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GOT QUESTIONS?

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Spinal Cord Injury BC

Change on the Horizon

As the philosophical comedian Steven Wright once quipped, "Change is inevitable...except from vending machines." As readers of *The Spin*, I know you don't need an essay on change. Don't worry—this is not that. It's a farewell and a heads-up about a change coming to *The Spin* this summer.

After 12 years, 48 issues, and 1,600 pages, the managing editor and designer of our beloved magazine, Cliff Bridges, is retiring. You'll be forgiven if Cliff's



name is not a familiar one to you. Despite writing almost all of the stories and doing the layout for every issue we've published, Cliff preferred to let the peers, researchers, clinicians, and others we featured be the focus of attention.

Cliff has a long, proud history of writing about the world of SCI over the past three decades. After beginning his career as a TV news and sports reporter, he took on several senior communications roles that saw him publishing magazines for the Alberta government, SCI Alberta, SCI Canada (some of you will remember *Total Access*), and others.

I first met Cliff in 2006 when we were part of the management group tasked with establishing the Canadian SCI Solutions Network (which morphed into the Rick Hansen Institute and is now the Praxis Spinal Cord Institute). As my manager of communications, Cliff suggested we publish a magazine that highlighted the impact of the research connected to the organization on the people with SCI who participated in it. So was born the *SCI Solutions* magazine, which was later identified as one of the most valuable products of the organization's work.

Not surprisingly then, one of the first things I did after accepting my current role at SCI BC was to reach out to Cliff to see if he would be interested in publishing a new magazine for SCI BC. To my delight, he accepted with enthusiasm, and in the spring of 2011, we published the first issue of *The Spin*.

Based on the overwhelmingly positive feedback we received on that first issue and every issue since, I know that *The Spin* has become an important part of SCI BC's work, and something you look forward to receiving each quarter. Putting the magazine together without Cliff will be a challenge, but be assured that we will continue to bring you interesting, relevant, useful stories in *The Spin*. It just may look and feel a little different.

Cliff and I have been through a lot together over the years. We made a good team and became good friends. I've dreaded the day he would lay down his pen (or unplug his keyboard). Now that the day is here, there is a bit of dread remaining. But there is excitement for Cliff and his well-deserved retirement, and for the opportunity for others to bring their creativity and knowledge to what will be a new era for *The Spin*. True to our mission, we will adjust and adapt so that *The Spin* will continue to thrive.

For now, I'm sure you will join me in thanking Cliff for bringing us *The Spin* all these years, and in wishing him the best in retirement.

—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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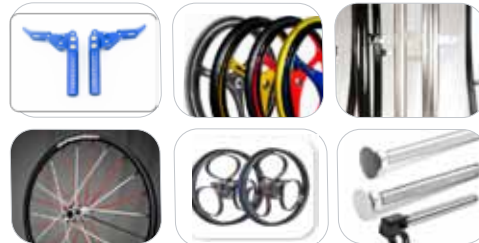
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Innovations

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

L'ORÉAL HAPTA

Makeup giant L'Oréal recently unveiled Hapta, a handheld, motorized device that helps people with limited hand and arm function apply lipstick. It's essentially a miniature robotic arm that helps users stabilize a tube and apply lipstick. HAPTA is equipped with a magnetic attachment that allows for 360 degrees of rotation and 180 degrees of flexion. A "clicking" feature allows the user to intuitively set and keep the intended position during use. It comes with a built-in rechargeable battery that provides an hour of continuous use. Hapta is only compatible with Lancôme lipsticks for now, but L'Oréal plans to create fittings for other brands. L'Oréal engineers have also been working to make the company's packaging easier to open for people with disabilities. See loreal.com for more information and availability.



GLOVES FOR LIFE

The right wheelchair gloves for paraplegics often don't work well for people with quadriplegia. Enter Gloves for Life, which are designed specifically to help quadriplegics and others with limited dexterity push more efficiently. They're made from durable yet soft suede material, and incorporate a tacky rubber palm pad that grips pushrims without needing a great deal of strength. They're secured with a hook and loop strap equipped with a D-ring that can be pulled with a thumb or teeth, allowing for easy and independent adjustment. Users report that the gloves can also be used as a cuff to hold a fork, pen or other utensils. Gloves for Life are available in four sizes and 16 colours, which you can see at glovesforlife.com.



EXEROTECH SPIKE

Norwegian adaptive sports equipment company Exero Technologies has developed Spike, an innovative wheeled mobility/exercise device that allows for a cross-country-like workout and experience on dry land. As with a para Nordic sit ski, poles are used to generate forward propulsion, while riders tilt their bodies to steer. The Spike's wheels are at home on smooth trails or off-road surfaces, and a variety of adjustments can be easily made to accommodate users of different sizes. Straps for your feet and waist keep you secure, and a thigh belt can be added for additional support. There are two types available—one is for users who have full trunk strength and can kneel, while a sitting version accommodates those who lack trunk stability. Learn more at exerotech.com.



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Spinal Cord Injury BC

CHARITY CHALLENGE

Virtual Race: June 1- 30 | In-Person Race: June 25



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Connect with Christina at clee@sci-bc.ca to register



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Walk, run or wheel for SCI BC.

From June 1 to 30, people from all over BC can participate in this year's Charity Challenge and raise funds for Team SCI BC. The virtual race takes place all month—you can take part wherever you live. And you can also participate in the big in-person race in Vancouver on June 25. Funds raised support our provincial peer and information services programs. Connect with Christina Lee at clee@sci-bc.ca to register or learn more online at sci-bc.ca/charity-challenge-2023.



Connect with your community.

ConnecTra Society's flagship event, the Abilities Expo, brings together exhibitors, vendors, resources, guest speakers, and more to further enrich the disability community's well-being and connectedness. This annual event is back for its 12th year and the theme this year is Adventure Awaits. It all happens on May 18 at the Roundhouse Community Centre in Vancouver. More details and information can be found at connectra.org/abilitiesexpo.

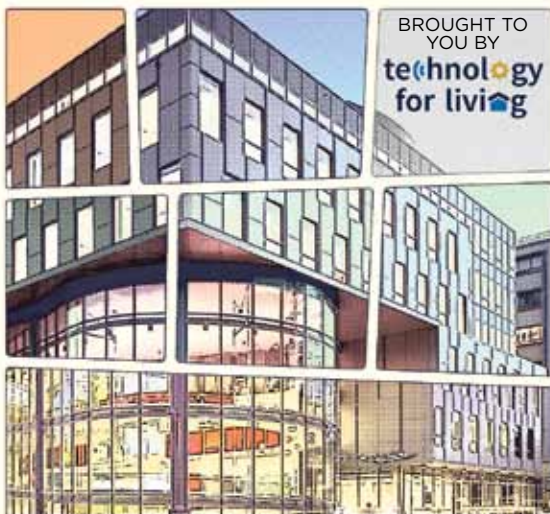


Connect with our new LTC group.

We know our online events are a big hit with our peers, so we decided to add a new one. Our new online peer group is for residents of long term care (LTC) facilities, along with their families and support staff. Meet the host, Jeff Gartrell, and others who understand LTC life, for some laughs and discussion. The long term care peer group runs on Zoom weekly—visit sci-bc.ca/online for details and to discover even more online groups and meetings.

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peers

Congratulations to Kamloops' **JESSICA Vliegenthart**, who was selected for full partnership by her law firm, Fulton & Company LLP on January 1.

"First joining our firm as an articled student, Jessica was called to the bar in 2013, and since then has developed her legal practice in litigation, primarily personal injury," her firm wrote in a news release. "Jessica comes armed with the determination of an Olympian and the affable people skills that made her a leader on Team Canada, both on and off the basketball court."

Jessica, who has been a valued member of our board of directors in the past, completed her BA at Simon Fraser University in 2008, and then her Juris Doctor at the University of Victoria in 2011.



A high-powered shoutout to Kamloops' **TORY JONES** who, just a year after obtaining his professional bodybuilding status, placed 8th in the wheelchair division of the recent Mr. Olympia competition.

Tory, who we profiled in the Spring 2022 issue of *The Spin*, was one of 12 elite competitors from around the world who qualified for bodybuilding's most prestigious event, held in December in Las Vegas.

