SPRING 2020

Out of the Box

Leo Sammarelli and other SCI BC Peers are pursuing sports and hobbies that are anything but ordinary



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





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

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Cover: Leo Sammarelli, founder of the West Coast Wheelchair Adaptive Boxing Society (photo credit: Black Rhino Creative)









Knowledge is a click away.



Refusing to be pawns...

All too often, progress comes at a cost. That cost comes in many forms and, in some cases, can undermine the progress that is otherwise made. This is why, as a society, we must carefully steward the progress we make, being careful to avoid or minimize unnecessary or reckless costs so that changes can truly benefit all—and not just some at the expense of others.

When it comes to positive change for Canadians with disabilities, a tremendous amount of progress has been made over the past decade. Sure, as a society, we still have a long way to go, but we shouldn't sell short the significance of the progress made with respect to access and inclusion in this country.

The Accessible Canada Act and the Accessible Standards Canada group tasked with establishing standards by which the Act can be enforced are examples of this progress. The provincial government's steps to developing accessibility legislation for BC is another example, as its recent commitments to enhancing accessible tourism by making our communities more accessible for all.

These are clearly positive indicators for progress on advancing access and inclusion. They indicate the growing understanding and appreciation for the importance of having people with disabilities fully participating in our economy and society as a whole. Unfortunately, we are seeing politicians, businesses, and others seizing on this recognition and using people with disabilities as leverage to achieve political or economic ends.

Take, for example, the Official Opposition's decision to drag out debate on Bill C-81 (the Accessible Canada Act) through a mostly irrelevant filibuster tactic to achieve some political gain. With passage of the Bill in doubt, the Federal Accessibility Legislation Alliance immediately jumped into action, encouraging its member organizations and individuals with disabilities to send messages to the Opposition to stop delaying approval of Bill C-81. It worked. After a flood of messages on social media, the Opposition backed off and the Bill passed. We now have the Accessible Canada Act.

A more recent example of using people with disabilities as pawns in negotiations recently played out closer to home. To escalate their ongoing dispute they have with BC's new ride hailing legislation, BC taxi companies essentially threatened to stop providing accessible rides for people with disabilities in Metro Vancouver. The taxi companies used the increasing recognition of the value and influence of people with disabilities as a bargaining chip in their fight with government over the ride hailing. Again, the tactic has largely backfired.

That people with disabilities are increasingly being used as pawns to achieve political or business-related ends may speak to their emerging role of influence in Canadian society. But those who have chosen to use people with disabilities as pawns are quickly learning that such a strategy can come at a political or economic cost; that the increasing influence of the pawns they're trying to use can be used against them.

As with conflicts between employers and employees that see students or pa-

tients caught in the middle, those who seek to use people with disabilities as pawns in their negotiations should think twice about doing so. As champions of progress toward full access and inclusion, people with disabilities must not tolerate being caught in the middle.



-Chris McBride, PhD, Executive Director, SCI BC

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

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Submissions, suggestions and comments are greatly appreciated—please email these to thespin@sci-bc.ca or send by regular mail to: Assistant Editor, *The Spin* Spinal Cord Injury BC, 780 SW Marine Drive Vancouver, British Columbia V6P 5Y7

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

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

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

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

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Dining with Dignity Flatwear is adaptive cutlery for people with quadriplegia or anyone with a weak or impaired grip. The patented design enables anyone with grip impairment to "hold" a fork, spoon or knife using a stainless steel yoke attached to the handle. The yoke's double loops can be adjusted to fit various hand and finger sizes, and gripping angles, by simply twisting them to meet your specific grip and strength. A person with no grip has the ability to hold these utensils and eat with no assistance. All cutlery pieces are standard Oneida flatwear, with a yoke attached to each piece. All are entirely dishwasher-safe. Visit diningwithdignity.com to see video of the cutlery in action.

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 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



events



Be well in the BC Interior.

Our Wellness Retreat returns for its second year in the beautiful BC Interior. Join SCI BC friends and family at the Naramata Centre as we enjoy a weekend of adapted yoga, outdoor exploration, and nutrition and cooking lessons. Reconnect with nature and embrace new experiences in a supportive environment. Space is limited. Date is to be announced, so see our events calendar (sci-bc.ca/events) for more details, or contact Jenna at jwright@sci-bc.ca or 604.326.1210.



Meet the Challenge.

Join the SCI BC Walk 'n Rollers for the Scotiabank 5K Charity Challenge. Last year, more than 100 team members raised over \$90,000. This year, we're aiming even higher! Join us on June 28 for an amazing day of comradery, fun and accomplishment as we take on the new fully accessible 5K course at Stanley Park. Sign up now and help raise money to support others living with SCI and related physical disabilities. Learn more at sci-bc.ca/scc-2020.



Be well in Prince George.

Relax and reconnect with friends at our first-ever Prince George Wellness Day on May 2, from 1 to 4 PM. This restorative day, which will take place at the stunning Two Rivers Gallery, features an art therapy session, an adapted yoga session (led by SCI BC Peer Coordinator Josh Dueck), and healthy and nutritious food. Space is limited. For more information or to RSVP, please contact Brandy at bstiles@sci-bc.ca or 250.563.6942. We hope to see you there!

Are you a BC student living with a spinal cord injury?



GRAGOPEAN Scholarship Trust



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Spinal Cord Injury BC APPLY NOW: sci-bc.ca/scholarships

van<mark>co</mark>uver foundation

Funding For Your Education

SCI BC is proud to partner with the Vancouver Foundation to administer the **GRAGOPEAN Scholarship Trust**, a fund specifically for students with SCI that just completed its second year.

The fund was established by a group of donors to assist persons with SCI attending post-secondary schools in BC with tuition, books and learning aids. In some cases, it will also support other expenses related to their disability, such as housing and transportation. Over \$250,000 is available through the trust each year, making it one of the largest scholarship funds of its kind.

In 2019, we were pleased to provide funding to the following 24 students, with a combined total exceeding \$183,000.

- Max Arsenault, University of British Columbia
- Tomas Bourassa, Simon Fraser University
- Gabe Chesman, Athabasca University
- Emily De Boer, Emily Carr University of Art + Design
- Sam Douglas, British Columbia Institute of Technology
- Dan Duffy, Langara College
- Ben Hagkull, Camosun College
- Alyshia Joinson, University of Victoria
- Natasha Kaweski, Kwantlen Polytechnic University
- Taylor Kingshott, British Columbia Institute of Technology
- Riley Martin, University of Victoria
- Abdul Mohseni, Langara College
- Agasha Mutesasira, Vancouver Island University
- Kenneth Ngai, Canadian Payroll Association
- Kristian Oakenshield, Thompson Rivers University
- Pierce Pineau, University of the Fraser Valley
- Barbara Schober, University of British Columbia
- Rahul Shandilya, University of British Columbia
- James Shaw, Selkirk College
- Robert Shaw, University of British Columbia Okanagan
- Ethan Spencer, Trinity Western University
- Holli VanderWyk, University of British Columbia Okanagan
- Mitchell Wheeler, Thompson Rivers University
- Daryl Yuen, Vancouver Community College

We were also pleased to continue our collaboration with the **BC Paraplegic Foundation Bursaries** program, which are awarded annually to support individuals with their post-secondary education. Funds are provided by the foundation and individual donors.

Last year, BC Paraplegic Foundation Bursary Awards were provided to Nathan Dewitt and Karma Keenan. Sam Douglas was awarded the Scott Stanley Scholarship (Mr. Stanley, who is a lawyer with Murphy Battista LLP, established this award four years ago). And for the second year, Thomas Venos was awarded the James H.G. Roche Memorial Scholarship, established years ago at Vancouver Foundation by the partners, family and friends of James Roche, a former SCI BC director and board chair.

The deadline for the next intake of the GRAGOPEAN Scholarship Trust and the BC Paraplegic Foundation Bursaries is May 13.

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All proceeds from this program support PARC operations.



