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# thespin

SPINAL CORD INJURY BC

FALL 2019

## Into the Great Wide Open

SCI BC Peers enjoyed an amazing summer of eye-opening events in every corner of our province

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Assistive Technology Services are available to individuals who have a work related barrier due to a disability or functional limitation. Learn about how this service can benefit you by attending a Lunch and Learn or Webinar.

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Webinars take place online on the 3rd Wednesday of every month from 12:30pm to 1:00pm.

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

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Canada

BRITISH COLUMBIA

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and the Province of British Columbia.

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FALL 2019

## features

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**COVER:** SCI BC Peer Richard Peter and volunteer Jodee Meyers celebrate a great paddle at the recent KASA Bike Camp in the Kootenays.

## Now online: SCIsexualhealth.ca

When it comes to sex and spinal cord injury, we're all about kissing and telling.

# Legislation is not enough.

Since the last issue of *The Spin*, the *Accessible Canada Act* officially came into force. As stated in a July 11 federal government news release, "The coming into force of the *Accessible Canada Act* establishes a framework to create a barrier-free Canada through the proactive identification, removal and prevention of accessibility barriers. It will also ensure that persons with disabilities are no longer required to fight barriers to accessibility on an individual basis. With this legislation in place, millions of Canadians with disabilities can rely on the Government of Canada to remove the barriers that hinder their full participation in society."

This is exciting, welcome and historic news. But is it enough to lead to meaningful advances in the integration and inclusion of Canadians with disabilities?

Unfortunately, recent research published by the Canadian Disability Policy Alliance (CDPA) suggests that legislation alone is not enough.

The authors from Queens University compared integration and inclusion between Canadians and Americans with disabilities. They used daily time use (the amount of time spent doing things like paid work, screen time, sleeping and housework) as an indicator of the degree of integration of people with disabilities in society. Remember, until now, Canada has not had federal accessibility legislation—but the *Americans with Disability Act* has been in force in the United States since 1990. That's almost a 30 year head start! Logically, if federal disability/accessibility legislation promotes inclusion and participation of people with disabilities, the prediction would be that Americans with disabilities are more integrated with wider society than Canadians. But is this the case?

The answer is no. What the time use data show is that Canadians with disability are more integrated with wider society than Americans with disabilities, even in the absence of federal accessibility legislation in Canada.

While there are many, many factors that contribute to the differences in integration between Canadians and Americans with disabilities, this study highlights the simple fact that federal (and soon provincial) legislation on its own is not sufficient to bring about equal opportunity for people with disabilities to participate in society. Legislation must be accompanied by programs and policies targeted at changing attitudes and behaviours; at removing both physical, systematic, and attitudinal barriers to access; and promoting inclusion for all. You can read more about this study on the CDPA website (disabilitypolicyalliance.ca).

The lesson for Canada is that to fully realize the potential for change offered by new accessibility legislation, we need to be both creative and bold in developing and undertaking federally and provincially-funded programs and policies that promote and support access and inclusion. Taking lessons from the field of behaviour change research, we must resist taking ISLAGIATT (it seemed like a good idea at the time) approaches and, instead, employ theory and evidence-based strategies that are co-developed and implemented by all relevant stakeholders. We must be patient and critical of these programs and policies to see if they are having the desired impacts over reasonable periods of time, and make adjust-ments as required.

Make no mistake: the *Accessible Canada Act* is a milestone. It took a dedicated and coordinated effort from the diverse stakeholders within and beyond the non-profit disability sector and government. It emphasized the need for input from the lived experiences of Canadians with disabilities. In short, it's the result of a lot of work. However, to achieve its ultimate goal of creating a barrier-free Canada in which everyone can fully participate in society, a great deal of ongoing collaboration and sustained effort by an even broader spectrum of stakeholders is required. Let's get to work on it.

CBM

– Chris McBride, PhD, Executive Director, SCI BC

**thespin**

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**SUBMISSIONS**

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

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### BRA ANGEL

Limited hand fucntion often makes it difficult to put on a bra. The Buckingham Bra Angel has been specifically developed with this problem in mind. The Bra Angel is placed around the neck, with its telescoping arm positioned between the cleavage. A soft chin pad allows the user to maintain its position and still clearly see the bra's fasteners. One end of the bra is then placed in the clip, which holds it tightly in place while the other end can be brought around the body and secured. It can be used with all different styles and types of bra, and all neck sizes. The aid can be also be used with a single hand. You can find the Bra Angel at many online stores including amazon.ca.

### BELLYAK FREQUENCY

The Bellyak Frequency kayak offers an adaptive paddling opportunity for people who feel more comfortable and stable in a prone position instead of being seated—for example, anyone with comprimised core strength resulting from SCI. A gently-contoured body area with a thick foam pad supports the body in an ergonomically correct position with a low centre of gravity, and it's easy to get aboard with minimal assistance. The kayak is used with any of the many hand paddle or hand fin options that are currently available. A drop-down skeg at the tail end allows users to track in a straight line with ease. It's about 2.5 metres long, and weighs 14 kilograms. Visit bellyak.com for more information and video.

# Innovations

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

### UPPKOPPLA

IKEA, prosthetic company Unyq, and e-sports company Area Academy have formed a partnership to create UPPKOPPLA, a line of accessories for gamers. The 3D-printed accessories are meant to provide custom-made fits for gamers, including those with mobility issues. The first products include an ergonomic wrist brace (shown in the photo), textured key caps for better grip, and a mouse bungee that keeps cords out of the way while you play. The wrist brace is particularly intriguing—using an UPPKOPPLA app and their own smartphone, consumers will scan their hand and wrist in order to create a 3D-printed product that fits them personally. The three companies hope to create more accessible products for gamers with physical disabilities. The UPPKOPPLA line will launch in 2020. Visit tinyurl.com/y262pfpe to find more information.

### LORO

Loro is a wheelchair-mounted smart companion that's being developed by a team of engineers, designers and entrepreneurs at Harvard's Innovation Lab in Boston. It's intended to increase independence for users with high level disabilities by enhancing their vision, communication, and safety. Loro's panoramic camera and app work together to let the user see farther in all directions, read or translate writing that's too small or distant to be read unaided, identify people with face tracking, gesture with a laser pointer, and direct a built-in flashlight beam. Text to speech is built in. The team is working to create a prototype in preparation to secure seed funding and move into manufacturing. More details can be found at loro.xyz.

# Supporting Chairstuff Supports SCI BC!

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> **– Kevin**

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*Founder & CEO*
*Chairstuff*

CHAIRstuff

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## Pick up a brush in PG.

Join other Northern Peers Oct 19 for a fun how-to-paint with acrylics event suitable for creatives of any level. Local artist Laura Chandler will lead Peers through the steps of creating a masterpiece regardless of their previous experience using acrylics. All materials for this event, which takes place at a private home, are supplied free of charge for Peers. Email Brandy Stiles with questions or to RSVP: bstiles@sci-bc.ca.

## Discover your hoops talent.

New wheelchair sports crop up all the time—but it's hard to beat the great workout, camraderie and availability of one of the original Peer team sports, wheelchair basketball. This fall, the BC Wheelchair Basketball Society is making it easy for anyone to get into or return to wheelchair basketball, with a variety of opportunities to "give it a go" at the Richmond Olympic Oval facility. Visit bcwbs.ca/news/events to learn more and see event dates.

## Let's talk about sex, babies.

In our upcoming SCI Forum After Hours, we'll be screening the new *Wheel Love* documentary, and then talking sex, fertility, family, and more with sexual health rehab clinicians and couples who've been there. Hear stories, ask questions, and learn! There will also be snacks, information on local sexuality and fertility resources, and some fun giveaways!. Planning to join us on Oct 9? Please RSVP at scibcforum.eventbrite.com.

## THANK YOU!

Thanks to your support, Spinal Cord Injury BC raised a record-breaking **$89,525** at this year's Scotiabank Charity Challenge!

Your incredible generosity will go directly towards helping people with spinal cord injuries or related physcial disabilities **adjust, adapt, and thrive**!

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# PEOPLE WITH C4-C7 SPINAL CORD INJURY NEEDED

**We are conducting a research study using volunteers to test a medical device intended to improve voluntary reaching and grasping in individuals who have arm and hand paralysis as a result of a spinal cord injury.**

**The device uses a non-invasive Functional Electrical Stimulation (FES) technique with surface electrodes to stimulate from 3 to 8 muscles to create purposeful movements in one or both hands/arms. The study will compare the efficacy of the FES technique to intensive conventional therapy.**

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ii) 40 one-hour sessions of intensive conventional therapy over 8 to 14 weeks.

**You will need to complete:**
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**If you decide to participate:**
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## PRINCIPAL INVESTIGATOR:

**Dr. Jacqueline Pierce** - BSc. PT, MSc. PT, MD, FRCPC, CSCN Diplomate (EMG)
Specialist in Physical Medicine, Rehabilitation and Electromyography

**For more information, please contact Natasha Campbell at:**
**778-874-7758 or natashacampbell@healthtechconnex.com**

# The Dark Side of Testimonials

**There is no scientifically-validated or government-approved stem cell treatment for SCI, anywhere in the world. Yet people with SCI continue to travel abroad to receive treatments that are unregulated, unvalidated, expensive and potentially dangerous. A new study suggests one reason for this is the highly unethical use of testimonials in promotional videos.**

In 2018, a group of researchers published an alarming paper in the journal *Stem Cell Reports*. Led by Dr. Gerhard Bauer, an assistant professor of hematology and oncology at the University of California Davis Institute for Regenerative Cures, the researchers reported that they had identified 35 cases of significant injury or death resulting from unproven stem cell treatments. These interventions are mainly offered at clinics in countries where there are little or no scientific approval processes or regulations. And 35 seems to be the tip of the iceberg, as the authors concede that these cases were only the ones noted in scientific literature or widely publicized in the media.