"I definitely didn't get the place I was looking for, but that's how she goes and I'll learn and get better going forward," says Tory. "But all said and done, it's pretty cool to say I'm ranked 8th in the entire world among wheelchair bodybuilders."

At the time of writing, he was weeks away from competing in the Arnold Schwarzenegger Sports Festival in Ohio, and was also planning on attending the Arnold Schwarzenegger Sports Festival in Brazil in May and the Toronto Super Show in June. And he'll be back at this year's Olympia in November, which is being held in Florida.

Peer Shoutouts

A salty shoutout to Canadian Para surfer **VICTORIA FEIGE**, who became the winningest woman in Para surfing history in December when she won her 4th straight world title.

Victoria, who is 37, once again finished at the top of the women's kneel division during the 2022 International Surfing Association (ISA) Para surfing world championship held at Pismo Beach, California.

"It's amazing," Victoria told CBC Sports after her victory. "I never thought this would happen. After my spinal cord injury, I never thought that I could surf at a high level. It's been a wonderful, joyous surprise to progress in my surfing, and also do so well in the competitions."

Victoria is a highly qualified physiotherapist from the Lower Mainland, but has put that career on a hold while she continues to focus on surfing while living and training in Hawaii. The ISA is pushing for the sport to make its Paralympic debut at the 2028 Games in Los Angeles. If that happens, we fully expect to see Victoria compete and win for Canada.





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

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Butting Out

Researchers at UBC Okanagan are teaming up with SCI BC to develop a smoking cessation program specifically for people with SCI, and our peers can help roll it out.

When it comes to vices, few are as remotely bad for people with SCI as smoking cigarettes. Yes, it's true that smoking isn't picky about who it kills—lung cancer and heart disease are huge risks of smoking that don't discriminate between people with or without disabilities. But research has revealed that many secondary complications of SCI—skin breakdown, pneumonia, compromised immunity, bladder cancer, osteoporosis, pressure ulcers, chronic pain and others—are made even worse by smoking.

The irony is that, despite the elevated risk, people living with SCI seem to be smoking in far greater numbers than the general population.

"There are a few studies from the US, UK, Netherlands, Australia, and Canada that report high smoking rates among people with SCI," says Kelsey Wuerstl, a third year PhD student at UBC Okanagan and an ICORD trainee. "These studies report smoking rates between 20 to 45 percent, while the able-bodied population typically reports smoking rates between 13 and 15 percent."

Help could soon arrive via a promising SCI-specific smoking cessation program

being co-developed by Wuerstl, several other UBC Okanagan and ICORD investigators, and SCI BC.

Wuerstl says the idea for the program emerged several years ago during discussions between Dr. Heather Gainforth, an associate professor at UBC Okanagan's School of Health and Exercise Sciences, and Dr. Chris McBride, Executive Director of SCI BC.

"Dr. Gainforth and Dr. McBride noticed that a lot of people with SCI smoke," says Wuerstl, who works in Gainforth's Applied Behaviour Change Laboratory (ABC Lab) at UBC Okanagan. "So we started looking into research focused on

smoking cessation and SCI, and found very, very little research, and no smoking cessation interventions or programs specifically for people with SCI. This was very eye-opening and motivating.”

Wuerstl, Gainforth and McBride were soon joined by ICORD investigators Dr. Kathleen Martin Ginis and Dr. Rhonda Willms, and SCI BC officially signed on as a community partner.

From the beginning, everyone involved knew they were on to something. “Talking with various people with SCI at coffee groups and wheelchair rugby, we saw how many people were excited by this work,” says Wuerstl. “Some people volunteered to participate in our studies on the spot before we even had anything to offer.”

The collaboration set its sights on developing a community-based program that makes use of scientifically-validated behavioural change techniques to address the unique circumstances of people with SCI who are grappling

with the often enormous challenge of quitting smoking.

The rationale is obvious: smoking cessation programs work, and research bears this out.

“Whether you have an SCI or not, stopping smoking is really hard,” says Wuerstl. “It takes most people on average seven attempts at quitting before they’re successful. In the general population, when an individual uses a combination of counselling services—for example, quitnow.ca—and smoking cessation medication or nicotine replacement therapy like Nicorette gum or patches, they’re twice as likely to be successful quitting smoking than trying to quit cold-turkey.”

Despite that success, smokers with SCI who want to quit don’t seem to be looking to these types of approaches for help.

“One study out of the US found that more than 70 percent of people with SCI who smoked tried to quit, but less than 30 percent sought professional help

through medication or counselling services,” says Wuerstl. “So we know that people with SCI are motivated to quit smoking, but that only a small number of those are turning to professional services. This might be because the services aren’t relevant—for example, they don’t include topics and information that are important or useful to people with SCI. Or they simply aren’t known to people with SCI—maybe not enough physicians and other health care professionals are referring people with SCI to smoking cessation services.”

For these reasons, the collaborators began work on a smoking cessation program that specifically targets people with SCI.

“For example,” says Wuerstl, “our program will have health information on topics relevant to people with SCI such as pressures injuries, UTIs, pain, and respiratory infections.”

Work began with the researchers conducting three studies to better understand cigarette smoking and smoking cessation behaviour among people with SCI. The findings from these studies were then presented to other researchers and clinicians. In turn, their feedback helped clarify what the finished program might look like. But input and feedback was still missing from an important group—those who might benefit from the program.

“To ensure it’s relevant, people with SCI themselves must play a major role in the program’s development,” says Wuerstl. “That’s why we’re taking the findings from the three studies and the feedback from researchers and clinicians and presenting them to people with SCI for their review and input. We need peers’ input because we want to make sure that the program we design is relevant, useful, and usable by those who could or will use it. This smoking cessation program is for people with SCI, and so we want to make sure it is being informed and designed by people with SCI.”

Which brings us to the researcher’s current study, aimed at gathering insight and feedback from you, dear reader.



The smoking cessation program is being co-led by PhD student and ICORD trainee Kelsey Wuerstl (left), with oversight from her UBC Okanagan supervisor Heather Gainforth.

"The study includes a short survey and a three-hour online meeting," says Wuerstl. "The meeting uses what's called a 'World Cafe' approach. The purpose of a World Cafe is to facilitate discussion and generate ideas on a particular topic in a casual and relaxed setting. This approach encourages meaningful engagement, connection, and creative problem solving."

If you're interested in taking part in the study, Wuerstl invites you contact her directly via email (kelsey.wuerstl@ubc.ca) to learn if you're eligible.

Once feedback from peers is incorporated into the design, the next step will be to finalize the intervention and roll it out so that people can start to benefit from what could be a life-saving intervention.

"Broadly, we see this program being delivered online through SCI BC," says Wuerstl.

She explains that, while the exact details won't emerge until feedback from peers is obtained, the program will likely have two components.

"The first component is ensuring that people with SCI know how to access smoking cessation medication or nicotine replacement therapy, which is key to help with cravings and urges to smoke," she says. "Accessing affordable smoking cessation medication and nicotine replacement therapy can sometimes be confusing, so we want to make sure we have a system in place that makes it easy for someone to navigate the process."

The second component, she explains, is provision of behavioural counselling and relevant health information.

"We'll create a section on SCI BC's info centre with general and SCI-specific information about quitting smoking. We also want to work with SCI BC's peer support network to provide them with the tools and training so they can help support someone to quit smoking with confidence. By including the peer support network, we can ensure that those who want to talk with and access support from someone with shared experience can do so."

Other principles of the program will be flexibility and easy access. "We want to make sure that the program can be tailored to each person who accesses it," says Wuerstl. "Not everyone will need the same support, and so we want to make sure that the program is useful to lots of people across BC. By delivering it online, we can reach those living in rural areas and anyone who faces transportation barriers."

While an exact date for rollout isn't yet known, Wuerstl says it could be within a year if the remaining parts of the development process continue smoothly.

