

the spin

SPINAL CORD INJURY BC

SUMMER 2024

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Spinal Cord Injury BC

Unfriendly Skies

Recently, several horror stories about accessible transportation have made news headlines. From human rights complaints and class action lawsuits against Uber and Lyft for not providing accessible ride hailing options to horrific incidents experienced by air travelers with disabilities, the inequities of our transportation systems are being brought to light.

None of this, of course, is new to you. Challenges, barriers, and complaints about accessible transportation have always been near the top of the list of reasons people contact our InfoLine. Right from the early days of SCI BC's existence, accessible transportation has been a hot topic.

In 1968, we hosted safe driving "roadeo" and car rally events to demonstrate that people using hand controls were safe drivers, key events for advocacy that led to the removal of speed restrictions for drivers with disabilities. In the late 1970s, we ran an accessible van loan program to help people with SCI with their transportation needs. In the early 1990s, we worked with BC Transit to establish an accessible bus program in the Lower Mainland. In doing so Metro Vancouver became the first region in Canada to adopt a policy offering a fully accessible transit service.

It's ridiculous that several decades later, there are still so many barriers to accessible transportation. This is especially so for the air travel industry. The spate of inhumane incidents faced by wheelchair using travelers last fall and winter (and, frankly, for so long before this), including high profile members of our community, AccessNow's Maayan Ziv, and Canada's Chief Accessibility Officer, Stephanie Cadieux, prompted the federal government to convene the first-ever National Air Accessibility Summit. The Summit was held on May 9 in Ottawa. We were represented by SCI Canada's Joanne Smith, who shared her own long list of nightmare experiences with air travel and recommendations on how the air travel sector needs to improve.

Smith's recommendations included working together to enhance accessibility through education, training, and action; ensuring consistency in processes and service; and shifting corporate culture towards access and inclusion. These recommendations are echoed in Cadieux's clear and strongly worded post-Summit statement, which went further into a series of recommended actions.

As Cadieux powerfully states in her statement on the National Air Accessibility Summit, "In recent months, other incidents have occurred that fix a bright spotlight on how much this sector needs to change—and now. Mobility aids are extensions of the human body and need to be treated as such. Full stop. People with disabilities are passengers. Period."

We live in a world of rapid technological innovation and change. We are capable of creating equity when it comes to accessible transportation. Unfortunately, it's people and culture (corporate, societal, and political) that are too often barriers to timely change. In other words, if change is going to happen, we need to address more than just transportation infrastructure.



—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 Selilwiltuh (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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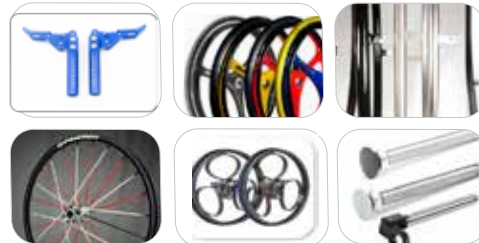
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Innovations

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

LAPSTACKER FLEX

You might be familiar with the Lapstacker from New Zealand's adaptdefy Limited as we mentioned this gadget in the Spring 2019 issue. This time we're introducing the new and improved version: LapStacker Flex. The newest product takes in customer feedback and is now easier to buy with world-wide shipping. The enhanced design includes a lighter strap material, finger loops for people with limited hand function, and a magnetic buckle system to safely secure items on your lap. Not only is it highly functional, the LapStacker Flex is stylish and will go with any wheelchair design. This easy-to-use product takes under five minutes to set up. Order the LapStacker Flex at adaptdefy.com.

NAIL CLIP HOLDER

Makers Making Change's Assistive Device Library contains over 200 open source plans for devices to help you with your daily life, including the Nail Clip Holder. Its featured design of anti-skid pads and contoured wrist lever can give you the grip you need to trim your nails and is perfect for someone with limited finger dexterity. Insert a nail clipper into the holding slot, put the Nail Clip Holder on a flat surface, and press down on the lever area to begin cutting your nails. The plans for this easy-rated 3-D printing build can be downloaded for free at makersmakingchange.com/assistive-devices. Contact SCI BC's InfoLine at info@sci-bc.ca and we can help you find access to a 3-D printer.



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Join SCI BC and our partners at BC Wheelchair Sports Association and Northern Adapted Sports Association for Wheelchair Tennis Have-A-Go Day in Northern BC! Try out the sport yourself in Terrace (July 21), Fort St. John (July 28), Prince George (August 11), and Quesnel (August 17). All ages and abilities are welcome with no experience necessary. Equipment will be provided. Connect with programs@northernadaptedsports.ca for more information.



BBQs & picnics all summer long.

What's a better way to take advantage of the sunny weather than a picnic or BBQ? You're invited to SCI BC's summer picnics and BBQs happening all across the province! Grab something hot off the grill or catch some rays under the sun and enjoy a meal on us. Reconnect with your local peers or meet new friends this summer. Join us in Quesnel, Prince George, Terrace, Metro Vancouver, and many more locations to come. Find your nearest picnic or BBQ at sci-bc.ca/events.



Get outdoors on the water!

Paddle away and soak in the amazing view at SCI BC's Paddling and Recreation Expo in Kelowna! Meet us at Pandosy Waterfront Park on July 17 at 10 AM and CRIS Adaptive will help you get started with your paddling experience, no matter your ability. Afterwards, grab your free lunch and meet our various partner organizations to learn more about how you can participate in adaptive activities. Let Scotty know you're coming by emailing him at sjames@sci-bc.ca.

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FIRST INTERNATIONAL TETRASKI CHAMPIONSHIP

Powdery props to SCI BC staff member Marta Pawlik for her peak performance in the world's first international independent mouth-controlled sit-ski race! The TetraSki, designed at the University of Utah and built by Tetradapt, is the world's only independent alpine ski for athletes with high level SCI and other complex physical injuries or illnesses. Athletes, including those who require mechanical ventilation, control the TetraSki using a joystick or sip and puff breath control that sends signals to powerful electric actuators. According to their website, "The TetraSki does not operate like a motor to push the ski forward or increase speed. The skier's skills and choices alone determine how fast the ski goes." Tanja Kari, TRAILS Program Director explains, "[This] is the change in adaptive ski culture we have to see." Pawlik was one of 32 athletes who competed in the International Championship in Tetra Ski at the 2024 Brian McKenna TetraSki Express in March. When Pawlik isn't shredding the slopes, you may find her at GF Strong connecting with newly injured peers in her role as an SCI BC Peer Program Coordinator. Plans are underway for another International Championship at Powder Mountain, Utah in 2025 and we hope to see Pawlik there again to represent Canada!



ACCESSIBLE TOURISM CHAMPION

A scenic shoutout to Kathleen Harvey for her continued leadership in accessible tourism. With nearly 40 years of experience in tourism, Harvey was recognized by TravelAbility as one of the 24 "Accessibility Champions to watch in 2024"! In her role as Destination BC's Manager of Visitor Services, Harvey led the development of

Destination BC's first Accessibility and Inclusion Advisory Committee and the implementation of Destination BC's three-year strategic framework and action plan focused on building a more accessible tourism industry in BC. She explains, "Our goal is to help ensure every person can participate in BC's transformative experiences." We are grateful to have passionate accessibility champions like Harvey who are helping make BC the best place for people with disabilities to live, work, and visit.

Community Highlights



Photo credit: Martin Dee/UBC

THE NEXT GENERATION OF INDIGENOUS SCIENTISTS

Kudos to our research centre partners at ICORD, the world-leading SCI research centre within UBC and the Vancouver Coastal Health Research Institute, who are once again planting seeds of innovation and inclusion. The seed2STEM program, in its sixth year running, is a summer research program for Indigenous youth. Dr. Coree Laule, seed2STEM co-founder and associate director of education for ICORD, explains, "Our primary goal is to create a bridge to STEM and help dismantle barriers to post-secondary education for Indigenous youth in BC." Cheryl Niamath, seed2STEM co-founder and ICORD communications and administrative manager, adds, "It's important for the students' colleagues to understand some of the reasons why Indigenous people are underrepresented in STEM. We want to make sure that happens before students arrive, so they feel welcomed and supported." With the program cultivating the next generation of Indigenous scientists, we can't wait to see how seed2STEM participants and alumni influence and impact the world! Learn more at icord.org/issp.

A button-weight congratulations to **SONJA GAUDET** for her induction into the World Curling Hall of Fame! Gaudet is Canada's first wheelchair curler inducted into the World Curling Hall of Fame and is one of the world's most decorated curlers. Her rock-solid determination led her to be a three-time Paralympic champion and world champion in 2009, 2011, and 2013. We are grateful to have worked with Gaudet for over a decade. In her roles as SCI BC's Regional Universal Access Tourism Specialist and Peer Program Coordinator, Gaudet makes her community a supportive, accessible, and welcoming place for all.



Peer Shoutouts



Cheers to **LEO SAMMARELLI** who is on a roll with well-earned racing successes and recognition. At the BMO Vancouver Marathon, Sammarelli was the only participant racing by wheelchair and finished 6th amongst all racers, with an incredible time of 2 hours, 29 minutes, and 38 seconds! Weeks prior, Sammar-

elli came first in the 10 km Wheelchair division of the Vancouver Sun Run, finishing in just over 31 minutes. In addition to his athletic accomplishments, Sammarelli was awarded the Courage to Come Back Award in the Physical Rehabilitation category by Coast Mental Health (a quick shoutout to SCI BC peer Monica Gartner who also received this award). The award recognizes people who have overcome illness or adversity and who have 'come back' and 'give back' to their communities. Sammarelli says, "It's so important to give back to the community because, just knowing where I came from and how it all started and feeling that alone... My way of thinking shifted: my disability no longer defined who I was and what I could do. I became in charge of my own destiny." And he certainly embodies that as a mentor, athlete, coach, Director of BC Boxing, and founder of West Coast Wheelchair Adaptive Boxing.



