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SPINAL CORD INJURY BC

FALL 2018

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**COVER:** SCI BC Peer James Telep breaks trail with his electric bike.  
*Photo by Crystal Smith, All Things Crystal Photography.*

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## Exercise your most fundamental right!

In a few weeks, British Columbians can cast their vote and help choose the women and men who make up our province's local governments. But how many will? In 2014, the majority of eligible voters in our province chose not to exercise their most fundamental democratic right and, as a result, did not influence the outcomes of our last local general elections.

This is a shame because BC's general local elections are critical for shaping so much of what impacts our daily lives (and band council elections offer similar opportunities for First Nations communities).

This is particularly true when it comes to improving access and inclusion within our communities. Local governments are responsible for parking, sidewalks, snow removal, parks, libraries, and other public facilities, services, and spaces.

I'll concede that, with 162 municipalities and 27 regional districts holding elections for mayors, councillors, and trustees for park boards and schools, community trusts, and commissions, voters face a major challenge in learning enough about the candidates to determine who best represents their interests.

But isn't democracy worth the effort? And, by the way, you don't have to vote for every position available; if you're only comfortable voting for one or a small number of candidates you have confidence in, just vote for them.

Voting is critical, but it's important to remember that there are other ways to influence decisions made by local governments.

For example, run for office yourself! While BC may be leading the country in the number of people with disabilities elected to provincial office, the number of elected officials with disabilities is grossly under representative of the percentage of British Columbians with disabilities. This is particularly true of local governments throughout BC, which would benefit immensely from having the wisdom and experiences of people with disabilities at their decision-making tables.

Another way of influencing local decision-making is to sit on the various committees that advise local governments. Even just attending council meetings and other public hearings and consultations can make an impact. Volunteering or working for elections, campaigns and other political activities is yet another way to get engaged.

I also have a message to anyone reading this who is already engaged in the political life of our province. If you agree that input and participation from people with disabilities is vital, then work where you have influence to create more resources, programs, and mentorship opportunities that are aimed at encouraging and grooming candidates with disabilities for future elections.

Democracy depends on you. On us. It only works when we as citizens are engaged in democratic processes and flex our democratic right to vote. This is as true for local elections as it is for provincial and federal elections.

Which is why, on October 20, I will once again drag my butt out to the polling station and cast my votes for those I wish to represent me in local government. Please join me. And remember, if you think your vote doesn't matter, keep in mind that the traditional low voter turnout for local elections can have an upside—fewer voters means your vote carries more weight.

- Chris McBride, PhD, Executive Director, SCI BC



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

### SUBSCRIPTIONS

Free subscriptions are available for BC residents and health professionals:  
T: 604.324.3611 TF: 1.877.324.3611 E: [thespin@sci-bc.ca](mailto:thespin@sci-bc.ca)

### ADVERTISING

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### SUBMISSIONS

Submissions, suggestions and comments are greatly appreciated—please email these to [thespin@sci-bc.ca](mailto:thespin@sci-bc.ca) or send by regular mail to:

Assistant Editor, The Spin  
Spinal Cord Injury BC, 780 SW Marine Drive  
Vancouver, British Columbia V6P 5Y7

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Spinal Cord Injury BC, 780 SW Marine Drive  
Vancouver, British Columbia V6P 5Y7 T: 604.324.3611

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### SCI BC HEAD OFFICE

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

### REGIONAL PEER CONTACTS

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

Kelowna: Scott James, Peer Program Coordinator  
T: 250.308.1997 E: [sjames@sci-bc.ca](mailto:sjames@sci-bc.ca)

Nanaimo: Bert Abbott, Peer Program Coordinator  
T: 250.616.1186 E: [babbott@sci-bc.ca](mailto:babbott@sci-bc.ca)

Prince George: Brandy Stiles, Peer Program Coordinator  
T: 250.563.6942 E: [bstiles@sci-bc.ca](mailto:bstiles@sci-bc.ca)

