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SPINAL CORD INJURY BC

SPRING 2019

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The Importance of Feedback

Feedback. It's a word with many meanings, but at its core, it's a response to something. The intended message can be positive or negative, but how it's delivered can also help determine this. When the MC at a wedding stands with the microphone in front of the speaker, the resulting ear-piercing audio feedback makes everyone cringe. But when skilfully harnessed by the likes of Jimi Hendrix or Sonic Youth, feedback can make listeners want to crank the volume (at least for their fans).

In these ways, acoustic feedback is not unlike the feedback we get in our everyday lives: when not delivered well, it can yield negative consequences that are often opposite to the intended purpose. This is one reason we often dread feedback. But when delivered in a constructive way, positive or negative feedback can be received positively and be an essential ingredient in helping to improve ourselves or whatever it is we're doing, making, or delivering.

Don't worry, this is not going in the direction of a rant about the lack of civility and destructive feedback offered through social media. Instead, this is a positive look at feedback—the feedback you continue to provide SCI BC, and how it's helping us to improve and be more relevant to you. You, the readers of *The Spin* and those who are involved in our services, have a long history of providing us with feedback. Often, your feedback is unsolicited. You let us know when you like something and when you don't. Mostly, you provide it in constructive ways. And when we ask for your feedback about our services, as we're required to do for reporting to our funders, you're generous with your time, opinions, and ideas.

As an indication of the value we place on your feedback, we recently launched a new feedback-gathering initiative. Feedback February will be an annual opportunity for you to provide us with your thoughts and opinions on the services we're providing and ideas for services, events, resources, and whatever else you'd like us to provide. Our first attempt at Feedback February featured four online discussion groups through which Peers from across the province joined the themed discussions by phone or videoconference.

The feedback received through Feedback February has already changed how we approach one of our biggest events of the year, our annual SCI Health Forum. Instead of holding one day-long event, many of you suggested we hold a number of shorter, focused forums on topics of priority interest. This is exciting for us and will provide a better experience for you.

Sometimes the feedback you give us extends beyond what SCI BC does. We welcome this too. Although we're not an advocacy organization per se, we do get involved in advocating for changes that will make our communities, province, and country more accessible and inclusive. Often, we will support Peers in their advocacy efforts. An excellent example of this is highlighted in the story of the South Fraser Active Living Group in this issue of *The Spin*. The constructive and strategic feedback this group has provided civic officials in Surrey and other Fraser Valley communities has yielded many improvements to access and inclusion, with many more to come.

Your feedback is what keeps us going. It's what keeps us evolving and improving. Thank you for your feedback. Keep it coming!

- Chris McBride, PhD, Executive Director, SCI BC



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WIRELESS WHEELCHAIR CHARGING PAD

Researchers at Utah State University have designed a wireless wheelchair charging pad. Wheelchair users simply drive onto the pad to start charging. Using a mobile app, they can also instruct their wheelchair to go charge itself without actually being aboard. The pad detects the position of the chair once it's in place, and activates the closest of its 48 overlapping charging coils (using just one coil at a time protects users and nearby people or pets from harmful levels of magnetic fields). The system eliminates the need for a plug-in charger and promises to make it easier to keep your batteries topped up. Note that this device is not yet commercially available; you can find out more at www.engineering.usu.edu.

BIGPAW

BigPaw, developed by Australian paraplegic Adrian Hollis, is a retrofit wheelchair footplate designed to keep your feet safe and sound. Constructed from anodized aluminum, BigPaw is much longer than OEM footplates, and incorporates a soft rubber mat and a Velcro strap to keep your feet firmly in place, even over rough terrain. These features work together to prevent your feet from contacting the castors or being drawn under the footplate. Because of its size, BigPaw also reduces the pressure on the bottom of your feet. It comes in a variety of widths, and quickly installs on top of your existing footplate with no tools required. The strap can be easily tightened or loosened with finger loops. Visit www.bigpaw.com.au to learn more.



EASY REACH

The Easy Reach is a platform that bolts securely onto any elongated oval toilet and raises your existing seat ten centimetres. Large open areas on either side make it easier for people with disabilities or their caregivers to reach under the seat and wipe without heavy lifting. The front pillar also has a splash guard to keep floors and clothing clean. It will safely support up to 270 kg, and it's designed to allow your existing toilet seat and cover to be mounted on top. See more details at www.easyreachtiletseat.com.

Innovations

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

LAPSTACKER

The Lapstacker is a retractable strap system that allows wheelchair users to securely hold items on their laps while keeping their hands free to push. The device's tensioned straps are pulled over whatever you're carrying, and the buckles (either manual or magnetic) are then clipped together. The buckles tuck away on either side of the wheelchair when not in use. The straps have finger loops for those with reduced hand function. The device includes a mounting kit that's suitable for most wheelchairs. The Lapstacker was developed and is being sold by New Zealand's adaptdefy Limited—visit www.adaptdefy.com to learn more.



Room for Debate



What do you think of “inspirational” videos of people with disabilities?

Recently, a video from Brazil surfaced that showed two groomsmen helping a groom out of his wheelchair so he could stand while having his first dance with the bride. The video, which you can see at <http://tinyurl.com/yxf8relc>, went viral—it was even acknowledged by late night TV host Trevor Noah, who tweeted, “I only cried twice watching this video.” The public may see videos like this as “heartwarming”, but some people with disabilities don’t agree, no doubt because they don’t reflect reality and may set unrealistic expectations of all people with disabilities. So...do these “inspiring” videos send the wrong messages, or should they be celebrated for the personal achievements they reflect?



Ultimately, I support this video—but not without reservations, and certainly not because I find it heartwarming.

My initial reaction to the video was a full body cringe, and I had to stop watching. First, it’s beyond awkward that the guy is being held between two other men (surely there was a better way?) Second, it’s the same old “walking is everything” message. In order for the day to be truly joyful, there must be a public attempt at returning to the accepted norm—that is, the groom must stand to give his bride a meaningful embrace and dance. Third, it’s classic inspiration porn. The groom is so determined to stand at his wedding that nothing will stop him! What a guy! Fourth, the video is pared down to a short clip that spread like wildfire on social media, which meant well meaning but obtuse acquaintances would insist on showing it to me with breathless anticipation.

It’s denial of disability on multiple levels. The individual is in denial of his mobility impairment, and the viewers/sharers of the video are in denial that a life lived in a wheelchair can be worthwhile and fulfilling—the ONLY goal must be to stand or walk again.

And yet, there is no denying that the bride is full of happiness. And the groom appears to be as well. This is *their* wedding day. They are literally surrounded by family and friends and love. They have enlisted the help of others to make their dancing dream come true.

Who am I to say they are wrong? It’s their wedding. They chose to do this, and it’s making them happy. I, certified internet stranger, do not get to police their happiness. Disability is complex. Not everyone has their Champion Advocate hat on all the time. Sometimes, one simply wants to feel normal. And if normal to this couple means being held up by friends to enjoy a dance at their wedding, then go for it, you crazy kids.

A small part of me, however, does wish that this moment didn’t go viral because videos like these result in me having to wear my advocate hat, to explain yet again that no, I do not desire to walk again above all else and yes, I am quite happy with my life. Even if that life is lived from a wheelchair.

– J. Salman, SCI BC Peer, Vancouver



I’m really not sure of the reasons that this gentleman wanted to do this. Maybe he’s newly injured. Maybe his dream has always been to dance eye to eye. I can understand his desire to find a way to be closer to his partner.

But would I want to do this? No. I would feel like a spectacle, and my dream isn’t to walk.

I guess what I’m trying to say is that, when I look at this video, I see two friends trying to help their friend’s dream come true. But most of the world looks at this video and sees two friends helping their friend “walk” or become “normal” again. So that’s why I believe it shows the wrong message to the world.

My dream is to be seen as normal, just as I am, wheelchair and all. I believe I am normal. But there are many in the world that don’t think anyone with a disability is normal. And it’s videos and thoughts like this that serve to perpetuate that mentality.

Some might ask, “Why do you care what others think?” Well, in this instance, we should care. Because the reality is, if people don’t get on the disability train, the world will continue to be inaccessible, and hard for people with disabilities to seamlessly integrate into society.

The bottom line is that, to the general public, this video makes it seem that he just wants to walk again, and that reinforces to the public that every single person who uses a wheelchair feels the same way. Those of us who accept that we won’t walk again, and don’t care if we do, are unfortunately viewed just as others with disabilities are viewed, and lumped into the same category. And I think that’s what bothers us.

Hopefully, more normative videos can be shown, and we can feel comfortable with people wanting to walk and sharing their own moments for different reasons.

– Kirsten Sharp, SCI BC Peer, Vancouver

VOICE YOUR OPINION! Disability and controversy often go hand in hand. Visit facebook.com/spinalcordinjurybc and weigh in on this and other contentious topics.



Get some faith...or not.

Inspired by the true story of a Vancouver paraplegic's inexplicable recovery from paraplegia 13 years after injury, *Act of Faith* is a story that's celebrated by the religious community and questioned by others. *Act of Faith* is presented by RealWheels theatre company, which strives to deepen the audiences' understanding of the disability experience. The show runs April 11 to 20 at The Cultch theatre in Vancouver. For tickets and details, visit www.realwheels.ca.



Walk or roll for SCI BC.