"Smoking is deadly for everyone, but there are significant additional risks for people with SCI, who, on average, smoke more than the general population," concludes Wuerstl. "So if we can develop a program that helps people stop smoking, we want to do that. And we hope that by co-developing it with people with SCI, the program will truly be helpful for people with SCI who want to stop smoking." ■

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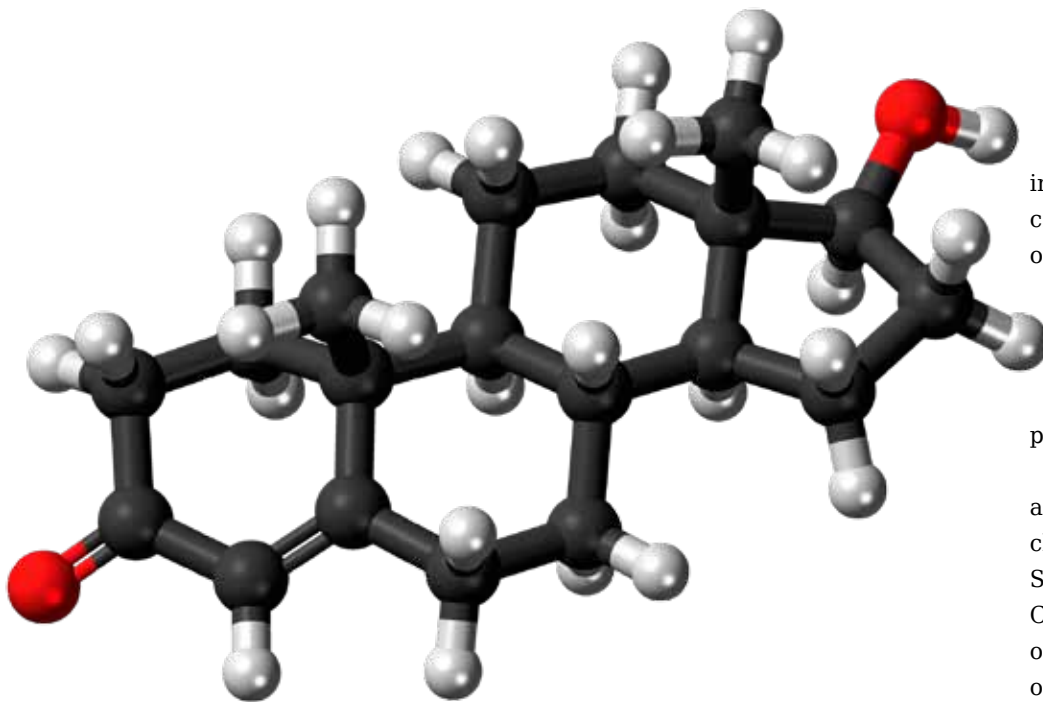
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Get Your Mojo On

A recently-published systematic review suggests that, when combined with exercise, testosterone therapy offers a safe and effective way for men with SCI to boost their vitality—and get some significant health benefits in the process.

We tend to only think of testosterone as the hormone responsible for male sexual drive. While testosterone is the secret sauce that maintains libido, it's also a hormone that has many more functions and benefits beyond sexuality—it has a huge impact on muscle and bone mass, strength and vitality, and mental acuity and health.

The body's production of testosterone gradually slows as men age, and research has demonstrated that there is a link between declining testosterone levels and health problems associated with the aging process, including loss of muscle mass, strength, vitality and overall wellbeing.

The problem is that SCI has been shown to dramatically decrease testosterone levels in many men of all ages,

including young men. Estimates of incidence range from 20 to 50 percent of men with SCI experiencing lowered testosterone (which is called hypogonadism), and it's generally accepted that the higher and more complete the injury, the more likely it is to be present.

The results can be really debilitating, according to Dr. Stanley Ducharme, a clinical psychologist at the Center for Sexual Medicine at Boston Medical Center and a Clinical Professor of Urology at Chobanian and Avedisian School of Medicine who specializes in sexual functioning and disability.

"A loss of muscle mass and strength can affect mobility and functional independence," Ducharme writes in an article on his website. "Fatigue, loss of energy and moodiness can ultimately impact on areas such as pressure relief, medication compliance and health maintenance. Motivation, dry skin and wound healing can also be affected if hormone levels are diminished."

He adds that emerging evidence points to lowered testosterone levels being implicated in the presence of osteoporosis in men with SCI. And he adds that, in addition to all these issues, loss of sexual interest because of lowered testosterone can add to the existing sexual dysfunction experienced by men with SCI.

"For these individuals, sexual activities are often seen as added work or as a burden that requires additional efforts," he writes. "Naturally, relationship or marital issues can emerge as the romantic, affectionate and intimate qualities of a relationship disappear."

An exact cause of lowered testosterone after SCI hasn't been identified. Although testosterone is made in a man's testicles, the levels are regulated by another hormone called luteinizing hormone (LH) made by the pituitary gland. Some research suggests that SCI compromises the ability of the pituitary gland to produce LH.

Regardless of cause, for some men with SCI, Ducharme and other clinicians are increasingly turning to testosterone therapy for help. It's a way of increasing testosterone levels via injections, patches or various gels.

But is it effective? And is it safe? Over the past three decades, there have been some small studies that have attempted to answer these questions. Unfortunately, these have not been well-publicized, conducted on a large scale, or resulted in any type of definitive recommendation for healthcare professionals.

Recently, a team of researchers at the University of Pennsylvania Perelman School of Medicine in Philadelphia set out to shed some light on this by completing a systematic review of existing research.

"I'm a physiatrist, or a physical medicine and rehabilitation physician," says lead author Dr. Ryan McLoughlin. "We treat a wide variety of patients, including those with SCI, with a focus on improving function and quality of life. It's pretty clear that people with SCI have an increased risk of developing testosterone deficiency. However, this can be overlooked. So I wanted to learn more about the benefits of testosterone therapy in those with SCI and potentially promote a treatment that could improve patient quality of life."

As with all systematic (or scoping) reviews, McLoughlin and his collaborators first did a comprehensive search to identify credible, peer-reviewed research projects that have been completed in this area around the globe. They then summarized the findings of these projects into one comprehensive paper, which appeared on January 27, 2023, in the journal *Cureus*.

The title of the review is *A Systematic Review of Testosterone Therapy in Men With Spinal Cord Injury or Traumatic Brain Injury*. As the title suggests, the research team wanted to include traumatic brain injury (TBI), as it's a condition where loss of testosterone also has implications. We'll tell you right up front that the review concluded that

there was insufficient evidence of any benefit for people with TBI, so we won't further discuss that aspect of the paper. But for men with SCI, there turns out to be clear benefits—particularly when it was combined with exercise.

A total of 12 primary research studies conducted over the last 30 years made the grade for inclusion in the review. Men with SCI were investigated in 11 of these, and chronic SCI, defined as an injury older than one year, was explored in 10 out of the 11 SCI studies. The duration of clinical trials ranged from eight weeks to 18 months, and the number of participants ranged from 13 to 35. Participant age ranged from 18 to 65 years. Testosterone patches were investigated in 10 articles while one article studied testosterone gel and one article looked at testosterone injections.

The review has a couple of results that clearly stand out. First, in a 16 week study combining testosterone patches and resistance training with functional electrical stimulation (FES) in men with SCI increased their muscle mass, strength, bone quality, and basal metabolic rate while testosterone patches without exercise for 16 weeks produced no significant changes in these parameters. And in another 12-month study involving testosterone patches and maintenance of a regular diet and physical activity regime in men with SCI also increased lean tissue mass (LTM) and resting energy expenditure (REE).

No doubt, you've noticed that these positive results all involve exercise.

"Exercise is one of the greatest things you can do for your body," says McLoughlin. "It builds muscle and bone strength, lowers the risk of disease, improves heart and brain health, and promotes healthy sleep. Unfortunately, there's no substitute for exercise. Testosterone therapy simply allows those with low testosterone to fully maximize these benefits. A way to think about it is if you want to build a house, you need to put in the work. However, it can be easier if you have the right tools."

As for safety, it needs to be noted

that testosterone therapy is not without risks. It's not recommended for men with evidence of prostate cancer, desire for fertility in the near future, severe sleep apnea, or severe urinary obstruction. But the review concluded that testosterone therapy was generally well-tolerated without major adverse events in any of the participants.

"Testosterone therapy with exercise," concluded McLoughlin and his colleagues, "may help improve muscle mass, bone health, strength, energy expenditure, and cardiac health in men with SCI without major adverse effects."

The authors point out that there were limitations in each study. Generally, study durations were short and sample sizes were small, and only one study had a placebo group. A major recommendation is made to have larger, longer and more comprehensive placebo-controlled studies to confirm benefits. We're happy to report that an ongoing randomized, placebo-controlled trial is currently underway and is investigating the combination of testosterone injection and FES exercise versus FES exercise and placebo injection in men and women with SCI.

