

the spin

SPINAL CORD INJURY BC

WINTER 2015

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Cover Photo: SCI BC Peers prepare to catch a few morning waves. Photo Credit: Michelle Cameron.



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The politics of disability are changing...

Winning isn't everything; it's how you play the game. As a long-serving volunteer soccer coach, I've used this line on many an occasion—usually after a loss. And while the statement is generally true, more often than not, winning comes from how you play the game.

Witness the recent federal election. How the Liberal Party of Canada played the election game was a huge part of their unexpected majority win in October. Their victory has been credited to their leader's charisma, but it was also built on a culture of trust in people, openness to ideas that matter to Canadians, and hope for a bright, prosperous, progressive and inclusive Canada. They set lofty goals and expectations, including those directly relevant to Canadians with disabilities.

They also vowed to form a cabinet that reflected Canada.

The national press made a big deal about Prime Minister Trudeau's creation of gender equity amongst the ministers in his Cabinet. "Why?" they asked. "Because it's 2015" was his response. Regional representation and cultural diversity are also well-reflected in his Cabinet.

What got the attention of Canadians with disabilities and the organizations that support and advocate for them was something new in Cabinet: a Ministry of Sport and Persons with Disabilities, represented by a highly respected and accomplished person with a disability—the Honourable Carla Qualtrough. As well, in the Ministry of Veterans Affairs, a person with an SCI was selected to co-lead—the Honourable Kent Hehr. So not only is the Liberal government reflective of Canada's gender balance, it also has strong representation from Canadians with disabilities.

The formation of a Ministry for Persons with Disabilities is not insignificant. It signals that the government takes the issues and challenges facing Canadians with disabilities seriously, and that it is backing up its election promises of creating a Canadians with Disabilities Act with ministerial clout.

The appointment of Qualtrough as the Minister of Sport and Persons with Disabilities may have, given her resume, been a no-brainer, and a better choice could not likely have been made. As a British Columbian, a former Paralympian and a lawyer with extensive experience in the areas of human rights and inclusion, she not only understands the issues, she has worked hard over the years to address them. Now she will do so from a position where she will have even greater influence to encourage and enact real change.

The sport and disabilities sectors alike are pleased. Early words from Minister Qualtrough are hitting the right notes. I particularly liked her comments on sport as a critical tool to promote access and inclusion.

But we've all been around long enough to not get too hung up on the hype and honeymoon the new Liberal government is enjoying. It will be important to remain optimistic about the potential for improvements, and to keep the pressure on to help ensure priorities are maintained and promises fulfilled. There's a lot of work to be done within a myriad of priorities and a challenging economic environment.

Where will the Persons with Disabilities portfolio end up against the full pallet of government priorities? Will we actually see a Canadians with Disabilities Act before the end of the Liberals' current mandate?

We'll wait and see. But if Minister Qualtrough and the Liberal government play the game as well as they've promised, real change may indeed be upon us. And that will be a win for all Canadians.

- Chris McBride, PhD, Executive Director, SCI BC



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G-LOVES GLOVES



G-Loves are the brainchild of an able-bodied, female weightlifter who wanted to develop a glove that provided protection while offering a touch more style than regular workout gloves. In the process, she may have created the perfect gloves for women who are wheelchair users (and more fashion-conscious men as well). Sewn from neoprene and a spandex and nylon blend, with padding in all the right places, G-

Loves feature cropped fingers, open knuckles, and open thumbs that combine to offer protection, freedom of movement and flexibility, while preventing overheating. They feature a Velcro closure, and are easy to clean in cold water. They're available in 50 different stylish patterns. Visit www.g-loves.com for a closer look.

NIKE FLYEASE

Nike, one of the world's most iconic athletic apparel company, has released a new line of sneakers featuring FLYEASE technology, intended to help some people with disabilities put on and take off their shoes with one hand. Instead of laces, the new sneakers have a zipper which wraps around the shoe and opens up near the heel, allowing the wearer to easily slip a foot in and out. Search online for "Nike FLYEASE" and you'll find videos and news stories, along with information about how and where to buy them.



Innovations

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The Suspendo is a wearable device harness that can be used to hold smartphones, tablets and cameras in front of you so that you have your hands free to wheel or perform other tasks. The Suspendo's aluminum band is worn around the user's neck and is attached to a D-Rig support system that can be set to hold your device horizontally or vertically. It's compatible with all smartphones and tablets on the market, and includes an extra-strong tablet support for tablets over seven inches. It also has a special support for Go-Pro cameras and pocket still cameras. It's completely adjustable for each individual user, so that you don't have to strain and hunch forward to get a good look at the screen of the device you're using. The system is currently available as part of a Kickstarter campaign—visit www.suspendo.com or www.facebook.com/suspendo for more details.

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Go behind the scenes



Talk amongst yourselves.

SCI BC's Bean There Peer Coffee Groups are your chance to get together with local Peers and chat about life with SCI or whatever else is on your mind. Bean There groups are happening in many communities throughout our province. Check the events page at our website (<http://sci-bc.ca/events/>) for one near you or contact us if you'd like to set one up in your community (call 1.800.689.2477 or email info@sci-bc.ca).



Cheer from courtside.

From February 13 to 14, Victoria's Spectrum High School will host the Breakers 2016 Wheelchair Basketball Festival from 9.30 AM to 4 PM each day. Come out and watch the Breakers take on Calgary and Edmonton. As well, the BC Wheelchair Basketball Society will be holding development sessions for women and girls interested in learning more about the sport, or trying it for the first time. There's no reason not to give it a shot!



Treat yourself.

Shake off the cold and join us for our 13th Annual Women's Tea, to be held in Vancouver in early 2016. SCI BC's celebration of womanhood invites all women, regardless of age or ability, to be spoiled, pampered and rejuvenated—with teas, delicious treats, swag bags, and much more. This free event is all about Y-O-U! Date, location, and time TBD; follow us on Facebook and watch our events page at www.sci-bc.ca/events for details.

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When we show up in our wheelchairs we are not just being active, we are being pro active! Spending resources on inclusion is more cost effective then the health complications for being inactive. Mobility Mount can help with that.



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Room for Debate

How revealing should people with SCI be?

Five years ago, Rachelle Friedman was injured in a swimming pool accident at her own bachelorette party. Quickly dubbed the “paralyzed bride,” she became famous for both her shattered dreams and for refusing to publicly reveal or blame the friend who had playfully pushed her into the water. Recently, Friedman, now a public speaker, author and model, made news again with a racy boudoir photo shoot. Clad in lace lingerie, Friedman exposes not only her sex appeal—she’s 30, fit, and girl-next-door beautiful—but also her catheter and leg bag. This month, we asked our Peers and online community to weigh in: Is Friedman’s shoot an eye-opening step in the right direction? Does the leg bag add to the message—or take away from it? And what is the message here, anyway?



JOCELYN MAFFIN, VANCOUVER: This kind of blows my mind—I have about eight conflicting thoughts about it.

I applaud women wanting to feel sexy in whatever way makes them feel sexy. I love it as a big F You to a very prevalent attitude about people with disabilities as inherently asexual or undateable. I love it as a sign of ownership of her body despite all of the ways that being both a “patient” and having paralysis can make your body seem not your own.

But the more I think about it, I’m disturbed at the idea of people posing Rachelle in sexy lingerie like a doll for public consumption—and then I’m disturbed because she chose that, and why should my feelings violate her self-determination? I have no issue with Rachelle seeing this portrayal of herself as sexy and sharing it with the world (holy balls of steel, girlfriend!)... but then I think, can’t indwelling catheters be capped off? Why would you leave the leg bag when you could tuck it away? Do you want to make a point with a urinary apparatus THAT badly?

I think it means something because she shared it online and encouraged people to share using #whatmakesmesexy. It’s definitely a statement!

Either way, she looks hot, seems to be enjoying it and is trying to say something with it that might help others (and maybe make some sexy fun for her and her husband!).

CHRIS MARKS, VICTORIA: I am 100% in favour;

this is part of redefining disability. Generally, people with disabilities are thought about as non-sexual, or deviant if they think about sex. Being an employer in your private residence every day of your life puts you at risk of sexual harassment charges if you even mention sexuality. Being sex positive and empowered, and reclaiming that space in a healthy, genuine way, is part of the way forward.

We can keep people alive and teach them how to live with a disability but can we help them have a life worth living? Sexuality is natural, like breathing, and to deny that is to deny one of the things that make life worth living. Creating and claiming



a space for sexuality to thrive is part of the way forward for people with disabilities. People won’t necessarily know what the leg bag is for, but including it is important; without it she would just be another sexy lady...Which she is. I believe her posting the picture of her with the leg bag is critical for her reclaiming her sexuality and blasting open doors for others to do the same. Like wearing a pair of glasses help to live your life (if you need them), having a leg bag helps other people live their lives and does not take away from them, or their sexuality.

I had an injury 10 years ago and before that had a good sex life and since then I have literally had some of the most incredible experiences of my life after spinal cord injury. I know firsthand how important claiming or reclaiming that part of your life is for a more rounded approach to recovery, confidence, health, and happiness.



SHYAM WAZIR, VANCOUVER: In a society which tries exceedingly hard to abnegate anything which may come across as being contrary to the status quo of what is “sexy”, pictures like these depict the reality of the human condition. Taking into consideration that we as a society have embraced the whole “BBW” (Big Beautiful Woman) thing here in North American pop culture, perhaps disability is the next frontier to surpass in the arena of sexual “taboo”? ...Or it might just remain in the “fetish” category of the internet tongue emoticon...It could go either way, though. But it’s up to the general public to define that, and it’s up to each individual as to whether or not we pave the way for it to become more front and center for the mainstream to view in order that it may then be open for discussion.