Lace up your running shoes, pump up your tires, and get your fundraising faces on—it's time to register for the 2019 Scotiabank Charity Challenge and #AccessPossibility! Join or donate to SCI BC's Walk 'n' Rollers team as they prepare to take on 5K on June 23. This is one of our most important fundraising events each year, and your support is vital. Register by connecting with Terry at tchen@sci-bc.ca or learn more online at www.sci-bc.ca/scotiabank-5k-2019.



Be well in a weekend.

Need a break from the hustle and bustle? We're hosting our first Wellness Weekend, May 23 to 26, in Merritt! Enjoy a meaningful weekend of restoration at the spectacular, fully accessible Abilitas Foundation Cold Water Ranch Lodge. Activities to be enjoyed include adaptive yoga, cooking, handcycling, Trail Rider exploration and, as always, forming and renewing Peer connections. Keep an eye on our events calendar for more details: www.sci-bc.ca/events.

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Hit the Wall

Antonio Ramunno was simply trying to find a way to exercise and improve his own independence and health after his SCI. But his inspired innovation, Wallgym, might be a game changer for any wheelchair user seeking a home-based way of getting in better shape.

ANTONIO RAMUNNO HAS ALWAYS BEEN A HANDS-ON GUY.

Up until four years ago, the 50-year-old father of four ran his own roofing and siding company in his hometown of Kamloops. When he wasn't up a ladder or on a roof, he could often be found tinkering in his garage. In short, he was used to solving his own problems with ingenuity and hard work long before the 2014 motorcycle accident that left him with C5 quadriplegia, so it was only natural that he solved one of his most pressing post-injury dilemmas in exactly the same way.

Ramunno spent a total of about one year in hospital and rehab. In that time, he became convinced that the key to maximizing his abilities and independence lay in exercise—nothing else was more important in his quest to regain range of motion and strength. He made the most of his time with GF Strong's physiotherapy staff, working with therabands (resistance training) and other accessible fitness equipment.

Back in Kamloops, he quickly discovered that continuing his exercise regimen

wasn't going to be easy. His funding coverage for physiotherapy ran out, and when he started to investigate accessible, assistive workout options at Kamloops-area fitness facilities, he struck out.

He then considered the idea of working out at home. But again, he hit a dead end.

"I needed gym equipment to get better but just couldn't afford it," says Ramunno. "But even if I could afford it, all I could find were huge machines that I just didn't have space for."

And that's when he hatched the idea for a wall-mounted gym station that would take up little room and be entirely usable without him needing to transfer out of his wheelchair. Back in rehab, staff would stand behind him and hold his resistance bands while he would stretch them in front of him. He began to envision a way of hooking the bands to the wall so he could use them independently.

His first attempt was simple—basically, hooks mounted to a board that was screwed to the wall.

"It was very simple," he says. "But then I started to add things to make it

more complex. Over the period of one year, with the help of my family, I slowly expanded my initial concept and built my first prototype. That gym is in my bedroom, and I still use it all the time."

People around Ramunno—his family and friends—began to take notice.

"Everyone kept telling me that I was on to something," he says. "So I got back to work and built two more refined versions—one was ordered by a local gym, and another one I donated to our local YMCA, which provided so much support for me when I was struggling to keep exercising and maintain my strength and range of motion."

By this point, Ramunno's brainchild had morphed from its humble beginnings into a polished piece of exercise kit—a one by two meter panel that mounts with lag bolts to the studs of a wall. The system, which has since been dubbed Wallgym by Ramunno, is thoughtfully laid out with eye bolts to anchor various tensions of therabands. In turn, the therabands attach to a variety of handle grips and bars. The system also includes



hand weights, a hand strengthener, an accessory panel, Bluetooth speakers, leg bands and ankle straps.

"I can literally exercise every muscle group in my body on Wallgym," says Ramunno. "I know it's given me more mobility and strength in my arms, and improved my ability to walk with a walker. For sure, it has totally improved my confidence. But it's not just for me—I designed it so it could be used by people with a wide range of requirements and disabilities."

Positive feedback continued to roll in, and it dawned on Ramunno that he might have a commercially viable product. He applied to Community Futures Thompson Country for assistance in developing a business plan. He was quickly approved by the community-based organization, which is funded by the federal and provincial governments in order to support entrepreneurs, business owners and job seekers.

With a completed business plan in place, he moved the production of the

Wallgym out of his mother's home, leasing a commercial space in Kamloop's North Shore business area.

Today, he's hard at work, ramping up production and getting prepared to officially launch sales. Wallgym continues to receive plenty of media interest, and Ramunno is already fielding queries from Peers, including several Paralympic athletes. He's looking into advertising, and recently launched a company website (www.wallgym.ca).

At the time of writing, he hadn't quite dialed in a price, but he hopes to offer Wallgyms for about \$1,200, with an option to discount to under \$1,000 for any Peer who can demonstrate financial hardship.

For the moment, he's juggling all aspects of the business himself, including building the actual product, which he says will continue to evolve.

"It's just the beginning; I have many more ideas," he says. "It will always be changing and advancing. As for assistance, I know at some point that I will have

to hire more workers and move into a bigger facility when demands increase."

Commercial success is the priority, but it's far from the only end game—simply refining the concept and being back at work full-time has been remarkable therapy for Ramunno, who admits he struggled at times in the early days after his accident. Not surprisingly, he's grateful to those who have helped him along the road.

"I would like to thank my immediate family for supporting me, and in particular, I'd like to thank my mom because she supported me through it all by letting me turn her living room into a construction site to start it all off—I literally turned it into a wood working shop! I would also like to thank GF Strong staff for their unbelievable care and dedication, and the tools they sent me home with to further my recovery. And I would also like to thank WorkBC and Community Futures for all the help they gave me."

Visit www.wallgym.ca to learn more and see more photos. ■

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Peer Shoutouts

A big wet high five to **VICTORIA FEIGE**, who was recently crowned the world adaptive surfing champion in her division. Feige, a T12 incomplete paraplegic from Vancouver, was one of five Team Canada athletes who participated at the 2018 Stance ISA World Adaptive Surfing Championship, held this past December in San Diego.

Feige's gold medal, along with the silver medal won by visually impaired surfer Ling Pai, propelled Team Canada to its best finish ever — we finished 10th place out of 24 nations. When she's not surfing or skiing, Feige works as a clinical physiotherapist at two Vancouver clinics, HealthOne and Treloar Physiotherapy Clinic. She's also a clinical instructor in the Department of Physical Therapy at UBC and teaches when her schedule allows.

"After my injury, I wasn't sure that I'd be able to really surf, maybe only be able to go straight in the whitewash," says Feige. "My improvement in the last two years, from duckdives to cutback manoeuvres, has really opened my eyes about how much is still left to explore that I had initially written off. The adaptive surf community has shown me how good adaptive surfers can be. I'm so stoked to win my final, but that sense of discovery and progression is what I'm most excited about. I feel like this is just the beginning."

Kelowna's **BRANDON PERGER** has only been playing wheelchair rugby for a couple of years, but that's been long enough for him to be recognized for his talents. In February, PacificSport Okanagan and the City of Kelowna honoured him with a Community Sport Hero Award during the 16th Annual Community Sport Hero Awards Reception, which recognizes Okanagan volunteers, athletes and service providers for outstanding contributions to sport in the Okanagan.

Perger is a gifted athlete who has played a variety of sports at an elite level, both before and after he contracted meningitis which resulted in his partial paralysis. Currently, he's playing for Canada's Next Generation talent pool rugby squad and has his sights set on being selected to Team Canada. He's also an enthusiastic sledge hockey player and golfer.

"Receiving an athletic excellence award in my community and being recognized for success in a sport that I love playing is a huge honour," says Perger. "Sports in general, especially wheelchair rugby, have completely changed my life."



Congratulations to **MOHEE MATAJI**, who became a Canadian citizen on December 15.

Mataji was born in Nowshar, Iran. At the age of 20, he sustained a T12-L1 injury in a car accident. He was undaunted by his injury and successfully pursued a Master's degree in international law. Intrigued by the idea of living in a freer and more democratic society, Mataji applied to immigrate to Canada. In 2013, after a four year process, his application was approved, and he moved to Toronto as a permanent resident. A year later, in search of warmer climates, he completed his journey when he took up residence in Vancouver.

"Life in Canada was super easy for me," says Mataji. "There were accessible buses, taxis and trains. Most importantly, there were nice, warm and welcoming people...I am very pleased to live here and choose Canada as my country. We all know the value of a country is not just based on its natural wealth and resources, but its people, and our Canada has some of the best people in the world."

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 info@thespin.ca.

Pleasure Principles

Every person with SCI should unlock their sexual potential. Getting started is easier than you think.

by Dr. Stacy Elliott

A close-up, profile view of a person's nose and mouth, showing the texture of the skin and the shape of the lips. The person appears to be looking slightly downwards and to the right.

Sexuality is a given right. Even the World Health Organization says so. Having an SCI does not change that. Many readers have no doubt heard ignorant assumptions about people with SCI being asexual or disinterested in sex, or have been on the receiving end of insensitive questions such as, “How do you do it?” But the fact is that sexuality is super important before and after SCI...and very possible!

Sex is healthy. Feeling that you’re a sexually whole person, and that you can still experience sexual pleasure among the daily grind of pain, bladder, bowel and other secondary issues you face after SCI, is really important to your quality of life. In your own privacy or with a partner, you deserve to have a sexual life (and children, if you want). This form of communication and intimacy is what bonds us as people.

