

the spin

SPINAL CORD INJURY BC

FALL 2016

Fashion Forward

Vancouver fashion designer Chloë Angus reveals her tips on style, the ups and downs of self-employment, and why her SCI made her better at her job





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Cover Photo: Fashion designer Chloë Angus at work in her Vancouver studio. (Maya Pankalla photo)



Sadly, the Paralympics have arrived

Perhaps the best indicator of a sport's mainstream success is when its athletes risk their health through performance enhancement cheating. By this measure, the Paralympics have arrived.

In August, the International Paralympic Committee (IPC) took the courageous, unprecedented, and morally right decision to suspend the Russian Paralympic Committee. As you'll already have witnessed by the time you read this, the entire Russian Paralympic team wasn't allowed to compete at the 2016 Paralympics.

"The Russian government has catastrophically failed its para-athletes," said IPC President Sir Philip Craven in his announcement of this decision. "Their 'medals over morals' mentality disgusts me. The complete corruption of the anti-doping system is contrary to the rules and strikes at the very heart of the spirit of Paralympic sport...It shows a blatant disregard for the health and wellbeing of athletes and, quite simply, has no place in Paralympic sport."

Cheating at the Paralympics is, of course, not limited to Russia. Elite athletes have and will always look for ways to gain a competitive advantage over their rivals. But when financial incentives for winning become big enough, the temptation to seek illegal ways of gaining a competitive advantage becomes great enough for some athletes to cheat. Or, in the case of Russia, for government sport programs to systemically foster cheating.

"Traditional" methods of illegal performance enhancement (like performance enhancing drugs), it would seem, have become more prominent amongst parasport athletes, but there are some unique ways athletes with disabilities risk their health in pursuit of illicit victory. Boosting, which involves harming oneself to stimulate increased blood pressure (in other words, autonomic dysreflexia or AD), rose to the fore at the 2012 Paralympics. Athletes with SCI have been known to boost by sitting on a sharp object, intentionally breaking a toe, or binding their testicles. AD, as we all know, is dangerous, so it's not surprising that boosting is illegal. To help prevent this type of cheating, ICORD researcher and physiatrist Dr. Andrei Krassioukov has advocated for the inclusion of physiological assessments in the classification of athletes. So far, the IPC has resisted his calls.

Perhaps this is because classification of parasport athletes is already a complex system and one that has been prone to abuse. It aims to level the playing field so that people with different levels of impairment can compete relatively equally. However, some athletes get away with inaccurate classification, allowing them to compete against athletes with higher levels of impairment than themselves.

It's unfortunate that the success of the Paralympics has increased the motivation for parasport athletes to cheat. Not only does cheating undermine the integrity of the sport, it also chips away at the positive cultural and attitudinal shifts regarding people with disabilities the Paralympics has helped foster.

The Paralympics are important for many reasons, including as a motivator for people with disabilities to engage in sport and physical activity. Canadians need all the motivation they can get: 85% of us don't get enough exercise. For people with disabilities, the challenge of getting enough exercise and the health consequences of lack of exercise are even greater. We need role models to inspire us to get active and our Paralympians can be great ones, but only if they play fair.

As I did with the Olympics, I will have watched the Rio Paralympics wondering who is competing fairly. But I will also have do so with greater confidence that the IPC has taken the issue of systemic cheating more seriously than their Olympic counterparts. I will have also watched with great enthusiasm and national pride—I love my country and the spectacle of human achievement. No doubt the Games will have inspired me to get off my butt and be a little more active.



— Chris McBride, PhD, Executive Director, SCI BC



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.

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Advertising rates and a publishing calendar for *The Spin* are available online at www.sci-bc.ca. You can also contact Shelley Milstein at smilstein@sci-bc.ca or 604.326.1222.

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Publications Mail Agreement #: 40684573

ISSN #: 1922-9445

Return undeliverable Canadian addresses to:

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

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

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ROMA WHEELCHAIR POWER PACK

The wheelchair Power Pack, developed by Britain's Roma Medical, provides a portable boost for anyone who relies on a friend to push their chair. The Power Pack attaches to most manual wheelchairs in a few minutes. Once fitted, your pusher simply walks behind with a thumb on the control lever to adjust speed. The Power Pack does the rest, with its electric motor delivering the power to a set of dual drive wheels. It's powered by a rechargeable battery, and strong enough to climb steep hills. With speeds up to seven km/h and a range of up to 16 kilometres, it has more than enough capacity for most days out. The unit dismantles easily for transportation and storage, and also disengages quickly for normal wheelchair function. It's suitable for users up to 136 kilograms. Learn more at www.romamedical.co.uk.



GENNY WHEELCHAIR

Genny is the brainchild of Paulo Badano, an Italian businessman and paraplegic who found traditional wheelchairs too restricting and bland. Genny, which recently became available in Canada, uses Segway gyroscope technology to stay balanced on two wheels. Users require some core strength, as the chair is moved by shifting the torso—forward to advance, backward to slow down and brake. A handlebar is used to turn or spin in place (it's extremely manoeuvrable), but when not turning, the user can operate the chair hands-free. Genny has a range of 25 kilometres and a top speed of 12 km/h. It has parking feet to stabilize it when stationary, and a sensor under the seat ensures the device remains static unless a passenger is onboard. It dismantles and folds into a compact form, allowing it to fit into the back of a hatchback. Here in BC, the Genny is sold by Active Healthcare Solutions—visit www.activehcs.ca.

Innovations

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

FLEXIMUG

The Fleximug is a hands-free drinking container that's intended to make it easier for wheelchair users to stay hydrated. It has a stainless steel finish, a 20-ounce capacity, and a highly-adjustable flexible straw that employs a patented air vent that makes it easier for those with limited lung function to draw liquids into their mouths. The straw, which comes in 24, 28, 32 and 36-inch versions, locks securely into the mug, and it stays in whatever position or configuration the user bends it into. The Fleximug is dishwasher safe and comes with a cleaning brush. There's also an optional clamp-on cupholder specifically designed for the Fleximug. See more at www.fleximug.com.



TETRAGEAR

Vancouver-based TetraGear, a social venture spin-off of the Tetra Society of North America, is now selling its flagship TetraGear LED safety lights for people who use wheelchairs—or anyone else on wheels, including cyclists and parents with kids in strollers. The lights are designed to make people on wheels highly visible at night. They're weatherproof, can be seen from 360 degrees, and can be adjusted to six pre-set flashing modes in multiple colours. TetraGear lights were invented in 2008, when Eric Molendyk, a Tetra employee, was hit by a car when he was crossing the street in his wheelchair, despite the fact that he was crossing legally and wearing reflective clothing. After his recovery, Molendyk worked with co-founder Radu Postole, a Tetra



volunteer, to engineer the original prototype. Since then, the pair have refined some 60 prototypes, and set out to release them to the public. A recent Kickstarter campaign raised more than \$70,000. For more information, visit www.tetragear.com.

Room for Debate

■ opinion

Should comedians be allowed to mock people with disabilities?

Recently, Quebec comedian Mike Ward was fined for mocking a young singer, Jeremy Gabriel, who became well known when he was flown to the Vatican to sing for the Pope. Gabriel, who has craniofacial deformities as a result of Treacher Collins syndrome, was awarded \$35,000 by the Quebec Human Rights Tribunal. What's your opinion? Should comedians be punished for making fun of people with disabilities during performances? Or should people with disabilities have thicker skin, and should comedians have creative license to mock us, just as they do everyone else?



In my opinion, it's a good thing for comedians to poke fun at people with disabilities for a number of reasons.

Comedians are known for pushing the envelope with their humour. Many of their jokes are mean or self-deprecating—that's how they get laughs. I'm sure most comedians occasionally offend someone at some point. While there is a grey area around what's covered by freedom of speech and what crosses the line, I think it's excessive to take a comedian to court over a joke like the one in the Mike Ward vs. Jeremy Gabriel case. Comedians often make jokes about people in the public eye. Imagine if there was a human rights lawsuit every time a comedian joked about Kim Kardashian.

Humour is also how many of us relate to each other. Having a sense of humour about one's disability can help break down barriers. It helps when coping with angry or sad feelings; it helps break the ice when meeting someone new; it helps create bonds with other people with disabilities. I'm comfortable joking about my disability and hope that comedians would be comfortable acknowledging it too. By saying that people with disabilities are off-limits for comedians, I feel it's saying that we're different or fragile. I think the Ward vs. Gabriel case could create a situation where comedians actually fear joking about people with disabilities, setting us apart even further.

Ward joked that he thought Gabriel's trip to sing for the Pope must have been part of the Make A Wish Foundation and that he was surprised to find out he was "just ugly." Ward brings up an interesting point with this (possibly unintentionally). Gabriel may be a talented singer but would he have had that opportunity if he weren't disabled? I'm not sure, maybe he would have.

In my opinion, giving people with disabilities special treatment is more damaging to the disabled community than a joke. It's ironic to me that the joke at the crux of this case acknowledges this exact sentiment and I think it's possibly less damaging than the act of flying Gabriel to see the Pope in the first place. Ward's joke basically questions what makes Gabriel so special.

— GABRIEL CHESMAN, Vancouver BC/Blaine WA



I think if people with disabilities use self-deprecating language and make fun of each other and everyone involved is cool with it, it's fine, because we're living the experience; we understand it.

When we talk like this, whether it's in fun or there's a serious connotation, we all know what we're talking about. But someone who's up on a stage—someone, who hasn't a clue about my life, who can walk on his two legs—doesn't really have the right to throw those words or jokes around because he isn't living in that space. I would never joke about someone who has some other disability or issue. I don't have that experience; I haven't earned the right to laugh about it or make fun.

I get that most comedians are just trying to create funny material and reach for the edge, but they can often be coming from a place of ignorance. If they get a laugh out of people, great; if a joke flops, they move on. But I've done a lot of public speaking and there's one thing that was always drilled into me: be aware of whatever you say, because people are listening to you. When you're on stage, you affect people. If you're using inappropriate words or poking fun in an audience situation, you're sort of giving people the right to join in. It's kind of like saying, "If I'm doing it, it's okay for you to do it, too."

Besides annoying a potentially large group of people, this sort of comedy desensitizes the people who we actually want to sensitize. I don't think we should all go around being super sensitive, walking on eggshells. I just think we should be aware. And when someone starts to make fun of that kind of thing, it takes all the awareness out of it. With comedians, as with public speakers, it's one-sided. If they're saying something, people are going to walk away and go, 'Oh, that was funny!' and not realize that maybe it was also rude or wrong. It's no wonder that Jeremy Gabriel, the butt of comedian Mike Ward's jokes about his disfigurement, was later harassed by his classmates. It's one thing to mock people with disabilities—most of us can handle it, and even give it back to you. But to single out a boy—a child!—and pick on him in front of hundreds of people? There's no way that's cool.

