

the spin

SPINAL CORD INJURY BC

SUMMER 2019

Clear Vision

Kelowna's Dr. Paul Clark has enjoyed an amazing 40-year career as an optometrist—and he offers some excellent eye health insight for others with SCI



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COVER PHOTO: Optometrist Dr. Paul Clark in his Kelowna office. (Chelsea McEvoy photo)

True accessibility and inclusiveness: new legislation is vital, but creating incentives might be more important.

History was made on May 29 when the House of Commons unanimously passed Bill C-81 into law, establishing what is now Canada's new *Accessible Canada Act*.

I am proud of the significant role we, as one of the 90 organizations of the SCI Canada-led Federal Accessibility Legislation Alliance, played in shaping this legislation. It may not be perfect, but we're pleased that more than 75 of our recommendations are included in it. We will continue to work hard together to strengthen the act and its related regulations and standards in the future. You can learn more and stay in the know by visiting include-me.ca.

On top of this, there's more good news: accessibility legislation is coming to BC. The provincial government will be rolling out a consultation process for its development, and SCI BC has been invited to take part in helping to shape this.

Make no mistake, all of this represents a massive step forward. But on its own, legislation and enforcement of it, isn't enough to affect the type of positive attitudinal and behavioural shifts required for Canadian society to become truly accessible and inclusive. These shifts will require significant investments. Thankfully, governments realize this and are starting to make the required investments.

Personally, I believe that incentives will be one of the biggest drivers of positive change. Yes, the threat of punishment for not complying with the law is necessary, but should be wielded as a last resort. We want people to change because they see the value in change, not because they have to. When we see the value in change, we're encouraged to do better than just grudgingly meet a minimum standard.

An interesting example of this is starting to emerge here in BC. The incentive is tapping into the accessible tourism dollar. The tourism sector and our government's Ministry of Tourism, Arts and Culture realize that globally, accessible tourism is an industry valued at more than \$80 billion, and making BC a leader in accessible tourism means grabbing a bigger share of this very large pie.

Of course, accessible tourism requires accessible communities, and accessible communities are required for accessible tourism—a relationship that SCI BC's Access BC program (accessiblebc.ca) has been helping governments and tourism industry associations understand. Over the past year, SCI BC has established memorandums of understanding (MOUs) with BC's five regional tourism associations, the Tourism Industry Association of BC, the North Central Local Government Association, and other local governments and associations. Through these MOUs, SCI BC's Access BC team is working with partners and stakeholders to establish a coordinated approach to developing accessible travel and tourism products across BC. The Thompson Okanagan Tourism Association was the first to jump on board, and we have subsequently created a jointly-funded Regional Universal Access Tourism Specialist position, the first of its kind. The role, filled by SCI BC Peer Support Specialist Sonja Gaudet, serves as a dedicated accessibility resource for the region.

Change is hard, and I'm certain that the punitive force of legislation will need to be wielded for some who overtly resist complying with our new accessibility laws. But I hope this is rare, and that, over time, all will come to see and realize the positive benefits that go hand in hand with making our communities meaningfully accessible and inclusive of all.

- Chris McBride, PhD, Executive Director, SCI BC



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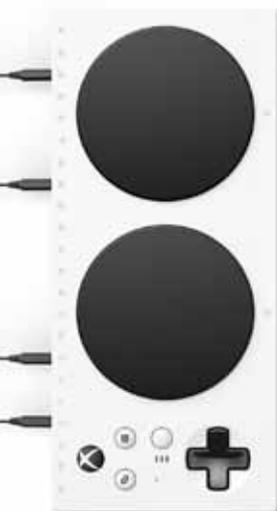


Innovations

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

XBOX ADAPTIVE CONTROLLER

The debut of the Xbox Adaptive Controller last fall by Microsoft marks the first acknowledgement by a mainstream video game company that there is a huge need for accessible products. The controller is longer, flatter, and wider than a standard Xbox controller. It features oversized A & B buttons that are ridiculously easy to activate—gliding your fingertip against them is enough. The oversized D-pad is a breeze to use for anyone with limited hand function. It also has 19 different input jacks, allowing for customization with more joysticks, switches, and other input devices. A nifty copilot function allows the the Xbox Adaptive Controller to be used together with a standard Xbox controller. Visit xbox.com to learn more.



RAM MOUNTS

Want to securely mount your phone/tablet/camera/game controller on your wheelchair? Seattle's RAM Mounts offers approximately 5,000 modular components to allow for highly-customizable mounting solutions. Of note are the company's 22 products that are designed specifically for mobility applications and are compatible with arm and seat tracks of most major wheelchair brands, including Invacare, Permobil, and Quickie. All of the company's mounting components are built on an interchangeable ball and socket system designed around an elastomeric rubber ball. Non-slip functionality, shock and vibration dampening, quick installation and adjustability, and durability are all features of RAM Mounts products. Learn more at rammount.com.

FORD ACCESSIBILITY MAT

Ford's Brazil subsidiary has created a trunk mat that doubles as a portable wheelchair ramp. The Accessibility Mat was developed for the Ecosport compact SUV, the company's most popular vehicle for wheelchair users, after research showed that Brazil has more than three million people living with limited mobility who face accessibility barriers to many public building and facilities, given the country's limited accessible infrastructure. The mat connects to an accompanying app every time it's used, allowing users to share data showing where improved accessibility is most urgently required. You can see it in action at ford.com.br/tapete-de-acessibilidade, but note that the website's language is Portuguese.



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Spinal Cord Injury BC



Get off the road.

SCI BC and the Kootenay Adapted Sports Association (KASA) present the second annual KASA Bike Camp, from July 5 to 9. Join your fellow adventuring Peers for five days of incredible adaptive mountain biking (aMTB) and lake experiences in the Kootenays. Peers will be camping out in New Denver, and all aMTBs and related equipment will be provided. The event is led by our own Peer Coordinator and Paralympian, Josh Dueck. For more information or to RSVP, email Josh at jdueck@sci-bc.ca.



Be an adrenaline junkie.

Join us from August 16 to 18 for our annual Adaptive Adrenaline weekend in Whistler. Connect with fellow Peers from across the province, and enjoy hiking, kayaking, mountain biking, and handcycling with the Whistler Adaptive Sports Program. Limited spaces are available, and priority is being given to those who have never attended this event. Cost is \$100 per person (note that transportation is not included). Email Jenna Wright (jwright@sci-bc.ca) or call her at 604.326.1210 for details or to RSVP.



Find your new passion.

Join your friends and Peers as SCI BC and our community partners offer a free, fun-filled day of adapted sport and recreation. It's a great opportunity to try something new and enjoy a BBQ lunch! This year's Multi Sports Day takes place on Saturday, September 14. At the time of publication, we were working on finalizing all of the sports and recreation opportunities, as well as the location (though we do know it will be near a beach in Vancouver). Watch for more details at the SCI BC events page (sci-bc.ca/events).



Freedom to Play!

A huge new playground in Surrey will feature standout accessibility for kids with disabilities, thanks to funding from Canadian Tire's Jumpstart Charities.

The 12,000 square foot playground will be built at Surrey's Unwin Park, which is already home to a universally-accessible water park. Among the playground's accessibility features will be ramps that crisscross all play areas, allowing kids with disabilities—including

those who use wheelchairs—and other users to enjoy the equipment.

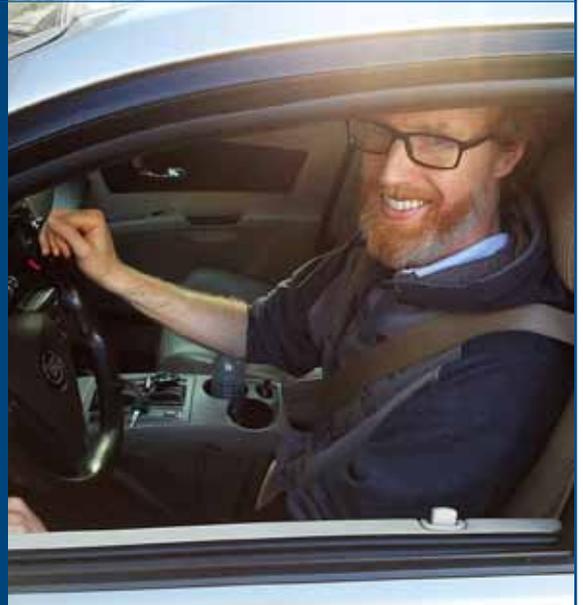
"This new inclusive playground is a welcome addition for our children and all members of our community for years to come," says Surrey Mayor Doug McCallum.

Construction start and completion dates have yet to be announced. An artistic rendering of the universally-accessible playground is shown above (courtesy City of Surrey).

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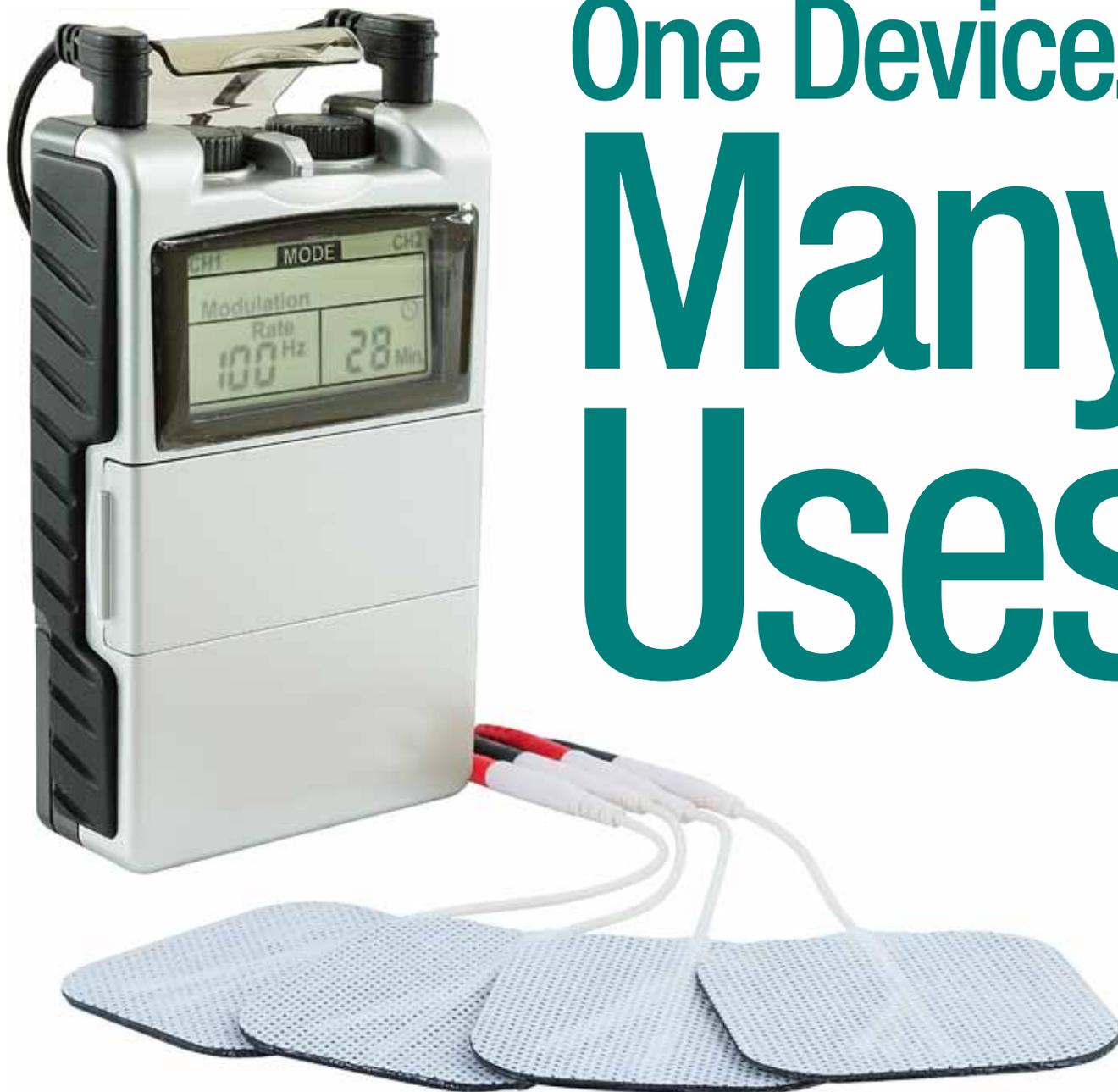