The willingness to explore, the interference of pain or other SCI complications, the feelings of sexual self-esteem, the idea of readiness to be sexual in the path of rehabilitation and getting on with life—all of these will affect sexual desire. But in general, sexual desire typically returns, and

may not be changed from pre-injury. Yes, it's true that approximately 40 percent of men with chronic SCI will have lowered testosterone, which can have a negative effect on energy and libido. But this can be addressed with proper assessment and replacement. The bottom line, again, is that you're as sexual as you were before injury—it just sometimes takes a little knowledge and perhaps a change in attitude and approach to maximize your potential.

Sexual rehabilitation is one way of achieving this. During SCI rehab, sexuality and fertility are often considered a low priority—sometimes they're not discussed at all. Yet people living with SCI rank sexuality as one of their highest priorities in quality of life surveys. For example, one survey of 681 persons living with SCI determined that sexuality was the second highest priority for people with quadriplegia, with only regaining arm and hand function being higher. And for paraplegics, sexuality was the top priority. This survey was done 15 years ago, by American researcher Dr. Kim Anderson-Erisman. Since then, other studies have confirmed her findings.

Given this, and considering that many people acquire an SCI at a young age, sexual rehab should begin in acute care (depending on the patient's readiness) and continue as an outpatient. In the Lower Mainland, this isn't a problem, as we have the Sexual Health Rehabilitation Service (SHRS) at GF Strong and Vancouver General Hospital, started many years ago by our mentor and Order of Canada recipient Dr. George Szasz. This service focuses on sexual rehabilitation—self-esteem, confidence, relationships, positioning issues, erectile enhancement, pleasure, pregnancy and more. It's also connected with The Vancouver Sperm Retrieval Clinic for men with SCI who wish to become biological fathers. As clinicians, we see people who have not had the opportunity for sexual or reproductive rehabilitation. We help these people develop a comprehensive plan to maximize their sexual potential.

But not everyone lives in the Vancouver area, and a lot of readers don't have easy access to this type of specialized rehabilitation expertise. And that's why I was keen to write this story for readers of *The Spin* who live in every corner of the province. The goal is to give you an overview of sexuality and SCI that hopefully encourages you to explore and maximize your sexual potential, and provide you with some knowledge and tools to begin to do just that.

So...what have we learned in the last four decades?

BRAIN POWER

What we've learned from our patients and others in the field is that, while motor and sensory healing reaches a plateau where no more improvement can be expected (and vigilance for loss of function becomes a priority instead!), sexual recovery continues for years, and it's all about the brain—our biggest sexual organ. If your mind is willing and accepting, repetitive positive feedback to the brain from areas other than those that may have been the jackpot before (i.e., your genitals, which you may no longer feel) can help to rewire the brain to interpret these newer areas as sexual. In other words, mapping areas of your body that bring pleasant sensations (it may be ears, neck, breast, the area of transition to injury, etc.) and combining this touch with erotic thought and arousal can lead to those areas becoming very responsive to sexual stimulation over time. That formerly non-sexual body part does not need to continue to feel nonsexual if you continue to stroke it and let your mind elevate into sexual arousal. It can turn into an erotic zone. But this takes practice, a lot of practice...and belief.

As just one example of many that I've seen, a woman I know—who has quadriplegia—has developed the most amazing erogenous zone: the hair on her head. Just having it stroked is incredibly arousing to her—it can actually be orgasmic.

People assume that this type of sexual learning has to occur with a partner. False! Giving permission to explore one-

self is critical after SCI. Think back to rehab—do you remember the exercises you did with your physio and occupational therapists? You might have been coached, but the rehabilitation itself was all you. It's the same with sexual rehabilitation. You use your brain (with sexual thoughts, reading or viewing erotic material), and envision your body as a source of electric energy and erotic feelings. This is known as body mapping, a part of self sensate focus.

In a shower or bath, or just lying or sitting quietly, take your hand (or someone else's) or a feather and, with eyes closed, begin to explore, starting with your face, neck and ears. Continue down your whole body while thinking positive and erotic thoughts. What is the most sensitive? What has potential, if you relaxed into the moment and became mentally aroused, to feel like a sexual stimulus? What parts of your body are neutral or negative to touch? What parts are not a source of pleasure, and can be avoided in the future? With deep, slow breathing, staying in your head and not criticizing or judging yourself, try to elevate that sensual feeling in your head while the stroking continues. When you feel yourself getting higher, your breathing and heart rate may increase. If you're stroking your genital area, you may even feel some increase in abdominal and lower body spasming. As long as you're not developing a headache (a sign of autonomic dysreflexia), this is okay and completely normal!

Congratulate yourself on this small but newfound change. When you continue to practice this in the presence of mental sexual arousal, things will slowly start to change. In a way, it's a form of mindfulness that allows acceptance of what your body has (versus what it doesn't have), and you're maximizing your body's potential by tuning in.

PLANNING MAKES PERFECT

Managing the factors that interfere with your sexual life and sexual pleasure before you are sexual allows you to be more present in the sexual act. In other words,

let go of the myth of spontaneity. Better planning makes for better pleasure.

You can practice this on your own. Figure stuff out in advance. What happens with the chance of incontinence if you become aroused? How long can you lie in a bed comfortably without worrying about leakage after you empty your bladder? What sexual positions can you get into and even hold? What's the biggest trigger for bowel accidents and how can you avoid this in a sexual situation? And lastly, envision the worst case scenario you dread in a sexual situation, minute by minute. Chances are you're thinking of a bowel or bladder accident. Well, do you really think a partner worth their salt will be so grossed out that they run away forever? Not likely. And if they do, they weren't worthy of you anyway! In any case, that's not the typical story we hear. Losing one's balance, kicking your partner in the midst of a spasm, and bladder and bowel accidents are part of a learning curve and seem to become less and less of a worry with experience. Partners are usually supportive, good sports and laugh it off with you.

O: GOOD, BUT NOT EVERYTHING

That's right: orgasm may not be the pillar of sexual gratification. Learning gratifying sexual arousal and enjoyment, and partners' enjoyment, is the key to intimacy, whether an orgasm occurs or not.

That's not to suggest that an orgasm isn't really nice. About 50 percent of women and 40 percent of men (with or without ejaculation) can achieve it after SCI. The more incomplete your injury and the more genital sensation you have, the more chance you can relearn this experience of climax of sexual release stemming from stimulation of the genitals. Some people can morph mild to moderate autonomic dysreflexia into a feeling of high arousal and release without a typical orgasm or ejaculation. Some men, mainly those with incomplete injury, can experience orgasmic sensations with ejaculation—if they can ejaculate at all (another issue after SCI). It may be possible that women with SCI

Sexual Aids For Every Body

Clockwise from right: the Ferti Care vibrator, the Intimaterider chair, the Hitachi Magic Wand vibrator, and The Liberator Flip Ramp positioner. This is a small sampling of the various aids that can be readily purchased to help you achieve pleasure.



have a higher likelihood of reaching orgasm after injury than men, as they may have had more pre-injury experience with non-intercourse arousal than men.

But again, orgasm is not the only end game. Orgasm potential after SCI may come from non-genital sources, like in Tantric sex practices, or orgasm when sleeping—that's your brain in action! And back we go to neuroplasticity, the brain's ability to rewire itself.

OPEN MIND = BETTER SEX

An openness and willingness to get some "help" can greatly improve your chances of maximizing your sexual potential. Sexual aids, tools and medications can be beneficial. Once body mapping has been explored (as explained on the previous page), additional help or aids may be in order.

For example, positioning aids such as positioning cushions or the Intimate Rider can really help you focus on pleasure. Photos and even erotic video (we hope tasteful and not exploitative in any way) may increase your options for becoming more active during sexual play. Medications can also help your sexual

responses—Viagra and similar drugs can be really effective to support the firmness and consistency of erections. On the other hand, too much anti-spasmodic medication (which can suppress the ejaculation and erection reflexes) or the use of some antidepressants (which may be needed) that are not sex-friendly and suppress libido or other sexual function can make response more difficult. Again, you may need what you need, but sometimes using or not using just one pill can assist with sexual functioning. This is something you need to discuss with your doctor.

And of course, vibrators for both men and women can really help you explore your sexuality, both alone and with a partner—more information on this can be found at the SCI Sexual Health website (again, see sidebar) and on our YouTube videos (<https://www.youtube.com/watch?v=MV1vGfnXJBg>).

Remember that the more open-minded you are, the more kindness you're prepared to offer to your body (a body that has changed so much), and the more willing you are to explore new things will all help determine how far down the line of sexual gratification you can go. Tan-



tric sex practitioners have led the way in showing how far the mind can direct the body—it's really worthwhile to listen to their philosophy and spend the time nurturing yourself this way.

Maybe all of this means attempting things (for example, using vibrators or other sexual aids, or Tantric sex manuals) you once felt you didn't need or are somehow "not proper." This is sexual rehabilitation! You use what you need to! You deserve it.

YOUR PEERS CAN HELP

As with most things related to SCI, peers are often the best source of advice and assistance. One good looking guy in his 30s, who was a "player" before his injury in his late 20s, once told me he felt his injury was, in a weird way, a gift. He's remained very sexual after injury, but now believes he is a much more intimate partner, with a depth of understanding and enjoyment he "never would have had before" in his pre-injury pursuit of conquests and orgasm. His experience offers a great lesson to peers.

Other times, peers are willing to explain all the issues they had, what helped

sexually, what didn't, and how they became involved in the partnerships they have. This form of openness and expertise gleaned from peer support is something we clinicians can't offer, so seek it out in person, on chats, blogs, wherever. It's very helpful.