Brooke Perepeluk

RYAN SCHWEIZER and **BROOKE PEREPELUK** are rocking the wheelchair rugby world! In March, Schweizer received the 2024 Sport BC President's Award in recognition of his many years of volunteerism and dedication to BC Wheelchair Sports. According to BC Wheelchair Sports, "Ryan is a positive role model who encourages individuals to get involved in sport, and face challenges head-on.

His easygoing and welcoming nature has helped countless people find community and transition to a new way of life." Schweizer has contributed to the wheelchair rugby community for over two decades as a coach, community mentor, board member, and volunteer. Perepeluk, a Prince George local, received the Judith Zelman Rookie of the Year award at the 2024 Canadian National Wheelchair Rugby Championships in Calgary. Perepeluk worked as a summer student in SCI BC's Prince George office, bringing her athletic determination, lived experience with cerebral palsy, and caring spirit to her work. We hope Schweizer and Perepeluk have a ball celebrating their success!



Ryan Schweizer



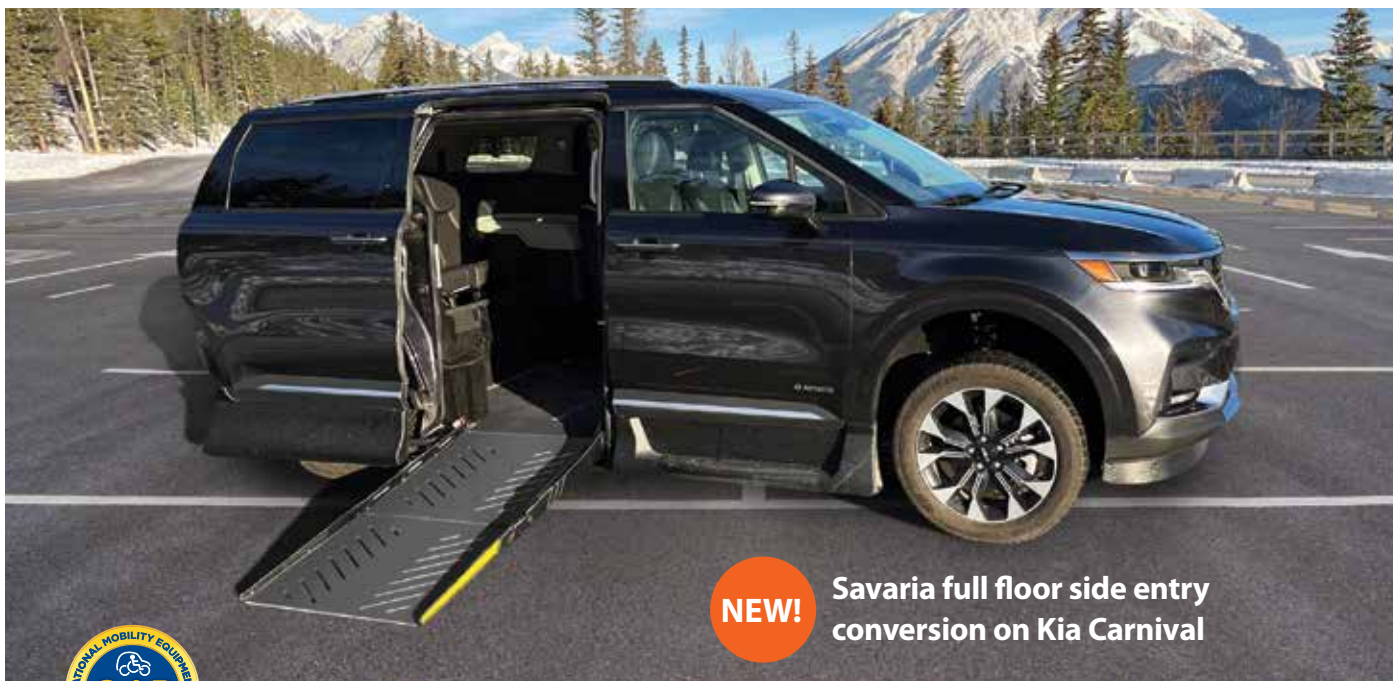
Colton Carrita



Joel Ewert

Neither an apple a day nor a disability is keeping these future doctors away! SCI peer **JOEL EWERT**, who some may know from his impressive involvement in wheelchair basketball and wheelchair rugby, was recently accepted into the Northern Medical Program at the University of Northern British Columbia (UNBC) in Prince George. In addition, **COLTON CARRITA**, who recently completed his first year of the same program, is committed to spreading education and awareness about living with a disability. For the Red Shirt Day of Action for Accessibility and Inclusion on May 29, Carrita spoke at UNBC and was interviewed by CBC Listen Daybreak North with Carolina de Ryk. He says, "Really the whole reason that I thought medicine would be a good fit for me is I've had experiences in the medical system ever since I can remember...

[I want patients to] have an understanding that I'm able to be empathetic and understand their situation to some degree that maybe another physician can't and I can give them the best care." We wish the best of luck to Ewert and Carrita in medical school and are excited for a future where more people with disabilities have the opportunity to see a doctor with a disability.



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It's not every day that you look up and see a wheelchair in the sky. But with modern technology, a supportive community, and one man's bucket list, adaptive paragliding may soon be coming to the sky near you.



It's a bird! It's a plane! It's a wheelchair in the sky!? Adaptive paragliding is gaining traction right here in British Columbia and we're excited to tell you all about it.

With humble beginnings in military parachuting, paragliding is a relatively new sport. In World War I, soldiers practiced landings by holding a tow rope while a truck accelerated until they floated. With practice, some soldiers

found they enjoyed floating along air currents more than landing.

Canadian Domina Jalbert patented the first gliding parachute in 1965. He refined his design in subsequent years, creating the ram-air parachute or parafoil, an aerodynamic parachute broken up into cells. Air "rammed" into the cells, inflating the parachute. In the decade following, French engineer Pierre Lemongine and NASA

scientist David Barish advanced the technology. In June 1978, Jean-Claude Bétemps, André Bohn, and Gérard Bosson determined that a ram-air parachute or “wing” could be inflated by running down a hill. They successfully launched from a 1000-metre elevation in Mieussy, France.

Since those early days of invention and exploration, paragliding has come a long way. Not to be confused with sky-diving, paragliding involves launching from a high elevation, typically a mountain. A pilot uses wind currents and air thermals (columns of rising warm air) to gain altitude and stay in the air for long periods of time. The length of the flight varies depending on the pilot’s skill and weather conditions. At the competitive level, pilots can remain in the air for as long as eight hours! Paragliding can be done solo or in tandem, allowing the novice passenger to enjoy the ride while the trained pilot controls the wing.

Adaptive paragliding uses a specialized chair (sometimes called a trike or rig) with an integrated harness to safely fly passengers with mobility challenges that prevent them from flying using the traditional foot-launched method. The Handivol flight chair is currently the only available flying chair designed and certified specifically for use in adaptive paragliding. Manufactured exclusively by French company Back Bone Paramotors, the chair costs approximately \$6,700 Canadian dollars. The wing itself is the same used by able-bodied foot-launching pilots. With the Handivol flight chair weighing about 45 pounds, adaptive paragliders typically need to opt for a medium-sized wing.

Taking Flight

Intrigued? Well, now you have the chance to try adaptive paragliding close to home, thanks to one man’s bucket list.

David Stanek came across paragliding during unusual life circumstances. Seeking safety in Austria, Stanek, his wife, and 2-year-old son fled from war-

torn Yugoslavia. A group of paragliders in the mountains directed them to train tunnels that crossed the border for their escape. The idea of paragliding lingered in Stanek’s mind. In 1992, he finally had his chance to try paragliding. Thousands of flights later, he hasn’t looked back.

“When you take off and you fly, everything goes away,” explains Stanek, who now lives in Chilliwack. Paragliding was his escape from the stress of running his own construction business. “[Paragliding] is not really physically demanding. It is more of a mental game. You have to pay attention, but yet you can be relaxed. Two hours later you land, and you think ‘Wow, I thought about nothing else but flying for those couple hours.’”

With his company now in the hands of his oldest son, Stanek is pursuing a long-time ‘bucket list’ goal of his. In May 2024, Stanek and his team launched Adaptive Airtime Paragliding, a BC-based non-profit organization dedicated to breaking down barriers and making the experience of free flight accessible to everyone. Whether you have an SCI, brain injury, mobility limitations, or any other kind of limitation, Adaptive Airtime wants to help you soar! Although able-bodied himself, Stanek says, “I came from a place where freedom was priceless. Flying is freedom. I think it’s important these days to give back a little bit. Everyone talks about diversity and inclusiveness. When push comes to shove, some people just don’t want to be bothered. I’m really on the receiving end because I meet amazing people.”

Stanek’s decades of flying, piloting, and teaching experience have introduced him to some incredible people, including American Chris Santacrocce. An SCI halted Santacrocce’s career as a full-time paragliding professional and Red Bull athlete. Santacrocce’s experience inspired him to start Project Airtime (projectairtime.org), a Utah-based non-profit organization providing free paragliding for people of all abilities for over ten years. “I was watching

Project Airtime for years and how they built it up,” explains Stanek, “They are just amazing and support me a lot as well.” In fact, the team came out to Mount Woodside in Agassiz, BC at the beginning of May for Adaptive Airtime’s launch event, ‘Wheels Up’ Flying Weekend. Now that’s what we call teamwork!