To learn more about Rachelle Friedman and why she posted her provocative photos, connect with her on Facebook (facebook.com/rachelleandchris) or at www.rachellefriedman.com. Visit us at facebook.com/spinalcordinjurybc and weigh in on this and other topics.

An Ounce of Prevention...

Properly maintaining your wheelchair will help you avoid expensive repairs and getting stuck in the cold...in the middle of a crosswalk...at two in the morning...

Rain gear? Check. Toque? Check. Layers and layers of clothing? Check. Every winter, you try to avoid getting sick. Why treat your ride any differently? Good tread on your tires and healthy bearings are a start, but there's much more you can do to get the most of your wheelchair or scooter. Our friends at Wheelin' Mobility, Vancouver's 24-hour on-site wheelchair repair service, share some of their top tips and tricks to bring your mobility equipment up to snuff before the worst weather of the year arrives.



1 Listen to your equipment and catch problems early on. Nobody knows your wheelchair or scooter like you do: the exact fit, feel, and sounds it makes. You can tell if it's listing to the right or the left, or when it makes a

new or odd sound. You live and breathe your equipment every day, and know what it can handle and what it can't. If it starts to behave differently, check it out. Catching a problem early will help prevent you from being stranded due to a major problem later on.



2 Pay attention not only to your destination, but how you're actually getting there. The harder you are on your chair, the more stress it absorbs—and that stress can add up. When you're moving on autopilot, it can be easy to accidentally go down a set of stairs instead of the ramp. Or to roll over garbage, dog poop, and even glass. Going down stairs is extremely dangerous and can be hard on your air tires if you're not expecting it, making it easy to pop a tube and put extra stress on your rims

and spokes. And picking up debris on your wheels is not only hard on your hands (yuck!) but could pop a tire or clog your casters. For power chairs and scooters—especially those with air tires—the risk is there too. Finally, beware of puddles—rolling through them with your casters is a great way to get rusty clogged bearings...and there's nothing worse than the high-pitched squeak of destroyed bearings.



Charge your battery regularly to maximize its life. Think of your battery the way you think of your own energy levels: you can't always overextend yourself and expect your body to keep going at full strength. Similarly, running your battery until it dies drains the battery life. For top performance, give your battery a regular charge—and get some sleep!



Say no to crack(s). If you're using a manual chair, regularly inspect your wheelchair frame for cracks—especially in areas that sustain significant stress, such as the cross brace of a folding wheelchair and the caster housing. Depending on the crack location, repairs can range from a simple welding procedure to a complete frame replacement. Any crack can be a serious threat to safety and should be tended to immediately. (Your owner's manual will tell you which parts of your chair are covered by the manufacturer, how long the warranty is good for, and about the service policy.)



Check for loose nuts and bolts at least once a month—and replace them correctly. Substitute damaged nuts and bolts with corresponding grades and configurations.

A number label on the head of the bolt signifies how strong it is—the higher the number, the stronger the bolt—and your replacement bolt should match this grade or strength rating. Avoid replacing a lag bolt (partly solid/partly threaded) with an all-threaded bolt (or screw.) And, outside of your regular checks, trust your instincts—if you felt, heard, or saw something fall off your chair, make sure to check it out.



Ensure electrical connections are firmly in place, and free of grime and corrosion. Regardless of weather, remember to occasionally check electrical connections on your power chair.

And if you live in a climate where harsh winters mean salty roads, you'll need to clean the electrical connections on your chair more often to protect them from salt corrosion. After detaching the cable from the connection, try removing buildup with a wire brush. (Hardware store products like Liquid Wrench can help to loosen stuck parts.) Apply a small amount of petroleum grease to limit corrosion. When someone works on your chair, confirm that all connections are tight—and right. If you're working with the wires, remove only

one connection at a time. A good chair design will colour code the wires, but putting them back incorrectly is quite dangerous. At the least, you could damage the electrical system of the chair—at worst, you could cause a short circuit that could burn you.



Tighten and adjust legrests, footrests, armrests and backrests once a month.

It's no fun to have your backrest come off in public, requiring some ingenious problem-solving to put it back on. If you're using a manual chair, conduct monthly checks to see if legrests, footrests, armrests, and backrests can be released (if originally designed to do so!) and put back into place with ease. These parts frequently wear down, so go easy on them and be aware if they need replacing. Power chair users should also inspect any moving parts that get a lot of use. Footrests, removable backs, tilt mechanisms, or adjustable armrests are likely to wear out sooner than other parts of the chair, but will last longer if kept tightened and properly adjusted.



Lubricate your manual chair at least once a year.

If you have a folding wheelchair, ensure that it opens and folds easily. The folding mechanism requires yearly lubrication (consult with the owner's manual for the type of lubricant to use)—more frequently if you live in a humid or wet climate. All pivot points on the chair, such as where the front casters turn, need to be lubricated as well. Consider lubricants that offer corrosion protection and are water resistant. Ball bearings will also need lubrication, but most manual wheelchairs have sealed bearings or wipers to discourage water and dirt from damaging them. These bearings require special care and should be serviced by a trained specialist.



Keep your manual chairs running smoothly with good (and clean) wheels, tires and axles.

Quick-release axles allow quick removal of your wheels. These axles should slide through the axle housing smoothly and click into place, or if threaded (like a screw), should thread easily and latch properly. Squeaking, binding or excessive side-to-side motion should not occur as you roll. Keep the axle housing clean of debris to help ensure that it functions properly—this area is highly susceptible to dirt and mud build-up and should be cleaned once a week for the active user, or on a monthly basis otherwise. Remove wheels and wipe the axles with a clean cloth containing a few drops of oil, and try cleaning the axle housings and around the bearings, too.



Check your wheel alignment monthly.

Just like cars, chairs need their wheel alignment checked. If your wheelchair tends to veer to one side while coasting, it could very well be that

your wheels are out of alignment or that your spokes have become loose or damaged. Inspect your wheels weekly to ensure that spokes from the axle to the rim are intact, that rims are not bent, and that your wheels are parallel to one another. A properly adjusted wheel may require the equipment and expertise of a specialist.



Inspect and repair the front casters every few months. You'll likely feel if there's something wrong when you wheel, but it's good to physically check if you sense a problem. There should be no wobbling of the caster wheel, no excessive play in the caster spindle, and the caster housing should be aligned vertically. Your chair will veer or squeak if things are not quite right.



Learn how to change or repair a tube (or have someone on hand who can help you). The dreaded flat tire...it's one of the most common mechanical problems in manual chairs.

Tires with pneumatic rubber tubes—versus airless foam or solid inserts—require more maintenance. If you're an active person who has frequent flats, carry (and learn to use) a patch kit, available at any local bike shop. These kits include several rubber circular patches that are either glued over the hole or, easier still, are self-adhering. It's cheaper than buying a new tube.



Check tire pressure once a week. Under-inflated tires can make it more difficult to push and manoeuvre your chair, cause the tires to wear faster, and prevent the wheel locks from seating properly against the wheel. Ensure you have the right pressure in your tube as indicated on the side of the tire. If you have air tires, you'll want to make sure they're full. A quick check method is to pinch the outer walls of the tire—the tire should be firm. You can inflate the tube using a hand-pump, or by electric or regular bicycle pump. (Just make sure you have the right pump for the type of tubes you have.) Foam-filled wheels on scooters should be replaced regularly—once the foam starts to break down there's no way to fix it.



Replace tires when the tread becomes worn or cracked, or when the side walls begin to bulge out when pumped. While you're at it, don't forget to check that your wheel locks are secured tightly to the frame, that they hold tires firmly in place, and that they're easily activated. Make adjustments if they interfere with the tire while rolling as this can cause undue wear and tear. Want to know which tire tread is right for you? Head to sci-bc.ca/stories/blog ■

For more tips from *Wheelin' Mobility*, or info on their Preventative Maintenance Packages, visit facebook.com/wheelinmobility.

Are you having difficulty passing an intermittent catheter?



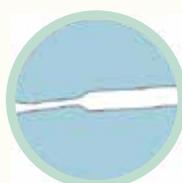
Bulges

in the urethra prevent an easy passage of the catheter and increase the risk of injury.



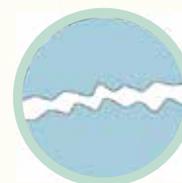
An enlarged prostate

or a spastic sphincter make passing the catheter into the bladder even more difficult.



Strictures

(urethral contractions) may make the usage of a traditional catheter impossible.



Scarring

after micro traumas result in a more difficult passage for the catheter.



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MinION

An inexpensive, pint-sized DNA sequencer passes yet another practical test—diagnosing UTIs in record time—with flying colours.

Most dictionaries define a minion as a loyal or faithful servant. In fiction and film, minions tend to be cast in a dark role—more often than not, they’re the mindless muscle that enables crime bosses, ruthless dictators and the like (even the yellow minions of animated film fame, despite being lovable and goofy, fall into this stereotype).

But the MinION, the flagship product of UK-based Oxford Nanopore Technologies, is a faithful electronic servant that is definitely working for the forces of good. And that’s great news for people with SCI or anyone else at risk of urinary tract infections, or UTIs.