Shoutou

An ice-cold shoutout to **TEAM MACDONALD**, which was recently crowned the top wheelchair curling rink in BC during the 2020 BC Wheelchair Curling Championship. In the final, which took place at the Cloverdale Curling Club on February 2, team members Bob Macdonald of Vancouver, Alison Duddy from Quesnel, Gary Cormack from Cloverdale, and Vince Miele of Richmond (yes, it's a double shoutout for Miele) beat defending champions Team Neighbour, which includes two gold medal-winning Paralympians—Darryl Neighbour from Richmond and Ina Forrest from Armstrong.

"I had a great team behind me," says MacDonald. "We shook things up and tried a few different players and it was a great team effort." The Macdonald rink next heads to nationals, scheduled for April 25 to 30 at Club de curling de Boucherville in Boucherville, Quebec.





A few issues ago, we gave a shoutout to former SCI BC employee **VINCE MIELE**, who might be retired, but is far from tired—particularly when it comes to battling for accessibility for wheelchair users.

As we were preparing this issue, we learned that Miele had completed yet another successful advocacy campaign, settling his BC Human Rights Tribunal complaint against Pat Quinn's Restaurant & Bar in Tsawwassen, where he had made a reservation for a wheelchair-accessible table for himself and three friends. When he arrived, he found his friends, all who are able-bodied, had been seated at a table that was only accessible by stairs. When he received little in the way of an apology, he filed the complaint.

The Tribunal ruled in favour of Miele, noting that "for many people with mobility-related disabilities, the physical environment is what excludes them from full and equitable participation in public life...They are the one of very few groups of people protected by human rights legislation who could be excluded, by design, from a public space because of their protected characteristic." The restaurant agreed to change the configuration of the restaurant, resulting in permanent wheelchair access to every table on every level.

A warm, welcoming shoutout to **TIANA HESMERT**, who reminds us that simply getting back to the business of living after an SCI is a notable accomplishment all by itself.

During the Elite Canada Trampoline Championships in Calgary last May, Hesmert fell during a routine, resulting in a C5/6 SCI. Just weeks after completing five months of intensive rehab, Hesmert was back at work part-time, teaching her Grade 2 class in Richmond.

"I wanted to return to work quickly, because I love teaching and I wanted to gain back as much of my life as possible," says Hesmert. "Being back has proven to me that I belong in the classroom and I enjoy working with the kids in my class."

If that's not enough, she's also embraced wheelchair sport.

"Being a gymnast for over 23 years, I missed being in the gym and working towards a goal," she explains. "I've tried several different adapted sports, and so far I like wheelchair racing, seated throws and wheelchair rugby. I enjoy the physical aspect of rugby and I get to let out my competitiveness during the scrimmages."

What does Hesmert attribute her positive attitude to?

"Waking up in the ICU after surgery, I decided that I was going to be positive about my injury and recovery. God has given me the strength to continue pushing in my recovery so I try to see all the new opportunities I now have...It has been hard, but so far positivity has helped me greatly."

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





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SPRING 2020 THE SPIN 11

Intermittent Catheter

Infyna Chic

Beyond the Hype

Slowly but surely, the promise of non-invasive spinal cord stimulation as a means of treating many secondary complications of SCI is being realized. Researchers at UCLA continue to be at the forefront of this work.

> nrealistic media hype—it's virtually guaranteed whenever a promising new SCI treatment is unveiled. A great example is stem cell transplantation, which was all but hailed by the media as a cure when it was first investigated more than two decades ago. It still might be some day, but to date, it's never panned out as a viable treatment for SCI.

> More recently, the hype has been over spinal stimulation as a means of restoring walking function. Here in Canada, this was on full display last November when video from Thailand appeared showing paralyzed Humboldt Broncos hockey player Ryan Straschnitzki moving his legs after an electrical stimulation device was surgically implanted in his spine. Predictably, the video sparked a wave of media interest—and a corresponding cry of outrage in the public that Straschnitzki wasn't able to have the procedure here in Canada.

> The reality, of course, is that spinal stimulation can't be considered anything remotely close to a cure for SCI. We were pleased to see that CBC News aired two stories that featured prominent, responsible researchers and a person with SCI reinforcing this fact and asking for the media and the public to dial down the hype.

Here at SCI BC, we continue to be excited by the potential of spinal stimulation—not for restoration of walking, but for real, tangible and increasingly well-documented improvements in a range of less-than-sexy secondary complications of SCI—poor hand and grip function, wild fluctuations in blood pressure, and bowel and bladder dysfunction. Credible evidence continues to mount that spinal stimulation can make improvements in the critically-important daily living activities that people with SCI have long identified as the most important things to focus research on, even if the media largely ignores this research.

And what's also exciting is the particular type of spinal stimulation that's primarily being used for this research. It's not the epidural stimulation that Straschnitzki went to Thailand to have surgically implanted. Instead, it's transcutaneous stimulation, which relies on an externally-worn device connected to electrodes that are placed on the skin in key locations above the spine to achieve the desired result of "reawakening" function. Transcutaneous stimulation isn't without its drawbacks, but it doesn't require potentially-dangerous surgery and is cheap by comparison. As a result, it seems to have a much higher chance of becoming a realistic treatment for people living with SCI who suffer from these types of secondary complications.

Across North America, there are many highly-respected researchers leading work in transcutaneous stimulation for improvements in daily living activities. Among them is neurobiologist Dr. Reggie Edgerton, acknowledged as a pioneer in the field (he's been director of his own lab at UCLA since 1968). As we've told you in previous issues of The Spin, Edgerton and other collaborators including fellow UCLA colleague and bioengineer Dr. Parag Gad have, in recent years, contributed enormously to the body of evidence supporting transcutaneous stimulation for the treatment of secondary complications of SCI. Not only that, Edgerton and Gad are also working hard to gain FDA approval to market a commercially-viable stimulation device, the spineX TESCoN (short for transcutaneous electrical spinal cord neuromodulator).

Edgerton's and Gad's most recent research in this area was published in the journal *Frontiers of Systems Neuroscience* at the end of January (the project was led by USC urologist Dr. Evgeniy Kreydin). The article, titled *Transcutaneous Electrical Spinal Cord Neuromodulator (TESCoN) improves symptoms of neurogenic bladder after stroke and spinal cord injury*, recounts the researchers' efforts to provide further proof of the ability of transcutaneous stimulation to treat overactive bladder—specifically, to promote better urine storage, reduce unwanted spastic bladder contractions and leaks, and promote the ability to urinate at will and more completely.

The ability of transcutaneous stimulation to promote better bladder function has already been well-documented, but in this study, the objective was to determine whether or not the effect can persist even in the absence of stimulation (in other words, after a course of "training" has been completed). And it was also intended to see if the same device could be used for the same purpose in not just people with SCI, but also with people with other disabilities who have similar problems with neurogenic bladder.

The study recruited 14 participants, five with SCI, five who had a stroke, three with MS, and one with ideopathic overactive bladder. All participants completed 24 sessions of stimulation over the course of eight weeks, as well as urodynamic studies before and after undergoing therapy in order to determine if the treatment resulted in improvements. Additionally, each subject completed a voiding diary and the Neurogenic Bladder Symptom Score questionnaire before and after receiving therapy.

"The key results were a significant improvement in the Neurogenic Bladder Symptom Score (a questionnaire that demonstrates overall bladder function), a 60 percent reduction in the number of incontinence episodes in participants with SCI, stroke and MS who have overactive bladder, and a significant reduction in the number of voiding cycles per 24 hours, especially between 10 PM and 6 AM," says Gad. "Also, this is the first study using the spineX TESCoN device, which performed flawlessly. And most importantly, this is one of the first studies demonstrating the impact of spinal





ABOVE: The spineX TESCoN transcutaneous stimulator. RIGHT: Dr. Reggie Edgerton (left) and Dr. Parag Gad.

neuromodulation on bladder and bowel function, not just when the stimulation was turned on, but also in between sessions when the patients were away from the clinic in their home or work places."

