SPINAL CORD INJURY BC

Doggone Dilemma

WINTER 2016

Not everyone is crazy about BC's tough new service dog legislation and testing. But is the criticism warranted?





Sidewinder improves quality of life and independence by providing reliable mobility solutions and service in a caring and professional environment. Whether you're an independent driver or assisted passenger, our staff of qualified experts can help you choose the right solution to fit your mobility and lifestyle needs.

VMI side-entry wheelchair vans, available on Dodge, Chrysler, Honda or Toyota minivans, offer industry-leading flexibility, ease-of-use and functional aesthetics. With power or manual conversion options, VMI vans provide the perfect blend of performance, safety and style and make an excellent option for both independent and assisted, manual and power chair users.

Sidewinder's RAV II (Rear-access Vehicle), available on Dodge or Chrysler minivans, offers ease-ofuse and flexibility to accommodate up to two wheelchair passengers and/or six ambulatory passengers, making this an affordable option for the whole family.



44658 Yale Rd. W. Chilliwack, BC V2R 0G5

PHONE: 1-604-792-2082 TOLL FREE: 1-888-266-2299



sidewinderconversions.com

Find us on **F**

🚺 PROUDLY CANADIAN 🚺

Transport Canada approved and certified CMVSS, FMVSS or CSA compliant. Licensed motor dealer registered with the VSA (Vehicle Sales Authority of BC). www.mvsabc.com



contents WINTER 2016

features

10 Royal Style

Fashion designer and SCI BC Peer Chloë Angus received a royal honour in September.

12 Cover Story

BC's tough new service dog regulations have some people barking mad and others applauding.

16 Vitamin Boost

A recent study suggests that vitamin D supplements can improve mood and energy levels for people with SCI.

18 Hello, Winter!

Some tips to stay warm, safe and happy this winter.

20 "Call me Taylor"

Transgender people are living more openly and confidently—and that includes one SCI BC Peer.

24 Golden Girl

MLA and Cabinet Minister Michelle Stilwell reflects on an amazing Paralympic performance in Rio, staying motivated, and balancing athletics with work and family.

28 Redline!

A new "wearable" may soon be available to help you save your shoulders from overuse.

30 Last Chance Surgery

Dr. Scott Falci has refined a life-changing procedure that offers relief for the most extreme SCI neuropathic pain.

departments

4 editor's message

Your opportunity to help make Canada more accessible and inclusive is here.

6 gear & gadgets

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

7 Room for Debate

Should we allow Uber to do business in BC cities?

- 8 events Important dates for your calendar.
- 27 ask the SPIN DOCTOR How to avoid pneumonia this winter.
- **32** Participate in Research ICORD research projects that need your participation.
- **34 last word** NASA's new electric bandage may speed up wound care.

Cover Photo: Rob Pullen with his service dog Cooper. (Maya Pankalla photo)















editor's message

Be careful what you wish for.

I'm always surprised by how much feedback I receive on my editorials in *The Spin*. Strangely, many of you actually read what I write.

If you're one of those people, you might recall my editorial from the Fall 2015 issue, entitled, "If I were Prime Minister (or Premier)..." I argued for federal and provincial legislation that would focus on access and inclusion for all Canadians.

In truth, this was all a bit of a far-flung wish leading up to the federal election. In fact, I stated, "I don't expect any disability legislation from the federal government anytime soon." I was wrong. The newly-elected Liberals quickly made it clear that developing legislation to improve accessibility and inclusion was a priority.

In that editorial, I wrote that, while we needed such legislation, it shouldn't be called a "persons with disabilities act" (like in Ontario and the USA) because I believe that the focus on disability continues to promote segregation rather than inclusion. The Honourable Carla Qualtrough, Minister of Sport and Persons with Disabilities, seems to agree—she has not set out to develop a Canadians with Disabilities Act. As stated on the federal government's website, "the Government of Canada is committed to developing new planned accessibility legislation to promote equality of opportunity and increase the inclusion and participation of Canadians who have disabilities or functional limitations."

What's exciting about this process is that the Minister wants to hear from you and learn what you believe would make Canada more accessible and inclusive. By the time this editorial hits newsstands, the Minister's in-person consultations in BC will be over. But there are still ways to share your thoughts and ideas.

SCI BC is a lead partner in SCI Canada's Canadian Access and Inclusion Project (CAIP), one of only five accessibility legislation consultation projects funded by the federal government to provide additional input into the Minister's consultation process. The CAIP project is a partnership of 28 nonprofit groups representing a broad diversity of disabilities, each of which will be going out to their own memberships to hear about the barriers they face to participating in daily life and their ideas on how to overcome these barriers. You can learn more about the project online at include-me.ca.

As part of this project, SCI BC will be holding in-person consultations in the new year. But you don't have to wait until then to contribute your thoughts and ideas—check out the Rant, Rave, Recommend form on SCI Canada's include-me. ca website or on the federal government's accessibility legislation consultation website (follow the links at www.esdc.gc.ca). Whether you provide your comments in person or online, your thoughts and ideas will be recorded and added to reports that the Minister will use when crafting the new legislation.

It's easy to be cynical about consultations like this, but for the first time in our nation's history, we have a government committing to create legislation that will make our country more accessible and inclusive, and we have a federal Minister who is listening and wants to hear your thoughts on how to achieve this.

Back in the fall of 2015, I wished for legislation that focused on access and inclusion. Well, here we are: we find ourselves in the privileged position of supporting a process developing just that. This is our chance to help make history; to help make our country more accessible and inclusive through federal legislation.

So, if you have ever wished you could tell the government about the barriers you face and how you would remove them, now is your chance. Just be careful what you wish for—there is now a good chance it could come true.



- Chris McBride, PhD, Executive Director, SCI BC

Season's greetings!

thespin

The Spin is the quarterly magazine of Spinal Cord Injury BC. An online edition of *The Spin* is available on the SCI BC website www.sci-bc.ca.

Executive Editor	Chris McBride
Managing Editor	Cliff Bridges
Assistant Editor	Maya Pankalla
Design	Ćliff Bridges
Administration	Maureen Brownlee

SUBSCRIPTIONS

Free subscriptions are available for BC residents and health professionals:

T: 604.324.3611 TF: 1.877.324.3611 E: thespin@sci-bc.ca ADVERTISING

Advertising rates and a publishing calendar for *The Spin* are available online at www.sci-bc.ca. You can also contact Michelle Smith at msmith@sci-bc.ca or 604.326.1259.

SUBMISSIONS

Submissions, suggestions and comments are greatly appreciated—please email these to thespin@sci-bc.ca or send by regular mail to: Assistant Editor, *The Spin* Spinal Cord Injury BC, 780 SW Marine Drive

Vancouver, British Columbia V6P 5Y7

COPYRIGHT

You are welcome to reproduce material from *The Spin* after gaining permission from the Executive Editor. All reproduced material must be appropriately acknowledged.

The opinions expressed in *The Spin* are not necessarily those of SCI BC. Also, SCI BC does not endorse nor is responsible for the products or services advertised within *The Spin*. The information contained within *The Spin* is presented for the purpose of educating people about spinal cord injury. Nothing contained in *The Spin* is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider.

Publications Mail Agreement #: 40684573 ISSN #: 1922-9445

Return undeliverable Canadian addresses to: Spinal Cord Injury BC, 780 SW Marine Drive Vancouver, British Columbia V6P 5Y7 T: 604.324.3611

To update/change delivery address, email thespin@sci-bc.ca or call 604.324.3611.

SCI BC HEAD OFFICE

780 SW Marine Drive, Vancouver, British Columbia V6P 5Y7 T: 604.324.3611 TF: 1.877.324.3611 F: 604.326.1229 E: info@sci-bc.ca

REGIONAL PEER CONTACTS Chilliwack: Pete Froese, Peer Program Coordinator E: ofroese@sci-bc.ca

Fort St. John: Lori Slater, Peer Program Coordinator T: 250.787.1912 E: peervolunteerfsj@sci-bc.ca

Kelowna: Scott James, Peer Program Coordinator T: 250.308.1997 E:sjames@sci-bc.ca

Nanaimo: Bert Abbott, Peer Program Coordinator T: 250.616.1186 E: babbott@sci-bc.ca

Prince George: Brandy Stiles, Peer Program Coordinator T: 250.563.6942 E: bstiles@sci-bc.ca

Quesnel: Alison Duddy, Peer Program Coordinator E: peervolunteerq@sci-bc.ca

Vancouver: Teri Thorson, Peer Program Coordinator

T: 604.714.4185 E: tthorson@sci-bc.ca Vancouver: Richard Peter, Peer Program Coordinator T: 604.714.4185 E: rpeter@sci-bc.ca

Vancouver: Ryan Clarkson, Peer Program Coordinator T: 604.714.4185 E:rclarkson@sci-bc.ca

Vernon: Sonja Gaudet, Peer Program Coordinator E: sgaudet@sci-bc.ca

Victoria: Scott Heron, Peer Support Specialist T: 250.812.0773 E: sheron@sci-bc.ca

SCI BC acknowledges the financial support of the BC Gaming Commission, the Rick Hansen Institute, and the BC Paraplegic Foundation.

SCI BC Info Line: 1.800.689.2477





BERT ABBOTT Nanaimo

Our SCI BC Peers don't just ook great in ugly sweaters.

HEATHER LAMB Prince George







Every day, our Peer Coordinators work hard to help others with SCI and related physical disabilities adjust, adapt and thrive.

This holiday season, please consider saying

by making a donation in their name to Spinal Cord Injury BC.

Give online at bit.do/thankSCIBC











LORI SLATER Fort St. John

SCOTT HERON Victoria







Quesnel **RANDEEP SHARMA** Surrey

gear & gadgets 🔳



PHOENIX INSTINCT

Phoenix Instinct travel luggage was specifically designed for people who use wheelchairs. The set consists of a smaller hand luggage piece which easily clicks into place on the back of the larger main bag. Once together, the set clips on to the back of your wheelchair for easy and worry-free towing, even over curbs and around tight corners. Another key feature is the use of the large, omnidirectional wheels which allow the set to be wheeled, pulled or pushed in virtually any direction. The product was being readied for commercialization as this issue was going to press. Have a look at www.phoenixinstinct.com for details and videos of the luggage set in action.



UNGRIP

Cell phones might be getting smarter, but they aren't getting any smaller-in fact, just the opposite. Enter Ungrip, a device that makes it easier to hold and use any mobile phone, even if you have little or no grip. The Ungrip base attaches securely to the back of your smartphone or case, thanks to 3M's VHB (Very High Bond) industrial strength tape (which is also easily removable without leaving any residue). Once attached, you can slide your choice of finger or thumb through the material loop, allowing you to safely hold your phone at any angle. A swivel allows you to rotate quickly from portrait to landscape. It's available in a variety of different colours and designs. More details at www. ungripyourphone.com.





CARE E ON

The Care E On isn't new, but somehow it's slipped under our radar since it was invented in 2008. The Care E On is a skateboard-like ride-on trailer that attaches to your power wheelchair-your friend, spouse or companion can jump on at any time for a tow. It's available in two sizes-a 10 by 13 inch version, and a 13 by 15 inch version. Both versions have three wheels underneath. The device easily mounts to the back frame or battery case of most power chairs and flips up when not in use. The Care E On is designed in such a way that it will pivot, enabling the wheelchair user to navigate tight corners while towing a companion. Capacity is 300 pounds. For details, visit www.thecareeon.com.