The MinION is a miniaturized DNA sequencer slightly larger than a standard USB stick. It uses “nanopore” technology to identify biological molecules contained within fluid that’s injected into the device. At the heart of

the MinION is a flow cell containing hundreds of nanopores—tiny holes or pores—which are electrically charged. When molecules pass through the nanopores, they create a change in the current. Those changes are analyzed by the device to identify the molecule in question.

Oxford Nanopore Technologies began working on the device in 2005. In 2014, the company debuted the device amid a great deal of anticipation by the research and medical communities—after all, up to this point, DNA sequencing was a costly, time-consuming endeavour requiring bulky and expensive equipment. In comparison, the MinION is cheap, small, and highly portable—it plugs into a laptop’s USB port, and displays data on the screen as they are generated, rather than at the end of a run that can take days.

But researchers who began using the MinION reported several drawbacks—for example, they observed less than perfect accuracy rates, and it became apparent that the

device lacked the capability to sequence large molecules, such as the human genome. Thus, the early response was lukewarm.

Gradually, however, the device began chalking up a string of successes around the globe. In 2014, researchers from the Ontario Institute for Cancer Research and the University of Birmingham succeeded in developing methods to overcome the high error rate. Earlier this year, a team from University of California San Francisco reported that the MinION was able to detect Ebola, hepatitis C and the chikungunya virus in human blood within four to 40 minutes. Another study published by the University of Queensland found that the MinION could identify bacterial species and strains in less than an hour. In May, Italian biologists demonstrated the device's true portability, using MinIONs in a rainforest in southern Tanzania to sequence the genome of a native frog.

And then came a breakthrough that should be of great interest to our readers. On September 19, at a conference in San Diego, a team of researchers from the UK's Norwich Medical School at University of East Anglia reported that they had successfully used the MinION to detect bacteria directly from urine samples—and determine the best, highly-specific antibiotic to eradicate it—four times quicker than the traditional method of starting a culture in the lab.

"Antibiotics are vital (in UTIs), especially if bacteria has entered the bloodstream, and must be given urgently," said team leader Professor David Livermore in a statement. "But unfortunately it takes two days to grow the bacteria in the lab and test which antibiotics kill them. As a result, doctors must prescribe a broad range of antibiotics, targeting the bacteria most likely to be responsible, and then adjust treatment once the lab results come through."

Livermore explained that the result is too often gross over-treatment of the UTI, which contributes to the growing problem of antibiotic resistance, and also leads to the destruction of many of the patient's "good" bacteria.

"This 'carpet-bombing' approach represents poor antibiotic stewardship, and it is vital that we move beyond it," continued Livermore. "The way to do so lies in accelerating laboratory investigation, so that treatment can be refined earlier, benefitting the patient, who gets an effective antibiotic, and society, whose diminishing stock of antibiotics is better managed."

In addition to the immediate benefits of being able to quickly identify a UTI and prescribe a highly-effective, narrow-spectrum antibiotic treatment for it, the findings could potentially usher in a new era of antibiotic development.

"The development of rapid diagnosis will make it easier to develop new drugs that are specific to a particular pathogen," said team member Dr. John Wain, Professor of Medical Microbiology at the University of East Anglia. "This means that narrow-spectrum drugs that cure the infection and do least harm to the body's normal flora can be used instead of broad-spectrum drugs. It is this technology that is paving the way for the development of new antibiotics that target only 'bad' bacteria."

The researchers caution that, at this time, the device is only effective with

highly-infected urine and can't predict antibiotic resistances that result from mutation. But they're confident that the technology will continue to develop and these limitations will be overcome soon.

Could your local hospital or doctor's office provide MinION analysis next time you show up with a suspected UTI? Perhaps—by all medical equipment standards, the device is ridiculously cheap. It's currently available to qualified researchers or medical professionals for an access fee of \$1,000. This gives them a MinION starter pack and membership to the MinION Access Programme, or MAP, a community-focused access project which started in spring 2014. The goal of MAP is to enable a broad range of people to collaborate and explore how the MinION may be useful to them, to contribute to developments in the device's analytical tools and applications, and to share their experiences and collaborate.

Next time you have a UTI, consider telling your doctor or healthcare team about the MinION, and point them to www.nanoporetech.com where they can learn more about the device. ■



PHOTO CREDIT: Andrew Kilianski



Dads *and* Daughters

Family connections are forged in the waves during a memorable weekend surf trip for SCI BC peers and their daughters



For Scott Heron,

SCI BC's Victoria-based Peer Support Specialist, the only thing better than catching a wave was watching his daughter catch her own.

"Surfing is exhilarating," he says. "That excitement and rush as you catch a wave. It lifts you up and you almost feel a sense of weightlessness as you speed down the wave. The only feeling that matches it was being able to see my daughter stand up and catch her first wave."

Scott and his daughter, Breanna, 13, were one of four family duos from Spinal Cord Injury BC on the father-daughter surf trip with Power To Be this fall. Based in Victoria and Vancouver, Power To Be works closely with community partners to facilitate adventure-based programs and outdoor activities. This second annual trip, a weekend adventure in Tofino, provided a chance for the participants to try something new and challenge their perceptions of what is possible—and to strengthen family bonds in doing so.

"This isn't something that I went to watch her do; this is something we did together," Heron says. "Often, as a parent with a disability, we end up being

spectators to our kids' achievements. This, I was a full participant with her in those achievements."

This year, three other father-daughter teams from the Island—Terry and Melina Fowler, Miles and Lilly Stratholt, and Michael and Madeline Cameron—shared a similar experience in the waves.

With additional funding from the United Way of Greater Victoria and support from surf instructors with Pacific Surf School, the group spent two days in the ocean using a variety of adaptive equipment to transition from beach to board. With TrailRiders and all-terrain wheelchairs, as well as special seats for the boards, the fathers were able to get comfortable in a new environment.

"The biggest challenge was getting people to and from the water," says Carolyn McDonald, Power To Be community development coordinator. "We would transfer from their wheelchairs into the TrailRiders, which we would walk right out into the water so it was waist deep. Then they could transfer right onto the board, using their arms and the added buoyancy of the water."

With Power To Be staff waiting to catch the surfers in the shallows and Pacific

Surf School instructors supporting them in the swell, the duos learned the nuances needed to conquer wave after wave.

"Seeing the growth was amazing," says Gaby Emmett, Power To Be program facilitator. "Especially in some of the participants who came out last year, both the daughters gaining confidence in standing up and the dads catching waves on their own."

After the first day, the families shared a meal and talked about the experience. It was an opportunity to swap stories of soreness and achievement, Heron says, noting tackling the waves was like doing 500 push ups in one day. The next morning they were all eager to do it again.

"It was equally powerful for the daughters to see their dads as it was for the dads to see their daughters cruising around on the water," says McDonald.

As the weeks pass after the trip, Heron and his daughter are still talking about it. It comes up in conversation, and always with laughter. It doesn't escape him that the weekend was also an opportunity to show his daughter that a disability doesn't have to limit experiences.

"To show her that there are abilities and possibilities to do things together with the assistance of a group like Power To Be is just amazing," Heron says. "How many other people can say that? Here I am, a person with a disability who has been out surfing with my daughter. She's sharing this event with her friends and they're getting to see her dad in a completely different light." ■

This story is adapted with permission from Power To Be, which offers adaptive recreation programs such as kayaking, hiking, and surfing in Victoria and Vancouver. Power To Be uses adaptive equipment—like adding pontoons to a kayak for stability or using a TrailRider for hiking—to support people with different levels of mobility. To learn more about participating or volunteering in a program, contact info@powertobe.ca or search SCI BC's online event calendar for 2016 events. Photo Credit: Michelle Cameron.

CLOCKWISE FROM TOP LEFT: Michael Cameron and his daughter Madeline catch a tasty wave; Scott Heron perfects his technique; the venerable TrailRider made it easy to reach the beach (and water); two thumbs up from Scott Heron and his daughter Breanna; getting a lift to the surf; early morning instruction on the beach.



Get Your Butt Moving!



Meet SENSIMAT—an inexpensive way to stay diligent with your pressure sore prevention program.

When it comes to pressure sores, the road to the emergency ward is often paved with good intentions. Even the most diligent of wheelchair users can lose track of when it's time for some critical pressure relief, and even the slightest lapse is sometimes enough to put you at risk.

But what if there was a device that could warn you when you've been immobile in your chair for too long—and even tell you what areas of your butt are most at risk?

Well, there is a made-in-Canada device that can do just that. It's called SENSIMAT, and it's intended to help wheelchair users prevent pressure sores from forming in the first place.

The system consists of a mat that's tailored to fit under a wheelchair user's existing cushion, and an app that

works with your smartphone or tablet. The mat contains six sensors—three on each side. Two monitor the pressure on your upper thighs, and the other four monitor pressure on your butt. Once you sit in your chair, the mat uses Bluetooth technology to wirelessly sync with your device, and then begins to send signals to it. The signals alert you when and where pressure has begun to build up, using either a beeping sound or vibration on your device.

The app also displays red or blue for all six sensors—red is for trouble spots, and blue for pressure-free zones. This lets you know exactly where pressure is building, so you can then take the necessary steps to relieve the pressure by either leaning to the left, right, or forward, or lifting yourself completely off your cushion. After a few seconds, the sensors turn grey, indicating that the pressure has

been relieved. You can easily set the number of reliefs you want to achieve in an hour, and also how often you want to be alerted.