Quesnel: Alison Duddy, Peer Program Coordinator  
E: [peervolunteerq@sci-bc.ca](mailto:peervolunteerq@sci-bc.ca)

Vancouver: Teri Thorson, Peer Program Coordinator  
T: 604.714.4185 E: [tthorson@sci-bc.ca](mailto:tthorson@sci-bc.ca)

Ryan Clarkson, Peer Program Coordinator  
T: 604.714.4185 E: [rclarkson@sci-bc.ca](mailto:rclarkson@sci-bc.ca)

Vernon: Sonja Gaudet, Peer Program Coordinator (Okanagan)  
E: [sgaudet@sci-bc.ca](mailto:sgaudet@sci-bc.ca)

Kamloops/Kootenays: Joshua Dueck, Peer Program Coordinator  
T: 250.306.7061 E: [jdueck@sci-bc.ca](mailto:jdueck@sci-bc.ca)

Victoria: Scott Heron, Peer Support Specialist  
T: 250.812.0773 E: [sheron@sci-bc.ca](mailto:sheron@sci-bc.ca)

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# Innovations

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

## KEY TURNER

The Key Turner is a simple tool that helps people with limited hand and wrist function operate keys. Users loop their finger through the hole and twist to



lock and unlock doors with minimal wrist movement. The large key bed can accommodate various shape of key heads, and a machine screw holds the key in place. Developed through the Neil Squire Society's Makers Making Change initiative, the Key Turner is just one of many practical aids-to-daily-living prototypes that are offered on an open source basis—you simply visit [www.makersmakingchange.com](http://www.makersmakingchange.com) and download the 3D printer files you need (you'll need access to a 3D printing service, which are becoming relatively common—for example, some UPS stores now offer 3D printing).

## JAMBOXX

The Jamboxx is a harmonica-like instrument that connects to most Windows and Mac devices. It can mimic the sound of guitars, drums, violins, pianos and saxophones. Notes are played by sipping or puffing via the mouthpiece, and moving the mouthpiece left or right determines which note is played. Proprietary Jamboxx software allows playing of 12 notes on any scale, and a “modulation wheel” allows for changing octaves, bending notes, or playing flats or sharps. With its included bracket, the Jamboxx can easily be played hands-free, and it also adapts to the musician's range of head motion and breath capacity, even when both are limited. There are two versions: one for accomplished musicians, and another for students. Check out [www.jamboxx.com](http://www.jamboxx.com) for more details and video.



# Room for Debate

■ opinion

In May, Vancouver became the first major Canadian city to ban plastic straws. This ban, which takes effect next year, is part of a suite of waste-reducing policies adopted by City Council. Environmentally-minded people applauded, but many people with disabilities who can't hold a glass have cried foul. In this issue, we ask, "Do you agree with the new ban on plastic straws?"



## What's all the fuss about?

Banning plastic straws is a good thing, period! The way so many people with disabilities are carrying on about this seems excessive.

First, the restaurant and food industries are responding quickly, coming up with new eco-friendly straws, and spawning a new industry in the process. I see evidence of this every day, with so many new straws in specialty stores. Recently, I was asked to trial a new disposable straw for A&W—it was a bit large, but really, there was nothing wrong with it.

Then there's the non-argument that many plastic straws offer flexible bends, making them easier to use. But how many restaurants have actually offered you a flexible straw? I suspect few, because they're too expensive. Yes, we've had the choice to buy flexi straws in stores. But again, there are now straws made with eco-friendly materials that are bendable.

As for the argument that improperly cleaning reusable straws will lead to contamination problems, should we apply the same argument to glasses, plates and cutlery?

In my view, these arguments are just not tenable. Finding replacements for plastic straws is a minor problem, one that each of us can solve. There are so many other barriers in front of people with disabilities everyday: lack of accessible taxis; not enough full serve gas stations; lack of accessible housing; not enough funding for attendant care, mobility equipment and medical supplies. These are all problems we should come together to resolve. In contrast, arguing for some kind of disability exemption from the plastic straw ban just seems petty.

