak recommendation to limit new patients with CNCP to a maximum of 50 mg of morphine equivalents per day and a strong recommendation to limit new patients to a maximum of 90 mg of morphine equivalents per day. They also acknowledge that some patients may benefit from higher doses but recommend that these patients should be evaluated by a second colleague. For patients already on higher doses of opioids for CNCP, the recommendation is to attempt to reduce the dose to the lowest effective level, including potentially discontinuation, while also acknowledging that some patients may experience a persistent increase in pain or a decrease in function that may require a pause in tapering, or to abandon tapering.

"These guidelines are entirely reasonable and based on evidence," says Negraeff. "The only quibble I have is the numerical limits of 50 mg and 90 mg are somewhat arbitrary based on the available evidence, whereas the risk is known to gradually go up with total dose and not magically get worse at these numbers."

But the problem was, despite co-commissioning this generally well-received

Canadian guideline, the BC College of Physicians made the decision not to wait for its release and instead, in 2016, jumped

Opioids & CNCP: The Current Reality/Know Your Rights!

If you're an SCI BC Peer who has safely and responsibly used opioids for your chronic pain but has recently encountered difficulty in accessing them, you may be dealing with a physician who is not up to speed with the revised prescribing standards published by the College of Physicians and Surgeons of BC.

The standards now state that "physicians must not exclude or dismiss patients from their practice based on their current use of, or request for, opioids or sedatives, or a suspicion of problematic use of prescription medications." They also state that "Medications must not be abruptly discontinued — 'bridging' prescriptions during assessment of these patients is entirely acceptable to avoid dangers of withdrawal."

As well, a FAQ accompanies the new standards, which stresses this important point: "Some physicians may have misinterpreted the document as a standard of dosage alone when it was intended to be a standard of documentation of thoughtful prescribing. It does not say that a physician must not prescribe >90 MEDD per day, it states that if prescribing greater than 90 mg MEDD, physicians must have and carefully document the rationale for their decision." MEDD, by the way, is "morphine equivalent daily dose."

the gun and introduced legally-binding prescribing standards that BC physicians had no choice but to follow. These standards were based on the opioid guidelines released in early 2016 by the Centers for Disease Control (CDC) in the United States.

Negraeff explains that there are important distinctions between a standard and a guideline. A standard, he says, is made up of statements starting with "must" and "must not" actions for the physician, of which there are serious penalties for not following. A guideline provides a framework but leaves ultimate decision-making to the clinician.

"The prescribing standards were not based on best evidence but instead on fear and the belief that opioids were being dangerously provided, and generally should not be used in CNCP," says Negraeff. "The standards were released without any consultation with stakeholders from the public and consumer groups, doctors, or the government. The tone of the standards, and the fact they were standards rather than guidelines, created a very high level of fear in the physician community about prescribing opioids. Notably, the standards did not say anything about patients already on doses of opioids higher than the 50 mg and 90 mg limits recommended for new patients in the guidelines. The result was a fear that any physician prescribing over this

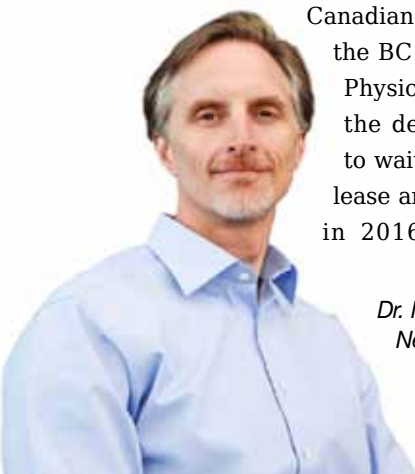
recommendation was immediately in violation of the standards. Some physicians started cutting patients down drastically or cutting them off completely."

Negraeff and other pain experts, along with Pain BC, immediately worried about the negative effects and began hearing from patients being cut off.

"We advocated fiercely with the College for reconsideration of their standards. For months, the College was very reluctant to change anything. But as pressure mounted from other physician groups, patients and Pain BC, it relented and made a change in the standards, which were published in 2018. The revised standards included a recommendation to follow the newly released 2017 Canadian Guideline for the Safe and Effective Use of Opioids for Chronic Non-Cancer Pain—the very same guideline that the College had asked for in the first place."