Setup is easy—the SENSIMAT simply slips right under your cushion. After you download the app (Android or Apple iOS) and register your mat, the system starts communicating with your device. In addition to allowing you to track your pressure reliefs in real time, the app also lets you analyze your relief trends over a period of time of your choosing, so you can see what time of the day you're most prone to lapses, or determine what activities are most likely to lead you to forget to relieve pressure.

Alerts can also be monitored remotely via a web portal, so the system can be used by family members, caregivers, and even OTs who want to track their patients' level of activity outside the clinical setting.

SENSIMAT is the result of a joint effort between Toronto electrical engineer David Mravyan, and Dr. Milos Popovic, the Associate Director of Research at the Toronto Rehabilitation Institute. You may recall that, in the December 2014 issue, we profiled Popovic and his work developing the MyndMove, a promising therapy for hand paralysis caused by SCI or stroke.

"Back in 2007, after finishing my electrical engineering degree at Ryerson, I was looking for opportunities to enter the healthcare and medical devices field," says Mravyan. "I visited a University of Toronto open house and met Dr. Popovic. After visiting his lab and having numerous discussions with him, I established that the issue of pressure ulcer prevention was an interesting and challenging area of potential technological development."

With advice from Popovic, Mravyan started tinkering with pressure sensor systems in his spare time, and by 2009 he had developed a prototype and filed a patent for the technology. But with little funding available, the project stalled.

It was resurrected in 2011, when Mravyan decided to obtain an MBA at the Richard Ivey School of Business. "I decided that it would be a neat idea to use the pressure ulcer prevention system I'd prototyped for a "new venture" class project. He joined forces with classmate Will Mann, and through the course of the year the pair moved the concept forward.

"After completing the MBA, we formed SENSIMAT Systems in 2012, raised some initial capital through a number of grants, and started improving the product as well as testing it at Dr. Popovic's facility," he says.

In 2013, with the system somewhat refined, the company launched a crowdfunding campaign which

helped get the word out and generate some initial sales. Then, in 2014, the company was awarded a Rick Hansen Institute Emerging Interventions & Innovative Technologies grant. This allowed them to further refine the system (for example, they were able to increase the battery life to over a week), come up with a better manufacturing process, create an online web portal, and develop the Android application.

It also allowed them to continue testing the cushion to determine its effectiveness.

"The SENSIMAT was tested at Toronto Rehab in a number of studies," says Mravyan. "First, it was important to verify that the system functions as intended and could detect pressure, classify seating behavior and alert the individual if they haven't shifted or modified their sitting position for a prolonged period of time. This study was first conducted with able-bodied individuals, and then, after getting ethics approval, it was also performed on groups of SCI patients in the Lyndhurst Centre at Toronto Rehab."

Additional studies were done at the George Brown College simulation hospital and, most recently, at the Stan Cassidy Research Centre in New Brunswick. In that study, five patients used the SENSIMAT over a period of four weeks—first with no alerts, then with alerts, and then again with no alerts. "Some initial reports indicate that there was an increase in pressure relief behavior in the patients during the two week use of the SENSIMAT," says Mravyan. "Further data analysis is ongoing."

What's refreshing about SENSIMAT is that the company is not restricting itself to either a self-managed or institutional business model, as other companies in this space seem to. In other words, the company markets equally to individuals and to institutions or settings where a number of patients are monitored by professionals—for example, a seating specialist who could use the technology to monitor all of his or her patients.

"The reason we focused on both was because we've found that there is no such thing as a typical wheelchair user," says Mravyan. "There are instances where the individual is able to perform the repositioning themselves, and there are instances where the caregiver has to perform them for the individual. We wanted to target a larger population and make a system that was usable in either scenario."

At the moment, there is no coverage for the system from any of the provinces (including BC), although Mravyan says the company is working through the application process, beginning with Ontario's Assistive Devices Program. But meanwhile, you can purchase a SENSIMAT for a modest price of \$299, which includes the system, a charger, the free app download and access to the web portal.

"Currently, we're selling the SENSIMAT directly," says Mravyan. "Individuals, rehab centres or university research facilities email us the sizes they would like and we send them an invoice for the systems. In order to grow, we will need to secure larger orders. For that reason, we're actively looking for distribution and manufacturing partners. We understand

David Mravyan



that in order to achieve any kind of scale, we need strategic partners that have access to distribution channels, and that can really increase our monthly orders. Besides the wheelchair system, we are looking at using our sensor technology in hospital beds and office chairs. We're also working with a car manufacturer to potentially integrate our technology into car seats. This obviously takes a lot of time, but could be very rewarding for us in the future."

Mravyan says that developing and marketing SENSIMAT has been a gratifying experience. "We've had numerous cases of individuals that have been suffering from pressure ulcers and know firsthand the dangers of not being active with their pressure relief. For one individual, it took about five years to heal and required numerous surgeries. He was happy to try our system because of the potential insights he would get regarding his seating habits."

Visit www.sensimatsystems.com for more information or to order. ■



The SENSIMAT pad (left) contains six sensors to monitor the pressure on your upper thighs and butt, and is customized to fit unobtrusively under your existing cushion. The web portal (below) allows users to check and evaluate their pressure relieving tendencies over any length of time, on any device or computer.



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ask the SPIN DOCTOR

“My resolution this year is no more pressure sores,” writes Aarav. “I’m going to get serious about pressure relief and getting a better cushion, but I also think I’ve read that diet can play a big role. Can you please shed some light on this?”

We recruited Joanne Smith, a Toronto-based certified nutritionist & co-author of *Eat Well Live Well with Spinal Cord Injury*, to answer Aarav’s question. To learn more about Smith and her work, visit www.eatwelllivewellwithsci.com. One other note: our monthly cooking classes at ICORD feature recipes from Joanne’s book—all SCI BC Peers are welcome to attend.



Pressure sores are more than just a pain in the ass (or any other boney prominence). These severe skin breakdowns can significantly hinder your quality of life and, in some serious cases, be life-threatening.

After an SCI, your skin is much more susceptible to damage and breakdown. This is due to loss of sensation, decreased muscle mass, altered blood circulation and chronic pressure exerted over areas such as your buttocks, elbows and heels.

It’s estimated that 10 to 30 percent of us who live with SCI will develop a pressure sore within our first year of injury, and that 50 to 80 percent of us will develop one at some point in our life. This high prevalence of pressure sores accounts for a large number of SCI re-hospitalizations, and research indicates that our risk of developing them increases with time since injury.

Given these facts, what’s the best way to treat a pressure sore? The answer: do everything in your power to prevent them from developing in the first place. So, in addition to using proper seating devices and practicing pressure relief techniques, one of the best ways you can maintain your skin integrity is to ensure you’re getting the essential nutrients needed to support healthy, strong skin. Here’s my list of must-have nutrients and foods that are rich in them:

PROTEIN: essential for tissue synthesis and healing. Meat, fish, poultry, eggs; two to three servings per day (one serving equals the palm of your hand).

VITAMIN A: has immune-boosting and skin-reparative properties. Orange/yellow vegetables and fruits; 5000 IU per day.

VITAMIN C: has multiple immune, collagen and elastin-building functions. Citrus fruits, berries, red/green peppers, broccoli; 2000 mg per day.

VITAMIN E: a powerful antioxidant that can help reduce free radicals which can damage tissues. Almonds, sunflower seeds, olives, spinach; 400 IU per day.

OMEGA-3 FATTY ACID: helps reduce inflammation, assists in transporting nutrients such as vitamin A and E, and is needed for the growth and support of cells and tissues. Flax seeds, salmon, nuts (walnuts), seeds; 1.5 grams per day.
ZINC: supports collagen production. Pumpkin and sesame seeds, spinach, beef; 30 mg per day.

It’s also important to eliminate refined and processed foods, as these can cause tissue inflammation, which inhibits the body’s ability to heal tissue.

The following recipe, which contains all of the above nutrients, is a delicious prescription to help keep your skin healthy and whole!

SALSA CHICKEN SALAD

- 4 cups baby spinach
- 2 chicken breasts (can also substitute white fish)
- 1 tsp sea salt
- 3 tbsp butter, melted
- 1 tbsp garlic, minced
- 1 cup tomato, peeled, seeded and diced
- 1/2 red pepper, diced
- 1/2 green pepper, diced
- 3 tbsp white wine vinegar
- 4 tbsp olive oil
- 4 tbsp sesame seeds
- black pepper to taste

1. Season chicken with salt
2. In small bowl, combine butter, garlic
3. Grill chicken seven minutes per side, brushing with garlic butter blend
4. While chicken is cooking, combine tomato, peppers, white wine vinegar, olive oil, salt and pepper in bowl and stir well
5. When chicken is cooked coat with sesame seeds and place on bed of spinach
6. Serve salsa over grilled chicken and enjoy.



The Migraine Connection

Recent research at ICORD points to a significant link between migraines and SCI.

When Freda Warner began to investigate a link between SCI and the most debilitating of headaches, migraines, she had her suspicions that people with SCI were at greater risk than able-bodied people. But she had no idea of the extent of the risk that her work would reveal—or the magnitude of impact on the lives of those who suffer from migraines.

“Although we suspected there might be an association between SCI and migraine headaches, I think the magnitude of the odds was a big surprise for all of us,” says Warner, who is a research assistant at ICORD and a PhD student at UBC, focusing on SCI-related chronic pain. “The odds of having migraine headaches in the SCI population was almost five times greater than in the non-SCI population. This finding became even more interesting when we observed the degree to which migraine headaches and SCI affected quality of life together, when compared to SCI or migraine alone.”