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One Device... Many Uses



New research from UCLA suggests a single, non-invasive neurostimulation system could be used in variety of ways to improve many aspects of your life.

Neurostimulation—electrically stimulating the circuitry of the spinal cord to awaken dormant function—continues to be a hot research topic. In the time that’s elapsed since the excitement dwindled over stem cells, nothing else has captured the interest of people with SCI, the SCI research community and the media more than neurostimulation.

We’ve published several features on neurostimulation in the last couple of years, focusing on the potential of this technology to make a difference in those aspects of your lives that you’ve long identified as priorities: having better and stronger hand function, having better bowel and bladder function, and maintaining consistent blood pressure.

UCLA’s Dr. Reggie Edgerton, who has been investigating neurostimulation for

four decades, and his collaborator and colleague, Dr. Parag Gad, are two researchers who are concentrating their efforts on neurostimulation as a means of improving these functions, and in the process, returning greater independence and quality of life to people with SCI. Their primary interest is in transcutaneous stimulation—in plain speak, achieving results with a non-invasive system that requires no surgery. We think

it's safe to say that most readers would agree: providing you get similar results, this approach is a lot more desirable than the prospect of having an epidural system, with electrodes and transmitter, surgically implanted in your body (and, when the battery needs changing, it's back to the operating table as well).

In the past, Edgerton and Gad have successfully demonstrated that transcutaneous neurostimulation can be used to improve hand function for quadriplegics, restore bladder and bowel function, and improve cardiovascular function in the small number of participants studied to date. Along the way, they have also developed their own proprietary neurostimulation device. (Note: a photo of this device was not available in time for publication; the photo at left is only intended to illustrate the concept.)

Recently, with colleague Dr. Yury Gerasimenko, they completed yet another fascinating project that provides a realistic glimpse at what this technology could mean for people living with SCI.

"I think there are two key takeaways from our recent paper," says Gad. "First, this is the first time we can show definitively that hand, arm and leg function, including overground stepping, can all be initiated with transcutaneous stimulation.

Second, a single device can be used for multiple improvements—someone with chronic SCI could buy a single, modestly-priced device and use it for many of their functions that are compromised."

The study involved a single participant—an adult in his early 30s who sustained an incomplete SCI at C7 in 2003 and has some sensation and movement below the level of the lesion. He was first given a thorough neurological examination to determine the level of his functional abilities, and then began treatment and training. For the first four weeks, he underwent a combination of transcutaneous neurostimulation and hand grip exercises. During the eight weeks that followed, he underwent another regimen, this one combining transcutaneous neurostimulation with walking and stepping exercises with a treadmill and walker. All neurostimulation was done with the researchers' own proprietary device.

After the four weeks of hand therapy, grip strength significantly improved, and these improvements remained long after the therapy was concluded. Similarly, the participant's stepping ability improved, with increased weight-bearing capacity, stepping speeds, increased ground clearance during the swing phase, and

improved coordination between left and right legs. At the 12 week time-point, the subject was capable of standing independently without any external support except the stimulation.

But that wasn't all. The participant reported significant improvements in hand dexterity. He was able to hold a fork while eating, open a sealed bottle of water, remove a fortune cookie from its packaging, and twist open a locked door. Most of these improved functionalities persisted for several months after neurostimulation was terminated.

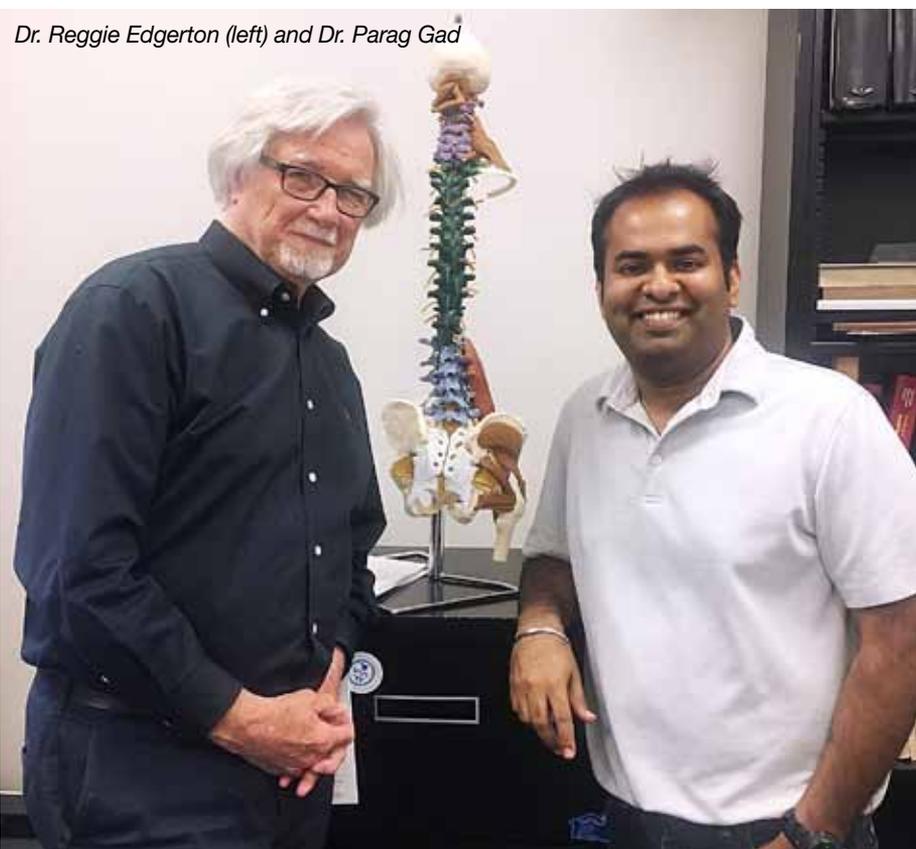
During the same period, the participant benefited from improved trunk function, including the ability to sit up in a chair without back support.

There were also improvements in autonomic functions. He also reported significant improvement in bladder and bowel function. The time required to complete his bowel program was reduced from an hour to 20 minutes within the first three weeks, and this benefit persisted for the duration of the study. Finally, he also reported improved bladder sensation and control, and felt his bladder function was returning to normal in terms of frequency, urge and capacity.

When all these improvements are considered together, this latest paper seems to prove that a single, non-invasive device can be used for many functional improvements in chronic SCI.

"Even though this work involved only a single participant, it's more than just a proof of principle," says Gad. "Now that we've demonstrated this in one patient, it can be repeated in others. A key factor here is since every SCI is so different, we may not expect identical responses from two patients. Remember, the first report that came out on the spinal stimulation technology in 2011 also involved a single participant, and it led to path-breaking work around the world."

While using neurostimulation to restore walking or stepping function captivates the media's and the public's attention, Gad says it's really important for him and Edgerton to continue to investigate the range of benefits that the



Dr. Reggie Edgerton (left) and Dr. Parag Gad

technology offers—particularly since people with SCI themselves have indicated in many studies that walking is far less of a priority than more mundane things like being able to open a door or urinate on demand.

“SCI impacts everything; it’s important to treat the entire body as an organism and not single end organs,” says Gad. “The transcutaneous approach provides us that platform to go after multiple indications in a single subject, either at the same time or sequentially. No other therapy—for example, epidural spinal stimulation, stem cells, or robotics—has so far shown the impact on multiple systems simultaneously.”

And this is why Gad and Edgerton have focused their energies on the non-invasive, transcutaneous approach, rather than the epidural approach that requires invasive and potentially risky surgery. It’s not just that there is significant risk with the epidural approach, it’s also that the transcutaneous approach might actually have greater benefits.

“We’re confident that the transcutaneous approach may have a larger impact than the epidural,” says Gad. “For example, when we stand, we don’t stand with our legs only. Our trunk needs to be involved, our head and neck need to be in the right places, our arms to be balanced. By having a very focused current with the epidural approach, we may not get the global responses needed. We believe the transcutaneous approach gives us that advantage. Apart from the lower cost and the ease of application, the multiple indications it can target represent huge advantages.”

He concedes that the daily donning and doffing of the system may be difficult for some end users, but is adamant that the lower cost and benefits of the transcutaneous approach outweighs this limitation—particularly since electrodes, which may have a limited lifespan, are currently bought off the shelf and are relatively inexpensive.