Gad says it's important to point out that the study wasn't large enough to be conclusive, nor did it have any controls participants to compare who did not receive the treatment. But he adds that it was designed and carried out as a pilot in preparation for a much more rigorous, randomized, placebo-controlled trial involving more participants.

That trial will begin sometime later this year. In addition to further confirming the ability of transcutaneous stimulation to improve bladder control, it will also seek to expand the benefits to bowel control. It will also be a first step in achieving FDA approval for TESCoN. The device began life in the lab, and last year, Gad and Edgerton launched a company, spineX, to further develop and commercialize the device. Their hope is that, with successful results, the FDA could provide approval to market and sell the device by late 2021 or early 2022.

Many researchers have been conducting similar research with other transcutaneous stimulation devices that have been developed for other purposes. Gad is confident that the spineX TESCoN offers advantages because it has been developed exclusively for this type of application.

"There are unique differences in the waveforms we use, as well as our overall approach compared to other devices," he says. "Most of this information is still proprietary at this stage. But I can tell you that, apart from the fact that our device offers several advantages to ensure safe and effective delivery of therapy, the key feature of our TESCoN is that it has the potential to be a treatment to improve function in many parts of the body that are impacted due to an SCI, including bladder, bowel, sensation, hands and arms, and cardiovascular function, and even standing and stepping."

He adds that spineX is currently in conversations with other researchers

from across the country who are interested in collaborating and using the TESCoN in their work.

"An official announcement will be made once all the legalities are sorted out," says Gad, adding that spineX recently closed a round of seed funding which is being used to complete engineering development and to initiate clinical trials.

"Our initial plan is to get FDA approval for bladder function as a clinical device," he continues. "Our long term plan is to develop this technology into a clinical and home device for all functions that are compromised due to SCI. The hurdle we face now is finding a way to receive reimbursement for this therapy relative to the function we are targeting. The other hurdle that needs to be overcome is receiving approval for multiple outcomes simultaneously. Regulatory bodies such as FDA approve one indication at a time, which slows things down."

You can learn more and follow the progress of spineX and its TESCoN device at spinexmed.com.



Looking for SCI research projects? Check out SciTrials.org

Here at SCI BC, we see incredible value in helping to connect our Peers with our local research community. When people with SCI and researchers engage each other in a frank and open way, good things happen. Peers can help researchers understand their priorities and determine what research streams are important and which aren't. Meanwhile, researchers doing important work have a greater likelihood of getting people with SCI to participate when there is an ongoing and open dialogue. That's why we've forged such a strong relationship with ICORD, as one example.

We also believe this is starting to happen on a larger scale. Consider SciTrials.org, an easy to use website that provides the SCI community with a way of finding out about SCI-specific clinical trials that are relevant to them. Up to this point, people had to search for relevant SCI trials by sifting through hundreds of thousands of research projects dealing with every medical condition. SciTrials.org provides our community with a way of searching for SCI-specific trials via location, injury details, therapies and outcomes, sign up to receive email updates on new trials of interest to them, and apply to participate quickly and directly. Perhaps the best part is that all information on the website is presented in plain English with as little scientific jargon as possible.

At the moment, SCI trials that are posted are all sourced from clinicaltrials.gov, which is inclusive of most North American researchers trials. But plans are underway to add trials from other registries from around the world. Trials are not shown if they're not about SCI, or if they're asking for money for the research procedures or treatment.

The aim is to balance the needs of both communities, resulting in more people participating in trials, and trials having more candidates to find better matches.

SciTrials.org is endorsed by dozens of community-based organizations, including SCI Canada and SCI BC.



Row for Health

ICORD researchers Dr. Jaimie Borisoff and Dr. Carolyn Sparrey are testing the concept of stationary rowing for people with an SCI. If they're successful, the result could be an excellent new method for readers to maintain their fitness and health.



revor Green really wanted to row again. The 55-year-old Nanaimo resident was once an elite-level rower. But in 2006, when the former Canadian Forces Army Reserve captain was struck in the head with an axe while serving in Afghanistan, his competitive rowing came to an abrupt end.

Green, shown in the photo to left, suffered a catastrophic brain injury in the attack and was left substantially paralyzed. Initially, he and his family were told not to expect much in the way of meaningful regaining of function. His well-chronicled recovery, however, has been nothing short of amazing. While he's still unable to walk, his progress has become textbook material for the brain's neuroplastic ability to rewire itself.

In 2017, he met Dr. Carolyn Sparrey, a mechanical engineer who is a Principal Investigator at ICORD and an Assistant Professor in the School of Engineering Science at Simon Fraser University. Green told Sparrey about his desire to exercise with stationary rowing—and his frustrating search for a rowing ergometer that could accommodate his functional challenges while giving him a decent workout.

Sparrey met the challenge and designed a preliminary custom solution for Green. In the process, she connected with Martin George, a para-rowing coach with Rowing BC. She learned from George that, despite rowing being an excellent upper body workout and suitable in many ways for people with SCI, there were limited solutions for people with SCI and other disabilities to use indoor rowing as an alternate workout.

Sparrey was intrigued, and by this time, had found a willing collaborator in Dr. Jaimie Borisoff. As a fellow ICORD Principal Investigator, Canada Research Chair in Rehabilitation Engineering Design at the British Columbia Institute of Technology, and someone who lives with an SCI, Borisoff needed little convincing to join Sparrey and further develop the concept of a rowing ergometer for people with disabilities. He'd had successes with similar projects over the years, including the development and commercialization of the Elevation wheelchair.

"After working with Trevor on his custom rowing solution, a study was published by Dr. Kathleen Martin Ginis and several ICORD researchers that highlighted the importance of physical exercise for overall health for people with SCI, and the team thought that a diversity of exercise options is important for keeping people engaged in exercise long term," says Sparrey. "The rowing motion engages different muscle groups, allowing for rigorous exercise without exhausting already overused wheeling muscles. It also provides the opportunity to engage trunk muscles at whatever level the user has available while providing stability and support as needed."

Borisoff and Sparrey recognized that they didn't need to reinvent the wheel they just needed to make it usable by someone with an SCI. In other words, their approach was to retrofit a commercially-available rowing ergometer, rather than build an SCI-friendly ergometer from scratch.

"We call it the ARM, which is short for Adapted Rowing Machine," says Borisoff. "The device consists of a support arm that connects to the front end of an existing rowing ergometer. The arm provides adjustable chest and lap support to accommodate users with a range of injury levels."

The sliding seat component of the rowing ergometer is also removed, allowing users with disabilities to simply wheel up, set their locks, and get down to the business of grinding out a workout—all without having to transfer.

Borisoff explains that adding the ARM to existing machines would likely make





Dr. Carolyn Sparrey and Dr. Jaimie Borisoff

it that much easier to get it out there for people to use, much more quickly.

"We wanted to make it available with a limited financial commitment, to encourage gyms and other facilities to be able to provide an alternative accessible exercise option," he says. "Many gyms already have commercial rowing ergs, making the additional costs minimal."

Make no mistake—this isn't a device exclusively for use by paraplegics.

"The chest pad is there to provide support for users who have limited or no trunk strength," says Borisoff. "This allows for an arms-only exercise, while also allowing someone with higher function to engage different levels of trunk musculature by simply adjusting the chest pad attachment. People with good hand function should be able to use the ARM on their own; users with limited hand function may need some help getting setup. It can be used with a variety of off -the-shelf accessories like Active Hands gloves."

The immediate goal is to test the ARM in a variety of situations with a variety of users and confirm its design and benefits. Sparrey has been leading a research study of the device at PARC (Physical Activity Research Centre) at the Blusson Spinal Cord Centre in Vancouver for the past six months (recruiting for the study has been advertised here in *The Spin* for the past couple of issues).