— MARIKA VAN DOMMELEN, Vancouver BC

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 disability as a comedy act, as well as a variety of other contentious topics.



Holiday shopping...check.

It's hard to believe—the holiday season is just around the corner. But there's no need to fret! SCI BC will be holding its 2nd annual Holiday Season Online Auction at the beginning of December. Once again, there will be a great range of gifts to be had no matter where you live in the province. Take care of your holiday shopping and support SCI BC's great services! Browse and place your bids at 32auctions.com/giftsforgood.



Rewind and unwind.

SCI BC's AGM is more than a boring meeting. It's a time to celebrate another great year with peers and supporters. This year's Great Rewind party and AGM takes place from 6 to 9 PM on October 27 at the Blusson Spinal Cord Centre. Join us for great food and refreshments, interesting displays and presentations, and fun with friends. Visit www.sci.bc to RSVP, or contact Maureen at 604.326.1225 or mbrownlee@sci-bc.ca.



Hit the ice.

Join the good folks from Sportability for a fun day on the ice! The 2016 Sledge Hockey Jamboree, open to all ages and skill levels, will include a round robin tournament and fun skills competitions. Teams will be created once all participants have arrived. It all happens on October 15 at the Surrey Sport and Leisure Complex. Cost is \$20 per player. To register or find out more details, visit www.sportabilitybc.ca/2016shj.

ACCESSIBLE BC: Access BC's North Country

SCI BC's innovative partnerships with corporate Canada, the Province of BC, regional and local governments, Crown corporations, and key non-profit organizations are enhancing accessibility in our province's northern recreational areas—and making information about those spaces easy to obtain for tourists with disabilities. One of those places is the Great-West Life Mobility Nature Trail at Dougherty Creek, just south of Prince George. The trail was recently expanded to 1.5 kilometres, thanks to leadership from SCI BC and the Tabor Mountain Recreation Society, and officially re-opened in July.

"The trails are a gentle slope, they're hard-packed, easy to wheel on, and the gazebos are easily accessible with lovely picnic tables that have extensions on them," explains Pat Harris, Project Manager and SCI BC's SCI Resource Centre Manager.

Moving forward, there are plans for a universally accessible campground in the area. "We've already had that engineered and designed, and putting everything together, we hope to start that early next year sometime—possibly even this fall," says Randy Ellenchuk, President of the Tabor Mountain Recreation Society.

Also in July, the Access North initiative was launched to gather and publicize information about the area's accessible destinations. With leadership from SCI BC, and with \$214,000 in provincial funding and another \$100,000 from the Northern Development Trust and other regional partners, 16 EI-eligible individuals are now in the process of



visiting over 200 Northern BC parks, trails and roadside heritage sites to catalogue their accessibility. The data collected during the 27-week "Access North" project will be used to develop an interactive website.

"This project is going to give participants work experience that will benefit their search for full-time careers while giving us a much better awareness of the accessibility of the northern parks," says Shirley Bond, Minister of Jobs, Tourism and Skills Training. "Thank you to SCI BC for their leadership and ensuring that improved accessibility is a key priority in outdoor recreational settings."



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Cannabis Revisited



PHOTO: JINNEY PHOTOGRAPHY

We suspected that we'd get some feedback from last issue's *Cultivating with Cory* feature, but we were surprised at just how much we received—and how positive it was.

While cannabis' neuropathic pain and spasm-relieving qualities have never been fully scientifically-validated specifically for SCI, they have for many other conditions such as diabetes, HIV and MS.

That, combined with growing anecdotal reports from peers, less stigma, and improving access, seems to have led to a surge in people with SCI using cannabis to improve their quality of life.

Based on the feedback we received from last issue, we thought we'd ask a couple of our peers to relate their experiences about using cannabis for pain and spasticity relief.

Once again, our thanks to chef and organic grower extraordinaire Cory Parsons (that's him in the photo at left) for sharing his extensive knowledge with his peers.

Kyle Gieni: No more hiding.

In 2003, when I was 20 years old, I was rendered a paraplegic with a T-4 complete injury after a mountain bike accident.

Before my injury, cannabis was always around when my friends would consume it daily. I always loved the smell of fresh weed, but up until my 21st birthday, I never even had a toke. I wasn't into drugs of any kind, not even alcohol.

After my SCI, I had pain in my back and spasms that would almost make me stand as my legs would get so tight. I was offered prescriptions for baclofen, gabapentin, and Percocet—none of which I wanted any part of, mostly because I didn't want to deal with the side effects of such harsh pharmaceuticals. I did not even want morphine when I was in the hospital, and when the nurses brought me my medications, I threw them away

or flushed them down the toilet.

A year post-injury, I heard that cannabis had healing qualities, so I figured, "What have I got to lose?" I had a couple of hits on the way to The Calgary Stampede and wow, what a show it was. The weed made me forget about the pain I was experiencing, relaxed my legs, and put me in a much happier place than I was prior to taking this medicine, which was only found on the streets at that time, and not the pharmacy.

I began medicating on a daily basis and would have to hide the fact that I was a "stoner" to those who were against illegal drugs, which was most of the people in Calgary. Oddly enough, I volunteered as a probation officer, and the officer that took me under his wing also smoked weed for his pain, which really opened my eyes.

I moved to the Lower Mainland in 2006 for many reasons, one being that I heard of the dispensaries that offered different strains of weed and different modalities to taking this medicine. I tried glycerine tinctures, coconut oil, and edibles like brownies, which helped me out a great deal and all of which I now make in the



comfort of my own home. I use a variety of strains such as Jack Herer (Sativa dominant) for the daytime in order to function without being sluggish, and any type of Kush (Indica dominant) for the night in order to calm my body down so I can relax and have a good night's sleep. I take my now doctor-prescribed medicine with a Volcano Vaporizer to reduce the smoke inhalation, since this basically cooks the weed at around 400 degrees Fahrenheit instead of burning a joint at over 1,000 degrees Fahrenheit.

When I'm away from home, I usually bring a vaporizer pen that looks like an e-cigarette and inhale weed or shatter (weed concentrate) to curb my pain and spasms. Sometimes I take honey oil in caplets to take a break from inhaling cannabis vapor. All these various strains and concentrates can easily be found at your local dispensary, Canna Clinic being my go-to place.

One piece of advice that I would give to those trying different modalities of marijuana is don't overdo it! I've had

friends eat too much of a weed brownie and they literally could not function for a couple of days.

One such instance of somebody taking too much was when my brother's girlfriend at the time called the police to my house after consuming a brownie—she wanted to go to the hospital in an ambulance because she was convinced the house was going to burn down from a lit candle.

Funny enough, she was charged \$420 for the ambulance ride.

Jocelyn Maffin: Measure carefully.

I read the article on cannabis in our last issue of *The Spin* the morning after one of those long, frustrating nights being kept up by spasticity (hard to sleep when it feels like someone's kicking you right in the arse, repeatedly), and that was enough to spur me into action.

Months before, I'd asked my family doctor about it, but she felt uncomfortable prescribing something she had no dosing guidelines for. She referred me to my psychiatrist, who essentially whispered to me, "I could prescribe Sativex tablets for you, but they don't work very well. Why don't you just check out a dispensary and give it a try?"

I should explain that I'm probably the squarest person you'll ever meet. I didn't try pot in high school, I don't smoke or drink, and I've never done drugs. Sanjay Gupta, the American neurosurgeon who moonlights as a CNN medical correspondent, was my main source of information about pot until the article in *The Spin* gave me enough confidence to actually enter a dispensary.

I don't know what I was worried about—it was basically like a low-key jewellery store staffed by hipsters. First surprise: they didn't need a doctor's note. Policies vary, but this one just wanted photo ID and a printout of my prescriptions for the past year to prove I was being treated for a condition they could dispense for. A quick trip to my local Shoppers Drug Mart pharmacy for the printout, and soon I had my own dispensary membership card.

Second big surprise: the lingo. I knew about THC and CBD, but "tincture" I'd never heard used outside of *Game of Thrones*. Apparently the part of the marijuana plant you smoke is the flower. Go figure. I definitely didn't want to smoke it; I wanted to be able to control the dose, given Cory's advice in the article. And I wanted to start small, so I focused on the non-smoking section. Another surprise—in Vancouver, dispensaries can't sell cannabis edibles like cookies or brownies. Instead, this shop had a bewildering array of oils, butters, tinctures (small bottles of mixed, flavoured cannabis oils), and capsules that you can add to food or drink, or swallow directly. After a long chat with the owner, I settled on a 15 mL cherry-flavoured tincture for

about \$12. The owner indicated that it would probably be at least two doses, maybe more. "One full tincture is too much for me, but I have a low tolerance for greening out," he told me. I nodded like I understood what that meant.

A few weeks ago, those familiar arse-kicking spasms showed themselves just before bed. I eyeballed about half the tincture bottle into a spoon, swallowed the sour, slightly funky-smelling oil, and then took the dog out for a walk. I noticed only a slight, strange sensation on my face—like a slight numbness or tingling. I felt relaxed and sleepy within 15 minutes, just in time to tuck into bed. I had the best sleep I've had in months, overslept my alarm, and woke up clear-headed. I declared it a success.

The second time, however—not so much. Last night I was sore and the spasms started up again, and so I swallowed the rest of the tincture about two hours before I normally go to sleep. Within ten minutes I was feeling really strange. My face was warm and numb, I felt really slow, and my mouth was so dry. I got up to take the dog out but was too tired to move, so I went to bed instead—not before eating an entire bowl of cereal. I lay in bed in front of the fan, feeling like I was already sleeping even though I could hear my husband in the background. My face felt numb, I kept thinking dopey thoughts about the dog, and I imagined a whole conversation with my husband (who told me later we did talk, but I sounded pretty out of it). I felt like I was observing my dopey, dreamy self, noting all of the odd effects and trying to drift myself off to sleep. I woke up a bit hungover next morning and vowed that a third of a tincture would probably be enough next time.

The moral of my story is shake well and measure your doses with an actual measuring device—eyeballing doesn't cut it. ■



**FIND****YOUR****MOJO**

ICORD researcher Dr. Hugh Anton is striving to understand the extent, prevalence and treatment options for SCI-related fatigue

Feeling fatigued? Wondering why your energy seems to have left you? Searching for something that will restore your vitality? Dr. Hugh Anton wants to help you.

Anton is a Clinical Professor in UBC's Division of Physical Medicine and Rehabilitation, Clinical Research Coordinator for the GF Strong Rehabilitation Centre, and a Principal Investigator at ICORD. One of the central focuses of his work is SCI-related fatigue—understanding how serious of a problem it is, how and when it occurs, and what can be done about it.