Negraeff believes the revised College prescribing standards are reasonable, particularly since they include specific key statements that recognize and offer protection for patients with CNCP who rely on opioids.

However, it seems that, by the time the standards had been amended, the damage had been done. Many physicians continued to be fearful of opioids, mistrustful of patients, and wanted nothing to do with opioid prescribing despite reassurances from the College.



Dr. Michael
Negraeff

So now what? Negraeff argues for a measured approach; one that balances the need to work within the standards and the Canadian guidelines, educates physicians about the revisions to the standards, reinforces the need for physicians to provide opioids when needed, supports research to find better alternatives to opioids, and creates better access to treatments for CNCP in a multidisciplinary team approach.

"The current Canadian national opioid guideline for CNCP is good, but I don't think it went quite far enough in supporting patients already benefiting from opioids, or stuck on opioids without alternatives even if they weren't benefiting as much as everyone would like," he says. "We need continued research—for alternatives to opioids, but also how to support people with severe needs using opioids safely and effectively. We need to reduce the stigma of people using opioids for CNCP, and lower the climate of fear. What are called 'legacy' patients on opioids need to be handled carefully and not threatened, stigmatized or cut off without consent. They need support. In recent years, most clinicians continued to see some patients doing quite well despite the 'average' outcome from studies. Some people have indeed had good benefit with pain reduction, and functional improvement, and avoided any substantial problems."

But he also stresses that opioids are not a panacea, and they are not without risks, even for the most responsible of patients.

"Overall, medical practitioners were probably overzealous in recommending opioids for CNCP," he says. "In hindsight,

benefits were overly optimistic, and harms were under-appreciated. As more experience was gained, clinicians and patients began to observe that opioids weren't always working as well as initially thought."

This is why he believes it's important to acknowledge that there are alternatives to be explored.

"I have seen many people who reported they were doing well on moderate to high doses of opioids who were then gradually reduced, in a compassionate and reasonable way with other supports provided. They often reported better function with less pain on lower doses of opioids or no opioids. These patients are often skeptical that this is possible at the beginning but are willing to try."

For this reason, he believes that new patients should be encouraged to initially follow the guideline and given as much non-opioid support—drug and non-drug—to manage their pain as is possible.

Here at SCI BC, we'll continue to monitor the situation and provide our readers with updates. If opportunities are presented for us to play a role (for example, working with partners to further amend provincial guidelines), we'll strive to do so. ■

Editor's note: this feature began life as one of our regular Spin Doctor columns. The magnitude of the problem led us to expand it. The Spin Doctor will return in the next issue.

Supporting your independence.



At Regency Medical Supplies, we're proud to have supported the independence of SCI BC members and people with spinal cord injuries for more than 50 years. Today, we're still your specialist for daily care needs and mobility equipment. If you're in the Lower Mainland, please stop by our 6,000 square foot showroom to learn more about the products we carry. If you're anywhere else in BC, shop online at www.regencymed.com or call us toll-free at 1-800-663-1012 to speak with a customer service representative.

• Coloplast/Mentor Condoms & Catheters	• Urocare Condoms & Leg Bags
• Tyco/Kendall Catheters & Condoms	• Rusch Urology Products
• Med-RX Intermittent Catheters	• Hollister Condoms & Leg Bags
• Bard Urology Products	• Golden Drain Condoms



Regency

MEDICAL SUPPLIES

Putting people first since 1966.

4437 Canada Way, Burnaby BC V5G 1J3
Within BC's Lower Mainland: 604-434-1383
Toll free within Canada: 1-800-663-1012
www.regencymed.com



Discretion by design

Introducing a discreet catheter with design that is truly inspired.

The Infyna Chic catheter was designed with input from clinicians to help provide a high level of discretion for women who use catheters. It is beautiful and easy to use. The Infyna Chic catheter can help a woman feel better about having to use one.

To learn more or to request a sample, visit www.hollister.ca/en-ca/infynachic or call us at **1.800.263.7400**

Prior to use, be sure to read the Instructions For Use for information regarding Intended Use, Contraindications, Warnings, Precautions, and Instructions.