IT'S NOT ALL FUN AND GAMES

While there are many wonderful benefits to being sexual, there are a few risks to keep in mind. The primary one is significant autonomic dysreflexia (AD). Those with injuries above T6 are most at risk, especially if they have complete high level injuries. But remember: the typical AD symptoms of bad headache, sweating and impending doom are not always experienced, even when your blood pressure is very high, so saying you "feel fine" does not always mean you are fine. This is really important to remember, particularly for men attempting to ejaculate by using a vibrator—ideally, they should go to a clinic and have their blood pressure measured while attempting this. At the very least, they should get a home blood pressure cuff and check it themselves in the heat of the moment. The same goes

for women with AD with high arousal or who use a vibrator on their genitalia or in their vagina.

While mild AD can sometimes lead to pleasant almost orgasmic sensations, higher levels of AD need to be avoided. If it occurs, stop sexual activity, sit up and put your feet down if possible. There is possibility of preventing AD in these situations with the use of medications that can be prescribed by a physician familiar with SCI, or your physiatrist.

ONE FINAL THOUGHT

Even though this article has focused on sexuality, a common related topic that often comes up is fertility and the possibility of having a family after SCI. If you'd like to be a biological parent, we say—go for it! Men can undergo sperm retrieval techniques such as penile vibratory stimulation (PVS) or electro-ejaculation (EEP). There are also surgical options, but we recommend trying the PVS and EEP options first. Semen quality does change following SCI; however, we have seen babies conceived and born healthy with sperm that was not great (it just means that the insemination part may

need to be more advanced; for example, using in-vitro fertilization). Women's fertility is unaffected after SCI, so you can become pregnant and carry a child (with a few more complications that require monitoring) and deliver very similarly to women without SCI. Most can even breastfeed (but it's OK if you can't). More information on these topics, along with contraception, can be found at the SCI Sexual Health website (more info on side bar at the right). It's important to note that, with both male and female fertility, age is an important factor to consider.

PUTTING IT ALL TOGETHER

In the 35 years I have been practising clinical sexual medicine, and lecturing and writing on the subject, one thing has become abundantly clear to me: I am not the expert. The people we strive to help are the true experts. Beyond a bit of book neurophysiology, it's my patients' journeys with sexual rehabilitation, along with my colleagues' stories about patient experiences, that have taught me all I know. No one knows their own body and their own feelings about being sexual after SCI better than a person with an SCI.

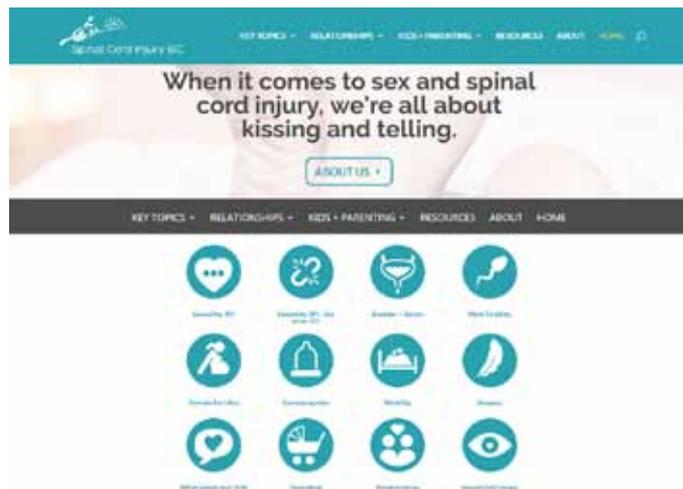
Because every injury is different in level and completeness, and every person had their own values, comfort and perception of sexuality before the injury, there is no cookie-cutter message to give a newly injured person as an able-bodied clinician, except the three basic principles of sexual rehabilitation: 1) maximize your own physiology and psychology before moving onto medications and assistive aids, 2) adapt to the new limitations of your body with the help of such medications and assistive aids, and 3) stay open to new experiences—and maybe that means even pushing your envelope in the sexual area.

In other words, focusing on what remains, instead of what's been lost, opens up a whole new world. Your brain is an amazing thing when it comes to sexuality and still remains the most important sexual organ. ■

Dr. Stacy Elliott is a Sexual Medicine Physician whose interests lie in the sexual and reproductive consequences of medical or surgical problems, particularly neurological disability. She is a Clinical Professor in the Departments of Psychiatry and Urologic Sciences at UBC and a Principal Investigator at ICORD. She is the Medical Director of the



BC Centre of Sexual Medicine, Co-Director of the Vancouver Sperm Retrieval Clinic, and Physician Consultant to the GF Strong Sexual Health Rehabilitation Service. Shea Hocaloski, a rehabilitation nurse and sexual health clinician, also contributed to this article.



More help is but a mouse-click away.

Want to know more about sexuality and SCI? Point your browser to www.scisexualhealth.ca, an online resource that's a collaborative effort between Spinal Cord Injury BC and Vancouver Coastal Health's Sexual Health Rehabilitation Service.

Virtually all aspects of SCI and sexuality are sensitively covered at the website—there's no subject that's taboo. Browse in the privacy of your own home, on your own time.

One of the most important features of the website is the ability for visitors to tell their stories and share their successes and frustrations. In the spirit of Peer-to-Peer sharing, we urge you to get involved and explain what works—and what doesn't—for you.

Need more personalized information and support? Consider seeking a referral to the Sexual Health Rehabilitation Service, which offers specialist clinical services at two sites: Blusson Spinal Cord Centre at Vancouver General Hospital, and GF Strong Rehabilitation Centre in Vancouver.

This is an entirely unique service in Canada. Four sexual health clinicians and a sexual medicine doctor (Dr. Stacy Elliott, the author of this article) are available to help. They're trained to facilitate the sexual health rehabilitation of clients and their families through medical intervention, education and emotional support. They also provide education to health care providers, students and health care consumers. And they lead in advanced research initiatives that will expand the knowledge base of sexuality and disability.

Services are provided in a manner that's respectful of individual and family values and beliefs. Your privacy is paramount, and staff employ a nonjudgmental approach that's inclusive of all sexual orientations, and geared towards the readiness of you and your family, and your sexual health goals.

The Sexual Health Rehabilitation Service takes referrals for clients in Canada, primarily within BC. If you're outside of this area, staff are able to do phone consultations, and may be able to connect you to a clinician closer to you. If you're interested in being referred to the service, or have questions about what you've read online, use the website's contact form to get in touch.

ask the SPIN DOCTOR

Vivian from Vancouver asks, “It seems that anemia is prevalent for people with chronic conditions such as SCI. I think it’s a big deal, but not much is shared about it. Can you help out here with an article or information? Our last coffee group had 12 participants, and six were talking about anemia; they all have it. They said that their toe nails go around the base of their toes like talons. They thought it was just a SCI thing, and not a big deal.” To answer this issue’s question, we delved deep into the ether. Below is what we gleaned from online searching. Note that this is not intended to be medical advice; it’s only a summation of what we able to piece together from various reputable sources. As always, don’t hesitate to seek medical attention if you have questions or concerns.



Anemia is a condition that develops when your blood lacks enough healthy red blood cells, which are essential to deliver oxygen to the cells in your body. Healthy red blood cells contain hemoglobin, a complex protein that binds to oxygen in the lungs so it can be delivered by red blood cells throughout the body.

Anemia is a widespread problem in the general population, and there are more than 400 types of anemia. These are divided into three main groups: anemia caused by blood loss, anemia caused by decreased or faulty production of red blood cells, and anemia caused by the destruction of red blood cells. Symptoms common to many types of anemia include fatigue, rapid heart beat, shortness of breath, headache, difficulty concentrating, dizziness, pale skin, insomnia, and koilonychias—an upward curvature of the finger and toe nails.

Anemia is an even greater problem for people with SCI. Estimates point to a prevalence of 50 percent or more for those with SCI. And it is a big deal—if left untreated, anemia can cause serious health problems. For example, vital organs can be damaged without enough oxygen, and the heart may have to work dangerously hard to compensate for the lack of red blood cells or hemoglobin.

If you, as a person with SCI, experience any of the symptoms outlined above, you should seek medical attention.

A diet rich in dark green, leafy vegetables can help reduce iron deficiency.



Your physician will work to determine the underlying cause of your anemia and develop a treatment plan.

The first thing your physician will investigate is any type of blood loss, through chronic internal or external bleeding—this is an unlikely cause, but obviously critical to rule out.

It’s much more likely that your cause is related to either iron deficiency, or another serious underlying chronic condition related to your SCI.

Iron deficiency anemia is caused by a shortage of iron in your body. Without adequate iron, your body can’t produce enough hemoglobin for red blood cells. Often, this type of anemia can be resolved by diet changes—eating foods naturally high in iron such as dark green leafy vegetables and meat, as well as foods high in vitamin C (oranges, berries, broccoli, or other fruits and vegetables) which is vital to help your body absorb iron. Other diet changes that may help are eliminating caffeine and alcohol.

However, research has shown that anemia in people with SCI is often due to an underlying chronic health problem, including pressure ulcers and UTIs. This type of anemia mimics iron deficiency, so it’s really important to have your body’s iron levels tested. If your iron levels are high, but anemia symptoms persist, the presence of chronic health problems such as UTIs and pressure ulcers need to be investigated, as normal hemoglobin levels can be attained only after the chronic disorder is eliminated.

