

# the spin

SPINAL CORD INJURY BC

FALL 2021

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# contents

FALL 2021

## features

### 12 Breakdown Blues

New research sheds light on just how unreliable wheelchairs are—and the high costs of getting them fixed.

### 14 Agent of Change

A conversation with recently elected MLA and SCI BC peer Dan Coulter, who is working hard to usher in a new era of accessibility for British Columbians with disabilities.

### 18 Ready to Go?

It's a good time to prepare for next wildfire season—or any other emergency situation that might force you to evacuate at a moment's notice—by putting together a GoBag.

### 20 Great Pains

Three distinct research efforts are focusing on novel, pharma-free strategies to treat SCI-related neuropathic pain.

### 26 Cover Story

Exploring the real world practicalities of home-based neuromodulation treatment to restore function.

### 30 A Matter of Style

Derek Jezewsky is on a mission to help other peers revamp their wardrobe with comfortable, stylish accessible clothing.

## departments

### 4 editor's message

It's a balancing act on the waves of COVID-19.

### 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.

### 28 spin doctor

Treating toenail fungus naturally.

### 33 participate in research

ICORD research projects that need your participation.

### 34 last word

As our online games night host knows, making connections can be fun—and much, much more.

**COVER PHOTO:** The SpineX SCONE neuromodulation system being used for hand/grasp rehabilitation. (Photo courtesy SpineX)



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# Balance on the Waves

It's been 18 months since the BC government declared a provincial state of emergency in response to the COVID-19 pandemic. I remember exactly where I was that infamous day. I happened to be on the west coast of Vancouver Island. It was a grey but atypically calm day, with the waves gently lapping against the shoreline. It wasn't the kind of day Canada's adaptive surfing team would have been stoked about.

But while the seas were calm, the pandemic situation throughout the province and around the world was not. Walking down the beach with friends that day, a remark by one of them gave me pause. She imagined that governments' decisions to shut things down must have been hard ones to make, and wondered aloud how they will decide when to open things up again. How, she asked, would they balance safety from the virus with removing harms caused by pandemic restrictions? Clearly, she predicted, this will make for even harder decisions.

I've reflected on that beachside conversation often, and just how challenging the process of opening things up has been—for government, for SCI BC, for all of us. Good leadership and so many British Columbians doing their part have allowed us to avoid the strict lockdowns seen in so many places around the world. But it hasn't made the careful process of opening up any less tricky or worrisome for many.

The need to bring back restrictions as new waves of infections crashed in on us is evidence of this. The decisions behind these moves cannot have been easy ones to make, but they have been thoughtful and timely. And there's no doubt they have been effective.

SCI BC has taken a cautious approach to restarting our in-person services. Ensuring the health and safety of our members and staff is of utmost importance to us. The province's move to Step 3 of their restart plan was a signal that we could take our first steps to resuming in-person peer activities. We're starting slow and small. Things will look a little different as we must have measures in place to ensure we minimize the risk of COVID-19. And, like the province, we will need to adjust our safety protocols and the types of events that take place as pandemic conditions within the province continue to evolve.

Looking out on the open ocean back in March 2020, we seemed a world away from the pandemic and the historic period of our lives that was just beginning. The first wave was just breaking and we hoped we could ride it out to safety. As we know now, a set of COVID waves were lined up, each proving trickier to ride than the first one. There will be more waves to come, but we've learned an incredible amount over the past 18 months and we will continue to tame them so that someday soon we can truly open up and "return to normal."

For that to happen, we must all continue to do our part. Stay healthy and please get fully vaccinated.



—Chris McBride, PhD, Executive Director, SCI BC

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Executive Editor..... Chris McBride  
Managing Editor/Designer ..... Cliff Bridges  
Assistant Editor ..... Alison Brierley  
Editorial Support..... Holly Birch  
Administration..... Penaaaz Sidhu

### SUBSCRIPTIONS

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

### ADVERTISING

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### SUBMISSIONS

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

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

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Vancouver, British Columbia V6P 5Y7 T: 604.324.3611

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### SCI BC HEAD OFFICE

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

### REGIONAL PEER CONTACTS

Fort St. John: Lori Slater, Peer Program Coordinator  
T: 250.787.1912 E: [lslater@sci-bc.ca](mailto:lslater@sci-bc.ca)

Kelowna: Scott James, Peer Program Coordinator  
T: 250.308.1997 E: [sjames@sci-bc.ca](mailto:sjames@sci-bc.ca)

Nanaimo: Bert Abbott, Peer Program Coordinator  
T: 250.616.1186 E: [babbott@sci-bc.ca](mailto:babbott@sci-bc.ca)

Prince George: Brandy Stiles, Peer Program Coordinator  
T: 250.563.6942 E: [bstiles@sci-bc.ca](mailto:bstiles@sci-bc.ca)

Quesnel: Alison Duddy, Peer Program Coordinator  
E: [aduddy@sci-bc.ca](mailto:aduddy@sci-bc.ca)

Metro Vancouver: Teri Thorson, Peer Program Coordinator  
T: 604.714.4185 E: [tthorson@sci-bc.ca](mailto:tthorson@sci-bc.ca)

Metro Vancouver: Ryan Clarkson, Peer Program Coordinator  
T: 604.714.4185 E: [rclarkson@sci-bc.ca](mailto:rclarkson@sci-bc.ca)

Victoria: Scott Heron, Peer Support Specialist  
T: 250.812.0773 E: [sheron@sci-bc.ca](mailto:sheron@sci-bc.ca)

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

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### DELUXE SOCK AID

The Deluxe Sock Aid from Royal Medical Solutions promises to simplify the chore of putting on socks or stockings for people with quadriplegia, anyone who has weak hand strength, or those who have trouble bending over. You start by slipping the sock or stocking up and over the aid. Next, you insert the foot into the centre of the sock opening, and then pull the looped cord to bring the sock up and over the foot. The contoured plastic shell is soft and flexible, which makes it easy to insert socks onto the device. Soft grip foam handles and adjustable braided cords also add to the ease of use. You can find instructional videos on YouTube; the Deluxe Sock Aid can be purchased at many online retailers including Amazon.

### SMALL ITEM GRIPPING AID

The Small Item Gripping Aid from Active Hands is designed to allow people with quadriplegia to hold and use small items—for example, make-up applicators, bathroom essentials such as hair brushes and razors, and art and office items such as pens and paint brushes. It's a two-part system, consisting of a comfortable neoprene glove and a Velcro palm pad. You can secure the glove around the hand and wrist using the two Velcro straps, which can be tightened using plastic rings requiring little or no finger strength. The palm pad is a Velcro-backed square with a plastic clamp attached. The clamp holds the item in place—you put the item inside the clamp and pull two ribbon loops to close. You can switch between palm pads quickly and easily, and the palm pads can be attached to allow you to hold items at any angle you want. The Small Item Gripping Aid comes with one glove component and one palm pad, and additional palm pad twin-packs are available so that you can leave one attached to your most used items. Two sizes are available. You can learn more at [activehands.com](http://activehands.com).



# Innovations

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

### PEGASUS DREAM TOUR

For those that didn't get quite enough of the Paralympics, or would like their own competitive experience, check out The Pegasus Dream Tour—the first-ever Paralympic video game. In this highly-polished role-playing game developed by JP Games, you create your own avatar, equip it with a wheelchair or other adaptive equipment, and then train and compete in a variety of Paralympic sports, including wheelchair racing, wheelchair basketball, and others. There's even a social aspect—when you're not competing, you can explore the massive open world of Pegasus City and interact with other players and character avatars of some top Paralympians, including Canadian wheelchair basketball star Patrick Anderson. Pegasus Dream Tour, which is officially licensed by the Paralympics, was released on June 24 and is available for PlayStation, Nintendo Switch, Windows and Xbox One. You can find it at Google Play and the App Store.



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**Continence Care**



**Find out about in-person events.**

As BC moves through its restart plan, we're continually adjusting to the ever-changing landscape of health recommendations for in-person activities. Tune in to our social media channels for the latest announcements and check out our events calendar to see what's been added. As we cannot plan too far into the future, it's also a good idea to keep a look out for emails from us, which will let you know about new events as they come up.



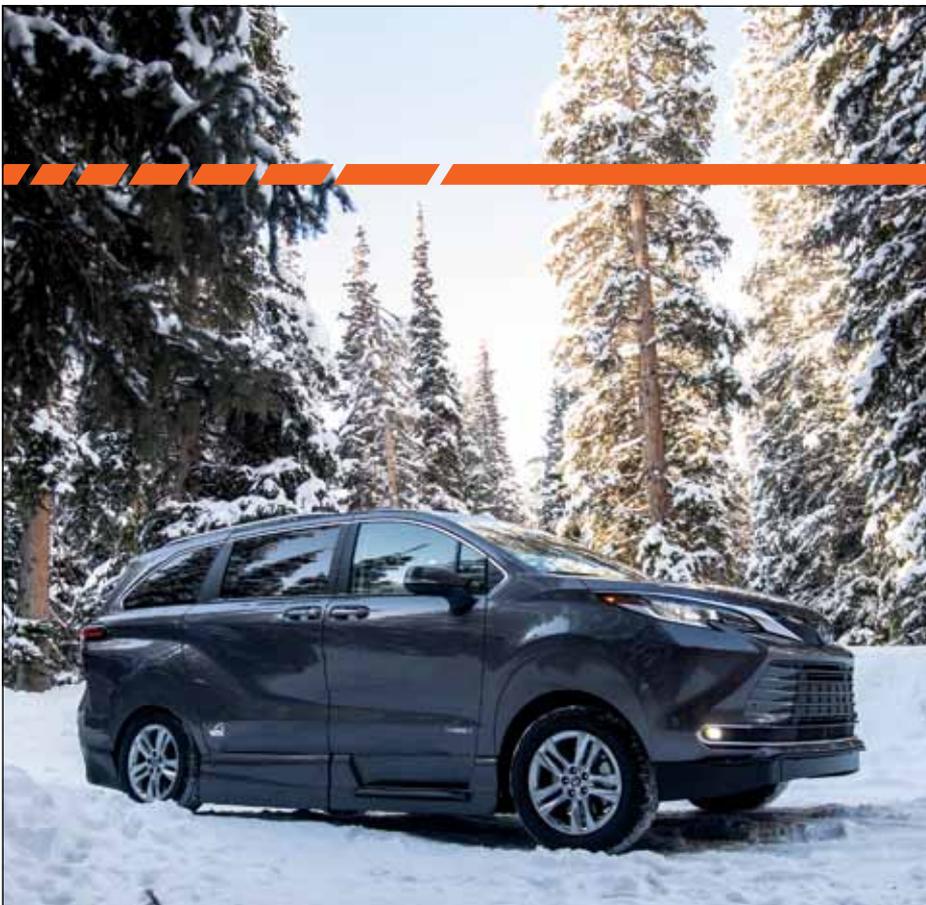
**Stay connected and have fun.**

As we wait for in-person events to roll out, our online events are going strong! Our Peer Coordinators and volunteer online hosts have an array of activities to keep you connected. Trivia, Adaptive Boxing, Book Club, Coffee Groups, Mindfulness and Games Nights—there's something for everyone. You can join in through Zoom or dial-in by phone. Visit [sci-bc.ca/events](http://sci-bc.ca/events) or call our toll-free InfoLine (1.800.689.2477) to find out more.