I'm putting my money where my mouth is. I use a catheter, so I need to drink a ton of water. I use straws to make this easier. I take straws with me wherever I go; I have a number of different types now, and it's great to see them being made from such an increasingly wide range of eco-friendly materials.

On a worldwide basis, the benefit of eliminating plastic straws can't be understated. So instead of complaining about not being able to buy plastic flexi straws, try some alternatives that are out there—perhaps something will work even better for you! Stop fighting the banning of plastic straws, and come out to fight the fights that really need attention.

—Patty Clark, Vancouver

## Straw bans are performative.

I believe the straw ban is one of those movements that, well-meaning or not, are only performative environmentalism when you look at the science behind what they accomplish. There's just not enough meaningful benefit to offset the negative impact on individuals with disabilities.



This lack of benefit was well-argued in a recent editorial on Bloomberg ([www.bloomberg.com/view/articles/2018-06-07/plastic-straws-aren-t-the-problem](http://www.bloomberg.com/view/articles/2018-06-07/plastic-straws-aren-t-the-problem)). Meanwhile, efforts to cut down on the use of other disposables like cutlery and take-out containers are largely being ignored by the public. And it's well-documented that the greatest environmental benefits result from initiatives taken by a small number of big corporations, not the average consumer. We could do far more for the environment by urging companies to stop using unsustainable packaging, disposables, and, in particular, fishing equipment (over 46% of the plastics in our oceans are fishing nets, according to the same Bloomberg article referenced above) than to focus on individual use of plastic drinking aids, which are vital for a significant segment of our population's ability to easily access a drink of water or coffee.

Alternatives to plastic straws work for some, but there is no one-size-fits-all solution. Unilaterally saying, "Disabled folks can just bring their own straws" ignores a number of very real barriers that exist for certain individuals.

Yes, some of us may be able to carry reusable straws in their bags, and some might be able to access them without help. But this doesn't mean they'll be able to clean them unassisted. The majority of restaurants and bars deemed "accessible" actually don't have accessible bathrooms, so they lack a place where a disabled person could clean their reusable straw. This could lead to some throwing out their reusable straws due to contamination—which is worse for the environment. Finally, consider the high cost of alternatives for those who are already more likely to be economically marginalized.

If you don't need a straw, then great, don't take one. But don't fight so adamantly to make them inaccessible to those who require them.

—Micaela Evans, Vancouver

Got an opinion? Visit [facebook.com/SpinalCordInjuryBC](https://facebook.com/SpinalCordInjuryBC) to join in on this and other conversations.



**Join us at our AGM.**

Help SCI BC celebrate the gains we've made on your behalf this year, including the progress of our Access BC project, which is striving to making our province's outdoor spaces accessible. This year's outdoor party and AGM take place from 6 to 9 PM, October 25, at the Blusson Spinal Cord Centre. Enjoy great food and drinks, intriguing presentations, and fun with friends and family. To RSVP, please visit [www.sci-bc.ca](http://www.sci-bc.ca), or contact Maureen at 604.326.1225 or [mbrownlee@sci-bc.ca](mailto:mbrownlee@sci-bc.ca).



**Celebrate 30 years of VAMS.**

The Vancouver Adapted Music Society (VAMS) celebrates three decades of empowering musicians with disabilities with a 30th anniversary fundraising concert. The interactive and nostalgic evening will showcase ability and creativity, with VAMS musicians and special guests rocking out tunes from the 80s, 90s, 2000s and 2010s. It takes place October 18 at the Roundhouse Community Centre. For details, visit [www.vams.org](http://www.vams.org) or contact [nkarakoyun@disabilityfoundation.org](mailto:nkarakoyun@disabilityfoundation.org).



**Unite to fight paralysis.**

Join Unite 2 Fight Paralysis for the 13th annual Working 2 Walk Science and Advocacy Symposium, being held October 19 and 20 at the Sheraton Vancouver Airport. This is the first time this event has been held outside the United States. It's a great opportunity to hear about cutting-edge research from top-tier scientists, network with leaders in the biotech field, and advocate for the SCI community. To learn more and register, visit [www.u2fp.org/working-2-walk](http://www.u2fp.org/working-2-walk).