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

ACTIVE HANDS

Active Hands General Purpose Gripping Aids are ideal for people with quadriplegia or anyone with limited hand strength and function. They make it easy for you to hold and use a variety of objects—gym equipment, video game controllers, hand tools, sports equipment, paddles, garden implements, or simply a glass or bottle. The key mechanism is a strap at the end of the finger section, which, when tightened, gently pulls the hand into a closed shape and allows you to hold items in your palm. The wrist strap is adjustable, and padding reduces chafing. Ingenious use of rings and Velcro allows most people with quadriplegia to put Active Hands on and take them off independently. They're built from tough webbing and comfortable but durable neoprene, are machine washable, and are available in a variety of sizes. Check out www.activehands.com for more information.

opinion

Room for Debate

Do you believe Uber should be allowed to set up and operate in BC?

Ride-sharing juggernaut Uber has gained a foothold in many Canadian cities, but none in our province. Many people eagerly await Uber's arrival, believing it represents another sorely-needed option for transit (and employment). But not everyone thinks Uber is a great idea. That includes some people with disabilities, even though Uber has implemented two initiatives specifically for people with disabilities—uberWAV and uberASSIST (uberWAV provides wheelchair accessible vehicles equipped with a ramp or hydraulic lift; uberASSIST does not offer wheelchair accessible vehicles, but drivers are trained to assist seniors and people with disabilities). So the question is: are you ready for Uber?

I learned of Uber from my son. He likes Uber for several reasons: its use of an app and credit cards bypasses the need for hard currency, getting a ride is done online in real time (no wondering how long till your ride comes), and customer service is an Uber priority.

Most of the time, when I take a taxi, I get the feeling it's an inconvenience for the driver to help me get in and secured. And their attitude gets worse when, forced to raise my voice from the back where I'm sitting, I say I'm only going a short distance.

With Uber, you get to rate your driver immediately (and vice versa). Compare that with the time-consuming and frustrating experience of lodging a complaint against a taxi driver.

One of the taxi industry's responses to the prospect of competing with Uber was the launch of the eCab app. My husband and I tried it. We ordered a wheelchair-accessible cab well in advance of our trip, only to watch cab after cab on the "real time" app drive by where we waited. Wheelchair users should have priority when it comes to wheelchair-accessible cabs, instead of, for instance, people with a lot of luggage heading to YVR.

There is a lack of transportation options for those of us with disabilities. Driving your own car or using a schedule-ahead service like HandyDART might work fine sometimes. But we need on-demand transportation periodically, just like everyone else. The taxi industry isn't coming close to meeting that demand.

Even though I have yet to experience an Uber ride, my expectation is that I will have good experiences that mirror those of my son. I believe with Uber, and particularly with its uberWAV and uberASSIST programs, having a disability won't hinder that experience, as it does most of the time when I'm forced to put up with taxi drivers' attitudes. Uber drivers commit to providing a certain level of customer service, and if they don't, they won't last long. Yes, taxi drivers have had training to assist customers with a disability. But I'm hard-pressed to remember many, if any, of those who stood out when it comes to great service. Obviously, getting to a destination safely is priority one, but for me, customer service—being treated with kindness, respect and dignity—comes a close second.

-SHERRY CAVES, Vancouver

Uber has accrued its lion's share of controversy since its inception in 2009. Today, Uber is battling more than 170 lawsuits. In the latest courtroom attack against Uber, competitor Flywheel says Uber has an illegal monopoly and must be stopped.

Dig deeper, and you'll discover that Uber—which, at its latest valuation of \$62.5 billion, is the world's most valuable private startup—has paid huge legal settlements around the world (some \$162 million by April 2016, according to *The Guardian*). And according to an extensive report by *Forbes* magazine, the company's wild-west approach will result in more lawsuits.

One reason appears to be its strategy of disrupting traditional taxi businesses, and challenging political and legislative hurdles through confrontation.

Through legislation, we set and maintain societal standards. Legislation ensures consistency, best practice and safety. Startups like Uber seem to operate without consideration of rules and regulations. But transportation is more than a good app—it needs to be based on a sound strategy and infrastructure, with rules and regulations to protect all stakeholders. So if sharing economies are the way of the future, it's fitting to take a serious look at how companies like Uber operate and are regulated.

So far Uber isn't scoring great. Uber's detractors claim the company doesn't provide adequate insurance for drivers or passengers, forces drivers to pay for vehicle maintenance, gives drivers false promises about how much money they can make, and misleads passengers about pricing and safety. And another complaint focuses on discrimination against passengers with disabilities. A new lawsuit from prominent Chicago-based disability rights group, Access Living, claims that, between September 2011 and August 2015, Uber only offered 14 trips in Chicago to those requiring wheelchair access. The company has faced similar complaints in other states. Only time will tell if the newly-implemented uberWAV can improve the situation.

Clearly Uber's clout and savvy have kept the wheels turning in a difficult patch of road. But for many, the concerns are mounting and the path forward is not certain.

-MARY-JO FETTERLY, Vancouver

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 Uber, as well as a variety of other contentious topics.



events



Shred some gnarly pow.

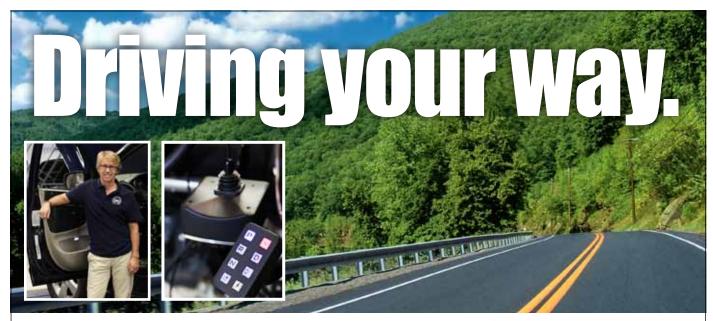
Hit the slopes this winter with the Vancouver Island Society for Adaptive Snowsports (VISAS). Try adaptive skiing, sit-skiing, snowboarding, or Nordic skiing. You pick the day and VISAS will hook you up with a free one-day pass to Mt. Washington and all the equipment you need to carve up some fresh tracks. For details, contact Peter at 416.363.4972 or peter@playsthatwork.com.



Do some social climbing. In partnership with Canadian Adaptive Climbing Society, SCI BC is hosting a free adaptive climbing and social day at the Edge Climbing Centre in North Vancouver on January 15. Learn the basics from experts and reach new heights. Space is limited to the first six participants. Learn more at our online events calendar at www.sci-bc.ca/events or contact Maddy at mmcdonald@sci-bc.ca.



Enjoy a girls' night out. Celebrate International Women's Day with SCI BC! Join us in Vancouver on Wednesday, March 8 for a delicious cocktail-style dinner and kick-ass motivational speakers, and make priceless connections with other amazing women from the SCI community. For more information, contact Maddy at mmcdonald@ sci-bc.ca or visit our events calendar at www.sci-bc.ca/events.



Want to get back on the road?

Our Driver Rehabilitation Specialists provide the highest quality driver evaluation and rehab services—when you want, and where you want. We are the only program in BC that offers a mobile service throughout the province, as well as Alberta and the Pacific Northwest. We offer assessments, training, and driver rehabilitation in either a sedan or high tech (electronic controls) van.

Access Driver Rehab Specialists – your key to independence.



Phone: 604-263-5218 email: AccessDriverRehab@gmail.com www.accessdriverrehab.com

Make Your Home Safe for Independent Living



Home Adaptations for Independence Are you a low-income senior or a person with a disability who wants to live safely and independently in the comfort of your home?

Do you have difficulty performing day-to-day activities?

Does your home need to be adapted to meet your changing needs? If so, you may be eligible for financial assistance under the **Home Adaptations for Independence (HAFI)** program.

Find out today if you are eligible and if you meet all of the requirements as a low-income homeowner or as a landlord applying on behalf of an eligible tenant.

To apply or learn more, visit www.bchousing.org/HAFI

You can also contact BC Housing: Phone: 604-433-2218 Toll-free: 1-800-257-7756









n our last issue, we featured Chloë Angus, the Vancouver fashion designer who has made a remarkable comeback after she sustained an SCI in 2015 as the consequence of a rare medical condition.

Angus had already established herself as a Canadian fashion icon well before her injury, thanks to her beautiful collaborations with well-known First Nations artists and her elegant, wearable clothing. But rather than slow down after her injury, she seems to have gained even more momentum. This past summer, Angus told us that having an SCI has made her a better designer, and she also let us in on her dream clients: Sophie Grégoire Trudeau and Princess Kate.

A mere month later, Angus got to place yet another feather in her already fashionable cap—she was given the opportunity to be a part of the Duke and Duchess of Cambridge's royal tour of BC. She was commissioned by Premier Christy Clark to create five gifts, which she presented in person to the Royals and their children during a ceremony in Victoria. "I chose to make a Spirit Wrap for the Duchess and Princess Charlotte, bowties for the Duke and Prince George, and a Spirit Blanket for the whole family to commemorate their visit to BC," says Angus. "All the gifts had a Bear design by Haida artist Clarence Mills the Bear represents strength and family."

nonal style

Angus was also commissioned by the Chief of the Heiltsuk Nation, Marilyn Slett, to make gifts for the Royals. She worked with Heiltsuk artist KC Hall to create a Button Blanket and Spirit Wrap depicting the Great Bear Rainforest, which were presented during a traditional gifting ceremony in Bella Bella.

"Meeting the royal couple was a dream come true," says Angus. "The Duke and Duchess are truly lovely people. They are excellent at small talk with strangers and make all who meet them feel like they are genuinely interested in what they have to say. They come across as a strong team who work very well together. One might not think





LEFT: Premier Christy Clark presents a Chloë Angus Button Blanket and Spirit Wrap to the Royal Couple. ABOVE: Angus meets with Prince William and Kate Middleton, with Premier Clark looking on.

of Royals as hardworking, but their schedule is gruelling—I only had to keep up to them for four days and I was exhausted!"

If all that wasn't enough to firmly cement Angus' reputation as one of Canada's leading designers, she was also selected as the exclusive wardrobe provider for our Premier throughout the royal visit.

"We made over fifteen pieces in two weeks. It was nerve-racking to say the least, as the timeline was so short and everything had to be perfect. It was not until I watched the Premier welcome the royal couple to BC looking flawless in her red dress and jacket that I realized we had done it. I was overwhelmed with pride for my team and all we had accomplished."

Would she do it again?

"Absolutely," says Angus. "My team and I had a golden opportunity and we went for it. The chance for international exposure and having something you've designed fall on the shoulders of the future King and Queen is a once in a lifetime chance to be recognized for your craft. Years of hard work and honing of skills led up to this moment, and it went off without a hitch. The immense exposure from the royal tour has led to an increase in sales and more recognition for the Spirit Collection and the artists I work with to create it."

All of the items created for the royal visit, as well as her other designs, can be viewed and purchased at www.chloeangus.com.



Doggone Diemma

Earlier this year, the BC government modernized its service dog legislation. The changes include allowing dogs trained in small schools and by private handlers the opportunity to earn official government certification. But some critics say the legislation is too restrictive, and others say it doesn't go far enough to ensure all dogs are legitimate and trained to meet the standards. wo years ago, Rob Pullen was sitting at home with his new puppy, Cooper, a white and brindle French Bulldog-Beagle, when he began having a posttraumatic flashback. An army veteran, Pullen regularly relived the horrors of his military tour in Bosnia. To his surprise, his family pet sprang to action, standing on Pullen's lap and caressing him neck to neck. Eventually, Pullen relaxed. The episode passed.

"I immediately knew I needed to find out if I could get him certified," recalls Pullen.

After searching online for three weeks and dodging several suspicious trainers who wanted big money up front, Pullen found Citadel Canine Society, a local nonprofit organization that helps to train pets and rescue dogs for first responders and veterans like Pullen. The organization assessed Cooper and deemed him a candidate, and the new handler-dog duo began Cooper's service dog training.