"It is expected," wrote Bauer and his colleagues in their paper's conclusion, "that the true number of cases involving unproven stem cell treatments is much larger than the one reported."

In other words, stem cell tourism is a burgeoning industry in corners of the world where oversight doesn't exist, and even in places where it does, including the USA. The University of Alberta's Dr. Timothy Caulfield believes one reason for this is the highly unethical use of patient testimonials in promotional videos.

Caulfield is uniquely qualified to comment on this. He's a professor of law at the U of A, Research Director of the U of A's Health Law Institute, and current Canada Research Chair in Health Law and Policy. He's also well-known for his psuedoscience-busting books (for example, *Is Gwyneth Paltrow Wrong about Everything?*), and his own highly-regarded Netflix series titled *A User's Guide to Cheating Death* (the title is, of course, tongue in cheek). Little wonder that the *Globe and Mail* recently suggested that he is the "Canadian nemesis of psuedoscience."

One of Caulfield's longstanding missions is to shed light on unproven and unregulated stem cell treatments. Recently, Caulfield joined forces with several US researchers to publish a paper in *Stem Cell Reports* titled *How to Peddle Hope: An Analysis of YouTube Patient Testimonials of Unproven Stem Cell Treatments*.

During their research, Caulfield and his colleagues found 159 videos posted to YouTube that relied on patient testimonials to promote unproven stem cell treatments. Of these, all but three were produced and published by unregulated clinics. Almost all featured on-camera footage of the patient. None had any concrete, credible data to support the anecdotal claims, or any discussion of the risks and expenses involved.

Despite the lack of scientifically-credible supporting evidence, these videos are highly effective because the testimonials they rely on prey on people's hopes and emotions, explains Caulfield.

"This study highlights the degree to which narratives are used to sell unproven therapies," he says. "We know that a good story can overwhelm a mountain of scientific evidence. Using patient stories seems particularly exploitative. If you are suffering from a disease or injury, it can be very persuasive to hear a patient with a similar problem espousing a miracle cure."

Caulfield would like readers to remember that a testimonial—no matter how heartfelt or well done—is simply not good enough to justify travelling to a foreign country to receive a costly, unproven, and even dangerous procedure.

"People should never make decisions about treatments based solely on anecdotes, especially when it's coming from a for-profit clinic," he says. "Instead, look to the body of evidence as presented by an independent, trusted entity. Remember that science is hard. If (stem cell treatments for SCI) worked well, we would know! Keep in mind that we don't know how or why the people in these videos got better, or if they did at all, and that these clinics are selling a product."

Alarmingly, Canadians were the third largest group of patients who provided testimonials in these 159 YouTube videos, although at 7.5 percent, they trailed significantly behind patients from the USA, who provided testimonials in 65 percent of videos. Patients from India were second at 11.3 percent. ■


Dr. Timothy Caulfield

# Wheel Love

Whether you're a Peer interested in relationships and having a family, or just someone who appreciates stellar film-making, you don't want to miss a compelling new short documentary conceived and produced by Kelowna's Chelsea McEvoy.

Three years ago, Chelsea McEvoy and Samantha (Sam) Baxter realized that, when it comes to real world insights about love and relationships involving a partner with an SCI, the internet is sadly lacking. So the two friends, who live in Kelowna, created *Wheel Love*—a brilliantly-written blog based on their own experiences as women in love with men who have an SCI.

"When I first started my relationship with James, of course there was the excitement that comes with new love, but what also followed was unexpected isolation," says McEvoy. "No one could relate to our situation and no one could laugh or cry with me as this new relationship evolved. I then turned to Sam. She was dating Shawn, a T4 paraplegic. After our first coffee together, we instantly knew we had a long-lasting connection and something special. Many coffee dates later, we realized that others may be feeling alone in their situations. The *Wheel Love* blog was born, and we never expected it to reach as many people as it did."

McEvoy accepted from the beginning that she and Baxter would have to open up about deeply personal experiences for the blog to have any impact. But she had no idea that, just a few years later, she'd be doubling down on the soul-baring by turning the spotlight and video camera on some of the most intimate parts of her relationship with James Hektner, an SCI BC Peer with T6/7 paraplegia.

"After a few years of trying to conceive from home, James and I decided to get help and seek out fertility clinics. As a documentary filmmaker, I found this process fascinating and started to film our journey. I never thought anyone would see the footage; I shot it to remind us of the process and moment in time. Then I came across a Telus Storyhive grant opportunity for a short documentary and thought, "What the heck?" I put together a little teaser trailer of what we shot so far, and guess what? We got the grant!"

The goal from the outset was to chronicle a very real and emotionally-charged process of trying to conceive in the particularly challenging circumstance of a male partner having an SCI.

"In all honesty, I did not want our journey to be exposed to the world," she says. "But hey—if we weren't going to do it, who was?"

McEvoy quickly recognized that, as much as she wanted to, there was no way she could direct the documentary while she was revealing so much of her personal life with Hektner. So she hired longtime friend and Kelowna filmmaker Ryan Tebbutt to take on that role.

"Ryan did an amazing job directing this film," she says. "It's an emotional topic. Infertility brings out so many emotions I didn't even know I had. Ryan created a safe space for James and I to open up and feel all the feelings. The emotion and vulnerability is what makes this film unique, powerful and special, and without Ryan, a lot of those tears wouldn't have been shared."

The documentary, which is also titled *Wheel Love*, is 23 minutes long. It tells McEvoy's and Hektner's story as they struggle to capture viable sperm and conceive through intrauterine insemination. But it's also much more—their story is beautifully interwoven with interviews with 11 couples from across the Okanagan, all with one of the partners having an SCI or other disability, who have children.

"It was very important for James and I to incorporate our amazing community of Peers," says McEvoy. "The Okanagan has such a special community of Peers and their partners who I am happy and blessed to call my friends. Like James and I, these couples thrive on educating and helping others going through similar struggles. This is not just our story; this is a story told by many. We will forever be grateful to them for allowing us into their lives and answering so many personal questions. It was so imperative for us to showcase other people's stories because, just as no SCI is the same, no one's journey is the same—but we can all share the same pain and emotion."

While emotions run raw at times in the documentary, McEvoy says it was vital to stay away from 'inspiration porn.'

"We are here to educate, not inspire, and I feel we all did an excellent job in achieving that," she says.

One way this was achieved was via generous injections of humour. For example, in the scene picutred below, McEvoy and Baxter have an on-camera discussion about the vibrators they use to come up with viable semen samples.

"They're vibrators, and they're used to make our partners ejaculate," says McEvoy to the camera. "We have grossly—TMI—shared this one. I don't even know why it's duct-taped!"

"I didn't duct tape it," Baxter manages to get out between giggles.

"James and I have gotten through a lot of difficult times using laughter and joy," says McEvoy when asked about this exchange. "Our community of Peers in Kelowna pride themselves on using humour to mentor those with new injuries or get through tough situations life throws at us. I honestly believe laughter in film is the best tool. Sometimes, you can educate using comedy better than using tears. And let's be honest—some of this stuff is just naturally hilarious!"

The documentary is also that much more captivating because it's beautifully shot and edited, with audio and soundtrack equally as compelling as the visuals.

"Other than humour and staying away from 'inspiration porn,' our biggest priority was production value," explains McEvoy. "The quality of this film is a testament to the amazing crew behind the scenes. Ryan not only directed this thing, he was behind the camera as well. His creative eye and camera work inspires me every day. A film is also only as good as it sounds, so a big shout out goes to Mike Pedersen from Mountain Stream Audio for making it sound so good. Production value is by far the most important consideration in creating a film—if it looks good and sounds good, people are going to watch it. And with *Wheel Love,* we had the best team to achieve that."

McEvoy hopes people around the world will watch the documentary and get something out of it. But she's particularly hopeful that SCI BC Peers will view and benefit from it.

"I hope readers of *The Spin* just enjoy this film. I hope it can help someone realize they're not alone, and that they're surrounded by people who can relate to them. I hope it can encourage someone with a new injury to not give up on love or the dream of starting a family. I hope it can reassure someone that they can raise a family or continue being a parent. I also hope it can break some stigmas held by the able bodied community that a wheelchair defines a person."

As for the couple's success in achieving their goal? At the time of writing this feature, they were still working to conceive. But that doesn't mean the documentary has a sad ending.

"We're still plugging along," says McEvoy. "We have a journey ahead, and we will keep trying until we are successful in starting our family—or keep trying until we decide it's time to move on. Either way, we're happy to be going on this journey together. It's happy, sad, frustrating, hilarious and messy, but with the right partner, it's all about the adventure!"

Whatever the outcome, we wouldn't be surprised to see a sequel.

"My interest in film-making began in high school," says McEvoy. "I knew I liked all aspects of art, but never really succeeded on any platform. I made my first film in Grade 10 and instantly knew it was what I wanted to do for my entire life. This career has taken me on a roller coaster the last 15 years, and I am so proud it has lead me to this film. *Wheel Love* has been the most important project to date. It won't be the last, but I am so proud of myself, the crew, my peers and my man for telling a story not many want to touch on."

You can see *Wheel Love* on Youtube (tinyurl.com/y2hp2cn8). ■

# Peer Shoutouts

A big, bluesy shoutout to SCI BC Peer **SIMON PARADIS** and his new band, Farm Team, for the release of their new CD *Grooves and Ruts*.

The CD showcases 14 new soulful tracks with great melodies and stories. Most were written by Paradis, but some were co-written with his wife, Kara Stanley, and Michael Barnholden, a well-known author and artist who lives in Roberts Creek.