As for their proprietary stimulator that controls and powers the electrodes, Gad

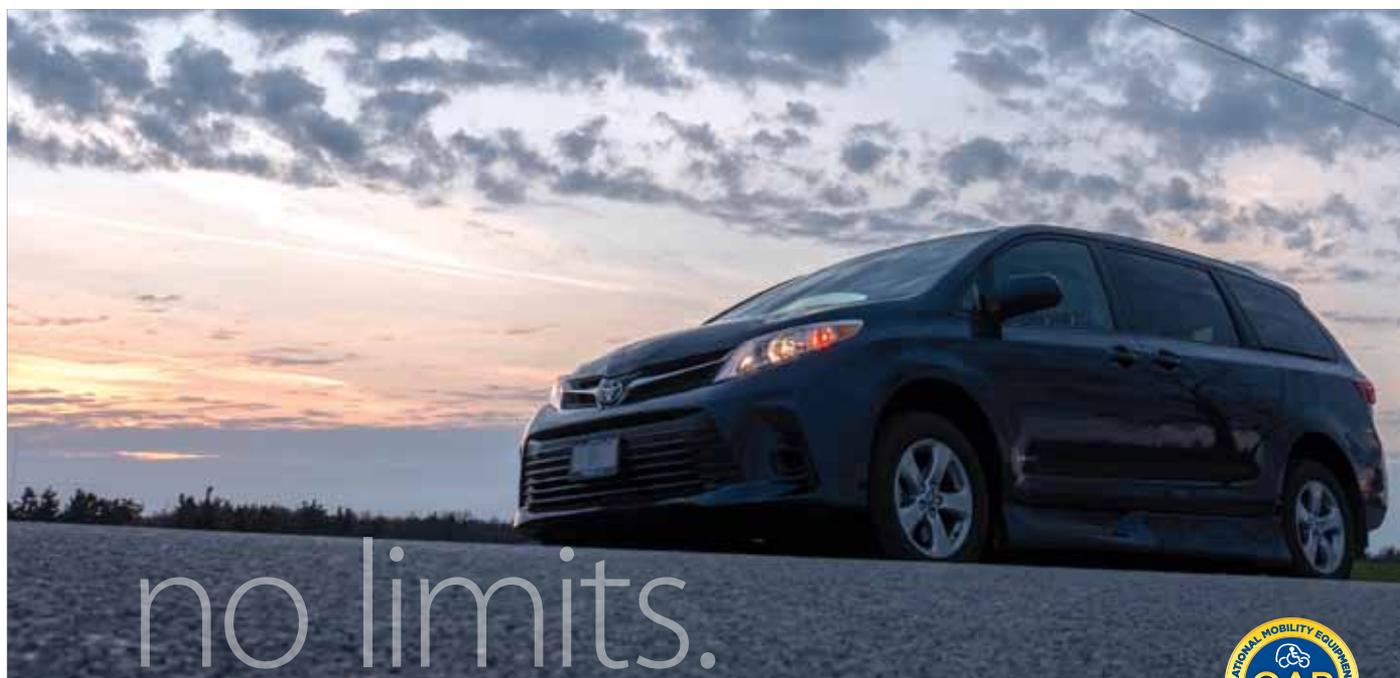
and Edgerton are optimistic enough that they have been pursuing commercialization of the device for some time. They recently severed ties with a commercial partner in order to be able to influence its development more directly.

“Reggie and I have co-founded a new company, spineX inc (spinexmed.com), to commercialize the technology. With spineX, we are driving everything. Our prototypes are under fabrication right now, and we are getting significant investment interest.”

What’s next?

“The only point I add is the transcutaneous approach provides us with some key answers very quickly and can be on the market soon,” says Gad. “However, it needs to be combined with other rehab devices and protocols for it to be most effective. We’re currently designing multiple studies to combine technologies to see the impact, because we believe one plus one may be greater than two.”

Stay tuned for more developments in this intriguing, rapidly-unfolding story. ■



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ask the SPIN DOCTOR

John from Vancouver Island writes, “As a paraplegic, I always thought my lower legs looked pretty good in shorts. They never seemed to get really skinny. Then I got a pretty bad pressure sore and had to spend about a week in bed. During that time, I noticed my calves didn’t seem to be as ‘full’ as they usually are. That’s when I realized that normally, when I’m in my chair, my legs are actually swollen. I’m thinking this can’t be a good thing!” To answer this issue’s question, we scoured the internet and found some excellent answers from multiple credible sources. However, please keep in mind that this should in no way be considered definitive medical advice; as always, please don’t delay visiting your physician with any doubts about your health-related issues.



You’re right—it’s not a good thing. What you’re probably experiencing on a daily basis is edema. It’s a condition that’s pretty common for people with SCI and other neurological conditions. Left unchecked, it usually gets progressively worse, and it can lead to some serious complications. For example, it makes you prone to pressure sores and cellulitis, a potentially serious bacterial infection that leaves your skin swollen, red and painful.

The good news is that edema can be managed and reduced, but we’d strongly suggest taking steps to do this as soon as possible.

Why are people with SCI prone to edema? The simple answer is that when leg muscles contract and flex, they help pump blood back to the heart. When you take away the ability to flex these muscles, blood and other fluids begin to pool in the lower leg. This puts pressure on your skin, which makes it fragile and susceptible to splitting. The same pressure reduces blood flow, which is critical to deliver nutrients and antibodies needed for healing and fighting infection after a skin split or any wound.

All of this helps create a perfect storm: with edema, a scratch or mosquito bite can quickly morph into a pressure sore or cellulitis.

If you notice swelling in your lower legs, particularly with redness and warmth, you need to be evaluated by a physician as soon as possible. While edema and cellulitis are the likely culprits, your doctor will also look for other

dangerous conditions such as a bone fracture or deep vein thrombosis (DVT), which is a dangerous clotting of blood. Additionally, there could be a more serious underlying cause of your edema, including heart failure, renal and liver impairment, chronic venous insufficiency, or a medication side effect. These serious conditions need to be ruled out ASAP.

If, however, your edema is due to paralysis, there are ways to reduce and control it. You should avoid soaking in hot water, and also avoid sunburns on your legs—both of these exacerbate edema. You should also avoid consuming salt as much as possible, as sodium causes fluid retention throughout your body. Fluid retention is also worsened by dehydration, so it’s yet another reason to flush your body with water throughout the day. And there’s no doubt that regular cardiovascular exercise—anything that gets your heart pumping—will reduce edema.

Another great strategy is to elevate your legs above the level of your heart whenever you can—while sleeping, watching TV, or reading. Try putting pillows under your legs whenever you’re able to get into a reclining position.

With stubborn cases of edema, properly fitted and prescribed knee-high compression stockings may be required. You need to put these on in the morning when you have little swelling, and worn throughout the day (but not at night).

Other options for more serious cases include a sequential compression pump or lymphedema pump, which rhythmically compresses your calves to work blood and fluids out of your lower legs, and lymphedema massage, in which a massage therapist manually works your legs to remove pressure.

As for medications, be wary of anything prescribed unless it’s coming from a physiatrist or a physician who is well-informed about SCI. Diuretics like Lasix, which increase urine output, are sometimes prescribed to reduce edema, but these drugs can really wreak havoc on your body’s sodium/potassium balance, which can lead to other serious problems.

In closing, we’ll stress again that any type of swelling in your lower extremities needs to be taken seriously and addressed as soon as possible—and your first step should be to consult your doctor.

Hammacher Schlemmer offers these open-toe zipper compression socks that are easy to put on and remove, even for those with limited grip strength. See hammacher.com for more info.



Reality Check

The buzz keeps growing about the potential of neurostimulation to restore function for people with SCI. Is the hype warranted? ICORD's Dr. Tom Nightingale helps us put it all into perspective.

In April, the Australian version of *60 Minutes* aired a feature about Dr. Bryce Vissel, a respected Professor of Neuroscience at The University of Technology Sydney, and his efforts to convince the Australian government to invest millions in order to make neurostimulation available to every Australian with SCI.

"Our goal," said Vissel, "is no less than a cure."

The show was intended for an Australian audience, but the audacious nature of Vissel's assertions and funding request resulted in media attention around the world.

Here at SCI BC, we are also bullish on neurostimulation. In the past couple of years, we've published numerous research stories about neurostimulation, which involves electrically stimulating the damaged area of the spinal cord in order to reawaken dormant nerves and restore function. Neurostimulation's apparent ability to restore some level of walking or stepping function has garnered most of the mainstream media's attention, but we are particularly intrigued by its promise of restoring many less glamorous but critical functions in people with chronic SCI—for example, hand, bowel, bladder and cardiovascular function.

But is neurostimulation ready to be thought of a potential cure for SCI, as suggested by Professor Vissel? Should researchers in Canada be spearheading a similar effort, to have our government make a significant investment in neurostimulation research, or make it available to every Canadian with SCI? Or is the hype overshadowing the reality, as with many SCI research streams in the past (think stem cells)? Perhaps most importantly, what is the real promise of neurostimulation: is it to restore walking function, which the mainstream media tends to focus exclusively on? Or, as we've suggested in the past, is the excessive focus on walking overshadowing its potential to make improvements in areas considered much higher priority by people with SCI themselves, such as better bowel, bladder and hand function?

Recently, we posed these and other questions to Dr. Tom Nightingale, a postdoctoral research fellow working in the autonomic function laboratory of ICORD principal investigator Dr. Andrei Krassioukov.

We learned of Nightingale's interest in neurostimulation after reading a piece that he wrote on the subject for *The Conversation*, the respected not-for-profit global media outlet that relies on content sourced from academics and researchers. We discovered that Nightingale, who is originally from the UK, is greatly interested in using neurostimulation strategies to restore autonomic function following SCI—in fact, he's currently a co-investigator on a joint ICORD and University of Calgary transcutaneous spinal cord stimulation clinical trial that will soon be open for enrolment, and is involved in other neurostimulation projects as well.

When we reached out to him, Nightingale graciously offered to lend a hand. Relying on his expert assistance, our goal was to try to put the current state of neurostimulation research into perspective for our readers; to sift through the hype and gain a better understanding of its true potential to restore function and quality of life for people living with SCI.



Q What prompted you to write the piece for *The Conversation*?

A Towards the end of last year, I was amazed by the media buzz generated by the two case-series published in *Nature* and *New England Journal of Medicine* demonstrating that neurostimulation, coupled with intensive physical therapy, allowed participants with SCI to walk again.

While extremely exciting, this media hype is seemingly inconsistent with consumer priorities. We have known for some time that certain autonomic functions—for example, blood pressure control, bowel, bladder and sexual function—are of a higher priority for everyday quality of life than the ability to walk again in individuals with SCI. These seminal findings, published over a decade ago, have been replicated with recent evidence from the 2019 North American Spinal Cord Injury Consortium Report from the SCI 2020 Panel and Consumer Survey. It confirmed that the restoration of bladder, bowel and sexual functions are of utmost importance for people with SCI. Specifically, it revealed that 98 percent of the 1,825 respondents agreed with the statement that “treatments with the potential to restore small functional improvements that positively improve daily life are highly desirable.”