**Let your voice be heard.**

Our Annual General Meeting takes place on Thursday, October 21, at 6:30 PM. Voting members are invited to help us celebrate the past year of adapting to the realities of COVID-19 while keeping our community informed and connected. Note that due to the ongoing pandemic, only fully vaccinated voting members may attend. Venue information and meeting materials will be sent in advance of the meeting. See page 31 for details.



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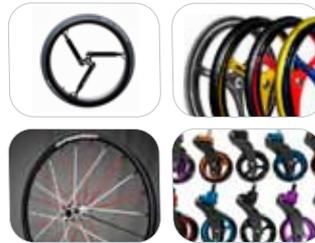
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*"I can't stop thinking 'bout him now he's gone/And the lives he touched with all he's done/That positive vibe and smiling face/Now everywhere he was is a special place to Shine On."*

Those are the opening lyrics of a new track created by Vancouver's **JAMES SAUNDERS, DAVE SYMINGTON** and **JEFF STANDFIELD**. The song, titled *Shine On*, blew us away when we heard it—because of its outstanding musicianship, and because the trio created it as a tribute to their good friend Brad Jacobsen, SCI BC's former Peer Program Coordinator who passed away earlier this year.

"I was inspired to write a poem based on Chris McBride's editorial about Brad in the last issue of *The Spin*," explains Symington. "It really had to do with the notion of light that Chris talked about."

"Dave asked if I would create a song around lyrics he wrote inspired by Brad's memory," says Standfield, who recorded the song solo in his home studio. "I really liked what he wrote and I was excited to work with him on this. I was talking to James around the same time and



told him what Dave and I were doing, and he was keen to contribute too, as he also knew Brad well."

What makes the song so special is the upbeat feel—it truly sounds as though the song celebrates their friend's life.

"We know Brad loved Jack Johnson and The Tragically Hip, so I thought a simple reggae feel would fit perfectly, punctuated by electric 'Hip' sounding lead guitar riffs as well," says Standfield. You can hear the track on Soundcloud ([soundcloud.com/jeff-standfield](https://soundcloud.com/jeff-standfield)).

# Peer Shoutouts

A hugely harmonious shoutout to five melodically-inclined peers, who have been using their pandemic time in a most creative and inspiring way.

Victoria's **JOE COUGHLIN** is one of Canada's most award-winning jazz vocalists. With a career spanning more than three decades and seven albums, Coughlin has been honoured with numerous accolades, including one Jazz Report Award and two National Jazz Awards. At age 67, he hasn't slowed down a bit.

His latest album is actually a remake of his first, which was simply titled *DEBUT*. It was released 40 years ago, and received rave reviews. But sadly, as peripheral damage of the producer's messy divorce, only a few copies ended up being placed for sale, and the original master recordings were lost. Recently, Coughlin found and purchased a pristine vinyl copy of the original *DEBUT*, which was then digitally transformed by the genius wizards at Abbey Road Studios in London. The remastered *DEBUT* – 40th Anniversary Edition was released in May.

Every nuance of Coughlin's fine and seemingly effortless baritone, along with every instrumental note of the original performances, has been restored and enhanced with a fresh, crisp and contemporary sonic perspective. The 11 tracks include jazz standards and infrequently performed songs from Quincy Jones, Wes Montgomery, Chick Corea and Thelonious Monk. CDs are available through [indiepool.com](https://indiepool.com) and [joecoughlin.ca](https://joecoughlin.ca), and the album is also available digitally through Spotify, iTunes/Apple Music, [amazon.ca](https://amazon.ca), Tencent, and others.



Our own **AGASHA MUTESASIRA** somehow finds time to pursue her musical aspirations despite a busy schedule as an international student at Vancouver Island University in Nanaimo and a Regional Access and Inclusion Coordinator with SCI BC. We're glad she does, because her music is truly remarkable.

Mutesasira, who is originally from Uganda, recently recorded her first single, which you can hear on YouTube. It's a chill pop song titled *Glide*, and it features Mutesasira's lush vocals and some great grooves, which she put together with her producer.

"*Glide* took me about three days to write and be content with the words I put together," she says. "The song is a representation of how life has brought so many unknown situations my way, some hard, but I've been able to make it past them."

Mutesasira hopes that music will take on an ever great role in her life. "Since the release of my song, I have been able to get in touch with other artists," says Mutesasira, who writes using her guitar to explore ideas and melodies. "So I'm working on small projects with them and hoping to get an album of my own out real soon."

Visit [bit.ly/AgashaGlide](https://bit.ly/AgashaGlide) to listen to *Glide* on YouTube.





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

# Breakdown Blues

New research sheds light on just how unreliable wheelchairs are—and the high costs of getting them repaired.

**W**heelchairs are a critical piece of kit for the majority of our readers. They're not a luxury, nor are people confined to them. They are replacements for legs that no longer work; a lifeline to independence and the world around us.

So you'd think something as fundamental as a mobility device would be engineered to bulletproof standards, wouldn't you? But the reality, as many readers know, is that wheelchairs break down. A lot.

Just how often they fail hasn't ever really been determined, but a new study by a team of US researchers from the Spinal Cord Injury Model System sheds some light on the problem.

The researchers surveyed 533 wheelchair users at nine Spinal Cord Injury Model Systems Centers located across

the United States about their experiences over the prior six months. How often did participants require wheelchair repairs? What was the impact of needing repairs on participants' independence, and how long did these consequences last? Which types of wheelchairs are more likely to need repair, and what are the most common repairs needed? These were all questions in the study's survey.

The results of the study, titled *Factors Influencing Incidence of Wheelchair Repairs and Consequences Among Individuals with Spinal Cord Injury*, were published this past April in the *Archives of Physical Medicine and Rehabilitation*.

They revealed that 56 percent (310) of the wheelchair users surveyed experienced breakdowns needing repairs within the last six months. Of these, about 42 percent were impacted with significant financial and personal con-

sequences (such as being stranded in their homes) as a result of the breakdown. For many, consequences lasted for more than two weeks, and those with the least financial resources were the most commonly impacted. Many participants reported that the high cost of repairs limited their participation inside and outside the home in an effort to reduce the risk of damaging their wheelchair. Others reported that the cost of repairs prevented them from getting the wheelchair fixed altogether.

Not surprisingly, power wheelchair users were almost twice as likely to experience a repair—and an adverse consequence—as manual wheelchair users.

"The higher incidence of repairs and consequences secondary to needed repairs among power wheelchair users is likely tied to them using more complex systems," says lead author Dr.

Lynn Worobey, assistant professor in the Department of Physical Medicine and Rehabilitation at the University of Pittsburgh. “The electrical and control systems are what are most likely to require attention based on user reports. The other caveat for power wheelchairs is we know repairs are much more often completed by a vendor, as opposed to manual wheelchairs, in which users may be able to complete maintenance themselves more often.”

Worobey adds that the leading types of repairs needed, regardless of type of wheelchair and in order of incidence, were for tires, positioning supports, cushions and brakes. Among power wheelchair users, controllers, batteries and seating required the most repairs.

The research team concluded that this ongoing problem needs to be addressed with action—creating higher standards of wheelchair quality, expanding access to faster repair service, and providing enhanced user training on wheelchair maintenance and repair.

“Reliability is certainly a component of it,” says Worobey. “Independent testing has shown that manual wheelchairs and power wheelchairs commonly do not pass minimum durability standards outlined by ANSI/RESNA (RESNA is the Rehabilitation Engineering and Assistive Technology Society of North America, which creates minimum standards for mobility devices for ANSI, or the American National Standards Institute). One of the big takeaways that was neutral to manufacturers is that, for the 10 most frequently prescribed wheelchair models in the sample, repairs exceeded 50 percent across all of them.”

She adds, however, that a lack of usage data has limited the ability to make accurate comparisons across chairs or manufacturers. “We have started to collect some of this data,” she says.

Competitive bidding required by public funders is likely another contributor to the high incidence of repairs, according to Worobey. “The institution of competitive bidding has likely led to cost-cutting practices across the continuum—from



Lead author Dr. Lynn Worobey

manufacturers to suppliers related to how wheelchairs are built, tested, provided, and serviced—that has impacted repairs across the board. While it may reduce Medicare program costs, it also forces suppliers to reduce payment levels. Because the acquisition costs aren’t changing, it’s likely that quality of wheelchairs, and the quality of maintenance and repair service, are sacrificed.”

To illustrate her point, she explains that a lower quality chair may end up being prescribed or “pushed” because it may have a higher profit margin for reimbursement.

The researchers believe that there are relatively simple ways of improving the situation.