With the exception of one track that was recorded at the VAMS studio, the CD was recorded at Paradis' home in Halfmoon Bay on the Sunshine Coast over a long weekend.

"Originally I had wanted to record at Afterlife Studios in Vancouver, but my issues with chronic pain made it so that I was unsure if I could commit to a schedule without losing my deposit if things got too bad," says Paradis. "So I opted for turning my living room into an adult pillow fort and recording here."

A graduate of Concordia University's Integrative Music Arts program, Paradis has been playing in blues, rock, country and roots bands across Canada for 35 years. He's featured on numerous recordings as a session guitar player and producer, and since his injury 11 years ago, he has developed impressive skills as a songwriter.

The CD was supported by the Canada Council for the Arts. You can stream it on Spotify and purchase it many places online, including CD Baby, Amazon and iTunes. Learn more at simon-paradis.com.

A savoury shoutout to **DAN DUFFY**, AKA the QuadChef, for leading our recent Peer cooking class in Surrey.

Duffy has always been a foodie, but he became even more of an avid cooking enthusiast after his 2016 C5 SCI brought an end to his career as a stonemason. His inspiring cooking session focused on using adapted kitchen tools to help make meal prep quick and easy, then moved on to creating breakfast egg bites and a delicious pasta dish with either sausage or eggplant.

Volunteering his time is more than enough to warrant a shoutout, but Duffy also deserves credit for other recent achievements. He was just announced as a recipient of the SCI BC-adminstered GRAGOPEAN Scholarship Trust award for the second year in a row (he's enrolled in second year Arts at Langara College), and in May, he was one of the BC Rehab Gert Vorsteher Award winners in recognition of the courage and perseverance he demonstrated during his recovery at GF Strong. Check out Duffy's delicious food porn on his instagram page (instagram.com/quadchef).

A huge, decades-long shoutout to SCI BC Peer and former longtime staff member **VINCE MIELE**, who continues to be a formidable disability rights advocate in his retirement.

You've probably seen Miele in the media spotlight in recent months—he's been featured on CBC News and other news outlets for sounding the alarm on the lack of accessible parking throughout the Lower Mainland, and the lack of enforcement for existing accessible parking stalls. The main issue, he says, is that rules are incredibly inconsistent across municipalities. For example, he notes that, in 2018, Vancouver issued more than 1,600 tickets for parking in accessible spaces in 2018, while Surrey issued 24.

"I guess I'm still so passionate about this and access in general for people with disabilities because I'm disheartened at what I call the ongoing erosion of access in the built environment, and the apathy and lack of interest I sometimes see around me," says Miele. "I find it unbelievable that after so many positive changes in the past 45 years that I've been using a wheelchair, attitudes as well as laws concerning access to our built environment still need our attention and our action."

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

*Aaron McHardy (left), Executive Producer, EA SPORTS FIFA, playing against Milad Hajihassan, Systems Developer at Neil Squire Society and a local gamer with a disability. Both are using adapted technology.*

# ACCESSIBILITY: It's in the game!

## Electronic Arts teams up with the Neil Squire Society for a massive buildathon of accessible gaming products

A couple of years ago, Neil Squire Society Executive Director Gary Birch and Electronic Arts (EA) Vice President of Finance Jon Lutz met at an event. They talked about each other's work, and over the course of visits to each other's workplaces, developed a relationship that would ultimately lead to an incredible one-day event: on July 25, a huge contingent of EA staff members volunteered their day to build accessible gaming switches and buttons, all to be donated to Vancouver area gamers with disabilities.

"There were over 150 EA employees present, and together they built more than 170 devices," says Chad Leaman, who, as Neil Squire Society's Director of Innovation, led the organization of the event. "This buildathon was the kickoff for EA's season of giving around the globe, so they wanted to have a large event. The fact that we're nearly neighbours in Burnaby helped create a very local connection while showcasing the company's worldwide commitment to making its products accessible."

Leaman explains that all the devices built were alternate switches that can be used in multiple applications—in addition to inputs for video game systems, they can be used with other switch-enabled products such as computers and environmental controls.

"If a gamer with a disability has a difficult time using a standard controller—for example, if pushing a couple of the buttons are difficult—you can connect alternate input switches and remap that button from the joystick to the alternate switch," he says. "While there are commercial switches, they can often cost $100 and up. The switches we built were made of 3D-printed parts and required some soldering and gluing. They are the direct result of our work with our Makers Making Change initiative, which has a list of open source hardware projects and plans that can be reviewed by occupational therapists and other disability professionals, downloaded freely, and made by makers, engineers, and tinkerers in their communities."

"The event was a huge success," says EA's Lutz, who was on hand to watch the day unfold at the company's Burnaby headquarters. "There was a lot of interest and excitement all over our studio, and we had more volunteers than we had devices to make. We're so happy to think that these 170 buttons and devices will go into gamers' homes or into rehabilitation centres and give so many people an opportunity to play games and have fun."

As a global leader in digital interactive entertainment and the world's largest gaming company, EA is no stranger to the concept of accessibility. For example, many EA games have accessibility features such as customizable visual, audio, controller, and style settings that can be tailored to the player's ability.

## Makers Making Change

The EA buildathon was held under the umbrella of Makers Making Change, an initiative launched by the Neil Squire Society (one of SCI BC's partners in the BC SCI Network) in 2016 to connect highly-skilled volunteers with people with disabilities who need assistive technologies. It provides an opportunity for skilled workers to practice knowledge philanthropy—they use their skills, learn some new ones, and make a difference.

Makers Making Change has organized similar events with TELUS, Microsoft, university groups and other community-based knowledge programs.

"We now have more than 70 projects that are all open-source and listed on our website," says Chad Leaman, Neil Squire Society's Director of Innovation. "If you have an interest in any of the projects, connect with us—you can request to be involved with any project on the site. Likewise, if someone has a great do-it-yourself solution that enables them to overcome a disability-related barrier, please share it with us so other people in other communities can benefit from your ingenuity."

Check it out at makersmakingchange.com.

"EA exists to inspire the world to play, and when we say 'the world,' we really mean it—everyone should be able to play and enjoy our games even if they have disabilities," says Lutz. "To this end, Neil Squire Society is a very natural partner—we each love what technology can do for people's lives. The Society is a Canadian leader and is providing us with expertise and advice on how we can empower people living with a disability, and help them to live life to the fullest."

Perhaps the most exciting part of the event was the fact that four gamers with disabilities attended the event and played a vital role.

"They were able to show the video game developers how they play EA games with alternate inputs, using mouth-operated cursors, alternate button controllers and other accommodations," explains Leaman. "It was very powerful for the maker to see how people with disabilities play with their products. Some EA staff members, after making their switch, used it to play with the gamers with disabilities. It shaped the event into something more than just making assistive technologies; it created awareness and empathy about what needs to be in a game to ensure everyone can enjoy it. It started a wider conversation about accessibility as part of the Game Development Framework, and also helped start other conversations around testing games with users with disabilities and other ways to ensure that everyone can play."

If you're a gamer with a disability who is interested in seeing if one of these switches might make playing easier and more enjoyable, Leaman urges you to get in touch.

"Thanks to EA's generous support, which covered the cost of parts, these switches can go out to our partners and clients free of charge. If any readers use switch access for computer control or for other input control, we'd love to hear from them and have their feedback on these switches."

Learn more at neilsquiresociety.com or makersmakingchange.com. ■

# Start the 3D Printer!

**Swedish home furnishings giant IKEA recently sponsored a hackathon in Israel, leading to 13 innovative products designed to make some of the company's products more accessible for people with disabilities.**

A unique partnership between IKEA and two Israeli accessibility organizations has resulted in the development of a suite of new accessories that can be added to some of the company's furniture in order to make them more usable by people with disabilities.

The collaboration between the world's largest retail furniture chain and non-profit organizations Milbat and Access Israel led to a new product line that's been dubbed "ThisAbles" (which is a play on the word disable). The best part is that, in addition to making the products available for sale in its stores in 127 countries around the globe, IKEA has made the plans available on an open-source basis—you can download them and have them 3D-printed for a fraction of the retail cost.

According to Access Israel's Facebook page, the project got underway in 2017 to test the accessibility of existing IKEA products and develop special add-ons to enable disabled customers to more easily use some of them. It was launched at one of Israel's IKEA stores with a hackathon involving IKEA's product engineers and consumers with disabilities that enabled better understanding of how some of the company's products were difficult to use for some—and how simple accessories easily improve usability.

In a sense, it's a gesture by IKEA that is at once altruistic and a recognition that consumers with disabilities are not to be ignored. The company noted that at least one in every 10 people in Israel has a disability, and addressing the needs of consumers with disabilities is a corporate goal.

A few of the innovations are shown below. Visit thisables.com to see the full suite of products and find downloadable plans.

1. Insider mirror holder lines Kalax shelves to make objects on them visible to wheelchair users
2. Couch Lift extender legs raise some IKEA sofas and make it easier for people to transfer onto them.
3. Friendly Zipper attaches to bags or quilt covers to make it easier for them to be grasped and opened.


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# Summer Sizzle!

**When people with SCI get together, great things happen.**

For 62 years, Spinal Cord Injury BC's top priority has been ensuring that our Peers, regardless of where they live in our great province, have opportunities to meet each other. When you gather, you share valuable insights—insights that only come from the perspective of actually living with an SCI or living with someone who has an SCI. You learn about ways to manage your lives, tackle challenges, and maximize your independence. You give and get support. You make lifelong friends. And if you can do all this in the context of learning a new activity, broadening your horizons, and getting out of your comfort zone, all the better.

Summer is a great season to make the most of these opportunities. This summer, we held some amazing Peer events in every corner of our province. You can see a few glimpses of these gatherings on this spread. We hope they bring back great memories—and encourage other Peers to reach out and seize future opportunities.