"Fatigue is a common problem in persons living with the late effects of SCI," says Anton. "It can negatively affect quality of life, independence, and participation in work and social activities. It's one of many secondary problems faced by persons with SCI that can greatly affect function and quality of life, but don't get the attention they deserve from researchers. I hope that increased awareness of fatigue within the SCI community and among health professionals caring for persons with SCI will improve our understanding and ability to manage this challenging problem."

Anton's interest in fatigue was piqued earlier in his career when he was perplexed by the case of a young woman who had done well during her inpatient rehabilitation, but

struggled after her discharge. "She came to my office several months later and reported she was having difficulty at work, not because of her SCI, but rather because of her fatigue," explains Anton. "I subsequently observed a similar problem in many other patients and that triggered my interest in the subject."

Some of the work Anton has completed in the field of fatigue includes a formal evaluation of the Fatigue Severity Scale (FSS), an important tool for clinicians attempting to diagnose and treat fatigue. Working with colleagues as part of the F2N2 group (F2N2 is short for Fatigue and Function of Neuromuscular and Neurological conditions), Anton has confirmed that fatigue is common in people with SCI and is often associated with pain. Another of his studies has linked higher levels of fatigue with medication—an important consideration for clinicians when assessing patients and prescribing new medications.

F2N2's most recent work, a study led by Anton and titled *The Course of Fatigue After SCI*, was recently published in the journal *Spinal Cord*. The objective was to determine the prevalence and course of fatigue following acute spinal cord injury (SCI) during rehabilitation and after discharge.

"We require better understanding of the causes of fatigue to help us provide the best evidence-based

recommendations for treatment to people suffering from fatigue,” he says. “Almost all the available research on fatigue has focused on chronic fatigue. There has been relatively little research on fatigue in the acute stage after SCI.”

The study identified 52 patients admitted to rehab with a new, traumatic SCI. The patients were then followed and assessed throughout rehab and after discharge into the community.

“That differs from prior studies in which fatigue was evaluated in people living in the community to obtain a one-time snapshot of their fatigue,” explains Anton. “The advantage of our study is that it allowed us to determine when fatigue occurred and how it changed over time.”

Using a variety of measurement scales including the one that he helped to evaluate, Anton and his colleagues discovered that approximately half of all people with SCI suffer from fatigue throughout rehab and into their life in the community. There was no relationship between fatigue and injury level or completeness.

“Our research showed that fatigue is common, even early after SCI,” says Anton. “We thought we had a good understanding of the medical and personal factors associated with fatigue when we designed our study. We were surprised that some of our ideas about fatigue we had going into the study were not confirmed. We were not able to identify any specific predictors of fatigue after discharge into the community. It does appear that people who had fatigue early were at increased risk

for fatigue later on. That is potentially useful for patients with SCI and their health care professionals because

it may allow them to better target interventions for the prevention and management of fatigue.”

He also says the study helped confirm that fatigue after SCI is a complex phenomenon—one that can have multiple causes. “For example, we know that pain is common in patients with SCI and there is a relationship between fatigue and pain. We also know that people with SCI are at increased risk for depression, and that there is an overlap between fatigue and symptoms of depression. Autonomic dysfunction and particular problems with cardiovascular function are well described in persons with SCI. It’s likely that a subset of persons with fatigue have autonomic dysfunction and, if that can be effectively treated, then their fatigue would get better. Sleep disorders are also common in persons with SCI and may contribute to fatigue. Finally, fatigue may arise from a mismatch between physical capacity and physical demands in day-to-day life. We know that persons with physical disabilities like SCI must expend greater amounts of energy to perform tasks of daily living.”

For these reasons, Anton says, the first component of treating fatigue is to identify medical factors that may be contributing and try to treat those—for example, as listed above, pain, depression, and sleep disorders, but also medical conditions such as hypothyroidism or anaemia.

“If no treatable cause of fatigue is identified, then the focus should be on identifying strategies to conserve energy and prioritizing energy for activities that are really important,” he says. “The analogy is that of an energy bank account. A person only has a limited amount of energy available in that account and one must therefore make careful choices about where best to spend it. In some cases, that may be work, family activities or recreational pursuits. Each individual, as

with their financial bank account, needs to make his or her own decisions about where to expend that limited energy.”

One potential research avenue for fatigue treatment that’s of interest to Anton is nutrition. “As a general rule, a healthy diet with adequate calories and protein, and a good balance of vitamins and minerals, is sensible for general health purposes and could, by optimizing general health, help reduce fatigue.”

However, he also believes that certain supplements added to an already healthy diet may prove to be an effective treatment for fatigue. In particular, Acetyl-L-Carnitine (ALCAR for short) is on Anton’s radar screen. ALCAR, which is made in the body but can also be consumed through food, is an amino acid the body uses to turn fat into energy. It’s believed that, as a supplement, it may improve the ability of certain tissues to produce energy.

Working with fellow ICORD investigator Dr. Andrea Townsend, Anton devised a small study of ALCAR as treatment for fatigue after SCI. “Our results were encouraging,” he says, “but the size of the study was such we could not reach definite conclusions. At this point, I would say there is evidence ALCAR may be effective, but we would need to do a much larger study to confirm that.”

Meanwhile, as he and his colleagues strive for a greater understanding of fatigue after SCI, Anton offers this advice for anyone struggling to reclaim their mojo.

“Fatigue is important when it starts to affect function and enjoyment of life,” he says. “As a first step, you should consult your family physician or a physiatrist to begin the process of identifying any potentially treatable medical causes of fatigue. If no medical cause is identified, then consultation with an occupational therapist regarding energy management strategies and techniques to reduce energy expenditure during daily life should be considered.” ■

“We were surprised that some of our ideas about fatigue we had going into the study were not confirmed.” – Dr. Hugh Anton

For more information on Dr. Anton and his work: www.icord.org/researchers/dr-hugh-anton





makeover maven

Only six years into her Mary Kay career, Independent Sales Director Kristen McBride has a devoted client base, her own fleet of consultants, the second highest sales in all of Canada, and the respect of her corporate colleagues.

There are a few things you immediately notice about Kristen McBride. She's bubbly as hell. Her determination is really contagious. And, yes, she just sold you that three-in-one facial cleanser you now have in your hand. (And she's totally right—you'll love it.)

McBride (no relation to SCI BC Executive Director Chris McBride) is an Independent Sales Director with Mary Kay. She's also an encyclopedia of dates and numbers. She started her job as an early childhood educator on July 2, 2003 when she was 20 years old. She had her car accident 25 days later, on July 27. When she was discharged from GF Strong in February of 2004, she made a gradual return to teaching. Then, in January of 2010, she changed her career course and sold her first Mary Kay product. By April 1, she was on track to earning her first Mary Kay car. She debuted as a full-time Mary Kay director, the lead of 24 sales consultants, on September 1, 2010. In doing so, she became the only Mary Kay director in Canada who uses a wheelchair.

These days, McBride puts in 20 to 30 hour work weeks and gets about eight hours of nightly sleep. She got engaged on her birthday and will be married next

August 5 which, to her delight, is the same day her and her fiancé Brandon, a heating and air conditioning contractor, exchanged their first messages on the dating app Tinder. (His friend thought the wheelchair warranted a left swipe—in Tinder-speak, a pass; he couldn't have cared less and swiped right.)

But this summer, when McBride found herself on stage at the annual Mary Kay Awards Night, it seemed there was only one number that mattered.

"I had this goal and so much support from so many people," says McBride of her 2016 push to achieve the highest personal Mary Kay sales in Canada. "I felt like if I wasn't number one that I would let those people down. I thought I had to be number one to do what I wanted to do—to inspire and break belief barriers."

In the end, McBride was just \$200 shy. The Mary Kay tiara went to someone else.

"It really humbled me. I felt like I needed to be on that throne, to be in that position to inspire. This showed me that I didn't have to. I had ladies coming up saying, 'Can I take a picture of you in your wheelchair so I can show my customer, or friend, or family member that she can do it, because she needs to see that you're up there in your director's suit?' It's not just about what someone in a wheelchair

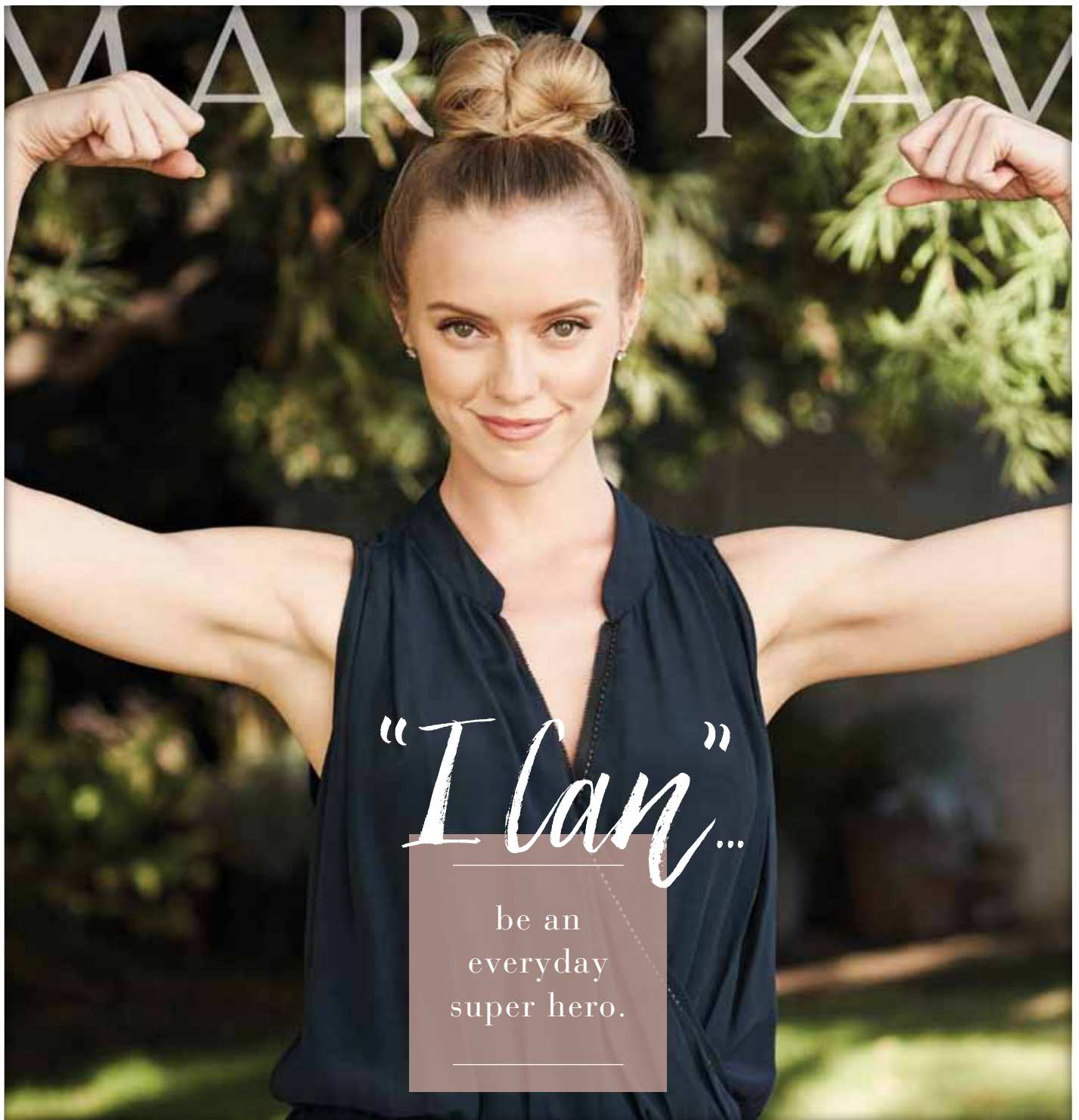
can do, but what *everyone* can do."