“Based on what we learned in the survey, there are some simple measures, such as providing a borrowed wheelchair to people so they have mobility while their chair is being repaired, that could reduce the adverse consequences,” says one of the paper’s co-authors, Dr. Trevor Dyson-Hudson, director of the Center

for Spinal Cord Injury Research and co-director of the Spinal Cord Injury Model System Center at the Kessler Foundation. “Other facilitators include increasing the speed of repairs, training people in wheelchair maintenance, and routinely scheduling follow-up appointments after a repair is made, so any subsequent problems can be caught early.”

Currently, there are no clinical or industry standards for wheelchair maintenance, and surveys tell us that fewer than 50 percent of wheelchair users are trained in wheelchair maintenance. This lack of official guidance prevents the implementation of best practices that could significantly reduce adverse consequences related to wheelchair breakdown and time for repair, explains Worobey. She also believes that policy related to repairs is inadequate and incomplete. One example is that many funders won’t cover preventative maintenance.

“In other words, something has to break before they will fix it,” she says. “We know that the timeline to when that repair is completed is protracted, and wheelchair users are suffering because of that. Wheelchair users learning how to complete basic maintenance—cleaning the casters, lubricating moving parts—like one would with a car can help, but policy changes are needed as well.”

Until the situation changes, Worobey says wheelchair users will need to largely rely on themselves and be proactive.

“Repairs are prevalent and it’s a scary trend that has been increasing over time,” she says. “Until we are able to make policy changes, it’s important to advocate for yourself to get repairs done in a timely manner. And learning how to complete preventative maintenance can help prevent some of these repairs.” ■

**Want to learn how to DIY?** There are many online training resources that peers can look to in order to improve their ability to perform preventative maintenance and many repairs. Some excellent examples can be found at the US Model Systems Knowledge Translation Center—check out the one page guides at [msktc.org/new-resources-safe-wheelchair-transfer-and-wheelchair-maintenance](https://msktc.org/new-resources-safe-wheelchair-transfer-and-wheelchair-maintenance). Also, SCI BC has created a wheelchair repair and maintenance guide, with assistance of our friends at Macdonald’s Home Health Care—you can find it at [sci-bc.ca/wheelchair-maintenance](https://sci-bc.ca/wheelchair-maintenance).



# Agent of Change

Recently elected MLA and SCI BC peer Dan Coulter is relying on his track record of public service and his lived experience as he works to usher in a new era of accessibility for British Columbians with disabilities.

**D**uring our 2020 provincial election, Dan Coulter defeated Liberal incumbent John Martin to earn the right to represent constituents in Chilliwack—a riding that had been considered a Liberal stronghold up to that point.

It's been a whirlwind year for the 46-year-old, as he was quickly tapped by the NDP caucus to take on the role of Parliamentary Secretary for Accessibility under the Ministry of Social Development and Poverty Reduction. The primary role of his new position? Overseeing the final development, approval, and implementation of the new *Accessible British Columbia Act*.

Coulter sustained an SCI in 1999 when he was working as a millwright. He brings his personal lived experience of dealing with inaccessibility to his new positions, as well as his impressive track record of community involvement—for example, he is the former chair of the Chilliwack Board of Education, has served on the Mayor's Task Force on Inclusion, Diversity and Accessibility, and is a director for the Chilliwack Restorative Justice Society.

Coulter lives in Chilliwack with his wife, Rebecca. Recently, we caught up with him and had the opportunity to ask him a few questions about his post-election life and *The Accessible British Columbia Act*, which was recently passed into law on June 17.



**How has life changed for you since your election? How's the learning curve been? Are you getting used to commuting to Victoria, having a hectic schedule, etc.?**

Life has gotten a lot busier for me as there is a very steep learning curve for new MLAs. I had to learn a lot very quickly to get up to speed on the rhythm of the Legislature and set up my community office. Then I had a whole other steep learning curve to navigate when the Premier appointed me to be the Parliamentary Secretary for Accessibility. While I have some lived experience, I have not worked within the disability advocacy world and I learned so much about our stakeholder advocacy organizations and how they interact with government.

**Can you tell us about the moment you learned you were going to be Parliamentary Secretary for Accessibility and would be stewarding the process of seeing the *Accessible BC Act* become law and enacting it? What were your thoughts when you accepted the position?**

I was incredibly honoured but also a bit worried! I was aware of the commitment that the government has made to making British Columbia a leader in accessibility and how hard the previous Minister of Social Development and Poverty Reduction, Shane Simpson, had worked to set us on this path. I found the role intimidating as I wanted to do the work justice and honour all the hard work that activists had done to see the legislation get as far as it had.

**Can you describe your role in the implementation of the *Act*, and how it differs and complements that of Minister Simons?**

Minister Simons has been the one leading the way and making sure the legislation made its way through government and passed into law, and he'll continue to be responsible for promoting greater accessibility.

It's my job to support him in that work by engaging directly with advocates, communities and businesses to ensure that the legislation is effective and well understood.

We make a great team and it's been a lot of fun working with the Minister.

**What is the most important thing you believe our readers should know about the *Act*?**

Our work is being guided by the principle of "nothing about us, without us." This legislation has been shaped by British Columbians with disabilities every step of the way, and we'll continue to rely on their expertise and lived experience as we develop new standards to make BC more accessible.

A new Provincial Accessibility Committee will guide government in identifying, removing and preventing barriers to accessibility and help shape these new accessibility standards. At least half of the committee members will be people with disabilities or be representatives from organizations that support them. Applications to sit on the committee closed last month and the Minister and I are excited to announce our founding members this fall.

In addition to the Committee, our work in developing standards will be assisted by new technical committees and I will continue to engage with different organizations and communities to ensure we get this right.

**What is your vision for accessibility and inclusion in our province? If you could look ten years down the road, what kinds of changes do you believe the Act will help bring about?**

Long-term, I believe this legislation will create a province that is more accessible and more inclusive for everyone.

My hope is for a future where a kid with a spinal cord injury in BC is provided with the same opportunities as their peers. Whether it's over the course of their education, employment or in their communities, all those living with a disability deserve to live in a barrier-free BC.

**Development of a Provincial Accessibility Committee is identified as a first priority. Can you tell me about this committee? When will it be announced, how will it undertake its work, and what kinds of powers will it have?**

As I mentioned previously, the Provincial Accessibility Committee will play the very important role of guiding government as we move forward with identifying barriers and developing accessibility standards under the Act.

The committee will have a range of responsibilities, including advising government on standards development and implementation, providing advice to the Minister on the government's forward-looking accessibility plan and on the implementation of the Act itself.

We want to ensure that anything developed or implemented under this law is informed by the experience of people living with disabilities.

We will announce the committee membership in Fall 2021.

**The plan appears to make BC government institutions a first priority for government's accessibility plan under the Act. Why is it important to begin this process with making government more accessible and inclusive?**

We know how important it is to lead by example. By taking the lead, we'll be able to show people, communities and businesses how to approach the identification, removal and prevention of barriers disproportionately impacting people with disabilities. And through our work, we'll be able to better develop resources and supports for organizations.

With nearly one in four British Columbians identifying with a disability, I'm excited for government to take on this important work.

**For many people, lack of access to and within businesses is the most glaring example of inequity in our built environments. Given that, many might judge the Act on its ability to create change in the province's business community. What is the timeline for this?**

I know how frustrating it can be to arrive at a new local business only to find out they don't have a wheelchair ramp. I also know that other folks feel that frustration when they come across a website they can't access, can't find an accessible taxi to take them to an appointment or, when upon, disclos-

ing their disability, are prejudged and denied a service. In the years ahead, we will be developing a number of new accessibility standards to address all these issues. The Provincial Accessibility Committee will help us identify the order in which accessibility standards are developed.

As a first step in supporting the business community, this spring we provided \$4.8 million to Small Business BC to administer a new grant program to help small businesses make their workplaces more accessible.

We continue to work with the Presidents Group—a group of 25 BC business leaders who champion more accessible and inclusive workplaces.

Over the development of our legislation, the Presidents Group has been a great sounding board and we look forward to continuing to work with them in the months and years ahead.

**The Act has been criticized by several disability organizations. The primary complaints are that it has no firm timelines or deadlines for development of regulations and implementation, and there is no complaint mechanism for individuals or organizations to report violations. Do you think the criticisms are valid? Can you tell us how you respond to those criticisms?**

In reviewing the progress of other jurisdictions that have introduced accessibility legislation, we've learned that setting deadlines for an accessible province are not effective.

We believe our work to identify, prevent and remove accessibility barriers, just like our work to safeguard human rights or to advance reconciliation needs to be ongoing. We're always learning and understanding more about what living with a disability means, and we want to ensure that any new standard is as effective as possible.

That said, we have released a timeline breaking down our work over the next 10 years to build a barrier-free BC.

When it comes to enforcement, like other provinces with accessibility legislation, a Director will be appointed to carry out the enforcement of standards under the Act, and the Director can hire inspectors if needed.

Initially, our focus will be to support organizations in meeting their obligations, especially through education and awareness of best practices. We know that removing barriers to accessibility and inclusion ultimately benefits everyone, and we know that businesses and organizations will be more eager to make changes once they see the positive impact.

And while it isn't necessarily meant for reporting violations, government is developing a feedback tool for people to report barriers to accessibility. We will also be working with other organizations so they can also develop feedback tools, accessibility plans and accessibility committees.

In the upcoming months, I'll have more to report on that.

**Can you tell us what you believe to be the greatest barriers or biggest challenges to implementing the Act?**

I believe that tackling attitudinal barriers will be our biggest challenge. If we want a province that is truly accessible, we need everyone to understand the benefits of removing barriers and promoting inclusion—and that means addressing personal biases. People with disabilities are not unhealthy or unwell, but they do have needs that aren't being met by society. And it's only by working together that we can build a barrier-free BC that works for everyone.

**Is there anything British Columbians with disabilities should not expect to be resolved by the Act? Are there any actions they can take to help expedite the deployment of the Act?**

Obviously, we would love it if the Act immediately resolved every barrier people with disabilities face, but we have to recognize that addressing barriers will be an ongoing process. Fortunately, the legislation is designed in a way that ensures accessibility will be an ongoing priority for government well into the future.