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1. Ron and Yuko Holmberg and their son, Aaron Holmberg, get acquianted with kayaking, thanks to Power to Be staff member Graham Bos at the Learn to Camp event in Delta.
2. Good food and friendship were the focal points of our Surrey Peer BBQ. From left to right: Jaspal Singh, family friend, Amit Sharma, and Wald Huseini.
3. Agasha Muteseseira takes a spin on the track during the Nanaimo Peer BBQ and Handcycling event (photo by Jessica McLennan).
4. Co-captain Kristen McBride (seated) and part of her crew from Squamish were on hand to enthusiastically support SCI BC's Walk 'N' Rollers team at the Scotiabank Charity Challenge.
5. Competition in giant jenga was fierce during our Guy's Garage in Vancouver. Steve Milum and Ryan Schweizer square off in a classic.
6. Joel Ewert and Josh Holdon do battle during a wheelchair rugby session at this summer's Multi-Sports Day in Prince George.
7. SCI BC Peer Program Coordinator Josh Dueck leads an adapted yoga session during our first ever Wellness Retreat, held in Merritt.
8. Making music at our Guy's Garage in Vancouver (left to right): Ryan Clarkson on harmonica, Graeme Wyman on bass, Dave Symington on drums, Danny Sloan on guitar.
9. Members of our Okanagan Coffee Group explore beautiful downtown Kelowna. From left to right, Scott James, Ian Wright, Christa Akins, Anand Kannan and Spring Hawes.
10. Jana Husseini learns some new kitchen skills and recipes at a recent cooking class held at the Chuck Bailey Recreation Centre in Surrey.

**Check out all of our photos on Facebook @SpinalCordInjuryBC.**

# Garden Sculpting

From humble beginnings 25 years ago, Victoria's Alistair Green and Garry Curry have worked hard to create a reputation as stone sculptors. Recently, their tenacity paid off with a prestigious appointment as artists-in-residence at The Butchart Gardens.

When we heard through the grapevine that two sculptors who use power wheelchairs had set up shop and were wowing visitors at Victoria's world-famous The Butchart Gardens, we had a sneaking suspicion that it was none other than SCI BC Peers Alistair Green and Garry Curry—who we believe to be the only commercially-successful quadriplegic stone carvers in the world.

We were right. Green and Curry, who we first profiled in the Summer 2013 issue of *The Spin*, have been artists-in-residence for the past two summers at The Butchart Gardens, a National Historic Site of Canada. That means every Thursday, Saturday and Sunday afternoon, they take a break from their Victoria-based studio and move their operation to a stunning pergola next to the water wheel at the entrance of the gardens, where staff have set up their display, workbench and tools prior to their arrival.

"We got the opportunity in 2018 to become the resident artists by way of Gary's mother," says Green. "She's also an artist and works with a jeweller who is friends with the Butchart family. He told Butcharts about us, and once they had seen our work, they extended an invitation to become artists in residence."

After receiving glowing reviews from their first summer, the Butchart family invited Green and Curry back for 2019.

"I believe they were just extremely happy with us and the way we represented the gardens while we were talking with the general public," says Green. "We took it extremely seriously as we were representing our disability as well as our art. The opportunity that presents itself through working and having our art in the gallery is being associated with the prestige that goes with The Butchart Gardens name. Exposure to more than one million visitors a year opens the doors for us to have our work in other galleries, or other points of sale."

For Green and Curry, who have worked in the privacy of their own studio space for the bulk of their career, one of the pleasures of being artists-in-residence is seeing the "Aha!" moment when a visitor to the gardens takes an interest.

*LEFT: Longtime friends and artistic colleagues Garry Curry (left) and Alistair Green divide their time between greeting visitors and working on projects at The Butchart Gardens. RIGHT: Green with some of the duo's pieces in The Butchart Gardens gallery.*

"Our time is spent pretty evenly between speaking with the general public and working," explains Green. "The reception from the public is amazing! They see the work and time that goes into our art. Visitors love to watch the techniques and are always interested in our adaptive braces and the huge variety of tools that we've made accessible for ourselves. A lot of the time, they don't notice the wheelchairs until we actually point out the fact that we have spinal cord injuries."

Green adds that they try to get across to every visitor they meet that an SCI doesn't preclude being creative, productive or successful.

"Our message is definitely about what's possible after injury, and one of perseverance. There's always a way to get back to the things we love to do and that make us happy if we think outside the box and believe in the possibilities instead of the adversities."

Not surprisingly, the opportunity has generated new business and income.

"There's been a lot of positives to come from this so far, as it's pushed us to begin making castings and copies of our work out of other materials. Gary has been doing some bronze work, and I've been experimenting with hydra stone and acrylic paint. Now, with the new castings and bronzings we're doing, it opens a door for us to sell in numerous locations other than the gardens."

Among their most popular subjects are J pod orcas and other whales such as humpbacks, gray whales, and right whales. They also sell a lot of other wildlife and abstract pieces.

It would be a mistake, however, to think that success has simply been dropped in their laps with this opportunity.

"Gary and I broke our necks in the summer of 1991 in separate motor vehicle accidents and became friends in rehab," says Green. "He moved back to the island before I did, and then once I moved back, we hooked up again and I started carving with him in his apartment. We used to cover his computers with bed sheets to try and keep the dust down! We made Christmas and birthday presents for family and friends as a way to get some sort of therapy through the stone."

Therapy gave way to the serious pursuit of art in the mid-nineties when they designed and created carving braces and splints that allowed them to better handle the power chisels and other tools they use. The result was increasingly impressive works of art, many of which began to find homes in galleries and collections around the world.

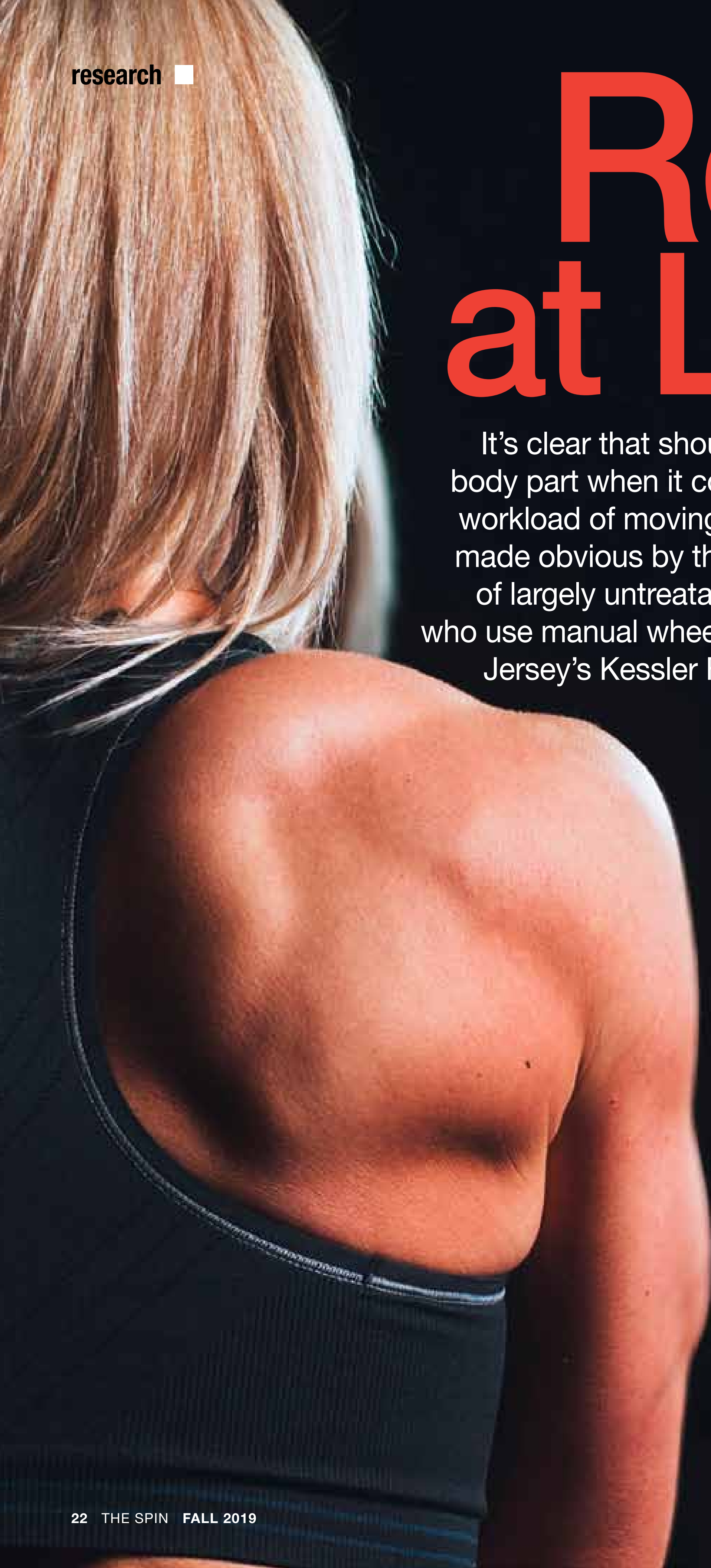
"That's when we decided to put all our energies towards being stone sculptors," says Green. "It's been about 25 years now that we've worked together. In the early days, it was all about promoting ourselves and getting our names out, as well as pushing the envelope of what people thought artists with disabilities were capable of. The biggest difference now is the fact that we do more mainstream items instead of focusing on the commissioned pieces we survived on in the early days. It's hard to get a body of work for a gallery showing when you've dedicated a year or two to creating a work of art for somebody privately."

Given the opportunity, would they have done anything differently?

