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COVER: SCI BC Peer Program Coordinator and aspiring model Ryan Clarkson takes a spin on the runway during the FashionABLE fashion show at the recent American Spinal Injury Association (ASIA) conference in New Orleans. Photo by Grace Jun, Open Style Lab.



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Spinal Cord Injury BC

Be an Influencer.

Has anyone seen August? I'm not sure where it went, and I wasn't quite done with it. But I confess that, as the daylight hours grow noticeably shorter and the nights get colder, I begin to look forward to the change in season and the rituals of the fall.

Along with the changing of the leaves and the ubiquitous appearance of pumpkin-spiced drinks, fall brings us Diwali, Oktoberfest, Halloween, Thanksgiving, Dia de los Muertos, the Moon Festival and many other celebrations.

Every four years in BC, fall also offers a critically important opportunity: General Local Elections. Granted, local elections may not evoke the same autumnal sentiment as other fall events, but their results can shape our communities for years to come.

Historically, voter turnout for local elections is woefully low, which is perplexing given the influence decisions made by elected local officials can have on our day-to-day lives. This is particularly true when we think about accessibility and inclusion. While the *Accessible Canada Act* and *Accessible BC Act* create national and provincial standards and regulations related to accessibility and inclusion, it's local governments that make many of the decisions that more immediately impact accessibility and inclusion in our communities. General Local Elections are opportunities to influence positive change in our communities, and there are three key ways for people with disabilities to exert that influence.

The first is the easiest: vote. Preparing for your vote requires a bit of homework to figure out which candidates are most aligned with your views, but it's time well spent. After all, low voter turnout for local elections has one upside—it means your vote can be even more influential.

The second requires more commitment: apply to become a member of a local government advisory committee. This doesn't have to be limited to disability or accessibility advisory committees; representation by people with disabilities on all advisory committees is necessary for committees to be reflective of the communities they are there to serve.

The third requires a deep commitment: run for local government office. Whether it be for mayor, councillor, or a trustee, we need more people with disabilities to be represented on councils, school boards, and park boards throughout the province. Nearly 20 percent of people in BC identify as having a disability, but the number of elected officials with disabilities is nowhere close to this.

In this issue of *The Spin*, we highlight a number of individuals with SCI who have been or are campaigning to be elected to office. Although we do not endorse any individual candidate or political party, we think it's important to highlight those who are engaging in our political process—to commend them for doing so and to encourage others to do the same.

The General Local Elections are on October 15, so get to work learning about your local candidates and figuring out where and how to vote. If you need information about accessible voting options, give our InfoLine a call or email. Then, be an influencer and vote.



—Chris McBride, PhD, Executive Director, SCI BC



thespin

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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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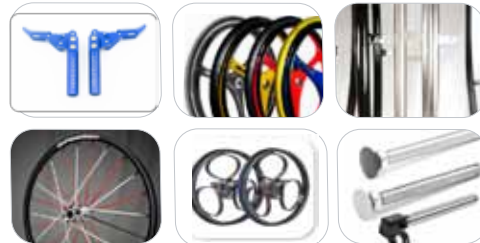
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COYOTE QUAD

The Coyote quad, made by US-based Outrider, is a powerful, long-range electric 4WD chair that will fit into many SUVs—and then get you into the most hard-to-access backcountry after you unload it. The company markets the Coyote to disabled and able-bodied riders alike, but we think it's ideal as an extremely capable all terrain wheelchair for hunting, fishing and hiking enthusiasts who have an SCI or other disability. It features independent long-travel front and rear air-shock suspension, and an exceptionally quiet 5000-watt hub motor 4WD system provides oodles of power. Semi-recumbent seating and hand controls make for easy operation, and you can add up to four lithium-ion battery packs for a range of 320 kilometres, at speeds up to 35 kph. It can be outfitted with a variety of adaptive options for users with disabilities, including hand controls with tri-pin adapters, harnesses, seatbelts and other seating options. More details at outriderusa.com.



EVOLUTION

The Evolution is a unique, compact and versatile home gym that combines benefits of many individual pieces of exercise equipment. It wasn't specifically designed for adaptive exercise—it provides able-bodied users with an opportunity to do more than 200 exercises—but was quickly adopted by people with a range of disabilities seeking a convenient, accessible, and inclusive workout experience. With its one meter by one meter footprint, it can accommodate most standard wheelchairs, providing a stable platform that allows users to safely employ resistance bands to perform modified versions of exercises to suit their specific needs. Additionally, the parallel bars can be used to help you stand. Visit evolutionvn.com to learn more and see videos of the Evolution being used by wheelchair users.

Innovations

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



WOWEASE

The owners of Wowease developed the easy-opening one-piece bathing suit for young girls, but demand from women convinced them to create adult versions. The result may be a great solution for women with SCI and other disabilities who have trouble getting in and out of a wet bathing suit when nature calls. It looks like a traditional one-piece but has the ease of a two-piece. The

patented design uses secure hidden magnetic fasteners and snaps at the waist. You simply unfasten the magnets and snaps and secure the flap to the back of the suit with the hidden back magnet, which keeps the flap up and out of the way. To reattach, simply pull the flap down the back and replace the magnets along the line at the front, then snap into place on the sides. Learn more at wowease.com.

REEBOK FIT TO FIT

Sports and footwear giant Reebok recently unveiled its first-ever adaptive footwear collection, joining the likes of Billy Footwear and Nike FlyEase in a bid to woo consumers with disabilities. The Reebok Fit to Fit line has two initial offerings: the Nanoflex ParaFit TR and Club MEMT ParaFit. Each features traditional laces with a zipper on one side that's equipped with a thumb loop, allowing for easy access and better fit. Extra width to prevent pressure points and skin damage is standard on both styles. The Nanoflex ParaFit TR is a unisex shoe intended specifically for workouts and activity, while the leather Club MEMT ParaFit is more of a casual, everyday style. The Reebok Fit To Fit collection is available now on Reebok.com and Zappos.com.



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Make your voice and vote count.

SCI BC's Annual General Meeting will be held Wednesday, September 28 at 6:30 PM at Vancouver's VanDusen Botanical Garden. Voting members are invited to join us for refreshments as we celebrate our successes in the past year. Venue information and meeting materials will be sent in advance of the meeting. Due to the ongoing COVID-19 pandemic, attendance will be limited to voting members who are fully vaccinated. See page 15 for RSVP details and more information.



Listen to your peers play live.

The Vancouver Adapted Music Society (VAMS) is bringing back its flagship Strong Sessions concert on Thursday, October 6, at 6:30 PM. Experience a fun and interactive evening to celebrate nearly 35 great years of VAMS. The concert, which takes place at Roundhouse Community Arts & Recreation Centre, will feature performances from a variety of VAMS musicians with disabilities. Learn why disability is no barrier to musicality! Visit bit.ly/VAMScconcert for more information.



This fall, click to connect.

SCI BC'S online events are just a click away. We'll continue in-person events as conditions allow, but we can't deny how popular some of our virtual meet-ups on Zoom have become in the past two years. They're a great (and easy) way to make new friends or stay connected with old ones. From adaptive boxing, book club and games night, to dance classes and regional coffee groups, we've got you covered. Visit sci-bc.ca/events for a calendar of online events coming soon.



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We could give a shoutout to Vancouver's **KYLE GIENI** for many reasons, from his prowess at sledge hockey and wheelchair floorball, to his incredible contributions to SCI research (he's participated in more than 50 studies). But his recent performance at the annual BMO Vancouver Marathon, which took place on May 1, is worthy of a shoutout all by itself. The longtime PARC participant completed the race in a time of 3:11:52, placing 236th out of the 4227 finishers.

Gieni, a Resource Coordinator at a Vancouver law firm, had completed a half-marathon for the past eight years, manually pushing his wheelchair. He's always wanted to do a full marathon, but shoulder pain prevented that. His solution this year? Instead of pushing his way through the circuit, he poled it, using ski poles with tungsten-carbide tips that dig into the pavement.

"While manually pushing a wheelchair uses shoulder and chest muscles, poling uses more of the bigger back muscles, making it easier

and faster, and with no pain the next day—even after a marathon," says Gieni, adding that he credits the result to the work he puts in on ski ergs at home and at PARC. "Overall, the marathon experience was really fun. Most of the runners were very positive, giving me encouragement the whole way. I was called a 'beast,' a 'monster,' and an 'inspiration.' Two different people jokingly called me a cheater, which I found hilarious."



JOHN DENNISTON PHOTO

A shoutout to Victoria's **RYAN YELLOWLEES** for hanging out his shingle as student practicum counsellor at Island Community Counselling. Yellowlees, who has Duchenne muscular dystrophy and uses a power wheelchair, is offering his counselling skills on a practicum basis as he completes his Master of Counselling at City University.

"My counselling approach is derived from my Master of Counselling studies and my lived experience of having a chronic illness," says Yellowlees. "When I graduate, I plan to do further training in my specialization of disability and illness counselling, narrative therapy training, grief and loss counselling, and end-of-life palliative counselling. Also, when I graduate, I will fully pursue my disability activism career."

He's hoping to finish the Master of Counselling program this December and then will apply for his Registered Clinical Counsellor designation. He offers phone and online counselling to anyone living on Vancouver Island and the Sunshine Coast. You can learn more about him, and contact him, at the Island Community Counselling website (islandcommunitycounselling.ca/staff/ryan-yellowlees).



Peer Shoutouts

When we mention SCI BC peer **ROB SHAW**, you'd be forgiven if the first thing that comes to mind is his exceptional talent as a wheelchair tennis player—after all, he won the gold medal at the 2019 Parapan American Games in Peru. But this shoutout is to recognize the fact that, after completing his Doctor of Philosophy in Interdisciplinary Studies at UBC Okanagan in June, he's now Dr. Rob Shaw—and also the 2022 recipient of UBC Okanagan's prestigious Governor General Gold Medal, which is awarded yearly to the doctoral student with the most outstanding academic record.

"Looking at past winners, I can't help but feel humbled by this award," he says. "Five years ago, my supervisor and I committed to completing a PhD that would make an impact beyond the silos of academia and extend into the community to benefit people living with SCI. I'd like to think that this award reflects that we achieved that goal."

