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FALL 2017

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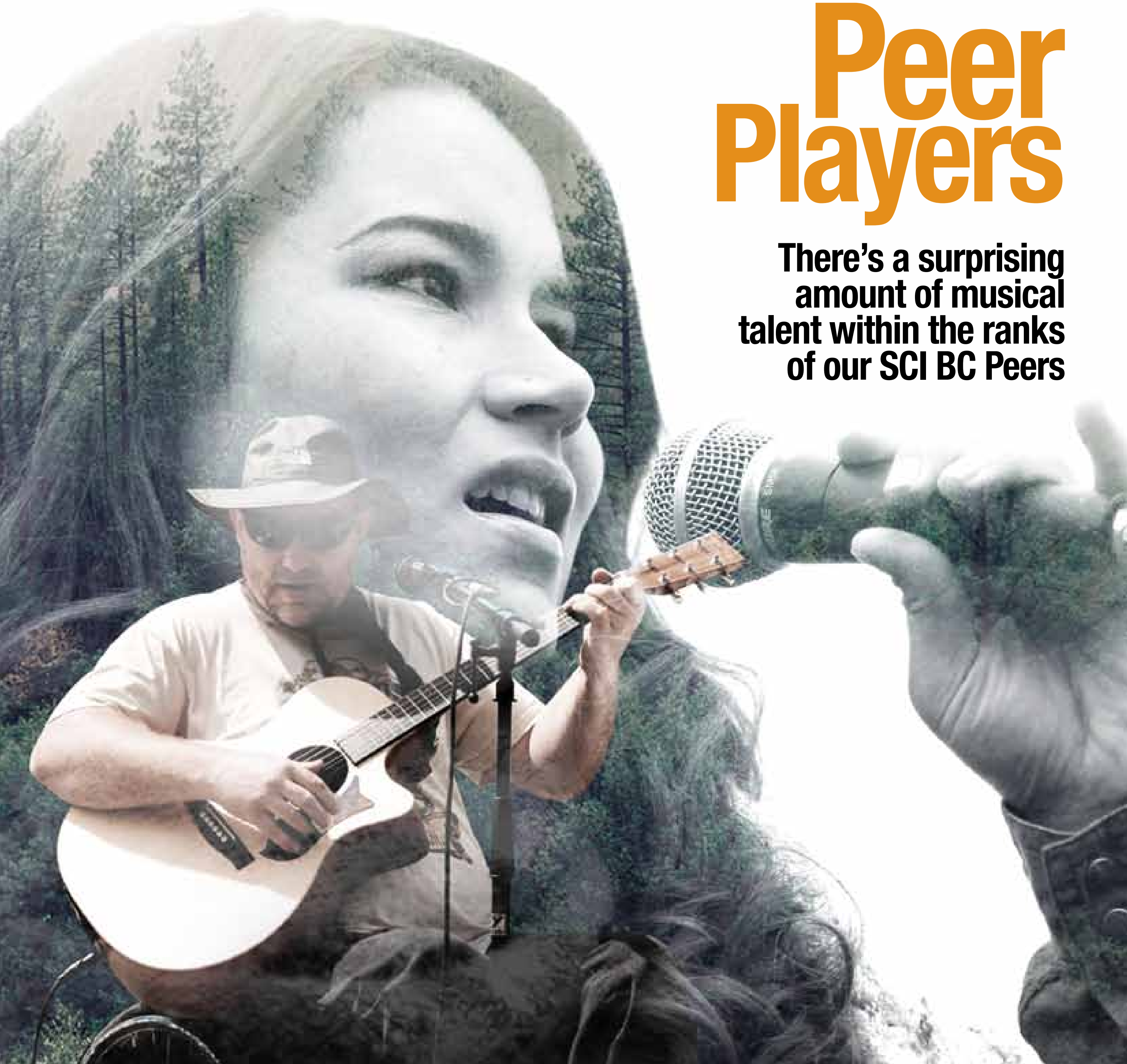

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COVER PHOTO: *Singer-songwriter Kristina Shelden and blues musician Danny Sloan jam together in a duo called Salt of the Earth (Maya Pankalla Graphic)*

Revisiting Diversity

If you've been following the news, perusing politically-oriented social media posts, or even watching a CFL football game, you will, no doubt, have come across the buzzword once again making headline news these days: diversity.

Diversity is often used to describe the differences within a group of people.But in our current socio-political reality, it's taken on greater meaning—diversity is being used as a powerful counter to those who promote intolerance and hate.

Diversity is not just about different ethnicities, cultures, religions, genders, or orientations. It's also not just about different disabilities or abilities. Today, diversity has grown to include differing opinions, ideals, ideas, and values. If we're to respect and embrace diversity, then we must do so on all of its levels.

This doesn't mean we always have to agree with the diverse views people express—agreement and respect for diversity are two different things. We may not agree, but that doesn't make my views superior to yours. The exception, of course, is when views are based on hate and are intended to harm others—views that often arise from ignorance, lack of respect, or just plain malice.

When it comes to disability, society and our social institutions like to lump everyone with a disability together, often referring to them as part of a community of people with disabilities. I've stated before that there is no such community and that there is as much or more diversity amongst people with disabilities as there is between people who identify as having a disability and those who don't.

SCI BC represents a diverse membership. That's why we must be sure to respect our members' diverse challenges, needs, cultures, and opinions. Yes, we do take positions on some matters, like those we have expressed about untested stem cell treatments, but on others, we must take a neutral position and separate personal biases from supporting the interests of our members. One example is hunting. Not everyone is in favour of hunting; many are vehemently opposed. But there are many SCI BC members for whom hunting is an important part of their lives and integral to their ability to adjust, adapt, and thrive after SCI. This is why we feel it's important to tell the stories of those who have figured out how to return to hunting after their injury.

Another recent example is the Miss Wheelchair Canada Pageant, which was held in Vancouver on September 2 and which we feature in this issue's Room for Debate. Knowing the cultural debate surrounding such pageants (i.e., the objectification of women versus choice and empowerment), we took some time to consider our response when the organizers approached us requesting our assistance in promoting the event. I started by soliciting the opinions of my Peer Support and Information Services staff. I received a consistent response: while many were not personally interested in beauty pageants and questioned whether they were constructive for advancing values of equality, they all acknowledged that such opportunities were likely important to at least some of our members and that many could have a positive experience participating in or watching one.

I totally get that. Just because I may not be supportive of beauty pageants doesn't mean that SCI BC should not be supportive. Similarly, it doesn't mean that we need to endorse them, but we should let our members know about it and support those who take an interest in participating.

This is how we must embrace diversity. Unless we know something will be harmful, hateful, or discriminatory, we must serve the diverse interests of our members and those in the broader community. If all Canadians adopt this approach, we will be well on our way to advancing the societal shift required to ensure access and inclusion for all Canadians.

To paraphrase the federal government and the CFL alike, diversity is our strength. I couldn't agree more.

CBM

– Chris McBride, PhD, Executive Director, SCI BC

thespin

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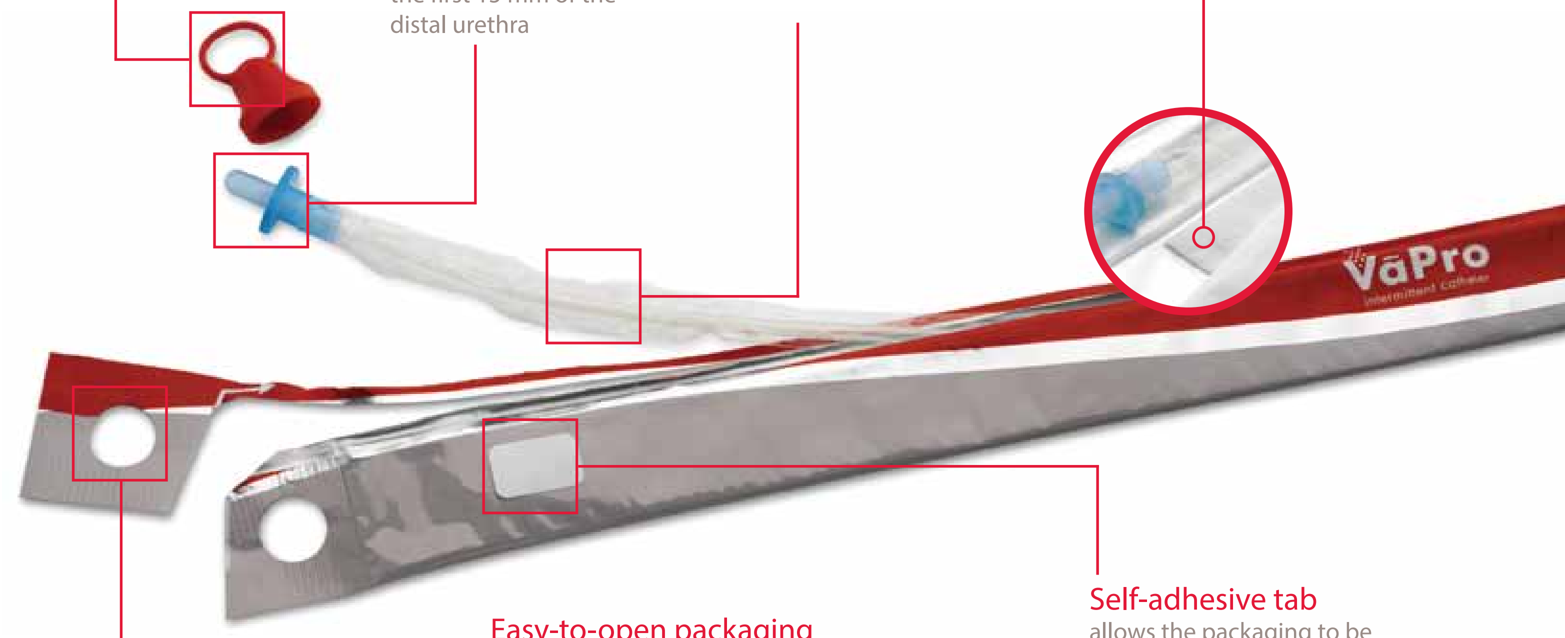

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Innovations

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

THE VAMP STAMP

Winged eyeliner is a popular look when done right, but it can be a tricky skill to master—particularly for women with limited hand function. Enter The Vamp Stamp, a patented device that allows for a smooth and perfect winged liner look. You simply dip the stamp into liquid liner, align to the edge of your eye at the preferred angle, and press on. You then continue the line along the upper lid. The device is the brainchild of Veronica Lorenz, a celebrity makeup artist who lost the feeling and strength in her hands as the result of a spinal tumour. Veronica plans to continue to develop and launch other innovative solutions for makeup application for people with limited hand dexterity. Visit www.thevampstamp.com for videos and more details.