Also, we noted that all the studies included in the review focused primarily on physiological changes, which we asked McLoughlin about.

"You're correct," he says. "The studies in the review mostly focused on physical changes. In the able-bodied population,



Dr. Ryan McLoughlin

testosterone therapy has been shown to improve mood and sex drive in those with low testosterone. It's unclear whether testosterone therapy can improve cognitive function or energy. It's possible these benefits could apply to men with SCI. However, I think it would be worth investigating, because those with SCI represent a unique patient population."

If you're reading this far, you might be wondering if you're a candidate for testosterone therapy.

"Men with SCI should speak with their doctor about screening for low testosterone one year after injury—especially if they are experiencing low sex drive, depressed mood, lack of energy, and weight gain," says McLoughlin.

Your doctor can determine if you're deficient in testosterone with a simple blood test. If the test confirms it, you'll likely be referred to a physiatrist, urologist or other specialist, who can better determine if testosterone therapy is the best course of action for you.

But while testosterone therapy for

people with SCI seems to be becoming more accepted among medical professionals, it's important to remember that there are risks associated with testosterone therapy—again, it's not recommended for men with evidence of prostate cancer, desire for fertility in the near future, severe sleep apnea, or severe urinary obstruction. It's not a lifestyle enhancement or to be taken for an energy boost. Testosterone therapy is not a self-help program; it's always conducted under careful medical supervision and requires

ongoing blood monitoring. It should never be attempted by yourself.

Finally, as the systematic review makes clear, it's a therapy that works best when combined with exercise. In fact, getting more active and eating healthier is a route that you might want to try before you pull the trigger on therapy.

"Men should optimize lifestyle changes before considering testosterone therapy, because exercise and a healthy diet alone can help improve testosterone levels," concludes McLoughlin. ■



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*Products installed depend on the individual characteristics of the home and other program criteria. Only FortisBC natural gas heated, FortisBC electrically heated or BC Hydro electrically heated single family homes, townhouses and duplexes may be eligible for insulation upgrades. In addition, only FortisBC natural gas heated homes may be eligible for furnace replacement. Other program criteria apply. Apartment units and mobile homes are not eligible for insulation or furnaces. Offer subject to change.



Back Behind the Wheel

For SCI BC peer Brayden Methot, a return to driving has been central in his quest for independence—and it's been an unusual journey to say the least.



Like many SCI BC peers with quadriplegia, Brayden Methot's return to driving after injury revolves around a van—after all, vans are really the only vehicle type that can be modified to include a wheelchair lift and offer the ability to drive from a chair using a lockdown system and hand controls.

But Methot's van is unique among the thousands (or maybe tens of thousands) of modified vans in use on Canadian roads. In fact, his van literally stands head and shoulders above the field. That's because it's a Mercedes-Benz Sprinter—the first in Canada to be modified for use by a quadriplegic driver. And it's not just any Sprinter—it's a 4x4 with extra high ground clearance which, combined with the Sprinter's already high raised roof, makes it about two feet taller than other vans on the road.

Mercedes-Benz debuted the first Sprinter models in 1995, throughout Europe. Since then, it's become a common sight in North America. That van

that delivers your Amazon packages? It's probably a Sprinter. But while it's still mainly used as nimble but spacious cargo and personnel transport vehicle, it's being increasingly embraced for personal use, and many have discovered that it makes a great luxury van or RV.

Now it turns out that it can also be an excellent vehicle for someone with quadriplegia, as Methot has discovered—although not without considerable trial and error.

"My first van was a Toyota Sienna, but it just couldn't do what I needed it to, being front-wheel-drive," says Methot, who lives outside of Williams Lake in a rural setting with deep snow and poor road conditions a constant reality. "I had to do the Sprinter because it looked like the only option for four-wheel-drive. And I'm 6'1" and I straight up cannot fit in a regular size van from my power chair. Besides, it's also nice to have a big-ass van to fit everybody in!"

The Sprinter did not, however, end up in Methot's driveway overnight. In fact, it's the culmination of a sometimes ardu-

ous eight-year journey, dating back to his stay in rehab. At that time, all he had was a loosely-formed plan to be driving something soon, even if it wasn't on the road.

"I've always been huge into bikes," he says. "And in the early days of my injury—like I'm talking in the first couple weeks—I told myself, 'Well, at least I'm gonna have a bad ass side-by-side to ride with my friends and race.'"

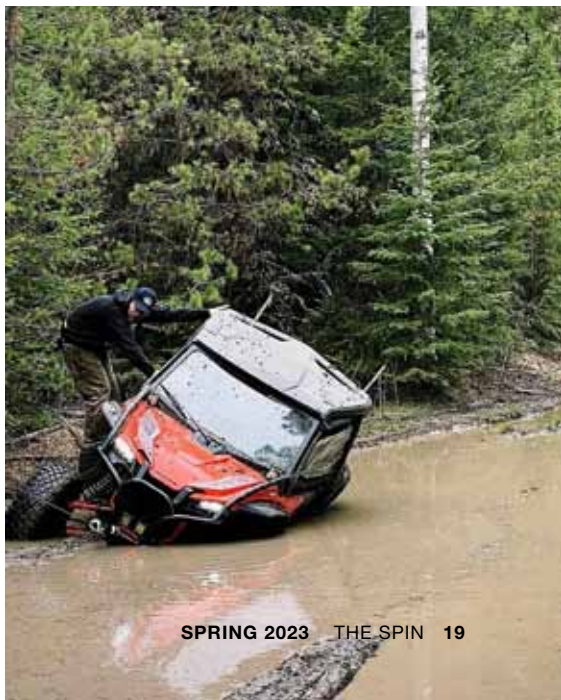
So that's what he set his sights on, reasoning an off-road side-by-side would allow him to return to the backcountry with his friends—and perhaps even help him prepare to get his driver's license again someday.

Thus began his quest to find a side-by-side that would work for him.

"The first one I had was a Polaris RZR 900," he says. "It had hand controls in it, but I was never strong enough to drive it with its manual steering. Then I moved to a Polaris General, which was equipped with power steering. I gave it an honest shot with some custom hand controls and upgraded power steering. I could drive it a little bit, but the power steering would always cut in and out on me, and we never really did figure out a proper setup. It was super frustrating with lots of time and money invested."

Then he discovered the Honda Talon.

"I moved to the Talon when my friend from my local bike shop told me it was the easiest steering wheel to turn that he's seen," says Methot. "So I went down





Driver's seat view of the Sprinter (left) and the Talon.

there, duct-taped my hand to the steering wheel and could spin it, no problem.”

He had a custom deep bucket seat, harnesses and Sure Grip hand controls installed in his new Talon. He developed a routine to transfer into it (he slides the seat back as far as it can go, and gets a friend to lift him in). And soon he found himself ready to take it for a spin.

“The first ride was amazing—I was good at everything except for brakes,” he says with a chuckle. “We were only out for half an hour or so, and I was getting overconfident. I blew a corner, hit a tree and folded the radiator, so friends had to come and tow me back home that night.”

To this day, he drives the Talon constantly, rain, shine or even snow (as you can see in the photos, he equipped it with tracks this winter).

“I love it, despite all of the trial and error,” he says. “We have this thing dialed. I usually use it for weekend rides—sometimes we’re gone on big rides Saturday and Sunday checking out new locations out west, and sometimes it’s just

a quick afternoon ride after work on a Wednesday. When we’re out, I am at no disadvantage to everybody else on these rides—I’m just as fast and enjoying the same ride that my friends are.”

This spring, Methot plans to get involved in local off-road races with the Talon.

But all along, he’s had a more serious use for the Talon. Along with tendon transfer surgeries and five-day-a-week workouts in his home gym, it’s been a great way for him to build his strength and fine-tune his driving skills in preparation to legally get back on the road.

His quest to regain his driver’s license began in earnest in 2018. That’s when he sold the Toyota he’d been considering modifying, and ordered a brand new, third generation 2019 Sprinter 2500 4×4 turbo diesel with an optional automatic sliding side entry door.

When it arrived in 2019, he began the extensive modifications needed to make it work for him. The van was first sent to Mahadev Wheelchair Accessible Vans in

Richmond, where the floor was modified to make it possible for him to drive from his wheelchair. After that, it ended up at Alliance Mobility in Kelowna, where the wheelchair lift was installed.