"The concept device has been designed, assessed by focus group participants and now fabricated as prototype devices," says Sparrey. "Research is ongoing regarding the ergonomic and physiological benefits of ergometer rowing for people with SCI compared with traditional handcycle exercises. We're looking to expand the research by deploying additional systems to community recreation centres across the Lower Mainland and beyond."

The design and benefits have yet to be confirmed by the research, but Borisoff and Sparrey say that preliminary results have been successful. For that reason, they're already looking down the road at ways of getting the technology out there to as many people as possible.

"Plans are being made available open source, so that anyone can have the device made by a local machine shop or Tetra volunteer or a high school tech class," says Borisoff. "We have also created a handyman wooden version of the ARM that can be made by someone with access to basic woodworking tools. For those who have space for the equipment, it can be used in their own home, but the design has also been made robust enough for repeated use in public gym facilities."

"The intention," adds Sparrey, "is that these systems can be deployed in any gym facility, not only in a specialized setting like PARC. A key part of this research is to be able to embed accessible

What do users say about the ARM?

- "I was able to get my heart rate up to a level that I have not been able to achieve in 10 years. I was very impressed with the work that you could actually do. And it was very easy to use."
- "It is similar to a ski erg in that you're pulling backwards. With wheeling, you're always moving forward; you tend to be always curved forward, just even sitting in a day chair. Getting that backwards movement is huge, and just even the full body movement too."
- "I think it was just the uniqueness of it. I mean, it's just a rowing machine. But there is no adaptive rower machines out there right now."
- "It was a nice smooth operation. It was easy to get in. There were no barriers. With a lot of adaptive equipment, you have to transfer out of your wheelchair...But this was (easy), you just roll in, drop the bar down and away you go."
- "I loved it actually. To be honest, I would have taken it home with me if I could."

exercise options where people are, with the goal of making exercise convenient and more feasible."

Borisoff, Sparrey and other members of their team have created an online resource library (adaptederg.commons. bcit.ca) where you can find design plans, demonstration videos, instructions, and links to other resources for adapted rowing—for example, harnesses, binders, gloves, handles and grips.

If you've read this and want to get involved with the ARM research project, please contact Johanne Mattie by email (Johanne_Mattie@bcit.ca).

The work was funded by the Craig H. Neilsen Foundation (based in the USA) and an ICORD SEED grant. ■

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recreation



Wheelchair basketball and photography are all well and good, but have you ever heard of drone racing? What about adaptive boxing or Sashimono? Our SCI BC Peers are always up to something interesting, but we wanted to learn more about some of their passions that are truly outside of the norm. We talked to six Peers from across the province who are breaking down barriers in unusual sports or hobbies and are excited to share what they've learned along the way!

LEO SAMMARELLI T8 | VANCOUVER

What's your unique passion?

Wheelchair adaptive boxing.

How long have you been doing it?

I started teaching my adaptive boxing class in June 2019, but I've been boxing for a total of 10 years and teaching for three. The class came out of my passion for boxing and a desire to introduce the sport to others.

How did you get involved?

I was introduced to boxing through my uncle in Italy and fell in love. Before my injury, I was a high level boxer with national and international titles, including Canadian Lightweight National Champion, three-time Golden Gloves Champion, and Italian Inter-regional Champion. My goal before my injury was to make it to the Olympics and become a world champion in professional boxing. After my injury, I was encouraged by my family and friends and my boxing community to get back into the sport. I see boxing as a type of rehab and a great way to stay active and athletic. I'm motivated to continue by my love for the "sweet science" and my personal mantra: "Can't stop. Won't stop." And that's why I decided to create the West Coast Wheelchair Adaptive Boxing Society.

What do you love about it?

Boxing is not only an all-around sport; it's a spinal cord injury sport. Since I returned to it, I feel better mentally, physically and emotionally, and have gained movements I never thought I would still be able to do. Boxing is a great core and fat-burning workout. It's one of the most technical sports I've ever done. When you're in the ring or training, you're really living in the moment. I love that.

What adaptations did you require?

I've had to learn different techniques in punching and defences. In class, we adapt each move to the individual. For example, we look at each athlete's level of injury and find the most effective way to deliver punches, hooks or uppercuts with balance and stability.

How can readers learn more and get involved?

All levels are welcome to learn! We train at Raincity Boxing in Vancouver with boot camp-style classes that focus on conditioning, strength and movements. We cover techniques for punches, combos, defence, chair skills, partner work and more.

Leo (below right) welcomes your questions — call him at 778.836.5406, or connect on Instagram (@Sammarelli) or Facebook (@sammarelli94).





DARRYL TAIT T5 | YUKON

What's your unique passion?

Snowmobile racing and snowmobile freestyle.

How long have you been doing it?

I think I was four or five when I got on a snowmobile, but when I moved to Yellowknife with my family is when I really got into freestyle stuff and racing. After my accident in 2009 I knew I wanted to get back out there and I've been back on the snowmobile since I got home after rehab.

How did you get involved?

My whole plan before my accident was to go to the X Games for freestyle snowmobiling, but then I couldn't. While I was in rehab I learned that they were going to have the first-ever adapted snow cross event for athletes with prosthetics and paralysis. There was a guy competing who had been paralyzed for quite some time named Doug Henry, who is an ex-pro motocross racer and had his snowmachine adapted to race. He helped me a lot when I started to adapt my own snow machine and he really got me back into the scene. I actually ended up being able to compete in the X Games in 2013 and that meant a lot.

What do you love about it?

Just the thrill of being in a group of riders on the line and all racing into one corner, strategizing and passing to work your way to the front. It's physically and mentally demanding—you're so focused on the moment that you can't really focus on anything else. It's a great escape. I was never big into team sports and I like being in an environment that I feel free. Snowmobiling gives me that.

What adaptations did you require?

My snowmachine has been adapted for racing. It has a go-kart bucket seat, suspension, and an axle integrated into it so I can articulate left and right and do corners. We ended up with three prototypes before we got it right, but I've been super happy with it ever since. After making those changes my whole world opened up.

How can readers learn more and get involved?

I'd suggest start by renting one and see if you like it. The throttle is on hand controls so you don't really need to make any modifications until you decide you want to start racing or doing freestyle. I'm happy to forward photos and information on adaptations and how to improve your technique or speed, but it's also important to recognize the risks that go along with that. My accident was a result of doing a back flip on a snowmachine, so there needs to be a risk assessment on everything you do. It's a powerful machine with powerful results, but I love it.

You can learn more about snowmobile racing by connecting with Darryl on Instagram at @d_rail.



MARK SAUNDERS T5 | NANAIMO

What's your unique passion?

FPV (First Person View) drone racing.

How long have you been doing it?

I've been doing it for two years now. The drone racing league was becoming more prevalent on TV and I really liked the idea of flying without having any lag between what I see on my screen or goggles to what the drone is doing.

How did you get involved?

I've been using remote control cars since I was a kid and it was something I have always had a passion for. I ventured into flying planes a few times, but they always seem to end up in trees. When I learned about drone racing, it seemed like the perfect fit. I started flying in fields and found a Facebook Group in Nanaimo with a few mutual friends who were involved. I met the group and started flying with people and learning lots. It's amazing to see how much better I've become over the years.

What do you love about it?

I love the feeling of flying, the competition of racing, and the act of getting together with people who enjoy the same sport. We've been putting on races for two summers now and it's been a blast. It was really cool to share this hobby last year at the Annual Peer BBQ in Nanaimo that Bert Abbott puts on. I had a spare set of goggles that I could pass around for anyone who wanted to see the live footage—it's great to get more people involved!

What adaptations did you require?

The sport of FPV racing is fully accessible. I haven't had to make any adaptations in order to get flying. If I do crash, my fellow flyers can help me get my drone.

How can readers learn more and get involved?

We have a Facebook Group (Nanaimo/FPV Mini Quads/Drone Racing) that you can join to learn more. I also did a lot of research on drones via YouTube.