I think the best way for people with disabilities to get involved with our work will be through the feedback tool once it's released. We want to hear from you!

It's also important to keep in mind that while the *Accessible BC Act* is working at a systemic level to remove barriers—if a person with a disability encounters what they believe is a breach of human rights they can contact the BC Human Rights Tribunal to lodge a complaint.

**One of your other responsibilities is to work with the Attorney General and Minister responsible for Housing on BC Building Code changes to improve the accessible housing crisis in our province. Can you shed any light on work underway in that area?**

I'm working with the Attorney General and Minister Responsible for Housing to fulfill the mandate commitment to include changes in the next BC Building Code to make new buildings more accessible for all people.

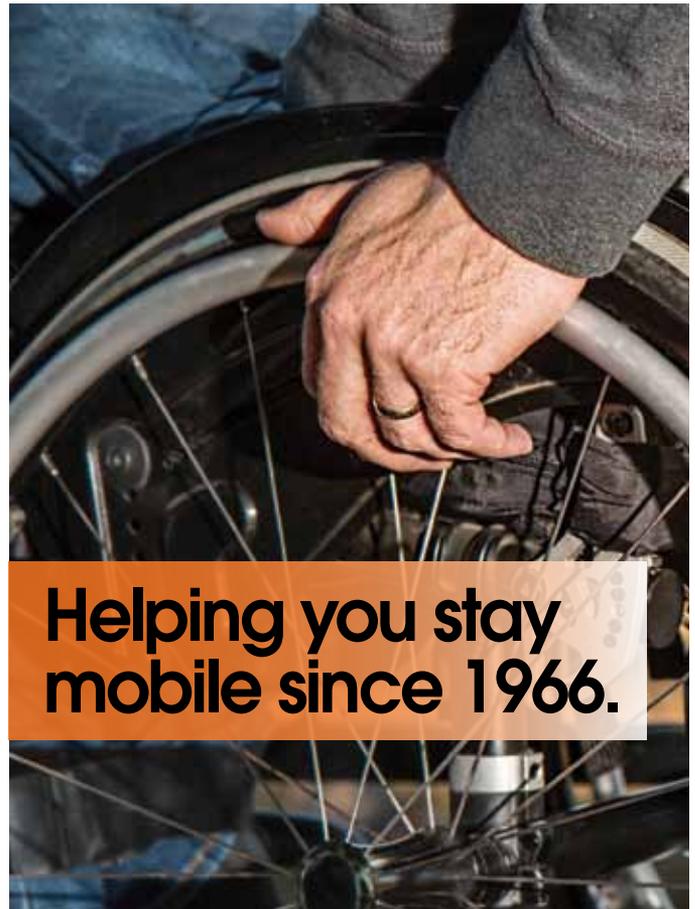
I can share that we've made a number of improvements to a BC Housing program that helps seniors and people with disabilities with the cost of making adaptations to their homes for independent living. The Home Adaptations for Independence program is now the BC Rebate for Accessible Home Adaptations program, and it can provide people with a rebate up to \$17,500 for home adaptations.

In June 2021, we partnered with the SAFERhome Standards Society to help improve liveability and accessibility in existing and future public housing buildings, and in the fall, we'll be hosting an online public engagement to gather feedback to help inform proposed changes to the BC Building Code.

Together we're working to remove and prevent accessibility barriers to help create better buildings that work for everyone.

**Is there anything else you'd like to add?**

I am a long-time reader of *The Spin* and appreciate having the chance to share my experience! ■



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# Ready to go?

Hopefully, by the time you're reading this, a brutal BC wildfire season is easing. But it's always a good time to prepare for next wildfire season—or any other emergency situation that might force you to evacuate your home at a moment's notice—by putting together a GoBag.

A GoBag is not the same as an emergency kit, which is a collection of supplies that you keep in your home that will allow you to stay healthy, hydrated and fed for a week or more in the event of a natural disaster. You can think of a GoBag as a downsized version of your emergency kit. You'll want to keep it with you at all times, or prepare several versions that you can keep at home, in your car, or at work. The idea is that, regardless of where you find yourself during an emergency event that forces you to evacuate, you'll have a 72-hour supply of everything you'll need to be safe and healthy.

GoBags are obviously personalized depending on needs and abilities. But there are some basic items that should be kept in the GoBag of anyone who lives with an SCI. We've made this visual list based on the BC government's recommendations, a variety of other emergency preparedness websites, and a few SCI-specific recommendations from a variety of sources, including some of our own peers.

1. Travel bag, backpack or duffel. It should be just large enough to carry your must-have items, and made of a durable, water-resistant material. Some sort of strap or ability to attach to your chair is ideal, and people report that having compartments helps keep your essential items organized.
2. Ready to eat food. In particular, freeze-dried packages take minimal space and weigh the least.
3. Bottled water. You should have at minimum half a liter a day, so at least 1.5 liters.
4. Charger and a portable, rechargeable battery bank to charge and operate your phone.
5. Small battery-powered or hand-crank radio. This will allow you to hear the latest emergency broadcasts and information.
6. Small battery-powered or hand-crank flashlight and/or headlamp. You never know what you'll need to do at night.
7. Extra batteries. These are backups for your radio and flashlight batteries.
8. Power wheelchair charger. Make sure it's tested for your ride.
9. Tire repair kit. Make sure you purchase the appropriate type (i.e., tubeless) for your ride.
10. Personal medications. Ensure you have a three day supply of important prescriptions.
11. Personal toiletries. Small travel sizes are ideal.
12. Three day supply of bowel and bladder management supplies.
13. Seasonally-appropriate, practical and lightweight clothing.
14. Small first-aid kit. Make sure it has the basics.
15. Extra pair of glasses or contact lenses.
16. Copies of important documents. Emergency plan and contact list, insurance papers and identification are examples to consider.
17. Local map, with your family meeting place identified.
18. Whistle.
19. Cash in small bills and coins.
20. Pen and notepad.
21. Garbage bags.
22. Hand sanitizer.
23. Emergency blanket.
24. Masks.



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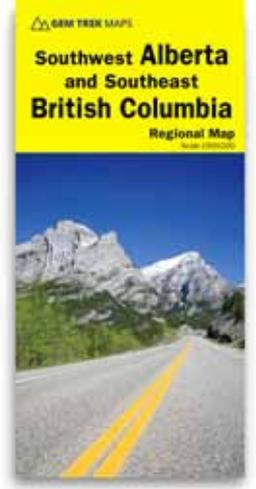
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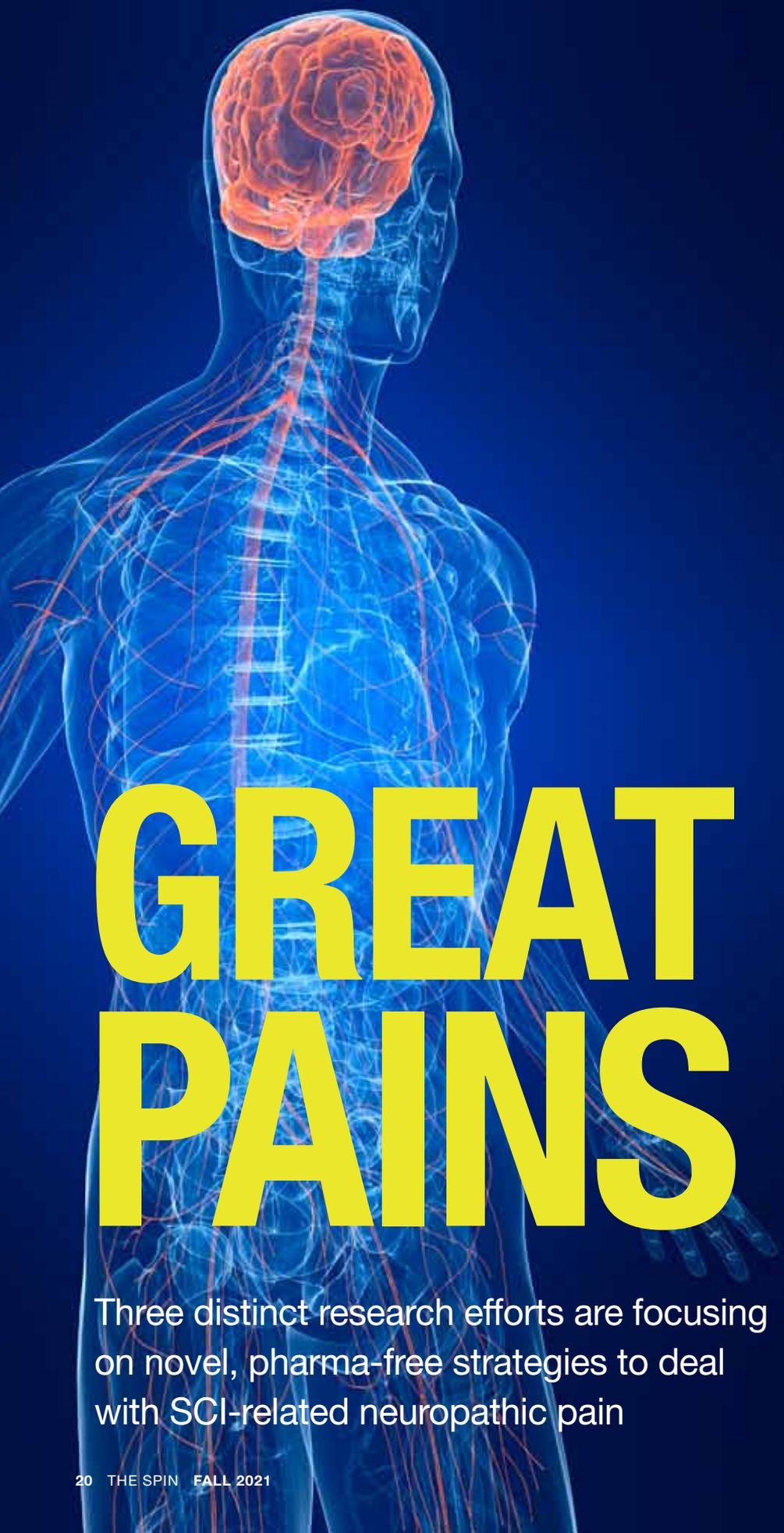


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# GREAT PAINS

Three distinct research efforts are focusing on novel, pharma-free strategies to deal with SCI-related neuropathic pain

If the headline caught your attention, it's likely you're one of the legions of SCI BC peers who deal with neuropathic pain. We know you're out there. We know that many of you haven't found any effective way of managing your pain—and that it can be crippling in your lives.