His research, conducted under the supervision of Dr. Kathleen Martin-Ginis, focused on how peer mentorship can improve the health and wellbeing of people who live with an SCI.

"An excellent scientist can produce a lot of great research," says Martin-Ginis. "But an excellent scientific leader finds the potential in people and has the courage to inspire and support them. Rob has achieved excellence and acclaim as both a scientist and scientific leader. Through his research and leadership, and his outstanding global citizenship, Rob is making the world a better place."

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





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Can-do Cadieux

A portrait of Stephanie Cadieux, a woman with short brown hair and glasses, wearing a maroon blazer. She is smiling and looking towards the camera. The background is a blurred image of the British Columbia Parliament Building in Victoria.

After an outstanding 13-year, three-term career as an MLA, SCI BC peer Stephanie Cadieux has embraced a new challenge—becoming Canada’s first Chief Accessibility Officer.

Looking back, many of us who were here at SCI BC during Stephanie Cadieux's tenure with us always suspected that she was destined for great things.

"Steph was always very bright and ambitious, so I can't say I was surprised when the Liberals asked her to run for MLA," says our recently retired Operations Manager, Maureen Brownlee, who enjoyed working with Cadieux for eight years back in the early 2000s when she was SCI BC's Director of Marketing & Development. "And I certainly wasn't surprised in the least about her recent appointment. It's a pretty good fit! I do think that she would have had a great career in the corporate world as well. Glad she chose the direction she did, though."

Cadieux, now 50, was injured in a car accident at age 18. She started her career with SCI BC as Provincial Peer Coordinator—along with the late Brad Jacobsen, she developed what is now our Peer Support Program. In 2004, she became our Director of Marketing & Development.

In 2009, The BC Liberal Party asked Cadieux to join its ranks. Soon after, she was elected as MLA for the riding of Surrey-Panorama. In the process, she became only the second BC MLA to use a wheelchair (the first, of course, was the founding father of SCI BC, Doug Mowat). She was re-elected twice, in 2013 and 2017. She held four cabinet positions during the Liberals stay in power: Minister of Children and Family Development; Minister of Social Development; Minister of Labour, Citizens' Services and Open Government; and Minister of Community, Sport and Cultural Development. When the NDP assumed power in 2017, she took on the role of Opposition Critic for Advanced Education.

During her time with SCI BC and government, she also took on many other challenges and positions, including Manager of Accessibility for 2010 Legacies Now Society, President of the Realwheels Society, Ambassador for the Rick Hansen Man in Motion Foundation, researcher and member of the advisory panel at ICORD, member of the Diversity Advisory Committee for Global BC, and mentor with the YWCA.

In April of this year, Cadieux resigned from her MLA position to take on perhaps her most challenging role yet,—becoming Canada's first Chief Accessibility Officer. Recently, we caught up with Cadieux, and she graciously reflected about her political career, and gave us some insight about her new job.



Looking back to 2008/2009, what motivated you to run for office? Was it a difficult decision?

After working with SCI BC and other disability groups doing advocacy work, I realized that having an advocate on the inside would help drive change. Around the same time, I was recruited to run for office, which was both exciting and unnerving. It took me a few months to decide if I should take the leap.

Do you remember what your thoughts were when you realized you'd won your riding and were heading for the legislature?

My first thought was, "I have no idea what I'm doing!" It was very exciting and very intimidating. I was overwhelmed when we had our orientation meeting and I sat in the chamber for the first time, realizing I was the 849th MLA to sign the Parliamentary Roll, the second wheelchair user, and the first woman with a physical disability.

What do you think were your most important accomplishments during your time as an MLA?

I advocated hard and long for my ridings, which helped to bring about 14 new or expanded schools since 2017, with four more underway. I'm proud of the work that I was able to do for individual constituents to help them get the services and supports they needed. That's the first and most important job of an MLA.

I also had the honour to serve in cabinet, and as a Minister, I was able to drive systemic changes to income assistance policy, reforms on asset exemptions and annualized earning exemptions that continue to lead the country. I put a focus on kids that were languishing in foster care, with the goal of finding them adoptive homes. We saw a record number of children find permanency—nearly 1,400 youth over a three-year span, which was more than double the previous rate. I also championed the single-parent employment initiative to help parents on income assistance get the training and, ultimately, employment to support their families. It's the only program of its scale in this country, and I'd love to see the current or a future government do something similar for people with disabilities.

What was your most memorable moment(s) during your time in office? How about least memorable?

It's hard to pick one most memorable moment. The whole experience was impactful. It was a pretty good day, though, when we opened the "Mowat Entrance" to the legislature, named, of course, after Doug Mowat, former MLA and SCI BC's founding member and long time executive director. Knowing my influence had played a part in the decision to renovate the building to allow for a fully accessible entrance for the public at the front definitely made me feel like I was making a difference.

The least memorable? Well, the thing I want to remember the least would be the days and weeks I spent under attack in Question Period. In fact, Question Period itself was probably my least favorite thing, regardless of my role in it.



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Based on your experience, what are currently the most pressing items for our current provincial government when it comes to policies that impact PWD?

Housing. It's a pretty big plank in most platforms these days. Affordable housing. However, leaders are completely missing the most basic fact that, for people with disabilities (and for most people as they age), we aren't building housing that meets their needs, affordable or otherwise. We need laws to ensure accessible or adaptable housing is built across the continuum—from subsidized to market, and single to multi-family construction.

How and why did you make the decision to leave politics and take the position as Canada's first ever Chief Accessibility Officer? After being an integral part of the party in power, did the job lose any of its lustre when you were relegated to the opposition? Or was the opportunity too enticing?

When I decided to run for office, I was ready for a new adventure, but I really had no idea what being an MLA truly meant or how long it would be for. I did know it was a chance to make a difference and that it wouldn't be forever. This decision point was similar. I have had the opportunity to serve in both government and opposition. There were positives and negatives to each, but really, after four elections in three ridings, I was just ready.

The federal government made a big commitment by passing the *Accessible Canada Act*, and I wanted the opportunity to drive change at the national level.

Can you give us a sense of what the new job entails?

In a nutshell, I'll be serving as an independent advisor to the Minister responsible for the *Accessible Canada Act*. I'll monitor, report and provide independent advice to the Minister on a range of accessibility issues in areas of federal jurisdiction. Inside government, I will be a champion for accessibility and disability inclusion. My office will be looking at accessibility plans used by federal organizations and federally-regulated bodies, and tracking accessibility trends within and outside Canada. I'll also be working hard to establish ongoing, honest dialogue with the disability stakeholder community across the country to inform the work I do, foster a common understanding of the issues we're facing, share best practices, and flag any potential or existing problems so we can identify solutions.

I know you've barely started, but what are your most pressing priorities?

I'm going to work hard to help change the narrative around disability in meaningful way—where creating spaces and building infrastructure and organizations that are accessible to all is just the way things are done, and is not viewed as “nice to have” or as an afterthought.

Creating a barrier-free Canada is a big goal, and there's a lot of work to be done to get there. So right now, our office is working to determine what will have the biggest impact.

Ultimately, what would you like to accomplish during your time in this position? In the future, when you look back at your time in this position, what would make you feel like you've had an impact?

This is a brand new position, and while being the first to take it on might seem daunting, one of the pluses is that we have the opportunity to help define what success looks like. Conversations with our partners and diverse people and groups will help us to do that.

For a start, I know that I want to see decision-makers across jurisdictions and sectors commit to proactively ensuring their communities and workplaces are accessible and inclusive, on an ongoing basis—without waiting for it to be raised by either myself or an employee or a member of the public who encounters an issue.

How is it working in this position from your home in BC? Do you travel to Ottawa regularly?

The pandemic showed us we can pivot and innovate when we need to. By necessity, businesses realized remote working was possible and even productive. Many of the things that have now been mainstreamed were things people with disabilities have long been asking for in the way of job accommodations. While it can be a bit lonely at times, not having to relocate was a big plus. I will be travelling back and forth a fair bit, but I'm looking forward to that.

Would you ever reconsider moving back into politics, perhaps at a federal level, and if so, why?

If you had asked me would I ever be a politician, I'd have said, "Not likely." So I guess I can't say for certain that I'd never consider it. For now, however, I'm really enjoying the non-partisan role, focusing my energy directly on the issues I care about the most.

What influence has having an SCI had in your career?

I had a vision for my life at 18 when I started university. My SCI interrupted that rather abruptly—but it also taught me lessons about perspective, perseverance, adaptability, the power of choice, and reframing.

I think that my own experience with disability (ever evolving as it is) has made me a more compassionate person, and has fuelled my drive for seeking solutions to challenging issues.

Looking back at your early post-injury life, or even your time at SCI BC, did you have any idea of what kind of an incredible career you would have?

I had a hard time focusing my career in my early years, which were also my immediate post injury years. I wasn't sure I'd be able to stick to anything for very long.


No one was more surprised than I was when I seemed to find my groove at SCI BC—but no, I had no idea where my trajectory would lead. It has been an incredible ride so far.

What would you say to other peers with SCI who might be considering running for public office?

Do consider it. It is exciting and challenging. But it's not easy, so talk to people who've done it, and learn from them. Make sure you have a solid support network behind you. It is whole-life-encompassing, so your family and closest friends need to understand and support your decision.


You need to have thick skin or some emotional armour. People judge others by their political stripes, and in today's world, with social media as a megaphone for anyone with an opinion, you will face personal attacks. The focus should be on critiques of policy, not of people. The state of public discourse has deteriorated, and it isn't good for democracy, because it keeps good people from stepping forward, and is further eroding trust in our leaders and institutions.

So in my opinion, now is an incredibly important time for more good people to put their hand up, lean in, and create positive change. ■



**ANNUAL
GENERAL
MEETING**

The Annual General Meeting for the Canadian Paraplegic Association (BC), operating as Spinal Cord Injury BC, will be held Wednesday, September 28 at VanDusen Botanical Garden in Vancouver. Please note that, due to the ongoing COVID-19 pandemic, attendance will be limited 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 can make these arrangements by contacting Maureen Brownlee at 604.326.1212. Detailed venue information and meeting materials will be sent in advance of the meeting.