So we prepared the piece for *The Conversation* because we wanted to showcase pioneering work from our laboratory and others that demonstrates neurostimulation has the potential to safely and effectively restore crucial autonomic functions. We are currently following up these interesting preliminary observations with larger clinical research trials, enrolling a larger number of research participants.

Q Everywhere you turn these days, there seems to be yet another study result confirming efficacy of neurostimulation. Given that, along with the efforts of someone like Professor Bryce Vissel to convince the Australian government to invest deeply in this science, is there a growing confi-

What is neurostimulation and how does it work?

The International Neuromodulation Society defines neuromodulation as “the alteration of nerve activity through targeted delivery of a stimulus, such as electrical stimulation or chemical agents, to specific neurological sites in the body.” Neuromodulation therapies, in common use since the 1980s, can help restore function or relieve symptoms that have a neurological basis.

Neurostimulation is a form of neuromodulation and refers to techniques that rely on electrical or electromagnetic stimuli to modulate the target nerves within the body. Typically, neurostimulation involves a transmitter (control unit and pulse generator) and electrodes. The transmitter emits electric impulses, which are delivered to the target area via electrodes.

There are two primary forms of neurostimulation being investigated for use with SCI: epidural and transcutaneous. Epidural approaches are known as invasive, as they involve surgically implanting a stimulator and electrodes into the space around the dura mater of the spinal cord. Transcutaneous approaches are non-invasive, as they rely on an externally-worn transmitter and electrodes that are adhered to the skin above the target areas of the spinal cord.

How does it work? Well, interestingly enough, nobody has a definitive answer to that question. In other words, the mechanism by which it restores function isn't truly known.

Perhaps the best stab at theorizing about the underlying mechanism comes courtesy of UCLA researchers Dr. Reggie Edgerton and Dr. Parag Gad (see page 10). In a recent paper, this is how they described what they believe happens during neurostimulation: “...the most logical interpretation of our findings is that there are multiple networks above, within, and below the lesion in a significant number of individuals with severe chronic paralysis that can be transformed into a functional state by receiving a certain critical level of modulation via spinal stimulation and descending cortical input.”

We asked Gad to elaborate on this, and here's how he responded: “The spinal stimulation seems to work in three ways: awakening the dormant circuits below the injury, strengthening the descending cortical signals (intent) that are passing through the lesion site, and allowing proprioceptive (sensory) information to ascend through the lesion to allow the brain to regain sensation. One analogy to explain this phenomenon is a ‘bidirectional hearing aid’. The brain can listen to what the periphery wants to say and the periphery can listen to what the brain wants it to do. The spinal cord is capable of figuring out how to make it happen.”

dence among the research community that this truly represents a leap forward in terms of providing a real world solution to improve the lives of people with SCI?

A Exciting data exists showing neurostimulation can help to restore critical functions for people with SCI. You would be hard-pressed to find an existing therapy that has such promising acute effects as neurostimulation for restoring certain functions—for example, modulating blood pressure, resolving orthostatic hypotension (dangerously low blood pressure), improving lower urinary tract function and substantially reducing the time needed for bowel

management. These are seemingly significant functional improvements that would undoubtedly lead to enhanced quality of life.

Emerging evidence is now starting to demonstrate that, after a prolonged period of daily repetitive stimulation is concluded, these improvements persist, indicating long-term benefits.

At the recent American Spinal Injury Association 2019 Annual Summit, a specific neurostimulation symposium was delivered over a whole day, where researchers presented their findings on potential mechanisms, lower and upper-extremity function and important autonomic functions, such as bowel,

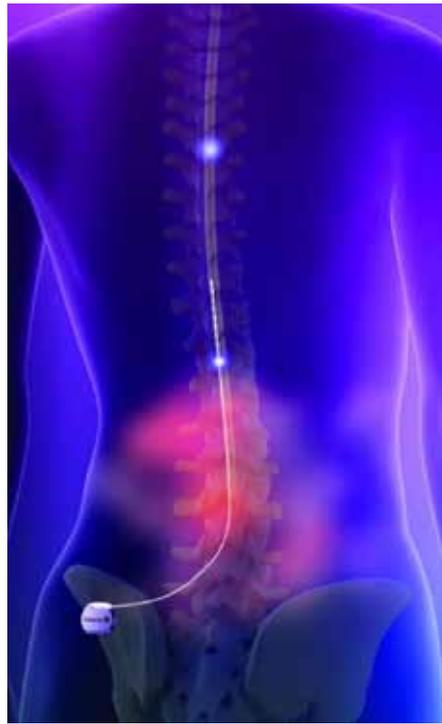
bladder and cardiovascular control. There was also an extremely interesting consumer perspective session, where researchers heard the experiences of individuals who had been implanted with an epidural stimulator. To have such a heavy neurostimulation focus at the premier North American SCI conference suggests that researchers are excited and intrigued by the therapeutic potential of such strategies.

Unfortunately, while there is an increasing number of studies confirming the benefits of neurostimulation, the number of participants enrolled in these is small. For example, in epidural (invasive) neurostimulation, it's pertinent to remember that only approximately 40 individuals with SCI have had an epidural stimulator implanted worldwide. Therefore, while the optimism is warranted based on exciting preliminary data, it is perhaps wise to be somewhat cautious and realistic. To date, some other treatments that have showed promise in pre-clinical research either did not reach clinical trials or failed to demonstrate therapeutic benefits at the clinical stage.

The pipeline for clinical translation is such that larger studies are necessary, with upwards of 100 participants, for achieving health regulatory authority approval. To recruit the necessary amount of volunteers with SCI to sufficiently determine the treatment efficacy and safety of neurostimulation, these trials will need to be multi-centre and run for an extended duration. Given the size of such trials and their comparatively long duration, they are the most expensive, time-consuming and difficult trials to design and manage.

Consequently, monumental efforts by researchers such as Bryce Vissel to secure a substantial amount of government funding to investigate these emerging technologies is necessary to further advance the field.

Q What are your thoughts on the two primary approaches to neurostimulation for SCI—the invasive, surgically-implanted epidural approach, and the non-invasive



transcutaneous approach, such as the pioneering work of Dr. Reggie Edgerton and his efforts to develop a device and bring it to market?

A The transcutaneous neurostimulation paradigm specifically may offer a simpler, less risky and more cost-effective solution. This approach uses conventional electrodes and stimulators that already have a well-established safety profile.

In contrast, despite utmost care and the highest surgical standards, patients undergoing surgical implantation are at potential risk of surgical complications that could lead to additional treatments, hospital re-admissions or even surgical removal of the device. Although rare, there are numerous reports of implanted electrodes leading to epidural hematomas in chronic pain patients, with a potential risk of spinal cord damage and paralysis due to compression.

Therefore, less invasive devices may represent a more accessible real-world option that considers patients' comfort and safety. Transcutaneous spinal cord stimulation has the potential to emerge as a widely-used therapy as it provides similar neuromodulatory effects as more invasive stimulation, without the

need for surgery and permanently implanted devices.

Q Can we ask you to do a very unscientific thing? If you're comfortable, please speculate and tell me how confident you are that this technology may offer a real benefit at some point in the near future for our readers.

A Transcutaneous stimulation, which is a non-invasive, routine procedure that uses conventional electrodes and isolated current stimulators, is already approved by some health regulatory authorities, including the USDA and Health Canada, for various indications such as transcutaneous electrical nerve stimulation (TENS) to treat pain. Although displaying a good safety profile, the specific indications for use of transcutaneous spinal cord stimulation for motor control, lower urinary tract, bowel and sexual functioning, remain to be approved. As a conservative estimate, I believe it will be possible to be approved and accessible to readers within the next decade. On the other hand, I think it's challenging to speculate on if and when epidural stimulation might be a commonplace procedure for individuals with an SCI.

For both epidural and transcutaneous neurostimulation techniques, larger-scale, pivotal studies are necessary in individuals with SCI to determine the efficacy and safety of such class III medical devices. These studies are essential prior to receiving health regulatory body approval and translation into clinical practice for specific indications.

On a positive note, some funding agencies, such as the Craig H. Nielsen Foundation, encourage research funding proposals to include a full clinical translation plan. This includes an outline of all major project milestones that are expected and necessary to demonstrate sufficient potential as a future therapy. This streamlines the process and, along with specific translational funding opportunities such as NINDS CREATE and the NSF Innovation Corp programs, will

hopefully ensure faster progress in the translation of research breakthroughs to clinical practice.

Q What are the specific avenues of neurostimulation research that you'd personally like to be involved in?

A Given my training as an exercise physiologist, I'm particularly interested in the potential of neurostimulation strategies to improve autonomic cardiovascular regulation during exercise, with the potential to translate to considerable health and performance benefits. Less fatigue and an improved physical capacity has the potential to not only improve health-related quality of life, but also maximize the benefits of exercise training—for example, enabling it to be performed for a longer duration or at a higher-intensity without tiring.

Q Finally, what do we all need to be cautious about, in terms of realistic hopes and limitations of neurostimulation research?

A This is a great question. I believe we are some way from optimizing these techniques for specific bodily functions. There are many, many unanswered questions.

For example, with transcutaneous neurostimulation, what is the optimal location of electrodes to restore lower urinary tract voiding and storage? Are these the same, or do they differ for certain bowel and sexual functions and across individuals? As the electrical current may bleed across different locations, does this technique offer the specificity provided by epidural stimulation whereby very localised parts of the spinal cord can be stimulated? If not, is it possible transcutaneous stimulation isn't as effective as epidural stimulation?

Transcutaneous stimulation itself is not without risk. Improper use can lead to skin burns or irritation. Furthermore, the precise positioning of electrodes may be problematic for individuals who have experienced a loss of hand strength and dexterity. If necessary, how feasible or expensive will it be to replace or reposition electrodes? Given that SCIs can be so different, do certain neurostimulation approaches work better for individuals with specific injury characteristics—for example, those with the greatest degree of spinal cord preservation?

Regardless of the approach used, what are the best stimulation parameters—for example, intensity, pulse width, and frequency—and do these differ depending on the functional response trying to be restored? From a long-term stimulation perspective, in a similar fashion to exercise prescriptions, what is the most appropriate frequency, intensity or duration of stimulation, and does this differ depending on the specific indication? What is the minimal amount of stimulation someone needs to see improvements?

I believe these are some of the key questions the research community need to address to maximize the efficacy of various neurostimulation strategies. ■

Presidential Appointment

Many of our readers know him as Doctor K. His colleagues in the SCI clinical and research realms around the globe regard him as a leading expert in the study of autonomic dysreflexia. Now Dr. Andrei Krassioukov has a new title: president.

Krassioukov was recently appointed to the position of President of the prestigious American Spinal Injury Association, or ASIA. He will hold the position until 2021.