"I didn't go outside for 14 or 15 years, other than taking the dog to the park—

and that was when there was nobody there," says Pullen, whose frontline military experience led to two decades of self-medication (he's sober now) and a gradually worsening SCI. "And with Cooper, it's like, 'Okay, where's the busiest place? Let's go!' I'm always challenging myself now because I know he's going to be there for me."

Under BC's new Guide Dog and Service Dog Act (see sidebar below), which came into effect this past January, dog-handler teams like Pullen and Cooper are eligible for official service dog certification. It's part of a new set of training standards under which canine graduates from small schools and privately-trained dogs can be considered for the same certification as service dogs from larger and well-established organizations that are accredited by Assistance Dogs International (ADI) and International Guide Dog Federation (IGDF)—organizations such as Pacific Assistance Dogs Society (PADS).

But the big "if" is whether Cooper and other small-school pups can pass the Ministry of Justice's 40-task test (see sidebar.) "With assistance dogs, people think labradors," says Kristina Shelden, who lives with an incomplete SCI and thought she was too high-functioning to be "allowed" a service dog. But she learned about Leash of Hope, a new program in BC that procures rescue dogs from across the continent and retrains them with people with disabilities in mind. Shelden was soon paired with Sierra, a malamute. Despite some small hiccups through the training process—Leash of Hope is still relatively new and finding its footing—Shelden's since come to rely on Sierra for help with stability issues.

"When a different breed is in a vest, people are like, 'What the hell is that, that's not real!'" says Shelden. "But it is. It's just different from what you're used to. It means nothing in the grand scheme of things and people have issues with change."

Tara Doherty, Communications Manager and a Puppy Program trainer for PADS, wouldn't exactly agree. She's raised three labs and three golden retrievers—animals purpose-bred with top

BC's New Guide Dog And Service Dog Act

Guide dogs and service dogs provide integral support and independence for people with disabilities that range from visual impairment (guide dogs) to epilepsy, diabetes, mobility issues, and PTSD (service dogs). On January 18, 2016, BC's new *Guide Dog and Service Dog Act* came into effect. Here are some highlights:

- Certified service dogs as well as retired service dogs can legally reside in non-pet rental buildings and strata properties.
- Certified dogs "in training" with accredited ADI and IGDF schools have the same public access rights as certified dogs.
- People and businesses refusing certified service and guide dogs access to public places can be fined up to \$3,000. New, clearer guidelines and official government identification for dog-handler teams help eliminate confusion.
- Dogs trained by private handlers or non-ADI/IGDF accredited schools are eligible for certification via an application process and a 40-point assessment carried out by the Ministry of Justice.
- Dogs from out of country are required to complete the same certification assessment to benefit from the Act.
- Fraudulent dog-handler teams falsely purporting to have proper certification are subject to a \$3,000 maximum fine.
- Emotional support and therapy dogs, and animals other than dogs, are still not eligible for certification.

The new Act, a commitment in the BC government's Access-

ibility 2024 plan, is still in the education phase, and enforcement with fines won't occur for the next few years.

Fit for Service?

Whether a service dog was bred and trained by a large organization, rescued and re-trained by a smaller school, or bought as a pet and self-trained, all are eligible for government certification.

In addition to submitting the appropriate application documents and veterinary and medical forms, dog-handler teams must undergo a \$200 in-person assessment. This 40-skill test, administered by the Justice Institute of British Columbia, gauges the training standards, temperament, etiquette and attentiveness of the dog in a general public setting, and includes items such as:

- Obedience before entering a doorway.
- Calmness around traffic and noise.
- Ignoring food and other distractions in a restaurant.
- Ability to be led 20-feet away by a stranger for one minute, without displaying aggression, stress, or whining.
- Successfully and calmly boarding and exiting a city bus or train without soliciting public attention.

Each team must pass all 40 exercises without fault in order to be successful. How would your canine companion fare? For the full assessment list, visit jibc.ca and search "service dog". stock from around the world to be service dogs, as per the PADS model. Of those six pups, two have gone to a client. She estimates that well-bred dogs that are not purpose-bred for service work have a one in ten chance of succeeding—and just one percent of all rescues dogs have the potential to make it through the rigorous PADS training.

"One of the reasons we promoted this legislation is that it allowed these people a form with which they could get certified, but would be unlikely to," says Doherty, admitting that, although this sounds terrible, the test needs to be hard. "The dogs have to pass (each of the 40 prescribed tasks) with 100 percent, which is the standard that we hold our dogs to. When the dog passes another dog on the street, it has to ignore it; when it passes food on the ground, it has to ignore it. It can't bark or vocalize in public, it can't toilet in public. We're not asking anyone to do anything that our dogs don't. "

As a member of the small team that helped draft the new Service and Guide Dog legislation, Doherty is well aware of the benefits of the human-canine connection for people with disabilities. She says that, in addition to vital companionship, studies show that having a service dog reduces the amount of healthcare that individuals with disabilities use, decreases the amount of home care they need, increases their independence, and even makes them more employable.

"Often, when you're in a wheelchair, it's like you're invisible," says Doherty. "But as soon as you have a dog, it's like running an obstacle course—everybody wants to talk to you, everybody wants to compliment your dog, everybody wants to pet your dog. And then they follow the leash up and start a conversation."

But, like many others in the service dog community, she's worried that new organizations and private trainers for-hire aren't upholding the rigid training standards that are essential to owner, animal and public safety—and that recipients of new service dogs don't know any better.

"It's quite challenging for us to look at people calling themselves organizations,

when really they're a group of individuals that are passionate about something but have no training or expertise, and they're not a registered charity," says Doherty. "A lot of times we're getting those people after they've been through a horrific experience with a 'school' that doesn't really know what they're doing...The experience I have with other organizations is that they try to pound that square peg into a round hole—they turn a blind eye to issues and they try to make that dog successful no matter what, which is not really ethical from a dog's perspective or from a client's perspective."

Nicole Whitford, whose golden PADS labrador, Walker, allows her to live independently with cerebral palsy, agrees. "I don't mind other schools coming up, just do it properly—do it under code," she says, adding that unqualified assistance animals could be a real liability to their owners and a risk to passersby. She's also worried that improperly-trained dogs can act up in public, creating a bad name for all service dogs, causing mistrust and discomfort within the general population, and further limiting public access.

While Whitford supports the PADS model—with the organization retaining ownership and responsibility for its animals, and training specific breeds from birth—both her and Doherty recognize that the non-profit's waitlists, currently up to four years, can be a real deterrent.

Danielle Main, who co-founded Leash of Hope with SCI BC member Tessa Schmidt, believes that another obstacle with the larger, established organizations is that they seem to give preferential treatment to people with higher-level disabilities. Legally blind, Main says she looked into some of the larger guide dog schools when she was younger, but was constantly deemed a low-priority on account of being "too high-functioning." Now, she and Schmidt believe Leash of Hope can help fill that gap.

"We are an organization that specifically tries to tailor dogs to people with higher-functioning disabilities who want independence," says Main. "We are small and it means that we can take our time for complex clients or complex situations, and that's kind of our focus and niche. We probably will always stay this size, though we're working on getting ADI accreditation."

Main is satisfied that Leash of Hope's careful rescue animal selection process and its hands-on five-level training curriculum are up to industry standards, and that dogs from her program are unlikely to fail the government's current assessment. (At least a couple of Leash of Hope clients we spoke to were also optimistic, but hardly as confident.) She feels there's stigma around small organizations and their levels of training and accountability. And she already sees some big holes in the new legislation.

"To go through the (certification) right now to do that test (costs) \$200, and they have to redo a public access test?" questions Main. "Could you imagine coming here from England and having a service dog from where you're accredited from and then being told you can't have your dog in the hotel?" Not only does she see the fee as prohibitive, she's also worried the accreditation process doesn't hold independent dog-handler teams account-



able after they've passed the test. And she's not quite sure the new Act will do enough to eliminate the fakes.

She may have reason to be concerned. A quick search on amazon.com brings up 305 full pages of service dog vests, leashes, and other paraphernalia. Novelty ID cards inscripted with "Full Access Required by Law" run from as little as \$7.95 USD, while a Service Dog ID Pro Bundle, which includes an official-looking metal badge, key tags, 50 informative handout cards, a digital ID card, and a physical card, comes in at \$79.99 USD. That's about half the cost of the certification test—and it ships within the week.

"It's horrible! The whole fake service dog thing is a racket," agrees Whitford. "Another problem is that, unfortunately business and public managers don't really ask for ID and enforce it, and that's something that they have a right to do, but don't really want to."

Main, too, emphasizes that as far as identification is concerned, there's still a major lack of education among BC transit operators, and business owners and employees. "They see someone who looks able-bodied or has more of an invisible disability—whether they have an SCI and they're ambulatory, or they're autistic—and they harass them to no end," she says. "However, we witness on a daily basis people who are in wheelchairs with non-accredited dogs that aren't doing their job and aren't behaving, and they don't get bothered at all."

For all the discord between the various organizations, it's clear that weeding out fake assistance animals is a shared priority—though what qualifies as fake is a bit murkier. Untrained dogs wearing novelty service vests are clear no-nos. But what about private trainers who charge \$10,000 to turn your pet into a service dog? Or well-meaning schools whose curricula focus on tricks rather than tasks? Or rescue-dogs-in-training who, due to their past experiences and temperament, may never pass the government test, but will continue to accompany their owners out in a service dog capacity anyway?

As was the case under the previous legislation, there is currently no legal requirement for guide dog and service dog handlers to get certified. However, the public access ensured in the *Guide Dog and Service Dog Act* only applies to certified dog and handler teams. And, unlike the previous law, this new legislation does have the ability to fine fraudulent dog-handler teams up to \$3,000 (though how they'll find and carry these out in public access situations remains unclear).

For his part, army veteran Pullen wants to see identification standards go a step further, with vests and leashes colourcoded based on the dog's specific job, be it a guide dog, a service dog, a diabetes or epilepsy alert dog, a therapy dog, or a PTSD dog.

Colour codes aside, Pullen's pup Cooper could soon lose the "in-training" from his own service dog vest. Both the Citadel Canine Society and Pullen feel Cooper is nearly ready to take the government's certification test. And over at Leash of Hope, Main is preparing to take the organization's first group of graduates through that same pass/fail assessment later this month. She's confident that each of her rescue dog and handler teams are worthy of certification.

It remains to be seen whether, after the teams have attempted their 40 tasks, the Ministry of Justice agrees.





LEFT: Nicole Whitford worries that dogs who are improperly trained and act up in public could create a bad name for her lab Walker and all other certified service dogs. **BELOW:** Kristina Shelden believes that established training organizations don't offer enough for people with incomplete SCI—and that they bypass many dogs, such as her Leash of Hope dog Sierra, because they aren't traditional service animal breeds such as labs and retrievers. **BOTTOM LEFT:** Rob Pullen relies on Cooper to help him deal with lingering PTSD, and has rigorously trained his dog in the hopes that he will pass certification.

research



Vitamin BOOST

A recent study confirms that most people with SCI have low levels of vitamin D in their bodies—and suggests that taking a daily vitamin D supplement

can improve their mood and energy levels.

t's been a bad year for vitamins. An emerging body of evidence suggests that for healthy, able-bodied people, vitamin supplements provide no benefits. But the story appears to be different for vitamin D and people with SCI. A surprising amount of research in the past two decades has demonstrated a clear link between SCI and vitamin D insufficiency—and even deficiency.