The Hollister logo and Infyna Chic are trademarks of Hollister Incorporated. ©2018 Hollister Incorporated.

CE
0050



Infyna Chic
Intermittent Catheter



Continence Care

New and Improved

The Physical Activity Guidelines for Adults with SCI has been updated and now spells out just how much exercise you need to improve not just your fitness, but reduce your risk for heart disease, diabetes and other cardiometabolic disorders.

In 2011, when a Canadian-led coalition developed the *Physical Activity Guidelines for Adults with SCI*, it was a breakthrough. At that time, there was no scientifically-developed fitness guideline anywhere in the world specifically for people with SCI. The only guidelines people with SCI had to inform them in the pursuit of better fitness were those developed for the general public—which, in many cases, simply weren't appropriate.


And that was a problem. Research clearly showed that far too many people with SCI were physically inactive, yet physical activity promotion to people with SCI was woefully lacking.

"At the time, researchers knew that physical activity promotion is difficult without evidence-based information on the type, amount and intensity of activities that people should be doing to achieve fitness benefits," explains Dr. Femke Hoekstra, a Post Doctoral Fellow at UBC Okanagan who is leading promotion and supporting implementation of the new guidelines, along with Dr. Kathleen Martin-Ginis and SCI BC Executive Director Chris McBride. "A global search for the best available data was completed, and subsequently the *Physical Activity Guidelines for Adults with Spinal Cord Injuries* were created so that people with SCI would have a clear understanding of what they should be doing, and how often, in order to improve their fitness."

The 2011 guidelines, however, had one major shortcoming: they were only focused on fitness benefits. At the time, researchers knew that cardiometabolic diseases were the leading cause of death in people with SCI, but there wasn't enough high-quality evidence of what

exercise and activity levels people with SCI should strive to reach in order to improve their cardiometabolic health in addition to improving their fitness.

Fast forward to 2017, when a literature review revealed that there was finally enough evidence pointing to the positive outcomes of exercise on

PHYSICAL ACTIVITY GUIDELINES
for Adults with Spinal Cord Injury 

The physical activity guidelines, based on the best scientific evidence available, have two levels. If you're just starting out, consider incorporating the recommendations as stated in the *starting level* in your daily routine. If you're already physically active, you might want to begin using the *advanced level* recommendations.

STARTING LEVEL	ADVANCED LEVEL
AEROBIC ACTIVITY 20 MINUTES 2x A WEEK of moderate to vigorous intensity	AEROBIC ACTIVITY 30 MINUTES 3x A WEEK of moderate to vigorous intensity
AND	AND
STRENGTH-TRAINING ACTIVITY 3 SETS 10 REPS 2x A WEEK for each major muscle group	STRENGTH-TRAINING ACTIVITY 3 SETS 10 REPS 2x A WEEK for each major muscle group

START MEET EXCEED

The starting level is the minimum level of activity needed to achieve fitness benefits.


The advanced level will give you additional fitness and health benefits, such as lowering your risk of developing Type 2 diabetes and heart disease.

PHYSICAL ACTIVITY GUIDELINES
for Adults with Spinal Cord Injury 

A stronger, healthier you starts here.

<p>Aerobic activities Aerobic activities are physical activities that are done continuously and that increase your heart rate and breathing rate, such as wheeling, swimming, hand cycling or dancing.</p>	<p>Moderate intensity activities Moderate intensity activities require you to work somewhat hard, but you should feel like you can keep going for a long time. You should be able to talk during these activities, but not sing your favourite song.</p>
<p>Strength-training activities Strength-training activities are activities that increase muscle strength, such as exercises using resistance bands, or lifting weights.</p>	<p>Vigorous intensity activities Vigorous intensity activities require you to work really hard, and you can only continue them for a short time before getting tired.</p>

www.sciguideines.com

  THE UNIVERSITY OF BRITISH COLUMBIA 

cardiometabolic health outcomes for people with SCI. That, says Hoekstra, suggested that there was also sufficient evidence and data to develop exercise guidelines to improve cardiometabolic health for people with SCI.