Assuming your anemia is not from blood loss, your doctor will likely begin diagnosis by asking you about your medical history, performing a physical exam, and ordering blood tests. Blood tests will not only confirm the diagnosis of anemia, but also help point to the underlying condition.

Because of the high incidence of anemia in people with SCI, it’s important to remain vigilant for its symptoms. And again, you should seek medical attention if you experience any symptoms. If you don’t have access to a physiatrist or another medical professional familiar with SCI, you’re not located in a major city, or you believe your family physician has little SCI-specific experience, please don’t hesitate to relay your concern that, if you’re diagnosed with anemia, your underlying cause may be due to a SCI-specific chronic condition such as UTI or pressure ulcer.

Questionable Timing



In the past, scientists have found evidence that SCI disrupts the body's internal clock. Dr. Andrew Gaudet, a University of Texas at Austin researcher and former ICORD investigator, is working hard to confirm and better understand the mechanisms and implications of this disruption—and develop strategies to lessen the impact.

The human body runs on a 24-hour biological clock known as the circadian system. It's a vital system, one that plays an important role in regulating virtually all of our body's functions.

The actions of the circadian system are triggered by light—specifically, blue light. The presence of light at the beginning of the day, for example, triggers the circadian system to tell the body that it's time to get up and get to work. As our world becomes darker each night, it tells the body that it's time to sleep and focus on the processes of replenishing our cells. These are known as circadian rhythms.

Scientists have hypothesized for decades that any injury to the spinal cord compromises our circadian system and circadian rhythms. The fact that many people with SCI report experiencing significant sleep disorders provides evidence of this. But the extent and the implications of this circadian disruption, throughout the time from acute to chronic SCI, aren't really well understood to this day.

Enter Dr. Andrew Gaudet, an assistant professor of psychology at the University of Texas, who has chosen to focus his research on the link between SCI and circadian functioning.

"It's been an interesting road that ended up merging my interests in SCI and circadian rhythms," says Gaudet, who lived in Vancouver for ten years.

His interest was first tweaked when, as an undergrad at UBC, he worked in the lab of ICORD's Dr. Matt Ramer, studying the immune response after SCI. After graduating with his PhD in 2010, he moved to Ohio State University to work with Dr. Phil Popovich, who is renowned for his work in nervous and immune system interactions after SCI.

"I completed postdoctoral research there between 2011 and 2014, studying inflammation and axon growth after SCI," says Gaudet. "In that time, I also met my future wife—a fellow researcher named Dr. Laura Fonken—on the 7th floor of our research tower, and we began collaborating on research related to inflammation of the nervous system, metabolism, and biological clocks. These studies continued at our next research positions, at University of Colorado Boulder—I was there between 2015 and 2018. This is where Laura and I collaborated, along with my supervisor Dr. Linda Watkins, in completing studies related to SCI and biological clocks."

The couple then secured their current positions as assistant professors at The University of Texas at Austin, where the

focus of their research collaboration is almost exclusively circadian functioning after SCI.

"I'm developing a research program that involves SCI, and determining how biological rhythms influence post-SCI metabolism and functional recovery," says Gaudet. "My wife is an expert at neuro-immune interactions, endocrinology, metabolism, and circadian rhythms. We have lab meetings together and will continue to collaborate, which creates a unique perspective for studying issues after SCI."

This husband and wife synergy was very much in evidence with the recent publication of an animal study in the online journal *eNeuro* that confirms the disruption of circadian functioning in the first days and weeks after SCI delays—and suggests the disruption might actually limit recovery.

"Previous research has focused on how SCI affects other parts of the body, but this is the first study to reveal the widespread, domino-like disruption an injury might have on these rhythms that are crucial for health," says Gaudet. "It was known that SCI impairs metabolism—for instance, predisposing individuals to cardiovascular disease and increased fat mass. It was also known that circadian disruption alters metabol-



ism—for instance, eating the same amount at the wrong time of day can lead to obesity. However, no one had systematically addressed this question: does SCI disrupt circadian rhythms?”

In order to explain his research, Gaudet suggests that we think of the circadian system as a corporate structure.

“It consists of a president or CEO—the suprachiasmatic nucleus of the brain,” he says. “That part of the brain only responds to light—particularly blue light—from the eyes, and sends this information to middle managers, which include certain hormones, body temperature, movement and activity, eating, and autonomic function. The middle managers integrate this information from the CEO with other information from the body—about stress, for example—in order to tell every organ and cell in the body what time it is, and what each cell should be doing. So the liver knows what time it is and is ready for food at 7 AM, whereas the liver releases stored energy and is not timed for food at 12 AM.”

In their study, Gaudet and Fonken compared the rhythms of two of these middle managers, body temperature and movement/activity, in two groups of rats—one with moderate SCIs, the other uninjured. What they observed was that these rhythms almost com-

Circadian disruption: much more than a bad night's sleep

Probably the most well-known form of circadian disruption is jet lag. When we cross time zones rapidly, our bodies are unable to adjust rapidly to the new light cycle and we “feel bad” for several days. But long-term circadian disruption has been demonstrated to seriously impact our health.

For example, shift workers—those that work night shifts, or have rotating shifts—are exposed to long-term circadian disruption, and are predisposed to obesity, certain cancers, and metabolic disorders. People who routinely rely on artificial light to stay awake late into the night tend to snack at inappropriate times (that is, during the evening and night), which can contribute to obesity, cardiovascular issues, and metabolic syndrome. And long-term circadian disruption can result in or worsen mental health conditions such as anxiety, depression, and seasonal affective disorder.

Most able-bodied people can make a conscious decision to make life changes that reduce circadian disruption. But SCI by itself seems to cause long-term circadian disruption, and those with SCI obviously don't have the luxury of switching it off. This underscores the importance of trying to better understand the mechanisms behind SCI-related circadian disruption and develop strategies to reduce or prevent it.

pletely disappeared immediately after injury, but gradually recovered within one to two weeks. They also assessed levels of another middle manager, the hormone corticosterone, and found that it too was disrupted soon after injury, but recovered within two weeks.

“Overall, this moderate injury disrupted rhythms in various middle managers and outputs of the circadian system,” says Gaudet.

Armed with this knowledge, he next wants to push forward with research to determine if and how circadian disruption also restricts neurological recovery.

“Since every cell in our body contains its own clock, and this clock is linked to many other functions in our body, I would predict that circadian disruption could worsen inflammation, increase post-injury damage in the spinal cord, and harm potential repair mechanisms,” he says.

But he adds that even if this is the case, it might not all be bad news—accelerating recovery of circadian rhythms soon after injury could boost the body's ability to limit further damage and to repair itself.

“If disruption of these rhythms harms recovery after SCI, efforts to restore a patient's routines—for example, optimizing daily schedules of meals, sleep, physical rehabilitation and bright light—could pro-

vide recovery,” Gaudet explains. “Future studies of SCI that incorporate circadian factors could inform the development of such chronotherapies. Early after injury, there are several strategies that could be used to boost rhythms. Light is the strongest activator of the circadian system, so optimizing the amount and timing of light would be a great start: bright light in the morning—for example, having a window in the room soon after injury—and dark nights. If light at night is necessary, then it could be red light, which does not activate the circadian system. When possible in the intensive care unit, hospital staff could try to consolidate visits—studies I've read suggest that an ICU patient receives an average of 50 or more visits per night; this surely disrupts sleep at this critical time post-injury.”

Other strategies could include ensuring patients eat at the optimal time of day (particularly starting with breakfast), avoid eating anything beyond early evening, exercise only during the day (ideally in the morning), and avoid extra stress. And Gaudet says there are also drugs being tested that can alter the circadian system.

“Of course,” he says, “none of this would be a miracle cure, but these are easy-to-implement steps in the right direction, it could help with recovery, and



Dr. Andrew Gaudet

it also would provide a healthier overall state for treatment with other effective therapies.”

If you’ve been reading this and wondering what it means for you as someone who’s lived with SCI for many years, we can tell you that Gaudet is also intrigued by circadian function in chronic SCI and is considering how best to study this.

“As for what relates directly to chronic SCI and circadian rhythms, some have worse sleep or sleep issues. In addition, individuals with chronic SCI can have disrupted melatonin, blood pressure, activity, and sleep/wake rhythms. The circadian-related deficit likely relates to severity and level of injury—more severe and higher injuries would likely have worsened circadian disruption. I think it would be interesting to incorporate this into my work in the future—how strengthening circadian function could influence metabolic function and overall health in chronic SCI.”

In the meantime, Gaudet says it just makes sense for anyone with chronic SCI

to consider their circadian system and its relation to health when making day-to-day decisions.

“Individuals with SCI are more susceptible to worsened body composition, obesity, cardiovascular disease, and metabolic issues,” he says. “Our data (from the study described above) showed that SCI disrupted circadian rhythms and metabolic function in parallel. One potential take-away is that circadian health may be particularly important for people with SCI. Individuals with chronic SCI may be more sensitive to circadian disruption, which could influence overall health and metabolism. To maintain or boost circadian health, we all could focus on our lighting environment and how we’re responding to the time of day. Light, eating, activity, stress, and sleep all feed in to the circadian system, so optimizing timing of these factors when possible could be useful for individuals with chronic SCI.”