That's why publishing news about neuropathic pain research is a priority for us. At the same time, we know it's sometimes frustrating to read about research, because you need solutions now, not a decade from now. With apologies, there is nothing conclusive in this story, and we can't say if or when recommended or approved treatments will result from the three research projects described below. However, two of three involve products that are readily available at retailers near you; for all we know, you're already trying them. And we hope that you take some comfort from the fact that many bright scientific minds around the globe are working on the perennial problem of neuropathic pain, and that some of their work is, in fact, promising and intriguing.

None of the three research projects involve opiates or medications of any type. One approach deals with blunting neuropathic pain with the use of a skin cream—we'll get to that in a minute. The other two involve strategies to mitigate neuropathic pain signals in the areas of the brain where they're received and processed, and that's where we'll start.

## RESTORING BODY AWARENESS

Body awareness is your ability to innately sense where your extremities are—even when you can't see them, and even when they're in motion. Central to body awareness is proprioception. This feedback loop in our central nervous system allows us to map, in 3D and real time, the location, movements, and actions of various parts of our bodies. The most obvious example of proprioception is being able to touch your nose with your finger while your eyes are closed.

SCI often leads to loss of proprioception and, as a result, body awareness, in our paralyzed extremities. And this

loss of awareness seems to be linked to neuropathic pain, says Dr. Ann Van de Winckel, a Belgian physical therapist and assistant professor in the Department of Rehabilitation Medicine at the University of Minnesota.

She explains that, after SCI, some parts of the body, such as the pelvis, buttock, thighs, legs, and feet, gradually become unrepresented in the body map.

“But those parts of the body,” says Van de Winckel, “are still receiving inputs from the environment—contact sensation, pressure, and weight—because they’re in contact with the wheelchair or bed. This causes a conflict between the sensory messages that are being sent from the lower parts of the body and the brain, which can’t interpret this information correctly because those parts of the body are not represented anymore in the body map. This conflict gives rise to neuropathic pain.”

So what would happen if you could somehow restore the ability of the brain to proprioceive paralyzed limbs? Would this somehow turn the neuropathic pain amplification down? Van de Winckel believes this is the case, and is in the process of testing her hypothesis.

For many years, she studied the potential of a treatment called cognitive multisensory rehabilitation, or CMR, in people who had experienced a stroke, as a means of improving movement and sensation. Her research demonstrated



## Neuropathic Pain: A Primer

A simple explanation of neuropathic pain is that it’s what happens when our brain tries to make sense of chaotic or missing signals from a damaged nervous system—it searches for recognizable signals, and when it can’t find or understand them, it turns up the volume, amplifying the experience of pain, even in locations with little to no sensation or feeling. This is neuropathic pain, and the harder the brain tries to locate or make sense of the signals, the worse it becomes.

“Because of the SCI, there is a diminished or complete loss of sensation and movement below the lesion, so those parts of the body are sending altered information about sensations to the brain,” explains Dr. Ann Van de Winckel, who is leading a study involving body awareness and neuropathic pain. “The brain receives this altered information, and then is confused because it’s not the information it expects to receive. So it’s like a radio channel that isn’t working properly—a lot of noise comes through, with only a little bit of music. So the brain cranks up the volume to listen better, and that is the neuropathic pain. Another way of explaining what probably happens is that when the brain cannot identify the information—because it is different from the normal sensation it is expecting to receive—then it labels it as pain.”

There are several different types of SCI-related neuropathic pain that manifest themselves in different areas of the body. SCI pain, or central pain, occurs below the level of injury (possibly the most problematic because of the severity and that it reports from areas of the body that no longer have sensation or movement). Segmental pain occurs in a band, including arms, at the level of injury. Nerve root entrapment pain occurs at or just below the level of injury.

that a CMR regimen improved proprioception and allowed people to “remap” their sense of body awareness, which led to significant improvements.

Using MRI scans, Van de Winckel determined that CMR treatment in these stroke patients resulted in partial restoration of two parts of the brain that are vital to body awareness—the parietal operculum and the insula.

“The brain is plastic,” she explains. “The changes seen in the brain occurred alongside sensorimotor improvement in all participants, and alongside pain reduction—we had one person who had a 10 out of 10 intensity level of pain at the beginning of the study; this went down to three out of 10 after three sessions, and remained this low with only peaks to a maximum of five out of 10 for up to one year after the intervention stopped.”

She knew that these parts of the brain are also vital to both body awareness and pain perception, and it occurred to her that using CMR to improve

*Dr. Ann Van de Winckel*

body awareness might lead to restoration of the pain processing network and reduce neuropathic pain brought by SCI. So she collaborated with Dr. Leslie Morse, professor and head of the University of Minnesota’s Department of Rehabilitation Medicine, to design a study to test her hypothesis.

The project, which got underway earlier this year, is seeking to evaluate approximately 26 adults with paraplegia and SCI neuropathic pain. They are being randomized into two groups: one receives six weeks of CMR followed by six weeks of observation; the order is reversed for the second group. In addition to measuring changes in their pain levels, all participants will undergo three brain MRIs to see if and how the function of their brains changes. Additionally, their brain function will be measured against a similar-size cohort of able-bodied recruits.

At this point, you’re probably wondering what CMR involves.

It can be described as “thinking” rehabilitation—in other words, it’s exer-



*The goal of this CMR exercise is to restore awareness and a 3D map of the pelvis, which can then be used as a reference to connect the upper part of the body with the lower part. The therapist is asking the participant (who has her eyes closed) to recognize if the sponges on the left and right are felt in the same position. In order to solve this problem, the participant has to do a mental body scan to map the dimensions of the pelvis, starting from the back (where the therapist has her hand—see image in the mirror) to the front where the pelvis joins the upper part of the legs. The scan helps the participant rebuild the 3D map of the pelvis and to search where there is pressure (from the sponges) on the upper legs. This is one of the starting points to create awareness of the rest of the legs.*

cises for your brain, rather than physical exercise. The purpose is to help people with SCI recreate their 3D map of their lower body, despite a lack of sensation and movement. A session typically begins with participants sitting with their lower body concealed from their vision with a barrier. They can only see their upper thighs, the barrier, and a CMR-trained therapist kneeling in front of them. The therapist then asks them a variety of questions. For example, the therapist might ask, “If I reach out with my hand, do you think I can touch your leg, and, if so, where on your leg?”

“To answer the question, participants have to reconstruct an image based on what they see of the upper part of their legs,” explains Van de Winckel. “They must envision and understand the relationship between the arm of the therapist and their own leg. They must also understand how much space their legs occupy. When this awareness is restored, the therapist

will also use exercises to increase sensation and even, in some situations, help the participant regain some movement.”

When repeated over time, the exercises improve the participant’s ability to proprioceive their legs, stimulating the brain to rewire itself in the process so that benefits are lasting, if not permanent.

“Restoring the awareness of the body and thus the body map through CMR actually helps the brain interpret those sensations correctly,” says Van de Winckel. “Instead of labelling the sensation as ‘pain’ the brain will now correctly identify the sensation as pressure, texture, etcetera, in the correct body part.”

So far, eight people with SCI have already completed the research project. The data gathered from their experiences cannot be published until the entire study is finished, but Van de Winckel offers some cautious observations to date.

“Even though we have only collected preliminary data, and data collection is ongoing, we have consistently seen in all participants so far during the CMR intervention that, when they start to regain awareness of their body and use the sensory experiences to create a correct body map, the pain goes down,” she says, adding that some have also reported some degree of recovery of sensory and motor function.

For fulsome results and conclusions, we will have to wait for the project’s completion until late in 2022.

## THE POWER OF ILLUSION

While Van de Winckel’s approach of using specialized rehabilitation to restore body awareness and reduce neuropathic pain is novel, another strategy of targeting neuropathic pain in the brain has been investigated for a couple of decades. We’re talking about using virtual reality technology, or VR, as a way of “tricking” people into believing they’re using or feeling their legs—and alleviating neuropathic pain in the process.

VR creates an immersive virtual world—users experience the illusion of “moving” and interacting in it. VR can be very simple—for example, it can be experienced in 2D using a regular computer screen. But it can also be very complex and realistic, as with the 3D type of VR that’s created when users put on VR goggles.

While a number of studies have been done, most have been small scale and, while pain relieving effects have been determined in many, they are inconclusive and leave many questions unanswered—for example, what is the active mechanism, and what is the duration of pain relief?

One researcher with a healthy interest in the subject is Dr. Phil Austin, a postdoctoral research fellow at Greenwich Hospital in Sydney, Australia.

In the past two years, he’s been part of two scoping reviews, in which he and his colleagues attempted to find and assess all high quality research papers related to VR’s ability to relieve SCI neuropathic pain. What he and his colleagues have confirmed is that VR appears to provide a reliable short-term

analgesic effect, even with a simple 2D system. But he says that the evidence also points to VR's potential for more lasting benefits.

"If used regularly, especially with cognitive-based applications, long-term relief is also shown," says Austin. "This applies to the use of both 3D and 2D VR applications. The key message with the regular use is that the patient has a non-pharmacological adjunct therapy to help control their pain."

The cognitive-based applications he's referring to rely on cognitive-based therapy, or CBT, in which patients are taught methods of challenging and changing how they perceive pain, and developing personal coping strategies. Used in tandem with VR, Austin says the pain relieving ability is that much greater.