That only left the control modifications themselves. But as Methot would discover, getting the controls vetted and installed ended up being a lengthy—and sometimes frustrating—process. Being that it was the first Sprinter in Canada to be modified this way, he understood that he would have to work with the fee-for-service Driver Rehab program at GF Strong to determine what control system was appropriate for him. But he was adamant that he wanted regular hand controls and steering, and not electronic joystick controls that many people with quadriplegia default to.

“I rode around as a passenger for probably six months to a year just doing assessments and tests to deem myself safe on the road,” he says. “They decided what controls I needed in the van, and then I was allowed to order them. All

of the trial and error with my side-by-side is definitely what saved me when building the proper setup for the Sprinter. It's maddening having someone at the driving clinic telling you what controls they think are gonna work best for you, especially when they don't know your ability or have even met you before. A lot of the appointments were a complete waste of time, especially at GF Strong. There was no need to drive eight hours each way to do something that we could've done over the phone—and then be charged \$1,200 for the appointment."

He persevered, and eventually completed the process (which included a driving assessment in downtown Vancouver with a van he was completely unfamiliar with).

"I had to wait probably three years for them to finish testing and deem the Sprinter van safe to drive from my power chair," says Methot.

At that point, he was given the green light to use low effort steering and standard push/rock hand controls with elbow switch signal buttons. The Sprinter went back to Alliance Mobility in Kelowna, where technicians sent the Sprinter's steering pump to California to be modified for the low effort steering, and then completed the rest of the modifications.

But there was still a lot more work to do, and he would have to wait many more months to get his driver's license.

"Once it was all modified, I had to practice driving for my final test, which would be in downtown Vernon, straight into rush-hour," he says.

He finally became officially licensed last November.

"The test went pretty good," he says. "I made sure that I was comfortable as possible so I wouldn't have to do it twice."

Since then, he's been rediscovering the joy of driving, and says that the wait was worth it.

"It's definitely a game changer," he says. "I'm still working on the highway driving for long distances, but it's coming back slowly. It's pretty amazing to be able to take my dog out to the lake for the afternoon—you just miss the little things that most people take for granted, I guess."

He says the Sprinter is close to perfect—it's durable and strong. It allows him to visit friends on a whim, or haul his side-by-side out to the backcountry for a day of adventure. But he's quick to point out that the effort he's gone to wasn't just about leisure.

At the time of his accident, he was working as a blaster at a coal mine north of Chetwyn. It was a job that he really enjoyed. He knows that he can't return to that kind of work, but he's eyeing alternatives.

"I'm planning to get back into the workforce finally, and make some money again," he says. "I have a couple ideas locally that I could get back into and start filling up my days. We live a little ways out of town, so having a driver's license is obviously crucial for work, among other things. Getting back behind the wheel has been super important—it took way longer than expected, but I just started chipping away at it and everything started to fall into place." ■





Sea Change

Access to commercial seaplane service in BC appears to be improving in one fell swoop, thanks to some willing captains of the industry, a unique made-in-BC accessibility device, and the tenacity of one SCI BC peer.

Flying on Canada's big commercial airlines as a wheelchair user is far from perfect—but at least it's possible. In contrast, it's never really been a viable option for most wheelchair users to take flight on any of the seaplanes operated by our province's small coastal airlines, despite the fact that they are a vital transportation link in the fabric of BC life.

But thanks to some committed individuals and companies, some innovative technology, and a healthy dose of syn-

chronicity, the situation seems to be rapidly improving.

On December 30, SCI BC peer and prominent fashion designer Chloe Angus and her husband Gabe were trying to book a flight with Harbour Air from their home in Vancouver to Salt Spring Island to celebrate New Year's Eve with her family.

"When we asked the Harbour Air agent on the phone about the plane and accessibility, the agent immediately said that, unfortunately, they couldn't accommodate a person in a wheelchair who

couldn't walk on to the airplane," says Angus. "I replied that she must be mistaken, but was then directed to review Harbour Air's assistance policy online. It clearly stated that, although they're willing to assist passengers as best they can, 'All passengers travelling with Harbour Air must be ambulatory in order to fly.' It was shocking to me that, in 2022, the world's largest seaplane company had this policy and language in place. As a result of an outdated and extremely discriminatory policy, I did not get to spend New Year's Eve with my family. I

will admit this made my blood boil and my heart ache.”

But the story doesn’t end there. Angus has a streak of tenacity that’s clearly evident in the success of her fashion design business—despite the many challenges that came with a tumour resulting in paraplegia in 2015, she barely hit the pause button. So not surprisingly, her anger and frustration gave way to a resolve to change the situation.

“I decided to do something about it because it was the only way I could

feel better about what happened,” says Angus. “As exhausted as I felt with the whole situation, I could not just sit there and allow this to happen to me or others. I learned to adapt after my injury, but I refused to accept exclusion when there are solutions.”

And Angus knew there was a viable solution, because one of Harbour Air’s competitors, Seair, had recently introduced accessible boarding for wheelchair users on its flights between Vancouver and Nanaimo.

As she waited for a requested follow-up call from Harbour Air’s customer service department, Angus reviewed what she knew about Seair Seaplanes, BC’s second largest seaplane operator. She had flown with Seair for many years, before and after her injury. A couple of years ago, she was invited by the Rick Hansen Foundation to help develop seaplane accessibility solutions, and that’s when she learned that Seair owner and CEO Peter Clarke was truly an ally.

“He had donated time, money, and

The Wright Lift at the Right Time

One big reason that seaplane travel has been so inaccessible is a lack of a safe, viable device to lift a passenger with a disability from the dock to their seat in the plane’s cabin. The Wright Lift, by Vancouver Island’s Aircraft Access Solutions, has changed all that.

The high-strength aluminum frame of the lightweight lift is customized with length and rise suitable for the aircraft it’s intended for. At the top, it’s secured into place inside the cabin of the seaplane, while the bottom is free to move on the dock thanks to casters—this is what allows it to continuously self-adjust in the presence of waves or wind.

The chair’s sides drop to allow easy transfers. The chair locks into position for loading, lifting and lowering, but at the top position, it swivels the user into cabin, at which point one of the sides flattens into a transfer bridge to the regular seat. The seat and its passenger are smoothly raised and lowered with a winch powered by a cordless drill, or by hand. It takes about 30 seconds for it to load passengers weighing up to 300 pounds.

Portability is key—it can be wheeled down a dock and secured into position in minutes, and deployed in the most remote of locations. In addition to seaplanes, it’s also intended for use on small fixed wing aircraft like Cessnas, small private jets, and helicopters.

Passengers unable to transfer independently from their wheelchair to the Wright Lift can use the Wright Handler (inset photo). Made of durable water-resistant webbing and fabric, it’s placed under the user in their chair, and wraps around their thighs and chest. Multiple handles allow two to four people to lift people with relative ease.

Five Wright Lifts are in use. Seair has three of them—one at their Vancouver terminal, one at their Nanaimo terminal, and one that can be carried in any of the company’s seaplanes. Two others are in private use. User feedback is excellent, and the company reports interest in the device is growing, from BC, and from other provinces and countries.

The Wright Lift is the brainchild of Aircraft Access Solutions owner and CEO Butch Wright, who lives in Duncan, BC. He built the first Wright Lift four years ago, but has been designing mobility lift devices for years. His inspiration for doing so has been his younger brother Kenny, who sustained an SCI in 1974.

“My experience is firsthand; I understand the challenges of helping those with motion disabilities access the world around them,” says



Wright. “In 2023, it’s ridiculous that people with mobility issues can still not access so many places. Finally, the public is aware and it’s time to have accessibility everywhere for everyone. We look forward to helping many people travel to places they only dreamed about.”

The Wright Lift has a patent pending. To date, it has not required approvals from Transport Canada. Aircraft Access Canada says it is currently working through all channels to gain support from the federal government and hopes to soon see Transport Canada welcome the Wright Lift as a safe and affordable solution. You can learn more and see video of the Wright Lift in action at aircraftaccesssolutions.com.

seaplanes to help come up with accessible solutions for all,” says Angus. “Since that time, Seair has taken leadership in developing and implementing universal accessible solutions into their flight policy and is finding it to be very successful, both in terms of passenger satisfaction and increased revenue.”