Visit www.gaudetlab.com to read more about Dr. Gaudet and his work. ■

Dr. Gaudet recommends:

- Getting as much bright light as possible in the morning (e.g., sitting near a window or going outside)
- Using low light and/or red light in the evening (especially an hour before bed; red light does not activate the circadian system)
- Using blue-light filters on your phone and other devices in the evening and before sleeping
- Eating a meal in the morning
- Avoiding eating anything beyond early evening or during the night
- Scheduling activity or rehabilitation for the morning to help boost rhythms
- Avoiding stressful activities in the evening, as related hormones could make the body think it is a different time of day
- Keeping a regular sleep schedule, which could be helped through the strategies above.

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Much More than Coffee

In two short years, the South Fraser Active Living Group has taken Peer power to a whole new level

One of SCI BC’s highest priorities is to nurture the formation of Peer groups throughout our province. When Peers come together, great things happen—knowledge and success stories get shared, lasting friendships are formed, and people discover the power of a collective voice as a tool to create opportunity and positive change.

Over the years, we’ve been gratified to see many success stories throughout BC. Peer groups are flourishing in all corners—in our northern communities, the Okanagan, the Lower Mainland, and Vancouver Island. But by all accounts, we’ve never seen anything quite like the South Fraser Active Living Group, or SFALG. In just two short years, SFALG has evolved from a Peer coffee group to an advocacy force majeure that is helping to bring accessible recreation and

fitness opportunities to all Peers who live in Surrey, North Delta and other areas of the Fraser Valley.

SFALG got its start in April 2017, when three of its founding members—Kim Egger, Renuka Senaratne and Marney Smithies—met at an SCI BC Peer forum on hobbies and passions. The trio hit it off, and discovered a mutual desire to become more active—particularly after a brutal winter that saw the Lower Mainland struggle to deal with a freakish amount of snow for an extended period of time.

“Many of us experienced cabin fever that winter, as many streets remained impassable, even for pedestrians,” says Egger. “We had all been travelling to Vancouver to do a lot of our physical activity and rehab. Marney and I had been going to PARC at the Blusson Centre, and Renuka had been going to the Mary Pack

Arthritis Centre. When we realized we lived close to each other, we set out to find fitness and recreation opportunities in our communities that were as good as what we had used in Vancouver, so we didn’t have to travel so far.”

With help and guidance from SCI BC staff members Jocelyn Maffin and Teri Thorson, the trio formed a coffee group. A couple of months later, fellow SCI BC Peer Aaron Gelowitz joined the group as the fourth founding member. And that’s when the conversation began in earnest.

“We soon recognized that there was little to no information available online or in the community recreation guides about accessibility in recreation facilities in our communities,” says Senaratne. “Together, we all began visiting and evaluating various city recreation centres and for-profit gyms in the Surrey, Delta and Langley areas to see what recreational opportunities were available for people with physical disabilities.”

What they found was disappointing—accessible facilities and adaptive equipment were sparse at best. So they set their sights on a lofty goal: improving the situation.

“We attended the grand reopening of the Newton Recreation Centre on September 30, 2017,” says Senaratne. “That day presented the perfect opportunity to introduce ourselves to people involved with recreation in the city of Surrey. We also introduced ourselves to then Sur-



ROCK STARS: From left to right, Aaron Gelowitz, Marney Smithies, Renuka Senaratne and Kim Egger—the four founding members of the South Fraser Active Living Group (SFALG).

rey Mayor Linda Hepner and a couple of councillors, and explained that some of us were residents and taxpayers of Surrey who were looking for better recreation opportunities for people with physical disabilities. They all seemed quite shocked that we were all traveling to Vancouver.”

Since that time, SFALG has evolved into a powerful force for change. Membership has expanded, regular meetings take place, and, most importantly, the group has achieved some excellent results that are already making a difference in the lives of Peers who live in the Fraser Valley (see sidebar on the next page).

“We are similar to many Peer groups, we would guess—we get together and share similar stories and interests,” says Gelowitz. “We can surely say we have seen the birth of some good friendships and partnerships. We work well together as a team with similar interests. But what might make us different from other SCI BC Peer groups is that we have also developed into an advocacy group. We continue to lobby leaders from the cities of Surrey and Delta for better oppor-

tunities for recreation and active living, while also asking that barriers to our inclusion be prevented or removed so that we can fully participate in the community that we live and pay taxes in.”

Being so engaged in their communities means that SFALG is continually consulting its growing membership.

“Large group meetings are on a monthly basis,” explains Smithies. “We started meeting at a local mall food court—typically three to five people attended initially. Now we’re meeting at the Surrey Central City Library once a month, and on average 12 people attend. The group continues to be led by its four founding members, who meet as needed but are in regular discussions with each other, and are also in regular communication via emails and social media—Instagram, Facebook and Twitter.”

Smithies adds that most members volunteer to participate in a variety of Delta and Surrey public events as representatives of SFALG. “Some of our members have even attended city council meetings, again in Delta and Surrey,” she says.

And of course, because SFALG is all about active living, many members play sports or work out together—to encourage each other and also to use the facilities and adaptive recreation and exercise options that SFALG has helped to create.

“We also hope our presence will encourage others and spread the word of the abilities of people with physical disabilities,” says Egger.

As for establishing priorities, SFALG relies on group discussions to identify needs, wants, current issues, and requests.

“We have started some sub-committees to address emerging concerns,” says Egger. “Once the group expanded and new members joined, SFALG came to realize there are many other significant barriers preventing us from participating fully in active living opportunities, including transportation, parking, financial and health concerns such as home care. We also ask for volunteers to tackle issues as people identify them. It’s a great group effort.”

Looking to the future, SFALG plans to continue to be a catalyst for increased year round indoor and outdoor recreation opportunities for people of all ages with temporary or permanent physical disabilities living in Surrey, Delta, Langley and in the Fraser Valley toward Chilliwack.

“A major goal is to work with other community organizations like The Arthritis Society, The Disability Foundation, Power to Be, etc.,” says Senaratne. “Together, we can accomplish even more.”

Gelowitz adds that group members hope that SFALG’s approach and success leads to the formation of similar groups, and inspires existing Peer groups around the province to take on more active roles in their communities.

“We hope we are setting a good example and encourage others to champion similar goals in their local communities. Like a pebble landing in the water, we hope changes in one community leads to a ripple effect in other parts of the Lower Mainland, and other areas of the

province. A group can start with just a few people who meet up and share common interests. Through sharing of ideas and friendship, you can work towards a goal. We suggest new groups tackle one issue/concern to start with. They don't need to do it all."

The best way to learn more about SFALG and connect with its members is to visit the group's Facebook page at www.facebook.com/SFActiveLiving. ■

SCI BC has been pleased to support SFALG with financial support, promotion, referrals, moral support and encouragement, and facilitation where necessary. As SFALG has gained momentum, we've helped spread the word about it and made it easier to attract new excited members. If you'd like to learn more about how we can help you form a Peer group in your area, or expand your group's role into an agent of change in your own community, please get in touch with Bert Abott (babbott@sci-bc.ca) or Teri Thorson (tthorson@sci-bc.ca).

SFALG's Impressive Accomplishments

- Created a database of the current recreation facilities in Surrey, Delta and Langley and their accessible equipment that has been shared with the various municipalities
- Were instrumental in getting a chair exercise program started at the Newton Recreation Centre in Surrey
- Successfully lobbied Surrey city councillor Bruce Hayne and other city representatives to offer reduce recreation pass rates for people with physical disabilities
- Encouraged its own members to try new activities such as trail riding, sledge hockey, camping, bowling, bocchia ball, and curling offered by groups such as BC Wheelchair Sports and Power to Be
- Established new curling opportunities in Delta
- Attended social meetings and indoor/outdoor recreational events in various Fraser Valley communities, to demonstrate ongoing demand for accessible recreation opportunities
- Presented to the Measuring Up Committee in the City of Surrey, which has very similar goals
- Successfully advocated (with support from researchers at UBC Okanagan) for adaptive exercise tool kits at each of the ten Surrey Recreation Centres
- Advocated for the repair of arm ergometers and other specialized adaptive fitness equipment already in place at Surrey Recreation Centres
- Advocated for more and better disabled parking
- Formed relationships with other groups with common goals including SCI BC, CP Association of BC, Tetra, Richmond Centre for Disability, and the City of Surrey.



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No More Blind Spots

Dr. Pooja Viswanathan, roboticist and former UBC researcher, has developed and commercialized an innovative backup sensor system for wheelchair users

Have you ever bashed a wall or parked car while backing up your ride? If so, you're not alone, says Dr. Pooja Viswanathan, a roboticist who completed her PhD at UBC.

"According to one report, 20 percent of powered mobility device users experience at least one major collision per year, resulting in property damage and

hospitalization," she says. "The most commonly-reported accidents involve collisions with doors, walls, objects such as shop displays, and cars."

And while there's no further breakdown of the nature of those accidents, it stands to reason that many of them—maybe even the majority—occur while reversing.

Viswanathan, an expert in assistive technologies who has been working with smart wheelchair technology for more than a decade, was determined to help find a technological solution to the problem and bring it to market.

Her goal was realized in 2016 with the incorporation of Toronto-based Braze Mobility. Working with University of Toronto professor Dr. Alex Mihailidis, an internationally recognized researcher in rehabilitation engineering, Viswanathan formed the company to develop and market blind spot sensor systems specifically designed for use with wheelchairs.

Today, Braze Mobility offers two systems: the Braze Sentina and Braze Hydra. Both feature blind spot sensors that can be easily installed on virtually any wheelchair or scooter. The sensors work in concert with a standalone controller that's mounted

on the wheelchair's armrest (there's no need to sync with a smartphone or tablet).