Intrigued by what he discovered in the existing literature, Austin set out to add to the body of knowledge with his own study of VR. He teamed up with colleagues at the University of Sydney to specifically compare the pain-relieving capabilities of a 3D head-mounted VR device with a 2D screen. Sixteen men with SCI and chronic neuropathic pain participated in a single-session randomized cross-over trial.

"We used commercially-available VR hardware, namely Oculus Rift goggles for the 3D and an Alienware laptop for the 2D experience," explains Austin. "We also used commercially-available software (Nature Treks) on both the 3D and 2D platforms. In other words, we

were testing the level of immersion (2D versus 3D) rather than what participants were watching."

Level of immersion is essentially the degree to which the VR experience is convincing, or realistic. Obviously, a 3D experience is a more powerful and convincing experience than watching the same "walking experience" on a 2D laptop screen. The software, Nature Treks, offers a relaxing ambient virtual reality experience—users are given the sensation of walking through a variety of peaceful, natural settings.

The results of the study were published in a paper titled *The short-term effects of head-mounted virtual-reality on neuropathic pain intensity in people with spinal cord injury pain: a randomized cross-over pilot study*. It appeared in the journal *Spinal Cord* last October.

The essence of the findings was that, as expected, the 3D VR experience provided the best bang for the buck.

"We were able to determine that the level of immersion, or presence, was associated with the level of neuropathic pain relief," says Austin. "Second, the short-term pain relief was also greater than most previous studies. Our findings suggest that 3D VR applications provide neuropathic pain relief in people with SCI. Given the lack of cybersickness and ease of access, including availability and price, 3D VR would be a helpful addition to neuropathic pain medication."

Austin and his colleagues also suggest that further studies using VR applica-

tions in concert with cognitive-based therapy, as well as physical rehabilitation, may show permanent reductions in SCI pain.

So why would something like VR result in pain relief? Austin believes there are two mechanisms.

"Concerning short term pain relief, VR provides a simple distraction away from pain towards an alternative stimulus—in other words, by hijacking attention, emotion and memory," he says. "Here, it has been shown that VR stimuli stimulate brain regions associated with pain modulation. Alternatively, neuroplasticity refers to more long-term pain relief. Here, with repeated use, it is suggested that more long-term changes in function and structure in pain-related brain regions takes place. This has been shown in other areas, where, for example, the practice of skills such as playing a musical instrument or a sport affects brain areas involved in proprioception and coordination."

Could it be possible that engaging in repeated VR treatments is also helping people to rebuild a compromised body map, just as the cognitive multisensory rehabilitation, or CMR, that Dr. Van de Winckel is testing at the University of Minnesota? As always, good research always seems to lead to more questions, and VR-based therapy for SCI neuropathic pain relief clearly needs to be investigated with larger trials to determine the answer to this question, along with its full potential. In the inter-

Dr. Phil Austin's study (that's him on the right) made use of the popular Oculus Rift VR headset with Nature Treks software to test the potential of virtual reality immersion as a way of treating neuropathic pain in SCI.



im, there's nothing to stop readers from trying the VR experience themselves—the new version of the Oculus headset, the Quest 2, sells for about \$400.

## HOT SAUCE RELIEF

Actually, what we're talking about isn't so much a sauce as it is a cream—a skin cream, to be exact.

Dr. Lukas Linde, a postdoctoral fellow in UBC's Department of Anesthesiology, Pharmacology, and Therapeutics and a member of Dr. John Kramer's ICORD lab, was recently awarded a Craig H. Neilson Foundation grant for a project titled *Less is more: Low concentration topical capsaicin to relieve neuropathic pain in SCI*. The project will expand on research by UBC master's student Hannah Goodings, and will explore the effectiveness of her recently-developed low concentration capsaicin intervention to manage a specific type of SCI neuropathic pain—segmental (or peripheral) pain in the arms, at the level of injury.

This likely isn't the first time you've heard about using capsaicin (the active or "hot" ingredient in peppers) to treat neuropathic pain. High concentration (eight percent) topical capsaicin patches have been successfully used to treat peripheral neuropathic pain for some time.

How does it work? Our skin has sensory neurons called nociceptors. One particular type, TRPV1, sends sensations of heat and pain to the brain. SCI often causes TRPV1 receptors at the level of injury to misfire or misreport burning sensations to the brain. Applying

high concentration capsaicin seems to deactivate or "burn out" these

receptors so that they lose their ability to send pain signals to the brain.

There are several problems with high concentration topical capsaicin. It produces incredible burning pain on the skin where it's applied (which kind of defeats the purpose), so it has to be mixed with lidocaine to numb that burning. It can only be administered under physician supervision, and isn't approved for use in Canada. Most important, however, is that while it does "burn out" rogue TRPV1 receptors, studies have shown that it does not prevent later development of central sensitization—more specifically, secondary hyperalgesia, which is heightened pain sensitivity in skin areas adjacent to the treatment area.

In other words, high concentration capsaicin seems to deactivate the intended TRPV1 receptors, but those receptors are still involved in later development of pain sensations from neighboring regions. Enter Hannah Goodings and her work with low concentration capsaicin.

"Hannah's MSc project explored the mechanisms of long duration, low concentration topical capsaicin uses in young healthy adults," says Linde. "The key finding from her study was that, over time and with repeated use, low concentration topical capsaicin not only defunctionalized the pain receptors where it was applied, but it further prevented the development of sensitization. This last part is the exciting part, as we may actually be interrupting some of the underlying processes that lead to the development of the hyperalgesia (increased pain) and allodynia (pain from non-painful stimuli) observed in neuropathic pain. This is an important distinction, as we are suggesting that, while both high and low concentration can knockout pain receptors in the region they are applied, only low concentration applied for long durations appears to also prevent the development of central sensitization like pain from neighbouring regions."

Linde's study, which is about to begin, will try to replicate these findings in people with SCI who have segmental pain in their arms. He is recruiting 40

candidates, who will be randomized to receive either a regular, over-the-counter, low concentration capsaicin cream or a placebo cream. Participants will apply creams twice daily for 15 consecutive days in the area of pain. They will undergo complete pain assessments prior to starting treatment, immediately following treatment, and 15 days after treatment concludes.

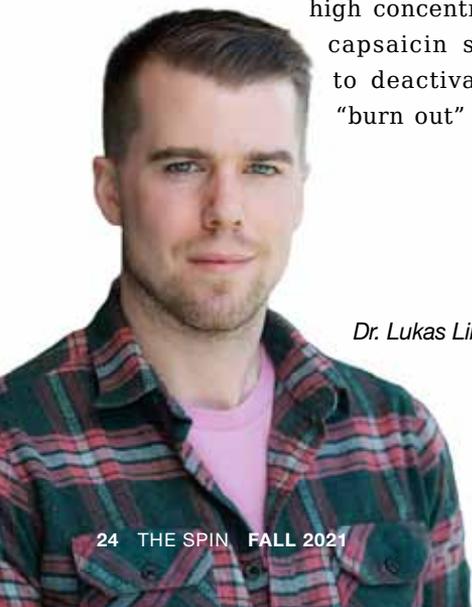
"Ideally, we will see two things," he says. "First, reduced pain ratings in the regions we apply topical capsaicin. Second, reduced secondary hyperalgesia (secondary pain) when we subsequently apply a heat pain model to induce a temporary state of central sensitization. For us, this would demonstrate that topical capsaicin works not only to "burn out" pain receptors in the periphery, but they also help mitigate the future development of pain in neighbouring regions."

Results won't be known until 2022, but if benefits are confirmed, Linde says he will work to promote adoption of the treatment into regular practice.

"Right now, low concentration topical capsaicin is readily available over the counter," he says. "It's often an ingredient included in various topical pain treatments found in drug stores. It's likely that people are already using topical capsaicin—and that it is providing some pain relief. Given good results, we will be able to help speak to mechanisms of how topical capsaicin is working, and be in a position to better provide recommendations on how to apply and use it to relieve pain—what region, for how long, how to assess signs it is working, etcetera."

He invites readers interested in participating, or who want more information about the project, to contact him directly via email at [lukas.linde@ubc.ca](mailto:lukas.linde@ubc.ca).

So there you have it—three pharmaceutical approaches under investigation to treat one of your most urgent health complications. The moment we hear of any news from these projects, or any other credible findings in treating SCI neuropathic pain, we will publish them in future issues of *The Spin*. ■



Dr. Lukas Linde

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# Neuromodulation In the Real World

More and more, it seems likely that transcutaneous neuromodulation will move from the lab into a home-based treatment to improve key functions after SCI. But what exactly would be involved?

**T**he evidence continues to mount that neuromodulation has the potential to improve many aspects of daily life for people with SCI.

Stimulating the damaged spinal cord has been successfully tested to improve arm and hand function for people with quadriplegia, along with bowel, bladder and even sexual function for quadriplegics and paraplegics alike.

As many readers know, there are two ways of delivering neuromodulation—epidurally through electrodes that are

surgically implanted on the spinal cord, and transcutaneously via electrodes that are attached to the skin next to the target area in the spinal cord.

Of these, we are particularly hopeful about the latter. If transcutaneous neuromodulation provides most of the same benefits without the need for surgery (both for implantation and for changing batteries), at a much lower cost, there seems to be a greater possibility of widespread adoption and use in the SCI community.

We've been writing about the potential for transcutaneous neuromodulation for a few years, but we'll confess that, like you, we're curious about what exactly it will look like. After all, unless poor results or serious side effects suddenly crop up as a result of the extensive research currently being conducted (something that seems unlikely since research to date suggests it's safe and effective), it's not a stretch to imagine that many readers may use transcutaneous neuromodulation at some point in their future.