Vitamin D insufficiency or deficiency is determined by measuring a person's blood levels of 25-hydroxyvitamin-D (which, thankfully, is often shortened to 25 OHD), a chemical compound that must be present in the body in order for vitamin D to be made naturally. Vitamin D insufficiency is defined as a blood level of 25 OHD below 32 ng/mL (that's short for nanogram per millilitre). Deficiency, which is somewhat more serious, is defined as a blood level of 25 OHD below 20 ng/ml. The level of your 25 OHD can easily be determined through a simple blood test ordered by your physician.

The percentage of at-risk people with SCI depends on the study referenced, but

it's safe to say that somewhere between 50 percent and 100 are either vitamin D insufficient or deficient (and likely closer to the upper end of estimates).

The reasons for this have never been exhaustively researched, but it's believed that it's likely due to a variety of factors including lack of exposure to the sun, obesity, and the use of medications that may affect vitamin D metabolism.

And that presents a real concern, because vitamin D is critical for our health. Vitamin D is a prohormone synthesized in the skin in response to ultraviolet-B radiation in sunlight. Its most important role is helping the body absorb calcium and phosphorus from the food we eat. These are nutrients critical for building and maintaining bone, so low levels of vitamin D can speed up bone loss and increase the risk of fractures. Evidence also suggests that our vital organs (including the heart, kidneys, colon and brain), as well as our muscle and immune system, all need vitamin D to function properly.

Now, a recent study completed by researchers at Stanford University and

the Santa Clara Valley Medical Center provides another reason for people with SCI to be concerned about their vitamin D levels: it appears that depression, fatigue and even pain can all be improved with daily vitamin D supplementation.

"There had been a lot of focus on vitamin D deficiency during my training in internal medicine and in physical medicine and rehabilitation," explains Dr. James Crew, study leader and Chair of Physical Medicine and Rehabilitation at Santa Clara Valley Medical Center. "Multiple studies had shown low (blood) levels of 25 OHD in patients with prolonged hospitalization and certain conditions such as SCI. We started checking levels in 2010 at our facility on every SCI patient admitted into our rehab center, and also in our chronic patients whom we see in clinic. We were surprised that over 80 percent of both acute and chronic patients were low in their 25 OHD levels. This led us to ask some questions, including, 'What is the best supplementation strategy? How does low vitamin D affect our SCI patients?'"

The study recruited 20 people with acute SCI and 22 with chronic SCI. All of these individuals were given a baseline test and determined to have either vitamin D insufficiency or deficiency.

They were then randomly assigned to either a low-dose group or a high-dose group. Those in the low-dose group received 800 international units (IU) of vitamin D daily for six months. Those in the high-dose group received 2,000 IU daily for six months if they were found to be vitamin D insufficient; if they were vitamin D deficient, they received 4,000 IU daily for the first month and 2,000 IU daily for the remaining five months.

All of these individuals were then tested at one month, three months, and six months. This included a blood test to see if levels of 25 OHD rose with supplementation, along with some standardized tests to assess levels of depression, fatigue, pain, and strength.

Not surprisingly, individuals in the group taking the higher dose supplementation were found to have higher levels of 25 OHD throughout the six month study period. As well, they scored much better on the tests to determine improvements in depression, fatigue and pain.

"We ended up with some statistically significant findings," says Crew. "We found that the higher dose group had improvements in mood and strength that were statistically greater than the lower dose group. Given it was a small study, I was most impressed with these findings."

He concedes that the results need to be confirmed through a larger scale study. Nevertheless, the results add to a growing body of evidence that suggests that people with SCI should be concerned

> about their vitamin D levels. One recent study published by the journal Archives of Physical Medicine and Rehabilitation found that low vitamin D is associated with decreased functional independence and physical activ-

What about vitamin D and osteoporosis?

It's estimated that up to 80 percent of all people living with SCI have osteoporosis. Since one of the main roles of vitamin D is to absorb calcium, it's fair to ask if it has a role to play in osteoporosis prevention in people with SCI. Numerous studies conclude that vitamin D supplements, taken in conjunction with a calcium supplement, reduce the loss of bone mineral density, which underlies osteoporosis. Not surprisingly, many credible sources of SCI health information stress the importance of taking calcium and vitamin D in tandem. One of those is the University of Washington's website, which concludes, "For persons with vitamin D deficiency, 2000 IU of oral vitamin D3 with calcium 1.3g daily for three months is recommended to safely raise vitamin D levels into normal range." Like vitamin D, calcium supplements are considered safe in recommended doses. If in doubt, consult your doctor and get some help determining how much of each supplement you should take.

ity in people with chronic SCI. And yet another study published in the journal *Nutrients* demonstrated that elite wheelchair athletes with SCI who had low 25 OHD levels showed improved muscle strength after 12 weeks of vitamin D supplementation.

So the question is, should you immediately start reaching for the vitamin D supplements each and every day?

"I would recommend that persons with SCI have at least a baseline level checked to see where they are at," says Crew. "We were surprised to see persons who were living in California have very low levels of Vitamin D-25 OHD levels less than 10 were common-within a couple weeks of sustaining an SCI. Additionally, very low levels were also seen in our chronic population. In these patients, it is important to be aggressive with supplementation given National Health and Nutrition Examination Survey (NHANES) research showing increased cardiovascular risk with very low levels of vitamin D. As such, I'd advise getting a baseline level and then deciding on a supplementation strategy."

Crew says that his patients with very low levels of 25 OHD are often prescribed up to 4,000 IU daily of vitamin D3 (the most potent form of vitamin D supplementation for humans). The effect of this dosage is checked after two to three months, and the dosage is often reduced to 2,000 IU daily at this point.

He adds that his team noted no serious adverse events from high dose supple-

mentation during their six month study, keeping in mind that the 4,000 IU daily dose was only provided to some participants, and for only one month.

Health Canada's official recommendation was updated in 2011 but remains very conservative: 600 IU for adults up to the age of 70, and 800 IU for adults over 70. Health Canada's safe upper limit, however, is 4,000 IU per day. So while we think it would be best to follow Crew's advice and have your blood levels of 25 OHD checked before embarking on physician-prescribed supplementation, it also seems pretty safe to say that, as a person with SCI, you more than likely have insufficient or deficient 25 OHD levels, and therefore should consider at least 2,000 IU of D3 supplements per day.

Vitamin D is, fortunately, one of the lowest priced supplements you can buy and available virtually everywhere you can buy groceries. Another strategy to get what you need is increasing your intake of foods that provide vitamin D naturally—salmon, tuna, eggs and cheese.

Finally, we should point out that vitamin D supplementation isn't without controversy. Excessive doses can build up to harmful levels, causing high blood calcium and damage to the heart, blood vessels and kidneys. And while vitamin D toxicity is unlikely at daily intakes below 10,000 IU, it appears that not everyone reacts the same to vitamin D supplements—some are more sensitive to the adverse effects of too much vitamin D. Don't overdo it!

1. LAYER UP



Wear layers that will retain heat while allowing your body to breathe. Choose a light base layer, a thick medium layer, and a waterproof outer layer. Wet clothing greatly increases heat loss, so find base layers that wick away moisture-cotton, nylon and polypropylene fabrics are favourites. When the temperature does drop, make sure to add layers: blankets, hats, gloves, and scarves. And don't forget about those toes-boots are worth it!

2. PLAN YOUR ROUTE

Your favourite way to work may not be so accessible in the snow, your bus may be late, or your parking spot may be flooded. In metro Vancouver, check Translink.ca for up-to-date information. In other parts of BC, see if your public transit has a website, Twitter, or Facebook page (social media often gets updated faster than local news). Ensure your vehicle is safe, obey winter tire and chain signs, and check out DriveBC.ca before you head out.



3. BE PREPARED



It's the Scouts motto for a reason. Always be prepared for adverse weather conditions by packing an emergency vehicle kit (flashlights, blankets, and reflective cones are a good start) and an emergency home kit (food, water, a radio and first aid supplies are musthaves). Store-bought kits can be useful, but they often lack the SCI-specific necessities you may need - an extra chair battery, medications, and adaptive equipment.

Winter! Hello,

Depending on where you live in our great province, surviving winter means dealing with snow, rain, slush, or some combination of the three. But don't worry—we've got your back. Here are a few warm and friendly reminders for navigating your neighbourhood in sub-zero temperatures, finding local events to keep active, and staying safe.

5. STAY ACTIVE & HEALTHY

4. TAKE YOUR VITAMIN D

The number of sunny days in BC dramatically decreases during winter, so it's important to get enough vitamin D. Consult with your doctor about this and any other winter health worries you may have. Fill your prescriptions ahead of time in case the weather makes it impossible to travel (tip: many pharmacies offer online renewal). Finally, pay attention to what your body tells you during the winter-even small changes may be important!





There's nothing quite like staying physically active to help you breeze through winter. Possibilities include SCI BC's wheelchair rugby and basketball programs, and staying fit at home (check out SCI Action Canada's Get Fit toolkit at sciactioncanada.ca/guidelines/ toolkit). And don't forget to eat healthy. Consider attending an SCI BC cooking class or check out our nutritional recipes online at www.sci-bc.ca.

6. STAY ENGAGED

During dark and dreary months, try to stay socially active. See our BC Events Map or visit www.sci-bc.ca/events for ideas. Stay positive by setting small, achievable goals daily. If you can't travel, stretch those brain muscles with books, puzzles, games, crafting, knitting, writing, or woodworking. And do as the Scandinavians do-embrace winter by enjoying comfort food, cosy nights with candles, and the company of good friends and family.



GET WINTER SOCIAL... ...with free accessible events throughout British Columbia

No matter where you are this winter, there is always something going on! Here are a few recommendations. For a full listing of events near you, check out www.sci-bc.ca/events.

PROVINCE-WIDE Every Month

- Bean There Coffee Groups
- SCI BC Peer Groups

Reach Out Virtual Peer Group

www.sci-bc.ca/events

VANCOUVER ISLAND

Adapted Fitness Classes (\$2/class)

City of Victoria Parks, Recreation and Culture Mondays until March 13, 2017 www.victoria.ca/recreation NORTHERN BC

Adapted Snow Tubing at Whitetail Ski Resort Prince George Parks and Recreation

Sunday, January 22, 2017 | 8:30 AM to 5 PM www.pgparks.com

BC INTERIOR

Wheelchair Curling Kamloops Adapted Sports Association Every Second Tuesday Facebook: @kamloopsadaptedsport

LOWER MAINLAND

Adaptive Yoga Classes Trinity Yoga Wednesdays in Vancouver www.trinityyoga.net

Free Adaptive Snow Sports at Mount Washington

Vancouver Island Society for Adaptive Snowsports Throughout Winter Email Peter at peter@playsthatwork.com Winterruption A Uniquely Vancouver Winter Festival at Granville Island February 17 to 19, 2017 www.granvilleisland.com/winterruption-2017

7. CHECK YOUR RIDE



Squeaks? Steering issues? Flat tires? If your chair has a problem, winter will surely make it worse. To avoid the stress of being stuck in a snowdrift, follow these winter wheelchair tips:

- Charge your battery regularly
- Change to winter tires—extra tread means more grip on slippery surfaces
- Inspect your chair frame and electrical connections often
- Remove debris from the axle housing

- Get a patch kit and learn how to use it
- Check your tire pressure
- Be aware of black ice, deep puddles and unpacked snow.

8. ASK FOR HELP



Maybe you need a ride, an extra set of hands, or a visit from a friend. There's no shame in asking for a little TLC from those around you. Practicing the buddy system may sound old school, but travelling with someone, or having someone you're able to reach by phone at any time, is one of the best ways to prepare for winter. If this seems difficult, SCI BC's toll-free InfoLine (1-800-689-2477) is happy to help—ask away.

9. BE SEEN



The low light, darkness and wild weather makes being seen an important safety priority in the winter months. Wear high-visibility clothing, add reflectors to jackets and bags, and consider adding TetraLites to your wheelchair, scooter or handcycle.