The Sentina, the most popular unit, uses a single sensor array to provide 180 degrees of rear-view blind spot coverage. It also allows up to three additional sensors to be added for more targeted coverage. The Hydra relies on up to eight smaller sensors, each providing 45 degrees of customizable coverage. The sensors rely on ultrasound technology, and so work in daylight or the dark.

Both systems alert the user with a choice of three types of signalling—an audio alert, a visual alert on the controller, or a vibration via a pad that can be placed in various locations such as the user's wheelchair cushion, backrest or armrest. You can use just one type of alert, or any combination of the three. They also feature two user-selected ranges. The short range mode is ideal for operating in close spaces—for example, in a home or workplace. The long range mode is more suitable when the user is travelling quickly outside.

The short range mode creates a warning when you're within 60 centimetres of an object, and a danger signal when you're within 30 centimetres of an object. The long range mode doubles these distances. These distances are also customizable.

Note that the systems will not stop or control your wheelchair; they only provide warnings that a collision is imminent. As well, current models will only detect objects and not curb drop offs, but



Viswanathan says the goal is to expand the sensing capabilities to include dangerous drops. Both the Sentina and Hydra are powered using a standard USB power bank. If your chair has a USB charging port, the systems can be plugged into it. But they also come with their own power units. Power usage is minimal.

“Our buyers include manual and powered wheelchair users, especially those with limited vision or upper body dexterity,” says Viswanathan. “Wheelchair users who have bulky headrests or other objects blocking their vision, alternative joystick controls that require them to face forwards when driving, hearing impairments, or just a general lack of confidence are finding our systems invaluable. Our customers also include seating clinics, rehabilitation hospitals, long-term care homes, retirement homes, and complex rehabilitation technology providers.”

Viswanathan, who is CEO and supervises product development and business development, says the feedback she’s received on the systems has been overwhelmingly positive.

“Customers tell us that they’ve observed a significant decrease in the number of collisions they experience ever since they started using our product, and have also told us that our product has increased their feelings of safety, confidence and security overall,” she says. “They find it easier to navigate doorways and tight corners, and get on and off public transit with the Sentina. We’ve also received several comments from users and therapists regarding the ease of use and installation of our product, which was something we had worked hard on during our beta client program.”

She attributes some of this early success to her company’s commitment to involve wheelchair users in every step of the design process. “We made sure to include wheelchair users right from the get-go. By connecting with commun-



ity partners such as March of Dimes, we were able to engage with wheelchair users and learn about existing challenges in wheelchair operation and navigation. We then worked very closely with our community of beta clients for almost a year so that we could get our design right. We have had several wheelchair users collaborate with us in various capacities—as advisors, contractors, interns, and business partners. This has been crucial, since building accessible technologies requires first understanding what the real challenges are. We have a lot more work to do in building a more accessible world, and awareness is the first step. That’s why even our team members who are not wheelchair users try to navigate the city in mobility devices so that we can walk—or wheel, rather—a mile in our customers’ shoes.”

For Viswanathan, the entire process of developing the technology and bringing it to market has been an incredibly gratifying journey which began when, as a young university student, she attended an assistive technology seminar at the University of Waterloo.

“I was in a computer science program and wanted to apply my skills to improve human quality of life, so the field of assistive technology intrigued me,” she explains.

Her first experience in the field came at the Intelligent Assistive Technology and Systems Lab at the University of Toronto, which had just started work on smart wheelchairs.

“When I started a summer research internship there and made my first visit to a long-term care facility, I noticed the majority of residents slumped over in manual wheelchairs because they didn’t have the strength to self-propel, and they were being denied the use of powered wheelchairs due to safety concerns. I then began a decade of research at the University of Toronto, UBC, and Toronto Rehabilitation Institute, with the goal of building technology that could enable safe and independent mobility. It’s all culminated with Braze Mobility, a company I started in order to prevent continued violation of our basic human right to mobility and independence. I wanted to see a future where individuals have access to technologies that support their independence, especially in long-term care settings.”

Prices for the systems start at about \$1,000—pretty reasonable when compared to even the most minor of autobody repairs, a few drywall patches, or the time and expense of healing from an injury. Visit www.brazemobility.com to learn more. ■

Grow Your Own

Have you ever thought about the benefits of growing your own therapeutic cannabis? Perhaps you should. Growing a small number of plants, which is now legal for every British Columbian, can cut costs, increase purity, and be a great hobby.

How's that whole legal cannabis thing working out for you?

We're now six months into the new era of legal recreational cannabis. If you're one of our readers who relies on weed to manage your SCI-related complications such as spasticity, neuropathic pain and insomnia, how would you rate our new legal framework?

For anyone who uses cannabis on a casual basis, our legal system is probably working okay. However, the roll-out

in a province that's always been at the forefront of cannabis enlightenment has been embarrassingly inept to say the least—at the time of writing, there were still only seven retail outlets open in our entire province. Of course, you can always order online from the government's website, but that requires credit card use, and even the office of Canada's Privacy Commissioner has warned against that. "Some countries may, for example, deny entry to individuals if they know they have purchased cannabis, even lawfully," it wrote in a December statement.

The bottom line is that, for many who rely on therapeutic cannabis in larger quantities on a regular basis, legalization has been somewhat of a letdown. And it's not just because of availability—there's a host of other drawbacks with legal recreational cannabis, according to Cory Parsons, an SCI BC Peer who is well-known for both his wizardry in the kitchen and the greenhouse.

"Legal weed bought from retail outlets will someday be a good solution for recreational users," says Parsons. "But I'm not sure it will ever be a good solution for people whose needs are more medicinal—people like me. High cost, questionable purity, and lack of access to strains that work well for a person's specific situation are some of the reasons for this."

But there is one aspect to the new legalization framework that Parsons is really excited about: it's now legal to grow your own cannabis without having a medical license from Health Canada. Here in BC, any household can grow up to four plants at a time, providing the grower operates within the requirements set out in the law (see sidebar on page 30).

"Growing your own cannabis is a great solution for SCI BC Peers who have found relief with cannabis," says Parsons, who has the credentials to back up that assertion—he's long been a designated legal grower for medical cannabis patients under Health Canada's





Two ways to legally grow on a small scale: inside your home in an expensive grow tent (above), and outside on a patio (right) as Cory Parsons does every summer. Parsons, who has quadriplegia, uses a standing frame to inspect and trim his crop.

old MMAR regime (MMAR is short for Medical Marijuana Access Regulations), and he has more than two decades of experience growing organic weed and experimenting with strains that help him and others deal with spasticity, neuropathic pain and insomnia.

The sheer savings is one of the primary reasons that Parsons cites.

“Legal cannabis costs roughly five to ten dollars a gram,” he says. “That’s fine if you’re a recreational user who partakes in a few puffs on the weekend. But anyone trying to manage ongoing neuropathic pain or spasticity could easily use a few grams a day, and many use much more than that. So buying at retail could cost the medicinal user \$5,000 or more a year.”

In contrast, says Parsons, the cost of growing your own could be as low as cents per gram.

“One plant could yield as much as a pound of cannabis depending on your growing situation and skill,” he says. “It’s unlikely that even those with the highest needs would consume more than four pounds in a year, and it’s more likely that most medical users would use a maximum of a pound or two in that time. What’s your cost to grow four plants? Your initial outlay for equipment to grow four plants can range from a couple

hundred dollars for growing outdoors, to \$1,000 for an indoor growing system with a tent. After that, all you really need are soil, seeds or cuttings, water, and light—and mother nature provides most of these for free. So your costs for four plants a year will only be for seeds or cuttings, some soil and fertilizer, and, if you opt to grow inside, some hydro—maybe a couple hundred dollars total.”

Parson says the second main reason to grow yourself is purity of product. “Our government is tightening up the regulations regarding fertilizer and pesticide use for retail cannabis growers,” he says. “But with any product that has multiple steps involved in getting to the end user, do you ever really know what you’re putting into your body? And how much of any fertilizer or pesticide is safe, particularly for those who use a lot of medicinal cannabis? When you grow yourself, you control what you’re feeding or treating your plants with. Ideally, as I’ve been doing for years, your best bet is complete organic growing—natural pesticides, and natural fertilizers. It’s all easily possible, particularly on a small scale.”

Yet another reason for growing your own, adds Parsons, is having the ability to inexpensively experiment with different strains that offer better therapeutic

benefits for your specific symptoms. For example, Parsons has dialed in strains for his own use that reduce his pain and spasticity, without making him so high that he can’t function in his daily work and routines.

Parsons says there’s a final reason people might want to consider growing their own cannabis: it’s a really rewarding hobby, particularly for those who are already green thumbs.

“The act of growing anything is a great stress reliever,” he says. “Cannabis is no exception. Taking quiet time-outs from your daily grind to tend to your plants can really help you forget about your troubles and focus your mind. Watching your crop grow and, ultimately, yield a great harvest, also provides a tremendous sense of satisfaction.”

If you’ve read up to this point and find yourself doubting you’ve got what it takes to successfully grow weed, Parsons has some encouraging words for you.

“Growing weed may seem complicated at first glance. It’s true that many enthusiastic growers, me included, are always pushing the envelope with advanced techniques in an effort to maximize yield and potency. But it’s really important to remember that cannabis is affectionately called weed for a reason: it’s a very durable plant that can grow in

the crack of a sidewalk. The bottom line is that, while you can expect some challenges, the basics of growing reasonably good weed are pretty simple.”