So, what is adaptive paragliding like? We chatted with a few peers about their experience taking to the skies.

Rob Gosse



When Rob Gosse discovered the opportunity to paraglide was right in his backyard, he knew he had to try it. The Langley man is a self-described “adventure seeker”, having competed at the international level in adaptive alpine skiing and adaptive waterskiing. In May 2024, he signed up for Adaptive Airtime’s launch event.

“First of all, we arrived at the parking lot and got a rundown of what’s going to happen. We loaded up, went to the launch site, and chilled out. We watched some people take off to see the basics of how it’s done. They explained the equipment and how it all works as they’re taking off. It was a long process to get loaded in and hooked up, just making sure all the safety checks were done and everything was right. We waited a few cycles before the proper wind came up. There were two guys launching the

two of us [Gosse and the tandem pilot]. Once we got airborne, it was such a cool feeling, feeling the lift, feeling the flight, and soaring with the eagles.”

“Working in Chilliwack, I recognized some of the sites. It looks so tiny up there and the cars looked like ants on the freeway down below,” Gosse explains. Overall, the tandem flights last around twenty to thirty minutes. If you’re hesitant, Gosse recommends that you, “Talk to David [Stanek] and watch some of the launches. We use this process when I coach water skiing. Just being able to see what happens takes the unknown out of it.”

Gosse has tried his fair share of adaptive sports and adaptive paragliding earns his stamp of approval. “Aside from the launch and the cleanup at the bottom, you could really be independent with it from right in the air and flying around,” he says. And Gosse is glad he’s found another activity he can do with his family. “I took my family, and we spent the day up there. It was a cool experience because they were able to fly as well. I was landing, my girlfriend was launching, and her son went before us, so we cycled through.”

Caleb And Andrea Brousseau



Caleb Brousseau brings a unique perspective to adaptive paragliding. After his L1/T12 incomplete SCI in 2007,

Caleb enjoyed activities like whitewater kayaking and ski-racing, even competing on the Canadian Para-Alpine Ski Team. While mountain biking in 2020, Caleb sustained a C5 compression at the cervical level. Transitioning from paraplegic to quadriplegic with his second injury, Caleb began to wonder which sports he would enjoy. “For someone like me that’s a C5 level, there’s not a lot of sports left that have that full range or full ability left in it. Going mountain biking again, it doesn’t feel the same as mountain biking before.”

Then came paragliding. “Paragliding is something I’ve always thought about doing and never really had the opportunity to do it,” he says. When the opportunity to participate in adaptive paragliding in Colombia arose, Caleb hopped on a plane.

So, how did Caleb find adaptive paragliding as a quadriplegic? “With paragliding, so far, it still feels like I was a low-level para or an able-bodied person out there flying. It’s cliché to say, but I definitely didn’t think after the second accident that I’d find another sport that would have that ability in it. As a para athlete before, I thought I knew most of the sports that would have that feeling in it. And paragliding is one that does.”

Caleb enjoyed his first taste of paragliding so much that he convinced his wife, Andrea Brousseau to travel from Terrace to Agassiz for Adaptive Airtime’s launch event. Andrea says, “Honestly, Caleb was the one who was super excited about it. It’s something that I’ve seen around, but I never felt a deep desire to try it out. I already had the sports that I felt settled in and I wasn’t really sure how that sport would be adapted.”

Andrea, an above-the-knee amputee, is an impressive athlete herself. Competing in alpine skiing since she was a kid, Andrea represented Canada at the 2010 Paralympic games. She also enjoys ocean and river kayaking, cycling, spin biking, yoga, and, more recently, mountain biking.



When Andrea arrived at Mount Woodside, she had a lot of questions. “How does this work? How hard is the landing? Should I do this outside of the adaptive rig or just with the prosthetic? David [Stanek] and I talked it over. With the limitations of the prosthetic in terms of shock absorption, we decided I should go in the actual adaptive rig. He was really open. At no point did I feel pressured or worried.”

With their background in outdoor sports, both Brousseaus know the importance of safety and risk management. Andrea explains, “We talked through what makes it a good or bad flying day. It’s important to not push boundaries around that and to respect the conditions around you, your ability, and your pilot’s ability. It was nice to see the levelheaded planning behind it.” Caleb points out, “There’s a nerdy side that I really enjoy. It’s very similar to skiing and nerding out over snow and different things for avalanche awareness.”

Caleb was pleasantly surprised to discover how learning created a sense of community. “Being brand new [to paragliding], I’m talking to everyone around me. They’re usually more than happy to talk about all the different things and what each cloud feature means and like what to look for in the sky. We’re constantly bouncing that knowledge around. The community that’s created around it is really cool.”

“I thought [launching] would be startling like a bungee jump, but really it was this gentle, cruising, floaty feeling where you’re supported and



then all of a sudden, you're lifted off the ground," recalls Andrea. Both enthusiasts agree that paragliding feels similar to powder skiing. Caleb says, "It has that very Zen and slow feeling, which is really cool... We did fun little air acrobatic stuff where you do very light spirals and turns back and forth, which have a bit of G-force in them."

Andrea explains that paragliding is, "one of the few sports that I think would give you exposure to that level of freedom and movement and flow that seems to come from sports that maybe aren't quite as accessible once you have a physical disability. Give it a try because it is surprisingly liberating. It is absolutely a once-in-a-lifetime experience."

Any worries the pair had about landing were quickly eased. "It's kind of like landing on a pillow," laughs Caleb, "Landing with the trike is less rough than using a power chair on your normal sidewalk." Andrea adds, "It was a surprisingly soft and gentle landing compared to the many times that I've hit the ground in other sports. The seating itself seems to be made to absorb shock."

Brenden Doyle

Flying comes naturally for Brenden Doyle. Born and raised in California, Doyle joined the US military straight out of high school and served for nearly nine years. A skydiving accident caused a T11 complete SCI, but Doyle

was determined to get back in the sky. "I contacted Project Airtime and got involved with Chris Santacroce and learned to fly with them. And I've been flying ever since."

In January 2024, Austrian-based non-profit organization, Wheels4Flying organized the first international paragliding meeting and World Cup competition for paragliding pilots with reduced mobility. Doyle joined eighteen pilots in Piedechinche, Colombia for the event (in fact, this is where he met Caleb!) He hopes to return to Colombia in the future for the next event.

According to Doyle, paragliding is, "all dependent on where you want to take it." As, "an avid skydiver with hundreds of jumps," Doyle says, "I was flying solo within the first few days of training. I've come from that background, so I picked it up fairly quickly."

Although most people won't have Doyle's background in air sports, Adaptive Airtime's Stanek stresses that, "if someone has the proper mindset and

determination, they can absolutely fly solo." The first step in learning to fly solo is ground school. You'll start in a field and practice launching, staying afloat, and landing and work your way up to small hills. Stanek estimates ground school will take a week for most people, followed by a couple months of flight practice under the supervision of a trained pilot. Unsurprisingly, all the peers we chatted with are excited to learn to fly solo.

On The Horizon

So, what's next for Adaptive Airtime? Stanek and his small but mighty team are gearing up for more events, fundraising, training, and community-building. "We are raising money, so we don't have to charge anyone anything. We provide all the tandem flights and ground school for free. When we fly companion people, like family members, we ask for donations to support the cause. All the proceeds go to equipment and instructors so we can keep doing this."

Adaptive Airtime has big plans for adaptive paragliding in BC. "My goal is to create a network of schools and outlets for adaptive paragliding, so people don't have to travel that far for tandem and make it accessible for athletes who want to learn to fly solo," shares Stanek. And, so far, the response from the paragliding community has been





incredible. The Adaptive Airtime team is actively working to build connections with every paragliding school in BC and to train their pilots to fly tandem with the trike. Experienced foot launch tandem pilots can complete training in as short as one weekend.

In June 2024, Adaptive Airtime joined forces with the West Coast Soaring Club to create what Stanek describes as a, “world class take off area which is much safer for adaptive tandems and solo flying.” Nearly 6,000 square feet of artificial grass was installed to create a smoother and larger launch area at Mount Woodside in Agassiz.

For peers who want to learn to fly solo, Stanek hopes Adaptive Airtime can be the stepping stone. “We will do the hard part, one-on-one ground school and first flight. And then we will send pilots to their area to local paragliding schools to teach them the progression to next level.” They also plan to fundraise for flight chairs for aspiring solo pilots. Stanek says, “The chair is the limitation. And I want to eliminate that limitation, because [able-bodied] solo pilots don’t have to buy chairs.”

Springtime marks the start of the flying season, so you can expect more events and opportunities from Adaptive Airtime in the coming months. To stay in the loop, you can check out Adaptive Airtime’s website (adaptiveairtime.com) or follow them on Facebook (@Adaptive Airtime) and Instagram (@adaptiveairtime). And if you’re interested in booking a flight or have questions, simply fill out the contact form on their website and Stanek himself will get back to you.

Stanek has one final piece of advice. “I love flying tandem because no one is ever disappointed. Just sit, take selfies, and smile.” ■



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Artificial Intelligence

as Assistive Technology

How can people with disabilities use AI to help solve everyday problems? The Neil Squire Society shares the latest in technology and trends.

“I think AI is a really big opportunity for the world of disabilities,” says Seaver Stafford. Stafford, an Assistive Technology Technician for the Neil Squire Society, manages the AT Help Desk website and connects people with disabilities with assistive technology information. The AT website is part of the AT Help Desk program that launched in 2013.