Spinal Cord Injury BC

Passing the Torch

SCI BC peers have a long tradition of being active in BC politics. We're pleased to introduce you to two peers who aspire to continue that tradition.

Doug Mowat's legacy is alive and well. A quadriplegic from the age of 17, Mowat was the founding father of SCI BC. He served as Executive Director from 1962 until his death in 1992, and we credit our organization's strength and success today to his vision, dedication and commitment.

But we also remember Mowat for a different reason. When he was elected as an MLA in 1983, he became the first wheelchair user elected to a legislature in Canada. He served the people of BC well in that capacity until 1991, and we think it's safe to say that he has been an inspiration to the peers who have followed in his tracks.

First came Sam Sullivan, who successfully ran for Vancouver City Council in 1993. In 2005, he was elected mayor of Vancouver, a position he held until 2008.

In 2009, Stephanie Cadieux followed in Mowat's tracks, becoming only the second BC wheelchair user to become an MLA—and the first woman to do so.

In 2013, she was reelected—and amazingly, was joined by two other SCI BC peers. After a five-year hiatus from politics, Sam Sullivan was elected as an MLA, along with Paralympian Michelle Stilwell. Both held the post for two terms, until power shifted in 2020. Here at SCI BC, we couldn't have been prouder to see three peers playing integral roles in the governance of our province for seven years running.

Most recently, Dan Coulter was elected in 2020 as MLA to represent constituents in Chilliwack. Since being elected, he's been tapped by the NDP caucus to take on the role of Parliamentary Secretary for Accessibility under the Ministry of Social Development and Poverty Reduction, where he's overseeing the final development, approval, and implementation of the new *Accessible British Columbia Act*.

Now we're pleased to report that two peers are making a bid to continue the tradition. Alexis Chicoine is running as an independent in the upcoming West Vancouver City Council election, while Hilary Brown has aligned himself with mayor Kennedy Stewart's Forward Together party as he seeks election to Vancouver City Council. We reached out to Chicoine and Brown for their thoughts as the election approaches on October 15. Specifically, we wanted to know how they got involved in political life, their motivation for doing so, their qualifications, where their SCI fits into the equation and the importance of people with SCI being involved in politics, and some of their priorities. Note that, while we believe it's important for people with SCI and other disabilities to run for public office, we want to be clear that we, as an organization, are unable to endorse individual candidates or parties.



ALEXIS CHICOINE

53 Years Old | C6 | West Vancouver

I was approached by present council members, as they had met me through my work as vice chair of a council-appointed committee that advises on accessible issues related to housing, parks, streetscapes, shared pathways, access to transit and more across the North Shore. I was intrigued by the opportunity, and ultimately it felt like the natural next step in the progression of all the community work I've been involved in over the years—from students' council in high school, to 13 years as strata president at my previous home and serving as board chairperson on numerous committees. I'm ready to work with my community to help shape West Vancouver into the future.

I like to address my different mode of mobility upfront, even before my resume of work, because it's one of my key strengths and benefits. I developed resilience, strength and confidence knowing I can thrive when life brings on challenges. Surprisingly, as I opened myself up to new opportunities, the people around me also grew—their perspective expanded, allowing them to view people and the world in new ways.

With seven plus years advising on the North Shore Tri-Municipal Advisory Committee on Disability Issues (ACDI), I'm highly informed of the challenges facing our community today. I also have extensive employment, board and committee experience that has prepared me to work in an environment where not all decisions will be straightforward or potentially even welcomed by everyone.

Creating inclusive communities, so people can work, live and play there throughout their lifespan, is an important overarching lens to apply in all policy making. People with SCI sharing lived experiences and educated perspectives from actively being out and about in the community can lead to an overall increase in political efficacy. Diversity in thought and experience are crucial to innovation. My unique journey can breathe new life into the issues my community needs to address.

West Vancouver has a housing crisis—we need to diversify our housing options and increase supply. To move this forward, I will work with the council to rezone properties when opportunities arise to sensitively develop—

architecturally and environmentally—laneway houses, townhomes, rental units, mixed-use developments, supportive housing for seniors and people with disabilities, and others.

Building this housing near transit is another priority, in order to lessen the reliance on personal vehicle transportation and ease our significant traffic congestion. I'd like to become a member of the committee North Shore Connects, to work with community partners to advance the Burrard Inlet Rapid Transit and advocate for faster implementation of bus rapid transit in the interim.

Protecting our natural environment and adapting to climate change is necessary. I will work with council to update goals in a new strategic plan and be guided by the *Community Energy and Emissions Plan* to implement steps to lower greenhouse gas (GHG) emissions. Planning decisions made today on infrastructure investments and land-use will have environmental impacts well into the future. Our foreshore, streams, parks and natural mountainside need to be sensitively maintained, so we can enjoy them for years to come.

It is also important to support the community by enhancing arts and culture, local businesses, and recreational amenities, so they can keep improving and expanding programming. Finalizing and moving forward with local area plans will also help to guide and strengthen the charm and vitality of the villages across West Vancouver.

My website shares more about me and opportunities to support my campaign—please visit www.alexischicoine.ca or email me at alexisforcouncil@gmail.com.



HILARY BROWN

56 Years Old | T8 | Vancouver

I'm running because I want to help improve Vancouver. From housing and accessibility to supporting community sport, arts and culture, there are a number of areas where my experience as an educator, grassroots organizer and person living with a disability will allow me to bring a valuable and unique perspective to city hall.

I am a strong supporter of what Mayor Kennedy Stewart has accomplished over the last four years and want to help ensure that we have a progressive majority on council so that we can make Vancouver a city that works for everyone.

As a science educator at Vancouver Community College, I hear firsthand from students about the struggles they face to find affordable housing in Vancouver and want to work to change this.

For more than three decades, I have been a paraplegic and have had to grapple with the lack of accessibility in our city. I have had to be carried up stairs by perfect strangers and have had to crawl across floors in order to use narrow bathrooms. We need to do more to make Vancouver a truly accessible and inclusive city.

I have been an active volunteer in wheelchair sports and other community groups—both disabled and able-bodied—for over 34 years and find great joy in community-based recreation and sport. I want to support programs like these that bring Vancouverites together.

Living with SCI for 32 years has given me greater empathy for all people who experience adversity. It has made me acutely aware of the shortcomings in our built environment and the need to embed accessibility and inclusion into how we design our cities.

Being a wheelchair user also has the advantage of making me more recognizable and memorable to people. My presence—whether it's at events, on the campaign trail or moving around the city—also forces those around me to think about accessibility and raises their awareness of accessibility challenges. Approximately 20 per cent of Vancouverites identify as having a disability, yet the proportion of our political leaders who are disabled is much smaller. We need to change this—not only because our governments should reflect the people they represent, but because it is



important to have people with disabilities directly involved in crafting policies that promote accessibility and inclusion.

Seeing someone with a disability holding political office also encourages other people with disabilities to step up and engage in political action.

If I'm elected, my priorities will be housing affordability, accessibility and community.

Through my work at Vancouver Community College, I have seen firsthand how students and young people are struggling to find affordable housing in this city. I want to increase the supply of affordable housing and boost renter protections so that students can focus more on their studies and less on putting a roof over their heads.

I am strongly aware of our city's shortcomings when it comes to accessibility and want to change that—not just for people in a wheelchair like me, but for everyone living with a disability in Vancouver.

As a long-time volunteer in wheelchair sports and other community groups, I want the City of Vancouver to support programs that increase participation in sports, arts and cultural activities.

Remember to vote on October 15! Municipal elections can be won or lost by a handful of votes, so every vote counts. Also, be sure to check out www.forwardvancouver.ca to learn more about how we want to make Vancouver a city that works for everyone. ■



We're Back!

This year, with safety top of mind, we finally resumed our in-person events—and as you can see from the photos on this spread, our peers across the province came out in droves to enjoy them. Looking ahead to the fall and winter months, we'll employ safety precautions and abide by BC Health recommendations in the hopes that we can continue meeting in person.

1. A bus full of excited SCI BC peers and family members destined for our Ambulatory Retreat, which took place June 17 to 20 at the Naramata Centre.
2. Everyone explored their creativity during the Women's Retreat, also held at the Naramata Centre from April 1 to 4.
3. Team SCI BC at the Vancouver Charity Challenge, June 26. Back, left to right: Karen Gillespie, Avery Albrecht, Jenna Wright, and Susie Jackson. Seated: Rod Bitz.
4. Lori Slater (left) enjoys spa day at the Women's Retreat in Naramata.
5. Left to right: Shafique Pirani, Sally Pirani and Tim Sader at our North Vancouver bird-watching event, which took place May 14 at the Maplewood Flats Conservation Area.
6. Shawn Baxter and his son Oliver discuss the finer points of angling at our Fishing Forever Event, held in Osoyoos on June 11.
7. The Jenga competition was furious during our Ambulatory Retreat in Naramata.
8. Teddy Dixon, Dan Duffy and Dan Duffy's partner Elena at the Surrey Fishing & Picnic Day, held at Green Timbers Lake on June 12.
9. Bert Abbott, SCI BC's Provincial Peer Program Manager (front of kayak) and Power To Be volunteer Jay Simpson (back of kayak), and Britt McLeod from Power To Be (back kayak) during our Victoria kayaking event, held at Prospect Lake on July 6.
10. Left to right: Cody Petrone, Stu Wymer, Shawn Baxter, Anand Kannan and his wife Kim at the Fishing Forever Event held on June 11 in Osoyoos.
11. Left to right: James Hektner, Stu Weimer and Rob Mabey take a break from fishing to soak in the amazing view during our Fishing Forever Event held on June 11 in Osoyoos.
12. Peter Chisholm (SCI BC Peer Program Coordinator) and Janice Laurence at an evening group handcycling event held by SCI BC's Adaptive Cycling Program on May 25.