"Call me Taylor"

A new, more accepting day is gradually dawning for transgender people, who are using the opportunity to move from the shadows and live more openly and confidently. Taylor Straw, who just happens to be an SCI BC Peer, is among them.

n June 2015, Vanity Fair magazine published one of its all-time most popular issues. The cover featured Caitlyn Jenner in a onepiece bodysuit with the title, "Call me Caitlyn," tempting readers to open up the magazine and learn why Jenner would trade her life as a former male Olympian decathlete to live as a woman.

peers

Well before this iconic issue of Vanity Fair appeared, the transgender movement had been gradually gaining momentum. But in retrospect, Jenner's bare-all (or almost all, anyhow) story might have been the turning point for transgendered people's quest to exercise their rights, battle discrimination, and move from a covert existence into society's mainstream. In the 18 months that followed, Jenner's Vanity Fair feature prompted a flood of transgender stories and coverage elsewhere in the media. At the same time, efforts were stepped up to enshrine transgender rights alongside those of other formerly discriminatedagainst groups such as gay and lesbian people. Here in Canada, most notable among these was the Trudeau government's introduction earlier this year of Bill C-16-legislation that would guarantee legal and human rights protection to transgender people across Canada (at the time of writing, the Bill was expected to be passed in a third reading in the

House of Commons and sent to the Senate before Christmas).

Of course, universal acceptance of transgender people won't happen overnight. In many parts of the world (including, sadly, here in North America), they are subject to appalling discrimination and even violence. But it seems as though those fighting for transgender rights now have at least a foothold—and it's unlikely that even a closed-minded US president-elect could change that.

In this environment of growing acceptance, more and more transgender people are stepping out of the closet, choosing to accept themselves and asking others to do the same. There are few reliable statistics to back this up, but plenty of anecdotal evidence. For example, in a *CBC News* story in October, Kris Wells, an assistant professor with the Institute for Sexual Minority Studies at the University of Alberta, explained how "more resources, better education and a more welcoming culture are allowing transgender people to come out at younger ages."

"It's a definite trend that we're seeing," Wells told CBC. "There are more and more positive role models, challenging old stereotypes of being sick or diseased or being treated as a freak or a monster. Thankfully, that discourse is changing."

One of those leveraging the opportunity to step out of the shadows is Taylor Straw, a 42-year-old SCI BC peer who lives on the Sunshine Coast. Clearly, Straw is not the first transgender person to live with an SCI. But she is definitely among the first to be so forthcoming about her journey and decision to move forward with a full male to female transition.

Straw, who was given the birthname Brandon but went by the nickname Buz from the age of five, grew up in the Lower Mainland. She knew at an early age that there was a disconnect between her biological gender and who she felt like inside. "When I was five, my sister, who is five years older than me, dressed me up in her clothes and did my hair and makeup," she explains. "At that moment, a light bulb went on. At that time, being transgender didn't have anywhere near the awareness that it does today, but the feeling I had when I dressed in her clothes was so comfortable and more right than anything I had felt before."

So began Straw's secret life—living her childhood and teen years outwardly as a male, but inside wrestling with gender and knowing she was somehow incomplete. It was a textbook case of gender dysphoria—the powerful feeling that one's emotional and psychological identity as male or female is opposite to one's biological sex. (Gender dysphoria used to be called gender identity disorder, but the name was changed to reflect that the medical profession, and society in general, no longer sees it as a "disorder", in much the same way that being gay is no longer thought of as being a disorder.)

"Mentally and emotionally, I was drawn to social girl circles, but because of my masculine appearance, I hung around with the guys," she says. "There are so many reasons that it was difficult to come to terms with my true self. For example, in high school, a very flamboyant fellow student was picked on, made fun of and eventually beaten up in front of the whole school for apparently being gay. At this time, if you were openly gay or trans you would be categorized as a freak. What I know now as my gender identity and being transgender was not even something I was aware of at this time, as it wasn't out in the social context. In my youth, there was absolutely no way I was going to reveal my gender identity to anyone, let alone those closest to me."

Straw kept up the facade into early adulthood. That included working in the male-dominated profession of construction. Then, at the age of 24, she was injured while doing demolition on the second floor of the Woodward's building in downtown Vancouver. She was operating a skid steer loader when she came too close to the building's edge. The machine tipped her out the side to the parking lot below. The result was incomplete C4/C5 quadriplegia.

During the gruelling six months of rehab that followed, and into the first few years of post-injury life, Straw's gender dysphoria took a back seat to simply trying to adjust to her new reality. And then, four years after her accident, love came knocking at the door.

Perhaps the biggest myth about being transgender is that sexuality and gender are one and the same. In reality, they are completely separate facets of human existence. In 2004, Straw married her girlfriend of two years. The couple moved to the Sunshine Coast, where they've been ever since. They wanted a family, and eventually had three beautiful children, conceived the old-fashioned way with assistance from Vancouver's Sexual Health Rehab Service.

Family life and being a parent came naturally to Straw. But she continued to wrestle with the gender issue. One of the by-products of gender dysphoria can be distress, anxiety, and depression. And for most, relief only arrives through acceptance.

"Every few years," says Straw, "there were some significant moments that signalled to me that transitioning was the direction in which my life needed to go."

Gradually, Straw became aware that the world was slowly changing. She'd seen some documentaries about trans people, and then, in 2015, Jenner's revelation gave her the push she needed.

"Once Caitlyn Jenner came out about being trans and her transition, that was a major springboard for me, as I could see how the public was becoming more aware and accepting," says Straw. "As a result, I felt more confident about sharing my identity with those closest to me. In the summer of 2015, my wife and I had a conversation in which I revealed that changing my gender was something I had to do."

That revelation didn't come as a complete surprise to her wife, as the couple



had discussed Straw being transgender many times previously. Nevertheless, Straw was relieved at her wife's reaction.

"When I came out to my wife, I knew it wasn't going to come as a huge shock to her, but I was surprised about just how supportive and encouraging she was. As much as I am sensitive to the feelings of those closest to me, I knew that I had to tell them about my transition in order for me to be functional and happy. Everyone I have told—my wife, kids, sister, parents and friends—are all supportive and happy for me."

And that, says Straw, all added up to a life-changing catharsis.

"It was the world's biggest weight being pulled off of me. I felt so free and happy. Months after I came out, my wife told me what a 'grumpy fu*#%r' I used to be. Now she sees how happy I am and how much more I'm enjoying life."

Not all transgender people transition. And there are degrees of transitioning for those who do. Some undergo hormone therapy to develop breasts and a feminine appearance. Others choose to move forward with a full transition, which includes sex reassignment surgery and other medical procedures.

For Straw, there was no doubt in her mind about her path forward.

"It was pretty much instant," she says. "Once I knew I was going to transition, I knew I wanted to fully transition. As a child I wanted to physically look like a girl; to have the body of a girl. Once I was older and learned that surgery was something I could do to make that happen, I was certain that top and bottom surgery was something I would work towards."

She describes herself today as being in the early stages of transitioning.

"I'm currently doing laser hair removal on my face. I'm taking hormones that are noticeably changing my body. I am in the process of legally changing my name and gender marker. I'm working with a GP who specializes in gender issues and we are working closely together to keep moving forward. Being older than others who transition means that the hormones I am on don't work as fast. It's a waiting game to see what impact they have on my body. Before doing top surgery you have to be on hormones for at least two years. Needless to say, it's a long process to get to where I really need to be."

She concedes that SCI presents a challenge in the transitioning process.

"The decision to transition was more difficult because of my SCI," she says. "I do have a high-level injury and need so much assistance in my life. I'm sure I would be further along if I were able-bodied. However, there's no way I'm letting it stop me from living as my true self."

Straw also points out that perceptions of male-to-female transgendered people being fixated on ultra-feminine dresses and other clothes is, for the most part, a stereotype that needs to be challenged.

"I have changed my clothes, but not to a feminine extreme," she explains. "Physically, I look very masculine, so for me to wear a dress and do my makeup would not be the look I am going for at this point. As my body changes more physically, I will embrace a more feminine style, but for now it just wouldn't look right. Again, this is a transition and I'm only at the beginning stages of making my community more aware of my true self. Once that's put out there, and more of my features have feminized, I will feel more comfortable going out in public, presenting in a more feminine manner. That being said, who gets to say what is feminine and what is masculine? I know lots of ladies who wear jeans, a T-shirt and a baseball hat and look really beautiful. Is that not feminine?"

She adds that she's realistic about how she looks—and realizes that, at this point, nobody is going to mistake her as female from birth. "Just because I identify as a woman," she says, "does not mean that I must conform to what society sees as a typically feminine style."

She also says that easing up on the ultra-feminine approach makes it easier for friends and community members to accept her—something that she's been pleasantly surprised to see happen.

"Everything has been very positive and supportive. My circle of support has gotten bigger and bigger, and everyone who knows has expressed their total backing. People who transition tend to be better, happier people than transgender people who don't transition. So although there is change, it's a good, positive change."

She's grateful for the support. And not surprisingly, she's grateful for the gradual acceptance of transgender people in our society—and to the people who have helped make it happen.

"In the last few years, the awareness and support for trans people has grown significantly. With the help of people like Caitlyn Jenner, who chose to transition so publicly, and Justin Trudeau, who acknowledges the trans community and their rights, along with so many other activists throughout Canada and the USA, there is more understanding and protection for the transgender community."

She's well aware that, while she's not setting any precedents when it comes to the general public, she is helping to break a trail for others with SCI who also question their gender identity.

"Our limited choices are expanding because of the complicated nature of gender. Just because you're born with a penis or a vagina, that does not define you as a man or a woman. Once I revealed to my loved ones that I am transgender, I took a huge sigh of relief that I could finally start living as my true self. If you are transgender, regardless of whether you have an SCI or not, you have to honour your true self. It won't necessarily be a smooth path, especially if you have an SCI, but that's the nature of life. We encounter hiccups and speed bumps every day and those experiences can ultimately enrich our lives and make us better people."

Want to know more? Straw suggests the book My Husband Betty, by Helen Boyd. "It's really well-written, and provides a wealth of information, both personal and scientific, about being transgender," she says. "Anyone who is on this path should take the time to read it."

Photos of Taylor were taken at Swish Ladieswear. Taylor's makeup was done by Tanya Plows.

TETRA 🏹 GEAR



Safety Lights for wheelchairs and mobility devices

🐓 Made in Canada | Tetragear.com | info@tetragear.com



Park Inn & Suites by Radisson Vancouver, BC 898 West Broadway, Vancouver, BC V5Z 1J8 T: +1 (604) 872-8661, F: +1 (604) 872-2270, pd_brbc@parkinn.com

(800) 670-7275 parkinn.com

Golden Giri

MLA and Cabinet Minister Michelle Stilwell reflects on an amazing Paralympic performance in Rio, staying motivated, and balancing athletics with work and family.

nily.

THIS PAST SEPTEMBER, PARKSVILLE MLA MICHELLE STILWELL took a few days off from her day job, packed her bags and racing wheelchair, and headed for Rio as part of Canada's Paralympic Team. There, she rose to the occasion, capturing gold in the women's 100 and 400 metre events. She now has six Paralympic gold medals, acquired over an athletic career that spans 16 years—and she's also one of the few Paralympians to win gold in two disciplines (her first was as part of the Canadian wheelchair basketball team that captured top honours at the Sydney Paralympics in 2000). When you factor in her ten world championship medals and her recent induction into the BC Sports Hall of Fame, it's obvious that she is one of Canada's elite athletes—and one of the most successful Paralympians our country has ever had. We recently caught up with Stilwell at her MLA constituency office in Parksville.

as it tough getting time off from the boss to compete in Rio? There are times of the year

when it would be harder to get away, but to take a couple of weeks at the beginning of September was something I was able to work out with full support from my family and the Premier. In fact, the level of support I received from my colleagues was amazing. Having said that, my colleagues do give me the gears about using my holiday time to compete for my country on the international stage because it's not exactly the most stress-relieving option. It's simply what I love doing in my spare time.