“Freda is right—the odds were shockingly high,” adds Dr. John Kramer, a neuropathic pain specialist at UBC and ICORD, and Warner’s supervisor. “Freda took the project one step further when she looked to see how migraines were affecting general health. This is really important because it not only shows that migraine headaches were present in people with SCI, but that they might have a serious effect on health.”

Warner, Kramer and two other co-authors—ICORD researchers Dr. Jacquelyn Cragg and Marc Weisskopf—published their findings in the August 26, 2015 issue of the journal PLOS ONE. Their paper, titled Spinal Cord Injury and Migraine Headache: A Population-Based Study, provides compelling evidence that migraines are indeed a much bigger problem for people with SCI than previously thought.

The paper is essentially the result of some sophisticated crunching of numbers contained in the 2010 Canadian Community Health Survey (CCHS) conducted by Statistics Canada. The CCHS is a national survey that collects data on a variety of health topics from Canadians. The 2010 version included a section on neurological diseases, and it was this data that the team obtained access to.

“Dr. Cragg had used data from the CCHS in some of her earlier investigations, and it was she who suggested that migraines might be an interesting avenue to explore next,” explains Warner.

“Freda was working on the data for a course at UBC,” adds Kramer. “We needed to come up with an interesting research question, which had not been previously asked. My area of interest is pain, and migraine, at its core, is a painful neurological condition. There were a few reasons to think that headaches would be problematic for people with SCI, so we started digging.”

The team looked at the sample of people who replied yes or



no to the questions regarding SCI and migraines. “We examined how much greater the odds of having migraine headaches were in the SCI population versus the non-SCI population,” explains Warner. “We then did this analysis again, while adjusting for factors we thought might be important—for example, age and gender. Finally, we looked at each of these populations—SCI with migraine headaches, SCI without migraine headaches, migraine headaches without SCI, and neither SCI nor migraine headaches—and observed how these groups rated their self-perceived health.”

Without a doubt, the most eye-opening revelation of the completed data analysis was the astonishingly high number of people with SCI who reported suffering from migraines. The finished paper summed it up with this statement: “The prevalence of migraine was higher in the population with SCI (28.9%) than in those without SCI (9.9%).”

“I agree that this number suggests that migraine headaches may indeed

be a bigger problem with people with SCI than previously expected—and is a finding that definitely warrants further research and investigation to confirm this,” says Warner.

Warner adds that further research should also attempt to answer the question, “Why?”

“This is certainly the most interesting question we have following this study—what is the cause of this association? Because this survey relies on self-reported disease status, and not diagnoses by a medical professional, we have to be cautious in interpreting the results. Although we’ve discussed some possible physiological explanations, this study is very much an introductory exploration, and isn’t strong enough to support a physiological connection on its own. We hope that our future investigations might shed some light on the topic, namely trying to establish that migraine headaches are occurring after SCI, and that those who are reporting them have truly been diagnosed with them and not other dis-

eases, such as non-migraine headaches.”

Kramer agrees that, at the moment, it’s difficult to do more than speculate as to the high prevalence rates. But he says there is some evidence that it is a standalone by-product of SCI, as opposed to being the result of another SCI secondary complication such as autonomic dysreflexia, or AD.

“Around the same time we published our finding, another group in Estonia reported that headaches were elevated in people with SCI,” he explains. “They had some additional information we didn’t have—for example, level of injury, and severity—and found that these factors didn’t matter. Combined with our strong findings, which were in a much larger sample, this indicates that headaches may not simply be related to other SCI problems, like AD. Rather, headaches might be, in themselves, a problem due to SCI.”

Beyond prevalence, Warner says the other important conclusion of the research is that those with SCI who

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MORE MIGRAINE INFORMATION

There are many treatments for migraines, and many strategies for living with migraines. Not surprisingly, there are hundreds of excellent resources online for people who suffer from migraines—far too many to list here. But one excellent resource to start with is www.migraine.com, a huge virtual community of migraine patients and experts. The site features articles written by some of the top experts in migraine treatment, education and social issues, along with a well-populated forum of people from all walks of life who write about their own experiences with migraines.

experience migraines also experience significantly poorer overall health, or perceived poorer overall health, when compared to those who have SCI or migraine headaches alone.

While the researchers have confidence in their analysis, they're careful to reinforce that there are some limitations of the study.

"The biggest limitation lies in the fact that the two main variables—SCI and migraine headache status—were self-reported," says Warner. "Firstly, the prevalence of SCI found in this report is higher than previously reported in other studies, indicating that there might be an overestimation in our sample. Migraines, too, may have been misreported. In SCI it is possible to have increased headaches from other sources such as AD, and head trauma, which are not actually migraine headaches."

Now what? It turns out that, following the 2010 CCHS, Statistics Canada performed a follow-up survey known as the Survey on Living with Neurological Conditions in Canada (SLNCC). "We hope to use this survey to perform a more in-depth analysis of our original question—namely, establishing the timeline of SCI and migraine headaches, and potentially limiting sources of misclassification using the extra available information."

As for readers who believe they are suffering from migraines and want to know what you can do about them, Warner and Kramer say step one is getting a firm diagnosis.

"In order to confirm that your headaches are migrainous, it's important to seek a diagnosis from a health professional," says Warner. "Although most current treatments have produced vari-

able results, it is possible that you may find something that will work for you."

"Talking to a physician about your headaches would be an important first step," says Kramer. "Identifying the triggers would also help understand if the headaches are, in fact, migraines. As Freda suggested, treatment success is pretty variable, but the first step towards that would be a diagnosis." ■

Abbott-Peter Inducted into CPC Hall of Fame



Congratulations to Vancouver's Marni Abbott-Peter, who was inducted into the Canadian Paralympic Hall of Fame at a Gala on November 27 in Ottawa.

Abbott-Peter, who is paraplegic, led Canada's national women's wheelchair basketball team to three gold medals and a bronze in her four Paralympic Games appearances (1992, 1996, 2000, 2004). She was the cornerstone on one of the most dominant teams in the history of Canadian amateur sport, which also won three consecutive world titles and produced a 43-game winning streak in world championship and Paralympic Games play.

Since retiring as an athlete, Abbott-Peter has focused her attention on coaching and giving back to the wheelchair basketball community. Today, she is a coach and mentor of young athletes and has recently been named the Director of BC Wheelchair Basketball Society's Let's Play Program.

"It's a great honour to be inducted into the Canadian Paralympic Committee Hall of Fame with the other outstanding inductees this year and those from past years," says Abbott-Peter. "I've been very lucky throughout my career as an athlete and coach to have the support from the CPC and Wheelchair Basketball Canada. Paralympic sport is a catalyst for positive change in our society; our Canadian teams have been very successful on the international stage because of the great leadership provided by the CPC. My life has been impacted in so many positive ways because of my involvement in sport."

Our congratulations also to Lauren Woolstencroft of North Vancouver, the other British Columbian inducted during this year's ceremonies. Born missing her left arm below the elbow as well as both legs below the knees, Woolstencroft is a three-time Paralympian who won eight gold medals, one silver, and one bronze during her skiing career. Off the ski slopes, Woolstencroft works as an electrical engineer with BC Hydro.

The Canadian Paralympic Hall of Fame was formed in 2000 to recognize and celebrate those who have made a significant contribution to the growth of the Paralympic movement in Canada. These individuals are acknowledged within the Canadian Paralympic Hall of Fame Honoured Members section located in the Olympic and Paralympic Gallery at Canada's Sports Hall of Fame in Calgary.



Spinal Cord Injury BC

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x



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=



WE HAVE A BIT



IF EVERY READER

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GIVES A LITTLE

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IS MORE THAN A
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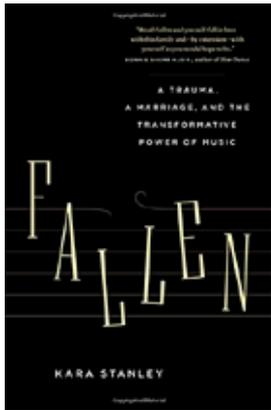
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Fallen: A Trauma, a Marriage, and the Transformative Power of Music

by Kara STANLEY • 320 pages • Greystone Books (April 2015)



Brain injury. Spinal cord injury. Music. Science. They're hardly the elements of your average love story. But they're central in the lives of Kara Stanley and her husband, Simon Paradis. And now, through *Fallen*, Stanley invites readers into her intimate, changing, and often vulnerable world.

"I wrote *Fallen* because that's what I do: I write," says Stanley. "I write to know what I am thinking;

I write to know what I am feeling. I write to remember. So, when Simon's accident occurred—this shattering event in both our lives—writing was the main tool I had for navigating and processing these big, traumatic changes."

The story details the aftermath of her husband's 2008 two-storey fall on the jobsite, which resulted in a T12/L1 SCI and a serious brain injury. With beautiful prose and profound honesty, Stanley combines the heart-wrenching narrative of her life partner's injury, the trying rehabilitation process, and the effects on their marriage. Part recovery narrative, part love story, *Fallen* portrays the transformative role of music in Simon's life, both before and during his ongoing rehabilitation.

"I wanted to be open and honest about that place of extreme vulnerability and I wanted to tell the story of how, with the help of each other, our family and our community, we were able to move through it," says Stanley. "One of the most powerful things I learned during this time was how resilient and adaptable we, as humans, are."