"We definitely have no regrets over our career choice," says Green, "It's opened up so many different doors and avenues and allowed us to not only show our work worldwide, but to meet other amazing artists and to also teach other people with disabilities how to be creative and work with the stone."

If you're someone with an SCI who has an urge to create art, Green has a message for you.

"Never give up, and embrace the challenges with a positive outlook—positive things will happen! I never dreamed when I first broke my neck that I would be living such a fulfilled, amazing life, surrounded by wonderful people. We were told all along the way about how it wasn't possible and how difficult it would be for us to make this possible, so it's nice that our stubbornness and tenacity has paid off. Our opportunity at The Butchart Gardens is a reward for our tenacity—it's great being able to meet people from all around the world who have different perspectives on what it means to be disabled and shatter those stereotypes through our sculpting." ■



# Relief at Last?

It's clear that shoulders aren't the most durable body part when it comes to, well, shouldering the workload of moving us through this world. That's made obvious by the staggeringly high incidence of largely untreatable injuries in people with SCI who use manual wheelchairs. New research at New Jersey's Kessler Foundation offers some hope.

Recently, a group of researchers based in New Jersey published promising preliminary results from a small trial to test a minimally-invasive, long-lasting treatment for manual wheelchair users who live with ongoing shoulder pain that doesn't seem to respond to other alternatives. It consists of carefully harvesting a person's own fat and processing it to yield micro-fragmented adipose tissue (MFAT), which is then injected into the required location in the shoulder joint using precise ultrasound guidance.

The use of adipose tissue as a treatment dates back at least to World War I; there are written accounts of battlefield surgeons packing autologous (which means the donor and the recipient are the same person) adipose tissue into open wounds in the hopes of preventing infection and accelerating the healing process.

In the last few decades, there has been growing research interest in the potential for adipose tissue to repair injured or damaged tissue. One company that has emerged as a leader in this space is Milan-based Lipogems International, which has developed its own patented MFAT transplantation process. It's been tested for safety, and in 2018, the FDA approved it for some orthopedic and arthroscopic procedures—for example, with arthritis in the knee. But it's never been tested for the specific purpose of treating the injured shoulders of people with SCI who use manual wheelchairs—until now, that is.

The study was led by Dr. Trevor Dyson-Hudson, who, as a physician and Director of the Center for Spinal Cord Injury Research at New Jersey's Kessler Foundation, specializes in the restoration of function and mobility after SCI, as well as treatment of SCI secondary complications. (As an aside, he is also a C6 quadriplegic.)

The results, while not conclusive, are promising and suggest that MFAT transplants could be an effective treatment for chronic shoulder pain.

"The idea to explore the use of MFAT as a possible treatment for chronic shoulder pain in persons with SCI really originated with my colleague, Dr. Gerry Malanga," explains Dyson-Hudson. "Dr. Malanga is a physiatrist, sports medicine physician, and Director of the New Jersey Regenerative Institute. I have known him since I first started at Kessler 22 years ago—he was one of my mentors. We had collaborated on a similar study investigating the safety and efficacy of platelet-rich plasma (PRP) injections for chronic shoulder pain in persons with SCI. The results from that study were promising, so I was in the process of applying for more money to do a larger clinical trial with PRP when Dr. Malanga suggested doing one in MFAT instead."

Malanga's rationale was that results from larger clinical trials of PRP in able-bodied persons were a mixed bag—some showed PRP was more effective than standard therapies such as physical therapy or corticosteroid injections, but others studies showed no difference.

"Dr. Malanga had started offering MFAT injections as an alternative to PRP injections and bone marrow cell injections in his private practice based on promising results he had seen in able-bodied persons with shoulder and knee injuries," says Dyson-Hudson. "He suggested that, rather than continuing down the path with PRP, we consider doing an exploratory study to look at the feasibility, safety, and effectiveness of MFAT injections in persons with SCI who had chronic shoulder pain."

Dyson-Hudson agreed, and the researchers (there are five on the team) recruited ten participants for the study. All had an SCI, used a manual wheelchair, and had chronic shoulder pain. The preliminary results, published in the May 13 issue of Spinal Cord Series and Cases, did not summarize the entire trial; it was a case report that focused only on the first study participant to complete the study, a 54-year-old man who had sustained a T10 complete injury ten years ago.

The participant, who wishes to remain anonymous, is an active manual wheelchair user and avid weight lifter. For three years prior, he had complained of chronic pain in both shoulders that was unresponsive to traditional treatments.

"He is a very active individual who had been severely hampered by shoulder pain the last few years," says Dyson-Hudson. "He had undergone surgery in one shoulder a few years earlier with disappointing results—the pain was coming back—and he was now doing repeated steroid shots to treat the pain in the other shoulder. The steroids would relieve the pain for a couple of months; however, it would always come back and he would have to get another injection to relieve it. Remember that repeated steroid injections are not recommended if it can be avoided—over time, they can actually damage tendons and interfere with healing. He really didn't want to do another surgery, so wanted to see if there were alternatives."

The researchers proceeded with Lipogems treatment of his right shoulder

## The Lowdown on "Wheelchair User's Shoulder"

It's a problem that has baffled SCI clinicians and researchers for decades.

A lifetime of wheeling, combined with a daily workload of supporting body weight during transfers, has a high certainty of resulting in some form of shoulder injury and pain for many people who use manual chairs. Some studies suggest that as many as seven out of every ten manual wheelchair users will experience this.

The specific injury is usually a tear in one of the tendons of the rotator cuff, along with degeneration in the bone structure of the entire joint. The clinical term for this is chronic refractory shoulder pain.

Too often, the real-life outcome of this is seen by some as much more disabling and independence-compromising than the original SCI. And it often occurs at a time when people are at an age where other health complications are beginning to crop up. Many Peers, even those with paraplegia, end up switching to powered mobility, being restricted in their recreation and exercise pursuits, and increasingly relying on caregiver support.

Up to now, there's been little to offer those with shoulder injuries from overuse. The importance of prevention is stressed during rehab, but it's pretty hard to convince a young and healthy person with SCI to continuously keep their shoulder health top of mind in the midst of their busy lives. Add to that the fact that there are typically few warning signs—that first twinge of pain is often a sign that serious and, to varying degrees, irreparable damage has occurred.

Treatments are few, and most ineffective. Physical therapy offers modest improvements for some. Corticosteroid injections provide relief, but only for a short duration, and they can also further compromise the integrity of the joint by thinning bone and contributing to tendon rupture. Painkillers only mask the pain for short periods and carry their own side effect challenges. Surgery is an option, but is expensive, risky, and has an alarmingly-high incidence of either little to no benefit—or worsening of the problem.

*Dr. Gerry Malanga (left) and Dr. Trevor Dyson-Hudson performing a post-treatment follow-up examination with their study's first participant—who is still pain-free today. (Photo courtesy Kessler Foundation/Jody Banks)*

only. The first step involved ultrasound and MRI examinations, which revealed a rotator cuff tear and degenerative changes of the acromioclavicular joint, one of the joints that's located at the top of the shoulder.

The participant's own fat was then harvested and processed using the Lipogems system to yield sufficient MFAT. This was then injected into key locations of shoulder, with the needle carefully guided by ultrasound.

For the first four days after the treatment, he minimized weight-bearing activity with the shoulder. He was then instructed to slowly increase his normal everyday upper-limb weight-bearing activities, using pain as his guide. He also began a functional rehabilitation program at home 24 hours after the procedure, which started with stretching and progressed to include strengthening exercises after one month.

The results were eye-opening. Dyson-Hudson and his colleagues used a variety of scientifically-validated tests to measure the participant's post-injury progress. He reported almost immediately following the treatment that his pain and discomfort were significantly lessened, and his ability to perform activities of daily living improved. His test scores continued to improve as months passed by. After one year, he remained pain-free and maintained his functional improvements. Not only that, the rotator cuff tear had shrunk by 50 percent when scanned with MRI.

"We were all excited and a little bit amazed at seeing the positive results and surprised that improvements were sustained even one year after the injection," says Dyson-Hudson. "Not only did test scores improve, but the participant's function improved too, which is much more important. We often base treatment need and success on what images show, such as those from MRI. However, results from images—the signs of tissue pathology—don't necessarily correspond to pain levels or levels of lost function. What's really important is how people feel and how they function."

There were no adverse side effects reported by the patient.

As for the other nine participants, the team has completed the treatment in a single shoulder of each, along with six-month follow-ups. They are currently in the process of writing that paper for publication.

"Not all have seen the same dramatic results the first participant saw—two had no change in shoulder pain," says Dyson-Hudson. "However, the majority have had significant decreases in shoulder pain and significant improvements in shoulder function even one year after their MFAT injection in those we've seen."

So just how exactly is MFAT improving shoulder health and mobility? Dyson-Hudson says the exact mechanisms aren't yet known conclusively, but he and other researchers in the area agree that it's helping in at least two ways.

"Adipose tissue can provide cushioning that supports and allows tissue to heal," he says. "There may also be growth factors and/or groups of cells within the adipose that may help strengthen remaining tissue such as tendon or cartilage, or help with healing."

Despite the positive results, the researchers did issue some cautions in their first paper. The first is that the results summarized and published to date are for only one of the ten participants. The researchers also concede that, aside from the measurable improvement in the tendon tear, the results are somewhat subjective—in other words, they are based on the perception of pain by the participant. As such, there is the potential for a possible placebo effect. As well, the MFAT injection was accompanied by needling of the tendon, which has shown some therapeutic effect for the treatment of tendon inflammation.