And yet, McBride's Mary Kay journey is intrinsically linked with her injury. Before GF Strong, she had never heard of the prolific makeup brand. Then, a few months into her rehabilitation, the rec program arranged for a Mary Kay consultant to do an on-site pampering evening for the girls.

"My own hands weren't super good because of my injury," recalls McBride, whose injury is at C6/7. "And the girl that was leading the whole thing? She was blind! Her Director, who was there to support her, did a makeover on me. And I felt so pretty! I was 20, in a wheelchair, and hadn't really worn makeup. I just felt human again—like I could do anything."

"I went upstairs afterwards and there was a man who I was really connected with, an inpatient who had broken his neck falling off a horse. He was a really high-level quadriplegic, so he couldn't move his arms at all. And I sat beside him and we took a picture and he said, 'Oh you look so beautiful, I just wish I could put my arm around you for the photo!'" McBride still cherishes a Polaroid picture of the day.

But it wasn't until she'd been using and loving Mary Kay skin products for five years that McBride learned about



Passionate, positive and powerful.

Mary Kay **Independent Sales Director Kristen McBride**, whose story is featured in these pages, is all that and more. She is our hero and a role model to so many women across the country. A woman who has never let an obstacle stand in the way of her dreams. We're proud to celebrate and recognize Kristen for her true example of leadership and excellence.

**Take charge of your life,
and join the "I Can" movement.**

Ask your Independent Beauty Consultant what she can do because of her business, or find out more about getting started today at marykay.ca.



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the perks of selling them too: a 50 percent commission and personal product discount, flexibility without territory restrictions or quotas, and a sisterhood of women, young and old, many of whom had been through a variety of struggles in their own lives.

"It's just such a great community," says McBride. "When something goes wrong, everyone's there to pick each other up; when people are succeeding, you're there to cheer each other on. I think that people can look at it in a negative way. My brother once joked, 'She's part of this cult thing.' But I think it's just a bunch of people who are positive and bettering themselves. It's so therapeutic."

McBride thrived in her new role as a consultant, talking diverse women through skincare and makeup choices, and watching many of them blossom with new confidence. Her client base quickly doubled, then tripled.

"When I started, I asked my Director, 'How will I ever find people who are interested in this?'" laughs McBride. "She answered, 'Make a list of everyone you know who has skin.'"

Suddenly, the same group of Mary Kay vendors McBride had earlier discounted as "lipstick peddlers" seemed more like a smart fleet of businesswomen.

"All of a sudden, I really wanted to become a Director, because I knew what being a Director meant," recalls McBride. "It meant I could quit my (teaching) job, I could have the flexibility, I wouldn't have to work for someone else. It meant I could have a little more harmony in my life, because it was hard sometimes with my injury—just getting up, going to work, and making it through the day. It's so easy sometimes thinking about why you can't do something, but you just have to re-strategize. What am I doing? Why isn't it working? How do I make it work? And quads are sometimes the smartest people at that."

Today, Kristen dons the black Director suit—an honour she's held for six years and one that she doesn't see herself giving up, ever. Her accessible van is tastefully adorned with Mary Kay sign-

age. And requests from steadfast clients, new Mary Kay converts, and her own unit members continually light up her cell phone.

"As a Director, I want the consultants in my unit to feel a part of something even if they're just doing the minimum required; that they're loved, they're accepted for whoever they are, they can achieve their dreams," says McBride, conceding that while her SCI may make her less tolerant of people's excuses, it also helps her better recognize their successes. "When I had my accident, it was baby steps—it was celebrating every little moment. I really take time and recognize every little thing that my consultants do to get them to wherever they want, because it's the journey. It's not just, 'Okay you're there.' You did all this stuff to get you there, and all those things are awesome."

As for new goals, McBride now has her sights set on something big, bold, and pink: the iconic Mary Kay Cadillac. The company has already indicated that, if her unit reaches the requisite member and sales amounts, they'll lease McBride a new adaptive SUV and wrap it in pink.

"How cool—a girl wheeling out, down the ramp of a pink vehicle!" she says. "If that doesn't break belief barriers, what does?"

Surprisingly, her most treasured reminder of her success this year is a diamond-studded bumblebee pin.

"When Mary Kay started her company in 1963, she started it with a dream in her heart," says McBride of the company's late founder, whom she talks about like a close friend. "She worked for other companies, and men would always get hired and paid double her wages when she was often the one that trained them. So, when she started Mary Kay, she wanted to use the bumblebee as a special symbol for when people would just fly."

McBride admires the golden insect pinned neatly to her Director's jacket before returning to the buzz of emails, requests, and appointments on her phone.

"She chose the bumblebee because, aerodynamically, the bumblebee was never supposed to fly, because the body's so big and the wings are so small. But no one told it that, and it flew anyway." ■

Kristen's Makeup Tips for Quad Hands

- **Consider the packaging.** Many store-bought makeup items are near impossible to release from their plastic wrapping, and the struggle doesn't end there. Minimize makeup stress by choosing packaging and containers that work for you. For example, cream eye colours with small screw caps are probably too tricky to open. Skip the struggle and opt for powder shadows that come in handy, easy-to-organize compacts sets!
- **Opt for makeup that multi-tasks.** By using makeup that cleanses and moisturizes, or covers up and protects from harmful UV rays, you can spend less time fussing around and more on putting your best face forward. I love that Mary Kay hears me on this one—their TimeWise 3 in 1 cleanser cleanses, exfoliates and tones, in one bottle, while the Colour Corrector Cream is SPF 15. Bonus: It comes in a quad-friendly pump bottle!
- **Use a cuff, if needed.** Brushes can make great friends when your fingers aren't quite up to the challenge, and can be used to apply anything from foundation and blush, to eyeshadow and even lipstick. A cuff or something to hold your brushes steady—I had a special splint made just for makeup when I was first injured—can help take the accidents out of makeup application.
- **Choose a liner that's easy-gliding.** Unlike pencils, the right eyeliners and lipliners go on with ease and don't require firm pressure to apply. Better still, you can kiss that pencil sharpener goodbye.
- **Go big or go home.** A mascara with a bigger applicator makes it easier to hold and apply. Having trouble finding the right grip? Try Mary Kay's new Lash Intensity Mascara. It takes volume seriously—from the size of applicator to the length of your lashes.



Wheelchair Clothing for Men & Women

IZ'S TOP 6 ADAPTIVE FASHION TIPS

For this Fashion Issue, SCI BC asked the designers at IZ – the Toronto-based fashion line that makes wheelchair users look and feel amazing – for their essential style tips.

- 1 Ban the butt-crack** – There's nothing worse than being exposed. IZ pants and shorts are cut higher in the back so we've always got you covered.
- 2 Capes aren't just for superheroes** – Make a statement with dramatic lines. Our brand new Pea Cape is effortless fashion.
- 3 Zip it real good** – Not all functionality needs to be hidden. Innovation this cool deserves to be shown off.

**“Compromise is over!
Choose fashion designed
exclusively for you.”**

- 4 Dress to impress** – A little black dress never goes out of style. With IZ's unique cut, you'll have a smooth, chic look. Finish the outfit with confidence by adding a Keep Your Knees Together.
- 5 On-trend, Ungendered** – Runways everywhere have popularized this relaxed fit suitable for everyone.
- 6 Ahoy, Sailor!** – New for Fall/Winter 2016, Sailor Jeans for men and women, are this season's hottest trend, with military influence and bonus functionality.

Shop the new season at
www.izcollection.com

Promo code: SCIBC20 for 20% off your next order



@izadaptive



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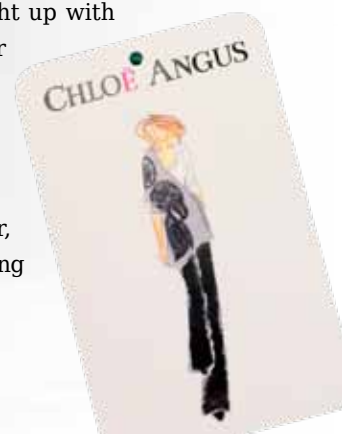
FASHION *forward*

Vancouver fashion designer Chloë Angus shares the trials and tribulations of keeping her business afloat after SCI, how her injury made her a better designer, and why she's looking forward to 2017.

YOU might not know her by name, but chances are you recognize her designs. Her versatile Button Wraps are available in major galleries and gift shops across Canada. Her Spirit Collection, a colourful collaboration with First Nations artists, draws the eye in BC Ferries gift shops. And across the province, political figures (from cabinet minister Stephanie Cadieux to Premier Christy Clark), starlets, First Nations leaders and women-next-door alike, are all proud clients of Chloë Angus Design.

Last June, after more than a decade being in business, Chloë Angus was diagnosed with a cavernoma. Although benign, the cluster of abnormal blood vessels bled into her spinal cord, leaving her with a rare and unexpected SCI.

Now, less than a year out of GF Strong, Angus is in the thick of all things fashion, shipping out her Fall 2016 collection and already showing Spring 2017. We caught up with the 41-year-old designer in her Vancouver studio to chat about how her injury has altered her business, why she thinks her work has saved her, and how she's redesigning her life from here.



You've had your own line, Chloë Angus, for 12 years. How did you get your start?

I grew up in Egmont, a small town on the Sunshine Coast. I had a sewing machine—not a TV—and like most fashionistas, Barbie had my first collection. But when I grew tired of how small her waist was, I talked my brothers into wearing my first garments. We lived rurally, so we didn't have a lot of choice for friends, and so my brothers agreed quite quickly to model my colourful dresses and be part of my fashion line.

What made you pursue it more seriously?

By the time I was 12, I worked in the summers in the only store in our town—it was a general store and it sold *everything*. I made some T-shirts, painted a live rock cod in psychedelic colours and printed the shirts with a fish print. I made more money selling T-shirts that summer than working in the store. I don't think I've had quite the same profit margin since then! When I moved to Vancouver, I went to the Helen LeFeaux School of Fashion Design.