LIGHT DRIVE

The Light Drive, developed by France's Benoit Systemes, is a fresh take on a manual wheelchair power add-on. It drives your chair's tires via motorized rollers behind your seat, making it more compact than other designs and easily stored in the trunk or overhead luggage bins on aircraft. The Light Drive is quick, agile and manoeuvrable, thanks to its two electric motors which are controlled with a joystick. To free wheel, you simply release the clutch. A three-kilogram lithium ion battery provides up to eight kilometres range. Visit www.benoitsystemes.com for more information and videos.

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The inFlow Intraurethral Valve-Pump is a non-surgical prosthesis that provides an alternative to urinary catheters for women with atonic bladder who are unable to spontaneously urinate due to impaired detrusor contractility. Since women with atonic bladder are unable to generate bladder pressure, the inFlow drains urine with a tiny pump, which is contained in a silicone housing available in a variety of sizes. Sizing and initial insertion are performed by a physician, with replacements inserted every 29 days by a caregiver or spouse. To void, the user sits on a toilet and activates the pump with a remote control. The valve reengages after drainage. Clinical trials have shown that the inFlow resulted in a significant improvement in quality of life, while being as effective and safe as clean intermittent catheterization. More details at www.vesiflo.com.

Room for Debate

The inaugural Miss Wheelchair Canada Pageant was held in Vancouver on September 2. Leading up to the competition, we began to wonder what our Peers think about these types of events. Are beauty pageants and, more specifically, beauty pageants solely for women who use wheelchairs empowering or detrimental to women with disabilities?

👍

The Miss Wheelchair Canada Pageant is a unique adventure for all women of all ages who use a wheelchair. By taking part in Miss Wheelchair Canada Pageant, I will experience an adventure that I will remember for the rest of my life.

This contest aims to change the image of women with disabilities, change people's perception of people with disabilities, and make it clear that these are people who need to be looked at beyond their wheelchairs—they are different and that is their strength.

They may be weak physically but have strong personalities and character. The fact that they have survived adversity speaks volumes about such exceptional persons.

The pageant will let us show the world that we are all beautiful in our own way.

This will be my opportunity to inspire others to make a change and help them gain confidence to be the best person they can be.

This pageant is exceptional because what matters is not just a beautiful face, but also a beautiful heart.

I know that some people see pageants of any type, wheelchair or able-bodied, as outdated in that they promote a view of women based largely on a traditional view of beauty. But that is the very reason that events like this can leverage an opportunity to change people's perception; seeing a woman in a wheelchair as "beautiful" needs the heart of a lion, and we humans have a very shallow perception of admiring and appreciating beauty.

I also know that some people believe pageants of this specific type do little to reinforce a message of inclusiveness regarding people with disabilities. But I believe such events and initiatives pave the way to change people's mindsets—which does not happen overnight, but instead will take a lot of time. It also gives people with disabilities a chance to put all the reservations and barriers aside and charge towards a new horizon.

Pageants like this are the very place to begin to foster inclusiveness so that future events will have able-bodied and people in wheelchairs parading on the same catwalk.

– Tabassum Chagani, SCI BC Peer, Vancouver

👎

Personally, I dislike pageants of all types because they don't promote the independent and capable female, but rather the outdated, one-dimensional version that so many of us are trying to move beyond.

Even more troubling to me is that the Miss Wheelchair Canada Pageant really isn't promoting inclusion. It's important to recognize the sometimes subtle but very distinct differences between integration and inclusion. In the context of disability, integration speaks to people with disabilities being encouraged to adapt in order to fit into an unchanged society, while inclusion speaks to society changing in order to accommodate the needs of all.

Creating a new, separate pageant for wheelchair users undermines the attempt for equality and doesn't really challenge the societal standard of beauty, because it's not a mainstream event.

It actually perpetuates the stereotypical belief that people with disabilities are somehow different. Sure, when it comes to getting to the upper level of a building, we might use a ramp or elevator instead of stairs, but that in no way affects how we look! Many of you will have heard ridiculous statements such as "you're really pretty, for someone in a wheelchair." This backhanded compliment is a prime example of what I'm talking about.

I can understand the need for divisions in some circumstances to create a fair and equal environment or playing field. In sports, for example, we have many options for people to compete within specific categories so there is opportunity for everyone to excel.

Although I'm not a fan, I would far rather see a Miss Canada Pageant where women (or people of any gender and of any ability, ethnic background, age, etc.) are valued for what they can do in an inclusive and welcoming environment. I believe this would go much further to changing the image of people with disabilities.

Let's see an event that removes all physical and attitudinal barriers so anyone who wishes to have that experience can seamlessly compete or simply attend.

– Brandy Stiles, SCI BC Peer Coordinator, Prince George

Got an opinion? Visit us at facebook.com/spinalcordinjurybc and weigh in on this and other topics. Plus, take our poll at sci-bc.ca/poll and see what others have said about the pageant and the perception of disability, as well as a variety of other contentious topics.

Celebrate our big 6–0.

Join fellow Peers, family, friends and supporters to celebrate SCI BC's 60th anniversary at our annual AGM. It's an opportunity for all of us to take a look back at just how far we've come. Join us for food and drinks, historical displays, and awesome presentations on October 26 from 6 to 9 PM at the Blusson Spinal Cord Centre. Visit www.sci-bc.ca for more info or contact Maureen at 604.326.1225 or mbrownlee@sci-bc.ca to RSVP.

Get fit in the North.

SCI BC is teaming up with Engage Sport North for a series of adaptive bootcamps to help people living with SCI in Northern BC improve their physical literacy and personal fitness levels. Explore workouts specific to your injury level, get fit, and have fun. Bootcamps in Prince George are scheduled for October 20, October 27 and November 3. Contact Brandy at bstiles@sci-bc.ca or 250.563.6942 for more information and to RSVP.

Take in a show.

Join Project EveryBODY for a night of cabaret-style entertainment featuring film, music, poetry, dance and more! PEBlive is an annual film and performing arts festival that showcases art by and about members of the disability community. This year's event will be held October 5 at the Roundhouse Community Arts and Recreation Centre. Point your browser to www.projecteverybody.ca/peblive to find out more about this sell-out event.

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Spinal Cord Injury BC

RYAN CLARKSON PHOTO

The SPINAL FRONTIER: STORIES from the ALASKA HIGHWAY

This year marks the 75th anniversary of Northern BC's iconic Alaska Highway. We checked in with a few SCI BC Peers living along the isolated 1,900 kilometre stretch for a snapshot of life on the road less travelled.

The road is long, with many a winding turn and 75 years worth of history, culture and epic road-trips to its name.

Originally spanning 2,700 kilometres, the Alaska Highway was built during World War II to connect mainland USA to Alaska via Northeastern BC and the Yukon. Once a rough, challenging drive, the highway has since been paved and straightened, bringing the length down to roughly 2,230 kilometres. Slowly, the communities along its path are growing, with services expanding.

The Mile 0 marker stands inside a roundabout on the east side of Dawson Creek. From there, the route runs north through Taylor, Fort St. John, Charlie Lake, Wonowon, Fort Nelson and beyond, offering standout views of snow-capped mountains, forested hot springs, and abundant wildlife.

Little wonder that the Alaska Highway Corridor is a top destination for nature lovers, history buffs, and road trip aficionados. Whether you rent an accessible RV and camp, drive from home and opt for motel pit-stops, or fly into a local town and take it from there, there are a few things to keep in mind. Keep your eyes on the gas gauge…and the clock (many stations open late and close early). Let your accommodations know about your needs in advance. And plan your trip wisely—if you use a power chair, you may have to fly into Prince George before driving to Fort St. John, as the local airlines can't accommodate you.

Most of all, enjoy the ride. After all, they say it's not about where you end up, but about how you get there…and perhaps how many azure waterways, grizzly bears, and northern lights you see along the way.

Visiting the northern communities along the highway is, of course, one thing. Living there, especially through the winter months, is something entirely different—particularly for wheelchair users. But, while life on this northern frontier may not be for everyone, it's home sweet home for more than 50 SCI BC Peers, along with their families and friends. Accessibility and SCI awareness in their communities is slowly improving, and any shortcomings are more than made up for by the area's tranquility, scenery, and small-town friendliness.

On the following pages, you'll get to meet a few of these stalwart Peers.

JACK DOUCETTE

Fort Nelson and Fort St. John | 73 | Quadriplegic

Jack Doucette moved to Northern BC in 1998, after a friend recommended him for a job in the oil and gas industry. Recruited over the phone from his home in far away Nova Scotia, Doucette had no idea where the Alaska Highway was, let alone Fort Nelson. He looked at a map, took a week's vacation in the area, and never looked back.

One day, Doucette was having trouble getting up; the next, he couldn't get out of bed at all. A staph infection in his leg had travelled up his spine, leaving him quadriplegic. He was flown from Fort Nelson to Fort St. John, and then onto Lions Gate Hospital where he had several MRIs and was treated with antibiotics. He eventually landed at GF Strong for rehab.

Although he may have benefitted from outpatient services, Doucette didn't want to relocate to Vancouver. Prior to acquiring his disability, he had been planning to sell his house in Fort Nelson and move to his property in Kiskatinaw, further south down the highway. "Everything went to hell in a handbasket," he says. Eventually, he relocated from Fort Nelson to Fort St. John.

Since his return to the North, Doucette has been working with a physio who, despite not having a lot of knowledge about his particular type of paralysis, has been helping Doucette navigate the recovery process. Doucette's condition has improved with therapy, and he is now able to stand and walk with a walker. He uses his power chair for additional mobility.

He now lives in an assisted living home, with friends and family close by. He uses HandyDART and bought a used van from SCI BC Peer Coordinator Lori Slater a few years back. He finds a lot of places in town are wheelchair friendly.

"Of course, some, like many people's homes, aren't," he says. "There are places I can't go, and places I can go." Chronic bladder issues restrict his freedom to travel.