It aims to provide the most up-to-date assistive technology (AT) tools to reduce the employment gap for persons with disabilities and increase access to education. “Sometimes we’re trying to fix multiple issues and having the resources to make that happen isn’t always easy to do,” Stafford says. “I think that our knowledge of AI to provide unique solutions to people that have unique disabilities is a way that we can work around limited resources and still help.”

AI, or artificial intelligence, is the ability of a machine to perform tasks that are commonly associated with human intellectual processes. Although AI has been making headlines recently for its potentially problematic application in industries ranging from Hollywood to human resources, the technology is not new. “A vast number of applications are already using AI to do a lot of stuff. It’s working in the background or is passively functioning in pretty much every piece of assistive technology software that’s out there. Things like grammar checkers or Siri or customer service chatbots,” Stafford explains. Have you ever played a game of chess on a computer? That’s AI. Used online banking? That’s AI. Purchased something online? Browsed streaming service suggestions? These are all examples of technology powered by or informed by AI.

“When it comes to being in the foreground, I think people are just starting to discover what they can do with [AI],” Stafford says. “I think one of the best things that it can do is become a way of searching for information and delivering information to you in an accessible way.” This functionality is best encapsulated by AI chatbots like OpenAI’s ChatGPT, Google’s Gemini, and Microsoft’s CoPilot.

The functionality of all of these tools is similar. Users ask a question, and the platform responds with an answer based off information pulled from multiple sources including an internal knowledge base, the internet, generative AI based on previous user answers, and testing carried out by the chatbot while in development. “Gemini, which is owned by Google, has a lot of utility for code writing and it also has a cool feature where you can upload an image and ask it questions about the image. CoPilot and ChatGPT can also do that too,” Stafford says. “Once you start looking into AI like this you’ll notice there’s a lot of similarities between them.”

From an accessibility standpoint, Gemini and CoPilot both offer built-in speech-to-text. Stafford recently learned of another AI chatbot alternative called Perplexity through a user’s comment on AT Help Desk website. Unlike the others, Perplexity shows users a list of related threads to

their query and provides an in-depth list of sources for the generated answer. "That's something these chatbots do well, is synthesize information clearly. Which is great for people who might not process things in the same way as everyone else or need a little bit more help," Stafford says. "At Neil Squire we want people to focus on the solution and on the task, rather than what you can't do. AI allows you to have really task oriented queries that are so specific." For example, you could ask, 'I'm a person with one arm and a T3 injury level, what are some ways I could drive a car?' and it will give you an answer without you having to go to multiple sources and dig for information.

Nakia Singh has been using AI to help him navigate everyday situations with a visual impairment for almost a decade. He shares his extensive knowledge with others as an AT Researcher with Neil Squire. "I am mostly blind. I use AI extensively to gather information, see things I can't, summarize massive documents to prevent eye strain, or handle my lights at certain times of day... If it exists then I should be able to interact with it with my voice, without ever having to touch it. That's my motto," Singh says. "I take things that aren't designed to do a particular task [and develop them] to do things that will help the disabled

community to avoid the ungodly prices of devices designed to help us, but financially out of reach."

Some of Singh's favourite AI tools include Envision AI, Live Transcribe, and Transit. Envision AI is a free visual assistance app that uses AI and machine learning to recognize visual information like text, colours, people, and more. Live Transcribe is an Android smartphone app that converts speech to text and produces live captions for the user. Transit is a real-time transportation app that gives users accurate arrival and departure times, service disruption alerts, and updated transit schedules based on live data from fellow travellers.

Stafford and Singh recently connected to discuss AI technology and trends on the AT Help Desk podcast, "We Have Solutions!". One of the most exciting tools they explored was the Insta 360 Link, an AI-powered motion tracking webcam. This tiny camera is under 5 cm tall and only 11 cm wide and connects to any computer to track your motion in real-time. The image it captures can be shared in 4K resolution on applications such as Teams, Zoom, YouTube, Facebook Live, and more. The camera can also be paired with gestures so you can control its zoom, rotation, and advanced features from anywhere it can see you. For example, if you are having a bad pain day and don't

feel like getting out of bed to take an online meeting or video call your friend, the Insta 360 Link can pick up your motions from bed and connect you instantly. For individuals with mobility challenges, this could be a game changer.

Of course, with any new technology comes new challenges. Stafford recognizes that some people may be intimidated by AI or uncomfortable with how it works. "I'd like to encourage people not to be afraid of AI. To know what its limitations are and to think of it as another tool in the tool belt," he says. "The cat's out of the bag already when it comes to AI and it's going to ramp up. A lot of it is open-source technology and when things are open source, the sky is the limit... I'm just hoping we can yield the knowledge that we have about AI and steer people in a direction where they can make some improvements in their lives without having to spend as much money or put as much effort into research. I'd be very happy if we played a role in that future."

If you want to learn more about AI or assistive technology you can email info@neilsquire.ca or visit the AT Help Desk website at athelpdesk.org. For further information, be sure to check out the AT Help Desk podcast "We Have Solutions!" available for listening on Spotify, Apple Podcasts, or wherever you listen. ■



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Ask InfoLine: Answering Your SCI FAQs

My 15 year old nephew recently broke his neck, and since rehab he is spending his time isolated and withdrawn at home. How can I help him and his family to adjust to their new life? —Morgan, Chilliwack, BC



Heather Lamb, MSW, RSW, is SCI BC's InfoLine Service Lead. InfoLine provides information and support by phone or email on any topic relating to living with physical disabilities in BC.

The adjustment period after SCI is challenging for people of any age,

but being a teenager can make the process more complicated. It's wonderful that you're asking how to support your nephew and recognizing that an injury affects the whole family. InfoLine is a great place to start.

In addition to the physical changes he has experienced, he is likely feeling isolated from his able-bodied peers. He might also be dealing with new barriers that make daily life harder, not to mention the activities that used to keep him busy and connected like recreation, hobbies, or school.

There is no single way to go through the adjustment phase or timeline on when he'll feel himself again. Everyone takes their own time and path. That said, here's what we've learned on the InfoLine and from our province-wide SCI peer network:

Make sure he's included: Help him and his family to adjust by ensuring that he is included in family events. This might mean adding a ramp to your home so he can visit or choose places for family events that are accessible. Recognize that he may not feel up to participating in every activity, but leave it open for him to join in if he changes his mind. Try not to single him or his needs out when making plans. Simply ensure that his needs are considered during the planning process.

Help him reconnect with activities and friends: What did he enjoy doing before his injury? Many activities are still possible with the right support and equipment. For example, if he enjoyed sports, share information for local adapted sports options and accessible gyms. Check out videos of adapted sports online together and encourage him to participate if there are opportunities within reach. Smaller communities will have fewer options, but InfoLine can give you the options in your area or major centres he visits.

Getting involved in sports has a number of benefits beyond physical activity. He will meet other para athletes, giving him a sense of community and connection. He will learn from their experiences and realize that he is not alone. Adapted sports are inclusive, so he can play with his able-bodied friends too.

If he enjoyed gaming pre-injury, there are adaptations that can get him back into gaming. Staying connected by technology is essential for young people and you can help him find the right

features and devices to allow him to use his phone, computer, and other technology independently.

Support his moves toward independence: Was he looking forward to getting his driver's license pre-injury? Driving is still possible for most people with SCI. Access to transportation offers a sense of independence that is an important part of growing up. Most people with SCI go through a driver training program such as the ones at the GF Strong Rehab Centre and Access Driver Rehab to learn how to drive with hand controls or other adaptations, and working toward it can feel like working toward more independence. This process can take time but you can help by sharing information and supporting his interest in it.

Talk about future career or education interests: Most people his age are thinking about what they want to do when they finish high school. Even if his injury might affect the career he was interested in, be an open minded ally and support his family in keeping these conversations going about career and education as you would have before. People with SCI can and do work in many fields and if he has an interest in a particular profession, we may be able to connect him with a peer in that field. There are several funding sources to help pay for his education and related costs of schooling if he chooses to pursue it into college or university.

Look out for his mental health: Some have more trouble than others adjusting to life after SCI. In these cases, it can be helpful to have professional counselling. This is not a sign that anything is "wrong"; it just offers some support and tools to process this major change in his life. Some people struggle to have these conversations with family or friends but can open up to a trained outsider to find healthy ways to process all of the changes that come along with an SCI. In addition to professional counseling, you can help by being a non-judgmental listener and encouraging his involvement in family events, community activities, and connections with friends.

Help him connect to peer support: Perhaps most importantly, you can point him to our Peer Program. Our staff across BC live with SCI and organize fun in-person and online events and match peers with mentors to create networks of support. Peer support can help your nephew feel less alone, see what's possible, and learn tips for managing daily SCI challenges. Check out our website: sci-bc.ca/peer-program.

InfoLine can provide location-specific information and resources for this and many other questions. **Don't hesitate to call or email us at any time. 1-800-689-2477 or info@sci-bc.ca. Check out this article on our blog for links to the resources mentioned: sci-bc.ca/youth-resources.**

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1. A Multi-Centre Clinical Investigation to Assess the Performance of GentleCath™ Glide intermittent catheters. Study U378 GentleCath™ Glide Final Report. July 2018. In vitro data on file. Convatec Inc.

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Fuel Up

Nutrition researchers and a sport dietitian weigh in on how to fuel your body for optimal health and performance.



For many of us, the Olympic and Paralympic Games are a source of entertainment, inspiration, and national pride. And with Paris 2024 set to take place this summer, the excitement is already starting to build.

While we know that some of you will be looking to punch your ticket to compete at the Paralympic Games—maybe you already have—we know that most of you, like us, will be cheering on Team Canada from the comfort of our own homes.