Today, the couple's strength, hope, and determination are paying off. And so is Stanley's writing. *Fallen* has been cathartic, allowing the family to carry their grief and loss forward; honouring it. And it's also been long listed for the BC National Award for Canadian Non-Fiction. The winner will be announced early in 2016—we have our copies ready for the signing, and our fingers and toes crossed!

Fallen is available in bookstores and at www.amazon.ca.

Me, Myself, and My Brain Stem Tumour

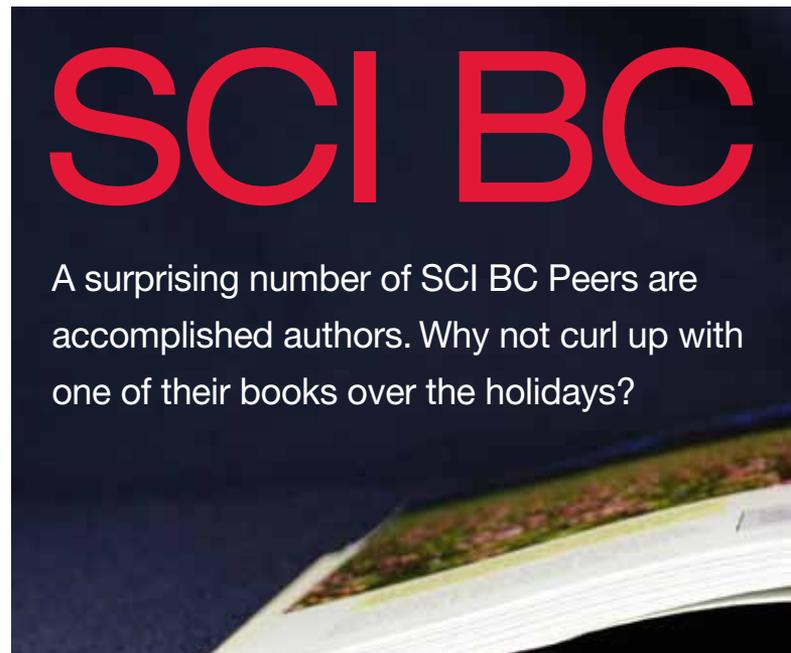
Bayan AZIZI • 226 pages • Everywhere Now Press (April 2015)

Bayan Azizi, a 26-year-old SCI BC Peer from North Vancouver, has always been a positive guy. Even when, at age nine, he was diagnosed with a tumour on his brain stem and given three months to live if nothing was done. Even through the three brain surgeries, the chemotherapy and radiation treatment, and the long bouts of hospitalization and rehabilitation to regain ability. Even through the three years it took him to write *Me, Myself,*

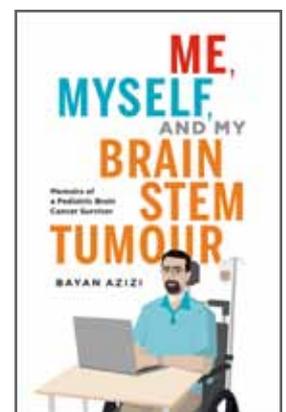
and My Brain Stem Tumour, typing with just one finger, until his memoir to date was complete.

Azizi's rare type of tumour wasn't malignant. But because it was located in such an important and easily-damaged part of his brain, outright removal was impossible. Even with surgery, the tumour could still affect all body function and easily lead to death; without it, it most certainly would. Today, Azizi breathes through a tube in his neck, speaks with a whisper, relies on a wheelchair for mobility, regularly experiences seizures, and has limited physical ability—but throughout his journey, he has defied the odds.

Azizi's book—honest, humorous, and beautifully designed—is an insider look at the life of a pediatric patient. In some ways, his childhood is that of an average Canadian boy: he lives and



breathes the Vancouver Canucks, adores the new family puppy, and slaughters his opponents in Scrabble, every time. In other ways, he's unique: when he's approached by the Make-A-Wish Foundation, he scrupulously weighs the pros and con of every possible wish; he attends classes with a nurse by his side; he contemplates throwing his clunky wheelchair off a bridge.



Despite his struggles, Azizi comes at every challenge—missing vertebrae in his neck, a tracheostomy, increasing weakness on his right side—with hope, a steadfast work ethic, and guru-like clarity: "A problem is a struggle you dwell on and feel sorry about, whereas a challenge is something you can focus on and overcome."

His book provides testimony that, no matter what position you're in, you shouldn't have to give up on yourself. "I chose to write my book mostly to share my story and give hope to

others,” says Azizi, whose tumour remains in remission. “I hope that the readers of my book will understand that no one should be limited just because of their disabilities.”

Me, Myself, and My Brain Stem Tumour is available in bookstores and at www.amazon.ca.

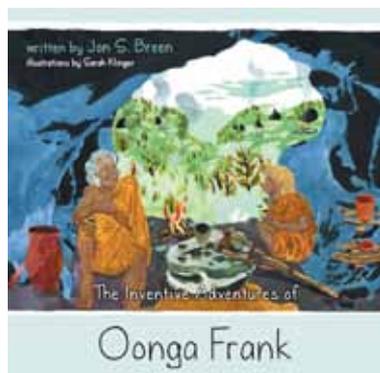
The Inventive Adventures of Oonga Frank

Jon S. BREEN • 40 pages • Friesen Press (May 2015)

Sometimes necessity really is the mother of invention—especially when it comes to children’s books. When, more than three decades ago, SCI BC Peer Jon Breen found himself falling asleep reading and rereading his son’s favourite books, he began developing stories of his own. And that’s how Oonga Frank, an inquisitive cave-dweller, was born.



The Inventive Adventures of Oonga Frank has a theme of difference—a different time and place, different needs, and a different set of challenges that aren’t so much problems as they are puzzles to be solved. In Oonga’s world, every victory, no matter how small, is an important improvement in the quality of life



of Oonga and his fellow “Cave Guys.” Like Oonga himself, the language in the story is playful and creative: when he discovers oatmeal (finally, a food “that doesn’t try to run away or bite you!”) he must gather the little round things before the fluffy white stuff descends

on the field. But he has some competition...

Much of the imagery in the book, illustrated in vivid watercolour by Sarah Klinger, comes from Breen’s own 20 years of experience living in the Yukon, prior to his move to Victoria

with his wife, Vanora. He hopes readers, “both young and not quite so young,” get some enjoyment from seeing how Oonga Frank solves problems. “The message in all of the Oonga Frank stories is that, if you really put your mind to something, you can figure out how to resolve a problem that appears to be insurmountable,” says Breen, whose own work experience over the years has been largely related to disability—from training and mobility aid development, to employment, policy and community development.

Like his creation, Oonga Frank, Breen clearly has a can-do attitude—these days, he’s working hard to complete his PhD in social work at UBC.

The Inventive Adventures of Oonga Frank is available in bookstores and at www.amazon.ca.

Traveling Light: Photographic Memories of a Global Nomad

Danielle HAYES • 110 pages • self-published (December 2014)

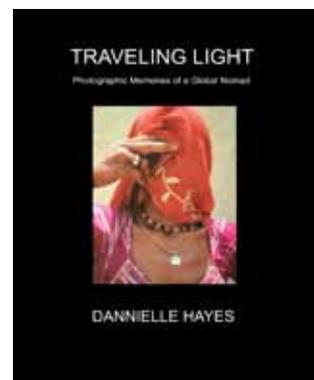
Dannielle Hayes’ first memory is of being photographed. Her second is of her family travelling by train “from east to the wild west” to take up in a log cabin in a rugged Vancouver Island logging camp. No wonder she became a travel photographer.

“I loved to read books about adventure—pirate tales, deep-sea treasure, wild animal stories,” says Hayes. “Re-reading my father’s letters from Peru also fired my imagination and sense of adventure. From an early age, I wanted to explore the world. And so I did.”

For nearly 50 years, Hayes worked as a New York City-based travel photographer, visiting more than 80 countries (and cheating death at least a half dozen times), teaching photography and video production, and contributing to numerous exhibitions in museums and corporate and private collections. In 1977, she released her first book, *Women Photograph Men*, and in 1991, she published the beautiful *Festival Indonesia Calendar*.

Then, in 2010, a stroke paralyzed her left side. “My stroke brought an abrupt end to my career but somehow put my brain into overdrive,” recalls Hayes. “I had a flood of memories; events, people, places, obscure addresses that I had not thought of in years. I just knew I had to write it all down. So began the first draft of *Traveling Light*.”

The book, an autobiography told in snapshot stories and stunning photographs, captures the world in splendid (and often hilarious) detail. From parties and palaces to charming locals and penis gourds, Hayes’ accounts of a life of adventure are bound to inspire and delight. Breaking rules of layout, and nestling images of used passports and original artwork within the 110 coloured pages, Hayes treated the entire book as a work of art. And she did all the writing with a single hand.



Today, the accomplished photographer and author lives in Vancouver, still taking photos, writing, and imbuing new adventures with her classic keen eye and trademark wit.

Traveling Light is available at blurb.ca.

Travelling the World with MS... ..in a Wheelchair

Linda MCGOWAN • 366 pages • Influence Publishing Inc. (December 2014)

Linda McGowan's high school graduation yearbook blurb reads: "Ambition: To travel." Today, despite some added obstacles, not much has changed. Since her diagnosis with multiple sclerosis in 1983, she's tenaciously pursued new adventures abroad, circling the globe in a wheelchair, and building up momentum and a book full of memories along the way.