You can learn more about FPV drone racing by emailing The Spin at thespin@sci-bc.ca.

RON HOLMBERG T11-12 | FRASER VALLEY

What's your unique passion?

Custom woodworking and Sashimono. Sashimono is a type of Japanese wood joinery where each piece of furniture is made by a single craftsperson with just their hand tools, from start to finish.

How long have you been doing it?

I've been woodworking for 15 years.

How did you get involved?

I was drawn to the handcrafted, hand-cut joinery aspect of the craft. I liked the idea of being able to really use my hands and create something. I learned most of my skills by going to the library and signing out books. I purchased tools as I needed them, one chisel at a time and experimented on personal projects. I also attended Inside Passage School of Fine Cabinetmaking in Gibsons, BC. Since then, I've started to work with hand-cutting dovetails, softening edges, hand planing and shaping all surfaces. I was introduced to Sashimono by my wife (who just happens to be Japanese and helped me translate books or articles to do a deep dive of understanding) and absolutely love it! I often use the Sashimono method in my work—no sandpaper, no nails, no screws or fasteners of any kind; even the brass hinges I use are handmade!

What do you love about it?

Everything! I love the incredible variety of hardwoods available to us. I love the tools and how careful, skilled hands bring out their potential. From sharpening blades and chisels to planing end grain with a properly sharpened iron and admiring the burnished surface on a coopered and tapered door panel, I love it all. Can you tell I'm excited about it? A person can't do this kind of work if your only goal is to make money. That's part of it, sure, but work like this is a true joy. I live in a great place and get to work at something I love and be close to my family while I do it. What more could one person want?

What adaptations did you require?

I haven't had to do a lot. I removed drawers from my workbench so I can roll under it and always practice good shop and tool safety. When I purchase equipment, I always make sure to keep in mind my prerequisites—things like making sure a band saw table is lower to the ground. One of the biggest challenges for me is hand planing. I have to keep my projects a manageable size and I have to plane with my hands and elbows up high, which makes it harder to use my body weight and get the full force behind each stroke. But, like most other people in my situation, we adapt.

How can readers learn more and get involved?

I hope someone out there might see a little of what I'm doing and realize it's something that they can do too!

You can learn more about woodworking and Sashimono by visiting Ron's website: rbholmberg.wordpress.com



SYDNEY SPRAGGS MS | VANCOUVER

What's your unique passion? Dragon boat racing.

How long have you been doing it?

I have been dragon boating for ten years.

How did you get involved?

In 2004, I moved back to Vancouver after retiring from my career as a teacher and professor in the USA. I came back primarily to be with my sister who was living with MS. I too had been diagnosed with MS in 2000. I met my sister's nurse, who paddled with a dragon boat team, and I decided that paddling might be a very good sport for people who have MS. I went to the MS Clinic at UBC to discuss plans to start a team with an OT and a PT, and they encouraged me to go ahead with my plans and gave me names of people to contact to help fund the start-up costs for a team. I met paddlers that first summer, as well as a woman who was delighted to be our team coach. We were soon on our way and named our team Off Balance.

What do you love about it?

My favourite part of paddling is looking back at the dock when we're heading out to the creek and seeing our wheelchairs, scooters, walkers and canes left behind while we move freely over the water with just our boat and paddles to propel us.

What adaptations did you require?

About 10 years ago, I approached the Tetra Society of North America, who designed a seat with a supportive back to fit over the common seats of a dragon boat and allow paddlers who need extra support to participate. Adaptions can also be made to paddles to keep them secure for those paddlers who need extra help with grip. The Dragon Zone Paddling Club, where we practise, has accessible ramps and lifts to safely transfer people with disabilities onto the dragon boat.

How can readers learn more and get involved?

We encourage people to consider getting involved with our team by networking, responding to posters and by contacting the MS Society. Since the MS Society provides our start-up funds, the cost to individual paddlers, once they have committed to paddling with the team, is minimal. All paddlers with disabilities (regardless of whether or not you have MS) are encouraged to join!

You can learn more about dragon boat racing by emailing The Spin at thespin@sci-bc.ca.





TYLER TINGLE T4 | KELOWNA

What's your unique passion? Drag racing and snowmobile racing.

How long have you been doing it?

I drag raced cars for about 25 years and then made the switch to racing snowmobiles on asphalt for the last 12. I raced three different cars and trucks for many seasons and then got involved with snowmobile racing after buying one from a fellow racer. I thought it would be interesting to try something different that I hadn't done since I was 16 and something I never tried since my SCI. I loved the sensation of racing at high speeds with the wind in my face.

How did you get involved?

Soon after my injury, a lot of people told me, "You should play wheelchair basketball." But I didn't play team sports prior to my injury, so I wasn't that interested in playing them after. I was more into cars, motorbikes, fishing, and camping. After I left GF Strong, a friend was heading to the track and suggested that I come along to watch the racing. He knew that I could still drive and offered to help me work on a drag race car if I was I was interested in the sport. I ended up finding an old wrecked Camaro and things continued from there. By the way, I did end up playing wheelchair basketball for many years.

What do you love about it?

Racing got me back into doing something I loved that I wasn't sure I would be able to do after my injury. It was part of the process of getting my post-injury life back in a way that was close to what my pre-injury life was.

What adaptations did you require?

I put hand controls in my drag racing cars. Over the years, I went through a few different cars and trucks (including a specialty built drag race car!) and did all my own work on my vehicles. That connection to the car and getting the job done was something I really liked about racing. For snowmobiling, there wasn't a lot that needed to be done to make them rideable for people with SCI, but I did have to do a lot of adaptations to make them run on pavement. Things like wheels instead of skis, a different type of track for pavement, and go-fast parts (mechanical or engine parts that increase speed). The fastest pass I made on the snowmobile was 9.947 seconds at 136.19 mph (219.176 km/hr).

How can readers learn more and get involved?

Make sure you have a driver's license and then find a local track. There are tracks in Mission, Kelowna, and Prince George, and on Vancouver Island. Airports have also been known to use their space as racing tracks a few weekends during the year. A simple Google search will tell you what you need to know!

You can learn more about drag racing and snowmobile racing on asphalt by emailing the thespin@sci-bc.ca. ■

technology

Major Milestone

The Technology for Independent Living Program celebrates half a century of helping members like Omar AI-azawi maximize their independence and quality of life.

- By Richard Harrison, Project Specialist, Technology for Living

ere at the Technology for Independent Living program (TIL), we're celebrating a major milestone in 2020: 50 years of service helping SCI BC Peers and people with other disabilities achieve greater independence and autonomy in their homes and communities.

TIL operates under the umbrella of Technology for Living (formerly The BC Association for Individualized Technology and Supports for People with Disabilities, or BCITS). Our technologists work with our members to develop a technology plan that will help them live independently in their homes and their communities. TIL technologists then move the plan into action, setting up appropriate equipment and teaching our members and their care teams how to use it. Often, this is all done with no cost to the member.

We could give you a ton of statistics, like how many people we've helped in five decades. But we think the impact we've had over the course of five decades is best illustrated with a personal snapshot of one British Columbian who has benefited from our services.

Omar Al-azawi lives and works in a neighbourhood close to the Sky-Train, with a beautiful creek just a few meters away from his back door. His mother and brother live close by and often stop over to visit.

But life wasn't always so idyllic for Al-azawi.

He was born and grew up in Iraq, where civil conflict, militia, and landmines were daily hazards. As a teenager, Al-azawi survived kidnapping and war, only to be

injured in the same way as many other SCI BC Peers.

"I had my accident in 2010," says Alazawi, now 26. "I was in Iraq and went swimming with my friend. I was hot; we were at a cliff by a river. I didn't see there was a rock under the water and I don't remember much after I jumped off. I broke my neck in C4 to C6 and I became quadriplegic."

War-torn Iraq isn't the best place to live for anyone with a high level SCI. Al-azawi had always wanted to come to North America, and when he had the opportunity to immigrate to Canada five years after his injury, he didn't hesitate.