Does pursuing your athletic dreams fit into your family life?

Supporting each other to achieve our goals and pursue our passions is just a part of our family fabric. Everyone has goals and passions, and part of their success definitely falls on whether they have enduring support, whether it's days, months or years, from family and friends to reach their goals. Mark, my husband, has given me that ten-fold since I met him 20 years ago. My son, Kai, well, he has loved travelling the world, making new friends and seeing amazing places. The life skills he has gained through these opportunities to see and do things he would have never had otherwise are invaluable. We have always been a team no matter what passion any one of us is pursuing.

How do your accomplishments in Rio compare to your other medals and records?

Every Games has memories and special moments that are part of my journey. Sydney was my first games, where I had the honour of sharing my journey with 11 other incredible athletes. Beijing was my first time on a podium for track, then London was my chance to repeat what I had done in Beijing.

The 400-metre race in Rio is significant for many reasons. I was ranked second in the world, up against the world record holder. I had never competed in this event at the Paralympic Games—prior games only hosted the 100m and 200m. That race held a lot of symbolic, as well as emotional, meaning for me, and to race to gold will always be a cherished accomplishment.

That being said, every Games has been driven by my desire to represent Canada on the world stage. Just thinking about having the opportunity to stand on the podium and hear our anthem while watching the flag rise was what pushed me through my training and preparation over the years. Bringing the medals home is what I get to share with all Canadians. It brings me so much joy to watch their reactions when they get to hold one—you can see the energy and emotion it brings.

Can you tell us about your training and preparation for Rio?

I did most of my training on my rollers at the Legislature or in my garage at home whenever the time presented itself, day or night, as my work schedule spans seven days a week and all hours of a day. I'm a morning person so I tried my best to get my session completed before my work day even started. The length of time depended on what was on the training plan. Some workouts were an hour, sometimes two.

Now that I'm back from Rio, I'm still fitting in workouts throughout the week, just not following a training plan. Healthy, active living is part of my life and always will be, whether I'm competing on the international stage or just keeping healthy and fit. As a person with a spinal cord injury it's important to stay strong and fit because it helps me with my daily activities, to keep my independence and stay out of hospital.



MICHELLE STILWELL: At a Glance

AGE: 42 HOME: Parksville, BC FAMILY: Husband Mark, son Kai JOB: MLA, Parksville-Qualicum; British Columbia Minister for Social Development and Social Innovation INJURY LEVEL: C7 incomplete COMPETITION CLASSIFICATION: T52 PARALYMPIC MEDALS: Six gold, one silver WORLD CHAMPIONSHIP MEDALS: Nine gold, one silver WORDS TO LIVE BY: "Remove self-imposed limitations anything is possible with a positive attitude."

Your career as an MLA and Cabinet Minister also comes with some long hours. How do you manage to juggle it all—work, training and competing, and your family life?

I just do it, like all the other Olympians and Paralympians do. The majority of Olympians and Paralympians have full-time jobs, so I'm one of many who have made the commitment to pursue my passion and career at the same time. Asking athletes how they do it is like asking a parent with young children, who works full time and also finds time to pursue their passions, "How do they do it?" We just do it.

If you think of a day as eight or 10 hours, then to fit everything in you need or might want to do could be a struggle. But realistically, if you get an average of seven hours of sleep a night, a full day is actually 17 hours long. Take away an average of ten hours for work and that leaves seven hours a day to fill, or almost 50 hours a week. That's a ton of time!

Also, there is busy and then there is productive. Time management, including scheduling, is probably the key to anyone's success who has a goal. My days are mapped out from the time I wake up to when I close my eyes. Sometimes things don't always go as planned, but it helps me keep focused on all the important aspects of my life, my goals, and what needs to be accomplished to make sure my time is well spent to reach those goals, whether it's career-focused, spending time with my family, or training to pursue my sport.

It's not for everyone, but for me planning, determination and being goal-orientated eliminates wasted time and energy and actually gives me the freedom to live my very best life.

My advice: make a list and don't procrastinate.

Clearly, you're a naturally competitive person, but to what do you credit your incredible and seemingly inexhaustible motivation? We only get one life. Determination, perseverance and discipline have allowed me to triumph over almost every obstacle on my journey to success, purely for the fact I do not not see limits, only challenges. I'm also a perfectionist, which some might say is a great attribute. But what that really means for me is that nothing is ever perfect. There is always a way to make something better, there is always something more to strive for.

What about Tokyo? What factors would make or break a decision to compete in 2020?

I haven't made a four-year commitment since Beijing. There are so many factors that play a role in a major decision like trying to go to the Olympics. I take it year by year now. Let's face it, I'm not getting any younger. It really is a family decision though and we constantly re-evaluate to see if it is working for us.

Are the life lessons and skills you've acquired during an incredible athletic career applicable and transferable to a career in politics?

Absolutely! Sport has taught me to never underestimate the power of the human spirit. I will always cherish the many opportunities that sport created for me—how it enabled me to see my abilities post injury, how it helped me regain confidence. My passion to compete has been my vehicle to success in all aspects of life. Let's face it, being a politician can be very challenging. There are many wins and losses during a political career. Some may like you and some may not. Sport builds resilience and confidence, whether you win or lose. I'll carry these traits with me throughout my careers.

How else has sport and competition had a positive impact in your life?

Friendship is the first thing that comes to mind. Sport builds community and my community spans worldwide. And for that I am so incredibly grateful.

The most rewarding impact I can easily say is how my sport has impacted my son's life. He has seen me at my most vulnerable, when life gets challenging, whether it's been after surgeries, dealing with chronic pain from my injury, or the struggles any one of us go through. But we don't let those things stop us from losing sight of our goals. We persevere and never give up.

Any advice for would-be Paralympians—or anyone considering a career in politics?

Surround yourself with people who love you and support you and never give up on your dreams or passion. It's inevitable that there will be setbacks during any journey, but it's how you respond to those setbacks that will help guide your way.

Speaking of setbacks, you've faced some challenges and criticism this year in your political career. Does your determination and success as an athlete help you work through rough patches as a politician? And how do you compartmentalize work from athletics?

As I mentioned, being a politician can be a tough job, particularly in a social ministry. I have faced some nasty criticism this year for policy changes we've made. At the same time, I've also received a lot of positive feedback. My ministry services about 100,000 people with disabilities and we've made significant policy changes since I have been the Minister. All of them are designed to help improve the lives of clients on disability assistance.

Having said that, my advocacy work goes beyond the clients my ministry serves. I am also responsible for Accessibility 2024, our vision to make BC the most progressive place for people with disabilities in Canada. There are about 400,000 British Columbians who live with a disability, and it's my role to advocate for a better British Columbia for all of them.

Anything else you would like to say or add? Wearing my political hat, there is, of course, always more to say! I'm sure you've heard the saying, "Never give a politician an open microphone." That aside, one of my true passions is seeing the possible in the impossible. No one is ever too young or too old to make a change or challenge themselves to live their very best life.

More than just numbers.



- CSIL bookkeeping services
- Fully computerized bookkeeping and payroll services for small to medium-sized businesses
- Personal and corporate tax preparation
- Provincial and federal fuel tax rebate
- Customized service to meet your needs
- Pick-up and delivery available

I'm Walter Gagen. Call me – I'm able!

(604) 597-5100 Toll Free (866) 277-2745 Email wgagen@telus.net Website www.gagen.ca

ask the SPIN DOCTOR

Michael from Vancouver Island writes, "Every fall and winter, I get reacquainted with my morbid fear of pneumonia—I think it's because a well-meaning doctor scared the bejesus

out of me during rehab. I'm a pretty low level paraplegic, so I'm wondering: is my fear warranted? And if it is, what can I do to minimize the risk?"



To answer this issue's question, we turned to Dr. Jeremy Road, Professor of Medicine at UBC and a Respirologist at Vancouver General Hospital and UBC.

Michael, the short answer to your question is, "Be afraid. Be very afraid." I don't want to panic readers of *The Spin*, but your fear is well-founded.

Pneumonia is an infection in one or both lungs caused by bacteria, fungi, or viruses. Pneumonia results in inflammation in your lung's air sacs, or alveoli. The alveoli fill with fluid or pus, making it difficult to breathe. Only about three percent of the general population will get pneumonia in any given year. However, pneumonia, when grouped along with other respiratory illnesses, is the leading cause of death in people with SCI.

One of the world's leading experts on pneumonia and its particular risk for people with SCI is my colleague Dr. Stephen Burns, who works just down the I5 as Director of the Spinal Cord Injury Service at Veterans Affairs Puget Sound Health Care System and professor in the Department of Rehabilitation Medicine at the University of Washington. "The average SCI person's risk of dying of pneumonia is 37 times higher than the general population," says Burns. This is a sobering statistic.

Some people believe that pneumonia is mainly a problem for people with quadriplegia. That's not the case. It's true that people with higher levels of injury have a compromised ability to inhale. But breathing is a two-step process, and expiration is a problem for those with all injury levels right down to T12. The bottom line is that this makes it harder to forcefully breathe out, cough, and bring up mucus from the lungs. Mucus pooling in the lungs is a perfect home for the bacteria that cause pneumonia.

So what can you do during the upcoming cold and flu season to minimize your risk?

 Get vaccinated for pneumonia. The Pneumovax vaccine has been demonstrated to be effective at preventing pneumococcal pneumonia which is a common and potentially lethal form of pneumonia. It's recommended that all people with SCI should receive it at least once, and every five years after if they are determined to be high risk. This vaccine has been in use long enough to be considered quite safe. Recently a new vaccine has become available to be used in addition to the Pneumovax: the Previnar vaccine can further boost the immune system to better prevent pneumococcal pneumonia.

- While you're at it, get your yearly influenza vaccine avoiding flu should be a top priority, as it can lead to and exacerbate pneumonia.
- Practice forceful breathing to help strengthen your chest muscles.
- Practice coughing. Strengthening the muscles necessary for a forceful cough will make it easier for you to bring up mucus in the lungs.
- If your cough is weak and you have trouble bringing up mucus, you may need an assisted cough, or quad coughing, which is a procedure that involves pressing down on the chest to force air and secretions out.
- People with a really weak cough due to a high level injury may need chest physiotherapy and/or postural drainage, and, in the event of mucus buildup, suctioning may be required. The strength of your cough can be measured by your physician as your peak cough flow rate. To further assist coughing, the lungs can be inflated with an Ambu bag (or bag valve mask) which, when followed with chest compression, can be very effective at clearing secretions. As another option, there are mechanical devices termed insufflator/exsufflator machines which can be very effective at clearing secretions.
- If you smoke, quit. Not on New Year's Day, not next week, not tomorrow. Right now.
- Focus on your posture. Sit up straight, and move around as much as possible—this will prevent mucus buildup.
- Be careful while eating to avoid aspiration of material from the back of the mouth into the lung—this is a common cause of pneumonia.
- Eat a healthy diet to help keep your immune system strong, and to stop you from gaining or losing weight, which can lead to lung problems.
- Drink plenty of fluids, preferably water—this helps prevent the mucus in your lungs from getting thick, which makes it more difficult to cough up.

Finally, and most importantly, get to know the symptoms of pneumonia—and contact your doctor immediately if you think you've got it. Even a few hours can make a difference. Symptoms include chest pain while breathing or coughing, elevated urge to cough, fatigue, sweating and chills, vomiting or diarrhoea, and shortness of breath. If you exhibit any of these signs, get in to see your doctor stat.