Clarke and his company had worked with a few different options to try to identify and deploy safe, durable technology that would allow passengers in wheelchairs to access its fleet of seaplanes. Eventually, they found a workable solution and a partner with Vancouver Island-based Aircraft Access Solutions, inventors of the Wright Lift for small aircraft boarding (see sidebar for more information).

“It’s a lift that truly works and overcomes the challenges of boarding seaplanes—moving docks, wind, tide, and waves,” says Angus. “It’s lightweight, easy to operate, and efficient in loading passengers of varied abilities. Most importantly, it offers a safe way to provide accessible seaplane travel to customers. Seair did not hesitate to put in the order and was able to get the first lift last June, which is when it started to offer accessible flights. Not only did Peter see the solution, he saw the value in investing in his passengers and expanding his market.”

Angus became determined to let Harbour Air know about the Wright Lift and Seair’s positive experiences with it. And she knew she had a staunch ally in Clarke, who, upon hearing about Angus’ problem with Harbour Air, agreed to share Seair’s successes with the Wright Lift and offering accessible travel in general.

“The bottom line is that Peter cares deeply about people,” says Angus. “Because of that, he is willing to share his knowledge and success with others in the industry, even his competition, to help expand accessibility across the board.”

Early in the new year, Harbour Air’s customer service manager got in touch with Angus to discuss the issue she had on New Year’s Eve. Angus explained her



Chloe Angus has found a committed ally in Peter Clarke, CEO and owner of Seair Seaplanes.

situation and requested an in-person meeting with the company’s CEO.

“Harbour Air took the incident and my request seriously, and the following week I met with their new CEO, Bert Van Der Stege, and his team,” she says. “We discussed in-depth the issues around accessible seaplane travel, importance of inclusion, and corporate responsibility. In the end, they expressed their appreciation for me taking the time to share my experience, expertise, and ideas with them. Looking me in the eye, Mr. Van Der Stege and his team committed to doing what it takes to improve services and accessibility.”

Angus was pleased to see that, soon after the meeting, Harbour Air updated its mobility page, removing a statement that only ambulatory passengers who require minimal assistance will be able to board its flights.

“This was a commendable first step towards making real change,” says Angus.

Next, Angus took Clarke up on his offer to share Seair’s knowledge and experience. In February, she arranged a

meeting between Seair, Harbour Air, the Vancouver Flight Centre, and Access Aircraft Solutions to demo the Wright Lift and to discuss next steps forward. That meeting, she says, went extremely well.

“I am happy to report that the entire thing is moving forward in a positive direction,” she says. “We hope to put together another demo for other interested airlines and community members in the near future. Seair has done everything they can, from developing and implementing the solution to writing accessibility into their flight plan policy, but if we’re going to see real change throughout the province, and Canada as a whole, the industry needs to work together and support each other in providing universal accessibility to all passengers. If they share information and pool their resources, change could be swift and the impact monumental.”

At the time of writing this story, which was late February, Harbour Air had not made a commitment to purchase and implement the Wright Lift or offer any alternative. One media outlet that covered

this story earlier this year as it was unfolding was CityNews 1130, which reported receiving an emailed statement from Harbour Air in which they described how they were proceeding. “Since not all lift systems available for seaplane operations today meet the approved safety standards or are deemed suitable for the variety of aircraft types that we operate, we continue to engage in conversations with several manufacturers to adjust and design tools that would increase our ability to safely carry travellers with mobility challenges,” read the statement.

Taking into account its importance and position in the market (its fleet of 42 seaplanes is three times the size of its nearest competitor, Seair), no one should be surprised that Harbour Air is exploring its options carefully. Here at SCI BC, we see its willingness to quickly take part in a dialogue and publicly state that it will make accessibility a priority as a good omen. And we should note that the company, which is the sole provider of seaplane service between Vancouver Coal Harbour and Victoria Inner Harbour, is clearly progressive—the fact that it is working so hard to develop electric seaplanes attests to this. So at this point, it seems Harbour Air deserves the benefit of the doubt. Angus agrees.

“Harbour Air has committed to continue updating their policy and working with industry and community to provide accessible travel for all passengers,” she says. “I choose to believe in people and trust that a person’s word still has value.”

As such, she will remain committed to being a resource to Harbour Air, along with the many other smaller seaplane companies operating up and down BC’s coast.

“Today the industry needs to be united in their collective corporate responsibility to provide universal access for all. Not only is it the right thing to do, it will increase revenue for all companies, big and small, that include people with a wide range of motion disabilities. The goal is to unite companies and community to support each other in providing universal access to air and aqua travel for all. As I always say, we have the solutions; all we have to do is apply them.

“Much of my life prior to my injury was adventurous and remote, from growing up in a remote location in Jervis Inlet to visiting and working with the many fishing and eco lodges all throughout BC that are boat or plane access only. I want to live that life again, and I want others to have that opportunity too.” ■



Boost for Accessible Taxis

Operators of wheelchair accessible taxis and people with disabilities in BC will benefit from a new financial aid program announced in February by BC’s Minister of Transportation, Rob Fleming.

The program will offer \$3 million in funding aimed at offsetting the high costs that taxi owner-operators face in profitably operating wheelchair-accessible vehicles, and it’s hoped this assistance will help boost the numbers of such vehicles throughout the province.

“Promoting equity in passenger transportation is an important way that we’re working to build a better, stronger future for all British Columbians,” said Fleming during a press conference in Vancouver on February 1. “By investing in a more inclusive transportation network we are helping people participate more fully in their communities by connecting with friends, attending appointments and getting to work.”

He added that the government is planning on launching three “additional funding streams” over the next two years aimed at further reducing the cost of operating, purchasing and converting wheelchair-accessible taxis.

One of the speakers at the press conference was BC Taxi Association president Mohan Kang, who said the new program is very timely.

“One of the BC Taxi Association’s goals is to increase the number of accessible taxis on the road and this new program is going to do just that,” said Kang. “The funding will help our members with important retrofitting and maintenance costs so they can provide the important accessibility services people across the province depend on.”

SCI BC’s Teri Thorson was among those representing consumers with disabilities at the press conference (that’s her in the photo above, sitting to the right of Minister of Transport Rob Fleming).

“I am one of those people that have waited for hours on a Saturday night to get home for an accessible taxi,” said Thorson, who is our ReachOut Peer Support Program Lead. “I also know that there are communities that don’t even have access to an accessible taxi, so they are even just unable to leave their homes to be able to join their friends for food or a movie.”

The program will be funded using revenue collected from a per-trip fee that was implemented in September 2019 as part of a BC government arrangement to allow ride-hailing services such as Uber. Taxi owner-operators anywhere in the province got the green light to submit applications to join the program on January 27.

Gadgets Galore

Interested in assistive technology and adaptive devices? You're invited to check out the 8th Annual Simon Cox Student Design Competition show and awards on April 29.

Attention readers of *The Spin*: this is your opportunity to see firsthand how assistive devices and technology for people with disabilities are incubated and brought to completion.

For the first time since the COVID-19 pandemic began in 2020, Technology for Living's prestigious Simon Cox Design Competition will come to a conclusion with an in-person show and awards ceremony, and you're invited to attend.

"The competition brings together the next generation of bright young minds to instill in them an awareness of the incredible difference they can make in the world," says Taylor Danielson, Technology for Living's Community Coordinator and one of the event's organizers. "It's a celebration of what's possible when we work together towards a common goal of a more independent future."

The event will be held from 11 AM to 3 PM at Vancouver's Blusson Spinal Cord Centre, where all of this year's teams will be displaying and demonstrating their projects—and hoping that the judges will rate their innovation above that of their competitors. The incentive?

Some serious cash prizes, along with the prestige of winning and opportunities to explore commercialization of their work.

The competition has been held every year since 2014, with the exception of 2020 when the pandemic forced cancellation. It was originally called the Student Engineering Design competition, but was renamed the Simon Cox Design Competition in 2017, in honour of Technology for Living's former Executive Director, Simon Cox, who passed away in 2016.

Since inception, the competition has generated an astonishing array of increasingly innovative technology solutions developed by teams of students representing a wide variety of disciplines, including biomedical engineering, architecture, and design, from post-secondary institutions from across BC. Last year's competition was the most successful yet, with 15 teams with a total of 58 students from five BC post-secondary institutions competing for \$7,500 in prize money.