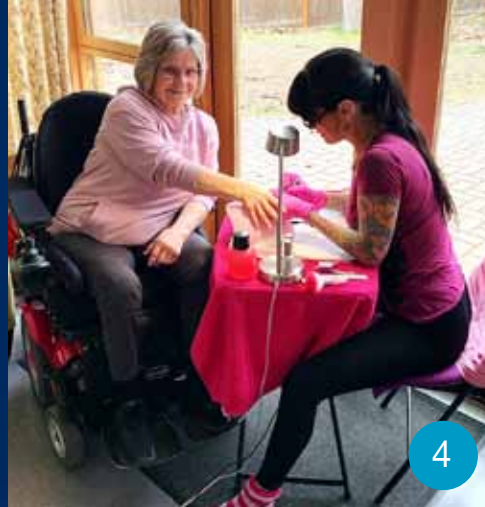
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Fashion

Where Form & Function Meet

Dr. Andrei Krassioukov's ICORD lab makes a surprising and welcome foray into the world of accessible and adaptive clothing for people with disabilities.

Few ICORD principal investigators are as stylistically inclined as Dr. Andrei Krassioukov, whose collection of sports jackets would surely put Don Cherry's to shame.

So maybe we shouldn't be too surprised that one of Dr. K's lab's current projects is adaptive clothing that doesn't sacrifice style. It must be noted, however, that FashionABLE is somewhat of a departure from Dr. K's typical research focus—after all, he's a physiatrist and globally-recognized authority in autonomic and cardiovascular complications in SCI.

"The project stemmed out of Dr. K's many years of experience working with people with SCI, and his observation of the lack of options with adaptive clothing," says FashionABLE project leader Tami Kalimullina, a graduate student in the Krassioukov lab. "He couldn't help but notice that there are limited commercial options available, and that often, what is available doesn't meet the unique needs of many people. He also noticed that, in making accessible clothing, fashion too often is an afterthought. The FashionABLE project was created to address these gaps, and brings together people with lived experience, healthcare professionals, and fashion designers."

The goals, says Kalimullina, are to identify and create more practical yet fashion-forward choices and options for adaptive clothing—and curate them into an easily-accessed online resource that lets people see what's already out there, and find

THIS PAGE: SCI BC's Teri Thorson (top) and John Chernesky, Consumer Engagement Program Manager of Praxis Spinal Cord Institute, take their turns on the runway during the recent ASIA conference in New Orleans. FACING PAGE: Dr. Andrei Krassioukov and SCI BC's Ryan Clarkson in New Orleans (top); FashionABLE project leader Tami Kalimullina (bottom).

ABLE

ways of getting what they need when they can't find a commercially-available option or an off-the-rack item that fits into their budget.

"Our immediate goal is to create an open-source resource for adaptive clothing, aimed to be a one-stop shop for clothing adaptations and designs that will be easily accessible to both individuals with SCI, and healthcare professionals," says Kalimullina. "We plan to integrate existing commercially-available clothing into our final open-source library, based on feedback we receive from in-depth surveys and interviews. In addition to providing links to adaptive clothing already on the market, the resource will act as a comprehensive guide to creating clothing from scratch, and have ideas for modifying non-adaptive clothing. And we will also include patterns of adaptive clothing that can be easily reproduced in any part of the world."

FashionABLE has other priorities. One is to explore options for adaptive workwear. Kalimullina was recently awarded a WorkSafeBC Research Training Award

for her to focus on return-to-work needs of people with SCI.

"Returning to work is crucial to regaining independence after injury, and we aim to create a resource with clothing tips and hacks to facilitate this transition, like modifications for ease of bladder and bowel care, and options for workplace-appropriate attire," she explains. "The plan is to reach out and conduct interviews with WorkSafeBC and other major employers to discuss clothing allowances and to determine potential articles of adaptive clothing needed for workplace environments."

Everything undertaken by FashionABLE will be passed under the "form versus function" lens. "On a broader scale," says Kalimullina, "we hope that this project can inspire changes in the field of adaptive fashion, where adaptive clothing will meet expressed functional needs, while adapting a more fashion-forward approach."

SCI BC is pleased to be a project partner and play a role in moving FashionABLE forward. Recently, Peer Program Coordinators Teri Thorson and Ryan Clarkson travelled with the FashionABLE team to the American Spinal Injury Association (ASIA) conference in New Orleans. Dr. K's team presented an adaptive clothing course and a fashion show showcasing adaptive designs developed by Chloe Angus, a Vancouver-based fashion designer and SCI BC peer, and Grace Jun, fashion designer at the Open Style Lab in Atlanta, Georgia. Thorson and Clarkson, along with SCI BC peer John Chernesky, were on hand to model the designs.

"Teri has been our consultant since the conception of the project and is one of the reasons the show in New Orleans was a massive success," says Kalimullina. "We hope to hold a similar event in the future to showcase more adaptive fashion-forward clothing and involve members of SCI BC to model these designs."

Currently, FashionABLE is recruiting participants to complete online surveys and interviews to learn more about the various perspectives and practices of adaptive clothing.



"If you're a person with chronic SCI, or a healthcare professional with more than a year of experience working with people with SCI, we would love to hear from you," says Kalimullina. "SCI BC members are more than welcome to participate in our surveys and interviews, and we hope to hear many perspectives. We also look forward to sharing the final FashionABLE resource with the SCI BC community and always value its members' feedback and suggestions."

We'd like to point out that, in selecting Kalimullina as the project lead, Dr. K appears to have found a real champion for adaptive clothing.

"Self-expression through fashion is important to me, and this project highly resonated with me—I believe individuals should not have to sacrifice their self-expression for functionality," she says. "I became involved with this project just before the current surveys were created, and will continue to assist with interviews, analysis, and creating the final resource. I've really enjoyed the process, as this is my first study where I interact with individuals and hear their perspectives, which gives more depth to my pre-clinical work. I've also had the opportunity to work with an excellent interdisciplinary team, from whom I've learned a lot."

The FashionABLE project is funded in large part by a grant from the Craig H. Nielsen Foundation. You can find out how to get involved and contribute by visiting icord.org/studies/2022/07/fashionable/. ■



Synchronized Stimulation

Open loop electrical stimulation has already shown promise as a treatment to improve neurogenic bowel for people with SCI. Researchers at Texas A&M University are hoping for even better results and close-to-normal bowel function via closed loop stimulation.

It probably seems like we're always fixated on bowel function here at *The Spin*. But the reality is that survey after survey of people with SCI make one thing clear: bowel routines are one of the biggest challenges you face, and you believe research in this area should be a high priority.

A couple of issues ago, we wrote about work being done in this area at Dr. Reggie Edgerton's UCLA lab. Using their own proprietary technology, the SpineX SCONE transcutaneous stimulation device, Edgerton, along with Dr. Parag Gad and other colleagues, demonstrated that electrical impulses delivered by electrodes attached to target areas on the skin above the spinal cord were able to restore some sensation and induce contractions in the rectum. And in a case study of one person, a stimulation training regimen of one hour daily for one week resulted in a dramatic reduction of time needed to complete a bowel routine—from 75 minutes to 15 minutes.

This study, and others like it, have been performed with what's known as an open loop stimulation system. It's called open loop because the participants receive a pre-determined stimulation set determined by the researchers involved.

The stimulation parameters—the timing, duration, strength and frequency of the pulses—are preset and remain constant throughout the treatment. It's only after the results of the stimulation become apparent that the parameters can be adjusted for subsequent treatments.

These type of open-loop stimulation systems are relatively successful and well-established. But it may be that there is potential for better results using closed loop stimulation.

In a closed loop system, there are two components. Like an open loop system, closed loop systems have a stimulation device and electrodes that work together to deliver electrical pulses to the target nerve or muscle to trigger the desired outcome. But closed loop systems also have a component that senses, in real time, the effect of the stimulation and, after analyzing that feedback, automatically and dynamically adjusts the stimulation parameters as required to increase the effectiveness of the therapy—and to reduce troublesome side effects.

At Texas A&M University, Dr. Hanguang Park and his colleagues are developing this type of closed loop stimulation system in an effort to replicate the natural rhythm of the digestive system and more normal bowel function after SCI.

"Although the effect of electrical stimulation on promoting effective colon movement has been previously investigated, no previous study has yet investigated the result of closed loop electrical stimulation on promoting colon movement," says Park, an assistant professor in the Department of Electrical and Computer Engineering. "The motivation of this work is to offer people with SCI, as well as their caregivers, a higher quality of life."

The underlying mechanism of a normal bowel movement is mass peristalsis—a natural, sequential and rhythmic constriction and relaxation of the muscles in the colon that propels stool to the rectum prior to voiding. It's this process that is often compromised in people with SCI. The result is neurogenic bowel—constipation, incontinence, and the need for a routine that can take hours to complete.

Finding a way to safely trigger mass peristalsis in people with SCI would, in essence, cure neurogenic bowel. But how to do that? Despite promising results, the open loop stimulation using the SCONE device that we referred to above does not fully restore peristalsis. It appears to be more of a blunt instrument that stimulates the vagus and pelvic nerves to induce some peristaltic contractions in one part of colon.

The approach taken by Park and his colleagues at Texas A&M is to surgically-implant highly flexible electrodes at key points on the surface of the colon itself. These electrodes can trigger the adjacent rings of smooth muscles in the colon in a sequence that mimics peristalsis—and also seem to “reawaken” the nervous system’s central pattern generator for peristalsis. Meanwhile, sensors that are also implanted on the colon provide electrocolonogram monitoring to determine what’s happening with the colon in real time. Information from these sensors is assessed by a computer and used to immediately change the stimuli as required to continue peristalsis and propel stool to the rectum.

In 2019, Park and his colleagues published a paper for a conference titled *A Real-time Electrocolonogram Monitoring and Electrical Stimulation System for Promoting Mass Peristalsis of the Colon*. Here’s what the authors wrote in the paper’s conclusion: “We have developed a real-time electrocolonogram monitoring and stimulation system and evaluated its efficacy on promoting peristaltic movement with a mouse model. The results obtained during benchtop tests and animal experiments clearly showed that the presented system could simultaneously record electrocolonogram and induce colonic activity and initiate peristaltic movements of colon with electrical stimuli.”