Released just last year, McGowan's travel autobiography, *Travelling the World with MS... ..in a Wheelchair*, whisks readers into the more magnificent nooks and crannies of the globe. She sees the top of the world from the basket on the back of a Nepalese porter, hob-knobs with Emperor penguins in the Falklands, befriends the local population—both human and animal—in Kenya, and consistently leaves her father wondering if her Lonely Planet guidebooks and determination will ever wear thin.

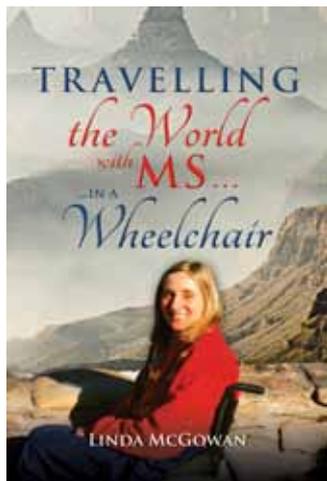
Beautifully written and ceaselessly entertaining, McGowan's book is a series of true anecdotes harvested from letters the globetrotter wrote to her father, as well as from her own memories, and penned using the Dragon Naturally Speaking voice dictation program.

"I travelled to remote countries where accessibility as we know it in North America is challenging and often non-existent," says McGowan, whose continued resourcefulness is a wonder and highlight. "I found with enough time and patience there was always a way to make it work—even if the situation appeared to present an impossible feat."

Today, McGowan continues to travel—she recently journeyed to the wilds of South Africa—and she's already looking forward to penning her next book. But don't mistake her work for "how to" travel guidebooks for people with disabilities, she says, adding that it's more about motivation and inspiration to encourage people to live their lives.

"I wrote the book to hopefully demonstrate that having a disability does not mean that you discard your dreams," she says. "It only means that you approach them with a little more ingenuity."

Travelling the World with MS... ..in a Wheelchair is available in bookstores and at www.amazon.ca.



Cooking with Cory: Inspirational Recipes for the Fearless Cook

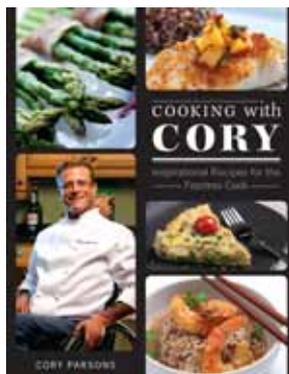
Cory PARSONS • 192 pages • Whitecap Books (February 2011)

Passion never goes out of style. When Cory Parsons, a Nanaimo-based chef and SCI BC Peer, decided to share his, the world took note—and cooks of all calibers took to the kitchen. Five years after its initial release, *Cooking with Cory*, an eye-catching cookbook boasting 100 full-colour recipes, is still as appetizing and relevant as ever.

"I chose to write this cookbook to keep myself connected to the culinary industry and to have something tangible that I could share with people in similar situations in hopes of inspiring, motivating, and relating to their situations," says Parsons. "By not just telling them they can do something, but rather by showing them that anything is possible."

A world traveller and seasoned restaurant-industry insider, Parsons' own life took a turn at 23 when a diving accident left him a quadriplegic. Armed with a new set of challenges and a steadfast life mantra—"it's never a matter of if, it's always a matter of how!"—the young chef delved further into his passions. The result is a book of recipes, equal parts elegant, adventurous and approachable, with an emphasis on fresh, locally-sourced ingredients and fuss-free preparation.

Peppered with Parson's own childhood reminiscences, culinary lessons, and reflections on healthy eating and fresh,



sustainable cuisine, *Cooking with Cory* is an instruction manual, a visual masterpiece, and a mini memoir, in one. (Which fragrant appetizer helped Parsons sell his house? The Roasted Garlic Spread, of course. Which dish gets Cory a second date every time? That would be the Prosciutto-Wrapped Sea Scallops with Chili Mayo.)

Perfect for entry-level chefs, this cookbook is less about technique than it is about mouthwatering dishes coupled with a "yes you can" attitude (the same attitude that helped the author type the complete book with one finger.) Parsons hopes his book motivates readers with SCI to become active in the kitchen, increasing their independence and involvement in their own care.

"I find that recipes are merely inspirations and suggestions that are open to interpretation and should always have a little of your own personal touch in order to make each dish truly your own," he says. "Unless you're baking, then you are messing with science and it will never turn out unless you follow the recipe exactly!"

Cooking with Cory is available in bookstores and at www.amazon.ca. ■

Have you written a book you'd like us to feature? Is there a book you'd like to recommend? Email the spin@sci-bc.ca. Plus, find more Q & As with these and other authors on our blog.

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, much more. In other words, it's about maximizing recovery, independence, health, and quality of life today. And 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. Please read about these studies below.

Evaluating a Fatigue Assessment for Adults with SCI

ICORD principal investigator Dr. Susan Forwell and her colleagues are seeking participants for their Comprehensive Fatigue Assessment Battery for persons with SCI (CFAB-SCI). This questionnaire is a self-report tool that assesses the many factors associated with fatigue, specifically in SCI. You are invited to participate if you sustained a complete or incomplete traumatic SCI at least one year ago, are 19 years of age or older, and have not been diagnosed with multiple sclerosis, cancer, arthritis or another condition that may be worsening your fatigue. The survey will take approximately 1.5 hours to complete. Location: anywhere in BC. Compensation for participation: yes. Contact: Kyle Diab (email kylediab@alumni.ubc.ca or call 604.364.2286).



Spinning People Into Neuromotion: Upper-Body Programs for SCI (SPIN UP for SCI) - Arm-Spinning for SCI

Led by ICORD principal investigator Dr. Tania Lam, this study will test the benefits of an eight-week "arm spin class" on aerobic fitness and core stability. Eligible participants will have had a traumatic or nontraumatic SCI at or below C5 resulting in complete or partial paraplegia or tetraplegia at least nine months ago; have near normal upper limb range of motion and no musculoskeletal injuries or other conditions which would prevent you from using an arm ergometer for 60 minutes at a time (with or without breaks); are a current PARC participant OR have a physician complete a PARmed-X form; are in stable medical condition; are over 19 years of age; do not have any cardiovascular condition or other medical condition for which exercise of this nature is contra-indicated, and do not have existing chronic shoulder pain. Amount of time required for participation: one hour per week for eight weeks of spinning, plus two to three hours of physical assessments before and after the program. Location: Blusson Spinal Cord Centre. Compensation for participation: no. Contact: Alison Williams (email parc@icord.org or call 604.675.8814).



Bowel Care and Cardiovascular Control After Spinal Cord Injury

ICORD principal investigator Dr. Victoria Claydon invites you to participate in a survey and/or clinical trial about bowel care and cardiovascular function after SCI. SURVEY: As an individual with SCI, you are the expert in this area and we would like to know your thoughts about your bowel care. If you are interested in completing the voluntary and anonymous survey online, please click on this link: <http://fluidsurveys.com/s/bowelcare-SCI>. Location: anywhere in BC or beyond. Compensation: yes (participants will be entered in a draw for one of three \$100 gift cards to a store of your choosing). CLINICAL TRIAL: Some individuals may also be eligible to take part in a clinical trial to see whether using a lubricant gel that contains local anaesthetic might improve their bowel care. For this part of the study, individuals would need to have an SCI at or above the mid thoracic level and be resident in the Greater Vancouver area. Contact: Victoria Claydon (email victoria_claydon@sfu.ca or call 778 782 8513).



BOTOX for Overactive Bladder and Prevention of Autonomic Dysreflexia Following SCI

ICORD principal investigator Dr. Andrei Krassioukov is examining the effectiveness of BOTOX (Botulinum Toxin A) treatment for overactive bladder for preventing the triggering of uninhibited bladder contractions causing AD. You are eligible to participate if you have had a traumatic complete or incomplete SCI (T6 level and higher) more than one year ago; are between 18-65 years of age; are affected by urinary incontinence and have tried at least one anticholinergic (i.e., Ditropan, Detrol, Vesicare, Uromax, etc.); have a known history of autonomic dysreflexia; have good hand function; and are currently intermittently catheterizing or have a care provider to assist with routine catheterizations. Amount of time required for participation and location: seven visits to the Blusson Spinal Cord Centre. Compensation for participation: yes. Contact: Mahsa Sadeghi (email msadeghi@icord.org).



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



Fitness by Pharma

In the future, could the benefits of a workout be achieved by simply taking a pill?

It's the stuff of your dad's old *Popular Science* magazines, ranking right up there with personal jet packs, flying cars, and vacuum tube-powered trains.

We're talking about exercise pills, or a pill that you swallow for fitness—a potential godsend for couch potatoes and perhaps people who simply can't work out because of their paralysis.

Lately, talk of such a pill has been buzzing about the internet and the media. So is such a pill coming down the innovation pipeline? And if so, what exactly will it do—and what will it not do? Those are some of the questions that Dr. Ismail Laher, a professor in UBC's Department of Anesthesiology, Pharmacology and Therapeutics, along with Shunchang Li, a student at Beijing Sport University, recently took a stab at answering in a paper titled "Exercise Pills: At the Starting Line."

The paper was published in the September 23rd issue of the journal *Trends in Pharmacological Sciences*. It provides an overview of the concept of exercise pills, the current state of the research into exercise pills, what the most promising candidates are, and how they work.