Your designs feature prints by well-known First Nations artists Clarence Mills, Corinne Hunt and Deborah Sparrow. Was working with these artists a natural progression?

Absolutely. I grew up in a little First Nations fishing village and have an incredible understanding of and relationship with the people, their belief system and their exceptional art. I wanted to create a fashion line that allowed me to take the art from the artists themselves—because I have a complete understanding that you cannot make native art if you are not native—and showcase the artists and their traditional ideas, but in a fashionable, modern way.

Fashion is so subjective. What does “fashionable and modern” mean to you?

It's clothing for everyone. Getting into the fashion business, I never wanted to be superficial. I didn't want to just show really thin, really beautiful women in my clothing to say, “Look how good I am!” I wanted to show real women in my clothing to say, “Look how good you are!” The

Chloë Angus line is classic for all women, for all ages, for all sizes.

I like to call my line a “wardrobe builder” because each season will go with the next. The line is well-made, the fabrics are quality, and the clothes will help build a good wardrobe for somebody. Not everybody has a lot of disposable income—certainly the disability community does not, and that's pretty eye-opening now that I'm part of it. Good thing I make my own clothes!

You've hinted that, on top of manufacturing locally and using quality, eco-friendly fabrics, body image is an important part of having a sustainable business. How so?

For me, it's all about sustainable body image. Really young and really thin is not sustainable. Everybody's going to get older, your body will change, your weight will shift, and that doesn't mean you're not worth making a great fashionable outfit for. I'm really proud to say that my line runs from an XS right up to a XXXL, and the same style of top will look as good on an XS person as it will on a plus-sized woman.

Has the way you think about body image changed after your injury?

I've always tried to include everyone, and part of that is dealing with people's body issues. Everybody has them—doesn't matter what size you are; doesn't matter how old you are. Doesn't matter if you're injured or not injured. There's things you like about your body and there's things you don't. And I've always tried to highlight the good thing about anybody's body. And there's always something good!

You'd think that having my own fashion line would have made it easier after my injury—that I wouldn't lose track of my confidence. But I did. I think a lot of people do. I mean, you're not your same self. I think that once you get to feeling that you want to put your old pants back on, that's a really good indicator of your recovery process—that it's going okay. And the day that you do put on something, and add jewellery and roll out of the house, and notice that somebody

else notices it—it's a great feeling, and a great part of recovery.

It seems like you're really big on inclusion and positive body image. Where do you think that comes from?

When I first started, I was feeling a little bit depressed about what I was doing. Was it really helping the world or was I just working in this superficial industry that didn't care about anybody? My sister is a neonatal nurse and she saves people's lives every day. I was feeling like maybe I should do something to help people, not what I was doing. And a few days later I had a lady who I'd made a dress for phone me, in tears, saying, “Thank you so much—I wore the dress out to my husband's Christmas party and it was the first time he'd seen me in 25 years. He really *saw me*.” So then the body image thing—I realized that I can make change that way.

Your chic Button Wraps can be worn in dozens of useful ways. In fact, a lot of your clothing line already looks adaptive. Is it?

Yeah, I was pleasantly surprised to realize that most of my wardrobe and the clothing that I was creating worked for me after my injury. Most of my ready-to-wear line is made from bamboo jersey so it's really, really soft. It's really good for your body. It has very few seams. All of those things work really well.

And have you thought differently about designing since your injury?

Every day! Every day there's something that's like, “Oh my god, I need to make this because it's not out there.” Or if it is, there's no design to it. We need more adaptive clothing and accessories that are in great bright colours and not just your standard medical green or beige. There's always things that I'm interested in designing and developing now that I'm in a wheelchair, and certainly it's changed my outlook and some of my ideas.

Changed your outlook? How so?

At first I was quite concerned that I wouldn't be as good of a designer be-



cause fit is so important to me, and I used to wear everything before it ever got produced. I would put it on—I would fit test everything. And I can't fit test everything anymore. Some of the dresses don't make sense or some of the pants don't work. Without being able to put something on, would I be able to get the same fit if I didn't know how it felt? And I have to say it made me better as a designer. Because now I can see it, and I'm sure of it, and I don't need to put it on. I know already. It's that second-guessing of one's ability when something is taken away from you—a sense I guess—and how you adapt to that. And you do! You fine tune your other skills to make up for it. I was pleasantly surprised that it wasn't as hard as I thought it was going to be.

How long after your injury did you get back to work?

Well, you know that one of the perks to owning your own business is that you own your own business. But one of the downsides of owning your own business is that there is nobody else to do it but you. I was still on the spinal cord unit. It was day three and it was payday, and there isn't anybody else in my office that signs cheques. So I had one of the girls in my office bring me the chequebook, and through blurry eyes and not the neatest signature I was able to get everybody's cheques paid. So as far as I'm concerned I had about three days off. But of course there's months of rehab and days and days and days of doctors appointments in between.

Did you take any kind of break?

Not really. I designed this season's collection at GF Strong, we fitted at GF Strong, the models all came in with the rolling rack and my team, and we fitted the collection there. And by the time I got out of GF Strong in the fall, I had sold that collection to buyers and we delivered it in the spring.

That seems like a quick pace to keep up with.

Yeah, it's fast. There's been a lot happening in a year. But for me, so many things are taken away from your life at first when you get an SCI. You go from being independent to being not independent, to begin with. And out of all the things I was losing, I didn't want to lose my business. This is my baby, this is everything. I put everything into this. I am that person who works eight days a week and is happy to. And that's what it takes to run your own business, particularly in fashion, particularly in Vancouver. I find work is a great distraction from the injury itself. And it also gives you a sense of ability when you're feeling pretty disabled.

Would you recommend self-employment for people with SCI?

Well, usually I try to tell people to *not* have their own business—it's a really bad idea! If you want any time off, if you want any life, and if you want to make any money, do not work for yourself! That said, there's a lot of days that I wouldn't have gotten out of bed if I didn't have to—and I'm glad I did. So, I

just recommend that you do *something*. Go out there and distract yourself with some great project or something that you had planned before your injury. It's probably still possible, in some way, that you can still achieve that idea. And small business is never easy, but it's always rewarding.

Is an eight-day-a-week schedule still realistic for you?

I used to work a lot, I used to fly east to do shows, and that's subsided a little bit this year just as I learn how to adapt and get things going. Travel is not as fun as it used to be—it's not quite as glamorous. Rolling in with a long black coat and pair of high-heeled boots to the wine bar five minutes before you have to get onto your flight isn't exactly what happens for me anymore. I still do about half a day in the office and I take the other half of my day for rehab, exercise and doctor's appointments. I was bad at balancing my life before and I didn't care, because I could manage it. But I think my family is happy to have me around a little bit more now.

Have you had to adapt your workspace at all?

Not really actually, which was totally amazing to me! I mean, my whole world had been turned upside down and nothing worked the same after I got my injury. Except when I came back to work...everything worked for me. I had moved into my new space only a year earlier and, luckily for me, the new space didn't need any adaptation at all. All the doors were wide enough for my wheelchair, and I was all on one level. I even owned a sewing machine that doesn't have a foot pedal. You can run it by hand, by push button. I bought it years ago, and it was just a feature that I thought was sort of funny at the time, one that I would never use. So you know, some things are a blessing in disguise. For me it's pretty apparent that I was supposed to come back to work.

Were the designs you created while you were still in rehab inspired in any way by the things you'd been going through with your injury?

At that time, I didn't have any consideration for my injury. In fact, I used it to escape—just get me out of there—and that helped a lot. But my collection that I'm working on now, certainly I take into consideration some of the things that are going on with me. I'm adapting to how something can work a little bit better, or how it will fit me better in a wheelchair. Long tops have been popular for a number of years, because of the popularity of leggings. But they don't work very well for me anymore. So this year we did some really great black cigarette pants that have a really soft stretch waistband but look like Audrey Hepburn, and the tops are getting shorter. You start to play with different proportions that you hadn't before, but that still work for everybody.

Can we expect a Chloë Angus adaptive collection?

I would guess that in the future I will produce an adaptive line for men and women. I'm not sure when, but we've got a few



Chloë's Style Tips

Wear clothing made from good fabric. Natural fabric like silk, wool, and bamboo are much better for your skin and will be more breathable than synthetic fabric like polyester or Lycra. It also looks and hangs better on the body.

Accessorize with a scarf. They look chic wrapped, twisted, draped, or tied over your shoulders, around your neck, or on your wheelchair. A nice scarf can add art and colour to your basic daily outfit, whether it's sweatpants or a suit. I always carry one with me and can use it as a tie for my legs if I need one. Don't know where to start with scarves? I highly recommend my Button Wrap as it works for all occasions (and it's even been called the multi-tool for women due to its many uses)

Never underestimate the power of jewellery. I have bracelets that give me power, earrings that make me feel sexy, and necklaces that remind me that I am loved. I choose what to wear depending on how I want to feel—powerful, sexy, or loved, and sometimes all together. Don't be afraid to layer necklaces or bangles, or to wear multiple rings. Mixing silver and gold, or beads and pearls, can also be interesting.

Fashion Fun Fact: Coco Chanel was famous for being the first to mix real jewellery with faux. She was not always wealthy herself but needed to keep up appearances (and she loved that the wealthy crowd couldn't tell!) I'm with Coco on this one—it doesn't have to be expensive, it just has to make you feel good. Remember that a big statement piece of jewellery is sure to distract from the fact that you now have to wear sensible shoes!

pieces on the go already—a rain jacket being the first thing I need. By the time it starts raining again, we should have something good out!

We're also working on a line of unsix vests. Part of that is due to my First Nations customers—the vest is such an important part of their culture and their ceremonies—but also, being in a wheelchair, vests are much easier to wear than jackets. Keeping your arms free to wheel about is great, but keeping your body warm with a vest is great, too. You can see that adaptivity is sneaking in there...

Anyone you'd really love to dress?

Kate Middleton would be great! But, ummm, Sophie Trudeau! I would like to dress her. She's great, she's a forward woman—and I like forward women and would like to partner with them. She has a really great policy on body image...I think we could work pretty well together.

So, how does that happen? Do you wait for her to approach you or do you reach out to her?

Oh yeah, reach out! Don't sit back in your wheelchair and wait for the world to deliver things to you. You definitely have to reach out—in this business and in any other, and certainly once you're in a wheelchair, then you've got a little bit more reaching to do. And we have sent her a note, so we'll see if she gets back to us. We'll have to do a follow-up interview for that one.

Any other future plans?

Oh, like seven floors of Chloë Angus, from sunglasses to ball gowns! Yeah, I would love to be the Ralph Lauren of Canada, but we'll see how it goes. My Fall line is out now, and for the Spring 2017 collection you will see some of my first work with an Ojibwe artist by the name of Jay Bell Redbird out of Ontario. And I'm really looking forward to his design, and also one by his wife.