Not surprisingly, the infamous northern climate is yet another obstacle. "The winters can be pretty severe," admits Doucette. "(Last winter) I went out with a shovel, and used my wheelchair like a snowplow."

Doucette's advice for north-bound paras and quads? "Unless you're from the North and want to live here, best to stay somewhere more southerly where the climate is milder."

DYLAN MOHART

Taylor | 45 | Friedreich's ataxia

When Dylan Mohart was 14, his family moved from Vancouver to Taylor, located between Dawson Creek and Fort St. John. Mohart admits that he was perplexed. "Why we chose to move to gravel roads over pavement, I have no idea," he muses.

Mohart was born with Friedreich's ataxia, a recessive inherited disease that causes progressive damage to the nervous system. By the age of 19, he was relying on a wheelchair for mobility in a largely unpaved, highway-side town of 1,500 people.

The family renovated their home, building an accessible addition onto the house. Soon after, the small-town boy began earning a living in a big-city gig as the town's de facto DJ. A lifelong lover of music, Mohart excels at reading his audiences and getting people up to dance.

"Up here you have to know your country [music], you have to know your two-stepping…then later in the evening the AC/DC can come out," he says.

As Mohart's DJ career progressed, so did his disease. After nearly 25 years of blasting the tunes at community weddings and parties, Mohart retired. A few years ago, when he needed a new van, the community held a benefit dance for him, raising $45,000 towards the cost of the $90,000 vehicle.

Taylor may be a small town, but accessibility is slowly improving, partly because of a growing desire to make it friendlier to those who are aging. The town even boasts an accessibility committee that Mohart is involved with. "But I'm blessed," he admits. "I still drive." He also uses both a power chair and scooter to get around.

Today, Mohart lives with his parents and caregiver on five acres of land out in the bush at Mile 30. Together they have three cats, one dog, and two goats that provide weed control around the property. The family home has been further renovated with lifts and superpoles to help Mohart stay as independent as possible. The next "big city" (Prince George) is five hours away, and winters can be brutal, but Mohart wouldn't have it any other way.

"The summers, they're just so beautiful up here," he says. "And the population isn't so…compared to going down south, to Kelowna or Vancouver, (where) it's a rat race. I enjoy being able to go outside and not hear sirens."

CAROL MCLELLAND

Fort St. John | 74 | C4 Quadriplegic

The Alaska Highway has a particular significance for Carol Mclelland. Nearly six years ago, at age 68, Mclelland was heading home during shift change. At 5 PM, the northern highway was bustling with trucks and heavy rigs. As Mclelland pulled into her driveway, directly off the highway, she was rear-ended.

After a stint at VGH and GF Strong, Mclelland returned home—not quite as mobile, but not brain-injured as her doctors had initially feared. At VGH her surgeon had inserted a titanium rod from T3 to C3. "If my friends tell me I have a screw loose, I just might!" she now jokes.

Prior to her accident, Mclelland and her husband had lived in the North for nearly 45 years. Self-described "country bumpkins," the duo enjoy the solitude, quiet and community that come from living in small town Northern BC. (They currently live outside of Fort St John, which they deem "too busy".)

For someone who loves "being in the bush", Mclelland hasn't found adapting to her post-injury life that difficult. She and her husband have moved to a more suitable home, and she has a care aide and lots of helpers. "I call them 'enablers' because they enable me to stay in my own home," she says. Mclelland's family and caregivers also help her tend her lush patio container garden, which she fills with sugar pansies, peas, corn, and even sunflowers that the squirrels help her replant each year.

Nearby, Fort St. John is quite accessible (thanks in no small part to the ongoing work of SCI BC Peer Coordinator Lori Slater), and yet one of the most disheartening things for Mclelland to adjust to has been the stigma around disability. Former friends and acquaintances have turned the other way when they meet her in the street because of their discomfort and unease around people with disabilities. Similarly, most local doctors and nurses don't have much training in SCI: being left unattended in slings has caused discomfort and pressure sores, and Mclelland has coded in four discrete instances when health workers laid her flat on her back.

For the most part, though, people are learning. "It is an accepting and great place to live," says Mclelland, who continues to make the most of the unparalleled Northern BC landscape. She travels with a 2x6 plank to use as a ramp when she encounters places she can't get into. She feels confident getting around in the snow (she's even contemplating attaching a blade to the front of her chair to help her plow her 62 foot patio in winter). And she regularly travels more than 100 kilometres into the woods to stay at a friend's ranch, where a log cabin has been retrofitted with a lift and enough space to house her hospital bed.

Recently, Mclelland and her husband bought an old school bus from the local school district, which they're retrofitting as a camper. They hope to hit the road to the Yukon by next summer, turning out of their driveway and following the very same road right up to their destination.

DID YOU KNOW?

Team Canada Basketball Player and Paralympic Gold Medallist Bo Hedges hails from a cattle ranch in Wonowon, BC (pop. 1,000). This farming community, located along the Alaska Highway, is named for mile number "one-oh-one."

In 1980, 15-year-old Hedges fell from a tree while on a family vacation. Back at home, the Hedges family desperately sought peer support and recreational activities for their paraplegic son, but few services were available. Fortunately, the BC SCI Network, comprised of Spinal Cord Injury BC (SCI BC), the BC Wheelchair Sports Association (BCWSA), the BC Wheelchair Basketball Society (BCWBS), the Neil Squire Society (NSS), and the Sam Sullivan Disability Foundation (SSDF), got together to replace limitations with opportunity.

Hedges had first discovered wheelchair basketball at the GF Strong Rehabilitation Centre in Vancouver. When the newly-injured teen returned to Fort St John, the BC SCI Network connected him to a peer network and made an effort to facilitate new adaptive programming, providing sport wheelchairs for the community and helping Hedges develop Fort St John's first wheelchair basketball program. Hedges' athletic career took off.

Today Hedges is a basketball force at every level of competition. Off the court, he's a coach, role model, and active volunteer. And, as a board member of BCWSA, he gives back to the network that helped start him on his journey. ■

Access the North at **accessiblebc.ca**

We all know British Columbia is supernatural. Now, a Spinal Cord Injury BC initiative is helping making it super accessible, too. In 2016, in collaboration with local government and businesses, SCI BC's Access North project audited more than 450 outdoor spaces in North-Central BC, including municipal, provincial and federal parks, recreation sites, and visitors' centres. The new Access BC website features in-depth accessibility specifications for each audited area, as well as virtual tours and videos, suggested driving routes and maps, accessible tourism tips, and more.

"It's an opportunity for partnership," says Shirley Bond, MLA for Prince George–Valemount. "And it's a chance for us to explore even further the concept of universal design, making sure that whether you're a senior, whether you're a parent who has a baby buggy, or whether you're a person with a disability, that there are fantastic places for you to enjoy here in Northern BC."

During the project's first phase, Access North auditors, hired through BC's Job Creation Partnership, used a custom assessment tool to measure and rate amenities in North-Central BC parks and rec areas, with the end goal of showcasing and helping to inform and improve accessibility in the great outdoors. Now, Spinal Cord Injury BC is hitting the road again to expand the program to other parts of British Columbia. Throughout 2017, the Access BC team will audit rest stops along the five major driving routes in BC and offer Universal Design training throughout the province. Park assessments for Vancouver Island, the Lower Mainland and the BC Interior are on the horizon.

"People with disabilities want to go outdoors, and we want to experience the beauty of our parks," says Access North Project Manager Pat Harris. "We've talked to people that have come to a park that is universally designed and they've told us that this is the first time in years that they've been out and able to enjoy an outdoor experience like this."

Are you considering a rugged rest stop, wooded stroll or lakeside picnic? Head to www.accessiblebc.ca to explore the accessibility of parks and rec areas near you!

Pat Harris explores the newly-opened, wheelchair-accessible Great West Life Mobility Nature Trail near Prince George.

Photo courtesy B-Temia

Taking a Closer Look at Keeogo

At first glance, the Canadian-developed Keeogo is yet another exoskeleton. But when you dig deeper, it becomes clear that it's a different device altogether—one that is providing remarkable restoration of function and stamina for some people with incomplete SCI.

Exoskeletons—full body, robotic-like devices such as ReWalk and Ekso—are certainly great fodder for the mainstream media. After all, who doesn't love a warm and fuzzy story about a machine that appears to enable someone who is paralyzed to walk? However, when it comes to the opinion of people who might actually use an exoskeleton, the reviews are mixed, with a surprising number being outright critical.

A good example is served up by William Peace, a paraplegic New Yorker who pens the popular *Bad Cripple* blog (www.badcripple.blogspot.ca). "The exoskeleton is inherently misleading and its benefit to paralyzed people has not been established," writes Peace in one of several anti-exoskeleton rants. "Screw the exoskeleton. Screw walking! Get me a good wheelchair, an excellent wheelchair cushion, and some adaptive sports equipment so one can remain in excellent physical health."

Here at SCI BC, we know many of our Peers feel the same way. And so we've adopted a kind of "wait and see" approach to find out if exoskeletons gain traction or become an expensive bust.

That's one reason that, when we first saw Keeogo™, our initial instinct was to lump it in with exoskeletons and put it on the back burner—after all, it appeared to be just another strap-on robotic device with questionable benefits for people with SCI.

But lately, we began looking at the Keeogo more closely, and we realized that we may have rushed to judgment. It turns out that the Keeogo is significantly different than an exoskeleton, and is designed to serve a much different purpose for a specific population—namely people who have a condition that has compromised, but not completely eliminated, their ability to walk. Many people with incomplete SCI fall into this category.

Unlike exoskeletons, which remain largely slow, cumbersome, and at a proof-of-concept stage, the Keeogo is already being actively used in real world situations, with surprisingly successful user testimonials readily available online.

Keeogo: A Brief History

Keeogo is a Canadian invention—a fact that also helped to pique our interest.

It's the brainchild of Stéphane Bédard, a Quebecer who seriously injured his knee while mountain biking (he lost the ability to walk during two years of surgeries and rehab). At the time, Bédard was a mechanical engineering grad student at Laval University. He was fascinated with robotics, and as part of his grad studies, he was inspired to begin working on the world's first bionic knee, which was eventually completed and marketed by his first company, Victhom Human Bionics.

That achievement eventually led him to develop what's now known as Dermoskeleton™ technology under the umbrella of a new company, B-Temia, established in 2010. This is the technology that Keeogo is based on.