Whether you're an athlete or not, how you fuel your body is vital to your overall health and physical function. What you eat affects how you look and feel, supports a regular bowel program, and helps to build and maintain muscle, strengthen bones, and bolster your immune system. And because people with SCI don't burn as many calories at rest or during exercise as they would've pre-injury, attention to diet and nutrition (in combination with regular physical activity) becomes even more crucial for managing weight and promoting long-term health.

"We often focus on the role of exercise in mitigating post-injury changes seen in metabolism, but what we're seeing in the literature and in my program of research is that we're reaching a plateau with the effect of exercise alone," says Dr. Gary Farkas, a postdoctoral researcher at the University of Miami Miller School of Medicine and the Miami Project to Cure Paralysis. "There's more that we can do to

make an impact on the long-term health of individuals with SCI."

According to Farkas, who studies metabolism and appetite after SCI, the relationship between diet and SCI is an area of research that is rife with opportunities. "We know a lot about post-injury changes in metabolism, and while we have relatively good research on exercise responses and interventions, we don't really have good evidence for diet interventions," he explains.

While exercise is one tool for managing weight and optimizing health, there are many barriers to engaging in exercise. In contrast, we all need to eat—making diet and nutrition potentially high-impact targets for intervention.

Nutrition Guidance For People With SCI: What We Know (And Don't Know)

To date, research in this area is largely observational in nature and focused on nutritional deficiencies, dietary intake, and whether or not people with SCI are meeting nutrition guidelines. However, existing guidelines—including Canada's Food Guide and the Dietary Guidelines for Americans—are based on evidence from people who don't have a disability. While the general principles still apply, specific recommendations may need to be taken with a grain of salt. At this point in time, we don't have solid evidence to say what the guidelines should be for people with SCI, says Farkas.

According to Dr. Jill Parnell, a researcher at Calgary-based Mount Royal University who studies sports nutrition for para athletes, including athletes with SCI, "There are some aspects of [the guidelines] that apply fairly well [to people with SCI], like guidance for protein intake, while there's evidence to suggest that other nutrients are metabolized differently, or the amounts need to be different, or there are other considerations."

"When we make practical recommendations [for athletes with SCI], we look at a combination of research done in individuals with SCI from a clinical perspective—there's more research in certain areas related to nutrition in individuals with SCI who aren't athletes or training at a high level—and then we also pull in the nutrition information from studies in athlete populations," adds Parnell.

The limited availability of evidence to inform nutrition guidance for people (and athletes) with SCI places a premium on the knowledge of nutrition practitioners, like dietitians, with extensive experience working in the SCI community. People like Dr. Elizabeth Broad, an Accredited Practicing Dietitian specializing in Paralympic Sport who holds a PhD in sport nutrition, fall into this group.

Broad served as the Senior Sport Dietitian for the United States Olympic and Paralympic Committee for seven years and is the current Lead Sport Dietitian with the Olympic Winter Institute of Australia.

Athletes with SCI from across a range of sports, from shooting to wheelchair rugby, have been a key part of Broad's work. "I'm drawing on many years of experience and a really solid understanding of where the guidelines have come from, how they've been developed, and what's actually happening in the muscle, combined with a lot of observation of Para sport," she says.

A Balancing Act

For many people with (and without) SCI, the goal is so often tied to regular exercise and a healthy diet is weight management. As many of our readers know, weight gain is a particular concern after SCI because of its impact on overall health and independence.

More specifically, SCI leads to a loss of muscle mass and reduced physical activity levels. In turn, people with SCI tend to expend less energy, both at rest and during exercise, than they did before their injury. And if energy intake (the calories you consume) exceeds energy expenditure (the calories you burn), the result is weight gain from an increase in body fat. Weight gain not only makes transfers more challenging, but it can also increase the risk of heart attack, stroke, diabetes, and other cardiometabolic diseases.

"Calorie restriction is often needed to manage weight and prevent secondary health conditions," says Farkas. "But what I often tell people is: Don't think about it in terms of the word 'diet,' think

about it in terms of lifestyle changes and long-term maintenance."

However, in some cases, focusing too much on weight could be detrimental to health and athletic performance. According to Broad, preliminary research shows that athletes with SCI can be at risk of low energy availability. This occurs when an athlete doesn't consume enough calories to support their training and their basic biological needs. It's like your body goes into 'low energy mode'—it still functions, but not at full capacity.

"One of the challenges that I've found is fairly frequently athletes with SCI underestimate how many calories they need to do the training," says Broad. "When they get their injury, there's an emphasis on 'don't put on too much weight' because extra weight makes life harder. But as an athlete, you have to focus on fuelling your body for performance. You think, 'I have to fuel, but I can't put on weight.' And so, trying to increase someone's intake to fuel their training effectively can be challenging."

Planning For Your Nutritional Needs

Whether your goal is to lose weight, build or maintain muscle, or perform at the top of your game on the Paralympic stage, what and how much you should eat depends on a wide range of factors.

"Everyone is different and requires an individualized approach," says Farkas. "It also depends on what your goals are. Once you know your goals, we can incorporate the best evidence we have into a plan to help you achieve them."

Parnell agrees. She focuses on three key factors when offering guidance to athletes with SCI: The injury, the sport, and the environment.

"First off, you need to consider the type and level of SCI," she explains. "The next thing you need to take into consideration is the type of sport that they're doing. For example, if you're doing something like a marathon, your needs are going to be very different from someone doing a shooting event like archery. Next, you need to take the environment that you're training and



Dr. Jill Parnell

competing in into consideration. So, this upcoming Paralympics in Paris, it's probably going to be really hot. And for someone with SCI, temperature regulation is going to be a key factor."

"It's all about the context and what the individual athlete is doing. You also need to consider what their clinical needs are. So, for example, we need to make sure that we're not doing things that have major impacts on bowel," says Broad.

If you aren't sure how to get started but you'd like some help making changes to your diet, dietitians with expertise in SCI can be an excellent resource.

"The best route to go is consulting with a dietitian. They're analyzing your food records. They're taking blood. They're measuring sweat rates. They're measuring urine outputs. But realistically that's not practical for most people, right? And they just don't have access to those types of resources," says Parnell.

If you don't have access to a dietitian, Parnell suggests that you start by paying attention to what's going on with your body. "If you're gaining weight and you don't intend to, then it's an indication that, okay, some of your food choices are too energy dense and you need to adjust that accordingly," she says.

You should also pay attention to how you're feeling. "If you finish every workout feeling fatigued and you have headaches after, that's a pretty good indication that you're dehydrated after your workouts, and we need to do something to increase both your fluid and your electrolyte intake," Par-



Dr. Gary Farkas



Dr. Elizabeth Broad

nell explains. “On the other hand, if you’re having to go to the washroom at inconvenient times, which is more complicated when you live with SCI, then it’s an indication that, okay, maybe I’m not drinking either the right amount or I’m not drinking it at the right time.”

If you’re in tune with your body, these are generally good indicators of when (and what) dietary changes might be needed.

Getting Started With A Healthy, Balanced Diet

Although nutrition planning is highly individualized and we don’t have enough evidence to create SCI-specific nutrition guidelines, there are a few things that everyone can do to optimize their health.

“The one thing that everyone can focus on, regardless of impairment, is a healthy, balanced diet,” says Broad. “You need to have a range of foods in your diet. You need to make sure that you’re getting a good intake of fruits and vegetables, whole grains, dairy, and good-quality protein sources. Not too much saturated fat. All of the things that we recommend for the general population absolutely apply to any athlete, and anyone with SCI.”

Canada’s Food Guide recommends eating a variety of healthy foods each day, including plenty of fruits and vegetables, whole-grain foods, and sources of protein.

If you’re focused on managing your weight, being aware of portion size is also important. “We know from research that

when larger portions are placed in front of you, you’re more likely to eat more than when a smaller portion is placed in front of you,” says Farkas. “Regardless of what you eat, if you eat too much relative to how much energy you expend, you’ll gain weight.”

You may also want to consider the energy density of the foods you eat—in other words, the amount of energy (or calories) per gram of food. “Foods with lower energy densities and a higher water content, like fruits and vegetables, often keep you feeling full longer,” says Farkas.

The same goes for foods with a high density of vitamins and minerals. “Choosing foods that are going to give you lots of vitamins and minerals relative to the number of calories is a good principle because everyone with SCI, athlete or not, is having to try to get more out of what they’re eating with less calories just because their energy needs are lower,” explains Parnell.

The key to success when making dietary changes is to start small and build habits that set yourself up for success in the long term, say Farkas and Parnell. For example, if you’re trying to reduce the number of calories in your diet, Farkas recommends picking one item (particularly if it has low nutritional value) to give up—like that can of soda you have with lunch every day. Try to maintain that habit for a month, and then move on to a new change while still maintaining the first change.

“It’s small changes over time that will make the biggest difference,” says Farkas. But it’s important not to restrict too many calories at once. “It needs to be slow. Maybe 100-200 calories per day. Anything above that could result in a loss of muscle. There’s also a rebound effect where the body tries to get back to its original state, so small changes are needed to offset the effect and limit reduction in muscle mass,” he explains. “Small changes on a daily basis have profound effects on monthly and annual weight changes,” Farkas adds.

“Make it as easy as possible for yourself to set yourself up for success,” recommends Parnell. “Be it meal planning or, you know, ‘I’m going to do all my shopping on whatever day’ or ‘I’m going to cut every-

thing up so it’s available for the week.’ I think we all struggle because the reality is the current culture and foods available to us don’t set us up for success.”

Get Your Vitamin D, Eat Your Protein, And Stay Hydrated

Whether you live with SCI or not—and especially if you do—the research that does exist reinforces a few specific recommendations that will help your body function at its best.