ASIA is widely regarded as the premier North American organization in the field of SCI care, education, and research. Formed in 1973, it currently has more than 500 members who are committed to enhancing the well-being of people with SCI through discovery research and knowledge translation, interdisciplinary collaboration between scientists and clinicians, promotion of standards of care excellence, and fostering research aimed at preventing SCI, improving care, reducing consequent disability, and finding a cure for both acute and chronic SCI.

Krassioukov's appointment marks the first time that a Canadian researcher has held the prestigious position.

"It is my great honour and privilege to accept the position of President of ASIA," says Krassioukov, who is a professor at UBC and Associate Director of ICORD. "I am proud to be a part of this organization that has contributed so much to the field of SCI research and care. I plan to build upon ASIA's 50 years of excellence to foster new areas of growth and collaborations that I hope will expand our membership and build bridges between clinicians, scientists, allied health professionals, and consumers, with the primary goal of advancing clinical care and research in all areas of SCI."

Krassioukov is held in high esteem by countless researchers who have launched their careers working in his UBC/ICORD lab.

"I specifically enjoy the training and mentorship of upcoming young clinicians and researchers," he says. "Therefore, during my presidency, I will work closely with ASIA Membership and Early Career Committees to foster the next generation of clinicians and scientists who will advance the field and continue to lead this organization. It is my firmly held belief that by being welcoming to new, young, and enthusiastic individuals, ASIA and the community of people with SCI will ultimately benefit."



CATCH A WAVE!

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“The feeling of catching a wave, and the speed and the exhilaration that comes with it, is addicting. It’s just a beautiful sport.”

These are the words of Gerry Burns, intrepid adventurer and SCI BC Peer. At the time of his injury in 2003, Burns (that’s him in the photo above) had given up his career as a pro motocross racer in order to pursue his passion of surfing around the world. An accident during a hockey game back in Vancouver left him with a C1-C2 SCI.

Inspired by a California quadriplegic who got back on a surfboard, Burns worked hard to make the most of his function that was spared by the incompleteness of his injury.

“I became incredibly passionate about adaptive surfing, and I soon found myself heading down to Mexico on my own, with my bags, my surfboard and my walker,” he says. “I was unable to even get onto beaches by myself, but always found ways to meet local surfers who’d help me, paddle me out to the waves, and take me out to some of my favourite secret spots that I loved surfing able-bodied 20 years prior. That was living life again!”

Breathing spasms prevent Burns from surfing anymore, but he’s stoked about developing the sport. He’s the manager of Canada’s competitive adaptive surfing team, and he’s also working hard to create opportunities for recreational adaptive surfing in our province.

“It’s a really great time to be getting into it,” says Burns. “Adaptive surfing has grown around the world, recreationally and competitively. Adaptive equipment and mods have advanced immensely, accessibility to and from beaches is way better, and even some of the local surf shops in Tofino now have even trained their instructors on preparing for adapted surfers. In the years past, you pretty much had to go with a group of friends to carry you through the sand and help you into the water, but now there’s beach wheelchairs and trained adaptive surf instructors available.”

Burns is working hard with local surf shops and organizations including SCI BC to create more recreational adaptive surfing clinics. And he’s also proud to be a driving force behind Surf Canada’s adaptive surfing team which competes at the world level.

“We’ve built a stronger, more competitive world class team every year,” he says, underscoring the point by noting the gold medal that fellow SCI BC Peer Victoria Feige brought home to Canada from the recent ISA World Adaptive Surfing Championships held in California.

Burns believes that anyone lacking the patience to wait for an event day can easily try the waters themselves in Tofino.

“You could rent all the equipment at a local shop—a longer and wider board is recommended for balance as a beginner,” he says. “A few friends can help you get to the water, paddle out to catch a wave, or get back aboard if you fall. But it’s probably best getting a trained instructor. Most of the surf shops in Tofino all have great supportive staff and a wide variety of boards that can work for adaptive beginners, but I would recommend asking Pacific Surf School for their adaptive trained instructors for anyone new wanting to try it.”

Burns adds that a couple of beach wheelchairs are available at the Kwisitis Centre at the Pacific Rim National Park. He says that people of all injury levels can find a way to have a go with adaptive surfing.

“Of course, there’s a variety of surfing positions, board shapes and adaptations depending on people’s abilities, but it can be done for pretty much anyone. In world-class competition, surfers are categorized by their disability classification and certain aids may be allowed for certain levels. The same standards pretty much apply to recreational surfing as well. For example, some paraplegics can paddle their own board and actually surf very independently from the moment they’re in the water in a laid down prone position. Some can also sit upright and surf using a Waveski and paddle. Quadriplegics require a few water assistants to help paddle them out to the wave and then release them independently when a wave comes, using the same prone position as a para. The level that can be attained surfing with a disability is mind blowing. Paras, quads, amputees, and people who are blind are taking on the worlds’ most challenging waves and ripping them these days!”

Burns adds that anyone seeking more information about adaptive surfing can contact him by email (burner5353@gmail.com) or Surf Canada (info@csasurfcanda.org).

PHOTOS

1. Vancouver’s Victoria Feige enroute to her gold medal at the 2018 ISA World Adaptive Surfing Championships.
2. Vancouver’s Samson Danniels on his Waveski, which allows some paraplegics to tackle impressive waves.
3. Team Canada manager Gerry Burns at the recent ISA World Adaptive Surfing Championships in San Diego.
4. Scott Heron, SCI BC’s Peer Support Specialist in Victoria, gets ready to catch a wave during SCI BC’s family surfing event held in 2015 in Tofino.
5. Scott Heron gets a lift back to dry land.



Clear Vision

Kelowna's Dr. Paul Clark has enjoyed a long and rewarding career as an optometrist. Not surprisingly, he has some excellent insight for people with SCI seeking to maximize their vision and eye health.

Back in 1973, if you would have told 15-year-old Paul Clark that he would soon embark on a career in optometry that would span four decades, he probably would have laughed at you. At the time, he was pretty sure that whatever he ended up working at would involve his hands and a chest of tools, no doubt in or around his hometown of Woodstock, Ontario.

In the blink of an eye, a T5 complete SCI courtesy of a dirt bike accident had him reevaluating most aspects of his life, including his occupational aspirations.

"I had no idea what I could do for work, not being very academic, so I decided

to buckle down and study," says Clark. "Amazingly, I found I was smarter than I thought, and increased my average by 15 percent. My options opened, and my experience as a nine-year-old getting glasses made me think of optometry—I could do it from a chair, I thought."

Three years later, after graduating high school, he enrolled in first year science at the University of Waterloo. A year later, he was accepted into the university's optometry program.

"I had six professors to convince that I could do optometry from a chair, compared to the two pros that other students would get for their interviews," recalls Clark. "With a very positive attitude, I

won them over and became the first optometrist in Canada to use a wheelchair."

Throughout university, Clark juggled his studies with his increasing passion for wheelchair racing (see sidebar on the next page). In 1980, while competing at his first Paralympics in The Netherlands, he met a Dutch volunteer, Karin, who would eventually become his life partner. In 1981, he and Karin moved to Terrace, BC, his first stop as a newly-minted professional doctor of optometry.

"Our first son was born in 1989, after which we decided to live in Holland for four and half years to avoid the record snowfalls of Terrace," recalls Clark. "Our second son and daughter were born in



The Netherlands in 1992 and 1995 respectively. Then, in 1997, we moved to Kelowna.”

It was clearly a good move, as Clark and his family have called the Okanagan home ever since.

For the first 16 years of his career, Clark owned and operated his own independent clinic. In Kelowna, he first worked for several other clinics. Then, in 2003, he made the decision to join IRIS The Visual Group, a Canadian company founded by the late Dr. Francis Jean. Today, the company’s branded group of optometrists, opticians and ophthalmologists represents the largest network of eyecare professionals in Canada.

Clark’s Kelowna store and clinic, which he owns in partnership with the company, is one of 170 IRIS locations in Canada.

“Dr. Jean started IRIS The Visual Group with the intention of helping Canadians see better,” says Clark. “As

a private optometrist, having juggled a business with the clinical and sales sides, I was ready to spend more dedicated time with my patients. IRIS offers that opportunity, along with quality products that complete the experience of better vision I wish for all my patients.”

All in all, Clark says that optometry is a profession that is surprisingly accessible for people with SCI, providing they have full hand function.

“As a paraplegic optometrist, I have only modified my seating height with a specific wheelchair that has 26-inch wheels and sits seven inches higher than my regular chair,” he explains. “This allows me to be equal to the height of my seated patients with the ability to move the equipment, which swings from a standing unit. I use as much portable equipment as possible in order to eliminate body balance issues that can be a problem when I’m not supporting myself with my arms.”

While the majority of his clients aren’t wheelchair users, many SCI BC Peers and others with disabilities naturally gravitate to his practice. Not surprisingly, he strives to make his facility as wheelchair-accessible as possible.

“I’m not specifically expecting others with SCI to choose my services, but they can be assured my space is accessible if they have experienced difficulty at any of my colleagues’ practices,” he says. “I’ve designed my office to be wheelchair-friendly with an automatic door opener, plenty of room in the waiting area to park, a pre-test room with generous space, and, of course, a wheelchair-size washroom where chairs can turn around unobstructed by any cabinets which, all too often, seem to fill up those disabled washrooms.”

He also maintains that it’s possible for him to examine almost everyone with an SCI, regardless of what level it is.

“Unfortunately, I’ve heard from some Peers that optometry offices have told them the eye exam wasn’t possible with them remaining in their chair. Certainly, the exam takes a bit longer, and there’s some creativity needed to get accurate

results, but it’s far from impossible. My exam with patients who can’t transfer is modified with the use of hand-held lenses and other equipment.”

His advice for SCI BC Peers seeking an eye exam is full disclosure at the outset. “It’s probably best to tell the optometry

World’s Fastest Optometrist?

As many readers know, Paul Clark isn’t just an optometrist—he’s also one of Canada’s most celebrated Paralympians.

In 1976, the same year that he began university, Clark first tried his hand at wheelchair racing. It was immediately clear he was a gifted athlete, and he spent the next 15 years of his life juggling his career in optometry with racing.

He qualified for the 1980 Paralympics in The Netherlands, but failed to reach the podium. Four years later, he hit his stride at the 1984 Paralympics in England, capturing gold in the 800-metre and five silvers in a range of other events including the marathon. In 1988 in Seoul, he set a world record in the 800-metre to earn gold, and also captured three more silvers.

Despite his Paralympic success, Clark says the highlight of his athletic career came later in 1988 during the Oita Wheelchair Marathon in Japan. He won the event, setting a world best time of 1:38:27 in the Open class.

Not surprisingly, fitness and athletics remain a big part of Clark’s life.