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# Caregiver Nightmares

In the last issue of *The Spin*, five SCI BC Peers spoke about their positive experiences managing their own caregiving through the CSIL program. Unfortunately, it doesn't always go so smoothly. Just ask Mary-Jo Fetterly and Terry LeBlanc.

Mary-Jo Fetterly



## For Mary-Jo Fetterly, the betrayal came completely out of the blue.

Fetterly, a C4-5 quadriplegic who is well known to many readers for her adapted yoga classes, has been a CSIL client since she was injured in 2004. For the first 12 years, she had great success with the program. But two years ago, things went off the rails.

"A long-time employee, who I trusted and treated like family, stole from me in calculated, multiple ways," says Fetterly, who has lived in Vancouver since her injury. "Once she had figured out my spending routine and habits, she manipulated hours on her time sheets, bought herself groceries when shopping for me and, at the very end, was taking out cash advances on my credit card—which is what gave her away."

Resigned to cutting her losses and moving on, Fetterly confronted and fired the caregiver, who she had employed for more than six years. But that's when the real struggle began.

"She smugly stormed out, insisting she would sue me and take me to court, which she tried in three different ways," says Fetterly.

Ultimately, Fetterly successfully defended herself in all three court battles. Additionally, the former employee was disciplined by Employment & Immigration Canada for lying on her EI claim after being fired. But this offered little consolation for Fetterly, who says the ordeal has been horrific. Beyond the monetary losses from the theft and cost of defending herself in court, it cost her dearly in terms of her health—the stress led to her developing PTSD.

"It's been a nightmare," she says. "Not only did I have to scramble to find someone to replace her, I also was devastated emotionally due to the betrayal and, adding insult to injury, the repeated slanderous emails and lawsuits that she plagued me with."

And the nightmare continues today, as she knows that her ex-employee could

conceivably do the same thing to someone else. “She’s still at large, able to continue this line of work. As a matter of fact, I saw her working with a resident in my building. Where I live. I do not feel safe or very good about that.”

Fetterly’s situation is not unique. We’ve heard from several other SCI BC Peers who have had similar negative experiences. One of them is Terry LeBlanc, who also makes his home in the Lower Mainland. Like Fetterly, LeBlanc has more than a decade of experience as a CSIL employer. For the most part, he says CSIL has afforded him a great deal of freedom and convenience—but it’s not all been rosy.

“I’ve had dishonest caregivers stealing money out of my wallet or items in

my locker,” he says. “Cash disappearing just before a scheduled leave was a big clue. Another time, it was a caregiver who was constantly handing out ‘gifts’—items she said that she no longer needed or wanted. Once I noticed that my items were disappearing, I clued in that they were probably being gifted to another client of hers.”

Like Fetterly, LeBlanc says his situation remains partly unresolved.

“Because of the extreme shortage of qualified workers, one of the suspects is still on the payroll,” LeBlanc laments. “Instead, I have taken steps to put all items of value under lock and key.”

For both Fetterly and LeBlanc, these nightmares have changed the way they manage their caregivers.



Terry LeBlanc

Fetterly concedes there were warning signs she didn’t catch as soon as she should have.

“The cheating on the hours—I should have been more assertive and proactive, but it was minimal and sporadic at first; easily disguised as a mistake,” she says.

But she adds that she’ll never ignore signs like that again. Going forward, she’s committed to conducting criminal record checks, having a witness present during interviews to verify information and add a level of security and authority, and verifying references and recent work history. And now she also requires a new employee to work three shadow shifts with another trusted caregiver.

“Often, the questions they ask the current employee when I’m not around are very telling,” she explains.

LeBlanc also says he now scans resumes “with an eagle eye.” Recently, his diligence was rewarded after a recent hire talked about working at a facility that she hadn’t listed on her resume. He soon discovered why.