"About four years ago, an international group of SCI scientists, people living with SCI, clinicians, and representatives from SCI organizations began working together to develop the updated scientific SCI exercise guidelines that include cardiometabolic health," she explains. "Then, in 2018, a Canadian group of SCI scientists, people living with SCI, clinicians, and representatives from SCI organizations (including SCI BC) worked together to translate and refine these guidelines into a simplified document that can be understood at a glance and easily used by individuals with SCI and in community and clinical practice settings across Canada."

The guideline couldn't be more straightforward: following the starting level will provide you with fitness benefits, while moving to the advanced level offers both fitness and cardiometabolic health benefits—for example, lowering the risk of diabetes.

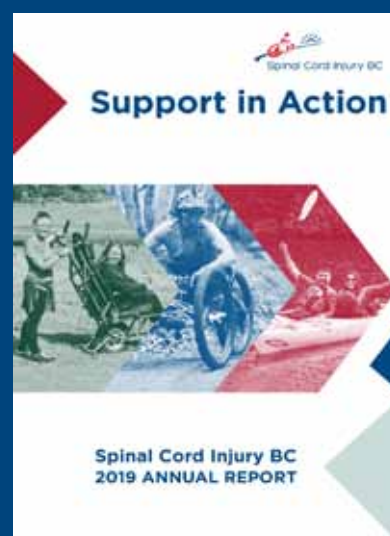
You can find out more information on the guidelines at sciguideguidelines.com. The website, managed by the SCI Action Canada Lab at UBC, also provides general information about physical activity options for people with SCI, as well as links to other related resources. Provincial SCI organizations, such as SCI BC, can provide specific information about physical activity options and assistance in your neighbourhood.

Hoekstra says the new guideline is truly the result of a focused team effort.

"Nearly 100 end-users—for example, adults with SCI, family members or caregivers of people with SCI, clinicians, therapists, and representatives of SCI organizations—provided feedback on the guidelines and the content of the website," she says.

Development of the guidelines and website was financially supported by the Canadian Disability Participation Project, Rick Hansen Institute (now Praxis Spinal Cord Institute), and the Social Sciences and Humanities Research Council of Canada. ■

The Year in Review



This year, SCI BC continued to change the lives of people living with SCI—through Peer groups, community events, mentorship, influencing change in new legislation, and promoting research. Read more about our work in our *2019 Annual Report*, available online at sci-bc.ca/annualreport2019.

"You will never experience the anxiety of running out of an essential product ever again."

**INSURANCE BILLING
FREE SHIPPING
PEACE OF MIND**



C6 Medical is a Canadian based supplier of incontinence, genitourinary, ostomy and mobility products. We offer free shipping on all orders delivered to any address in Canada.

"I know firsthand the frustration of going to the store ... only to be told that the product I want is out of stock and needs to be ordered ... This is why I created C6 Medical."

- Eric Mukendi, Founder

www.c6medical.ca

EMAIL: info@c6medical.ca

TOLL-FREE: 1-877-529-9729

DID YOU KNOW?

C6 Medical has a subscription program.

Subscription Benefits

- Pre-order products
- Save 10% on orders
- Cancel/modify your orders
- \$100 cash back on any monthly order over \$150 after three months of subscription

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.

Modified Rowing Machine for Cardiovascular Exercise

Overview: ICORD researchers Drs. Bonita Sawatzky, Ben Mortenson, Carolyn Sparrey, and Jaimie Borisoff want to compare the energetic and physiologic impact of adaptive rowing systems to traditional handcycle exercise. A secondary objective of this study is to explore the usability of the adaptive rowing system and the traditional arm crank ergometer through users' perspectives.

What to expect: Participants will be trained to use an adaptive rowing ergometer and tested on two separate days to compare the energy expenditure using the arm crank ergometry and the rowing ergometry at two intensities. Following the physiology components, participants will complete a short semi-structured interview and a usability questionnaire regarding their experiences with the two exercise modalities. The time commitment is approximately five and a half hours (three exercise sessions of an hour and a half each, and two half hour interview sessions).

Who can participate: You may be eligible to participate in this study if you currently work out at PARC (and are cleared to participate in physical activity based on the PAR-Q form) and use cardio equipment at least once a week; are above 18 years of age; understand written and spoken English; do not have any cardiac/respiratory illness (i.e., asthma) or known contraindications for exercise; do not have blood pressure of higher than 140/90; and use a wheelchair for primary mobility.