Perhaps the most important conclusion that Laher and Li reach in the paper is that exercise pills may indeed have a role in assisting those who are unable to exercise, for whatever reason. But as the title of the paper implies, Laher cautions that we're just at the tip of the iceberg stage when it comes to developing such a pill for real world use, that there are many hurdles and steps that have to be taken before a truly viable exercise pill is available, and even when that does happen, such a pill will not provide all the benefits that come with a true workout.

"Exercise pills interact with the energy producing and energy sensing pathways in muscle and, by doing so, you get faster and bigger muscles," explains Laher. "We already see them in use—they've already been implicated in cheating in professional sports. But exercise has a myriad of benefits for the heart, brain, pancreas, bone and other organs, and the exercise pills target only muscle."

To help people understand the potential role and limitations of an exercise pill, Laher compares it to a vitamin supplement—the benefits of fresh fruits and vegetables, he explains,

far outweigh the benefits of taking only pill supplements.

"This is something that people have been working on for quite some time, and the goal is not to replace exercise, but rather to assist those who are unable to exercise," he explains.

He adds that people with SCI and other physical disabilities stand to gain the most from the use of exercise pills, as they could prevent or at least retard muscle loss, and may complement physiotherapy.

The paper provides an overview of the eight exercise pill candidates with the greatest potential. The list includes a synthetic molecule developed by The Scripps Research Institute in 2012, as well as natural substances found in plants, such as a flavonol which is found in cocoa, tea and grapes, and resveratrol, which is found in red wine and blueberries.

But Laher says this avenue of investigation is just beginning to be explored. "I think that as more molecular targets are identified, we will have more candidate pills."

He concedes that his own lab is not yet engaged with testing any candidates, as he is more focused on regular exercise as a treatment strategy in several animal models of disease. However, his interest in exercise pills was sparked when he began to realize that some animals were unwilling or incapable of exercising, and he was curious if these animals could get some of the benefits of exercise in an alternate way.

The bottom line? Laher believes a viable exercise pill is in our future. But he also cautions that people need to temper their expectations of such a pill.

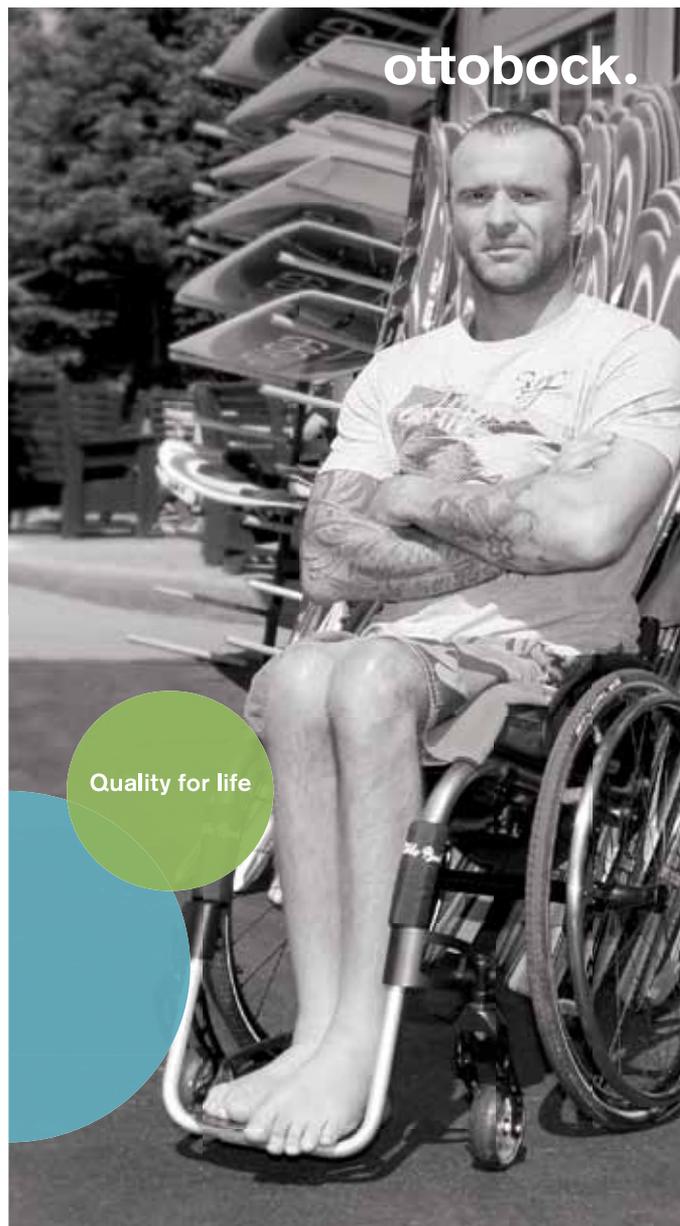
"It's important to note that these pills will not motivate someone to become more inclined to exercise," he says. "Homer Simpson will remain on the couch and in fact may eat even more donuts by taking the mistaken view that by taking these pills he has exercised and 'earned' another donut and more time on the couch."

So he remains a firm believer in exercise and advises that everyone, including people with SCI, should be far more concerned about getting any type of exercise they're capable of, instead of dawdling with Homer on the couch, waiting for an exercise pill panacea.

"If you really think about it," Laher concludes, "exercise is the best medicine you will ever have without having to pay for anything."

In related news, researchers at the University of Sydney recently published a paper that described their study of four untrained, healthy males following 10 minutes of high-intensity exercise, which led to their discovery of some 1,000 molecular changes that take place in the body during exercise.

"While scientists have long suspected that exercise causes a complicated series of changes to human muscle, this is the first time we have been able to map exactly what happens," co-author of the paper Dr. Nolan Hoffman said in a statement. "This is a major breakthrough, as it allows scientists to use this information to design a drug that mimics the true beneficial changes caused by exercise." ■



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Postscript: Back in the Hunt

In August, after a six year lobbying effort to convince the BC government to allow hunting by proxy, Reg Swanson was back in the bush for moose season.

In the Spring 2015 issue of *The Spin*, we told you about Reg Swanson, a 46-year-old who lives in Falkland, BC. You might recall that Swanson grew up in the backcountry around Prince George, with hunting being a huge part of his life until a 1988 accident left him a complete C4-C5 quadriplegic.

For the next two decades, Swanson often dreamed of hunting again, but just couldn't see how it would be possible.

Then, in 2008, he approached the Fish and Wildlife Branch of BC's Ministry of Forests, Land and Natural Resource Operations. Armed with the knowledge that hunting by proxy was legal in other jurisdictions such as Alaska, he made his case.

Swanson persisted for the next six and a half years. He provided government officials with everything they requested, such as letters of support from organizations, including SCI BC.

As he waited for the bureaucratic process to grind out change, Swanson stayed hopeful and kept busy preparing for the day he could legally hunt. One of the most important steps he took was to find a reliable and accessible way to travel into the backcountry. His father Andy, a gifted mechanic, modified his Ford F-350 diesel 4x4, lowering the floor and installing a hydraulic lift that safely raises him into the passenger position.

On April 1st of this year, Swanson's lobbying efforts finally paid off when the BC government introduced "hunting by proxy" licenses. These licenses allow a qualifying hunter with a disability to designate two people as proxies, or hunting assistants, who can aim and fire a rifle, and dress the kill. The assistants also need to hold a valid provincial hunting license, and both hunters and their assistants need to pass the Canadian Firearms Safety Course and successfully apply for a Possession and Acquisition License.

With assistance from his long-time caregiver, Brenda McGuire, Swanson got to work on his application. Three weeks later, he acquired his hunting license—the first he'd had in more than 25 years. He and his father, along with high school friend Ian Gilchrist, began to make plans for a late summer hunting trip to the Omineca hunting region, located north of Prince George along the

Alaska Highway route. Their goal was to each bag a moose.

The trio arrived on August 14 at a lodge at Inga Lake, located close to Mile 91 of the Alaska Highway. They set up camp, all the while wondering how long it would take to find and bring down their prey. As it turned out, it wasn't long at all.

"The next morning, which was opening day for moose, we got up well before sunrise and went out," says Swanson. "We went into a bit of clearing and, wouldn't you know it, there was a five point (a male moose with five points on each of its antlers) right there. We took that one as mine, because I saw it and pointed it out. I guess if Ian had seen it, it would have been his. Needless to say, it was pretty exciting."

Later that same day, Gilchrist also brought down a moose. Despite the trio's best efforts, only Swanson's father was unable to get his moose during the remainder of the trip. But given the team effort, the three split the bounty in three equal parts, and after all butchering was complete, everyone has a full freezer of steaks, roasts, ground and sausage for the winter.

Swanson says the hunting and the camaraderie of the hunt were both extremely gratifying after such a long absence.

"It does amount to a lot of work," he concedes. "There's a lot involved for someone like me to go and do something like this—for example, making sure I have a power supply for my CPAP machine and charging my wheelchair. But it's definitely worth it. Now everything's set up, and we know what we need for next time, which I'm already looking forward to."

Swanson says he's hoping that 2016 will bring an elk hunting trip. Meanwhile, he'll continue to work on his next ambitious hunting project—a chair-mounted rifle with a sip-and-puff control to aim and activate the trigger, which he's developing with a friend, Lance MacPherson, who is a marine engineer.

Such a device could allow Swanson to bring down his target without assistance. But until it's been tested and proven, he's ecstatic that he can rejoin the hunt legally with a proxy license.

"I encourage other people who are high level quadriplegics to do it. If you're interested in getting out there, there's a way. Don't let anything hold you back." ■



HUNTER & PROXY: Reg Swanson and his high school friend, Ian Gilchrist.

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