Recently, we spoke with Bédard, who is B-Temia's CEO, and Paule De Blois, the company's COO. They told us all about the Dermoskeleton technology, including why it's so different from exoskeletons.

"An exoskeleton is a technology platform comparable to the Dermoskeleton—so similar, in fact, that they are often wrongly considered competitors," explains Bédard. "Indeed, the two technologies are automated mechatronic systems, but they differ significantly in terms of both design and functionality."

The difference, he adds, is that while exoskeletons are rigid, walking robot-like devices that are limited to pre-designed ranges of motion, the Dermoskeleton technology allows for a lighter and flexible assistive device that integrates seamlessly with movements initiated by users themselves, and provides assistance based on the detected activity.

"Often, an exoskeleton is intended to help people carry 'compacted' heavy loads or to help people who have lost their neuromotor skills to walk, whereas a Dermoskeleton is intended to biomechanically protect the body by complementing or replacing the biomechanical capability of the users' lower extremities," he explains. "The Dermoskeleton can therefore be used by people with low to medium mobility impairment, as well as by healthy people who need to protect their musculoskeletal structure or require more endurance in their work."

Keeogo: How It Works

Keeogo is B-Temia's first generation, commercially-available device that's

Keeogo doesn't move your body—instead, it uses sensors to read your body's intentions to move and then augments those movements with as much energy as required.

based on Dermoskeleton technology and designed to augment mobility for people with partially-compromised mobility. People with MS, arthritis of the knee and hip, Parkinson's, stroke-related partial paralysis, incomplete SCI, and other conditions that limit mobility are all potential users of the Keeogo.

According to the B-Temia website, Keeogo is "a powered walking assistance device that helps you to walk and maintain your independence" by eliminating "musculoskeletal stress on the body structure by injecting biomechanical energy at the joints, and providing mechanical assistance to the users for the restoration, maintenance or augmentation of their biomechanical functions."

In simpler terms, here's how it works. The Keeogo, which is powered by a rechargeable battery, has sensors at the knees and hips that continually send messages about your body's movements and position to a tiny, integrated computer running proprietary artificial intelligence software. The user's mobility intentions are detected and interpreted, and the CPU in turn generates synchronized instructions for movement which are sent to the motorized knees. The system doesn't move for the user—instead, it senses the user's intended movement and provides the right level of assistance to augment the desired body motion. So if you start to stand from a sitting position, Keeogo will quickly activate and help you to push upwards. Similarly, as you start to sit down, Keeogo will slowly support you until you're sitting.

Clinical Trial Results

"Since 2010, the Dermoskeleton and its Keeogo version have been involved in field testing, product evaluations, and clinical trials," says De Blois. "In all, over 125 participants have tested the device in more than 20 studies. These studies have demonstrated, among other things, that the device can enhance the ability to walk, increase balance and stability, reduce compensatory movements, reduce pain, and improve kinetics and kinematics."

In addition, De Blois says B-Temia is currently completing a multi-centre study of over 60 patients with either multiple sclerosis or knee osteoarthritis. The purpose of this study is to gain US Food and Drug Administration approval for commercialization in the USA.

As for formal evaluation specifically in people with incomplete SCI, De Blois concedes that there has been very little work done.

"However," she says, "one pilot study with patients affected by incomplete SCI showed that there was significant improvement in timed walking tests for those demonstrating an ideal level of baseline function in regards to balance, power and walking speed. It was concluded that Keeogo seemed to improve these outcome measures immediately in those who needed additional assistance when walking and had adequate strength to initiate movement patterns that the Keeogo artificial intelligence could recognize."

One Peer's Excellent Experience

While there may be few formal test results specifically in people with incomplete SCI, there are many anecdotal success stories—some spectacularly so.

Case in point: Jessie Gregory, an incomplete paraplegic who makes her home in Wainfleet, Ontario. Sledge hockey fans no doubt recognize the name, as Gregory is the starting goalie for the Canadian national women's sledge hockey team.

Gregory became paraplegic in 2008 when she was hit by a car while working as a security officer. Her injury, at L4-5, turned out to be incomplete. A lifelong athlete, Gregory regained some ability to walk through a combination of hard work and a powerful work ethic. But despite her perseverance and progress, she is only able to stay on her feet for short periods of time.

Last year, a fellow sledge hockey player introduced Gregory to Keeogo. She investigated further, and in March of this year, she agreed to get involved in a Keeogo research project taking place at McMaster University—even though she was skeptical of the device.

"I wasn't really sure if it was going to work for me, and didn't understand how it really works or how they set them up for each person," says Gregory. "I wasn't sure how I would like it with it being mechanical; I wasn't very trusting with it when I first tried it."

But her doubts eventually began to fade. "How it improved my walking, stair climbing (which she had not done without crawling for eight years), getting up out of a chair, and, in general, everyday movements that I struggle with so much—all of these were so much more possible with the Keeogo," says Gregory.

She remained somewhat unsure about Keeogo for the remainder of testing at McMaster, but she was eventually allowed to try it on her own terms, in her home and during all of her typical daily activities. And that, she says, is when the light bulb switched on.

"I slowly started trusting it more and more each week," she says. "For me, the huge difference was being able to do all my daily activities without having to take a break all the time, getting assistance from my family or friends if I couldn't do it, or modifying how I did things. Being able to do so many daily things that I haven't been able to do without assistance or modification, which takes a lot longer, just makes my daily life so much better."

The difference Keeogo began to make in her life was perhaps most evident on the job. She and her father recently opened a food truck and convenience store business.

"Working in a food truck requires a lot of standing and moving around," she explains. "With the Keeogo, I can work in the food truck all day with only having to take a few breaks. With the Keeogo, I can do everything required in the truck that I usually can't do without it. It allows me to stand longer, I don't get as fatigued with it on, and I can get in and out of the truck a lot easier."

"Since I started using the Keeogo, the biggest thing that everyone keeps telling me is that I have a huge smile all the time." — JESSIE GREGORY

Gregory also works part-time at two YMCAs in the Niagara area as a fitness coach. "Having the Keeogo makes working with members at the gym a lot more smooth," she says. "I can get around the gym better, get in between weight machines, and adjust the machines or weights easier, which makes showing our members how to perform an exercise that much simpler and effective."

Other benefits that she's experienced with Keeogo are less body and arm pain, more flexibility in her hips, and improved posture.

"Since I started using the Keeogo, the biggest thing that everyone keeps telling me is that I have a huge smile all the time," she says. "The feeling of walking after not walking very much or very well for more than eight years, and being able to do so many things that I haven't done in that time, is one of the most amazing feelings I've ever had. There is really nothing that can describe how exciting and amazing it feels to be upright again for most or all of my days now."

The bottom line is that Gregory wants Keeogo in her life permanently. But after the trial, she's faced with the prospect of finding a way to afford one (they're about $45,000 plus yearly maintenance costs). She's doing her best to save for one, and she's also hoping to generate some funding via a GoFundMe campaign (www.gofundme.com/helpjessiewalkagainwiththekeeogo).

How to get into a Keeogo?

If you've been reading this and wondering if you're a candidate for a Keeogo, here's what you can do.

First, you can visit www.keeogo.com, learn more about the device, and then request to be sent a pre-evaluation questionnaire.

When the pre-evaluation questionnaire is completed and submitted, the answers are reviewed by one of B-Temia's clinical specialists. If you're identified as a good candidate for Keeogo, you'll be invited to try the device during an evaluation session. The evaluation session lasts about an hour and can be performed at home or in one of the partner clinics. (In BC, the partner clinic is HME Mobility & Accessibility, located in Richmond—see www.hmeinnovation.com).

If the clinical evaluation is positive, you'll be offered a three-week home trial, monitored by a certified clinical specialist.

At that point, if you've had a positive experience by the end of these three steps, you'll be able buy a new Keeogo, which is fully approved by Health Canada.

The process appears to be straightforward, but paying for your new Keeogo might not be so easy. At first glance, the $45,000 cost doesn't seem too unreasonable when you take into account that some high-end power wheelchairs have price tags approaching this range. But the difference is that, at the moment, there is no coverage from any provincial mobility aid programs or insurers.

"Yes, we are working on this very important aspect of the business," says De Blois. "However, things take time. For the moment, we are happy to report that Revenu Québec has approved the expenses related to Keeogo for the non-refundable medical expense tax credit. We are working on obtaining the same ruling from the Canada Revenue Agency. This will be a first step in the right direction to support the financing of Keeogo."

In the interim, if Keeogo is out of your price range, you can explore the company's rental program ($1,200 per month for 12 months), or look for alternate sources of funding as Gregory is doing via her gofundme.com efforts.

"I think the Keeogo should be covered or at least partly covered by our health care plans, because there are so many people that can benefit from having them," says Gregory. "There are so many people that have no idea there is such a device like the Keeogo available. Most people that may be or are interested in the Keeogo will not even try it because they know they can't afford it—which is really a shame, because there are so many people in the world that could really benefit if they had access to the Keeogo." ■

For more information:

- www.keeogo.com
- www.b-temia.com
- www.facebook.com/keeogo

FES Cycle Now Available in Victoria

Neuromotion Physiotherapy and the MOVE Adapted Fitness and Rehabilitation Centre in Victoria has acquired a state-of-the-art FES stationary cycle for its clients. FES is the acronym for functional electrical stimulation, in which groups of paralyzed muscles are electrically stimulated with electrodes in a pattern to restore some movement function.

FES cycles have been around for almost 30 years. Research has consistently shown that ongoing exercise with an FES cycle is a great way for people with SCI and other neurological conditions to prevent and reverse lower limb muscle atrophy, as well as improve lower limb muscle strength and endurance. Other benefits may include increased bone density, reduced body fat, improved cardiovascular health, reduced risk of diabetes, and reduced spasticity.

The FES cycle acquired by Neuromotion is the RT300 by Restorative Therapies. It's suitable for people with even complete SCI, as well as stroke, multiple sclerosis, brain injury and cerebral palsy.

"FES cycling has become a mainstream therapy in neurological rehabilitation settings throughout Canada and around the world," says Eimear Brogan, a physiotherapist at Neuromotion. "Our staff recognized that getting an FES cycle was imperative to better serve the rehabilitation needs of our clients and to keep up to date with current standards of practice."