This year's version promises to be even bigger. At the beginning of February, when this was written, 22 teams were working on entries. The finalists won't be

known until after this issue of *The Spin* has been published, but it's safe to say that there are going to be some truly innovative solutions on display.

How does it work? Each entry begins with an idea for a new piece of assistive technology. These ideas can be generated by student teams by themselves, but at the heart of the competition is peer involvement—peers are encouraged to get involved and team up with students (and their teachers and instructors) to identify needed technology, and ensure that their innovations truly address a need and create greater independence for anyone who lives with a severe disability. The Technology for Living program facilitates each team/peer collaboration, which then moves forward to bring the idea to life within the time-span of the competition.

Danielson says that, over the years, a trend in the competition has emerged: the best entries often have the most peer involvement.

"Many of the most impactful pieces of assistive technology were either invented by or made in collaborations with people with disabilities," he says. "My advice to all student teams has been to talk to peers and work with them. They are the golden ticket for success in this competition. Peers use assistive technology every single day in all aspects of their life. Instructors, professionals, technicians and others will have valuable advice which should be taken into account, but if the device doesn't work for the actual user, what's the point of it? I know from first-hand experience accessible technology that doesn't work or isn't an appropriate fit collects dust in a closet."

TIL's Taylor Danielson



The competition culminates with the finalists showcasing their creative and assistive technology design solutions. Up for grabs are four awards. The \$1,500 Heather Morrison People's Choice Award is selected by peers taking part in the competition. The \$3,000 Simon Cox Principal Award, the \$2,000 Luke Melchior Achievement Award, and the \$1,000 Don Danbrook Innovation Award are selected by a team of judges, who rate each entry for innovation, scalability, craftsmanship, quality of presentation, utilization of peers in the design process, and ultimately, for how they offer practical solutions to overcome barriers in the home.

Each year's slate of judges are experts in the field who have expertise along with a passion and dedication for assistive technology and improving the lives of people living with disabilities. This year, our own Executive Director, Dr. Chris McBride, is among those on the judging panel.

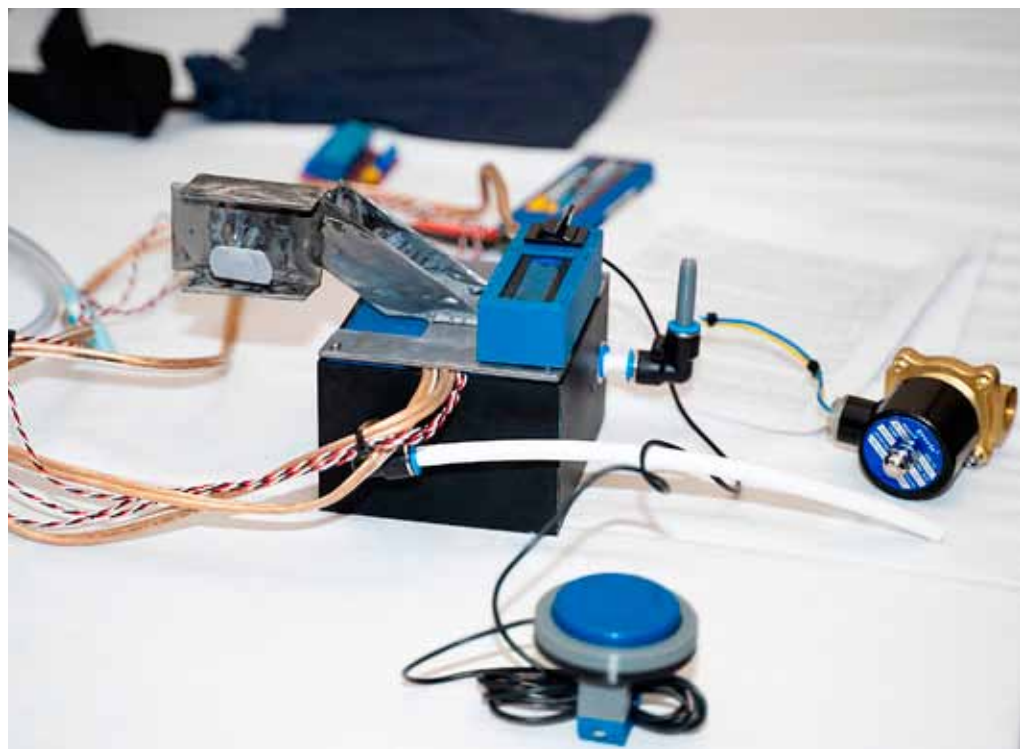
"It's going to be an interesting challenge," says McBride. "I know that the quality of the entries continues to rise year after year, and it's no doubt going to come down to some fine details when it comes to choosing a winner out of so many worthy contenders. I'm up to the challenge, and it's truly a pleasure to take part, as Technology for Living does so many worthwhile things that benefit so many of our members—particularly those with higher levels of injury."

If you attend, you'll no doubt see some very high tech kit on display. But you might be surprised to find out that many winning entries in the past have not been considered really high tech. For example, last year's People's Choice winner, Pea Wee, is a relatively-simple voice-activated catheter release valve that offers a significant improvement over similar products already in the market. Again, ability to positively impact the independence of people with severe disabilities is one of the most important criteria, and both high tech and simple solutions both have the ability to achieve this.

You can learn more about the event at simoncoxcompetition.com. ■



RIGHT: University of Victoria students Jacqui Moreland (left) and Kim Arklie show off the MobilArm, which captured top honours in 2021. BELOW: A catheter drainage device that's activated with the touch of a button captured top honours in 2022. BOTTOM: The UBC Okanagan team of Spencer Bell, Rhys Herzberg, Shane Rutley, and Runliang Wu, which designed the catheter drainage device.



ask the SPIN DOCTOR

Oleg in Campbell River writes, “My doctor told me I should change my eating habits for my health, but I’ve heard that people with SCI have different nutritional needs. Are there healthier eating strategies that are known to work for people with SCI?” For answers, we turned to Joanne Smith, a Certified Nutrition Practitioner and lives with an SCI, and Dr. David Ditor, a Professor of Kinesiology at Brock University and Director of the Power Cord Accessible exercise program. See their full presentation on this topic on YouTube: sci-bc.ca/spindocspring2023. *Note: This column discusses research-based nutrition for health after SCI and does not address the unique needs of people with eating disorders. Discuss any big changes to your eating habits with your doctor.*



There’s a lot of nutrition advice out there, and for people with SCI, it can be especially hard to know what’s real and what’s hype. Studies show people with SCI have poorer nutrition than the general population, due to a variety of factors that can make meal preparation difficult: lack of mobility and transportation, limited dexterity, low income, and fatigue. SCI complications can also present specific nutrient demands such as calcium for bone density and protein for wound healing. Conversely, good nutrition offers many health benefits to people with SCI: better sleep and bowel management, stronger skin integrity, increased energy, maintaining a healthy weight, and others.

After SCI, body composition changes due to the loss of lean muscle mass that would normally burn energy even at rest. This results in a 14 to 27 percent lower metabolic rate and lower daily calorie demand than that of non-SCI adults. It’s difficult to measure directly, so calculations give us an estimate of what ideal body weight could look like for paraplegics and quadriplegics, and to help estimate a daily caloric intake amount by weight, sex and level of function. (For details, see YouTube link above, and review with your doctor.)

Joanne recommends some key strategies for her SCI clients looking to maintain a healthy weight: reduce grains, fruits and refined sugars, and replace them with whole grains, legumes and lentils. Whole grains have more protein and fibre which can help us feel full longer, while protein is important for muscle development and wound healing; fibre is essential for our bowel health. Reach for more fibrous vegetables which are full of important nutrients and help us feel full with less sugar. For those looking to manage their weight, she suggests supplements or dietary sources of chromium, which may improve insulin sensitivity and lipid metabolism (especially for those who are deficient in it), and healthy fats including Omega 3 & 6 (particularly conjugated linoleic acid, or CLA) from eating fish regularly can help reduce inflammation and fat deposition.

David became interested in nutrition as a way to manage SCI health complications, particularly by its potential to decrease chronic inflammation. People with SCI generally have three to five times the inflammatory cells (cytokines) in their blood compared to the general population. This is because people with SCI are predisposed to infections—for example, from UTIs and respiratory illnesses—which can contribute to

a state of chronic inflammation (more on this in *The Spin*, Fall 2022). These cytokines negatively affect many body systems. For example, they can sensitize pain receptors and increase the risk of neuropathic pain, and decrease serotonin production in the brain and increase the risk of depression.