“I used the racing chair until just two years ago, but prefer the handcycle now mostly because it’s easier to maintain and easier to get in and out of. The racing wheelchair gives a much better workout, though. My biking partner is another ex-Paralympian, Diane Rakiecki, and we often bike 30 km together twice a week.”





office when you're booking that you use a wheelchair, and whether you can or can't transfer," he says. "Much like travelling by air, the better prepared the office is, the better experience you'll have."

Clark confesses he's always been greatly interested in learning and observing how people with SCI can maximize their visual health—the result, he says, of his own curious nature and personal experience. Not surprisingly, he's acquired a great deal of knowledge in the area, which he's only too happy to pass along.

To start with, he confirms that people with quadriplegia often experience some eyelid droop and have a smaller than average pupil size.

"Even in dimly lit situations, their pupils will fail to enlarge to a size that lets in a good amount of light," he says. "This is a disadvantage for seeing things well in the dark, but may be considered an advantage when it comes to the need for glasses. Smaller pupils give a greater depth of focus, making them less sensitive to minimal refractive errors. If a quad needs glasses because of eye strain or difficulty seeing, they probably have a higher prescription than their able-bodied friends who seem to wear glasses which, in contrast, have barely any power correction."

Since many people with SCI use it to relieve pain and spasticity, we also asked Clark for his thoughts on cannabis, given that it's also used by some to relieve glaucoma, a potentially serious disease that results in high pressure within the eye.

"Cannabis has always been thought of as having a pressure-reducing effect in the eye, although few studies have been done until recently, and one has even indicated the pressure rises," he says. "What we do know is that the effect of cannabis on eye pressure is much shorter-acting than drugs we currently have for glaucoma, so it's a poor substitute."

As for other medications, he cautions that some prescriptions for spasms and anxiety can slow eye focus and make the eyes feel dry.

Clark has some real concerns about excessive screen time, which we asked

about since it's reasonable to suspect that many people with SCI spend a great deal of time in front of screens, either for work or recreation.

"With the increase in screen time over a short 20 years, I'm hearing more complaints of discomfort and, more importantly, poorer vision," he says. "Perhaps because of mobility issues, many SCI people spend higher than average times on screens, especially small ones like smart phones, which have the highest concentration of blue light. Blue light contributes to focusing problems and even retinal damage over time. Often, my patients will blink to make things clear, and this is the hallmark of dry eye. Also, eyes that seem to become excessively watery is a form of tear instability which leads to reflex tearing, instead of providing a good, stable tear film."

Consequently, he advises readers (and just about anyone, for that matter) to take steps to limit their screen time.

Finally, and given the inevitability of declining vision for most people as they age, we asked Clark for his best advice on the best corrective strategies for people with SCI, taking into account that the majority are usually sitting and not standing, and their hands are often occupied with mobility and aren't available for quick eyewear changes.

He's a fan of progressives—multi-focal lenses that give you up to three vision powers in one seamless package. You simply adjust your head position to see three ranges of distance—bring your head up to see far away; look straight ahead for mid-range vision, and point your nose down to read or text.

"Many people with SCI usually have their hands occupied with wheeling," says Clark, "so progressives eliminate the need for people with multiple correction needs to continually switch between glasses—instead, with progressives, they can wear a single set of glasses for multiple purposes."

However, he cautions that not everyone with SCI is a good candidate for progressives.

"Due to mobility and dexterity issues,

many SCI persons are unable to position themselves to best use progressive lenses in glasses," he says. The reason, he explains, is that people with SCI who sit throughout the day look upward a greater amount of time than someone who stands, meaning they'll be looking through the distance correcting portion of the lens at times when they shouldn't be. But he adds there is a solution that works for some people—opticians can set the progression slightly higher in the eyeglasses frame to offset this issue.

He also cautions that not all progressive lenses are equal.

"Each progressive lens brand has its patented algorithm of power change, and some will cause considerable distortion for the wearer. In my office, I have an instrument which can map the distortions, helping explain the discomfort of the wearer. More expensive lenses are likely better designed than cheaper ones, and name brands like Zeiss, Nikon or even Essilor will ensure better quality. You should be given at least three options of good, better, best at your optical—if you're only given a single option, this will likely result in you receiving lenses which typically cost the optical the least and yield the highest profits."

What about contact lenses?

"With the advent of daily disposable contact lenses for everything from astigmatism to multifocal, they may now be a feasible option," he says. "Quads, of course, would have difficulty inserting and removing, but there are quads who have become successful and have posted YouTube videos of their technique. Some optometrists will feel comfortable letting their patients wear specific types of lenses overnight, but this should only be done with caution since overnight wear is one of the leading reasons for loss of vision in young people today. Some optometrists even offer the service of removing the contact lenses and inserting a new set at the prescribed time."

He adds that, unlike progressive glasses, multifocal contact lenses (think of them as progressive lenses in contact form) can't correct astigmatism,

so people who obtain the most success wearing contacts are those who wear glasses only for reading, or only for distance, and not both.

Another option, says Clark, is laser correction surgery. Typically, this procedure sees one eye corrected to provide good distance vision, and the other eye corrected to provide good reading distance vision.

"Some people with very high level injuries may enjoy the freedom of laser vision correction just because their mobility issues hampers their ability to use progressive lenses and glasses," he says, adding that high cost and the invasive and permanent nature of the procedure are sometimes deterrents.

Clark is also a big believer of the need to protect the eyes from sunlight. Quality sunglasses are a must, he says, with the ability to filter out 100 percent of ultraviolet light—the most harmful wavelength—being paramount. Adding polarization is also a good idea if you're concerned about minimizing eyestrain.

"Wheelchair users may find photochromic lenses in their regular eyewear best because it eliminates the need to switch glasses when going outside," says Clark. Photochromic lenses—the most well known of which are the Transitions brand—darken when exposed to ultraviolet light of sufficient intensity, and return to clear in darker settings.

"But," says Clark, "keep in mind that regular dress eyewear allows more light around the outside of the frames than proper sunglasses that wrap the face."

Clark offers a couple of final pieces of advice.

"Posture and neck tightness can lead to double vision or a tendency for the eyes to have difficulty working together. Sometimes the solution can be as simple as a neck massage and better posture. Also, our eyes feel dry when cells making up the cornea break down. We know now that supplementation with fish-based Omega 3 makes those cells stronger."

For more information, or to contact Dr. Paul Clark, visit Iris.ca/kelowna or Facebook: [iriskelowna](https://www.facebook.com/iriskelowna). ■

A Good Reason to Smile



Micaela Evans, SCI BC Communications & Events Coordinator, takes a spin on Dr. David Burdett's new wheelchair accessible dental chair.

Dr. David Burdett's New Westminster clinic debuts what's believed to be the first wheelchair accessible dental chair in British Columbia

With more than 40 years of experience as a dentist, Dr. David Burdett has seen his fair share of technological advances in the profession. But the owner of the Diamond Dental Centre in New Westminster had never seen anything quite like the wheelchair accessible dentist chair, built by UK manufacturer Design Specific (designspecific.co.uk).

"I saw it at a dental conference, and I was really excited," Burdett says. "I've had a number of patients in wheelchairs before and I thought, 'Wow, this is a great idea.' I was building a new office at the time that was close to the hospital. We had the financing available, so it made sense."

The fully adjustable, battery-powered chair can safely support a patient up to 300 kg. It's composed of three parts:



a compact wheelchair recliner, a bariatric bench, and a universal headrest. To access the dental chair, the bariatric bench is removed, and patients wheel backwards into the recliner until their chair rests against the backrest. Once positioned, the wheelchair recliner tilts back, and patients can use the headrest as needed. Both manual wheelchairs and power chairs can access the dental chair, and no transfer is required.

Sadly, you won't find this level of accessibility at most Canadian dental practices. Perceived lack of demand and financial burden are the most likely reasons: accessible dental chairs cost almost three times as much as regular dental chairs.

"Many (dentists) might think, 'I don't have many patients who could use that,'" says Burdett. But he says this isn't true. In fact, a recent finding in the *Journal of the Canadian Dental Association* states that dental care remains one of the most required health services for millions of people with disabilities in Canada, yet it

is also the hardest for them to find and access.

Burdett's new chair is a small step to help close this gap. It's the first accessible dental chair in BC, and one of only a few in all of Canada.

"Patients have seen the chair and mention they have a friend or a relative that could really benefit from this—those connections are everywhere," Burdett says. He also notes that the chair negates the need for extra staff for transfers, and saves time for everyone—him and his staff, and more importantly, patients—during appointments. The chair is also a good option for heavier and elderly people, as the size allows for more comfort and adaptability.

He concedes the chair has limitations. "It's great for short procedures, like checkups or cleanings," explains Burdett. "But long procedures may be difficult because the dentist would have to perform standing up or bent over, and that's putting our bodies at risk after long periods of time."

Still, Burdett clearly sees that the benefits outweigh the limitations.

"When I graduated dental school, going into a building with any kind of wheelchair access, let alone an office like this, would have been amazing," he says. "Things have changed over the years, but obviously there's still more to do."

Here at SCI BC, we're happy to give a shoutout to Dr. Burdett, in the hopes that more BC dentists might consider adding a wheelchair accessible chair to their clinics. Readers of *The Spin* can also spread the word—please don't hesitate to show your own dentist this story and tell him or her how this could make a difference in your life. ■

For more details about the accessible dental chair and Diamond Dental Centre, visit diamonddentalcentre.ca. Note that parking at Dr. Burdett's office is limited and located at a distance. Please contact the office directly for directions and further information on how to access the building.

We're proud to support Spinal Cord Injury BC.



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From Mice to Men

Research from the UK reveals a promising new strategy to promote nerve regeneration after SCI

In April, we came across an interesting research story from the UK. The science described involved animal experiments—something we typically avoid, since we think you’d prefer to read about research that’s already in the clinical stage with humans. But after a little digging, we decided to write about it because of a couple of interesting twists.

At first glance, the essence of the story appears to be this: researchers at Imperial College London, along with international collaborators, found that encouraging rats to be active before an SCI made it more likely that their damaged nerves would regenerate after injury.

At this point, you’re probably thinking, “Great...I just needed the ability to foresee the future before I got injured, so I could have been in the gym day and night getting prepared for it.”