Vitamin D is recommended across the board for everyone, and particularly for people with SCI. It aids with the absorption of calcium to support bone health and helps to strengthen the immune system.

“If you look at a group of athletes with SCI, almost all of them will have low bone density in their hips. And so, can we reverse that? Probably not. Can we prevent further decline? Absolutely. That’s where vitamin D is essential,” says Broad.

“We recommend vitamin D particularly in individuals with SCI to support bone and muscle strength, but also because exposure to sunlight is often less,” explains Parnell.

Although a very recent study indicates there may be some conflicting evidence with respect to vitamin D for people with SCI, it is still likely that if you spend most of your time indoors or you like to cover up in pants or long sleeves when you do go outside, you may need to increase your dietary intake of vitamin D. Health Canada recommends a daily supplement of 400 IU if you don’t get enough vitamin D from the sun or your diet.

Protein is another key nutrient. Protein helps your body to build and repair muscles and bones, as well as make hormones and enzymes. Most adults need 0.8 grams of protein per kilogram of body weight, and athletes may need more.

“Generally, we’d say at least 1.2 grams of protein per kilogram of body weight for athletes with and without SCI,” says Parnell. It’s also important to consume protein-rich foods (or supplements, if needed) within an hour or two of working out. However, it is not simply the case that the more protein in one’s diet the better, because consuming too much protein can damage kidneys, so be

sure to consult with your healthcare team and follow the recommended guidelines.

Finally, whether you're an athlete or not, staying hydrated throughout the day is vital. We know this isn't easy. When you live with SCI, there can be uncertainty and inconvenience involved with trips to the bathroom. But dehydration comes with several risks.

"One of the biggest issues I see in individuals with SCI, particularly related to travel, but also in some sports, is deliberate dehydration because they don't want to have to use the bathroom or they can't," says Broad. "Being dehydrated puts you at increased risk of bladder infection, increased risk of reduction in performance, and increased risk of illness because it dries out your airways, which are your first line of defence against [bacterial and viral] bugs. So, it's important that we work out a best-case scenario to minimize risk."

Don't Underestimate What Your Food Can Do For You

Before making any changes or adding supplements to your diet, it's important

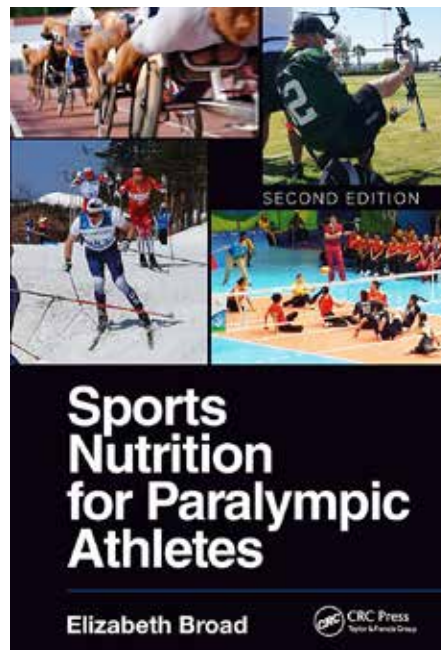
to consult with your healthcare team, says Parnell. In general, supplements are only needed if there's a specific nutritional deficiency in your diet.

For example, if you're feeling fatigued every day, you may want to speak with your doctor about getting your iron levels checked. You may be at higher risk of an iron deficiency if you're menstruating, and especially if you're an athlete.

"Particularly in our female athletes with SCI we've found that iron is often sub-optimal if not clinically deficient," explains Broad. "But because their energy requirements are lower after SCI, the ability to get the recommended dietary intake of iron is more challenging."

Medications can also inhibit the absorption of some nutrients, so you may want to ask your doctor or pharmacist about how your medications influence nutrient absorption and what you can do to supplement or enhance absorption in other ways.

"The general idea is you don't really recommend anything unless there's deficiencies. And my advice would be to ask



Dr. Broad's textbook.

your doctor or your pharmacist about any medications that you're taking to see if they have any influence on nutrient absorption," recommends Parnell.

No matter who you are, paying attention to what and how you eat can be a game-changer for your overall health and fitness—and it doesn't have to be a heavy lift.

"With the work that we're currently doing, there's no right or wrong answer when it comes to nutrition," says Farkas. "It's important to make changes in a way that aligns with your personal goals and that yield positive lifestyle changes for not just longevity but healthy longevity."

It's all about listening to your body, getting help when you need it, and considering the available evidence in relation to your needs. And according to Broad, it's important to remember the role that food plays as the fuel for your body:

"Don't underestimate how what you eat can influence how you feel physically and how your body will work for you."

For additional resources on sport nutrition for athletes with a disability, check out the "Para Sports Nutrition" podcast with Dr. Elizabeth Broad and *The Sports Nutrition for Paralympic Athletes (Second Edition)* textbook. For general nutrition guidance, Canada's Food Guide is available at foodguide.canada.ca/en. ■

Start your health journey with SCI BC!

SCI BC's Peer Coaching Program helps participants develop and achieve individualized goals and plans in order to help prevent secondary complications and increase self-management and self-efficacy skills leading to a healthier and enhanced quality of life.

Types of Coaching

ProActive Physical Activity Coaching: Participants who want to increase their level of physical activity or meet other health related goals.

Healthy Weight Coaching: Participants who want to maintain or achieve a healthy weight through medical support (provided by the participant's doctor), nutrition planning and/or physical activity prescription (referred to subject experts).

Trained SCI peers as your Health Coaches:



Olivia



Barry



Mary-Jo

Scan for more info





Work It Out Together

A new study shows that exercising together offers unique benefits for people with SCI and their care partners.

We all know that exercise is important. Getting active on a regular basis can prevent or manage a wide range of physical and mental health conditions, improve our mood, and boost our energy. You've heard this message before.

But here at *The Spin*, we know that "getting more exercise" is easier said than done. That's why you'll find stories about the latest research on technologies, equipment, apps, and programs designed to make exercise easier to access and more enjoyable for people with SCI in almost every issue that we publish.

The innovations we've featured offer a wide variety of options to help our readers with SCI get active. But what about the readers who care for and support people with SCI? What you may not know is that the health of people with SCI and their care partners is often linked—and that exercise can be an important factor in maintaining health and wellbeing on both sides of the equation.

That's what led Dr. Reed Handlery, an Assistant Professor in the School of Physical Therapy at Arkansas Colleges of Health Education, to design an exercise program specifically for people with SCI and their care partners. He is also the lead author of a new study examining the feasibility of the program and its impact on participant outcomes—a first of its kind to include care partners alongside participants with SCI.

"Care partners often experience worse health than people who do not provide care, including higher risk of cardiovascular disease and higher rates of depression and anxiety," says Handlery. "There hasn't been, to my knowledge, a lot of research specifically on the physical health of care partners of people with SCI, but we do know that it's a dyadic relationship where the health of one partner impacts the health of the other."

For example, if you live with SCI and your health is compromised—perhaps you develop a pressure wound or injure your shoulder—you may rely on a care partner for help with daily tasks like mo-

bility and self-care more than usual. And when care partners are faced with more demands, they are less likely to engage in health-protecting activities like exercise. Meanwhile, care partners who experience an injury or poor health may be unable to provide the level of support they might typically provide. This, in turn, can impact the health and wellbeing of the person they are caring for. It's a cycle that may repeat itself to the continued detriment of both people with SCI and the care partner, often a spouse or family member.

"Care partners seem to be neglected in terms of exercise and physical activity interventions," explains Handlery. "Usually, those interventions are just targeting the person with the diagnosis. But if care partners are helping with transportation or other things and they're going to show up to the gym anyways, let's go ahead and try to improve their health through exercise as well."

With an accessible CrossFit gym 200 metres from his office, Handlery wondered if the popular, often partner-based style of working out would be a good fit for people with SCI and their care partners. CrossFit is the most common form of High Intensity Functional Training (HIFT), an exercise program that uses various functional movements performed at a high intensity to improve general fitness and performance. It combines aerobic and strength-training exercises that specifically target regular, everyday patterns of movement—from wheeling or walking to bending over to lift an object from the ground. "It's a fancy way of saying exercise performed at high intensity that largely represents movements you do in daily life," says Handlery.

CrossFit, or HIFT, checked several boxes when it came to designing an exercise program that would benefit people with SCI and care partners. "HIFT has a lot of variety, which lends itself well to people with SCI and care partners who may have different ability levels," explains Handlery. "It also allowed us to meet SCI-specific exercise guidelines, which at a minimum is moderate to vigorous aerobic exercise for

20 minutes twice a week, and then strength training twice a week for three sets of 10."

Another feature of HIFT that appealed to Handlery was its emphasis on working out in community with others. "HIFT includes partner workouts where, for example, you and I work together to lift a weight that we wouldn't be able to lift individually," says Handlery. "It fosters a sense of community that I don't think you get with individual exercise programs or even group classes where the focus isn't necessarily on the team or on partners."

Facilities for HIFT are widely available around the world, and they're often accessible, adds Handlery. "They're usually giant warehouses with big garage doors, so you can roll or walk right in. These gyms usually have a very open floor plan, so you don't need to weave in and out of treadmills or anything like that. It's very bare bones, a lot of free space, which is important for individuals who may use a power or manual wheelchair."

So, Handlery recruited 14 people with SCI and six care partners to take part in a 25-week HIFT program. Participants took part in two sessions per week, each about 75 minutes in length, at a CrossFit facility with accessible restrooms, parking, and floor plan in Fort Smith, Arkansas.