Redine

A new "wearable" developed at the University of Alberta may soon be available to help you save your shoulders from overuse.

hat's the most complex joint in the human body? Judging from a quick browse on Google, it appears to be a toss up between the knee and the shoulder. But for many of our readers, the argument is moot—most can't make much use of their knees, while their shoulders are clearly critical when it comes to mobility and independence.

Shoulder injuries are a possibility for everyone, but in particular people who use manual wheelchairs should view their shoulders as vulnerable. Overuse and sometimes outright abuse—from wheeling and transferring can lead to a major and painful malfunction in the shoulders. These are often extremely difficult to fix, even with surgery. The result for many who have spent a lifetime wheeling is often irreparable damage which, in turn, leads to a significant loss of independence in their later years.

So when it comes to your shoulders, "feeling the burn" is the last thing you want when you're wheeling. But it's not that simple—often, people who use manual wheelchairs don't even realize when they're subjecting their shoulders to excessive strain, wear and tear.

That's where the Redliner could make a difference. The Redliner is a device that's

attached to a wheel of your chair. Sensors within the device record and make sense of many aspects of how you're pushing your chair—they measure the wheel rotations and estimate the amount of force put into each stroke. The feedback is relayed to users' smartphones so they can see how many strokes they're using, the length of those strokes, the resistance their chair is facing, how far they've travelled, and the number of 'redliner events' where they've overexerted while pushing.

The Redliner is the brainchild of Dr. Martin Ferguson-Pell, professor of Rehabilitation Medicine at the University of Alberta. He first conceived the idea when he was working in his native United Kingdom.

"When I was in the UK we did a study which confirmed that a very high proportion of wheelchair users have clinical evidence of upper extremity overuse injuries," says Ferguson-Pell. "Based on a rule of thumb used widely in physiology, we undertook tests to see under what circumstances wheelchair users exceed 80 percent of their maximum capacity to push their wheelchair. This is rather like over-revving your car engine or 'redlining'. Sure enough, our group of people with SCI, who were experienced wheelchair users, redlined in every circumstance, such as pushing up ramps, over thick pile carpets and so on."

He explains that this research relied on measurements taken with a Smartwheel—a sophisticated instrumented wheelchair wheel that measures push rim forces and other parameters.

"The Redliner concept grew out of this research," says Ferguson-Pell. "We tried many different approaches to measure push rim forces more simply, with the goal of providing a simple-to-use device for wheelchair users to purchase so that they could monitor when they redline and help them develop strategies to reduce the circumstances that lead to redlining. Eventually, we came up with a 'wheelchair wearable' that fits on the wheel and gives us good measures of push forces when we compare it to our benchmark, the Smartwheel."

Naturally, here at *The Spin*, we wanted to know exactly how the device measures and calculates these forces.

"We don't want to reveal too much more technical detail until the intellectual property is properly protected," says Ferguson-Pell. "Suffice to say that the sensors are low-cost, simple and robust, and the algorithms we have developed to make these measurements are a key to the way we make the measurements." Users will be able to view an activity log on their smartphones. Ferguson-Pell adds that developing a way to create a real-time alert for redline events is a priority.

"We have conceived of a simple wrist band, or a link to an existing wearable such as an Apple Watch, Garmin Connect or similar devices. Every time you exceed the redline threshold, the wrist-worn device could vibrate to provide feedback. We have not built this yet as we want to undertake some focus groups with users to get some guidance on how best to do this so that it's not annoying."

When can you expect to be able to buy a Redliner and start using it? It sometimes takes years and even decades to move technology like this to commercialization, but that won't be the case with Redliner. The technology has inspired Calgary entrepreneur David Evans to form Redliner Inc. Thanks to a licensing agreement negotiated by the U of A's commercialization incubator TEC Edmonton, the new company now has the exclusive rights to develop, manufacture and sell the device worldwide—something it is already in the process of doing.

Currently, a prototype is being refined in preparation to build a commercial version, which could be on the shelves in as little as a year, and would cost about \$200. Additionally, Evans plans on exploring the possibility of having major wheelchair manufacturers install Redliner as original equipment.

While the device's primary use will be to help people maintain shoulder health, there are some other potential benefits.



For example, data from every Redliner will be sent anonymously to a central repository that will help researchers better understand the root causes of shoulder pain and injury. And because all this data will be geographically linked, it would become possible to create open-access information within Google Maps that would allow wheelchair users to plan routes that don't require excessive redline exertion.

Other possibilities could include using Redliner data to help justify a request for a power wheelchair, or for a better ramp or smoother surface at a public facility or workplace.

For more information, visit www.redliner.ca or www.proactivehs.ca.



Last Chance Surgery

For two decades, Denver neurosurgeon Dr. Scott Falci has been refining a life-changing procedure to offer relief to people with the most extreme forms of SCI neuropathic pain.

uicidal pain. That's the grisly name given to the most extreme forms of SCI neuropathic pain—the hallmark of which is stabbing, burning, electrical jolts and shocks in areas of the body that should have no sensation because of paralysis. It's believed that roughly ten percent of all people with SCI neuropathic pain experience suicidal pain—pain that is so intense, unrelenting and unstoppable even when treated with the most powerful of drugs that they contemplate suicide.

The DREZ procedure, or DREZ lesioning, is one of the few options (and sometimes the only option) remaining for people with this type of pain. DREZ is an acronym for dorsal root end zone—an area or pathway of the spinal cord where sensory nerve fibres join the central nervous system. In simple terms, DREZ surgery destroys the area where damaged nerves join the central nervous system, with the goal of interrupting the passage of abnormal, inappropriate pain messages from nerves to the brain. It involves exposing the spinal cord, identifying the hyperactive, pain-causing sensory nerves to target, and then destroying those nerves through ablation—in essence, burning them with a fine electrode using a technique called thermocoagulation.

DREZ lesioning for neuropathic pain from SCI and other causes was developed in the 1970s at Duke University by Dr. Blaine Nashold. Early attempts with the procedure produced enough good results that it got the attention of other neurosurgeons. Among them were Dr. Robert Edgar and Dr. Scott Falci, of Denver Colorado's Craig Hospital—and it's generally agreed that no one else has been more instrumental in refining the technique and producing better outcomes.

Edgar, who has since retired, focused on being more selective with the surgery. Up to this point, the procedure was done using a kind of "blanket" approach, with many useful neurons often being destroyed alongside the troublemakers. This had the effect of the patient losing some useful function and sensation in the process of (hopefully) having their pain eliminated. Edgar began using a neurometer to measure electrical activity in target nerves and discovered he could isolate and then treat the hyperactive, pain-causing areas. His findings led to a refined procedure and significantly improved outcomes.

In the early 90s, Falci trained with Edgar, and then began to more extensively map electrical activity to determine exactly where the pain was being generated in the cord of each patient. Today, he's recognized around the globe as being the foremost expert with the procedure.

Over the years, Falci continued to make more improvements to the procedure. "We've further refined our signal processing of 'pain-producing' versus non pain-producing (areas of the) spinal cord," he explains. Another game changer is Falci's discovery that hyperactive, pain-causing neurons are located not just at the level of injury, but also below the injury. He explains that sensory nerves below the injury can sometimes detour around the injury and send pain signals to the brain. Targeting these neurons below the injury, as well as the neurons at the level of the injury, has improved outcomes as well.

The surgery is complex and considered last resort—candidates are desperate for relief, have ruled out all other options for relief, and are made aware of the high risk involved for the surgery. These include outright failure to achieve pain relief, as well as loss of function and sensation.

"We perform about 12 to 15 of these surgeries per year," says Falci. "We only perform on paraplegics and, in general ASIA A (or complete) paraplegics, as they will lose sensory in all regions where DREZ microcoagulation is performed, and they also risk preserved motor function 15 percent of the time."

"This surgery is by far our most satisfying, fulfilling, and exhilarating when it works about 85 percent of the time. This surgery is by far our most frustrating, depressing, and devastating when it doesn't work—about 15 percent of the time."

- Dr. Scott Falci

The surgery begins with peeling back skin and muscle to reveal the patient's spinal column, and then removing some bone to access the spinal cord. Based on pre-surgery assessments, Falci and his team then seek out individual DREZ, each the size of a small button. They then probe the individual nerves within each DREZ, searching for the hyperactive culprits which he refers to as "hot spots". Using the thermocoagulation electrode, each of these hot spots are killed with heat.

Often, hundreds of these hot spots are painstakingly identified and treated—lit-

tle wonder that the procedure can take up to 12 hours.

"This surgery is by far our most satisfying, fulfilling, and exhilarating when it works—about 85 percent of the time," says Falci. "This surgery is by far our most frustrating, depressing, and devastating when it doesn't work—about 15 percent of the time. We were the patient's last resort."

For many of those who fall into the success category, the results are lifechanging. One of those is Jon Forbes, Deputy Treasurer for the State of Colorado. A paraplegic, Forbes was desperate and suicidal prior to having his surgery performed by Falci in 2014.

"I'm not 100 percent without pain," he told *Voice of America* in a recent interview, "but I can live, and I want to live, which is...thank God for saving my life, Dr. Falci."

Falci says he has never done the procedure with a Canadian patient. And unfortunately, he isn't aware of any Canadian neurosurgeons performing this surgery.

"I suspect," he says, "that there are many who could benefit from the surgery who don't know about us."

Sex Ed...with an SCI Twist

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

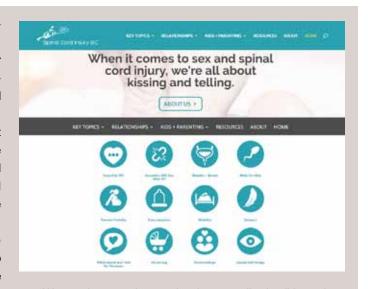
That's the fitting first line of text you'll read when you point your browser to scisexualhealth.ca, a powerful and comprehensive sexual health website that's the result of a team effort from SCI BC and Vancouver Coastal Health's Sexual Health Rehabilitation Service.

The Sexual Health Rehabilitation Service is unique in Canada. It operates at two sites in Vancouver—the Blusson Spinal Cord Centre and the GF Strong Rehabilitation Centre. Staff consists of five sexual health clinicians and a sexual medicine doctor, all trained in sexual health, disability and rehabilitation. The service strives to provide clients and their families with sexual health rehabilitation through medical intervention, education, and emotional support, all with the utmost respect and privacy, and a non-judgemental approach. It also seeks to educate other healthcare providers about the importance of sexuality and sexual health for people with SCI and other physical disabilities, and leads in sexuality and disability research.

In an ideal world, every British Columbian living with SCI would have the means and confidence to freely access the expertise of the Sexual Health Rehabilitation Service. But geographic distances make that difficult for some, as do a lack of sexual confidence and a desire for privacy. These are some of the reasons that we've teamed up with the Sexual Health Rehabilitation Service to create this new online resource, which allows anyone to freely and anonymously explore the facts—and debunk the many myths—of sexuality and fertility after SCI.

The site includes a vast amount of information and peer experiences in virtually every aspect of sexuality. Sex after SCI, bladder and bowel considerations, male and female fertility, contraception, mobility, information for partners of people with SCI, parenting, relationships, and sexual self image—these topics and others are covered in detail on the site.

"The dark days of people with SCI being thought of as asexual are long behind us," says Chris McBride, SCI BC Executive Direc-



tor. "We now know and recognize that sexuality, in all its various and wonderful forms, is vitally important for every human being's wellbeing, regardless of ability or disability. We couldn't be more pleased to team up with the Sexual Health Rehabilitation Service to offer this online resource that will help our readers and Peers maximize their sexuality."