If you're in the Victoria area and are interested in exploring FES cycling exercise, call Neuromotion Physiotherapy at 250.590.7878 or email neuromotionvictoria@gmail.com to receive an application package and more information.

Neuromotion Physiotherapy is a physiotherapy clinic that specializes in treating people with SCI and other neurological impairments. In addition to Victoria, the company has clinics in Vancouver and Surrey.

Low Pressure System

Does dynamic wheelchair seating pose a risk for people with SCI who are prone to orthostatic hypotension?

By any measure, the Elevation wheelchair is a true made-in-BC success story. The brainchild of ICORD and BCIT researcher Dr. Jaimie Borisoff, who is himself paraplegic, the Elevation's unique feature is its revolutionary dynamic seating—as you can see in the photo, its seat can move from a lowered sport-style position to a raised position. This allows the user to reach higher, work at elevated surfaces, and converse with standing people at a more natural height.

Since developing the Elevation several years ago, Borisoff has sold the rights to to Vancouver-based PDG Mobility, which markets the chair across North America.

Dynamic seating offers clear benefits to users. But does it have risks? Dr. Victoria Claydon found herself asking that very question. Claydon, who is also an ICORD researcher and an associate professor at Simon Fraser University, specializes in cardiovascular function after SCI. She wanted to know if using dynamic seating further compromised the health of people who experience orthostatic hypotension (dangerously low blood pressure) or cerebral hypoperfusion (decreased blood supply to the brain).

"It was clear the variable seat positions of the Elevation would be an asset to mobility, comfort and social situations, but I was wondering if, in some individuals, the elevated positions might decrease blood pressure and whether this could be to levels low enough to cause symptoms of poor concentration, dizziness, or even fainting," says Claydon. "In theory, people with high-level SCI might be at particular risk of these low blood pressure episodes because of the potential for their injury to affect the nerves that control the heart and blood pressure."

When Claydon posed this question to Borisoff and Dr. Lowell McPhail, ICORD's Managing Director, both were intrigued.

"Jaimie noted the potential for the lowered, or 'dumped' position—similar to sports wheelchairs like wheelchair rugby chairs—to improve blood pressure, so the three of us set about designing a study to test whether this was the case," says Claydon.

They recruited 19 individuals with SCI, along with 10 able-bodied people for control. Participants with SCI were divided into two groups by the severity of the damage done to nerves that control autonomic functions such as cardiovascular function. All were tested in supine and seated positions (neutral, lowered, and elevated) in the Elevation wheelchair. Blood pressure, heart rate and artery blood flow velocity (MCAv) in the brain were recorded non-invasively.

"We showed that blood pressures and blood flow to the brain were reduced in people with high-level SCI (above the 5th thoracic level) who had damage to the nerves in the spinal cord that regu-

Dr. Victoria Claydon

late cardiovascular control," explains Claydon. "For these individuals, using an elevated seating position decreased blood pressure and brain blood flow even more. People with lower level injuries, or in whom the cardiovascular nerves had not been severely injured, did not show these responses and were able to control their blood pressure and brain blood flow well regardless of their body position."

She adds that, in the individuals who were affected, the lowered seating position did partially recover blood pressure, and improved the amount of blood pumped by the heart. However, it did not increase the blood supply to the brain.

"The difficulty is that some individuals don't get typical symptoms of hypotension such as dizziness, and so have difficulty recognising when their blood pressure has gone too low," she says.

Claydon hopes the study will let people with SCI and their caregivers know about the importance of being aware of the status of their blood pressure control so they can make informed choices about the best wheelchair selection for their needs.

"It will be important to educate individuals with high-level SCI and damage to the nerves in the spinal cord that regulate cardiovascular control about the risks of low blood pressure and how to manage it," she says. "For example, it might not be advisable for some individuals to remain in elevated seating positions for long periods of time, and they should be aware of the symptoms or signs of low blood pressure when they occur so they can take action, such as lowering their seating position, if it occurs."

She also believes that physiatrists and occupational therapists should consider these issues when discussing seating options, and educate their clients as to the best options for their needs. "This may be even more important with standing wheelchairs, especially standing power wheelchairs which are more often prescribed to those with higher-level injuries who are more at risk of problems with blood pressure control," she says. "These issues will only become more important with advances in wheelchair design and promotion of standing using exoskeletons—numerous options for elevated or standing positions for wheelchair users are becoming available, and would likely produce similar blood pressure effects in at risk individuals. It will be important to be aware of, and better manage, low blood pressure episodes in individuals wishing to take advantage of these advances in mobility design."

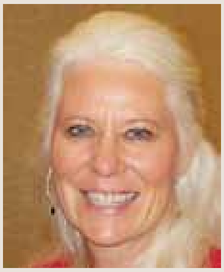
Claydon is careful to point out that the study was carried out with participants using the Elevation wheelchair in a somewhat different fashion than typical real-world usage. Users with higher injury levels typically use anti-shear side guards for elevated stability, which results in smaller angles between the trunk and thighs (more like normal seating levels) which may mitigate the blood pressure effects of higher sitting. Also, she notes that Borisoff's lab recently concluded that the highest seating levels (as used in the study) are infrequently used for long periods of time; those who do sit at higher levels for longer times have disabilities or lower injury levels with no blood pressure instability—for example, cerebral palsy.

As for the dangers of hypotension and cerebral hypoperfusion, Claydon says that while the long term effects of hypotension and reduced brain blood flow are still being investigated, it's clear that having very low blood pressure or frequent and severe episodes of low blood pressure over many years can be detrimental to health.

"They can be associated with impaired memory and cognitive function, and are associated with cardiovascular and cerebrovascular disease, with a higher risk of stroke, irregular heartbeats and heart attacks," she says "Individuals who are at risk for hypotension should speak to their doctor about how best to manage their symptoms and long term risks." ■

ask the SPIN DOCTOR

Normally, we base our Spin Doctor column on health questions posed by our readers. But for this issue, we were approached with a "burning" issue by two GF Strong clinicians. Over the years, Bonnie Venables, Clinical Resource Nurse (left), and Shannon Sproule, Physical Therapist, have both seen their share of burns sustained by SCI BC Peers, and offer some important advice about treating and avoiding them.



In the course of our work at GF Strong, we get a surprising number of clients dropping in or calling the outpatient department seeking guidance and care for burns—burns from electric space heaters, car floor heaters, seat heaters, hot water in bathtubs or spas, kitchen accidents, heating pads and blankets, cigarettes, hot beverages, sunburns, and more. Invariably, these requests become more frequent during the colder months of the year. In the absence of lower body sensation, avoiding these burns means knowing the threats and keeping them top of mind—not always easy, we concede.

Beyond the sheer inconvenience of a burn, there are many potential complications. There's always the risk of infection. There's the risk of AD if your injury is T6 and above, and spasticity may increase. There's the possibility of having your daily life activities and mobility compromised, depending on the location of the burn. Your costs for treatment (dressing care) and caregiver support may increase.

Meanwhile, healing time can take weeks depending on the depth of the burn. And healed scar tissue is never as strong or elastic as it was prior to a burn, so it sometimes limits movement (for example, in a joint area) and is subject to further breakdown.

The severity of burns is measured in degrees (first, second and third degree). Here's an overview of the signs, symptoms and treatments.

First degree burns are the least serious. They involve only the first or top layer of your skin. Your skin will be red and appear sunburned, and it will often peel. Treatment consists of cooling the burn with cool water or a cool compress (not ice) for 10 to 15 minutes, which will decrease the temperature of the skin and prevent the burn from becoming worse (remember, tissue continues to burn even after the heat source is gone). Aloe vera can then be applied to soothe the burn.

Second degree burns, which penetrate the top two layers of your skin, are a little more serious. These burns appear red and often blister, and may also be deeper in areas where you see white patches. The first treatment step is to cool and cover the burn with a cool compress, making sure you leave any blisters intact. If there are open areas, apply an antibiotic ointment such as Polysporin. If the burn is on a limb, elevate it if possible to help reduce swelling and improve circulation. If you're changing a dressing on a burn like this, and it gets stuck, wet the dressing with water until it loosens, and then apply a clean dressing (non-stick dressings are best). Finally, seek medical attention and direction for deeper second degree burns that may need prescription medications or special dressings.

Third degree burns are most serious, as they penetrate all skin layers. Signs are a waxy and white colour, noticeable charring or dark brown colour, a raised and leathery texture, and blisters that do not develop. Your first and only option for this type of burn: seek medical attention immediately.

If you're in doubt about the severity of a burn, don't hesitate to seek medical attention.

You should also seek immediate medical attention if any burn appears to be infected. Signs and symptoms of infections are increased pain or AD symptoms, warmth, redness, red streaks leading from the area, pus draining or a foul-smelling drainage, and fever.

Proper healing of any degree of burn requires that you stay hydrated and eat well.

Here's what you can do to prevent burns:

- Test water temperature. Remember that, as a general rule, skin without sensation burns easier than sensate skin.
- Use caution when cooking. Use hot pads or trays to carry hot dishes or cookware from the stove or microwave to the table. And remember to use short sleeves when cooking on the stove—you don't need clothing catching on fire.
- Avoid using heating pads, or electric blankets, with insensate skin.
- Use caution with spa treatments like hot massage oils, hot rocks for massage, foot baths, and hot tubs.
- Use lids on hot beverage containers such as a travel mug.
- Avoid smoking, especially in bed.
- Don't place plates or cups on or between your legs.
- Do not have insensate body areas close to fire pits or space heaters, or even your car heater ducts, for long periods. Check skin frequently if you are.

A final reminder: once again, if you're in doubt about a burn, don't hesitate to seek medical attention.

Peer Players

We've got some pretty amazing musicians within the ranks of our SCI BC Peers across the province—so we thought we'd showcase some of them in this issue of *The Spin*.

On the next few pages, we'd like to introduce you to some accomplished BC musicians who happen to have an SCI.

While music might not be their full-time job, the Peers you're about to meet are working musicians who perform their music at events, by themselves or as part of a band. Depending on where you live, you can often catch their performances live. Most of them also have recording experience, and you can hear their music online. We think you'll agree that they're worth checking out!

While their styles and music are all unique, these performers have at least one thing in common: they agree that music has been an incredibly important part of their lives as people with an SCI.

We know this isn't a complete list. There are more of you out there that we don't know about. Please let us know if we've missed you or someone you know, and we'll include your information and details in a future issue of *The Spin*. Email us at thespin@sci-bc.ca and give us as much information as you can.