"Some specific things that we brought in to make the gym even more accessible included things like grip aids and ropes with loops and knots. We also introduced a variety of lighter, smaller weights," explains Handlery. Otherwise, the program made use of common CrossFit equipment, including squat racks, air-bikes, row ergometers, and medicine balls.

Two coaches, both licenced physical therapists, one with a CrossFit coaching certification, led the program. The coaches tailored the sessions to manual wheelchair users first, then adapted the programming to meet the needs of powerchair users and people who walk. Each session was designed to meet or exceed SCI-specific exercise guidelines and consisted of three parts: a warm-up focused on shoulder strength and stability, a HIFT workout, and a cool-down.

The bulk of each session, called “the workout of the day,” lasted anywhere from 20 to 60 minutes. No two workouts were the same, and more than 100 different exercises were featured across the 25 weeks. “HIFT is kind of all exercises in a blender, so it’d just be everything you could possibly think of, adapted to meet the needs of each participant. And the important thing is that it’s performed at a high intensity. That doesn’t mean every single exercise, but for the most part you are trying to do things at a high intensity,” says Handlery.

While participants with SCI and their care partners would typically arrive and leave together, they would spend most of the workout interacting with others in the program. “During partner workouts, for example, we almost always split them up, so they weren’t with their respective partner. They were either with another participant with SCI or another care partner,” explains Handlery.

To evaluate the feasibility of the program (in other words, how practical or realistic the program is for participants

in the real world), the researchers tracked recruitment, attendance, retention, safety, and fidelity (exercise intensity) across the 25 weeks. The researchers monitored the number and type of adverse events (for example, injuries) to assess safety, and participants rated their perceived exertion during each workout on a 10-point scale to measure fidelity.

At the beginning, middle, and end of the program, the researchers assessed participants’ fitness using measures like cardiovascular endurance and muscular strength. Participants also reported on their level of confidence, social support, and health-related quality of life. Of note, the study did not include a control group—meaning participants’ scores were assessed for changes over time, but were not compared against people who were not participating in the program.

While the small sample size and lack of a control group mean the study is very much preliminary in nature, the results offer some promising findings and build a solid foundation for future research on



Dr. Reed Handlery

HIFT and exercise programs for people with SCI and care partners.

“The biggest finding for us is that the 25-week HIFT program was safe,” says Handlery. “We didn’t have any musculoskeletal injuries, which we were most concerned about.” Only one adverse event occurred when a participant with SCI experienced autonomic dysreflexia, requiring them to take a 10 minute break prior to returning to exercise.

Not only was the program safe, but it did what it intended to do: Meet the SCI exercise guidelines and improve fitness. Participants with SCI reported ratings of perceived exer-



Battle rope exercise.



Sled pull exercise.

tion consistent with high intensity exercise and demonstrated improvements in endurance, power, and muscle strength.

In addition, both participants with SCI and care partners reported increases in social support for exercise—a strong predictor of exercise adherence. “After the first few weeks, we noticed people that started to show up earlier and stay later to talk,” says Handlery, reflecting on the social nature of the program. Participants with SCI reported enhanced support from friends, whereas care partners reported increased support from both family and friends.

Although recruiting participants for the program was a challenge, participants who did join the program appeared to enjoy it and attended most sessions. Average program attendance was 73% for all participants—77% for people with SCI and 61% for care partners.

“We know there’s plenty of barriers to exercise and we’re in an area where people had to travel a decent distance to the gym. So we were really pleased with the 77% attendance rate for the people with SCI over the course of 25 weeks,” says Handlery.

Overall, the findings of the study bring to light some important considerations for anyone looking to offer HIFT programming in the SCI community.

“Most HIFT or CrossFit gyms already have what they need in terms of space and equipment. What you need is a champion,” says Handlery. “You want someone who’s passionate, and ideally, they’d work with a rehab professional to understand some of the nuances of working with people with SCI as far as looking out for things like autonomic dysreflexia, pressure injuries, or overheating.”

Another challenge that Handlery notes is the perception that HIFT, and more specifically CrossFit, is associated with a masculine, “push through the pain” culture—implying that HIFT might not be safe, when we now have data to show that it can be. “We heard from a couple of our participants whose healthcare providers specifically said, ‘No, you should absolutely not be doing CrossFit.’ And I don’t know if that’s ableism, but it is unfortunate and something that we need to keep pushing to change,” says Handlery.

Wasting no time, Handlery is already working on a larger study that aims to build on and validate the preliminary findings of this study. “We’re in year two of a two-year longitudinal study looking at HIFT for a larger group of people with SCI and their care partners,” he explains.

He’s also working on better ways to assess the physical function of people who use powerchairs. “There’s not a lot of good physical measures out there as far as looking at their cardiovascular endurance and strength,” he says. “And so we have that in the pipeline as far as validating and ensuring the reliability of those measures.”

But his work isn’t done yet: “We know exercise works. We know it’s beneficial. But how do we get people to exercise? How do we deliver exercise to the most people with the most impact? Getting a program like this, or any community-based exercise program, to more areas that just don’t have it. That’s the long-term goal.” ■

More exercise opportunities for people with SCI:

- PARC (Metro Vancouver): icord.org/parc
- ICORD Joy Active Study (Okanagan): icord.org/studies/2022/07/joy-active
- To see if there are accessible gyms near you, contact InfoLine at 1-800-689-2477 or info@sci-bc.ca.

PeerSAY: Top 10 Things I Wish My Doctor Understood About SCI

How much does your doctor know about SCI? If you're like one of the peers we chatted with, chances are they don't know enough (and that's if you have a primary care doctor in the first place). When it comes to your health and wellness, you deserve a doctor who is trustworthy, a good listener, and knows a thing or two (and hopefully more) about SCI.



In this issue we are giving the Spin Doctor a break—but we're not letting them off the hook completely. Instead of them giving advice to us, we're giving advice to them! Here's what our peers had to say.

1. I wish...my doctor had a basic understanding of SCI and was willing to learn more!

I wish my doctor would know anything about SCI, even just where to get the information when needed. And read the validated information I bring in. As well, if I am your first patient with SCI, now is the time to learn so your other patients can benefit!

2. I wish...my doctor listened to me when I talk about pain.

People with SCI can have pain below the injury site. It is not in my head, and it affects my daily life. I wish my doctor would understand pain after SCI and know how to treat it.

3. I wish...doctors and staff at the walk-in clinic and emergency room (ER) understood how they can help people with disabilities in our medical system.

It's not my fault I don't have a primary care doctor—it would be great to have one! I need your help to get a referral to specialists that are an essential part of my healthcare. And I wish you wouldn't ask me, "What happened?" every time I come to the walk-in clinic. I am not inspirational: I am just here to address an issue.

4. I wish...my doctor realized that my SCI makes early appointments hard!

Living with SCI, my basic body functions rely on strict routines and support from caregivers that make it challenging for me to go to early appointments. An 8 am appointment creates a scheduling headache! For me to have access to medical care, I sometimes need understanding and flexibility from those scheduling appointments.

5. I wish...my doctor knew about autonomic dysreflexia and how bodies can react after SCI.

I manage a range of blood pressure (BP) issues, from low BP to high BP. Threading the needle to keep it in a healthy range is important for my health. I wish my doctor could identify the symptoms and causes of autonomic dysreflexia (AD) and would know how to treat AD in a critical situation.

6. I wish...my doctor understood how physical barriers in their office affect my health and access to medical care.

My mobility and function impact my ability to transfer to a high exam bed, remove clothing, use a scale, and bear weight. I wish my doctor would see this as a problem they can help solve, rather than leaving it up to me. Height adjustable examination tables exist and allow for medically required exams for a larger percentage of wheelchair users. Having at least one in their clinic helps them better serve many patients. Accessibility includes things inside and outside the exam room, such as an entrance with power doors, accessible height reception counter, and accessible seating.



7. I wish...my doctor understood how UTIs are different for people with SCI.

I wish my doctor would know the best practice UTI protocols for a person with SCI, as opposed to how UTI's are typically treated in people without SCI. I use catheters, so there will always be bacteria in my urine. I know my body and I know when I have a bladder infection. I need an antibiotic prescription, not to wait for an appointment.



We wish doctors knew how inaccessibility affects our care: SCI BC's Jocelyn Maffin grabbed this shot of the reception counter at a local clinic where only the receptionist's ponytail is visible from a seated height.

8. I wish...my doctor understood that every injury is different, but there are common issues people with SCI experience.

I wish my doctor understood all the issues that come with SCI, such as bladder and bowel management, skin health, and autonomic dysreflexia. I want my doctor to understand that SCIs can vary widely between each person—and that walking doesn't mean the person is cured.

9. I wish...my doctor would work collaboratively with other clinicians and recognize when I need a referral for specialized care.

I wish my doctor would know where and how to refer someone with SCI who has more complex concerns. Sometimes it's just not working, and I might just be here for you to refer me to a specialist. You can connect me with specialists at GF Strong and the Blusson Spinal Cord Centre.

10. I wish...my doctor worked together with me on paperwork.

I rely on many basic services that require physician verification of my disability which is both time consuming and costly. I know you hate it too, but I hope you will work with me on it. If you're willing to review and sign, I will bring the forms or write a letter with details of the equipment, supplies, specialist referral, or prescriptions I need. I can help make it easier for you if you are open to it.

Let your doctor know!

So, how can we improve doctors' understanding of SCI? Recently, SCI BC partnered with SCIRE and others to co-create the **SCIRE Continuing Medical Education (CME) on Treating Spinal Cord Injury in Primary Care**. In the training, SCI experts and top physiatrists at GF Strong Rehab Centre in Vancouver cover topics such as blood pressure and cardiovascular, skin, and bladder health. Encourage your doctor to check out the training videos, which will be available on SCIRE's YouTube channel: youtube.com/@SCIREWebVideo/videos.