Since that paper was presented, Park and his team have continued to refine their system and research methodology. Much of the work has focused on the timing of stimulation—determining when is the best time to initiate stimulation, which is a complex problem as the colon is still a mystery to researchers in many ways.

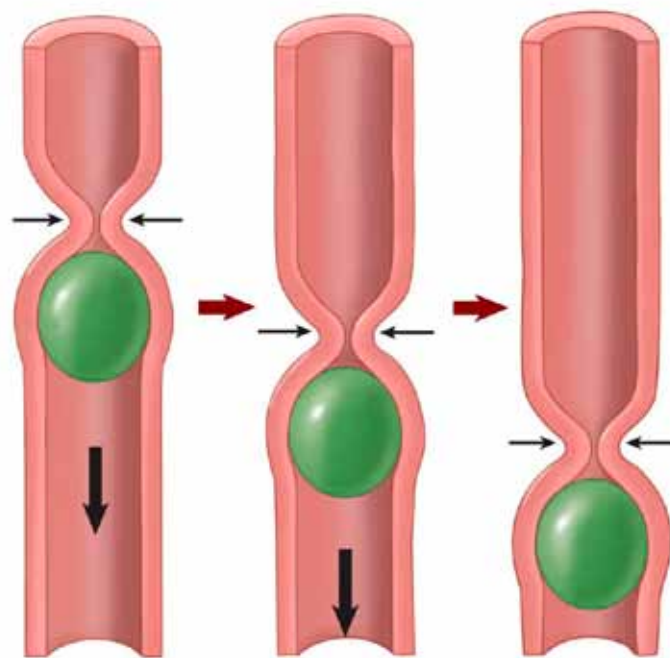
“With a series of experiments, we learned that e-stimulation should be carefully applied with a closed-loop optimization, based on the reading from the colon,” says Park, adding that timing of closed-loop stimulation is what gives it the potential to be a more effective therapy than the open loop stimulation.

“Timing of stimulation,” he asserts, “is a critical part for the efficacy of E-stim, and therefore closed-loop operation is inevitable.”

Another priority is to determine the optimal intensity of stimulation so that the effect is maximized, but without damaging the colon.

Recently, the Craig H. Neilsen Foundation announced financial support to Park and his colleagues so that they can move forward with their research.

“With the funding from Craig H. Neilsen Foundation, we are investigating how to optimize e-stimulation to recover the compromised colon motility after SCI, again using an animal model,” he says. “I would



Mass peristalsis occurs when the ring muscles of the colon contract sequentially in a wave-like rhythm to gently propel waste to the rectum. This function is impaired with neurogenic bowel.

say this is a very important step to increase the efficacy of e-stimulation, which is necessary for the translation into a human clinical study. Investigation onto the potential side effects is also necessary to move forward for the clinical trials. I expect we need three to five years until the clinical trial.”

He cautions that there are other hurdles to clear before that human clinical trials will be possible.

“Miniaturization is a critical part for translation to human studies,” says Park. “And installing electrodes to the colon may require an abdominal operation, which carries its own risks.”

Meanwhile, researchers using non-surgical transcutaneous stimulators such as SpineX’s SCONE system are pushing forward with their own research to build on recent successes in bowel function stimulation, and approval for actual real world use by Health Canada and the FDA appears more and more likely in the foreseeable future. If this happens, and if people with SCI experience significant improvement in bowel function by using these devices that require no surgery, the closed-loop system being investigated by Park and his colleagues may have to offer a far more effective solution to be viable, given the potential complications of any surgically-implanted device.

Only time will tell if the closed loop system will offer people with SCI a normal bowel experience. At the very least, Park’s work is likely to contribute to our collective understanding of the digestive system after SCI—and what it takes to resolve one of its most troublesome secondary complications.

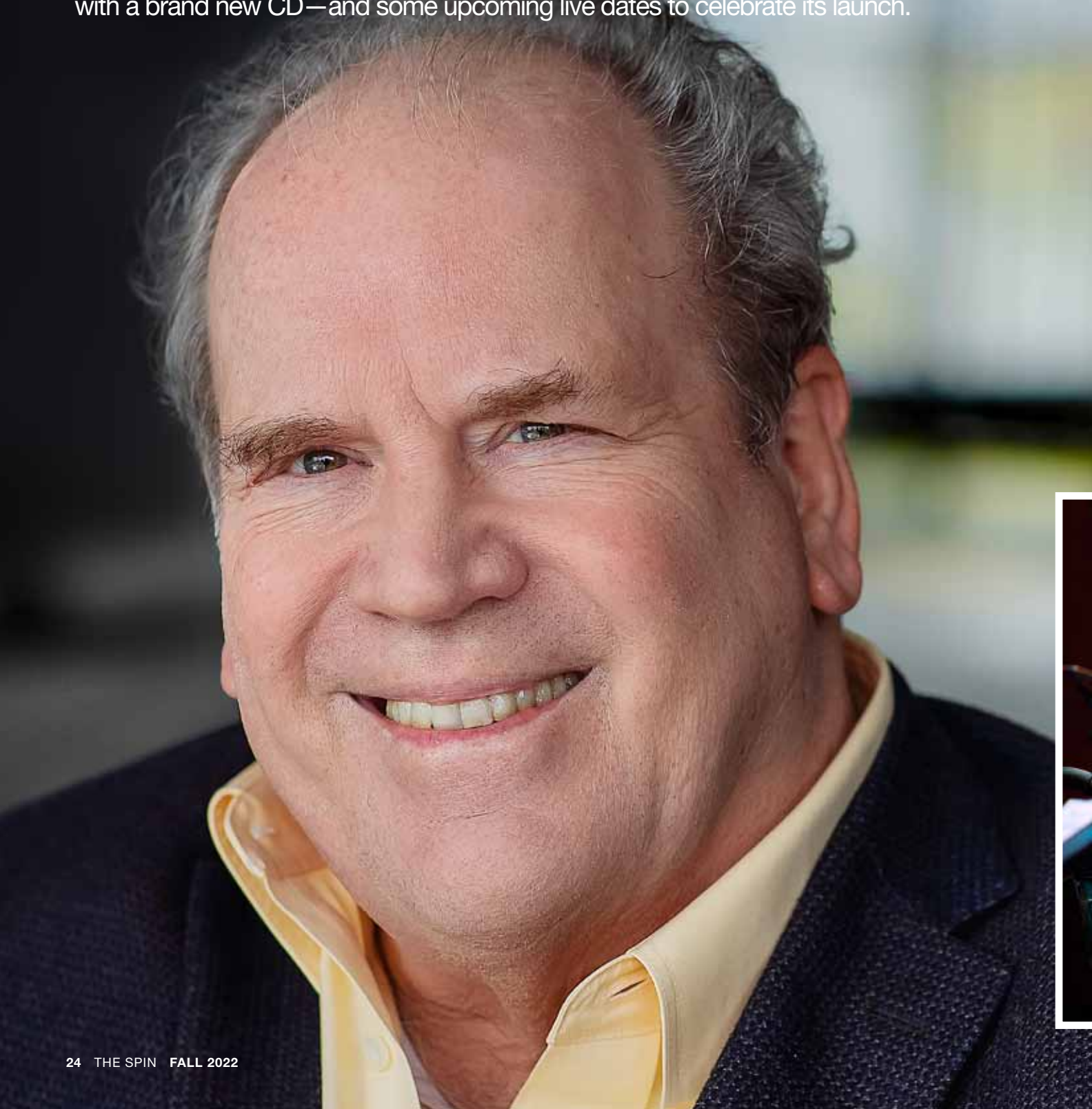
It should be noted that Park and his colleagues are currently working to publish new results of this ongoing project by year’s end. If the results are noteworthy, we’ll provide an update in a future issue of *The Spin*. ■



Dr. Hangue Park

Timeless

Victoria's Joe Coughlin, one of Canada's most iconic jazz singers, marks a major milestone with a brand new CD—and some upcoming live dates to celebrate its launch.



Joe Coughlin turned 68 in September—but you’d never know it by listening to his rich, pitch perfect baritone.

This year, the award-winning Canadian jazz singer is celebrating 50 years in the music business. How? By dropping a lush new CD, of course—and then marking its launch with a few live performances.

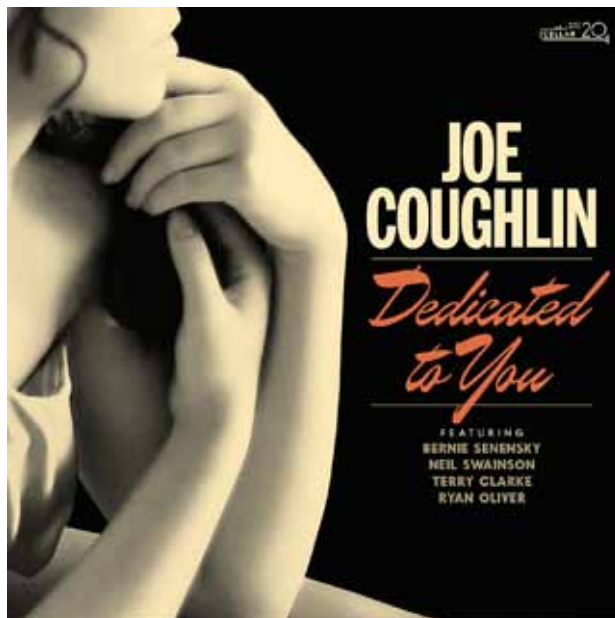
If you’re an SCI BC peer who happens to be a jazz aficionado, you’re probably already a Coughlin fan. But even if jazz isn’t your thing, you owe it to yourself to have a listen to Coughlin’s new CD, titled *Dedicated to You*. When you do, you’ll be hearing a voice that rivals that of some of the most famous jazz singers of all time, from Frank Sinatra to Mel Tormé and Tony Bennett. You’ll quickly understand why he’s a recipient of a Jazz Report Award and two National Jazz Awards—and why he’s toured with the likes of the late great Dizzy Gillespie.

Dedicated to You was released on September 9 and is available at most online music stores and streaming services, including Tidal, Apple Music and Spotify. It’s the culmination of a project that started last July, when Coughlin and a group of veteran musicians he’s

known for more than four decades got together at Vancouver’s The Warehouse Studio (owned by Bryan Adams) to lay down the CD’s 12 tracks.