TREVOR ADELMAN, QUESNEL

Instrument: Guitar/Vocals | Genre: Country Rock
Age: 32 | Injury: T11-12 Paraplegic

Trevor Adelman, who was injured in 2004 in a car crash, is a lifelong musician, singer-songwriter, and the front man for Quesnel's Rockin'Chair. The high-energy band, which came together in 2011, has played with some of the biggest names in country music and on stages across Western Canada, including opening for Travis Tritt.

Although they hail from Northern BC, you can sometimes catch Adelman and Rockin'Chair playing in the Lower Mainland, at Gabby's Country Cabaret in Langley and Roosters Country Cabaret in Maple Ridge. However, Adelman says the band is focusing more and more on festivals, corporate events, and private functions these days.

Adelman's other passion is speed, and he's a serious contender every year in the Western Canadian Auto Racing (WESCAR) stock car series—we believe he's currently North America's only race car driver who has an SCI.

"Playing music and entertaining has been a form of therapy for me," says Adelman, who is at the far right in the band photo to the left. "Music possesses so much power, emotion and relief, and makes an impact in my life every day."

Details/Dates: www.rockinchair.ca

JOE COUGHLIN, VICTORIA

Instrument: Vocals | Genre: Jazz
Age: 63 | Injury: Incomplete Quadriplegic

Joe Coughlin is a polished musician living in our midst.

An incomplete quadriplegic from birth, Coughlin began his musical career in the 1970s while fronting Whiteheet, a successful heavy metal band in Ontario. In 1979, he and his golden baritone were formally "discovered" while winning CBC's *Search for the Stars*. He landed his first recording contract shortly after that.

He's been performing ever since, notching a couple of Canadian top ten singles in adult contemporary in the early 1990s, but mostly making a name for himself as a jazz singer performing his own originals along with covers of the likes of Frank Sinatra, Ella Fitzgerald and Johnny Hartman. He has eight albums, one Jazz Report Award, and two National Jazz Awards to his credit, and he's performed with a host of great Canadian artists with international credentials. He's equally comfortable playing with small jazz ensembles and full orchestras.

He concedes that, at 63, he's slowly winding down his career.

"Without music, I don't think I would have developed into the human being I am today," says Coughlin. "Collaborating with other great musicians over the years gave me a sense of confidence I would never have had. God gave me a gift, and I've used it to create opportunities for myself that I don't think I would have ever had without music."

Details/Dates: www.joecoughlin.ca

TOM GARCIA, FORT ST. JOHN

Instrument: Guitar/Vocals | Genre: Country
Age: 66 | Injury: T10-11 Paraplegic

Ask anyone in Fort St. John about Tom Garcia and you'll discover that he's a local legend. The humble veteran has been playing in local bars, events and fundraisers since his injury 40 years ago, and along with his band, Colt 45, is an institution in the local music scene.

The only time you might not be able to hear him playing is the winter, when he flies south to Yuma, Arizona—where apparently, he has a following almost as large as he does back up north.

"Playing music brought me out of my shell after my injury," says Garcia. "It just gets you out, and keeps you from spending too much time watching TV or drinking beer. It brought me back to feeling like I'm on the same plane as everyone else. You never really play alone; you play with other people. And that really gives you a sense of belonging."

Details/Dates: Local news and events listings

PHOTO COURTESY ALASKA HIGHWAY NEWS

STEVE GROUT, VANCOUVER

Instrument: Guitar/Vocals | Genre: Rock
Age: 52 | Injury: Incomplete Quadriplegic

Steve Grout is a life-long musician and songwriter, and one half of Vancouver's Monkey Bar Band, which has been playing gigs around the Lower Mainland since 2003. Steve has adapted his playing style after becoming quadriplegic, and is a superb guitarist and entertainer. The duo covers Neil Young, the Rolling Stones, Blue Rodeo, Coldplay, The Tragically Hip, Ben Harper, Mumford & Sons to name a few, along with Steve's original music. They play pubs, clubs, corporate and special events, private parties, weddings and benefits.

Grout also released an impressive CD, *Way to the Ground*, back in 2006.

"When my highly athletic body was shut down from my SCI in 1985, I needed another outlet to express myself," says Grout. "After relearning to play guitar, I grew to love creating and showing my passion through my musical abilities. Playing music for me does nothing but incredible things for my body, releasing endorphins and happiness that I love sharing with others."

Details/Dates: www.monkeybarband.weebly.com

ROLF KEMPF, SURREY

Instrument: Guitar/Keyboard/Vocals | Genre: Folk/Jazz
Age: 70 | Injury: Polio

Rocker Alice Cooper and folk singer Judy Collins both recorded the same song, Rolf Kempf's *Hello, Hooray*, which he penned in 1968. For Cooper, it became somewhat of an anthem in 1973, rising to near the top of the charts. In 2016, Kempf was inducted into the Canadian Songwriters Hall of Fame in recognition of writing this haunting song.

Kempf, who uses a brace and cane as the result of a childhood bout with polio, hails from Toronto. He moved to LA in the late 1960s to further his music career. Since then, he's recorded 12 albums and played countless concerts and events. These days, he makes his home in Surrey. He's active in the local music scene, and regularly performs folk, world, jazz, and instrumental music. He's also a VAMS featured performer and a regular participant in VAMS concerts and fundraisers.

"The importance of making music in my life, besides that I can, is that it's also some way for me to hang together emotionally, as only music can do," says Kempf. "There's no way to make time stand still except maybe in your imagination."

Details/Dates: www.rolfkempf.com

MATTHEW WILD PHOTO

JUDY NORBURY, COURTENAY

Instrument: Dulcimer/Vocals | Genre: Bluegrass/Folk-Rock
Age: 68 | Injury: Polio

Judy Norbury has had an amazing life. She was born in India and spent her early childhood along the banks of the Ganges River. But when she contracted polio at the age of four, her parents made the decision to move back to Canada and set up home in Vancouver.

Norbury moved to an isolated coastal cabin at the age of 20. There, she was introduced to the Appalachian Mountain dulcimer and began to test the waters as a songwriter. Eventually, she moved to the Comox Valley on Vancouver Island, where she raised two daughters while establishing herself as a performing musician. Her songwriting skills, catchy melodies and audience rapport earned her a solid standing in the West Coast folk music circuit. She's played countless concerts, community events, and folk music festivals throughout BC.

She's also recorded three albums, including a recent release entitled *Did You Find the Door*, and her work has been included on several compilation recordings.

"As someone who loves to sing and who loves to entertain people, music has always been a large part of my life," says Norbury. "Songwriting gave me the ability to tell stories, convey emotions and fulfill me by sharing my gift with others. Though I play less these days, I rarely say no to a request to perform."

Details/Dates: www.judynorbury.com

PHOTO COURTESY ICORD

ADEL OTHMAN, VANCOUVER

Instrument: Tambour | Genre: Traditional Arabic
Age: 35 | Disability: T4-5 Paraplegic

In 2002, when the war in Syria left Adel Othman with an SCI, he turned to music. He set his sights on learning how to play the tambour, or tanbour, a long-necked string instrument that dates back to 1500 BC in Persia.

He took refuge in Lebanon, where he continued to learn the instrument and began to work as a music therapist with kids who were also refugees from the war.

In 2011, he immigrated to Canada and made his home in Vancouver. He continues to use his music to help others—he performs at fundraising events for refugees, playing traditional songs and originals in Kurdish and Arabic, which often express his hope for peace in his homeland. He also stays active with performances at churches and weddings.

"I learned to play by myself," says Othman. "I had some friends who play the same instrument who taught me as well. Music makes me feel like I'm walking again. It makes me happy. When I was injured, I really didn't like my life. After I began playing music, it got much better. It gives me power and energy."

Details/Dates: Local news and events

SIMON PARADIS, HALFMOON BAY

Instrument: Guitar/Vocals | Genre: Blues
Age: 47 | Injury: T12-L1 Paraplegic

Simon Paradis is another life-long musician who had to relearn to play after his SCI and brain injury in 2008. An accomplished singer-songwriter and guitarist, Paradis is one half of Stanton Paradis, a hot roots/blues/country duo that plays regular gigs around the Sunshine Coast and the Lower Mainland. He and picking partner Joe Stanton also play with their band, The Precious Littles, and they released an album titled *Good Road Home* in 2014.

"Getting back to playing was a way of rehabbing certain physical effects of my accident, and I also began writing songs for the first time in my life," says Paradis. "This provided me an artistic outlet that allowed me to better process and internalize my injury and its affect on my old self. Plus, getting out and performing was a great platform for providing accessibility awareness to my community on the Sunshine Coast. People hire you for gigs, and now have to be aware of accessible washrooms, stage access and parking, so in a way it puts SCI on the community map. Folks get a more intimate and transparent look at the person in the chair, rather than just accessibility itself as an abstract concept or equality initiative. Music is a fabulous vehicle for awareness."

Details/Dates: www.stantonparadis.com

KRISTINA SHELDEN, VANCOUVER

Instrument: Vocals/Guitar/Ukulele | Genre: Indie/Folk/Jazz
Age: 33 | Injury: C4-5 Incomplete Quadriplegic

Kristina Shelden has been singing, playing guitar and writing songs since high school. After that, she became determined to have a musical career. But in 2008, just after finishing a year of basic musicianship at Douglas College in Vancouver, she sustained a high level SCI. The injury turned out to be incomplete, but while she regained the ability to walk, she lost function in her fretting hand and was no longer able to play the guitar.

That did little to halt her dreams. She's continued with her indie-folk songwriting, polished her already impressive soulful vocal abilities, and substituted her guitar for a ukulele.

These days, she's an active performer around the Lower Mainland, playing solo gigs at various events and venues, and regularly collaborating with Danny Sloan, a fellow musician with SCI, in a duo known as Salt of the Earth. Shelden is comfortable singing a wide variety styles, including jazz, house and R&B.

"Music is my ambrosia, the food for my soul," says Shelden. "Music is the one thing that can stop time and serenade me in a limbo land of bliss. Despite any challenges I face because of my SCI, I can still sing. I can still make music. And there's nothing that makes me happier."