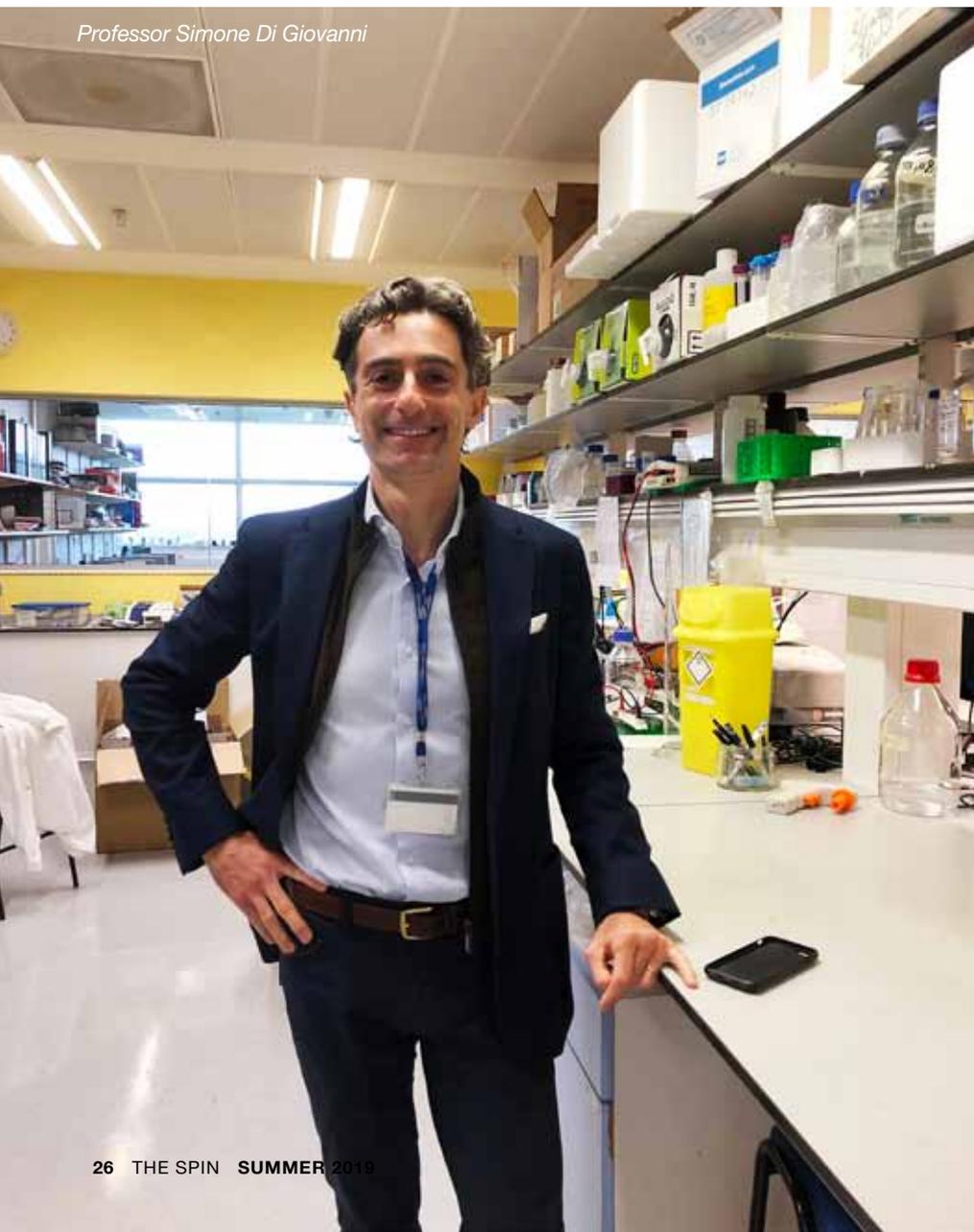
Bear with us—there’s more to the story.

First, while not part of the published research, the scientists involved say they have shown that encouraging activity immediately following injury also led to improvements (as such, it helps confirm the benefit of steering people into active rehab as soon as possible after an SCI).

Second, and more importantly, they were also able to mimic the effects of an active lifestyle with the use of a drug. Not only that, use of this drug leads to the same improvements when provided *after* SCI, during the acute phase. And they suggest that the drug’s benefits might even be seen in chronic SCI.

Third, while the safety of the drug in humans has yet to be confirmed, the researchers are already planning to do just that as soon as possible. The ultimate goal is to determine if it can offer the

Professor Simone Di Giovanni



same improvements in neurological outcomes in humans as it has already been shown to do in animals.

The research was led by Professor Simone Di Giovanni, from the Department of Medicine at Imperial College London. Di Giovanni was aware of the plethora of anecdotal evidence suggesting that people with an active lifestyle seem to recover to a greater degree after SCI than those who aren't so active. He wanted to confirm this—and determine why this happens. He theorized that there was a robust “physiological” mechanism involved that stimulates the regeneration of sensory neurons after SCI, which in turn promotes recovery of both sensory and motor function.

“These neurons convey sensory information from the environment and lie at the crossroad between the world around us and the nervous system,” he explains. “Therefore, I thought, ‘What would happen if we enrich sensory stimuli around mice with environmental enrichment? Would it promote plasticity and sensory axon regeneration? Would it be able to drive neuronal activity that promotes molecular changes that would reprogram the neurons to regenerate after an injury?’”

Di Giovanni and his colleagues designed a rodent study and began to test the theory. One group of mice were given enhanced environmental, physical and social stimuli—larger cages with more mice in it, more toys, and more tunnels, swings and running wheels. Meanwhile, a control group of mice was left in much more basic surroundings.

Lo and behold, when the spinal cords of all the mice were subsequently damaged, the researchers quickly observed that, in the group who had been provided with a more active lifestyle, there was much greater growth and sprouting of the nerve fibre at the site of injury. They also observed measurable improvements in functional and sensory ability in this group.

“We discovered that environmental enrichment increases the activity of neurons,” explains Di Giovanni. “This

increased activity resulted in changes in proteins that were able to enhance the growth ability after an injury. Essentially, by increasing the activity of neurons that sense enriched environmental stimuli, we have been able to promote the regenerative potential of nerves after SCI. From what we have seen, it's almost as

“The drug treatment that promoted regeneration and recovery in mice and rats after SCI offers an opportunity to be tested in patients.”

if the nerve cells are being ‘primed’ for regeneration and growth, which add to this enhanced recovery.”

On its own, this is interesting but hardly a breakthrough in terms of improving functional outcomes after SCI. But as we noted above, the story doesn't end there. Di Giovanni and his colleagues wanted to know about the underlying cellular mechanisms involved. If they could determine that, they reasoned, they might be able to develop a way to trigger the response in some other way—for example, with a drug.

Their diligence paid off when they identified the elevated presence in the environmentally-enhanced rodents of a key molecule known as CREB-Binding Protein (CBP). It appeared that CBP was responsible for effectively reprogramming the nerve cells, altering the expression of a number of genes in the cells and boosting their ability to regenerate. Based on this, the team tried using a recently-developed drug that activates CBP to reprogram damaged nerve cells, in the hopes of mimicking the regenerative effect of environmental enrichment.

“It's a small molecule compound that activates the same protein that we found to be triggered by environmental enhancement,” says Di Giovanni. “Therefore, with the drug, we can mimic after an injury what environmental enhancement did before an injury—promoting

regeneration and neurological recovery.

In additional trials with mice and rats, they found that giving the drug six hours after SCI, and once a week thereafter, promoted the regeneration and sprouting of damaged nerve fibres. Following injury and drug treatment, rats which were otherwise unable to walk properly regained significant mobility in their back legs, compared to control animals without treatment.

Di Giovanni is careful to point out that the drug has not been tested in humans yet. But he adds that it has been tested in other animal models of nerve damage, in learning and memory in mice, and in both cases it was beneficial and safe.

“The drug treatment that promoted regeneration and recovery in mice and rats after SCI offers an opportunity to be tested in patients,” explains Professor Di Giovanni. “In principle, this kind of treatment is not very far from being tested in the clinic. Further studies are needed to show the drug is safe in humans before it could be trialled.”

Another next step for Di Giovanni and his colleagues is to combine the drug treatment with neuromodulation (electrical stimulation) approaches that have gained international attention for their ability to restore function (see page 10). This will also be attempted in animal studies.

He also says that the drug's effect may also be enhanced by combining it with active physical activity rehabilitation.

While Di Giovanni is buoyed by the results of his work, he cautions that the results are far from conclusive—they need to be replicated in larger trials and, after safety has been determined, confirmed in human clinical trials. And it's always important to remember that SCI in humans is much more complex than it is in rodents.

The research was published in a paper titled “Cbp-dependent histone acetylation mediates axon regeneration induced by environmental enrichment in rodent spinal cord injury models” and appeared in the journal *Science Translational Medicine*, April 10, 2019. ■



A three point Peer shoutout to **all the members of the BC Breakers** women’s wheelchair basketball team, which recently brought home bronze medals from the national championships held in April in Montreal.

The Breakers did it in dramatic fashion with a 70-69 win over Saskatchewan. Down with 20 seconds to play, Kady Dandeneau gained possession in the defensive zone and lobbed a pass to teammate Tara Llanes (photo above), who wheeled in for an uncontested layup and the win.

“I think we got fourth the last four years, and it was just heartbreak every time, so we’re super pumped,” says Llanes. “I’m just really proud of our team for sticking to it.”

Our own SCI BC Resource Centre Manager Jocelyn Maffin, a long-time National team alternate, was coaxed out of retirement to help the Breakers reach the medal podium. Other members are Ryleigh Bissenden, Lannette Boland, Kelly Harris, Amanda Pinheiro, and Megan Smith.

Lori Slater, SCI BC’s Fort St. John Peer Program Coordinator, gets a well-deserved shoutout for her tireless support of the Achievers Toastmasters Club, which celebrated its 25th anniversary in April. Slater, who is an 11-year member and the club’s Vice-President of Membership, says the chapter has been vital to give a voice to immigrants and anyone uncomfortable with public speaking. She adds it’s given her an opportunity to share her own story and create awareness of SCI in Northern communities.

“I was public speaking beforehand for the Rick Hansen Foundation and I was great at telling Rick’s story; what Rick had done,” says Slater (photo right) “But part of what I was to do was also tell my own personal story of how I became a paraplegic. Toastmasters has allowed me to do that—to get vulnerable, to be able to show who the real Lori is, and not just the lady in the wheelchair.”

The Achievers’ Toastmasters Club meets every Thursday night, except in July and August, at Northern Lights College in Fort St. John.



Kudos to Victoria’s **Aidan Love** (below left), who was recently bestowed with the BC Wheelchair Basketball Society Male Athlete of the Year honours during the BCWBS annual awards evening held April 10 in Richmond. Originally from the Yukon, Love is a superb multi-sport athlete who most recently helped the BC Royals beat Saskatchewan to capture bronze at the national championships held in May in PEI. He credits the Bridging the Gap program for introducing him to wheelchair basketball, along with tennis and golf.