The CD features long-time collaborators pianist Bernie Senensky and drummer Terry Clarke, both of whom performed on Coughlin’s first ever jazz album 40 years ago. Also appearing on the new CD are Neil Swainson on bass, and Ryan Oliver on tenor sax. The music and score are flawless, and Coughlin’s effortless baritone amazes throughout. Not surprisingly, the result is impressive, and the CD has already garnered many rave reviews.

“This is an after dinner record,” says Coughlin, a quadriplegic from birth who grew up in Ontario but now calls Victoria home. “You know, you put it on when you want a glass of wine in front of the fireplace. That’s when you want to listen to a record like this. It was really a lot of fun making it—this record is just five



guys playing off the (studio) floor. And they’re all first takes.”

The CD was picked up by Cellar Live, the small but highly respected independent label based in Vancouver.

“I’m really happy that somebody thought what we put down in the recording studio last July was worthy of putting out on their label,” says Coughlin. “And it’s a pretty darn good label, too. They’ve got 250 releases in their catalogue. And they’re worldwide. I feel honoured and privileged that they felt that the record was good enough for them to put it out.”

The only thing that might be better than listening to the Coughlin’s new CD would be hearing it performed live, and that’s exactly readers can do in October. On October 8, Coughlin and his quartet will appear at Victoria’s 433-seat Dave Dunnet Community Theatre. A week later, they’ll do two shows, on October 14 and 15, at Frankie’s Jazz Club in Vancouver. Both are perfect venues to enjoy jazz vocals.

Interestingly, Coughlin didn’t begin his musical career as a jazz singer. He got his musical start in the 70s as the frontman of Ontario heavy metal band Whiteheet. But jazz was his first love, and in 1979, he and his golden baritone were formally “discovered” when he won CBC’s *Search for the Stars*. His first recording contract followed shortly after that. He’s been performing ever since,





THEN AND NOW: Joe Coughlin (left) performing in Toronto in 1981 (photo courtesy Toronto Star Archives) and at Frankie's Jazz Club in Vancouver last July. (Vincent Lim photo)

notching a couple of Canadian top ten singles in adult contemporary in the early 90s, but mostly making a name for himself as a jazz singer performing his own original songs, along with covers of the likes of Sinatra, Ella Fitzgerald and Johnny Hartman. With his latest, he has nine albums to his credit, and he's performed with a flock of great Canadian artists with international credentials.

Coughlin says that, despite feeling the aches and pains of aging, playing and recording music never gets old.

"You get old when you don't play," he says. "I think that the energy I get when I create with other people—I think that just feeds you. You get re-energized by that. And when you go into a recording studio like The Warehouse in Vancouver, you know there's a lot of magic in that studio. I don't know what it is, but it just makes you play better."

The only thing better than making a record, he says, is playing for an audience. Last July, after finishing the recording session for his new CD, he was asked by the tenor sax player to sit in on a live gig later that evening.

"I said, 'Yeah, sure.' We went through the first tune and then kind of cranked into this heavier swing. About halfway into that, I had this rush of adrenaline come up through the back of my neck. It kind of blew off the top of my head to the point that I almost fell out of my wheelchair—it was that strong. It was an incredible hit of adrenaline from seeing a full room of enthusiastic jazz fans who were digging what was going on. It was a real connection and a lot of fun. I thought, 'That's why I do this!'"

A reality for many singers is that their voice ages along with their bodies. But Coughlin's voice seems to defy father time, remaining powerful and supple. He suspects there are many reasons for this—good training when he was younger, never having his tonsils removed, religiously following his warm up

routine, and humming and singing throughout the day.

"It drives people crazy around you, but that's how you keep your voice in shape, by constantly using it. And I sing around my place too—it drives my neighbours crazy, but I don't care."

Another reason, he believes, is his style of singing. He recalls meeting the late, legendary Dizzy Gillespie for the first time, in the 80s—it was after he'd finished his set as Gillespie's opening act. Gillespie was waiting in the wings as Coughlin was leaving the stage, and waved him over.

"I said, 'Hello, Mr. Gillespie.' He said, 'People call me Dizzy.' So right off the bat, he levelled himself with me, because he was that kind of guy—he was a beautiful man. He said, 'You have a gift. And I'll tell you why—you have the same voice talking as you do when you sing. People will discourage you from continuing on with this. Don't let them do that. Just keep on doing what you're doing. And never give up.'"

Five decades after it started, Coughlin is nowhere near ready to pack in his musical career.

"No, that's not in the cards," he says. "I don't think I'll ever retire from doing this kind of stuff. Because it's still fun. And there's enough people that like it that I can sustain it."

He makes it clear that it's not about the money—after all, the audience for jazz, while enthusiastic, is limited in size in this day and age.

"I have no expectations about a Brinks truck rolling up in front of my apartment every day dropping off bags of cash. That ain't gonna happen. Maybe we'll get some airplay, some nice reviews, sell a few copies, maybe get a few jobs out of it—we'll see what happens. When it comes to unfinished business, I have two or three projects that are constantly in development. I have to focus on the next one. I'm pretty sure this record will do okay—these types of projects have to generate enough income to do the next one. And that's kind of how they flow. I'm just having fun. That's the only reason I do it." ■

Follow Joe Coughlin at joecoughlin.ca.



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Proactive Approach

The *ProACTIVE SCI Toolkit* is helping people with SCI embrace physical activity from the moment they're discharged from rehab.

When people with SCI are discharged from rehab, they're sent home with a myriad of prescriptions and referrals—for medicine, for aids to daily living and supplies, for mobility equipment, and more. But what they're not sent home with is any type of prescription, support or referral for physical activity. And that's truly a shame, because physical activity just might be the single most important intervention that people can embrace when it comes to maximizing their health after an SCI.

Dr. Jasmin Ma, ICORD researcher and assistant professor in UBC's School of Kinesiology, has made it her mission to change that. Working with Dr. Kathleen Martin-Ginis, who led development of the internationally-recognized *Physical Activity Guidelines for Adults with SCI*, and other colleagues at SCI Action Canada, Ma has developed the *The ProACTIVE SCI Toolkit*—a comprehensive, step-by-step guide for physiotherapists and other health professionals, along with peer support workers, to break down the barriers that prevent people with SCI to immediately embracing physical activity when they transition back to their homes and communities.

"The story side of it came from when I was working as a personal trainer at an exercise clinic for people with mobility impairment during my graduate studies," explains Ma. "Half of my clients came from referrals given by a single physiotherapist that worked in inpatient care. I thought to myself, 'Wow, imagine if all our physiotherapists had the same

training and excitement prescribing and promoting physical activity to their clients with SCI.' Meanwhile, on the data side of it, we conducted a national survey of physiotherapists, who identified a training gap in this area."

The seed of an idea to create a resource quickly germinated, and Ma found herself developing the toolkit as part of her PhD. Work began in earnest in 2016, with some 300 stakeholders—people with SCI, physiotherapists and other healthcare professionals and researchers—making contributions. Refinements in response to end-user needs continued, and the document made its debut in 2018.

"The toolkit is a guide for supporting people with SCI to be physically active," explains Ma. "While it was originally designed to be delivered by physiotherapists, the toolkit has also been delivered by peers with SCI and kinesiologists, and it could be used by other health professionals."

In a nutshell, the toolkit includes three components: education on the international physical activity guidelines and how to be physically active; referral to appropriate peers, programs, and organizations; and developing a tailored exercise prescription. The physiotherapist or peer works through the booklet's steps to impress upon the client or patient the imperative of physical activity, determine their physical activity abilities and interests, and source out anything they need to follow a personal fitness prescription—from equipment to organizations

offering physical activity opportunities in the community.

Currently, the toolkit, with accompanying training and checklist, is being used by physiotherapists at BC's largest rehabilitation hospital, GF Strong, where it's being evaluated for its ability to maintain or improve physical activity levels in the transition from hospital to the community. SCI BC is a project partner, with several of our Peer Program Coordinators providing physical activity coaching for peers transitioning from GF Strong to community.

"The preliminary results of the work are encouraging and the toolkit has been a good fit within GF Strong and SCI BC's current workflow," says Ma. "GF Strong is continuing to implement



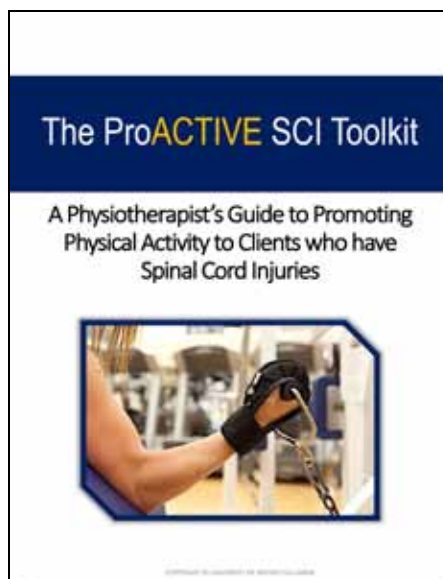
Dr. Jasmin Ma

a physical activity coaching conversation guided by *The ProACTIVE Toolkit* before clients are discharged, and then referring to SCI BC as discharged patients transition to the community in order to continue the conversation.”

SCI BC is exploring plans to train more peer coordinators as physical activity coaches and formally adopt physical activity coaching as an ongoing service.

“Additionally, we are examining how to support the implementation of the toolkit for sustained use beyond the research cycle,” says Ma, adding that the goal is to roll it out to other rehab facilities across the country and even beyond our borders. And the fact that research demonstrates just how effective the toolkit is should make that task easier.

“The toolkit has shown some of the largest improvements in physical activity among people with disabilities evaluated in a randomized controlled trial,” says Ma. “It has also been shown to support improvements in aerobic fit-



ness and psychosocial predictors of physical activity—for example, confidence, social support, and ability to stick to your plan.”

Readers with only a distant memory of rehab might find themselves wondering if the toolkit has any relevance in their lives. The fact is, the toolkit is readily

available for anyone to download, and while it's been written for a therapist to work through a process with a client, Ma says there's something in it for everyone, regardless of how long they've lived in the community.