Joanne’s nutrition recommendations gave us a chance to study whether an anti-inflammatory diet could actually lower inflammation and improve pain and depression in people with SCI. An anti-inflammatory diet is low in pro-inflammatory foods like refined sugars, cow’s milk, hydrogenated oils and fried foods, as well as alcohol and coffee. It also includes anti-inflammatory supplements such as curcumin, anti-oxidants, Omega-3 and an algae called chlorella. Over a series of studies we found that the diet was successful at significantly decreasing inflammatory molecules in the blood, decreasing neuropathic pain and depression, and participants reported weight loss of 15 to 25 pounds after 12 weeks. Even a modified version of this diet that was easier to sustain over time showed similar successes, with one major drawback—a loss of lean muscle mass.

This got us interested in whether people with SCI are able to lose weight on a reduced calorie diet without losing lean muscle mass. Muscle mass matters not only because it enables strength for independence and function, it also maintains or increases our basal metabolic rate and burns more calories at rest. We know from non-SCI adults studied that a combination of low-calorie, high protein and resistance training (such as resistance band exercises or using weight machines) is successful at reducing fat mass without losing lean muscle mass—but could people with paralysis due to SCI train intensely enough, or be able to fit in the required protein to a lower calorie diet?

Though the answer to this question is not completely settled, our studies and others on people with SCI show a few key ingredients to improving health through nutrition change: a lower calorie, low inflammation diet (two similar diets include the Mediterranean diet and the Time Calorie Displacement diet) with higher protein (two grams of protein per kilogram per day), together with regular resistance exercise training, can make it possible for people living with SCI to lose weight, lower inflammation and improve neuropathic pain and depression while retaining muscle mass for mobility and effective metabolism.

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.

EPIC-SCI: A Randomized Controlled Trial

Overview: ICORD researcher Dr. Kathleen Martin Ginis is evaluating the effects of following the *International SCI Exercise Guidelines* over the course of a six month period. Participants will be randomly allocated to one of two groups. One of the groups will follow an exercise program. The other group (the control group) will be asked not to change their daily lifestyle. After six months, the control group will have the opportunity to enjoy the exercise program.

What to expect: The exercise program consists of two to three hours of exercise per week, at home or in a local fitness facility. The study involves three visits to the testing site as well as questionnaires that will be filled out online or over the phone. During each visit, participants will be asked to complete fitness tests, participate in a brief test to see how the body responds to pressure and cold stimuli applied to the arm, and provide blood samples.

Who can participate: You may be eligible to participate in this study if you are 18 or older, have been fully vaccinated against COVID-19, have been diagnosed with an 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 contra-indications.

Why participate: Through participation in the study you will learn about your peak oxygen uptake and current levels of muscular strength. You may get fitness and cardiometabolic health improvements associated with exercise. You will be compensated a flat rate for travel to the testing site.

Location: The study will take place in the Okanagan and Vancouver, but is currently recruiting at the Blusson Spinal Cord Centre site in Vancouver only.

For more information or to sign up: contact Bobo Tong at bobo.tong@ubc.ca or 778.581.6487, or visit icord.org/studies/2021/11/epic-sci.

Heart Rate Variability and Anxiety During Urinary Bladder Catheterization

Overview: Intermittent catheterization following SCI is the preferred method for emptying the bladder. However, the experience of intermittent catheterization can be a challenging one—for instance, it can give rise to autonomic dysreflexia or feelings of anxiety and stress. Physiatrist and ICORD researcher Dr. Andrei Krassioukov and his team are interested in understanding the physical and psychological response to intermittent catheterization in this study.

What to expect: Eligible participants enrolled in the study will be asked to attend two visits at ICORD for a total of 2.5 hours. These visits will include three catheterization procedures, heart and blood vessel monitoring, and questionnaires to assess changes in anxiety.

Who can participate: You may be eligible to participate in this study if you are: a BC resident with active Medical Services Plan; 18-60 years old; more than one-year traumatic spinal cord injury at or above T6; motor-complete (AIS A or B) or motor-incomplete (AIS C or D) injury; and able to self-perform intermittent catheterization at home. You may be ineligible to participate in this study if you have a current urinary tract infection, or other inflammatory conditions of bladder/urethra; have a history of ureteral injury, or any urinary diversion procedures; or are currently taking beta blockers or other medications that may affect heart rate.

Why participate: The hope is that the information learned from this study can be used in the future to better understand and improve the experience of intermittent catheterization.

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

For more information or to sign up: Contact the study coordinator, Jennifer Phan, by email at anhduong.phan@ubc.ca or 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

Do You Share?

A new survey sheds some light on how people with SCI feel about sharing their data with researchers.

Research isn't just about making breakthrough discoveries. In many cases, it's increasingly about painstakingly confirming findings across large populations and viewing trends via open data sharing.

An open data sharing example specific to SCI is the Rick Hansen SCI Registry, or RHSCIR, which collects data from 30 hospitals across Canada. More than 8,000 participants with SCI have agreed to share their data with RHSCIR. Researchers can then apply to RHSCIR for permission to analyze data for their specific projects. If they're granted permission, the data is provided to them in an anonymized fashion—that is, there are no names or personal details attached to any of the data, which is often very sensitive and intimate in nature: for example, dealing with bowel, bladder, sexual, and mental health.

ICORD principal investigator Dr. John Kramer is a big believer in open data sharing. As an SCI pain researcher, being able to analyze the data from large numbers of research participants can be an effective way of determining, for example, which factors contribute to pain, or what treatments show the best promise for alleviating it.

"I became interested in open data after I worked with data from an old clinical trial, which is an incredible resource despite being 20 years old," says Kramer. "Typically, once a trial ends, the normal process is that data gets stacked up and disappears—and I thought this was an incredible waste of time, effort and money. To honour the legacy of research participants, I wanted to continue to use the data and ask new scientific questions—if, of course, they were

Survey Highlights

- Nearly 80 percent of participants said they generally support data sharing, and that answering scientific questions faster and helping other people with SCI were the top benefits of sharing data.
- Poor-quality science, stolen information, and for-profit corporations co-opting information for marketing purposes were ranked as top concerns.
- Sensitive topics were associated with the highest levels of discomfort about data sharing.
- Many participants said they would prefer that researchers request permission to share data; however, the majority were supportive of anonymous data sharing when permission could not be obtained.
- Perspectives on data sharing were influenced by participants' level of education and past participation in research, as well as concerns for misappropriation.

amendable to doing so. More generally, there is an ongoing discussion in the science world about open data, and much of this is being discussed by academics without input from participants—so I felt there was an opportunity to engage directly with people with SCI on a topic that I thought was important."

In the early days of COVID-19, Kramer and some ICORD colleagues set up a study to ask a reasonably large number of people with SCI about their overall thoughts on data sharing, including its risks and benefits. They also wanted to know the types of data that people were most willing to share, and what factors made them willing to share their data.

To develop the survey tool, the team relied on their own expertise, and also

consulted with other experts in the field, individuals with SCI, and organizations that work on their behalf. Both SCI BC and SCI BC peers played a role in the survey development.

Once the survey tool was finalized, recruitment began. In the end, 232 valid participants completed the survey. Of these, 52 percent were living in Canada and 42 percent were in the United States. More than 68 percent had been injured for five or more years, and almost 62 percent indicated that they had previously participated in research. Their responses were collected from July 2020 to August 2021. "I think the most important finding of the study is that research participants with SCI are, on a whole, supportive of sharing their data," says Kramer. "This wasn't entirely surprising—after all, most people participate in research for altruistic purposes rather than personal gain, and it is not a stretch to see the value in using data a second, third, fourth, or fifth time to ask new scientific questions. What was perhaps more interesting is the types of concerns voiced by individuals with SCI about sharing their data. These, I think due to the nature of SCI, were greater than what we originally guessed and points to the need to take extra care of data when it is shared for secondary purposes—for example, avoiding identification."

The results have been summarized in a paper titled *Perspectives on data sharing in individuals with spinal cord injury*, which is due to be published in the next few months. ■



Dr. John Kramer



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