"I even learned to speak English before I came here," he says.

Al-azawi's life in Canada started in 2015 with the first five months spent at GF Strong completing a long overdue formal rehabilitation. And this is where he started his creative journey.

"I started with traditional art in GF Strong," he says. "I noticed people in the studio taking part in a workshop and asked 'Do you think I can paint?' And (staff) said, 'Yes, come next week and we'll make it fun for you. I came the next week and they gave me a mouth stick, attached a brush and I started just painting. I felt so relaxed, I never felt so relaxed. I always wanted to paint."

While he was at GF Strong, Al-azawi also began daydreaming about living independently on his own.

"Some people thought I was joking, because a quadriplegic on their own may not sound like a good idea," he says. "But (staff) told me there are actually some people who are willing to help you live more independently and as freely you want."

So he forged ahead and secured himself an accessible apartment. But he still had so many questions about how to overcome the challenges of living by himself.

"Will I be able to answer my landline? Open my door? It was overwhelming. The first week I arrived in my apartment I received service from TIL. They came up here, asked me what I would need. I needed something to hold my phone and they hooked up a holder for my phone. 'How can I buzz people in?' I asked. And so they hooked up a sip and puff system in my bed so I am able to buzz people in, and also open the door and close it from my bed. 'How can I control the TV?' I asked. They came again with a new device called GEWA. This device has different channels. I puff twice to (turn on) the TV, so now I am able to control my TV. This is now part of my life that has become routine in my usual day. I can't imagine living without them. I became more independent."

Al-azawi had other goals. More than anything, he wanted to work in a field that would satisfy his need to be creative. So he decided to pursue a diploma in graphic design.

But to reach his education goals, he would have to deal with more hurdles than simply finding a way to open doors.

As he readied himself to apply to school, he received devastating news. A CT scan had raised concerns about his lymph nodes, and a follow-up biopsy confirmed that he had active thyroid cancer.

He met with a specialist who advised him that radiation treatment was not an option; surgery was necessary immediately. Al-azawi needed to make a quick decision. School was one month away and he was afraid to lose his spot in the program. One week before school started, he went through a painful surgical procedure which left scars around his neck. The doctor was surprised at the amount of cancer to remove.

"They were not able to remove it all; there was one last piece of cancer in my neck at C1 that could not be operated on," Al-azawi explains.

Doctors advised him to rest and not do anything for three months. Undaunted, he went to school the very next week with his neck bleeding and often uncomfortably soaked in rain.

He had a million questions as he started his educational journey: "How do I go to school? How do I open the door? How do I use SkyTrain service when I'm having difficulty with the gates?"

The fact that he had to attend two schools at the same time complicated matters. The full-time partnership course required him to take the technical component at BCIT and the theory of design through Emily Carr Institute. No issue gave him more cause for concern than the daunting challenge of commuting to both schools by SkyTrain.

"The gate was a big problem for me, but it has been solved with the help of TransLink staff," says Al-azawi. "It got easier as I got used to it." In fact, Al-azawi mastered his Sky-Train commute so well that he agreed to help demonstrate accessibility features for TransLink and give feedback as well.

"I was part of establishing that freehand gates system," he says. "It's very sweet to use, to open the gates at SkyTrain. The gates open themselves without touching anything. A scanner reads the small card with a serial number—it's done with a radio frequency scanning system. This was the first time in Canada this technology was used, and I was the first one introducing freehand gates to the media. BC is like the template for accessible cities."

As for his full-time load of four to five courses a day, he concedes that the first two months were difficult.

"How do I keep up with my classmates?" Al-azawi wondered. "How do I use my mouth-stick to do a final exam requiring me to design and finish a sixpage magazine in three hours?"

Again, he persevered. After six months, he was used to the academic load and had no problems keeping up with his classmates. He finished all but one course in October of 2018, and then immediately enrolled in the course he was missing. In February 2019, he graduated from Emily Carr and BCIT with a diploma in Communications Design. Today, Al-azawi is skilled in visual communications and is a talented freelancer who specializes in designing and creating publications, posters, brochures, logos, and business collateral, and being part of a marketing team.

Last year was a banner one for Al-azawi—and not just because he graduated. He got some great news about his health when his doctors told him his cancer was shrinking and he wouldn't need surgery. And then, last November, four years after he first arrived, he became a Canadian citizen.

Through all of his hurdles and accomplishments, Al-azawi has maintained a joyful attitude.

"It wasn't easy; eventually I decided I should just not worry about my situation or my health. And small things helped



ABOVE: Technology has helped Omar Al-azawi become a talented and creative graphic designer. RIGHT: A sample of his work from his portfolio, which you can see at omar92.com.

me with my life, like a small cup holder, a mouth-stick or anything that makes my life easier—these get me excited. It has been a blessing. The experience that I gained would not have happened otherwise. I set new goals once I achieve my previous goals."

When asked if he'd be willing to help TIL celebrate its 50th anniversary, Alazawi didn't hesitate.

"Sure!" he told me when I asked him if I could interview him for this story. "I have to pay back to the community, especially TIL because they helped me a lot. TIL makes me comfortable in my house. They let me live independently."

From our perspective, it's been an amazing experience to see Al-azawi thrive in Canada—and to help him achieve his goals. In fact, it's a privilege for TIL technologists to help anyone with similar needs, and see them achieve independence and success. Maybe TIL can help you! Many people need hands-free technology, whether that be setting up equipment and devices like an attendant call, automatic door opener, lights, a smart doorbell, bed control, fan, or a thermostat, or wiring a ventilator to run off of a wheelchair. We provide support for people who require custom adaptations for equipment, device mounting, voice-activated devices, environmental control systems and so much more to support independent living. In short, we're dedicated to the service of people living with disabilities throughout the province of British Columbia.

You can apply for TIL services, including automatic doors via our popular Open Door Program, at technologyforliving.org—click on TIL, "Learn More", then "Apply Now". You can also call us at 604.326.0175. I'd like to express our



gratitude to BC Rehab and the Kinsmen Foundation for providing financial support to our Open Door Program.

In short, there are no special needs. We all have the same needs. What's special are the solutions!

You can follow Omar Al-azawi—and see his work and portfolio—on Instagram (@omar92canada) and at his awesome website (omar92.com).



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The Personal Touch

Want to learn the safest, most beneficial approach to exercise that meets your specific needs and abilities? The new personal training program at PARC may be just what you need.

ny way you look at it, the Yuel Family Physical Activity Research Centre, or PARC, represents an amazing opportunity for our fitness-minded Peers in the Lower

Mainland.

Technically, PARC is a "communitybased research facility" that operates under the ICORD umbrella. Located on the ground floor of the Blusson Spinal Cord Centre, the facility is overseen by ICORD researchers and clinicians, and supervised by students (most are from the UBC School of Kinesiology) and volunteers. Basically, if you're someone with an SCI and agree to contribute to a body of knowledge around exercise and fitness for people with SCI, you can join PARC.

While it may sound sort of clinical, the vibe is all fun and fitness. Members can take advantage of a superb range of specialized fitness equipment that can either be used directly from your wheelchair or is easy to transfer to. They can also participate in an ever-increasing range of group classes and sports—for example, adaptive yoga, Pilates, adaptive boxing, table tennis, and wheelchair dancing. They can even get a massage, courtesy of Langara College's Registered Massage Therapy Program.

Recently, PARC introduced a new component—personalized one-on-one supervision and instruction by professional fitness trainers. Dr. Andrea Bundon, Assistant Professor at UBC's School of Kinesiology and PARC's Faculty Advisor, says it's a win-win for both PARC participants and personal trainers seeking to expand their knowledge.

"In many ways, it was a logical next step—the School of Kinesiology does not directly train students to become personal trainers, but many of our students do pursue certification and work in this area," says Bundon. "However, that certification is pretty general and doesn't necessarily prepare trainers to work with people with disabilities. This opportunity exists at PARC. So it made sense to create a program where already-certified personal trainers could

gain additional knowledge and experience working with clients with SCI. It's a way for our students to differentiate themselves from the hundreds of other personal trainers working in BC."