“For example,” she says, “the toolkit has several resources on how to be physically active—sport ideas, key organizations to connect with, home workout and equipment tips, strategies for sticking to your program, and much more. It's a great read for anyone interested in improving their physical health via exercise and activity.”

You can download and read the toolkit at sciactioncanada.ok.ubc.ca/resources/proactive-sci-toolkit. And if you're a physiotherapist or involved with another organization that provides physical activity opportunities for people with SCI and other disabilities, and are interested in implementing the toolkit, Ma invites you to contact her about training via email (Jasmin.ma@ubc.ca). ■



Now here's something we'd like to see a lot more of across our province.

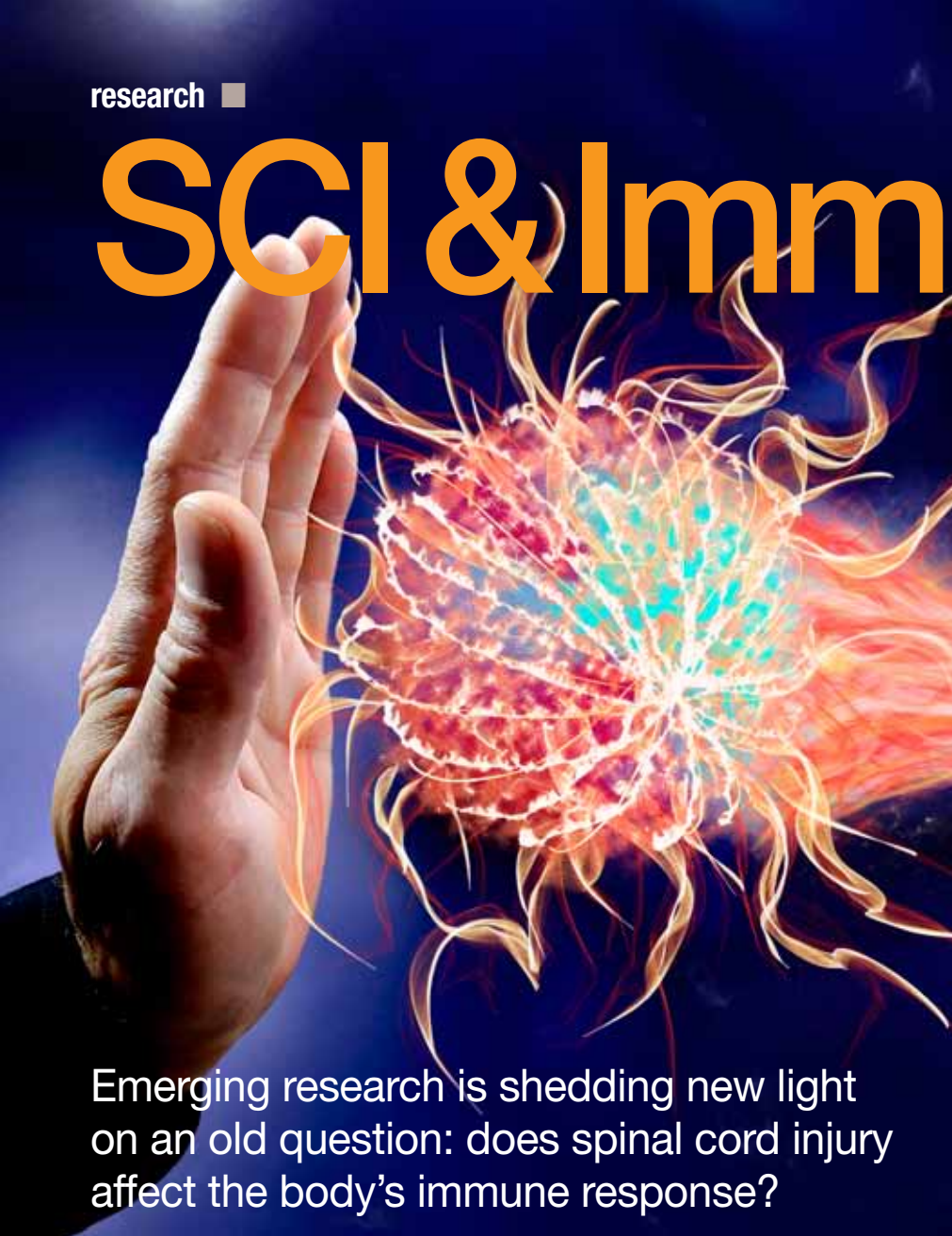
In August, the Columbia Shuswap Regional District (CSRD) installed a new access mat at the popular Cambridge Road Community Park public beach on Mara Lake.

The mat is made from a lightweight, durable, non-slip polyester. It's designed to provide smooth, safe access across the sand and into the water for people who use wheelchairs or other mobility aids.

The CSRD Parks Department installed the mat as a pilot project and will be monitoring its use. If it's deemed to be popular and successful, staff could install more of these types of access mats in other CSRD parks in the future.

The Cambridge Road Community Park is located just a short drive away from the town of Sicamous, which straddles both Mara Lake and the Shuswap Lake. Sicamous is home for many Shuswap houseboat companies that attract tourists from across Canada and around the globe.

SCI & Immunity



Emerging research is shedding new light on an old question: does spinal cord injury affect the body's immune response?

No doubt, the COVID-19 pandemic has prompted more than a few peers to ponder questions about immunity. Does SCI suppress my immune system? Does it make me more vulnerable to COVID, and should I be seeking booster vaccines earlier than the general public?"

The good news is that, at this point, there's nothing to suggest that people with SCI are significantly more vulnerable to more serious outcomes or death due to COVID-19. So it seems like prudent advice to continue taking your usual precautions—masking in tight social or caregiving situations, and getting vaccines and boosters as recommended by the Provincial Health Officer.

However, evidence and statistics do make it clear that some people with SCI are at an elevated risk of developing often serious infections. For example, consider the abnormally-high number of people with SCI who contract life-threatening pneumonia. Some of this is because of the physiological complications of SCI. Skin breakdowns, impaired ability to breathe and cough, neurogenic bladder and catheter use, neurogenic bowel, extended hospitalizations, and limited physical activity levels all contribute to increased susceptibility to infection. But these only explain part of the problem.

Recently, many research groups around the globe have concluded that an SCI more directly inhibits the body's

ability to fight infections and viruses that gain entrance to the body. There's even a name for it: SCI-induced immune deficiency syndrome, or SCI-IDS. At the moment, our understanding of SCI-IDS is limited, but work is being done on a number of fronts to learn more about the underlying mechanisms—and determine what some possible treatments might be, given that there are none at the moment.

There are dozens of research papers to sift through on the subject. Fortunately, two researchers at Drexel University in Philadelphia, Dr. Marisa Jeffries and Dr. Veronica Tom, have already done the heavy lifting. In the September 2021 issue of the journal *Biology*, Jeffries and Tom published a summary of research in the area with a paper titled *Peripheral Immune Dysfunction: A Problem of Central Importance after Spinal Cord Injury*.

In turn, we've made an in-house attempt to summarize their paper in plain language. Following are the takeaways that we believe are important.

First, there appear to be several consequences of SCI-IDS. It seems to result in a "persistent, low grade, peripheral inflammation" in a large number of people with SCI. In other words, many people with SCI have a continual low grade immune response in their bodies. As well, SCI-IDS increases susceptibility to serious infections. Finally, SCI-IDS appears to exacerbate many other secondary complications of SCI, including neuropathic pain, skin and bone deterioration, and cardiovascular disease.

Second, there appear to be several underlying mechanisms of SCI-IDS. The following mechanisms may be working by themselves or in tandem to suppress the immune system:

- SCI disrupts the ability of the central nervous system (CNS) to control the

body's most important immune organs, including the spleen, the adrenal glands, and lymph nodes. This effect seems to be worse as the level of injury rises, particularly above T6. Without control and coordination by the CNS, these organs do not work properly to create the necessary amount of infection-fighting cells.

- Research using animal models suggests that every bout of autonomic dysreflexia, or AD, contributes to SCI-IDS. AD triggers a release of hormones that suppress and even kill our infection-fighting immune cells. This appears to at least partially explain why immunity appears to become more compromised with higher level injuries, since the risk of AD increases with injury levels.
- Another mechanism of SCI-IDS appears to be dysfunction of the hypothalamic-pituitary-adrenal (HPA) axis, which is responsible for our body's stress response. When SCI compromises our ability to tightly control the HPA axis, abnormally high amounts of corticosteroids are produced, which suppresses the immune system.
- Disrupted bone marrow functioning is also implicated in SCI-IDS. Bone marrow is vital for replenishing immune cells. SCI, especially higher levels, impairs bone marrow functioning.
- Obesity, which affects about 66 percent of people with SCI, is a big contributor to the persistent, low grade inflammation discussed above.

- Repetitive infections (ongoing UTIs or pressure ulcers, for example) are known to contribute to AD events, which are a major contributor to SCI-IDS.

Third, there are no approved therapies aimed at improving immune function for people with SCI. That's why more research is needed. At the moment, the only thing that may improve immune function are certain types of exercise, which most people with SCI can do easily, without side effects. One promising avenue for improving immune function is limiting bouts of AD—for example, there is emerging evidence that electrical stimulation routines can stabilize blood pressure and interrupt dangerous bouts of hypertension during episodic AD.

It's important to point out that our understanding of SCI-IDS is incomplete, as acknowledged by Jeffries and Toms in the conclusion of their paper:

"Immune changes post-SCI have major implications in the quality of life of SCI individuals as well as their treatment. With disruption of descending CNS input to immune organs as well as secondary complications of SCI contributing to SCI-IDS, individuals with SCI are faced with a constant state of inflammation and increased risk of infection. Promisingly, recent preclinical research indicates a wide range of potential interventions that may be able to improve immune function and reduce the risk of infection. However, whether these effects

are replicated after chronic immune dysfunction has already occurred, which populations of immune cells should be targeted, and how this affects immunity to various infection types in persons are all unknown facets of immune modulation post-SCI. Importantly, while there are many gaps in knowledge regarding immune function and modulation after SCI that remain to be filled, potential opportunities to identify effective therapeutics to better immune function will undoubtedly result in improved quality of life for those living with SCI."