“Whenever you are recognized by your peers and teammates, it definitely feels good,” says Love, who works as a Portfolio Coordinator at BC Pension Corporation. “I’ve been playing wheelchair basketball for close to eight years now, and winning an award like this definitely tops off a great year. I’m a very competitive person in everything I do, and whether that’s provincially or nationally with Team BC, I will continue to push myself in the gym and on the court to get better. That’s the best part about wheelchair basketball—you can continuously improve and are humbled every day on the court.”

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 all of your details to thespin@sci-bc.ca.





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Home in the Okanagan

SCI Action Canada and the ABC Lab open new research facility at UBC's Okanagan campus in Kelowna

The University of British Columbia Okanagan is now home to an exciting new community-engaged research space for four world-leading researchers focused on promoting the health and wellbeing of people living with SCI or other physical disabilities, and those who have or are at risk of chronic diseases like Type 2 diabetes.

Thanks to Dr. Kathleen Martin Ginis and her SCI Action Canada research team, and Dr. Heather Gainforth and her Applied Behaviour Change (ABC) Lab, SCI research will be front and centre in the new research space, and SCI Peers in the region will have many opportunities to contribute to this work.

The new facility, located in the Upper Campus Health Building, was officially opened April 15 with the Honourable Carla Qualtrough, Federal Minister of Public Services and Procurement and Accessibility, on hand to preside over the ceremony.

"We're giving science, and specifically data, the opportunity to inform policy on issues of significant importance such as disability and accessibility," said Qualtrough during her remarks. "This investment in science will allow the health and wellbeing of the local community and beyond to improve for generations to come."

Martin Ginis says her team's work at the new facility will focus on promoting health and quality of life for people living with SCI and other physical disabilities.

"Our aim is to foster research excel-

lence that is responsive to the healthcare needs of our region—to develop, test and evaluate the latest interventions and deliver the most effective strategies directly to those that can benefit from them the most," says Martin Ginis.

Martin Ginis emphasizes the community-engaged nature of the new research facilities—an approach she says brings the community itself into the research process to help guide its direction and to ensure the resulting knowledge is immediately available to those that can use it best.

"We've designed our space to be open,

welcoming and accessible," she says. "For example, we've created a completely wheelchair-accessible demonstration kitchen that will allow us to run nutrition workshops. It was important that our space be fully functional for those who will be involved and engaged in making our research a success."

Martin Ginis and her colleagues have also created research space featuring accessible fitness equipment similar to that at ICORD's Physical Activity Research Centre (PARC).

On hand for the opening was Dr. Chris McBride, SCI BC Executive Director and long-time contributor to the work of SCI Action Canada and the ABC Lab, both of which are connected to ICORD.

"This is a superb new facility," says McBride. "It offers the opportunity for SCI BC Peers in the Okanagan to engage and participate in world-class research, and we're thrilled to be a fully engaged community partner helping to bring about timely advances that will help people with SCI and their families adjust, adapt, and thrive."

Visit sciactioncanada.ca for more information. ■



Left to right: UBC Okanagan Vice Principal Research Phil Barker, UBC Okanagan Deputy Vice-Chancellor Deborah Buszard, The Honourable Carla Qualtrough, BC MLA Stephen Fuhr, Professor Kathleen Martin Ginis, Assistant Professor Heather Gainforth, and Assistant Professor Mary Jung. (Photo courtesy UBC Okanagan)



Time Travel

The Great Gatsby would have felt right at home—providing, of course, he was comfortable being the only man in the room.

In March, SCI BC hosted its annual Women’s Event at Creekside Community Recreation Centre in Vancouver. Our Peers travelled back in time to a 1920s speakeasy, where they enjoyed wine tasting with Sommelier at Home, a painting session, swing dancing lessons courtesy of Fuse Wheelchair Dance, and wise words from guest speaker Alison McKenzie from ShEvaluesco, a non-profit association that strives to empower young women.

In particular, the dance floor was a huge hit.

“I love dancing so much,” says Par Bains. “But I never knew that we could dance like that in a wheelchair. You opened up my eyes. The possibility chapter began for me at that moment.”

The party continued throughout the afternoon with plenty of feathers and boas on hand, a 1920s makeup demonstration by Blanche MacDonald Centre, and a scrumptious spread.

Our thanks to The Hamber Foundation and Coloplast for supporting this event. See more photos of this roaring good time on the SCI BC Facebook page (bit.ly/womens-event).



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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.

Wrist-Worn Devices For Measuring Wheelchair Pushes

Overview: The Apple Watch and PushTracker are wrist-worn electronic devices that attempt to capture the number of wheelchair pushes a wheelchair user makes during their activities of daily living. As of writing, no independent studies have determined how accurately these devices measure wheelchair pushes, or if they are able to capture what they are intended to. Researchers in Dr. Bill Miller's lab want to determine the reliability and validity of these devices in measuring wheelchair pushes.

What to expect: Participants will perform wheelchair pushes through fast, slow, and unstructured wheeling tasks. Total wheeling time is around 10 to 15 minutes, with approximately three to five minutes of wait time between pushes. Participants will be guided through slow and fast wheeling tasks by an audio cue. The total time commitment is approximately one hour.

Who can participate: To participate, you must be 18 years of age or older, a community-dwelling manual wheelchair user in the Greater Vancouver area with at least three months experience using a manual wheelchair, able to propel the wheelchair bi-manually for 50 metres, and able to provide informed consent.

Why participate: Technology that is reliable and accurate has been shown to be able to positively motivate users to increase physical activity. This knowledge is particularly important for a manual wheelchair user population due to decreased physical activity levels within this population. Ensuring that these devices are reliable and accurate may encourage the users to engage in more wheelchair pushes throughout the day, thus increasing physical activity, and potentially decreasing de-conditioning and the health complications that occur as such.

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

For more information or to sign up: Please contact the study coordinator, Emma Smith, at smithem@alumni.ubc.ca or 604.714.4108.

Effects of a Single Exercise Session or Meal on Health

Overview: Dr. Kathleen Martin Ginis' lab is conducting a case series study on the effects of a single exercise session or meal on physical and mental health of people with SCI. The purpose of this research is three-fold: (1) to understand the effects a single meal on the inflammatory processes of the body, (2) to understand the effects of a single bout of exercise on inflammation, and (3) to better understand the relationships between inflammation and psychosocial outcomes (i.e., neuropathic pain, perceived stress, and affect).

What to expect: Participants will be asked to visit the Health and Wellness Laboratory at UBC Okanagan four times. Visit 1 will be for familiarization (including physiological and cognitive tests). Visits 2 to 4 will involve one of the following (in random order): an exercise day, a control day, and a diet day. Each visit will require approximately two to two and a half hours for a total time commitment of eight to ten hours.

Who can participate: You may be eligible to participate if you are 18+ years of age; experience neuropathic pain sensations; read, speak, and understand English; have been diagnosed with a SCI for at least one year; participate in a high intensity sport (e.g., wheelchair rugby, wheelchair racing, hand cycle racing, para alpine skiing), or train at a high intensity at least three times per week.

Why participate: Participants may gain insight into how exercise and high fat/high carbohydrate diet affects their neuropathic pain sensations/psychological outcomes. Given the minimal understanding of neuropathic pain, any additional information and general understanding may positively impact wellbeing and quality of life for persons with SCI. Participants will receive up to \$150 for full study completion. Parking and travel (\$0.42/km) will also be compensated.

Location: UBC Okanagan Campus (1238 Discovery Ave, Kelowna BC).

For more information or to sign up to participate: Please contact the study coordinator, Kendra Todd, at ktodd03@mail.ubc.ca or 519.546.3496.



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



Taking a Drive Down Memory Lane

One iconic car. Two larger-than-life owners and friends.

Big Red was a familiar sight to many older readers during the early days of Spinal Cord Injury BC (we were called BCPA back then). The 1975 Pontiac Grand Ville Brougham convertible first belonged to **Stan Stronge**, SCI BC's first employee, a pioneering builder of wheelchair sports in our province and a Peer mentor to countless men and women who, like Stan himself, lived with an SCI.

Behind the wheel of Big Red, Stan was a winning competitor at many of SCI BC's Safe Driving Rodeos in the 1970s and 80s. Originally started to promote our members' skill and ability using hand controls, this event ultimately convinced policy makers of the day to lift speed restrictions for drivers with SCI. It continued for many years as a favourite annual Peer event.

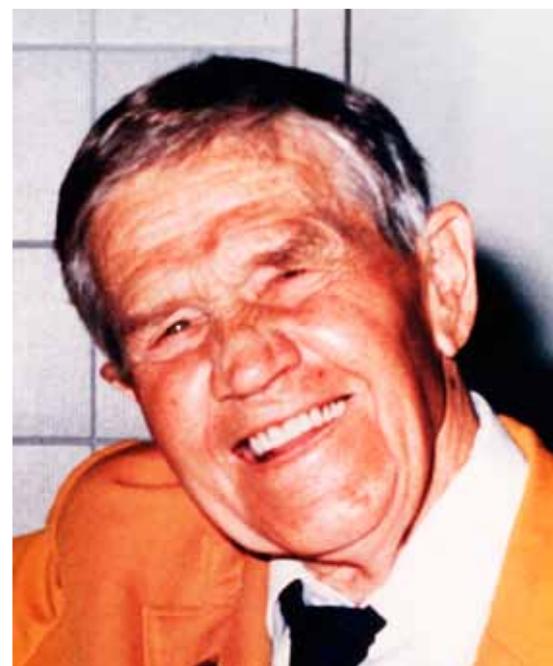
Big Red also gracefully and reliably provided transportation for numerous Peers during countless road trip adventures and jaunts to the White Spot drive-in, and represented SCI BC in various civic parades and other events. Some 45 years later, our older Peers still swap road trip stories about Big Red.

Over the years, Big Red's paint faded, the leather seats cracked and the motor didn't run as smoothly. But it was destined for a second life.

After Stan stopped driving prior to his passing in 1991, the car was purchased by one of Stan's former colleagues at SCI BC and certainly one of his biggest fans. **Wayne Moser**, who was a Peer coordinator for more than a decade until the late 1980s, lovingly restored Big Red from bumper to bumper over the course of several years.

Once again, Big Red could be found on parade routes, with Wayne behind the wheel in place of his old friend. Wayne was an extremely generous and kind person; he was always happy to share the car for charitable or community events.

Our community recently lost Wayne on April 6. Big Red is now resting at Wayne's home in Port Coquitlam. And perhaps Wayne and Stan are swapping stories once again. Rest in peace. ■



TOP: Wayne Moser behind the wheel of a restored Big Red. MIDDLE: Big Red back in the day. BOTTOM: Stan Stronge.

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