Details/Dates: www.kristinasheldenmusic.com

DANNY SLOAN, VANCOUVER

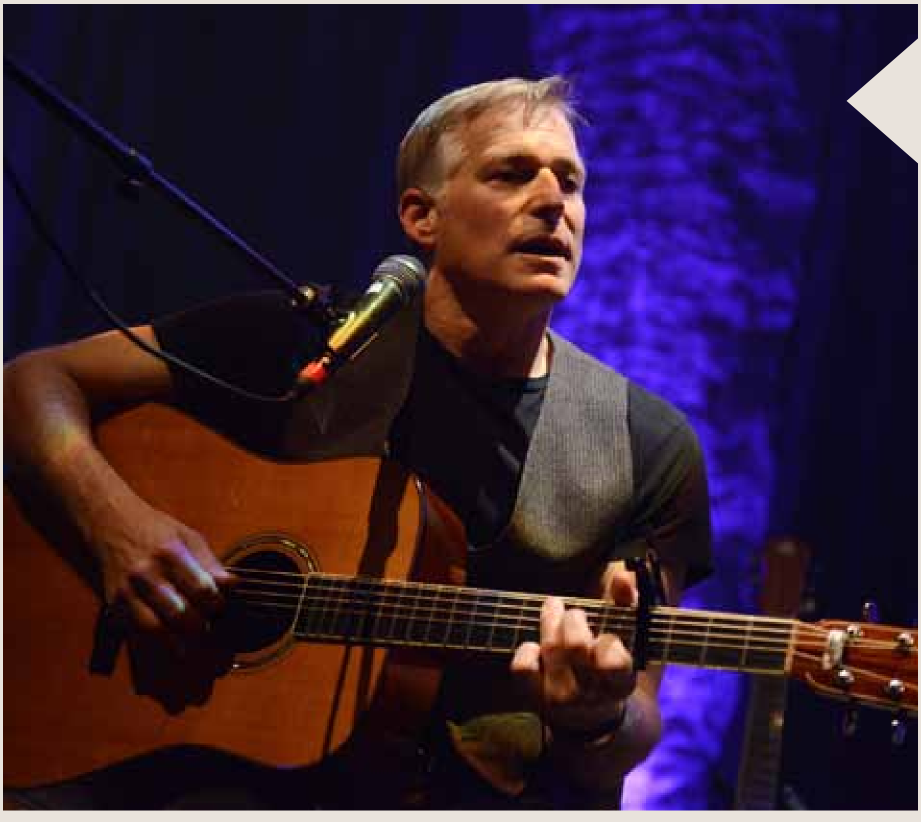
Instrument: Guitar | Genre: Blues
Age: 46 | Injury: T10 Paraplegic

Danny Sloan is a well-known fixture in the Lower Mainland's blues scene. With his band Digger Dan & The Dirt Brigade, Sloan plays many gigs in and around Vancouver. In addition to his superb guitar playing, he is a talented singer and songwriter, and his band is working on its first album. He also works with Kristina Shelden in a duo called Salt of the Earth. Regardless of where he plays, Sloan enjoys playing covers, but prefers to perform his own originals.

Sloan only started playing guitar when he was 20, and it wasn't a central focus in his life—until he was injured at the age of 27. During his recovery, and in the years that followed, music became a central theme, and he credits it with being an important part of his recovery and adjustment to living with SCI.

"With all the changes and extra time that my SCI brought me, at first music was a kind of soother," says Sloan. "The ball then just kept rolling faster and faster. Songwriting and singing exploded for me in university and, when I was at my lowest point emotionally, I turned to music. It may very well have saved me when I made the conscious decision to dedicate myself to it as much as possible."

Details/Dates: www.diggerdanmusic.com or www.facebook.com/diggerdanmusic



JEFF STANDFIELD, VANCOUVER

Instrument: Guitar/Vocals | Genre: Folk/Blues
Age: 58 | Injury: T4-5 Incomplete Paraplegic

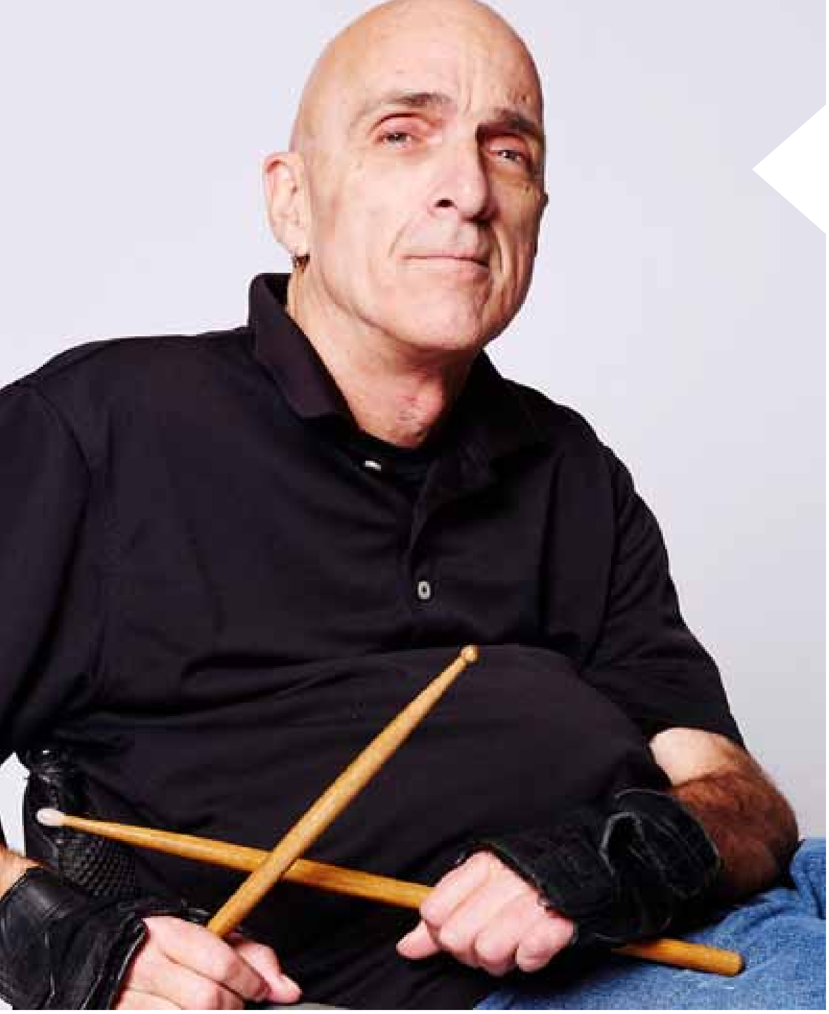
Jeff Standfield grew up in North Vancouver, and has been writing songs, singing and playing guitar since he was a kid. He plays a blend of acoustic and electric folk and blues, and he's known for telling amazing West Coast stories through his music.

Jeff has performed on TV, radio, and stage, and at folk festivals. He enjoys the songwriting process and is inspired by collaborations with other musicians.

"What I like about playing music is that it is separate to and is not significantly affected or influenced by my disability," says Jeff. "The fact that a musician has an SCI is not relevant to a listener in the end.

"Having said that, being a part of a community of musicians with a disability has been very rewarding and fun. It has allowed me to collaborate with many talented artists, form new friendships and perform where I would not have had the opportunity."

Details/Dates: www.facebook.com/TheJeffStandfieldBand



DAVE SYMINGTON, VANCOUVER

Instrument: Drums | Genre: Jazz
Age: 61 | Injury: C5/6 Quadriplegic

By now, you've probably realized that we've presented these profiles in alphabetical order. Ironically, that's allowed us to save one of the best for last, in terms of a musician who not only excels at his craft, but also has done so much to create opportunities for other musicians with disabilities.

Dave is a talented drummer and a cofounder of the Vancouver Adapted Music Society (VAMS). He plays electronic drums and has developed a Velcro glove to hold his sticks. Lately, he's been playing with SCI BC Peer Danny Sloan's band, Digger Dan & The Dirt Brigade. He has accompanied musicians at Vancouver's Kickstart Disability Arts Festival, played in a number of bands for local performances, and cut a video and achieved national radio airplay with the now-dissolved band Spinal Chord.

"Playing music, for me, is an incredibly freeing experience," explains Dave. "My favourite thing is having a jam session where there are no rules, no timelines and no structure. That's where the magic can happen and a temporary escape from the normal day-to-day responsibilities, timelines and pressures. More specifically, drumming is cathartic and puts me in a groove that I'm not normally in, or even aware of! Music is a level playing field where disability doesn't matter."

Details/Dates: www.facebook.com/dave.symington.9

VAMS: Supporting BC's Musicians with Disabilities

Interested in exploring how you can play music? The Vancouver Adapted Music Society (VAMS), part of the Sam Sullivan Disability Foundation, is an organization committed to helping musicians with SCI and other disabilities to fulfill their musical potential.

VAMS was co-founded in 1988 by two Vancouver musicians, Sam Sullivan and Dave Symington, both quadriplegic. Their goal was to identify and overcome the barriers faced by musicians with disabilities.

VAMS gained momentum in the 90s, constantly growing and reaching out to people with disabilities regardless of their musical ability or physical function, while building the infrastructure to help them and creating events to showcase their talents.

One of its crowning achievements was the 2008 completion of a state-of-the-art studio at GF Strong Rehabilitation Centre. Designed by studio guru Bobbi Style, it offers a wide variety of technological solutions that allow people with a diverse range of abilities to explore the world of music. VAMS members can make use of the studio to explore music making and composition, practice and jam, and record.

Additional VAMS programs include a community choir, gigs and performances, karaoke, sessions for beginners, informal jam sessions, and creation of professional music videos.

Vancouver Adapted Music Society (VAMS)
425 Carrall St #318, Vancouver, BC
604.688.6464 | www.vams.org | vams@disabilityfoundation.org

Well-known folk singer sylvi macCormac, who has MS, records a track at the VAMS studio. That's Dave Symington in the background.

MATTHEW WILD PHOTO

LiteGait Treadmill

FES Bike

Parallel Bars

Power Plate

Fecal Incontinence Treatment Gets a Vote of Confidence

In the Fall 2016 issue of *The Spin*, we told you about RDD Pharma, an Israeli pharmaceutical company that has developed a treatment for SCI-related fecal incontinence known as RDD-0315. Recently, the company received a vote of confidence from the European Medicines Agency, the European Union's equivalent of Health Canada.