So what does one do with this information? The research into SCI's effect on the immune system is in its early stages and much more work is needed before we can say definitively what the consequences of these possible effects are, if any. However, based on what is known so far, it may be wise to take a few precautionary measures to limit exposure to possible sources of infection and to adopt lifestyle behaviours that promote immune health. So, to repeat for emphasis, it may be best to err on the side of caution during the COVID pandemic and respiratory illness season by wearing masks in crowded spaces and keeping your immunizations up to date. Being physically active is important for your health and doing your best to avoid AD may maintain a stronger immune system. Keeping on top of signs of infection in order to catch or treat it early may also help stave off serious infections. ■

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

LivingwithSCI.ca



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SCIssexualhealth.ca

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Participate in Research

SCI research is about much more than test tubes, stem cells, and a far-off cure.

At ICORD (International Collaboration On Repair Discoveries), SCI research is also about improving bladder, bowel, and cardiovascular health; taming pain and autonomic dysreflexia; enhancing sexual health and fertility; new assistive technologies; wheelchair design and ergonomics; and much more. In other words, it's about maximizing recovery, independence, health, and quality of life. But it doesn't happen without you. That's why SCI BC and ICORD are partnering to help raise awareness and increase participation in world-leading research. Working together, we can make SCI research more meaningful and move it along at a faster pace, and we invite you to be a part of it.

Effects Of A New Method Of Low Intensity Blood Flow Restriction (LI-BFR) Exercise On Skeletal Muscle Development In People With SCI

Overview: ICORD researcher Dr. Babak Shadgan is determining if a new method for exercising forearm muscle is a more effective methodology for increasing muscular strength and size than existing methods.

What to expect: Participation in the study will require approximately two one-hour sessions for a period of eight weeks, and two half-hour measurement sessions immediately before and one week after completion of the training sessions. The twice-weekly exercise sessions will consist of a light hand-cycling warm-up, followed by four sets (75 repetitions total) of wrist flexion and extension exercises. Non-invasive sensors will be used to monitor vital signs and muscle function throughout the training sessions.

Who can participate: You may be eligible to participate (either in the LI-BFR or control group) if you are 18 to 65 years old; living with incomplete quadriplegia below C1 for more than nine months; are on the ASIA Impairment Scale in the B, C, or D category; have a wrist functional range of motion of 45 degrees; have grade 3 or 4 muscle function of the wrist extensors; and can understand and speak English.

Why participate: People with incomplete quadriplegia commonly experience upper extremity muscle wasting and dysfunction, which reduce their ability to complete activities of daily living independently. It has been shown that applying LI-BFR exercise results in similar increases in muscle strength and endurance as traditional high-intensity resistance exercise. The principle of the LI-BFR technique involves exercising the targeted muscle group while blood flow is restricted with a tourniquet for the duration of the training.

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

For more information or to sign up: Contact the study coordinator, Stefan Lazarevic, by email (stefanlaza97@gmail.com) or phone (778.388.9432). Learn more at icord.org/studies/2022/06/li-bfr/

The Joy-Active Project

Overview: Led by ICORD researcher Dr. Kathleen Martin Ginis, the goal of the Joy-Active Project is to better understand the experiences and perceptions of adults with disabilities participating in an exercise program, and the relationships between well-being, quality participation, happiness, and fitness.

What to expect: Participants will take part in a 12-week exercise program following the appropriate physical activity guidelines. The program includes a session with a fitness trainer, a personalized exercise prescription, and group-based exercise sessions in the research gym. The total time is approximately four hours. In addition, participants are encouraged to do at least 24 to 36 hours of exercise training (two to three hours per week) subject to ability and progression.

Who can participate: You may be eligible to participate if you are over the age of 18; are able to read, speak, and understand English; have been diagnosed with multiple sclerosis OR have been diagnosed with a SCI more than one year ago and have an injury level at C3 or below; are able to perform upper-body exercises; have no medical contra-indications to performing an exercise test; and have been fully vaccinated against COVID-19.

Why participate: This study will encourage participants to think deeply about how they are feeling when they participate at the research gym facility, and their motivation or reasoning which underlies their participation. This may prompt them to recognize the potential health, social and psychological benefits that may be associated with participation in the program. Participants will have free access to an accessible exercise gym twice a week over the course of the study period. They will also receive a free one-on-one session with a certified fitness trainer and a personalized exercise prescription.

Location: The study is taking place at the UBC Okanagan campus in Kelowna.

For more information or to sign up to participate: Contact the study coordinator, Kenedy Olsen, by email (kenedy.olsen@ubc.ca) or phone (236.970.6226). Further details are available at icord.org/studies/2022/07/joy-active/



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

Research Concierge

ICORD's new Study Liaison, Nicole Bailey, loves to help SCI BC peers get involved in the world of research.

Dear readers: it seems you're getting more and more involved in local SCI research projects—so much so that ICORD has had to create and fill a new position of Study Liaison to streamline the process of getting you onboard and participating.

"The ICORD administration team often gets contacted by people who want to participate in studies but don't know where to start," says Nicole Bailey, a grad student in Dr. John Kramer's ICORD lab who has been hired to take on the role. "Cheryl Niamath, our Administration Manager, and Katie Ashwell, our Senior Administrative Assistant, were chatting about better ways to help people than just referring them to the ICORD website. They thought it would be useful to have someone help people directly, and I jumped at the opportunity. I've been given a lot of freedom with this role and have really enjoyed creating it."

"Research concierge" might be a good way to think of Bailey and the support she offers. "I have phone conversations with people who are interested in participating," she explains. "I ask about their research interests and, if they're comfortable, about their injury. This information helps me narrow down what studies I think they may be interested in or eligible for. I send them personalized lists of the studies, along with the contact information of the study coordinators. I also offer to introduce interested participants with the study coordinators directly via email—I try to reduce barriers to participating as best as I can."

Another key part of her job is to record anonymously what types of research people are interested in and any feedback participants have. "Even if someone doesn't find a study they're interested in

or eligible for, simply telling me what they want to see in research can help shape future projects here at ICORD," says Bailey.

She is clearly well qualified for the new position, which she started in May. Born and raised in Malaysia, she lived in Moscow and Calgary prior to coming to UBC to earn an undergrad degree in studying neuroscience and cognitive science. Currently, she's in the process of completing a Masters in Experimental Medicine under Dr. Kramer, with her specific interest being in chronic pain.

"All my research projects investigate some aspect of pain—my two focuses are the impact stress has on pain and the experience of pain among indigenous people in Canada," Bailey says. "I have also been a Peer Facilitator with Pain BC for two years—I lead group meetings and educational topics for people living with chronic pain, and have recently transitioned to become a Pain Coach. With this role I meet with clients individually to work on techniques to live with and manage pain."

Her interest in chronic pain stems from personal experience.

"I broke the bones that hold my L5-S1 vertebrae together, resulting in loss of sensation in my legs and the inability to do a raise motion of my feet," she says. "Along with this came severe chronic pain. After two spinal surgeries, I have regained leg sensation and motor control of my feet, but the chronic pain has stuck with me." She points out that her injury isn't technically an SCI as it involves just cauda equina nerves at L5-S1.

No doubt many are reading this and thinking that Bailey must be an incredible multi-tasker.

"I am juggling quite a few things," she concedes. "My own research with the

Kramer lab takes up most of my workdays, but I always have time to take a call for this liaison position. I do most of my hours as liaison during evenings and weekends—I really enjoy this work, so it's never hard to find time for it!"

Bailey urges readers with questions about research to reach out to her.

"If you're interested in research, I would love to talk to you and find a study that fits with you. If you're not sure whether you are interested in research or not, I can speak to you more generally on what participating in research would look like. We can talk about what it means to participate, what types of research is out there, and what your rights are as a participant. I can also help advise you throughout the engagement process—no question is too small."

The best way to contact Bailey is via email (studies@icord.org) as she checks her inbox throughout the day. ■

"Getting involved in research can be justifiably intimidating and overwhelming; I really like that I can help act as the bridge. I hope this position makes the face of research more approachable, and research a safer space for people to engage in. At the same time, recruitment can be the hardest part of research, so I enjoy helping ICORD researchers find new participants."

— Nicole Bailey, ICORD Study Liaison





BC SCI NETWORK

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

Richard's Journey

"I'm never a one trick pony," says Richard Peter. Coming from an Indigenous leader, five-time Paralympian, mentor, sports advocate, research champion, husband, son, and so much more, this is an understatement.

Injured in a bus accident when he was four years old, Richard was introduced to SCI BC through Peer Program Coordinator Scott Heron. "He met with my mom and me and gave us information," Richard says. "As a young kid I didn't have much of a connection with him, but it's great now. I've known him for over 30 years, and it's great we still talk."

For Richard, it's all about this continued connection. "SCI BC opened the doors," he says, "then Wheelchair Sports did a demo at my high school and I got involved in para sports."

After competing in five Paralympic games on Team Canada's wheelchair basketball team, Richard focused on giving back. "Whether it's part of my culture, as an Indigenous person, or just who I am, I've always given back to my community," he says.

Over the years, he's done this in a multitude of ways. As a former Peer Program Coordinator for SCI BC at the GF Strong Rehab Centre office, Richard established relationships with newly-injured people and was often the first point of contact for them and their families.

"Everyone has different levels of acceptance about their disability," Richard says. "They may not want to get back into their favourite activities right away. It might take a couple of months or even years." He adds that having the BC SCI Network there to support people whenever they're ready is extremely important.

Now, as an ambassador for the BC Wheelchair Sports Association's Indigenous Bridging the Gap program, Richard helps shape the direction of programming for Indigenous youth with SCI. By using the experience and wisdom he's gained over the years living with an SCI, Richard is making a tremendous impact for Indigenous individuals with a disability. "I'm always pointing people in the right direction," he says. "Everyone is just trying to find where they fit in." Richard is committed to helping make this happen.

sci-bc.ca/BCSCINetwork



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