We'll look forward to it as well. It actually sounds like you may be on track for those seven floors...

Well, I'm lucky enough to just be in the business. It's something that I absolutely love. It's never easy to get back to the things that you lost when you had your injury, but it is possible and it feels great! ■

The Chloë Angus Fall Collection is on sale now. Point your browser to www.chloeangus.com for a store list or to order online. You can also find The Spirit Collection in gift stores in most major museums and galleries across Canada, and the full Chloë Angus line in stores on all major West Coast BC Ferries ships.

To read more about Chloë's design process and her work with First Nations artists, check out our full interview at sci-bc.ca/blog.

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Blueprint for Treatment

New Canadian clinical guidelines attempt to rank treatment options for SCI neuropathic pain

Our readers know that treating neuropathic pain—one of the most common and debilitating secondary health complications of SCI—is a complex business. There are many options for treatment, from a range of prescription drugs to a host of holistic approaches. But neuropathic pain is notoriously difficult to manage, and no single treatment option has ever proven to be entirely effective. In fact, it often takes a great deal of trial and error with multiple approaches to find a treatment regimen that offers even some modest relief for each individual.

What works best? What doesn't work well? What should be the first treatment options that physicians and their patients consider? Which ones should they shy away from? These are the questions that a group of researchers based at London, Ontario's Lawson Health Research Institute have been wrestling with during the past three years as they've attempted to develop Canada's first clinical practice guidelines for managing neuropathic pain experienced by people with SCI.

"We know that neuropathic pain has a significant impact on those with SCI, and in a number of surveys, it has been identified as one of the most bothersome issues for people after SCI," says Dr. Eldon Loh, a Physical Medicine and Rehabilitation Specialist at St. Joseph's Hospital in London who led the research team. "From our own survey data, we

found a desire among Canadian rehabilitation providers—therapists, physicians, and nurses—to have a guideline that they could refer to on this issue. I think the difficulty with neuropathic pain after SCI for any rehabilitation provider is successfully helping someone with this type of pain, and the previous lack of specific guidelines that could be used to assist in their care. Even internationally, there was no specific document that provided a rigorously developed approach to management of neuropathic pain after SCI, until now."

The culmination of the three-year process was the recent publication of new guidelines in the international journal *Spinal Cord*. The guidelines contain 12 recommendations for both pharmaceutical and non-pharmaceutical treatments. Of these, 10 treatments are sequential recommendations for treatment (sequential in that treatments with the strongest evidence are recommended first, and then failing their success, other treatments with less evidence are to be tried next). The final two recommendations are advice against the use of two therapies.

The guidelines were specifically developed for clinicians within the rehabilitation environment that treat those with SCI—physiatrists, physiotherapists, occupational therapists, and nurses. But Loh points out that many more health care professionals can make good use of the guidelines.

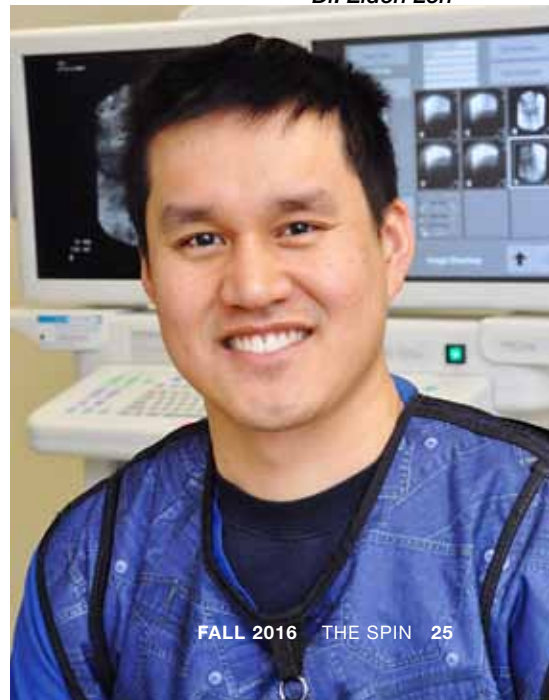
"These guidelines would certainly be helpful to anyone who looks after people with SCI, including family doctors," he says. "There are recommendations that can help guide the care of those with neuropathic pain after SCI, and there is information in the guidelines to help clinicians such as family doctors decide when more specialized care is necessary."

What about people with SCI themselves—should they familiarize themselves with the guidelines?

"Absolutely," says Loh. "One of the key principles advocated in the guidelines is establishing a self-management plan for neuropathic pain. Being aware that these guidelines exist and promoting the guidelines as a resource to someone's own healthcare professional are certainly important parts of that."

If you take the time to look at the individual recommendations (see sidebar on the next page), you might think at first glance that they are incomplete. For example, two strategies for self-management of neuropathic pain that we wrote about in the June issue of *The Spin*, cannabis and mindfulness, are not included. The reason? The researchers only made recommendations based on a review of scientifically-valid research. And the sad truth is that, despite a wealth of anecdotal evidence, there has never been any credible research completed about the use of cannabis specifically for use in SCI neuropathic pain.

Dr. Eldon Loh



"At the outset," explains Loh, "we established that these guidelines would look specifically at research that examined treatment within the SCI population. As there are currently no studies examining the use of cannabis for neuropathic pain in spinal cord injury, this specific treatment was excluded, in keeping with our methodology."

However, it's interesting to note that Loh and his colleagues singled out cannabis as a potential treatment for SCI neuropathic pain that should be studied as soon as possible.

"With widespread media attention on cannabinoids as a treatment for refractory chronic pain and more liberalized access to these agents in Canada, patients frequently request them," wrote the authors. "Although cannabinoids appear to be beneficial in multiple sclerosis, evidence in SCI is lacking. There is insufficient evidence at this stage to recommend the use of cannabinoids for the treatment of SCI-related pain, but more information is urgently needed to guide their use in patients with SCI."

Additionally, the authors offered this cautionary note about the guidelines.

"It should be strongly emphasized that the overall body of evidence for the management of at- and below-level (neuropathic pain) is inadequate," they wrote. "This includes the evidence that has been used to support recommendations put forward by our group...It is crucially important to recognize the limited evidence on which these recommendations as a whole are based. Limitations in the evaluated evidence include the use of mixed patient populations and SCI pain types, a lack of (randomized control trials), small sample sizes and potential lack of power...The lack of evidence for benefit of many therapies significantly hampers clinicians' ability to deliver optimal care to all patients. Research is therefore urgently needed on all the therapies in this guideline to better guide appropriate clinical use."

The guidelines will be updated as additional evidence becomes available. ■

SUMMARY OF RECOMMENDATIONS

The CanPain SCI Clinical Practice Guidelines for Rehabilitation Management of Neuropathic Pain after Spinal Cord

FIRST-LINE THERAPY

RECOMMENDATION 2.1: Pregabalin should be used for the reduction of neuropathic pain intensity among people with SCI.

Quality of evidence: High.

Strength of Recommendation: Strong.

"Pregabalin is recommended as the first choice of first-line medications, as it has the strongest evidence of any treatment modality in below-level neuropathic pain: all studies demonstrate a significant reduction in pain intensity."

RECOMMENDATION 2.2: Gabapentin should be used for the reduction of neuropathic pain intensity among people with SCI.

Quality of evidence: High.

Strength of Recommendation: Strong.

"Gabapentin is recommended as the next choice when pregabalin is not an option or has been proven ineffective, as the evidence supporting gabapentin in SCI-related NP is not as strong as that for pregabalin."

RECOMMENDATION 2.3: Amitriptyline can be used for the reduction of neuropathic pain intensity among people with SCI.

Quality of evidence: High.

Strength of Recommendation: Strong.

"If pregabalin and gabapentin have been ineffective, then amitriptyline is recommended; less evidence exists for the efficacy of amitriptyline than for the gabapentinoids."

SECOND-LINE THERAPY

RECOMMENDATION 2.4: Tramadol can be used for the reduction of neuropathic pain intensity among people with SCI.

Quality of evidence: Moderate.

Strength of Recommendation: Strong.

RECOMMENDATION 2.5: Lamotrigine may be considered in those with incomplete SCI for the reduction of neuropathic pain intensity.

Quality of evidence: Moderate.

Strength of Recommendation: Strong.

THIRD-LINE THERAPY

RECOMMENDATION 2.6: Transcranial direct current stimulation (tDCS) may be considered for reducing neuropathic pain intensity among people with SCI.

Quality of evidence: High.

Strength of Recommendation: Weak.

RECOMMENDATION 2.7: Combined visual illusion and transcranial direct current stimulation may be considered for reducing neuropathic pain intensity among people with SCI.

Quality of evidence: High.

Strength of Recommendation: Weak.

FOURTH-LINE THERAPY

RECOMMENDATION 2.8: Transcutaneous electrical nerve stimulation (TENS) may be considered for the reduction of neuropathic pain intensity among people with SCI.

Quality of evidence: Low.

Strength of Recommendation: Weak.

RECOMMENDATION 2.9: Oxycodone can be used for the reduction of neuropathic pain intensity among people with SCI.

Quality of evidence: Moderate.

Strength of Recommendation: Weak.

RECOMMENDATION 2.10: The dorsal root entry zone (DREZ) procedure may be considered in exceptional circumstances and as a last resort for reducing neuropathic pain intensity among people with SCI.

Quality of evidence: Low.

Strength of Recommendation: Weak.

ADVISE AGAINST USE

RECOMMENDATION 2.11: Levetiracetam should not be used for reducing neuropathic pain intensity among people with SCI.

Quality of evidence: High.

Strength of Recommendation: Strong.

RECOMMENDATION 2.12: Mexiletine should not be used for reducing neuropathic pain intensity among people with SCI.

Quality of evidence: High.

Strength of Recommendation: Strong.

ask the SPIN DOCTOR

Bob asks, “Back in rehab, I never gave much thought to the idea of being a father...it just didn’t seem like it was in the cards, and so I didn’t really absorb much information about the subject when it was presented to me. Well, things have changed—and now I need to figure out what my options are. Can you help?” To answer Bob’s question, we turned to Shea Hocaloski, Sexual Health Clinician at Vancouver Coastal Health.



The subject of male fertility after SCI is riddled with myths. For example, an often-voiced assumption is, “If I can’t ejaculate, I guess I will never have kids.”

The bottom line for the majority of men with SCI is that they indeed still have the ability to father a child. First, some basic facts:

- An SCI does not remove your body’s ability to produce sperm. However, an SCI may reduce sperm quality.
- Sperm quality is an important factor in fertility. It’s assessed by looking at how many sperm are present in semen, their size and shape, and what percentage are swimming and moving (sperm motility).
- Sperm exits the body in semen, and ejaculation is typically how semen comes out of the body. SCI can have a negative impact on men’s ability to ejaculate.