We don't know how this will all unfold, but it seems likely that treatment will be initially offered under the care of a qualified specialist, with a neuromodulation system being provided as a loaner during treatment. However, one of the most promising aspects about neuromodulation is that the same equipment can be used to improve function in a number of body areas. For example, someone with quadriplegia might use a system for both improving hand function, and then later, bladder function. Given this, it becomes easy to envision people with SCI actually being able to purchase (or, ideally, receive via our healthcare system) a neuromodulation system, and even learn to use it by themselves in their own homes.

So what would be involved, and what would the practicalities be for users? We asked Dr. Parag Gad to help us envision the possibilities. Gad is a bioengineer who works at UCLA with Dr. Reggie Edgerton, who has led research in this field for more than 40 years. In addition to collaborating with Edgerton on his research, Gad is also the CEO of SpineX, which was created to transform Edgerton's work into real world applications.

The company's flagship product is SCONE, short for spinal cord neuromodulator. SCONE has been recognized by the US FDA as a "breakthrough device." It's a small, portable, rechargeable system that's now being evaluated in several research studies around the globe. But Gad and Edgerton are working hard to make sure SCONE's roll-out eventually moves beyond the lab and hospital and into community and even home settings.

“There are two likely scenarios in terms of how people will actually use SCONE,” says Gad. “The first is stimulation during a therapy session, with sessions lasting one to two hours, perhaps two to three times a week. The second is stimulation during self-training—you might wear it during activities of daily living, and in this context, a user might receive stimulation from four hours up to 12 hours per day. With self-training, a user would likely receive stimulation at least three days a week, although it’s possible that they could train with the device every day. We are testing both these options in an on-going study.”

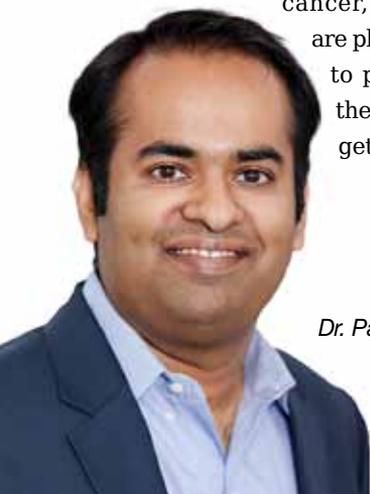
We asked Gad about different functional goals and if they would require different usage times and durations.

“In most cases,” he says, “you will need to optimize it for each function—in other words, treatment will be different depending on the desired goals. However, all the body’s systems overlap, and users will likely see multiple organ systems improving even when they’re targeting a single organ system or body area.”

What about actually wearing the device and the electrodes? How do you put it on, and can you do it yourself?

“There are two electrodes placed on the skin above the spinal cord,” he explains. “The locations on the skin above the spine can be within a half an inch of the intended location. Of course, the mapping for the electrodes locations will be done in a clinic.”

He says that he and his colleagues are currently exploring the idea of using tiny tattoos to permanently mark the locations, a technique that is used in other medical procedures—for example, with cancer, small tattoos are placed in the skin to precisely guide the delivery of targeted radiation.



Dr. Parag Gad



A participant in one of Dr. Parag Gad’s research trials uses the SCONE simultaneously while performing hand exercises, which has shown to be improve the ability to grasp small objects.

He adds that, ultimately, and depending on their level of injury and function, users in a home setting would be able to put on the device (which clips to a belt or the wheelchair) and the electrodes themselves, or have a caregiver provide assistance.

“We have already shown that this is possible in several studies,” says Gad. “Initially, electrodes will be attached and detached everyday. Subsequently, we will have a mechanism in place to leave the electrodes on for longer periods of time—possibly one to two weeks.”

We also wanted to know if users would be able to do other activities during a session, or if they have to remain still.

“During any neuromodulation to improve autonomic functions such as bowel and bladder, patients can be stationary if they want to. However, for any mo-

tor function therapy, such as standing, stepping, or improving hand and arm strength, they need to be practising those tasks actively while stimulation is on.”

We were also curious about what therapy actually feels like. “It initially feels like someone is gently tapping your back, and eventually turns into a massage-like feeling,” he says.

Our final request for Gad was to look into the future and make an educated guess as to what neuromodulation devices like SCONE might evolve into.

“Future versions will be smaller, more powerful and smarter as things develop,” says Gad. “They could possibly morph into a small wireless system, like a Band-Aid, that an individual could wear for a month with little or not inconvenience.”

You can learn more about SCONE research at [spinex.co](http://spinex.co). ■

# ask the SPIN DOCTOR

“Why do I always seem to have toe fungus, and how can I treat it naturally?” It’s a question we hear often from peers. We asked for assistance from The Rollin’ RNs—Americans Roberta Palmer (left) and Patty Kunze, who write about SCI-related health issues based on their experience as registered nurses who live with paraplegia.



Toe fungus is a fungal infection that gets in through cracks in your nail or cuts in your skin. Left untreated, a fungal toenail infection could spread to other toenails, skin, or even your fingernails. Affected nails will appear discoloured to a brownish-yellow, and they may become thick and brittle. They can even separate from the nail bed.

These infections are more than just a cosmetic embarrassment. For some, they can become a serious health concern. “If you are diabetic or immune-compromised, it’s important to get foot fungus issues under control,” says Dr. Pamela Ng, a dermatologist at the Cleveland Clinic. “The fungal infections can cause a breakdown of the skin and lead to conditions like cellulitis or foot ulcers.”

Those of us with SCI appear to be susceptible to toe fungus for a number of reasons. We have little or no sensation in our feet that would otherwise signal the onset of infection. We also tend to spend many hours sitting, which can lead to swelling in our feet. Another issue is poor circulation in the legs and feet, which can slow wound healing. A weakened immune response may also play a role. And finally, it can also be difficult for some of us to reach our feet for daily care.

To accurately diagnose toe fungus, your doctor may refer you to a podiatrist or a dermatologist. A common treatment option for confirmed cases is a prescription medication that you take daily for two to three months. However, it can negatively interact with other medications and compromise liver function. Fortunately, there are also topical home remedies to treat nail fungus. These might be worth trying because of the low risk of side effects and drug interactions, but keep in mind they take much longer to work. And remember that an infected nail needs time to grow out which could take weeks.

**Vicks VapoRub** is a topical ointment originally designed for cough suppression. Its active ingredients, camphor and eucalyptus oil, may help treat toenail fungus. A 2011 study found in *The Journal of the American Board of Family Medicine* that Vicks VapoRub had a “positive clinical effect” in the treatment of toenail fungus. To use, apply a small amount to the affected area at least once a day.

**Tea tree oil** is an essential oil with antifungal and anti-septic properties. According to the US National Center for Complementary and Integrative Health, some small-scale clinical studies showed that tea tree oil might be effective against toenail fungus. To use, paint the tea tree oil directly onto the affected nail twice daily with a cotton swab.

**Oregano oil** is an essential oil that contains thymol. According to a 2016 review, thymol has antifungal and antibacterial properties. To treat toenail fungus, apply oregano oil to the affected nail twice daily with a cotton swab.

One wheelchair user that we know of was able to combat her nail fungus using daily over-the-counter products. One was a foot soap containing tea tree oil, which she used to wash her feet in the shower. The other was a liquid nail polish with a blend of tea tree and oregano oil. She applied the polish after showering, allowed it to sit on her nails for about 15 minutes, and then removed it before putting on her socks and shoes. Over the course of several weeks, her nails grew out pink and healthy, without any need to take prescription drugs.

Of course, the best strategy to avoid toe fungus grief is to prevent it from getting a foothold in the first place. Inspecting your feet daily or as often as possible is essential. So too is keeping your feet clean and dry, paying close attention between and under your toes where moisture can lead to fungus. If your skin becomes dry, flaky, or cracked, rub your feet with a good moisturizer—but remember not to apply between the toes to avoid unwanted moisture.

Other preventative strategies include wearing shoes that breathe and don’t trap sweat inside of them, changing your socks often, and wearing socks that wick moisture away from your skin. Needless to say, if you have an SCI, resist the temptation to go barefoot to avoid skin abrasions. Finally, treat cuts and sores as soon as they appear on your feet. They can become easily infected and tend to heal at a much slower rate because of your SCI.

Toe fungus is hard to treat and has a high reoccurrence rate. So it’s important to treat the current infection and take steps to avoid getting it again. Keep in mind that each one of us is unique. Consult with your healthcare provider for diagnosis and treatment for persistent toe fungus to determine the best course of action for you.

It’s all good, so keep on rollin’.

*You can find other SCI-related features and information written by The Rollin’ RNs at [rollinrns.com](http://rollinrns.com) or [facebook.com/rollinrn](https://www.facebook.com/rollinrn). Meanwhile, if you have questions for The Spin Doctor, forward them by email to [thespin@sci-bc.ca](mailto:thespin@sci-bc.ca).*



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# A Matter of Style

Coquitlam's Derek Jezewsky has always enjoyed dressing and looking smart. With his new business, he's overjoyed to be helping other peers discover—or rediscover—their own fashion sense.



“I’ve always been pretty fashion aware,” says 25-year-old Derek Jezewsky. “Growing up, I was always taught to put my best foot forward and dress for the job you want—which was easy to do able-bodied, but putting your best wheel forward is a little harder. I think the hardest part is finding clothes that fit in the right places while seated, without being uncomfortable.”

Jezewsky grew up in Fraser Lake, in Northern BC. A self-described adrenaline junkie, he found himself pursuing a career in motocross racing at the age of 19. Those aspirations were sidelined in 2017, when Jezewsky sustained a T6/7 injury in a crash during a race in Kelowna.

After rehab, he embraced wheelchair basketball, and it wasn't long before he played his way onto our national team. And that's how he discovered Kinetic Balance—a world leader in fashion for wheelchair users based in the Netherlands.

“When I was living in Toronto, training with Team Canada, a friend of mine had come into the gym with a package from Kinetic Balance,” says Jezewsky. “He had pulled some things out and I automatically fell in love with the clothing. I think that for a lot of people, including myself, being in a wheelchair can be a foreign feeling. For many of us, we feel like people are staring. Pants that bag and shirts that bunch add to that feeling—they don't inspire confidence. I think that's why I fell in love with the idea of accessible clothing. It was cool, hip threads for people like me.”