She adds that there's no reason a personal trainer working in a private fitness centre or a community centre couldn't work with clients with disabilities, but that many are reluctant or afraid to do so because they lack knowledge or worry they'll cause harm.

"Having the opportunity to learn the most up-to-date, best-evidence practices from researchers and health professionals, and then being able to immediately put this into practice by working with clients with disabilities, is key to overcoming this fear," she explains. "At the same time, it provides another option for PARC participants who are looking to work one-on-one with a personal trainer towards their fitness goals."

She explains that most PARC participants have been introduced to personal training via the program's free introductory session.

"Many have taken us up on that option and, based on their experience, decided to purchase packages of five to ten training sessions," she adds. The price per session when purchased in a package of ten is \$42, significantly less than personal training costs in a private setting. Note that there is no charge for regular PARC participation (with the exception of adapted yoga, which is \$15 per session), and the proceeds of personal training are directed to support PARC programs and the salaries of personal trainers.

One of those trainers is Ian Standish, who is currently finishing the last se-

mester of a kinesiology degree at UBC. He was volunteering at PARC last summer when he was approached by PARC management and encouraged to apply for an upcoming position as an adapted exercise and health trainer.

"The PARC staff were aware of my previous experience as a personal trainer and thought I would be a good fit for the role," he says.

He decided to apply, and once hired, began work last October.

"I currently have six clients I see consistently," he says. "On average, I work with clients around one to two hours a day throughout the week."

He says that interest in personal training is steady, but not overwhelming.

"I believe the main reason it isn't higher is due to our participants' lack of awareness regarding the program, as well as the lack of knowledge regarding the benefits of customized training programs for those with SCI," he says. "However, the majority of participants who book their free orientation end up purchasing personal training. I believe this is the case once the participants are aware of the benefits of personal training on their daily function and how substantially less expensive PARC's personal training is than commercial gyms."

PARC personal trainer Ian Standish guides SCI BC Peer Kirsten Sharp through a customized workout. (Photos courtesy ICORD)

Standish, who has worked in several community and commercial settings including Gold's Gym, is a big believer in the services he's providing at PARC.

"I believe personal training at PARC is crucial because the programs I design are tailored to each individual's unique needs," he says. "On top of this, those with SCI must be performing each exercise correctly and safely to benefit themselves. I'd say that PARC participants have much more potential to improve the quality of daily living through personal training than the average able-bodied person. In addition to this, committing to a fitness program encourages participants to engage in other healthy habits that can influence how they feel about themselves and their bodies."

He adds that one of the best benefits of personal training is having someone keep you accountable.

"This accountability encompasses many aspects of my clients' lives beyond just their physical activity with me—for example, sleeping and diet," he says. "My clients and I experience small successes in every session we have together—maybe the training we did was easier than the week before, or their chronic pain is more tolerable in their daily lives, or they just feel better about themselves after working out."

When he compares working at PARC to mainstream facilities, Standish concedes that PARC is much more challenging.

"The most significant difference between working at PARC compared to being a personal trainer at a commercial gym is that, when I work with a client at PARC, I'm designing programs that aim towards increasing their quality of daily living," he explains. "All of my clients have unique functions and abilities, and as a result, I am continually problem-solving in order to adapt exercises and programs for each client's desired outcomes. I enjoy the challenge. It requires me to think in different ways and utilize the knowledge I have acquired throughout my degree. I enjoy witnessing my clients' improvements firsthand, whether it's their ability to transfer or a reduction in their chronic pain or spasticity. I continue to learn the different subtle nuances of SCI every time I work with my clients."

SCI BC Peer Kirsten Sharp is one of those clients.

"I received an email about it and was extremely interested because, with my work schedule, I often feel too tired to work out," says Sharpe, who has been going to PARC since it opened in 2012. "I figured if I had a time booked with someone, it would make me want to go to the gym. I find that having something in the schedule makes me commit."

What she most appreciates about working with Ian is how he considers every aspect of her daily life when he personalizes her workouts.

"As a wheelchair tennis athlete, it's important for me to get in some crosstraining that doesn't involve the sports chair. This includes weights, bands and stretching. I'm looking to improve my fitness goals, improve my posture, improve

pain. I'm also focused on using muscles that I don't use in everyday wheeling, to create a symmetry in my body. Often, the exercises that are the most frustrating to do and hurt the most are the best to improve your body. I find that with Ian's supervision and program setting, I do the exercises that I hate the most but I know are the best for my improvement. He listens to my needs, and figures out ways to incorporate and change exercises so that they work my body and my abilities."

If you're reading this and live outside Vancouver, PARC wants you to know that personal training is available to you.

"We know that not everyone with SCI can come to PARC on a regular basis because of distance and schedules," says Bundon. "But the personal training program means that someone from out of town or anywhere in the province can come to PARC, work with a personal trainer to establish a routine or set a goal, and then continue this program at their local gym, or in their home. They can then book more sessions with the trainers when they want to check in or when it's time to set a new goal."

She adds that, although these personal trainers are currently working at PARC, the ultimate goal is that they will take the knowledge gained through this experience and be able to work with clients with complex mobility needs in community centres and private gyms.

"The overall aim of the program," she says, "is to create more and better opportunities for people with SCI to engage in physical activity and exercise. It's through programs like this that we can scale PARC to benefit more and more British Columbians with SCI."

Learn more at icord.org/parc.

ask the SPIN DOCTOR

Marci in Sydney writes,"I find my spasticity is a lot better with exercise in general, but lately spasticity in my hips is causing me a lot more trouble than it used to. I stretch a lot and I try to spend time lying flat on my belly to stretch out, but I feel like I'm fighting a losing battle. The tightness makes me sore, especially when I wake up after lying flat all night, and can sometimes get in the way of things I want to do. I'm worried I won't be able to use my standing frame or lie flat anymore if this keeps up. Is this the kind of thing that Botox could fix? Is there anything new

on the spasticity horizon that I should know about? I really don't like taking medications for spasticity—the side effects bother me a lot." For this issue's answer, we turned to Dr. Paul Winston, a Victoria-based physiatrist who is Medical Director of Island Health Rehabilitation and Transition, President of the Canadian Association of Physical Medicine and Rehabilitation, co-founder of the Canadian Advances in Neuro-Orthopedics for Spasticity Congress, and co-founder of the Victoria Peripheral Nerves and Spasticity Clinic.

Spasticity affects up to 80 percent of people who live with SCI. Usually it remains quite steady. Any time there is an increase or change, it suggests that there may be some type of noxious stimulus in the body. So it's important to first check for infections (such as a UTI), impacted bowels, pressure sores or skin breakdown, and even in-grown hairs and hemorrhoids. Broken bones, formation of new bone (heterotopic ossification), or a hip dislocation may also be the cause, and can be diagnosed with x-rays. Increased bladder pressure can also lead to an increase in spasticity. It's important that your doctor or one of the many spinal cord injury physiatrists in the province rule out these possibilities.

What happens when these investigations don't turn up a cause? First, you raise a great point about committing to oral medications for a very long time. There are effective medications for spasticity, but they do have side effects of weakness and sedation, and some have effects on the liver. I usually avoid these if possible. If the spasticity is only in the hips, then taking a systemic drug for a focal problem is not the first choice, although some people do require medications and even need a Baclofen pump if spasticity is severe.

A thorough physical examination of the hips is required to see which muscles or muscle groups are the problem. Can you still put your legs flat on the bed, or press your pelvis onto the bed when on your tummy? Do your legs squeeze together, or do your knees bend up to the waist? These questions need to be answered. Once specific muscles are found to be the cause, botulinum toxin injections may be quite helpful. They serve to lengthen spastic muscles and stop their involuntary pull. Keep in mind that, if the pull is really strong, botulinum toxin can have limited benefit. There are many muscle groups we can try to target. Phenol, an alcohol, may be used to as well with specialized guidance.