If you have a complete SCI, chances are the ability to ejaculate will be quite low. If your injury is above T10 (higher level), there is a greater possibility that ejaculation can occur with the use of specialized devices. Lower injuries often require more invasive options.

If you have an incomplete SCI, the ability to ejaculate is difficult to predict and is often unreliable. This is due to messages being sent from the brain which can interrupt the ejaculation reflex.

The best method of determining your ability to ejaculate without any intervention or medically-oriented assistance is to explore. Do this with curiosity, but be cautious about your blood pressure getting too high, which can lead to autonomic dysreflexia (AD). Also be aware that if you’re trying too hard to ejaculate as your main goal, it can lead to frustration.

If you’re unable to ejaculate on your own, you have several sperm retrieval options.

Vibrostimulation is a procedure where a specialized vibrator is applied to the head of the penis to attempt to provoke ejaculation. The vibrators used for this procedure

need to be higher powered than ones you would typically find at a sex shop (the Ferticare, shown to the right, is one example). A consultation with a medical professional before trialing something like vibrostimulation is strongly recommended. AD commonly occurs with vibrostimulation, therefore it’s not recommended that it be done at home without medical advice beforehand.

Electroejaculation is one procedure that’s used when vibrostimulation fails and is most commonly used for sperm retrieval when the SCI is below T10. This procedure can occur either in the clinic (if there is no anal sensation; complete injury) or in the operating room (when anal sensation is present; incomplete injury). This procedure involves the insertion of a Foley catheter. This is to block the bladder neck so that the semen comes forward out of the penis rather than back into the bladder. A rectal probe delivers an electrical current to the prostate through the rectum. This procedure is quite effective in producing an ejaculate for reproductive purposes.

Surgical sperm retrieval is an option when vibrostimulation and electroejaculation have been tried and the results have been poor. This procedure is done by placing a needle into the testicle or surrounding structures to remove sperm cells. The number of sperm cells retrieved by this procedure is considerably less than the other methods.

It’s also important to know that sperm retrieval is the first step in determining your fertility potential. Once sperm is obtained, it needs to be sent to a lab for an analysis to determine semen quality. The quality of sperm will determine the most appropriate method for insemination.

Where can you go for help? Your best option is the Vancouver Sperm Retrieval Clinic, where you’ll find specialists working in this field. You need to see your own family physician to get a referral to the clinic.

Despite changes to ejaculation after SCI, becoming a father is still possible.



MORE ON SEXUALITY & FERTILITY...

SCI BC and Vancouver Coastal Health’s Sexual Health Rehabilitation Service have teamed up to create and launch an incredible online resource for people with SCI to learn about sexuality, relationships, fertility, parenting, and much more. Point your browser to sexualhealth.sci-bc.ca today and get the facts and help that you need.



not just standing around

A mobility aid first: a manual standing wheelchair that can be manoeuvred by the user in the upright position.

Standing wheelchairs are nothing new. In fact, several commercial versions have been available for nearly three decades. But they've either been power wheelchairs, or, if they are manual, they can't be moved with the user in the standing position.

That didn't sit well with Dr. Gary Goldish, Director of Extended Care and Rehabilitation at the Minneapolis Veterans Affairs (VA) Medical Center.

"For years I've felt so frustrated because my patients who could benefit from standing didn't have the ability to move once they stood up," said Goldish in an interview with the *Minnesota Star Tribune* last year.

Goldish started kicking around ideas for a manual standing wheelchair about ten years ago. In 2013, he teamed up with biomedical engineers Andrew Hansen and Eric Nickel to come up with a prototype—a modification of an existing standing wheelchair. The modification primarily consisted of separating the push rims from the drive wheels and tires. The push rims, which are connected to the drive wheels using bicycle chains, can be cranked upwards by the user at the same time as they raise themselves into a standing position.

Users can then wheel themselves around while standing, which has never been possible in any other manual standing wheelchair, such as the Levo.

If you're having problems picturing this, you can easily find a video online that shows you exactly how the technology works.

The wheelchair has no batteries or motors. The user and the push rims move easily into the standing position, thanks to a gas shock (similar to those that allow your car's trunk or hatchback to be easily raised). Two sets of casters—one at the front, one at the back—provide stability while the user is in the standing position.

Goldish and his colleagues debuted the device in late 2014. Not surprisingly, there was a great deal of public interest—and offers for financial support.

"While there are numerous manual standing wheelchairs on the market, at





needs to be redesigned from scratch—in other words, future prototypes will not be based on the commercial standing chair used with the first prototype.

“We didn’t build it from the ground up, so we couldn’t move the tire where we wanted it to be,” says Goldish. “It also is wider and heavier than we’d like it to be.”

Besides moving the drive wheels closer to the midpoint of the chair, other improvements in the new prototype under development include enhancements to stability and durability, hiding the chain drive behind a sleek looking cover, adding an automatic chain tensioner, and creating a new design for the push rims that will see them more optimally positioned for the user’s shoulders in either sitting or standing positions.

Goldish says the ultimate goal is to move from prototype to a commercially-available version within the next couple of years.

One local expert who has been following this story with great interest is Dr. Jaimie Borisoff, Canadian Research Chair in Rehabilitation Engineering Design at BCIT, adjunct professor at UBC, and a principal investigator at ICORD. Borisoff, who focuses his research on how technology can improve mobility and accessibility for people with SCI and other disabilities, has firsthand knowledge of what it takes to bring a product like this to market—he is the inventor of

the Elevation Wheelchair, which is currently built and sold by PDG Mobility (see www.pdgmobility.com).

“I have seen this standing wheelchair in person, although I haven’t tried it,” says Borisoff. “I think it’s a great additional feature to a standing wheelchair—an innovative method of achieving mobility while standing. So it has a chance to become the ‘go to’ solution as a manual standing wheelchair. Their challenge will be to refine the design and make it cost-competitive, as funding these things is always difficult. And of course, commercializing it, either themselves or with a company partner—which is easier said than done, although I don’t know the current state of the development, so maybe it’s all sorted out already. Unfortunately, at the end of the day, it’s still going to be seen as a niche product—a specialized chair that would not take the place of an everyday chair. It’s just too heavy to be used all day for community mobility. But I like it.”

There are many benefits that have been reported from using a standing wheelchair: greater independence at home and at work, the opportunity to take part in sports and recreational opportunities that require standing, health benefits such as strengthening the leg bones and relieving pressure, and the possibility of greater social interaction by being eye-to-eye with other people. ■

the time of the funding, there were none that offered the ability to move both in standing positions and sitting positions,” said Lana McKenzie, Associate Executive Director for Medical Services and Health Policy at Paralyzed Veterans of America. “That made it unique for Paralyzed Veterans of America to fund this project.”

With proof of concept successfully achieved, the team is now back to work in an effort to refine the first prototype. One of the problem areas was achieving efficient propulsion while in the seated position—testing revealed that the tires were too far forward to allow this. Moving forward with the second phase of development means that the entire chair

ANNUAL GENERAL MEETING: Thursday, October 27, 2016

The AGM for the Canadian Paraplegic Association (BC), operating as Spinal Cord Injury BC, will be held Thursday, October 27 at the Blusson Spinal Cord Centre, 818 West 10th Avenue, Vancouver, BC. Elections for the Board of Directors for the next two-year term beginning October 2016 will be held. Nominations for Directors may be made in writing and must be received by SCI BC ten days prior to the AGM. Nominations may also be made at the AGM by voting members in good standing provided that the person nominated is present and consents to such nomination, or the person nominated has previously consented in writing to the nomination and such consent is presented at the meeting. Voting members will also be asked to vote on a special resolution amending the Constitution and Bylaws, required to comply with upcoming changes to the BC Societies Act.

Registration will begin at 6:00 pm, with great conversation and refreshments to follow. Please contact Maureen (604.326.1225 or mbrownlee@sci-bc.ca) for further information regarding the nomination procedure or to RSVP. You can also visit www.sci-bc.ca/events/ for more details about the evening.

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



MANLY.

They ate. They drank. They conferred. They swapped manly advice and stories.

For nearly 60 years, Spinal Cord Injury BC has been helping British Columbians with SCI to adjust, adapt and thrive. But this past July 9, our organization did something unprecedented and long overdue: we held an event just for men. SCI BC's inaugural Guys' Garage was a smashing success, with live bands, awesome adaptive technology displays and demos, craft beer and pizza, and more than 140 guys from the SCI community in attendance.

"We have a lot of different events, but we wanted the guys to come out, talk freely, and showcase their interests," says SCI BC Peer Coordinator Richard Peter. "Whether you have a new injury, or you've been injured for 20, 30, 40 years, the Guys' Garage is a great opportunity for people to come out and see what other guys are doing—recreation-wise, health-wise, even music-wise."

The afternoon gathering, a brainchild of longtime Peer Coordinator Brad Jacobsen, will return next summer, with more tools and tech, another silent auction, and a decor do-over of the manly pepperoni-cheesestick "bouquets."

Visit sci-bc.ca/events for coming event listings and details.



Shut the Back Door!

An Israeli pharmaceutical company is working hard to develop a simple treatment to prevent fecal incontinence for people with SCI.

There have been plenty of studies and surveys that rank which secondary complications of SCI pose the biggest challenges for people with SCI. Consistently at the top of the heap are bowel issues and, in particular, fecal incontinence, or FI.

Some estimates suggest that as many as 75 percent of people with SCI deal with FI. Beyond the simple embarrassment of having an “accident” in public, FI can lead to skin problems, infections, depression and isolation, and even institutionalization. Little wonder that people with SCI believe that FI is a major contributor to loss of quality of life.

Simply explained, SCI results in the loss of a person’s ability to control and tighten the two muscles that control the anal sphincter—the external anal sphincter, a striated muscle that contracts as a response to a person’s conscious decision to squeeze it tightly, and the internal anal sphincter, a smooth muscle that maintains constant contraction at all times. Even people with the most effective bowel routines can experience episodes of FI because of the inability to tighten these muscles.

RDD Pharma, an Israeli company, is on a quest to develop a topical pharmaceutical compound that, in the absence of signals from the brain, works to tighten these muscles for a considerable length of time. The company recently reported some eye-raising results from its latest clinical trial, so we decided to take a closer look at what it’s doing.

The active ingredient in RDD Pharma’s compound is a variation of the drug oxymetazoline, which has been used safely for decades in a variety of over-the-counter medications such as Dristan nasal spray and Visine eye drops. Oxymetazoline is a known alpha-agonist, which means it binds and activates adrenergic nerve receptors to induce smooth muscle and blood vessel constriction. For example, as an active ingredient in Dristan and other nasal sprays, it clears up the nasal passages and eases congestion by narrowing the blood vessels in the nose.

RDD Pharma’s variation of oxymetazoline, which the company calls RDD-0315, is placed into a cream and applied manually to the inner anal rim.