When Jezewsky took a deeper dive into the Kinetic Balance website, he discovered the company specializes in premium clothing—jeans, pullovers, jackets, bags and more—that had clearly been thoughtfully created for wheelchair users. For example, all the company's jeans are sewn from four-way stretch fabric that stays in place during transfers, reduces skin friction, and doesn't create pressure on the abdomen. Both men's and women's versions come in regular or slim fit, and have either a magnetic or button fly, and in styles for men and women.

But while he loved the clothes, he was shocked at the price of shipping to North America.

“It was insane!” he says. “So fast forward three years later. I couldn't get the amazing clothing brand out of my head but was so hung up on the shipping. I pulled out my computer and drafted up a message to the company, proposing the idea of me selling their products over on my side of the world. Of course, I had no expectations of them getting back to me—they are an incredibly established clothing brand and I'm just a guy wanting to help others find clothes that make them feel as confident as they should. But I eventually heard back from a very eager accessible clothing brand that wanted to do business with me.”

Jezewsky and the company owners arrived at an arrangement that saw him acquire the North American rights to the clothing line. All of this happened as Jezewsky, along with his girlfriend Madison Olds, returned to BC from Toronto, setting up their new home and business in Coquitlam in 2020.



FACING PAGE: Derek Jezewsky wearing Kinetic Balance slim fit Garupa jeans and 3-1 jacket. ABOVE, LEFT TO RIGHT: black waterproof jacket with grey Raindek (a raincoat for your legs), slim fit jeans, and 3-1 jacket. Photos courtesy Kinetic Balance.

Jezewsky and Olds now find themselves with an increasingly popular E-Commerce website, where Canadians and Americans can discover and purchase the entire Kinetic Balance line. We asked him about his favourites.

“Everything is my favourite!” he says. “But joking aside, every one of the clothing pieces serves a different purpose and they do it so well. If I had to pick a few things I can’t live without, I would include the Raindek Original because it’s a must for any wheelchair user as nobody likes a wet lap, the 3-1 Jacket as it’s the perfect fall or spring jacket with a perfect cut, and obviously a pair of the slim fit jeans. The legs are absolutely perfect as there is no ankle showing and no back pockets, and they’re high cut in the back, so no matter how many times you transfer, they do not fall down and they feel normal.”

He stocks almost all of the company’s products, and if he doesn’t have an item and it’s in stock in the Netherlands, it’s only about a one-week turnaround.

As for the daily business of running the company, Jezewsky couldn’t be happier.

“Growing up, I always wanted to have my own company, so to me this is a dream come true. But from an SCI standpoint, I think a lot of people who don’t deal with SCI daily don’t realize how quickly things happen and how important it is to be able to have a flexible schedule; a safe space and time to be able to take care of yourself when you need to. So I would absolutely say my business is a perfect fit for me and I’m so grateful that my job doesn’t feel like a job at all, but more like a passion. We care so much about quality of life and being confident and comfortable in the things we wear. Kinetic Balance is a safe place for anybody looking to find those things.”

You can learn more and discover the entire clothing line at [kinetic-balance.ca](http://kinetic-balance.ca). Readers of *The Spin* can get 15 percent off their order—use the coupon “TheSpin” on at checkout. ■



# ANNUAL GENERAL MEETING

The Annual General Meeting for the Canadian Paraplegic Association (BC), operating as Spinal Cord Injury BC, will be held Thursday, October 21st at a Vancouver location to be announced. Please note that in order to comply with current Public Health Covid-19 regulations, attendance must be limited and therefore extended only to voting members who are fully vaccinated. A voting member is defined as a member who has paid an annual fee of \$10. Any non-voting members wishing to change their membership to voting and attend the AGM must do so by October 1st, 2021 and can make these arrangements by contacting Penaaz Sidhu at 604.326.1212 or [psidhu@sci-bc.ca](mailto:psidhu@sci-bc.ca). Venue information and meeting materials will be sent in advance of the meeting.



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# Participate in Research

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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.

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

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

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

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

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

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

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

## Designing an Inclusive and Accessible Website for a Research Partnership

**Overview:** ICORD researcher Dr. Ben Mortensen and his MAP research partnership is working to create, test and implement solutions to improve mobility, access and participation among Canadians with mobility issues. To support community engagement and share findings, they would like to create a website. The purpose of this study is to explore perspectives regarding the development of a website that is inclusive and accessible for the broader community of people with disabilities.

**What to expect:** Participants will take part in a formal, semi-structured interview of 30 to 60 minutes via Zoom. Research staff will lead the interviews and ask questions about participants' perspectives regarding accessible website design (e.g., examples of accessible websites, accessibility features).

**Who can participate:** You may be eligible to participate in this study if you have a disability or are members of MAP community partner organizations or municipalities; reside in British Columbia; are 19 years of age or older; can read, write and speak in English; and can provide your own consent.

**Why participate:** Your participation will inform how we can design a MAP website that is useful, inclusive and accessible for project participants and the broader community. A \$25 token of appreciation will be provided as an e-transfer in thanks for your participation.

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

**For more information or to sign up to participate:** please contact the study coordinator, Jodine Perkins, by email ([mortenson.lab@ubc.ca](mailto:mortenson.lab@ubc.ca)) or call 604.737.6491.



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

# Fun & Games

SCI BC's online games night offers peers a pleasant diversion—and, for many, an important connection.

“When you connect people, you have no idea what can happen next,” says SCI BC peer Nicole Saleh. “You might be surprised by how much that means to someone and how those original connections can turn into something bigger.”

Saleh should know. As the host of SCI BC's weekly peer online games night for the past year and a half, she's witnessed some amazing new friendships develop—and made some meaningful new connections herself.

While her online games night is relatively new (it began last year as a result of the pandemic and SCI BC's response to provide more online programming), Saleh's connection with SCI BC is anything but. After being injured in 1994, she became a regular at SCI BC events at the age of 11.

“I lived in Abbotsford, so my mom would drive me to events,” she says. “She wanted me to be really involved.”

Over the years, her involvement with SCI BC ebbed and flowed as she pursued an undergraduate and master's degree, lived in China for two years, got married, and had three kids.

After recovering from complications with her third pregnancy in 2020, Saleh was ready to get back to making connections. Unfortunately, COVID-19 had other plans. Forced to spend more time at home and unable to take part in her regular hobbies, Saleh turned to SCI BC.

“I was talking to Teri Thorson (SCI BC's Vancouver & Online Peer Program Coordinator) and mentioned that I really liked to play board games, and that my husband and I used to go to a games night,” she explains. “I told her that I might want to do an online games group, and we gave it a go.”

On Friday, May 22, 2020 SCI BC's online games night officially kicked off. Since then, the weekly event has been the one constant in a year full of uncertainty and change.

“For me, it's been liberating,” Saleh says. “I have a condition called short gut syndrome because, in my car accident, I lost a lot of my small intestine. So it makes it really difficult to go out and to hold a job and things like that.”

She quickly discovered that her games night, and other online events, allowed her an easy way to socialize and connect during a difficult time of lockdowns and social distancing. It introduced her to a group of peers who have developed friendship and camaraderie that extends beyond just playing games.

“We talk about everything...things like, ‘My elevator broke, does anyone know how to deal with this?’ Or, ‘I have a bladder infection, or I just broke my leg—what did you guys do?’

I feel like you don't have to explain stuff very much. People get it because they've been through it. And if you're trying to tell somebody about something you're going through, they're not just looking at you with pity, they're looking at you with understanding.”

The games night was also an unexpected catalyst for Saleh's journey into fitness. Her regular game attendees were avid exercisers and encouraged her to try another SCI BC online event: Leo Samarelli's adaptive boxing class.

“I was doing zero exercise before I started the board game group,” she says. “I started doing his class and I felt so much better after I got just a little bit of exercise once a week.” Now she has a full line-up of online exercise classes every day.

“My kids think it's funny and ask me, ‘How many classes do you do in a day?’ I'm the fittest I've ever been. I feel really good.”

Saleh also participated in our Scotiabank Charity Challenge for the first time this year. The annual fundraising event, which is usually held in-person in Vancouver, pivoted to an online format for the past two years and allowed for participation across the province.

“I did all the exercises online to meet my racing goal. It felt like I was a part of something. And the fact that I feel like SCI BC has done so much for me in the past year and a bit, I really believe in the cause and that it's genuine.”

Reflecting on her decades-long relationship with SCI BC, Saleh recognizes the immense impact that connections can have in someone's life.

“Meeting people and feeling like you're going through it together, and that there's other people who care—I think connection is key,” she says. “I have never been as involved with SCI BC as I am now because of the online programming. These people, who I have not known for very long, are so caring. They feel like my best friends.” ■

**You're invited!** SCI BC's online games night takes place on Fridays, from 7:30 to 9:30 PM. Visit [sci-bc.ca/events](https://sci-bc.ca/events) or call our InfoLine at 1-800-689-2477 to learn more.



Nicole Saleh is host of SCI BC's online games night.

# WHY I GIVE...

My relationship with SCI BC began in 1993 and since then, my life has been enriched by the people I've met along the way.

Some of my most rewarding moments have come from mentoring people who are newly injured, and from supporting those who've had long-time injuries. I know just how difficult it is to be vulnerable and open up. And when someone gives me that view into themselves, I'm profoundly grateful. I've been with people who've started to cry just because they see that I'm living. They see what's possible 20 years post-surgery. These visits are life-altering for both of us.

I hope people realize that when you're newly injured, life doesn't end, it changes—and it's what you do with these changes that makes a difference.

I love helping out and giving back to the community that's enriched my life. I know how much it costs to put these programs together and I know what a difference SCI BC makes for people. My hope is that the lives of peer members and their families will be enhanced and strengthened by the programs that SCI BC has to offer. This is why I'm a long-time donor.

## ***Kirsten Sharp***

***SCI BC Peer, Former SCI BC Staff  
& Donor***



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“ 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