It might take some time to work out an effective course of treatment. But there is something you can do in the interim—have the muscles stretched by a family member, friend or therapist if you can't do it yourself.

At the Victoria Peripheral Nerve and Spasticity Clinic, we're studying novel ways to treat spasticity by freezing nerves (cryoneurotomy) at -60 degrees Celsius, and performing small microsurgeries to target nerves and tendons. For certain muscle groups, we can temporarily paralyze muscles with nerve blocks to see which muscle is the most responsible. Orthopedic surgery may be required in severe cases.

Every case of spasticity is a unique pattern that requires a very thorough assessment. It may take several trials to find the optimal treatment. I would suggest you ask your family doctor to make a referral to a spasticity expert.

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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.

Exercise Guidelines Promotion and Implementation in Chronic SCI (EPIC-SCI): A Randomized Controlled Trial

Overview: Dr. Kathleen Martin Ginis and PhD student Kendra Todd are interested in evaluating the effects of following the International SCI Exercise Guidelines over the course of six months.

What to expect: Participants will be randomly allocated to one of two groups. One group will follow an exercise program for six months. The other group (the control group) will be asked to not change their daily lifestyle for six months. After this, the control group has the opportunity to enjoy the same aforementioned six-month exercise program. The study involves three visits to a testing site. During these visits, participants will be asked to complete fitness tests, fill in questionnaires; participate in a brief test to see how the body responds to pressure and cold stimuli applied to the arm, and provide blood samples. Each of the three testing visits require approximately three hours. The exercise program consists of two to three hours of exercise per week at home or in a local fitness facility. A personal trainer will set up the exercise program together with the participant.

Who can participate: To participate in this study you must be over the age of 18; can read, speak and understand English; have access to a phone; have been diagnosed with a SCI more than one year ago; have an injury level at C3 or below; experience chronic pain; participate in less than 40 minutes per week of structured, moderate intensity, aerobic exercise and less than two bouts per week of strength training; and have no medical contraindications to performing a maximal exercise test.

Why participate: If you choose to participate, you will learn what your peak oxygen uptake is, in addition to your current levels of muscular strength for major muscle functioning groups. Although there are no other guaranteed benefits of participation, increasing physical activity levels has known physical and psychological benefits for persons with SCI. Therefore, it is possible that you may develop fitness and cardiometabolic health benefits associated with exercise participation, which may lead to sustained exercise adherence. You will be compensated a flat rate for travel to the testing site in order to complete each testing visit.

Location: UBC Okanagan (also at ICORD Vancouver in the near future).

For more information or to sign up to participate: Please call Kendra at 519.546.3469 or email her at ktodd03@mail.ubc.ca.

Pain and Constipation Management for People with SCI

Overview: Dr. Krassioukov and his research team are interested in investigating the effects of oxycodone-with-naloxone (TARGIN®), an opioid medication approved by Health Canada, on pain management and reducing secondary complications of opioid treatment. Managing chronic pain in individuals with SCI is challenging because many of the medications used have side effects that contribute to health-related complications and limitations that come from having a SCI. For example, SCI can affect bowel function, including constipation and be accompanied by potentially life-threatening episodes of autonomic dysreflexia (AD). If you are on an opioid, this can make constipation worse and put you at risk for more frequent AD.

What to expect: Six visits to the Blusson Spinal Cord Centre over a period of eight weeks will be required. Three visits will take 30 minutes, and the three others will take between one to two hours. In addition, you will be asked to complete a take-home diary for five to ten minutes a week. You will be compensated for completion of the treatment visits.

Who can participate: You may be eligible to participate in this study if you are between 18 and 65 years of age, have had chronic pain for more than three months, had a traumatic SCI more than three months ago, have been taking an opioid medication prescribed by your physician for a minimum of three months, do not have a hypersensitivity or allergy to opioid medication and/or naloxone, are not breast-feeding or pregnant, are able to communicate well in English, and are a Vancouver resident who is a Canadian citizen.

Why participate: This study proposes that treating SCI patients with a combination of oxycodone and naloxone may improve pain management while alleviating opioid-induced constipation. The use of Targin may be more effective in treating chronic pain while reducing the number of side effects common with opioid use and therefore reducing the frequency and severity of episodes of AD. There is no cost for tests, examinations, and medical care required as a part of this study. We hope that the information learned from this study can be used in the future to benefit other people with SCI.

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 the study coordinator, Moe Saffarzadeh, by email (msaffar@alumni.ubc.ca), or Tahira Tejpar by phone at 604.675.8856.

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

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For more information on joining the research study email Dr. Swati Mehta, swati.mehta@sjhc.london.on.ca visit: www.onlinetherapyuser.ca/sci

Release

A UBC student project may yield an easy-to-use seat belt mechanism for people with quadriplegia.

hanks to some amazing technology, many of our Peers with high level SCI are able to safely get behind the wheel. But strangely, the basic design of one of the most important safety components of any vehicle hasn't changed for decades. We're talking about the common seat belt, which has never been updated or reconfigured in a way that makes it easier for anyone with limited hand function to easily buckle up.

The AccessiBelt might change that. The result of a unique partnership between UBC's Engineers in Scrubs program and the Praxis Spinal Cord Institute (formerly Rick Hansen Institute), the AccessiBelt is a small, portable device that can be taken from vehicle to vehicle and used with existing seat belts to make them easier to buckle for SCI BC Peers. It attaches to the metal tongue, or male part, of the seat belt, and provides users with a large flat surface to push down on with their palm or fist in order to buckle and unbuckle, rather than needing their fingers to grasp the buckle mechanism.

The idea was conceived when one of the employees at Praxis presented the problem to students enrolled in the Engineers in Scrubs course at UBC's School of Biomedical Engineering.

"This individual has limited hand dexterity and very weak fingers, and so they often have a hard time buckling and unbuckling car seat belts and sometimes need someone's help," says Alaa Heshmati, a biomedical engineering Masters student at UBC and one of the students in the course. "After researching this problem, we couldn't find any solutions or devices out on the market that address this need. So we determined that this is an unmet need that, if solved, could improve the life of many individuals with limited hand function."

Students in the course formed a team to tackle the problem. And it was Heshmati who came up with the concept for AccessiBelt and has been developing the prototype ever since.

"After the course ended, I saw a big potential in the last iteration of the prototype I had developed, and I really wanted to continue working on it," says Heshmati. "I discussed this with the course instructor and I was able to get the support I needed to continue working on the project."

Heshmati is now leading the AccessiBelt's development as part of her Masters work. She has 3D-printed multiple prototype devices for testing with users, a process which is well underway. "Right now, I'm completing user testing of the beta prototype and collecting enduser feedback to finalize the design of the device," she says. "Many users have found it to be very helpful. It's made it easier for them to buckle and unbuckle the seat belt, which saves time and reduces the number of attempts and effort it takes to buckle up. One tester couldn't unbuckle their seat belt no matter how hard they tried, and always needed someone's help with seat belts. But the AccessiBelt device allowed them to unbuckle their seat belt independently."

In addition to people with SCI, Heshmati says AccessiBelt might be ideal for other users.

"Anyone that has limited arm or hand function, dexterity and strength, such as people with arthritis or stroke, and even seniors, can benefit from this device," she says. "My goal right now is to partner with non-profit organizations such as the Praxis Spinal Cord Institute, Tetra Society and Neil Squire Society to make AccessiBelt available at a low price to people that need it."

We'd love to give you a good look at the AccessiBelt, but due to the need to protect the intellectual property, Heshmati and her team are not sharing any closeup photos of the device at this point.

If you're interested in testing the AccessiBelt or want more information on the project, you can email Heshmati at aheshmat@mail.ubc.ca.

ABOVE: Masters student Alaa Heshmati, who is leading development of the AccessiBelt

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