SCI Research Hits the Road!



SCI BC and UBC Okanagan researchers team up to share research across BC.

It's a familiar scenario for many people living with SCI. A survey arrives in your email inbox, a form passes around the room, a poster makes you stop and think—and then poof—the moment passes and the chance to get involved with SCI research goes with it. Or maybe you did participate in research and wondered what the results were. The Research Roadshow, a series of events facilitated by University of British Columbia (UBC) Okanagan SCI researchers and SCI BC earlier this year, aimed to solve these problems.

"The Roadshow came out of discussions looking for new or better ways to engage with the community," explains Kelsey Wuerstl, PhD candidate in Dr. Heather Gainforth's Applied Behaviour Change Lab (ABC Lab) at UBC Okanagan. "We wanted to connect with people. To share the research that's going on, get feedback, learn what we can do better, and where we can go next with our work. We also wanted to try to recruit for studies that are currently happening."

Current ABC Lab research is focused on improving quality of life and engagement for people with SCI through developing, understanding, and improving the application of evidence-based behaviour change interventions and advancing the science and practice of integrated knowledge translation. Wuerstl's research is concentrated on co-developing a smoking cessation intervention for person with SCI, and the Roadshow was a great way to share updates about her work, the ABC Lab, and related research from other organizations.

In partnership with SCI BC staff, Wuerstl co-hosted Roadshow events throughout the province. She travelled to Prince George, Kelowna, Victoria, Surrey, and Vancouver to present information about SCI research and answer questions from SCI BC members. To encourage participation, the Roadshow events were hosted during regular SCI BC coffee groups or located at unique venues. Vancouver hosted a session at ICORD's home in the Blusson

Spinal Cord Centre, Prince George opted for a golf club, and Kelowna members met in a coffee shop.

In Surrey, Wuerstl and SCI BC Peer Program Coordinator Rod Bitz co-hosted a session with stand-up comedy. "We hosted the Roadshow in conjunction with the monthly Surrey Pizza and Games night... However, comedian Ryan Lachance, who lives with cerebral palsy, substituted for the games portion of the event and that was a hit," Bitz explains. The event drew 42 attendees and exposed a whole new group of SCI BC members to the value of research. "We got a lot of engagement with that event because we had people who were there for the research and people who were there for just the comedy show," Wuerstl says, adding that no matter where she went, there was a clear desire from SCI BC members to be involved in research.

A variety of topics were covered during the Roadshow with two of the most popular being aging with SCI and physical activity. Of the topics not covered, atten-



Kelsey Wuerstl



Research Roadshow at the Third Space Cafe in Kelowna.

dees expressed interest in learning more about bladder and bowel spasticity, spinal stimulation, and chronic pain. “It was really valuable getting that feedback,” Wuerstl says. “I hope that in the future we can do more of these Roadshow events and branch out to other topics that we weren’t able to cover this time.”

For Wuerstl, one of the other most surprising and meaningful takeaways from the Roadshow was learning that there is a strong desire for SCI research in Northern BC and on Vancouver Island. “We got a lot of responses from Prince George and Victoria that people really want to be involved in research there. Our labs haven’t done anything in those areas yet so that’s a big opportunity,” she says. “Traditionally, research has been done in person and that’s still where most research is done. But COVID showed us that we can do a lot of our studies virtually or online. We have great videoconferencing and other tools that allow us to connect. The Northern region and the Island see that and are starting to ask, ‘Why can’t research be done online’? That’s exciting to hear.”

The Research Roadshow clearly demonstrated an eagerness by many SCI BC peers to learn about SCI research and to get involved in it themselves. “I think people want to be involved because they want to live more meaningful lives. They want to improve their quality of life and research is one way that that can happen,” Wuerstl says. “When people had a spinal cord injury 50 years ago the chances of surviving were low, but we’ve seen that through research people are now living full, long lives and that shows you what research can do. I think people want to contribute to that.”

The ABC Lab’s unique approach to research encourages participation from beginning to end. “We want to make sure that researchers are doing research with

people that can use their findings, and that it’s done in a way that is meaningful for people with SCI. Individuals with SCI can help in that process by helping us understand what our data means as it relates to them,” Wuerstl explains. “Oftentimes we get a lot of life stories and experiential data and it is crucial

people with SCI share their input and interpretations. We want to know things like, how does this relate to your day-to-day life? Or what you’ve experienced in the past? As researchers we don’t always have that lived experience to draw from... The Roadshow helped us learn from each other.” ■

Get Involved

Want to learn more about SCI research or participate in a study? Check out these resources.

SCIRE

The Spinal Cord Injury Research Evidence (SCIRE) is an international collaboration of scientists, health professionals and the community. The SCIRE website is one of the go-to places for systematic reviews of SCI research and news.

scireproject.com

NASCIC SCI Research Advocacy Course

The North American Spinal Cord Injury Consortium (NASCIC) has developed a free online course to help people living with SCI and caregivers feel confident about being research advocates and advancing SCI research in their communities.

nascic.org/nascic-sci-research-advocacy-course

ICORD

ICORD is a spinal cord injury research centre of the UBC Faculty of Medicine and VCH Research Institute. They recruit for studies on an ongoing basis and are always happy to help you get involved in research.

icord.org/research/participate-in-a-study

[Turn to the next page for ICORD research studies!](#)

SCI Action Canada Lab

The SCI Action Canada Lab is based out of UBC Okanagan and conducts research on how to inform, teach, and enable people living with spinal cord injury to initiate and maintain a physically active lifestyle.

sciactioncanada.ok.ubc.ca

ABC Lab

Also located at UBC Okanagan, the ABC Lab aims to conduct partnered research with a focus on its application for people living with a spinal cord injury.

abclab.ok.ubc.ca

abc.lab@ubc.ca

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.

Sleep Routines And Sleep Disturbances After SCI

Overview: ICORD researcher Dr. Victoria Claydon, her SFU research team, and community partner SCI BC are interested in learning more about the sleep routines, disturbances, and barriers to sleep supports experienced by individuals with SCI, as well as the impacts of these sleep problems on daily life.

What to expect: This survey study aims to better describe routine and physiological sleep disturbances after SCI. The survey asks about sleep quality, sleep routines (i.e., turning), and sleep problems (i.e., sleep apnea) as they present in the nighttime. We will also ask how your sleep affects your quality of life. This online survey is estimated to take 30-45 minutes to complete. You will only be shown questions for the sleep disturbances that you indicate.

Who can participate: You may be eligible to participate in this study if you have an SCI (inclusive of all injury levels, severity, duration, and cause), are living in Canada, are at least 19 years old, and are able to communicate and understand instructions in English.

Why participate: Poor sleep quality is widely documented among individuals with SCI, with consequences of excessive daytime sleepiness, high levels of fatigue, and reduced participation. With the support of patient and community partners, we hope that the results of this study will shed light on the under-recognized challenges of sleep post-SCI to provide context for meaningful change and inform clinical priorities. As a thank you for your time, participants will receive \$15 via e-transfer. At the conclusion of the survey, participants who wish to receive the honoraria will be linked to an external survey to enter an email to which the e-transfer will be sent. Your email will not be linked to your survey responses.

Location: This survey study will take place remotely (online survey/phone).

For more information or to sign up: Please contact the study coordinator Rebekah Lee by email (rebekah_lee@sfu.ca) or call 778-892-8560. You can also go straight to the survey at surveymonkey.ca/r/SleepAfterSCI.

Sex Differences In Cardiac Function In Individuals With High-Level SCI

Overview: Drs. Chris West and Alexandra Williams are investigating whether there are differences between the male and female heart in individuals with SCI between the C4 and T6 levels, in comparison to any sex-related differences that exist in uninjured individuals, and if the differences exist at rest and when your posture changes.

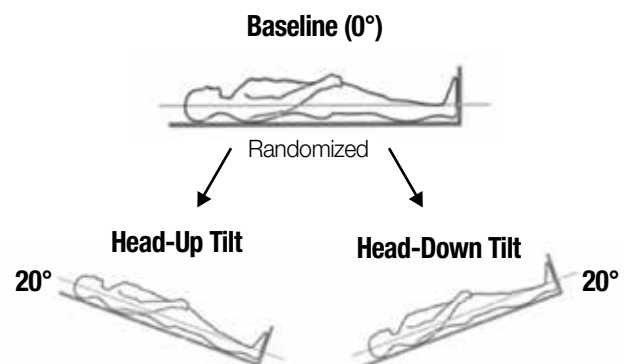
What to expect: A single visit to the laboratory at ICORD lasting 1.5-2 hours is required. The researchers will make sure they can get clear images of your heart with ultrasound, and if so, will collect ultrasound images of your heart and monitor your blood pressure while you are lying flat, and then during different postures on a tilt table.

Who can participate: You may be eligible to participate in this study if you are living with SCI or are uninjured, and are between the ages of 18-45. Individuals with motor-complete SCI (more than 1 year) will be included if they have a lesion between the C4 and T6 levels. See the study webpage for more information about eligibility.

Why participate: At the moment we don't know whether there are differences in the male and female hearts after SCI, so this study will be the first to look at whether those sex-related differences exist and how those related to blood pressure control. Compensation for participation is provided.

Location: Blusson Spinal Cord Centre (818 West 10th Avenue, Vancouver)

For more information or to sign up: Please contact the study coordinator, Alexandra Williams, by email (alex.williams@ubc.ca).



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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Reference: 1. Hollister data on file.

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