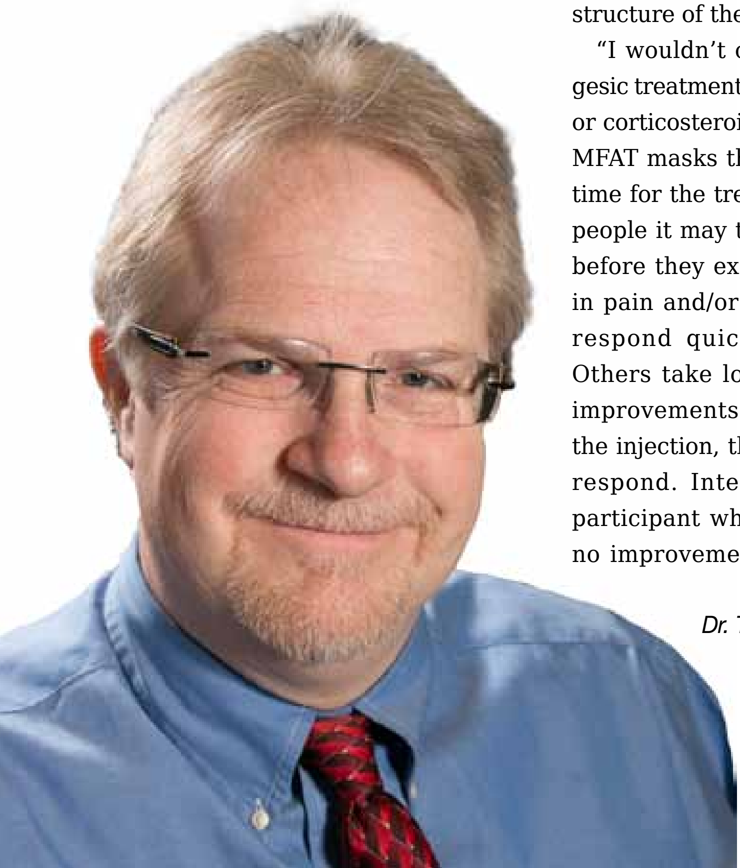
"Results could be from the needling of the tendon itself or placebo, because they're getting an intervention that is pretty involved and their expectations and hopes are high that they will get better," he says. "However, these are people who have tried other treatments such as physical therapy and steroid injections for their chronic shoulder pain for at least six months, and those treatments didn't work, or only worked for a little while before the their shoulder pain came back. In our study, of the first eight participants who reached their one-year follow-up point, six of them still experienced significant improvements in pain and function even after one year. And it's now two years and counting for our first participant, who was described in the paper."

The researchers also concede that the formal stretching and strengthening programs provided to each participant to complement the MFAT treatment have also shown benefits all by themselves in some people with SCI reporting chronic shoulder pain. However, they also point out that the study participants' untreated shoulders continued to be painful, in spite of the fact that the strengthening and stretching regime was done with both arms.

A final concern is that, while the tendon tear had clearly shrunk, other MRI-observed damage didn't improve—for example, the original inflammation in several tendons remained unchanged at 12 months. However, it's entirely possible that this means the most powerful benefit of MFAT transplantation could be its ability to reduce inflammation and pain signalling, as opposed to outright structural repair.

For this reason, we asked Dyson-Hudson about the possibility of further damage occurring if MFAT is somehow masking the pain as opposed to completely restoring the underlying structure of the shoulder.

"I wouldn't consider MFAT an analgesic treatment like ibuprofen, napoxen, or corticosteroid injection. I don't think MFAT masks the pain. In fact, it takes time for the treatment to work. We tell people it may take up to three months before they experience improvements in pain and/or function. Some people respond quicker—within a month. Others take longer. If they don't see improvements by three months after the injection, then they probably won't respond. Interestingly, we had one participant who reported he still saw no improvement in pain at his three-month follow-up visit, and then called back a few days after the visit to say his shoulder pain was completely gone. He was amazed—and so were we. This improvement—no shoulder pain—was still sustained at his one-year follow-up."



*Dr. Trevor Dyson-Hudson*

Clearly, a more rigorous trial with more participants is needed to confirm the promising results and rule out other explanations for the improvement. That will happen sooner rather than later, as Dyson-Hudson and his colleagues have been approved for funding to conduct a MFAT transplantation safety and efficacy study in 28 wheelchair users with SCI who have chronic shoulder pain.

This trial, which is just underway, is a randomized and controlled trial—the 28 participants will be randomly-assigned to receive either MFAT or, as a control, corticosteroid injections. All participants will then undergo a standardized home exercise program, and periodic follow-up for six months after the injection, including physical examination and imaging studies.

We'll attempt to wait patiently for science to take its course. But we can't help but be excited by the prospect of the preliminary results being replicated and confirmed—and the potential for a new standard of care for chronic shoulder pain to emerge for our readers and others with SCI all around the globe.

"All of our participants were very active," says Dyson-Hudson. "They worked, they travelled, they did wheelchair sports or other recreational activities such as water skiing or snow skiing. They all relied on manual wheelchairs for their mobility and relied extensively on their upper limbs for their other activities of daily living. The improvements seen even after one year were really amazing considering these people were going back to their regular everyday activities—the things they had enjoyed doing but had stopped or curtailed because of their shoulder pain."

You can read more information about Dr. Dyson-Hudson and his work at kesslerfoundation.org/aboutus/Trevor Dyson-Hudson. ■

# Cabin Fever

## New accessible cabins at Cultus Lake offer an amazing barrier-free camping experience for SCI BC Peers and their families

This summer, 25 new accessible cabins opened at Maple Bay Campgrounds in Cultus Lake Provincial Park—a first-ever for BC Parks and Spinal Cord Injury BC, who worked together on the project.

"It's nice to know that accessibility, inclusiveness and universal design is top of mind when planning parks like this," said SCI BC Peer Program Coordinator Ryan Clarkson during the official opening ceremony in July.

Clarkson, along with SCI BC's Manager of Philanthropy, Shelley Milstein, helped provide valuable insight on the inclusivity of the cabins and offered input to BC Parks on their project plans.

"Feedback from SCI BC was utilized to adjust our plans and make sure we were able to get it right," says Rob Wilson, Area Supervisor for BC Parks, who worked closely with Clarkson on the project. "BC Parks are for everyone, but the reality is that not everyone can easily access them, and BC Parks wants to change that."

Wilson adds that the lesson learned is to consider inclusivity from the start of planning through to the end of a project .

"I'm hopeful that we've found a way to incorporate the principals of universal access throughout this project. It's still a work in progress, but I'm very pleased with how it has turned out so far. I hope that together we continue to break down barriers to accessing our amazing outdoor spaces. They truly are special, and everyone should get to experience them."

The 200 square foot cabins have a queen bed, a single bed, and single bunk beds, and can sleep up to five people. Each cabin has its own covered patio with an accessible picnic table and level entry way. Heating, lighting, and a power outlet are all provided. Accessible washrooms and showers are on site, as well as a covered group picnic table area with counter tops and wash stations for cooking.

The cabins are located right next to the lake, with the lakefront area only a short wheel away.

***CLOCKWISE FROM TOP LEFT:***

*SCI BC's Ryan Clarkson speaks at the opening ceremony of the cabins. With him are the Hon. Lisa Beare, BC's Minister of Tourism, Arts and Culture, and a member of Canadian Armed Forces 192 Construction Engineering Flight, which assisted during construction.*

*Ryan Clarkson shows off the spacious interiors that can sleep up to five guests.*

*For SCI BC Peer Sheryl Newman, the cabins offer an opportunity to camp with her family. Left to right: son Justin, husband Christian, Sheryl, caregiver Jennifer, and son Matthew.*

*As Elan Van Herk and her family discovered, the verandas and accessible picnic tables offer a great way to stay out of the elements.*

Naturally, we invited ourselves over to try out the new digs. In August, several SCI BC Peers and their families, along with a few members of our staff, stayed overnight in the new accessible cabins and enjoyed the great outdoors.

"The trip was a great experience," says Peer Sheryl Newman. "Altogether, staying in Maple Bay Cabins gave me the confidence that it would be easy for me to go camping and enjoy the outdoors more. My family and I went to a cabin two years ago where there were stairs all over and I had to be carried to go to the lake. Rolling around was difficult and I couldn't access the outhouse, so I had to improvise inside the cabin. So we definitely would come back here again!"

Newman says highlights of the weekend included meeting new people and experiencing new activities like kayaking and biking. She ranks the best accessible feature as the washroom and the bed where it's level to transfer. She adds there's some room for improvement—she suggests that trash bins inside the cabin and in the washrooms, a clothesline for drying wet clothes, and a small lamp that can be dimmed through the night would all be welcome additions.

To make a reservation at the Cultus Lake cabins, visit discovercamping.ca and select "cabin" from your reservation type. You can book four months in advance, but remember that vacancies will fill up quickly in the summer. ■

## Save the Date:
## Spinal Cord Injury BC Annual General Meeting

The AGM for the Canadian Paraplegic Association (BC), operating as Spinal Cord Injury BC, will be held Thursday, October 24, at the Blusson Spinal Cord Centre, 818 West 10th Avenue, Vancouver, BC. Elections for the Board of Directors for a two-year term will be held. Nominations may be made in writing and received by SCI BC ten days prior to the AGM. Nominations may also be made at the AGM by voting members in good standing, provided that the nominee is present and gives consent, or their previous consent in writing is presented. A voting member is defined as a member who has paid an annual fee. This year's AGM and party will celebrate the highlights of our Support in Action over the past year, Join us to learn more, enjoy great food and drinks, and have fun with friends and family! Contact Maureen (604.326.1225, mbrownlee@sci-bc.ca) for more info or to RSVP.

# The Breast Experience

**Question:** what's something used by half the world's population that can improve respiratory function, posture and self-esteem, but is one of most commonly misinformed purchases? **Answer:** a bra. And for people with SCI, the benefits of wearing the right bra are even more significant.