Why participate: If this study shows that using an adaptive rowing system is effective in providing a cardiovascular workout, using muscles that are different from those most often used during wheeling, then adaptive rowing systems could be promoted. This is especially important for people who are not close to accessible gyms. Understanding users' perspectives of the adaptive rowing system will reveal barriers and facilitators of its use. These findings will help facilitate access to exercise for individuals with SCI, whether for health or leisure purposes, thus enhancing ones quality of life. Compensation for participation is \$75 (\$25 for each exercise session).

Location: Exercise sessions will take place at ICORD. The interviews can be done in person, by phone, or by video chat.

For more information or to sign up to participate: Please contact Dr. Sawatzky by email (bonita.sawatzky@ubc.ca) or call 778.388.2885.



Male Sexual Functioning after SCI

Overview: Sexuality is a major rehabilitation priority in men following SCI. Evidence from uninjured individuals demonstrates that physical activity can improve testosterone levels and certain health-related quality of life outcomes. However, it is unclear if physical activity has the same impact in persons with chronic SCI. The research team led by Dr. Andrei Krassioukov and Dr. Stacy Elliott intends to investigate quality of life, sex hormone concentrations and perceptions of sexual function across two groups of men with SCI who perform different amounts of habitual, free-living physical activity.

What to expect: Participation in this study consists of two visits. The first visit (two hours at ICORD in the Blusson Spinal Cord Centre) is for a series of assessments including blood samples, blood pressure, questionnaires, and an interview. The second visit (one hour at the Centre for Hip Health and Mobility) is for a dual-energy x-ray absorptiometry (DXA) fat and lean mass scan. You will also be required to wear a physical activity monitor for three days to provide detailed information on your physical activity behaviours.

Who can participate: You may be eligible to participate if you are male; age 18 to 50; have had a traumatic, C4-L2 SCI for at least 12 months; and can communicate clearly in English. Please see the full criteria list online (icord.org/studies/2019/06/male-sexual-function/).

Why participate: This study hopes to understand the relationship between physical activity, and testosterone, quality of life, and sexual function in men with SCI. Participants will receive an honorarium of \$20 per visit.

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

For more information or to sign up to participate: Please contact Dr. Tom Nightingale by email (tnightingale@icord.org) or phone (604.675.8856).



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

Safe & Happy Holidays...



...From the staff of Access Driver Rehab Specialists!

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



**ACCESS DRIVER
REHAB SPECIALISTS**

Phone: 604-263-5218

email: AccessDriverRehab@gmail.com

www.accessdriverrehab.com

Access Driver Rehab Specialists—your key to independence.

More than just numbers.



- CSIL bookkeeping services
- Fully computerized bookkeeping and payroll services for small to medium-sized businesses
- Personal and corporate tax preparation
- Provincial and federal fuel tax rebate
- Customized service to meet your needs
- Pick-up and delivery available

I'm Walter Gagen. Call me – I'm able!

(604) 597-5100 Toll Free (866) 277-2745 Email wgagen@telus.net Website www.gagen.ca

Inducted!

Two SCI BC Peer Program Coordinators were recently honoured with hall of fame inductions.

We love it when our own peeps get recognized for their accomplishments, as was recently the case for Paralympians Sonja Gaudet and Josh Dueck.

Long before Gaudet became our SCI BC Peer Program Coordinator in Vernon, she had an amazing run as one of the world's elite Paralympian curlers. Along with her teammates, she won gold at the 2006 Paralympics in Torino, the 2010 Paralympics in Vancouver, and the 2014 Paralympics in Sochi (that was also the year she was the Canadian flagbearer). She also helped Canada win its first World Wheelchair Curling Championships in 2009, a feat that was repeated in 2011 and 2013. Little wonder she was recently announced as an inductee into the BC Sports Hall of Fame.

"It's definitely an honour and this always overwhelms me with all of the stuff that's happened since my accident," said Gaudet, who will be officially inducted during the BC Sports Hall of Fame Induction Gala on June 4, 2020. "It's a privilege to be inducted with these great athletes and builders. It's great for our sport and great for the Paralympic movement."