He explains that growing up to four plants outside throughout the spring, summer and fall is the easiest and least expensive way to get your hands dirty. “It really can be as simple as growing four plants from legally-purchased seeds in pots or containers on your patio,” he says. “You’ll need to think about starting with the right soil or medium, and following some simple guidelines about fertilizing and watering. Raised beds are great for anyone who uses a wheelchair, and another easy technique is to buy or build some wheeled platforms for your pots so you can move them into the sun—or out of the rain—as needed.”

If you lack privacy in your outdoor growing area, or want greater control and yield, Parsons counsels buying a simple indoor grow tent system. The most basic of these systems, which can be purchased for less than \$1,000, typically include a Mylar tent with growing tray, a lighting system, a ventilation system that keeps the air inside pure and vents the smell of your budding plants outdoors, and fertilizers.

“A growing cycle for indoor systems is roughly three to four months,” says Parsons. “So for those with heavier needs, it is possible to grow up to 12 plants a year with a simple indoor system.”

Have we enticed you to consider grow-

Growing Your Own: The Fine Print

Here’s the essential legalities of growing your own cannabis in BC.

- You can grow up to four plants per household at any given time. The plants can’t be visible from any public places close to your home.
- Only seeds or clones (cuttings) purchased from government-licensed cannabis retailers can be used to grow cannabis at home. At the time of writing, the only place in BC with legal seeds is online at www.bccannabisstores.com, the government’s cannabis website. Clones were not yet legally available. We’ll concede it’s difficult to see how authorities could possibly determine if homegrown cannabis plants were sprouted from legally-obtained seeds.
- You’re not allowed to sell any extra cannabis that you grow but don’t need; you can, however, give away 30 grams to friends.
- Perhaps the trickiest legality to navigate is the issue of renting your home. Existing rental agreements signed before the date of legal recreational cannabis (October 17, 2018) are deemed to include a no-grow clause in or on the rental property, and landlords will also have the option of including a no-grow clause in any new rental agreements signed after that date. If you’ve got an unwilling landlord, but are determined to grow your own, your only solution is to become a MMAR-licensed medical grower, which allows you to grow your own medicine regardless of whether you own or rent.

ing your own therapeutic cannabis, but you don’t know where to begin? Help is available online. In fact, the main problem you’ll encounter is wading through the sheer number of easy growing guides you’ll find with a quick Google search.

But for anyone seeking some specific guidance about growing cannabis by and for people with SCI, Parsons offers the benefit of his extensive experience via a modest fee-based consulting service.

“I love enabling Peers who set their sights on growing themselves,” he says. “I’m happy to help with any aspect of growing—from simply providing advice

on what kinds of strains work for specific symptoms, to offering a complete start-to-finish consultation to someone seeking to set up any kind of growing situation, indoor or outdoor, and grow for the first time.

“Cannabis is finally getting the recognition it deserves as a therapeutic tool for many aspects of life with an SCI. It’s been a powerful force for good in my life, and any time I can help a fellow Peer experience the same benefits, well, I’m happy to help.”

You can reach Cory at cookingwithcory@shaw.ca. ■

NOW YOU’RE COOKIN’!

A small but enthusiastic group of SCI BC Peers braved the elements to cook up a storm at SCI BC’s recent cooking class in Surrey. The event took place on January 24th at the accessible Chuck Bailey Recreation Centre. As always, the focus was on learning new techniques and cooking some filling, nutritionally-healthy dishes. Among those present were Jaspal Singh (left) and Randeep Sharma. Our thanks to sponsors Envision Financial and the City of Surrey. Cooking classes will be a featured Peer event throughout 2019. Keep a close eye on www.sci-bc.ca/events for details.



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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.

Phone-based Peer Physical Activity Counselling

Overview: ICORD and BCIT researcher Dr. Jaimie Borisoff and his team aim to explore the impact of a Smartphone Peer Physical Activity Counselling (ALLWheel) program in a group of manual wheelchair users with an SCI. The 10-week ALLWheel program is led by a peer who uses technology to communicate with study participants.

What to expect: Participants will be randomly assigned to either an intervention group where they will be fully engaged in the ALLWheel program with a peer-coach, or a control group where they will be provided physical activity resources and recommendations but will not have access to a peer-coach until the completion of the study. All participants will be asked to engage in four data collection sessions. Some participants will be asked to participate in an interview to discuss their experiences. The time commitment will total no more than 13 hours over a six month period.

Who can participate: You must have been living with a traumatic or non-traumatic SCI for at least one year; have been using a manual wheelchair for mobility for one or more months; be able to self-propel for at least 100 meters; currently do no (or minimal) exercise; be able to effectively communicate in English; be between 19 and 64 years of age; and reside in BC.

Why participate: Participating in physical activity has numerous physical and mental health benefits. Meeting physical activity guidelines to attain such health benefits can be challenging, especially for manual wheelchair users with a SCI. Peer led programs and the use of technology to deliver programming have been shown to improve physical activity levels. ALLWheel is a unique program that combines these two approaches and could be an effective means for improving levels of physical activity for individuals with a SCI. Participants will be given an honorarium of \$50 for three of the data collection sessions (total of \$150 per participant). Participants completing interviews will be provided an additional \$20.

Location: The study will take place at the BCIT Burnaby campus or a quiet public location, or via video-conference.

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

SCI Research Participants' Views on Data Sharing

Overview: ICORD researchers in Dr. John Kramer's lab are investigating how SCI research participants feel about scientists using their data. Specifically, they are interested in learning more about how SCI research participants feel about data sharing—the process by which data collected in one research study is anonymously shared with others. This means that a researcher allows others to see and use the individual data they collected in a research study, after deleting information that could identify participants (for example, your name and exact birthdate). Other medical information is provided in full. As it is your information that would be shared (anonymously), Dr. Kramer and his colleagues are very interested to find out your opinions on data sharing.

What to expect: This study involves filling out an online questionnaire that asks about your health and SCI status, your opinion on the potential benefits and risks of data sharing, your preferences regarding informed consent and privacy protection, and your level of trust in researchers and others. We are collecting information regarding your health and injury to find out about the characteristics of the people who took this survey. The time commitment is approximately one hour.

Who can participate: You can participate in this study if you have an SCI and have previously taken part in, or are currently participating in, a research study of any kind.

Why participate: A potential benefit to participating in this study is the opportunity to add your voice to the debate around data sharing. We are also offering a \$10 gift card for participation. The surveys are completely anonymous.

Location: Online (via <http://icord.org/studies/2019/02/data-sharing/>)

For more information or to sign up to participate: Please contact the study coordinator, Jessie McDougall, by email (jessie.mcdougall@ubc.ca) or call (604) 831-7706.



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

Robot Ride

Are driverless vehicles such as the ELA the future of transportation?

As a 100 percent electric autonomous vehicle, ELA may seem like something out of *The Jetsons*. But this technology is already being used in many countries around the world. Similar driverless shuttles have been deployed in more than 20 countries in areas of dense, urban populations. They connect people to important destinations not always accessible by conventional public transportation, and within large facilities such as airports, hospitals, community centres and university campuses.

ELA (short for ELeCtric Automation) is part of an entry in the Smart Cities Challenge, a Canada-wide competition for up to \$50 million in funding for initiatives that will achieve meaningful outcomes for residents through the use of data and connected technology. Surrey and Vancouver teamed up to enter the competition and, with support from Pacific Western Transportation, brought ELA to life as an example of a connective technology that could be implemented in the two growing metropolises.

ELA uses sensors, cameras and computers to detect objects and understand its surroundings. It has an automatic ramp for accessibility (and a manual ramp if needed). Users activate the vehicle with buttons on the exterior and interior. Once activated, ELA follows a fixed or on-demand route and reacts to

its environment to avoid pedestrians, cyclists and other hazards.

“Driverless vehicles are anticipated to eliminate one of the leading contributors to collisions—human error,” says Vancouver Mayor Kennedy Stewart. “By piloting them on these corridors, we can learn more about how they can be used throughout the region to improve safety, reduce congestion, and create safer, greener, healthier, more connected communities.”

For SCI BC and our Peers, ELA and other driverless vehicles may someday be a viable option to connect people with disabilities to their communities more easily. So naturally, we had to see ELA in action for ourselves. In early February, several SCI BC staff and Peers took a test ride with ELA at the Surrey Civic Plaza. Their thoughts are to the right.

Visit www.smartertogether.ca to learn more about ELA and the Smart Cities Challenge. ■

Micaela Evans, SCI BC Communications and Events Coordinator, was among those who took a spin on the ELA in February.

“Interesting to see where the future of transportation is going and to see how autonomous vehicles may be a part of it. The vehicle itself was small, but had enough space for a couple of manual wheelchair users and some additional passengers. The ramp was similar to a modified van ramp, but it was quite steep—some users like me would need assistance.” – **Stephanie Cadieux, manual chair user**

“The vehicle itself was small, which isn’t the most ideal for folks with mobility needs or larger power wheelchairs like mine. But as a short distance form of transportation, I think it could work. I could see it working to support people with disabilities in accessing places like community centres, clinics or places that are not along the routes of existing transit systems.” – **Micaela Evans, power chair user**

“I was so excited to be on the first shuttle at the Surrey Civic Plaza. With the capacity of this bus being 12 able-bodied people or six and one or maybe two wheelchairs, it was limiting. [ELA] might mean greater independence for senior citizens, disabled people and people who don’t drive—it seems quite simple to operate and has a very quiet, smooth ride. Technology is amazing isn’t it?” – **Marney Smithies, manual chair user**



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