"A person is a person, and a body is a body, and it's important not to confuse the two," says Jolaine Crawford, an SCI BC Peer from Creston, BC who has spent a great deal of her post-injury life fighting for this distinction to be recognized.

Crawford explains that, after a medical error during surgery resulted in a T6 SCI, she's had to overcome many roadblocks in order to receive adequate care, feel confident in her body, and be recognized first and foremost as a whole person.

A recent bra shopping trip presented yet another of these challenges.

"It made me feel ugly, damaged, and self-conscious," she says. "I wasn't listened to, and my body's needs weren't appraised in the context of a whole person."

Because Crawford has diaphragmatic spasms and respiratory complications from her injury, her bra needs are different than those of many others. Her ideal bra would provide support without putting pressure on her lower sternum or rib cage, and would be comfortable to wear while sitting for long periods in her chair.

In other words, for Crawford and others with SCI, wearing the right bra is more than a matter of aesthetic or practicality—it's a matter of health.

Jolaine Crawford

Enter Esteem Lingerie, an independent lingerie boutique in West Kelowna that Crawford recently visited. The boutique is owned and operated by the mother and daughter team of Florenda Pickett and Angela O'Brien. For 13 years, the duo has been committed to providing women with high quality products and bra fitting education that results in improvements in self-esteem and health.

"We wanted Esteem Lingerie to be a place of acceptance of women's bodies, where women of all figure types and sizes could find bras and underwear that works for their bodies," says O'Brien.

When Crawford went to Esteem Lingerie, that's exactly what she found. "I felt resurrected," she says. "That's an odd word to describe a shopping experience, but I think it's fitting. I left feeling whole and far more knowledgeable about how to manage my heath condition."

Knowledge is key to Esteem's mission, says O'Brien.

"The purpose of a bra is to support the weight and volume of the breast in a position that supports postural alignment and allows for deep breathing," she explains, adding that, although this goal is often overlooked in favour of fancy colours and fabric, it's essential for overall health and wellness.

"An ill-fitting bra can increase the stress on the back, neck and shoulders, which contributes to poor postural alignment and can impact proper breathing," she continues.

For Crawford, getting the proper fit was immensely important.

"I learned the science behind the bra—how this would reduce stresses on my cardio-pulmonary system and vertebral column," she says.

Crawford encourages others to explore their bra options and to keep looking for solutions that work for them.

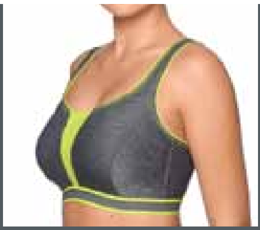
"Pick up the phone, look on the internet, find people like Angela," says Crawford. "The bra fitting wasn't dependent on anyone helping improve my life other than me following through...I survive by thinking outside the box." ■

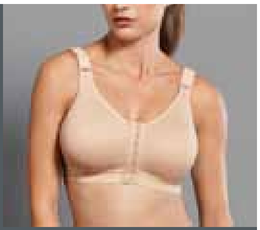
*Learn more about Esteem Lingerie online at esteemlingeriegroup.ca, by phone at 250.768.0171, or in-person at #23-2484 Main Street, Westridge Centre Mall in West Kelowna. Esteem Lingerie also offers seminars for groups and healthcare providers on the subject of bra health—they're always happy to connect!*

Florenda Pickett (left) and Angela O'Brien

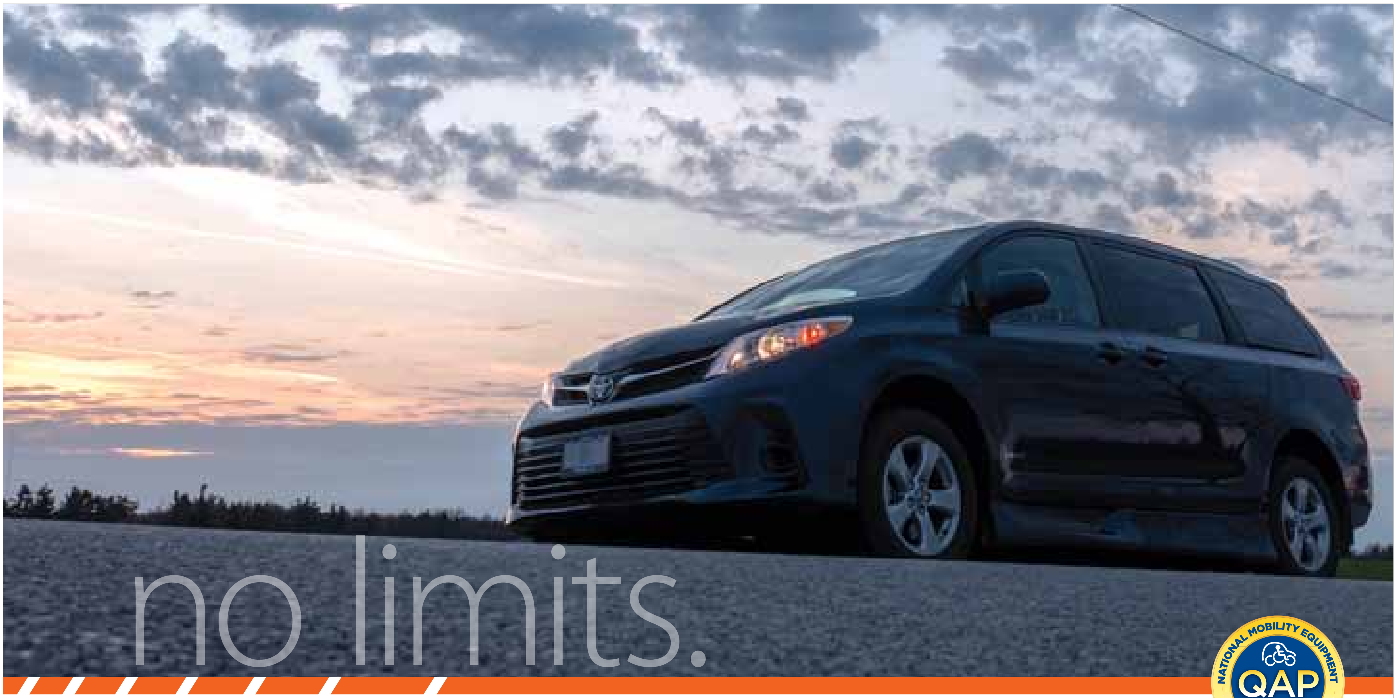
# The BRAss Tacks

**Angela O'Brien, co-owner of Esteem Lingerie, shares her top eight facts and tips about bras and breast health so you can avoid shopping trip fiascoes and find your perfect fit.**



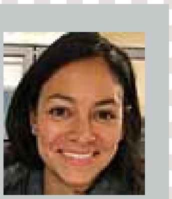


1. In order to provide effective support, a bra should fit like a comfortable second skin, offer a nice, snug hug, and have the flexibility to move with the body throughout the day. It's important to be honest and upfront about your body's needs so you can find the best possible fit!
2. Without the support of a properly fitted bra, breast tissue—which has no muscle—lays against the torso causing three main issues:
   - Skin breakdown under the breast due to a build-up of moisture, bacteria and heat in a dark environment.
   - The weight of the breast pulling on the upper back, neck and shoulder can lead to poor posture and increased tension and pain in these areas.
   - The weight of the breast laying on the lower rib cage makes proper expansion of the lower lungs while breathing even more challenging, even with good posture.
3. Non-wire bras that have more support across the back and under the arms can help lift breasts higher on the torso without the pressure of underwires.
4. Those with smaller breasts and limited hand function might consider looking for bras that can be pulled over the head, rather than done up behind the back.
5. A front opening hook and eye system on bras may also be a good fit for those with limited range of motion or lower hand function—you have a better view and more control!
6. Bras have 22 fit points, which may be different for everyone. You may be a C cup in one brand and a DD cup in another. Every manufacturer has a different fit, so be prepared to explore.
7. In North American, the average cup size on a given band is actually an E (sometimes known as a DD) to F cup, yet the average size range of bras carried by big box stores and chains only fit about 10% of people!
8. We suggest to clients with special physical considerations to purchase one garment and test it out before purchasing more. Quality bras may cost a little more up front but they tend to last longer and are well worth the investment.



# ask the SPIN DOCTOR

Recently, several Peers have asked us to address spasticity—toe spasticity to be specific. Spasticity is a common secondary complication of SCI, with some estimates of up 80 percent of people with SCI experiencing it in some form. It's hard to know how common toe spasticity is, but we know it can cause a range of problems, from simply walking for those with incomplete SCI, to putting on a pair of shoes when your toes are curled or clawed. Helping us address this problem is Rachel Abel, an inpatient OT at GF Strong.



Toe curling—it's an unconscious reaction to pleasure for many people. But for people with SCI, toe curling resulting from spasticity is often anything but pleasurable.

The first thing I would ask anyone complaining about toe spasms is if it's an ongoing problem for them, or if it's something that's just cropped up recently. If it's the former, then there are a number of strategies that can be used to reduce or even eliminate the spasms, or minimize their impact. But if it's the latter, there could be some type of health change that's triggering the spasticity—for example, a small fracture in the foot. If you've just experienced toe spasms for the first time, or a sudden increase in the frequency or severity, I would strongly suggest taking your concerns to your physician with the goal of having a scan to rule out fractures or other health triggers.

Assuming that toe spasticity is a common occurrence in your life, there are a number of ways you can attempt to minimize either the spasticity itself, or the impact in your life.

First, minimizing the problem. There are several strategies you can employ, depending on the frequency and severity.