It's not the first time Gaudet has been honoured with a Hall of Fame induction—in 2013, she became the first wheelchair athlete inducted into the Curling Canada Hall of Fame. And we should also point out that she was honoured with a Canada Post commemorative stamp in 2018.

Meanwhile, Kamloops and Kootenay regions Peer Program Coordinator Josh Dueck was inducted into the Canadian Paralympic Hall of Fame on November 15th at a ceremony at the Vancouver Marriott Pinnacle Downtown Hotel.

Dueck, who currently splits his working time between Free-style BC (he's the Executive Director) and SCI BC, is a legend

on the slopes. He was injured in 2004 during a ski jump gone wrong. When he recovered, he went on to become a multiple Paralympic medal winner, a world champion, and an X-Games champion. He also garnered worldwide attention when he became the first person to complete a back flip in a sit ski (he accepted an invite to appear on The Ellen DeGeneres Show after that jaw-dropping feat).

"Quite frankly, I'm in shock about the whole Hall of Fame nomination," says Dueck. "My time in sport was too much fun to consider it anything but a game. I have been blessed to have great coaches and mentors in my time and always felt it was a privilege to be able to play sport and to ski for Canada. My hope is to lever this incredible milestone in sport to build on the platform of sport to ensure other athletes have the same opportunities."

"We're so proud of Sonja and Josh for being honoured with these hall of fame inductions," says Chris McBride, SCI BC Executive Director. "Their accomplishments in sport serve to inspire every single Peer they have contact with—particularly those who have been recently injured. We're so fortunate that they now play for the SCI BC team."

There are a couple of other notable new BC-based inductees to the Canadian Paralympic Hall of Fame who we're pleased to acknowledge.

One is Kathy Newman, who, along with Dueck, was inducted in recognition of her 40-plus years as a pioneer and builder of wheelchair sport in Canada. Newman worked for 31 years with the BC Wheelchair Sports Association, including the last 26 as Executive Director. Wheelchair sport enjoys an elevated prominence in BC compared to many other provinces, and a lot of the credit is due to the efforts of Newman, who will also be inducted into the BC Sports Hall of Fame along with Sonja Gaudet this coming June.

Joining Newman and Dueck was Kelowna's Garrett Hickling, who was inducted in recognition of his two legendary decades of wheelchair rugby prowess. He helped pioneer the sport and led the Canadian national team to a gold medal at the world championships in 2002, a silver at the 2004 Paralympics in Athens, and a bronze at the 2008 Paralympics in Beijing. ■



LEFT TO RIGHT: New hall of fame inductees Sonja Gaudet, Josh Dueck, Kathy Newman, and Garrett Hickling

Your mobility freedom is our top priority.



Sidewinder Conversions is committed to enhancing your mobility freedom, independence and quality of life. Since 1999, we've been providing safe and reliable accessible transportation solutions and service in a caring, professional manner.

Our selection of side and rear-entry accessible conversions are available on most full-size vans and minivans, and feature industry-leading technology, ease of use and functional aesthetics. With power and manual options, along with a range of driving controls, mobility aids and stowage lifts, our conversions provide the optimal blend of performance, safety and style.

Whether you're an independent driver, an assisted passenger or a caregiver, our team of qualified experts can help you choose the right solution to meet your mobility and lifestyle needs.

SIDEWINDER 
Conversions & Mobility Ltd.

44658 Yale Rd. W.
Chilliwack, BC V2R 0G5
PHONE: 1-604-792-2082
TOLL FREE: 1-888-266-2299



sidewinderconversions.com

Follow us on:



 **PROUDLY CANADIAN** 



Transport Canada approved and certified CMVSS, FMVSS or CSA compliant
Licensed motor dealer registered with the VSA (Vehicle Sales Authority of BC) www.mvsabc.com



Did you know?

Smartphones
can magnify content
to improve visibility.

And did you also know?

TELUS has partnered with Neil Squire to help people with disabilities access the expertise to find the right assistive technology. Eligible participants will also receive a \$20 monthly discount on select plans.

Visit telus.com/techforgood to find out more and sign up.



the future is friendly®