“Our goal is to treat FI in populations where the smooth muscle in the anal sphincter is intact but lacking the signal

to contract adequately,” explains Jason Laufer, CEO of RDD Pharma. “SCI results in lack of neural input to these sphincter muscles. RDD-0315 bypasses the problem by providing the muscle with a pharmacological signal—rather than a neural one—to contract. RDD-0315 binds to receptors on the internal muscle, thus activating contraction.”

Dr. Nir Barak, chief medical officer and founder of RDD Pharma, stumbled across the idea while working in the lab on another of the company’s pipeline drugs.

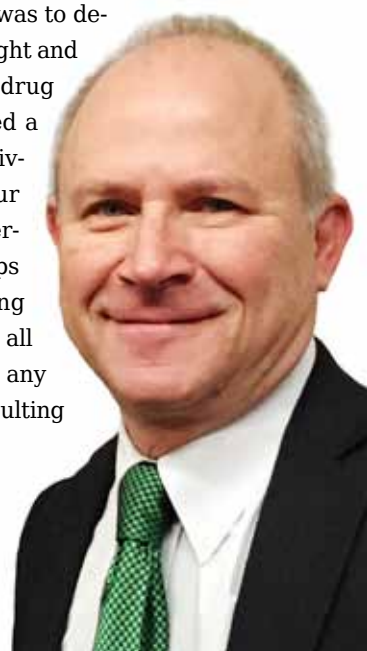
“The first product our company developed, which is currently in Phase 3 testing in Europe to treat anal fissure, relaxes the anal sphincter,” Laufer explains. “As Dr. Barak began to understand and become adept at relaxing the anal sphincter, we began to explore the utility and potential of tightening the anal sphincter to increase resting anal pressure. The root cause of FI in some populations such as SCI is inadequate resting anal pressure.”

The company discovered that there are no FDA-approved pharmaceutical agents for FI. “When further exploring this disorder we felt that, if RDD can bring relief to the SCI population, we could certainly provide some relief to patients who suffer from lesser degrees of FI,” says Laufer.

By that time, Barak had recognized that oxymetazoline was ideal to be repurposed for this application. Armed with an investment from the Israeli arm of OrbiMed, a leading healthcare investment firm, RDD Pharma began investigating RDD-0315’s potential. Their work culminated recently with the results of a Phase 2A proof-of-concept trial designed to determine efficacy.

The study included 19 people living with SCI—16 men and three women, with an average age of 42. Nine of these had complete injuries. The primary goal was to determine the number of FI episodes eight and 12 hours after receiving either the drug or a placebo. The study incorporated a crossover design, with patients receiving RDD-0315 or a placebo for four weeks, and then, after a two-week period with no treatment, the two groups switched. In addition to determining the number of incontinence episodes, all participants were tested to measure any increases in resting anal pressure resulting from treatment.

RDD Pharma CEO Jason Laufer



Episodes of FI during the eight hours after treatment averaged 25 in the placebo group and 18 in the active drug group. Within 12 hours after treatment, people in the placebo group experienced 36 episodes of FI, compared with 26 among those receiving the active drug. These numbers represent a statistically-significant 25 percent reduction. Correspondingly, in participants treated with the drug, resting anal pressures increased by 15%. All participants tolerated the drug well, with no adverse events recorded, and no residual drug detected in their bloodstream.

Buoyed by these results, Barak and his team are moving forward with a Phase 2B study, which will attempt to use higher doses of RDD-0315.

"We believe that higher doses to be evaluated in Phase 2B will provide even greater efficacy," says Laufer. "We can likely escalate dosages five or tenfold in future studies. Based on our Phase 2A study, which showed no systemic exposure, we estimate that we will be able to

safely escalate the dose to achieve more meaningful reductions in FI episodes."

Laufer says that, with even more impressive results and the drug's proven safety record, it may be possible to bring it to market in a relatively short time. He explains that authorities in the EU have been receptive to the idea of approving RDD-0315 for Orphan Drug status for FI in SCI patients (an orphan drug is one that has been developed specifically to treat a rare medical condition, and it's often easier in the US and Europe to gain marketing approval for an orphan drug).

"RDD submitted an Orphan Status application in July 2016, and we anticipate receiving an opinion from European Medicines Agency by this coming October," he says. "In our recent interaction in the US with the FDA, the agency commented that they would take the rarity of this condition into consideration."

He concedes, however, that the FDA has requested a formal pharmacokinetic study—a process that may slow fast-track approval in North America.

Nevertheless, RDD-0315 holds considerable promise for those who have had virtually no way of dealing with FI other than wearing diapers.

"Our mission is to provide people with SCI with greater ability and confidence to pursue active lifestyles in and outside their homes, while lowering the incidence of fecal incontinence," says Laufer. "We envision providing physicians with a topically applied drug that is easily prescribed and dosed. People with SCI will have the ability to self-administer the drug and adjust dosing per their physician recommendation. The ideal timing for applying RDD-0315 would be just after the individual completes their morning bowel routine. This would enable the individual to potentially enjoy a continent period of up to eight hours, and more fully and confidently participate in life events." ■

Visit www.rddpharma.com to stay up-to-date on developments with this promising treatment.

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Participate in Research

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

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

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.

What is the relationship between physical activity and heart function in people with SCI?

Overview: ICORD Principal Investigator Dr. Christopher West and his colleagues are conducting a study on the effects of physical activity and sympathetic cardiac regulation on cardiac function in individuals with chronic spinal cord injury.

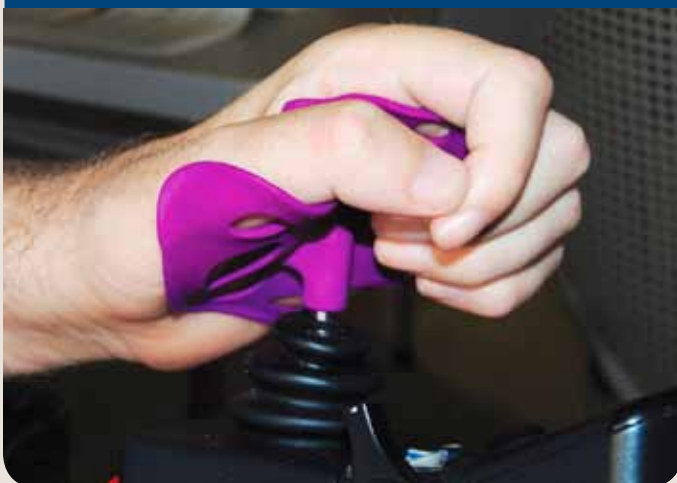
What to expect: If you participate in this study, you will take part in two sessions of two hours each at the Blusson Spinal Cord Centre. Researchers will take measurements of your heart and autonomic nervous system health, assess your daily physical activity levels, and monitor you during submaximal treadmill wheeling. There are no invasive tests. You will also be asked to monitor your physical activity for six days while wearing accelerometers and a GPS tracker. Participation will require a total of approximately four to four and a half hours.

Why participate: It's a new experience for anyone who's ever wondered just how active they really are! Compensation for participation will be provided.

Who can participate: You can take part in this study if you have a traumatic spinal cord injury, have used a manual wheelchair for more than a year, and are under 65 years of age.

Location: ICORD, Blusson Spinal Cord Centre, Vancouver.

For more information or to participate: Please contact the study coordinator, Laura McCracken, at 604.675.8809. You can also learn more by watching Dr. West's Stopwatch Session video, the latest episode in the SCI BC TV (www.youtube.com/spinalcordinjurybc).



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

Dear Dancefloor Companion...

In this open letter, quadriplegic athlete, model and occasional club-goer Jessica Kruger offers some polite advice to someone many of us have also met: the overly-inspired, able-bodied dance partner.

Dear Dancefloor Companion:

I wish you'd quit calling me an inspiration.

It's a word that many of us within the SCI community are used to hearing, but I've been struggling with it lately.

I'm not saying that your compliment is an insult; I recognize it's intended to be flattering, and never malicious. What I question are your underlying assumptions when you use this word. Why are you inspired by me? Are you inspired because you assume people in wheelchairs should be limited in what they can do? Put another way, are you inspired because your understanding of disability is one that propagates the notion of inability?

Should I really be celebrated for going out dancing with friends at a bar? Hell no! Have you seen my dance moves? They're not pretty, I promise. So I fear that the only reason you find my dancing inspiring is because you think that girls in wheelchairs can't dance, would be too embarrassed to try dancing, or simply don't go out dancing.

To be fair, dear Dancefloor Companion, I've lost count of the number of times I've had people tell me that I'm an inspiration for having a good time dancing. It's excessive.

Here's what I would like to ask you to do: stop for a minute and separate the activity (dancing) from the person (me). Now think of another person doing this activity, and then decide if it's still inspiring.

Are you going to tell every other dancing person at the bar that they're inspiring? Probably not. So recognize that the only reason you find my presence at the bar to be inspiring is because it's framed by the preconceived beliefs that those with disabilities are inherently limited; that we might be depressed or embarrassed; that we don't get out often. This is precisely the mindset that I'd like to stop perpetuating.

I understand that inspiration isn't something that we choose—it's something that we feel, so sometimes we can't help but feel inspired by something that isn't innately inspiring. I'm not saying to stop looking for inspiration, nor do I mean to imply that people with disabilities should never be the source of inspiration. I'm simply asking that you be conscious of why you feel that way.

Duncan Campbell is a quadriplegic who co-created the sport of wheelchair rugby, and continues to mentor newly-injured athletes. Duncan is someone who inspires me. Not because he

is in a wheelchair, but because he created a world that allows athletes of various abilities to compete in a sport that they love, and in doing so, he gave them a place where disability is the norm, and athletic ability is the goal.

Not only did Duncan create this world, but he did so with the utmost humility, which I find extremely admirable. If I remove Duncan from the equation and just consider his actions, I am still inspired. Why? Because he took an idea that started in a rehab centre gym, nurtured it, promoted it, and encouraged it to grow. And in doing so, he provided a community of belonging and gave purpose to many that may have lacked it. Duncan's accomplishments are inspiring in their own right, and it shouldn't matter who the man behind them is.

So where do you draw inspiration from?

Does a well-worded Instagram quote get you going? A photo of someone else accomplishing something you'd really like to achieve? Perhaps, like me, you've listened to a politician, world leader, or skillfully-scripted TED talk and allowed the words to move you into action.

I don't think that finding inspiration in unlikely or unconventional places is the issue—if my "dancing" really does inspire you, so be it.

The key, I'd argue, is to remember to be mindful. Let's acknowledge real accomplishments and distinguish actions from assumptions. Let's look at who is actually challenging the norm and reward them for being truly remarkable; not just for busting it out on the dancefloor...

Sincerely yours,

Jessica (a truly un-inspiring dancer) ■



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