"If you've got questions about any aspect of sexuality, relationships and parenting as a person with an SCI or other physical disability, this website will give you an incredible number of comprehensive answers without requiring you to leave the comfort of your own home," says Dr. Stacy Elliott, Sexual Medicine Physician with the Sexual Health Rehabilitation Service.

Of course, we recognize that the website, no matter how comprehensive and well-developed, can't satisfy all the sexual health information and support needs of our readers and Peers. We urge you not to hesitate contacting the Sexual Health Rehabilitation Service and seeking a referral when you're ready for individualized assistance, support and education. Simply click on the "About" tab at www.scisexualhealth.ca.

Participate in Research

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

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

Evaluating pelvic floor muscles with light technology

Overview: The purpose of this study, led by Dr. Lynn Stothers, is to measure the strength of pelvic floor muscles with light technology and to assess how strengthening pelvic floor muscles with exercise impacts bladder issues.

What to expect: The study involves two in-clinic pelvic floor muscle assessments at the Blusson Spinal Cord Centre. These assessments will include a review of any bladder-related issues and use of a vaginal tool to measure pelvic floor muscle strength. The use of ultrasound will also be used to observe any changes in the pelvic floor and bladder. In between these two in-clinic assessments, you will need to complete an eight-week exercise program at home. You will also be asked to complete a bladder diary and a short questionnaire.

Who can participate: You can participate in this study if you are a woman over 19 years of age and have symptoms of urinary incontinence and a history of neurogenic injury or disease for at least six months.

Why participate: Participation in this study will help researchers develop a better understanding of how pelvic floor muscle function is affected by neurologic injuries and disease. It will also help determine if pelvic floor exercises improve urinary incontinence related to neurogenic bladder complications. Findings from this study will be used to improve current therapies for management of urinary incontinence.

Location: The study will take place at ICORD (Blusson Spinal Cord Centre, 818 West 10th Avenue, Vancouver). Free parking available for research participants with a valid SPARC pass.

For more information or to participate: Please contact the study coordinator, Emily Deegan, by email (e.deegan@alumni.ubc.ca) or phone 604.675.8881.

The extent to which caregivers enhance the wheelchair skills of power wheelchair users

Overview: The aim of this study, led by Dr. William Miller, is to better understand how powered wheelchair users and caregivers interact to carry out wheelchair skills safely and confidently. An improved understanding of this topic will allow us to better develop educational experiences for wheelchair users and their caregivers functioning together.

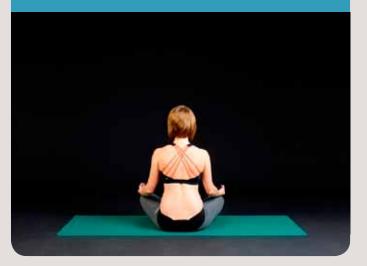
What to expect: This study involves a one-time session lasting approximately 90 minutes. The researchers will collect some background information from you (such as your age, gender, and length of wheelchair use). You will then be asked about your ability to perform specific wheelchair skills (alone, if you are the wheelchair user, or with caregiver assistance), your confidence in performing each skill and how often you perform that skill in your everyday life. If the skill is one that you have indicated that you are capable of performing, you will be asked to demonstrate how you perform the skill. The caregiver will be asked to complete a questionnaire intended to learn about the stressors and well-being of the caregiver.

Who can participate: This study is open to unpaid caregivers (e.g. a family member or friend) who spend at least two hours per week with the powered wheelchair user OR individuals who use their own powered wheelchair for at least six hours per week, are 18 years of age or older, live within 50km of Vancouver, and can read, write, and speak English.

Why participate: A stipend will be provided to you for your involvement.

Location: Rehab Research Lab at GF Strong Rehab Centre

For more information or to participate: Contact Kate Keetch via email (kate.keetch@ubc.ca) or phone 604.714.4108.





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

Do you need technology to overcome a barrier at work? You need Technology@Work



technology



training







funding





www.bctechatwork.ca

Supporting your independence.

At Regency Medical Supplies, we're proud to have supported the independence of SCI BC members and people with spinal cord injuries for more than 50 years. Today, we're still your specialist for daily care needs and mobility equipment. If you're in the Lower Mainland, please stop by our 6,000 square foot showroom to learn more about

the products we carry. If you're anywhere else in BC, shop online at www.regencymed.com or call us toll-free at 1-800-663-1012 to speak with a customer service representative.

- Coloplast/Mentor Condoms & Catheters
- Tyco/Kendall Catheters & Condoms
- Med-RX Intermittent Catheters
- Bard Urology Products
- Urocare Condoms & Leg Bags
- Rusch Urology Products
- Hollister Condoms & Leg Bags
- Golden Drain Condoms





4437 Canada Way, Burnaby BC V5G 1J3 Within BC's Lower Mainland: 604-434-1383 Toll free within Canada: 1-800-663-1012

www.regencymed.com

or common-law partner of a qualifying individual can also claim the credit.

The new HATC is a non-refundable credit that provides federal

tax relief of 15 percent on up to \$10,000 of eligible expenditures

per calendar year, per qualifying individual. For example, if you

Qualifying individuals are either seniors 65 years of age or older,

or anyone who is eligible for the Disability Tax Credit. The spouse

In 2016, a new tax credit was introduced for Canadians with

disabilities and seniors who renovate their homes to improve

accessibility. The Home Accessibility Tax Credit (HATC) was

34 THE SPIN WINTER 2016

introduced by the Conservative government in April 2015, but only came into effect at the beginning of 2016. In other words, it's available for accessibility renovations performed this year. The interesting thing is that here in BC, qualifying renovations may be eligible for triple-dipping-not only can they be used to claim the HATC as a standalone credit, they may qualify as a standard medical expense, and a tax credit under BC's Home Renovation Tax Credit for Seniors and Persons with Disabilities.

services that don't qualify.

and search for HATC.

tions made to an eligible home in Canada that allows a person to be more mobile, safe, and functional. An eligible dwelling is typically a principal residence, meaning a house, cottage or condominium unit that is owned, jointly or otherwise, by the qualifying individual and/or a spouse or partner, and ordinarily occupied. But it's still possible to claim the HATC even if you don't own your own principal residence. For example, if you're a qualifying individual who lives with a relative, the relative's home will be considered eligible.

The HATC may be claimed on gualifying renovations or altera-

Qualifying improvements must be of an "enduring nature" and be considered "integral" to the eligible dwelling. Wheelchair ramps, wheel-in showers and grab bars are a few examples. Costs paid for both labour and goods-building materials and fixtures-are eligible. However, furniture, tools, building permits, finance costs, regular maintenance, and appliances are examples of goods or

Obviously, you'll need all of your receipts-your HATC claim

must be supported by valid documentation. For more information,

visit the Canada Revenue Agency's website (www.cra-arc.gc.ca)

"Mia" Siochi, the senior materials scientist at NASA's Langley Research Centre who has been spearheading this work, pressure sores are a viable candidate to explore. "We (have been) testing this material to determine if it can aid in wound healing for diabetics, where healing can be a

these can be useful. But, as with any ap-

plication, we are hesitant to speculate

beyond what we are able to test."

Officially, NASA hasn't stated that the technology has been tested specifically with pressure ulcers. But according to Dr. Emilie

nology has the potential to be a safer and more effective solution because it combines healing and wound protection into one single bandage. It adds that the technology has huge potential for battlefield wounds, patients who have undergone surgery, patients who may have suffered from serious wounds and injured astronauts in space.

into gauze. The remarkable thing about the gauze is that it generates small amounts of electricity by itself, which speeds up the healing process while simultaneously protecting against

controls the flow and weave of the PVDF

fibres and allows them to be incorporated

infection. The electricity is stimulated by the heat of the body and the pressure of

cell growth-in other words, no external power source is required.

Electrical stimulation has been clinically shown to speed wound recovery by stimulating cellular migration to a wound site. But up to this point, it's never been developed into a viable or broadly-used method for wound care, as it's been associated with complications such as infection. NASA says its tech-

Renovating for accessibility? Don't forget this new tax credit.

last word

Space Age Wound Care

ASA is best known for its accomplishments with space exploration. However, it's also been an incredible research incubator for some amazing technological breakthroughs over the years-the current state of GPS, digital photography and wireless communications can be largely attributed to NASA spinoff work.

Most recently, and quite by accident, NASA developed an "electroactive" gauze bandage that could someday be used to more efficiently and effectively heal pressure sores.

The breakthrough took place as NASA scientists were undertaking work to develop coatings for aircraft that reduce drag and improve efficiency.

At the core of the technology is a gauze made from a polymer known as polyvinylidene fluoride (PVDF). The gauze is woven using a process called electrospinning, where an electric charge is used to create super-thin strands of PVDF only

Dr. Mia Siochi

challenge," says Siochi. "If pressure sores have similar characteristics and they're external wounds essentially, then perhaps



nanometres in diameter. NASA developed its own electrospinning apparatus, which

Movement for LIFE.

- 5 Unique Machines -Predictable Patterned Daily Range of Motion Therapy for

Increased: Circulation Flexibility of Muscles and Tendons Lubrication of Joints Long Term Maintenance

> Decreased: Spasm and Swelling Stiffness and Atrophy

> > **EXN'FLEX** Passive/Active Therapeutic Exercise

> > > Ideal for Para & Quadripleçia Multiple Sclerosis Strokes

website: www.exnflex.com email: info@exnflex.com

EF-250

1 (888) 298-9922

30 Day money back guarantee

EF-300

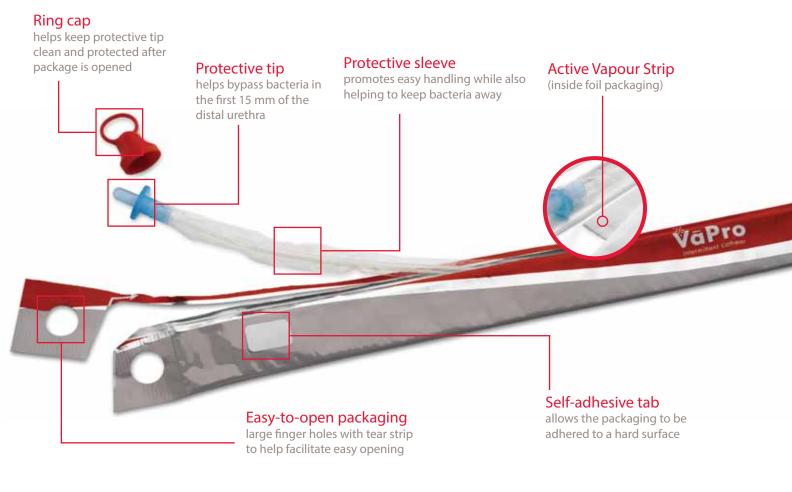
"I have been a T12-L1 paraplegic for nine years. I have now been using my EX N' FLEX for seven years and would not want to live without it. My pain has decreased, my bowel and bladder control has improved and my muscle spasms have decreased significantly. I have increased muscle tone, and feel better in general. This is a quality product with great customer service. I could not recommend it more."

Richi Sahey, Montreal

NEW! Hollister Tip and Sleeve Catheters



Simple. Clean. Independence.



Simple insertion and removal

- Ready to use with pure catheter hydration technology
- Designed to be evenly lubricated for easier insertion
- Helps provide ease of insertion and withdrawal with smooth eyelets

Touch Free

- The catheter can be gripped anywhere along the protective sleeve
- The protective tip helps shield the sterile catheter, during insertion and removal, from bacteria located within the first 15 mm of the distal urethra



For information or trial samples, contact Chair Stuff Medical Supplies at: 1-604-876-4133.