The agency granted orphan drug designation for RDD-0315, recognizing that the treatment may be of significant benefit to many people with SCI who are often unable to tighten the two muscles that control the anal sphincter—the external anal sphincter, a striated muscle that contracts as a response to a person's conscious decision to squeeze it tightly, and the internal anal sphincter a smooth muscle that maintains constant contraction at all times.

Even people with the most effective bowel routines can experience episodes of fecal incontinence because of the inability to tighten these muscles. RDD-0315, which is a topical cream applied to the inner anal rim, works to tighten these muscles for a considerable length of time in the absence of signals from the brain. The treatment has shown promising results in clinical trials to date, resulting in a statistically significant 25 percent reduction in episodes of fecal incontinence in people with SCI.

The active ingredient is a variation of the drug oxymetazoline. As we told you last year, it's been used safely for decades in many common medications such as Dristan nasal spray and Visine eye drops. It works by binding to nerve receptors, where it induces smooth muscle and blood vessel constriction. For example, it eases congestion by narrowing the blood vessels in the nose.

The orphan drug designation provides potential incentives from the European Union to develop a medicine intended for use in conditions or diseases that occur in less than five in every 10,000 people. Incentives may include assistance with further clinical trials, reduced fees, and protection from competition once the medicine is placed on the market, including 10 years of market exclusivity.

"First and foremost, (granting of orphan drug status) is a validation that the competent authorities for the EU share our view on the need and utility of RDD-0315," says Jason Laufer, RDD Pharma's CEO. "This approval will enable RDD to accelerate development, streamline registration, and provide at least 10 years market exclusivity in the EU."

In the USA, the FDA has agreed to allow RDD Pharma to conduct a human clinical study with higher doses in order to further establish safety.

Watch for more details in the *The Spin* when they become available. ■

SCI BC Annual General Meeting

Thursday, October 26th, 2017

The AGM for the Canadian Paraplegic Association (BC), operating as Spinal Cord Injury BC, will be held Thursday, October 26th at the Blusson Spinal Cord Centre, 818 West 10th Avenue, Vancouver, BC.

Elections for the Board of Directors for the next two-year term will be held. Nominations for Directors may be made in writing and must be received by SCI BC ten days prior to the AGM. Nominations may also be made at the AGM by voting members in good standing, provided that the person nominated is present and consents to such nomination, or the person nominated has previously consented in writing to the nomination and such consent is presented at the meeting.

A voting member is defined as a member who has paid an annual fee.

This year's AGM and Members' Reception is a celebration of SCI BC's 60th Anniversary. Registration will begin at 6:00 PM. Please contact Maureen (604.326.1225 or mbrownlee@sci-bc.ca) for further information regarding the nominating procedure or to RSVP.

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.

Dysport: Treating Urinary Incontinence Due to SCI Neurogenic Detrusor Overactivity

Overview: Urologist and ICORD researcher Dr. Lynn Stothers and her team are evaluating if a treatment called Dysport is an effective and safe way to manage urinary incontinence caused by neurogenic detrusor overactivity (NDO). NDO is a condition that may occur following an SCI in which the bladder muscle contracts too often and involuntarily, which may result in urinary incontinence. Dysport is a treatment containing botulinum toxin A, which, when injected into muscle, usually causes the muscle to relax for several months.

What to expect: Two doses of Dysport will be evaluated in this study. In order to evaluate the effectiveness and safety of these doses, it's important to compare them to a placebo. Some participants will receive the placebo during the first study treatment only. For the second and subsequent treatments, all participants will receive Dysport (600 units or 800 units). Participants will be assessed for approximately two years to gather long-term data and allow patients in the study to have multiple treatments if required.

Who can participate: You may be able to participate if you are aged 18 to 80 years old, you have been diagnosed with NDO, you have had urinary incontinence for at least three months as a result of NDO, you have an SCI at the T1 level or below which occurred at least six months ago, you have had an inadequate response to oral medications after at least four weeks, you are routinely performing intermittent catheterization to empty your bladder (every four to six hours during waking hours), and you are able and willing to complete all study requirements including regularly completing the seven-day electronic bladder diary and attending all scheduled visits. If you are a female of childbearing potential, you must have a negative pregnancy test result and be willing to use reliable contraception throughout study participation.

Why participate: Your urinary incontinence may get better from taking part in this study. It's expected, based on past studies, that Dysport treatment may improve urinary incontinence and reduce the pressure in your bladder. High-bladder pressure is associated with a long-term risk for damage to the kidney and urinary tract. Taking part will help care providers learn more about Dysport. This may help others with neurogenic detrusor overactivity in the future.

Location: Vancouver, BC.

For more information or to participate: Please contact the study coordinator, Ivy Allard, by email (ivy.allard@vch.ca) or phone (604.875.4111 ext. 69876). Further details are at www.icord.org/studies/2017/06/dysport.

What's Possible Outside of the Wheelchair

Overview: ICORD researcher Dr. Jaimie Borisoff and his research team are exploring how people with mobility impairments sit and position themselves when not in their wheelchairs (for example, when on the floor, or when participating in specific activities).

What to expect: If you participate in this study, you will share ideas (e.g., via email) related to floor sitting and positioning, and subsequently participate in a moderated focus group discussion during which you will be asked to talk about how wheelchair users sit and position themselves when not in their wheelchairs. You will also be asked to provide feedback on an existing prototype for a sitting aid device. Participation will require 60 to 90 minutes of your time for which you will be you will be given an honorarium.

Who can participate: You may be able to participate in this study if you are a wheelchair user who currently spends time or has an interest in engaging in activities out of your wheelchair (beyond sitting on the couch, sleeping, and bathing) and can communicate effectively in English. You may also be able to participate in this study if you are a health professional with a minimum of one year experience working with wheelchair users and/or people with mobility limitations (e.g., as an occupational therapist, physiotherapist, recreational therapist, seating specialist, retailer, or other health professional) and can communicate effectively in English.

Why participate: Results from this study will be used to guide further development of existing prototypes and provide future direction of potential research and design around seating and positioning technologies.

Location: The study will take place at the GF Strong Rehab Centre and the BCIT Burnaby Campus (4355 Mathissi Place).

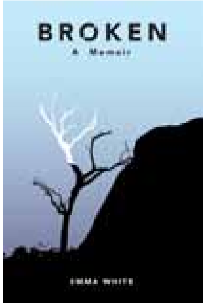
For more information or to participate: Please contact the study coordinator, Angie Wong (angie_wong@bcit.ca), by email or phone (604.451.6934).

Learn more about what makes ICORD one of the biggest and best SCI research centres in the world, and the research they are doing, by visiting www.icord.org/research/participate-in-a-study

Broken: A Memoir

Back in 2004, Kevin Hayley spent six weeks at GF Strong after he became a paraplegic in a motorcycle crash. Maintaining a constant bedside vigil was Emma White, Hayley's Australian girlfriend (now wife).

"The (SCI BC) peer counsellors gave us so much hope," says White. "At GF Strong, I remember Walt Lawrence, who is quadriplegic, saying mockingly to Kev as he rolled away one time, 'You don't have a disability, I have a disability!', which made me think of Crocodile Dundee saying, 'That's not a knife. *That's* a knife.'"



It turned out to be a fitting comment. Within a month of Hayley's discharge, the couple travelled Down Under and embarked on an 18,000 kilometre camping road trip across some of the harshest terrain on our planet.

"Back then, neither of us could even imagine living a normal ordinary life because we knew nothing about disabilities—which was terrifying," says White. "Travelling, trying, and occasionally failing made us less afraid, which back then was exactly what we needed. Kev grew stronger and we both learnt how to adapt to the injury, which was pretty much the entire point of our Oz trip—we reasoned if he can cope in the middle of the Australian desert six months post injury, then ordinary life would not be too hard."

Coping, however, turned out to be a tremendous challenge.

"We were in a bit of denial, I guess, thinking 'Ah, a spinal injury is no worries.' But getting a systemic bladder infection in far North Western Australia, thousands of kilometres from any sort of urban centre, was definitely a worry."

In the end, the trip was both a gruelling ordeal and joyous victory, as readers of White's recently published book *Broken: A Memoir* are discovering.

The book is based on a diary White kept of the trip and the events leading up to it. It chronicles the highs and lows of the journey and the couple's relationship as they struggled to come to terms with SCI in such a harsh setting.

"I started writing it a year or so after we got back from Australia and were living in Calgary," says White. "I'm not really sure why I started writing it—likely because I needed to write down what I was feeling and experiencing; writing gave me an outlet for my fears and doubts. As time went on and it came to resemble more of a book instead of incoherent ranting, I thought that my experiences may help other people. Because it's written from my perspective instead of Kev's, I think spouses of disabled people will be able to identify with it, and empathize with some of the challenges, doubts and fears I express."

White, who is incredibly candid about how difficult and painful that time was in her life, adds that writing the book was an incredible self-help project.

"Kev's injury was definitely one of the most momentous occasions in my life, and revisiting it was more challenging than I had expected but also allowed me to finally accept the injury and move on from it."

We asked White what she thinks distinguishes her book from other books by and about people with SCI.

"There are, of course, heaps of excellent books about disabled people doing really cool stuff— *Moving Violations*, *A Test of Will*, and *Man in Motion* are a few that I read in the early days after Kev's injury, and they really helped and showed me that disabled people could do anything. But, in general, the adventures described in books such as those occur years after the injury when the person is strong and capable and independent. Those people are not really relatable to a guy on the acute spinal wing of VGH. So I think what distinguished my book is how early after the accident we went travelling, and how completely unprepared we were for some of the problems we faced."

These days, White and Hayley are both hydrogeologists. They live in Melbourne with their two kids, and adventure travel remains a big part of their life. They also come back to Canada yearly to see their many friends in BC and Hayley's parents, who live in the Okanagan.

You can buy a copy of *Broken: A Memoir* at Amazon and other online stores. ■

PAST & PRESENT: Hayley and White in the Outback in 2004 (left); skiing at Big White in 2015.

Reader Reviews at Amazon

- "I thoroughly enjoyed this book...(the author) had me laughing one minute & sobbing the next. So brave, so courageous and so uplifting! I almost finished it in one sitting."
- "I just loved this beautifully written book...I was most impressed with Emma and Kevin's strength and determination to get on with life and not make the spinal injury a road block to an active and spirited life."
- "A fantastic read, real honest and open."