The first is doing everything you can do yourself to improve the tone of your toes—and every other part of your body that is prone to spasticity—through stretching and range of motion exercises. You can simply stretch your toes and feet, or have a caregiver do it for you. Many people report success with this alone. But many people with SCI report excellent success for spasticity throughout your body from committing to a daily, whole body stretching regime that you can do yourself, or with assistance from a caregiver. No doubt you had a daily regime tailored for you during rehab, but life gets in the way sometimes, and it's easy to become less diligent about keeping up the effort years later. A good overview of stretching/range of motion exercises for people with SCI can be found at the HealthLink BC website (healthlinkbc.ca/health-topics/ug2762).

*Many Peers report having good success with toe spasticity by using inexpensive gel toe spacers..*

There are, of course, medications for spasticity, including baclofen (Lioresal), clonazepam (Klonopin), dantrolene (Dantrium), diazepam (Valium), and tizanidine (Zanaflex). These can be tried, but many health professionals are reluctant to prescribe them because they have side effects that outweigh benefits.

However, an approach to severe, ongoing spasticity that is gaining popularity is botulinum toxin-A (the Botox brand is one form of this) injections. These injections are carefully placed using ultrasound to deaden the nerves and relax the muscles involved. Studies have demonstrated good results. The downside is that the length of time for relief is limited to about three months. As well, repeated use can permanently deaden the nerves, so caution is warranted.

Another option may be a neurotomy. This procedure, performed under a microscope, identifies nerves that contribute to spasticity and cutting them. This is a permanent procedure, however, and obviously not one that anyone who is ambulatory and needs their spared function in their toes. You definitely do need to be cautious about how this may affect mobility.

With the exception of stretching and range of motion exercises, all of these treatments listed above begin with a referral from your family physician.

Finally, there are ways to minimize the impact of toe spasms in your life. You can be fitted for a foot brace or splint, or even an ankle foot orthosis (AFO), all of which could hold your toes flat. Custom toe spacers and molds can be very helpful. Some people report having success using Yoga toe spacers. You could also consider buying and wearing shoes that open right to the toe so you can manually sort out your toes when putting them on. And a simple solution for some might be as easy as buying and wearing shoes that are a few sizes too large for you, as they'll leave that much more space for your curled toes. These can really be useful if you're wearing toe spacers or any type of foot brace or splint. ■

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# Participate in Research

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

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

### Male Sexual Functioning after SCI

**Overview:** Sexuality is a major rehabilitation priority in men following SCI. Evidence from uninjured individuals demonstrates that physical activity can improve testosterone levels and certain health-related quality of life outcomes. However, it is unclear if physical activity has the same impact in persons with chronic SCI. The research team led by Dr. Andrei Krassioukov and Dr. Stacy Elliott aims to investigate quality of life, sex hormone concentrations and perceptions of sexual function across two groups of men with SCI who perform different amounts of habitual, free-living physical activity.

**What to expect:** Participation in this study consists of two visits. The first visit (two hours at ICORD in the Blusson Spinal Cord Centre) is for a series of assessments including blood samples, blood pressure, questionnaires, and an interview. The second visit (one hour at the Centre for Hip Health and Mobility) is for a dual-energy x-ray absorptiometry (DXA) fat and lean mass scan. You will also be required to wear a physical activity monitor for three days to provide detailed information on your physical activity behaviours.

**Who can participate:** You may be eligible to participate if you are male; age 18 to 50; have had a traumatic, C4-L2 SCI for at least 12 months; and can communicate clearly in English. See the full criteria list online (icord.org/studies/2019/06/male-sexual-function/).

**Why participate:** This study hopes to understand the relationship between physical activity, and testosterone, quality of life, and sexual function in men with SCI. Participants will receive an honorarium of $20 per visit.

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

**For more information or to sign up to participate:** Please contact Dr. Tom Nightingale by email (tnightingale@icord.org) or phone (604.675.8856).

### AAPLEwalk: A novel gait mimicking exercise machine

**Overview:** Researchers in Dr. Jaimie Borisoff's lab are exploring exercise options for people with lower limb disabilities and looking for feedback on a new sit-to-stand exercise machine that aims to provide cardiovascular fitness and the therapeutic benefits of standing and walking like those provided by exoskeletons.

**What to expect:** For this study, participants will be required to participate in a two-hour moderated focus group discussion during which they will be asked to talk about exercise options and existing adapted exercise machines for people with mobility limitations. They will also be asked to provide feedback on a novel exercise machine being developed at BCIT.

**Who can participate:** You may be eligible to participate in this study if you have a spinal cord injury or other physcial disability that affects your ability to walk (for example, multiple sclerosis, cerebral palsy, post polio syndrome, stroke, etc); are 16 years of age or older; are able to communicate effectively in English.. See the full criteria list online (icord.org/studies/2019/06/aaplewalk/).

**Why participate:** Results from this study will be used to guide further development of the researchers' prototype exercise machine and provide future direction of potential research and design around adapted exercise machine technologies. Participants will be provided with a $75 honorarium for their participation.

**Location:** The study will take place at the Centre for Applied Research and Innovation, BCIT Burnaby campus.

**For more information or to sign up to participate:** Please contact the study coordinator, Angie Wong, by email (angie_wong@bcit.ca) or phone (604.451.6934).

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

## Find it difficult to get a healthy dinner together? Consider cooking an

# easy one-pan meal

— By Joanne Smith

As kids, hearing, “Supper’s ready!” was music to our ears. As adults with disabilities, the thought of pulling together a healthy dinner each night is much less harmonious. Orchestrating weekly meal plans, grocery shopping, washing, chopping and cooking can be daunting and difficult.

It’s well-documented that many people with disabilities experience malnutrition. Common deficiencies include macronutrients such as carbohydrates and protein. But they also include micronutrients like vitamins, minerals and essential fatty acids, vital for managing the complications of disability. Long term vitamin and mineral deficiencies in individuals with disabilities can contribute to the development of many common, recurring and potentially life-threatening secondary health complications such as constipation and bowel obstruction, bladder infections, sepsis and pressure sores, and cardiovascular and respiratory disease. These secondary conditions, in turn, place additional demand on the body for nutrients.

The nervous system requires specific nutrition, such as that provided by B vitamins and essential fatty acids, to function optimally. Therefore, it’s essential that individuals with SCI consume these vital nutrients every day.

Numerous challenges—whether chronic pain, transportation access or limited upper extremity function—can make it difficult to buy and prepare fresh, quality food on a regular basis. So many people with disabilities frequently rely on unhealthy, processed/fast foods that are low on vitamins and fibre, yet high in trans fats, which further deplete nutrients from the body.

But there are strategies to make meal prep and clean up easier and less time-consuming that can help replace burgers and burritos with healthy, balanced home-cooked meals.

### One-Pan Lemon Honey Chicken

- 2 chicken breasts or thighs (add more chicken for leftovers the next day)
- 1 bunch asparagus (or broccoli, cauliflower or Brussels sprouts)
- 1 small bag new potatoes
- 2 garlic cloves chopped
- 1 lemon
- ¼ cup olive oil
- 2 tablespoons soy sauce
- 2 tablespoons honey

Pre-heat oven to 400 F. In bowl, mix olive oil, garlic, honey, soy sauce and the juice of one lemon. Spread chicken, potatoes and asparagus on a baking sheet. Pour sauce mixture over everything until well-coated, and cover with foil. Bake 25 minutes.

One-pan dinners, also known as sheet pan dinners—where the entire meal is baked on the same pan—are one of my favourite ways to simplify food prep, cooking and clean up, while maximizing nutrient intake. Because you can throw starches, nutrient-packed vegetables and meats in one pan and cook them all together, one-pan dinners can provide all the nutrition you need without having to juggle multiple cooking methods at the same time. When you’re done, there’s often little more than a cutting board, a knife, a bowl and one pan to clean up.

Another benefit of one-pan dinners is that they make it easy to cook batches big enough for leftovers. For wheelchair users, simply getting enough food into your system is of great importance, as when the body does not get the calories it needs, it can break down its own muscle and tissue in order to function. Transfers and wheelchair propulsion are difficult enough without muscle loss and weakness resulting from malnutrition. Leftovers might not be sexy, but reheating a two-day old dinner is a lot better for your body than skipping a meal because of time constraints or consuming a nutritionally deficient replacement.

As one-pan dinners show, putting nutrients into your body doesn’t have to be complicated. Asparagus contains high levels of vitamins C, A, K and E, as well as folate, potassium and phosphate; chicken is high in vitamins B5 and B6; potatoes are high in vitamin C; garlic has excellent anti-inflammatory properties; and olive oil provides essential fatty acids. The recipe to the left contains all of these ingredients and more. You can find other great one pan recipes at joyfulhealthyeats.com, thelemonbowl.com, and cookinglight.com. And you can find more meal information at sci-bc.ca/category/recipes-and-nutrition.

This simple cooking method will soon have you singing, “Supper’s ready!” ■

*Joanne Smith is a certified nutritionist and owner of Fruitful Elements, a company that focuses on providing personalized nutrition programs for individuals with disabilities. She is the co-author of* Eat Well Live Well with Spinal Cord Injury & Other Neurological Conditions, *and has also been the co-lead in several university-based nutrition studies. Learn more at www.fruitfulelements.com.*

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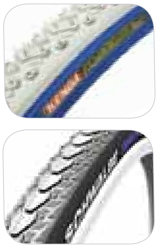

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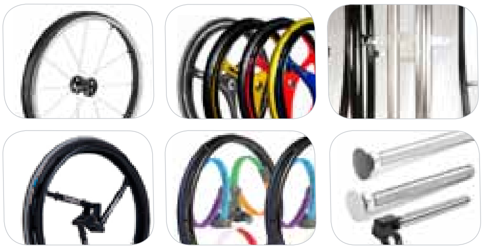

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