“As it happens, I have a friend who works in management at that facility, so I made an inquiry. I found out that my new caregiver had been fired for theft, solicitation of patients to invest in condominiums, sleeping on the job, and being caught in flagrante delecto with a coworker! So I let her go before the probation period was up.”

Meanwhile, Fetterly’s caregiver nightmare has prompted her to become a vocal critic of a system she believes offers little

## Caregiver Nightmares Aren’t Always About Theft

Spring Hawes, an SCI BC peer from Invermere, reminds us that caregiver nightmares can also involve inadequate care. That’s exactly what she experienced a couple of years ago, and the result was a dangerous compromise of her health.



“In my case, it was a pressure wound which wasn’t properly responded to,” says Hawes, who is quadriplegic and a longtime CSIL employer. “I couldn’t see it, so didn’t know how bad it was until I was very sick—it got extremely serious. I ended up in the hospital three times, and it was finally resolved by surgery 18 months later.”

Pinpointing where the blame lies, says Hawes, has been difficult. “It’s hard to say. There were multiple people involved, from care aides to RNs, so it should have been cared for. I think it was probably a combination of lack

of training and/or experience, and some ego mixed in when it became apparent how badly it had gone wrong.”

The experience made her change the way she manages her caregivers

“It makes me hyper-vigilant about all the little details that can get missed; in vetting who I hire, in training them, and in the day-to-day management,” she says. “I can’t over-emphasize how important it is for you to pay attention—personally—to the details.”

To underscore the point, Hawes says she had recently been dealing with recurring days of pain, often once or twice a week, which were so bad she couldn’t function.

“It always went away when I laid down,” she says. “It had been going on for at least a year, and I just couldn’t figure out a pattern. I thought it was catheter-related, and could not figure out how to fix it. It was so bad I sometimes had to resort to Ativan to cope. Then I hired a new care aide who remarked one evening when I was getting into bed that I had a ‘wedgie’. I put two and two together, and started specifically asking for a ‘wedgie check’ every day when I got dressed. Boom! Problem solved. That was about six weeks ago, and I haven’t had one of those days since. You wouldn’t think you’d need to tell someone you can’t have a wedgie, but apparently you do. My current CAs are all competent and very good. But they were all missing that detail from time to time.”

protections for the employer with the disability—even when the theft is blatant.

“I never would’ve expected that what has happened to me would be possible,” she says. “I had done everything according to the book—written a termination letter, and had a brief meeting with a witness present. Yet she was able to use the system—both the Canadian Human Rights Tribunal and BC Employment Standards Branch—and take what was a very brutal betrayal of my trust and resources and turn it around to make it look like my firing her made me the perpetrator and the one in the wrong. The disturbing thing is that the law does not at all protect the disabled or elderly, both in the Labour Standards courts and the Human Rights courts. I’d suggest seeking legal advice when firing; the law is not on our side, and people who abuse others know this.”

Fetterly feels so strongly about this that she’s joined the board of Civil Rights Now, a non-profit association that aims to “get statutes passed by the provincial government which will ensure persons with disabilities living in British Columbia receive equal benefit and protection of the law.” You can learn more at [www.civilrightsnow.ca](http://www.civilrightsnow.ca).

“We desperately need our own professional association or agency that provides a reporting system, accountability measures, standards, and a resource base for employers to do the necessary job of registering, reviewing, community reporting and disciplinary enforcement,” she concludes. ■

## Caregiver Warning Signs

- Refusal to supply references or a home address
- Refusal to submit to a background check
- Arriving late or departing early
- Noticeable decline in the cleanliness of your home
- Improper disposal of your healthcare equipment
- Evidence of drug use (smell of cannabis or alcohol on breath)
- Unexplained visitors in your home
- Inconsistent quality of caregiving
- Bids for sympathy; personal tales of woe
- Obvious attempts to cultivate a personal connection
- Frequent cell phone use on the job
- Receipts that don’t add up (if shopping is a responsibility)
- Increasing health problems such as UTIs and pressure ulcers
- Repeating instances of missing valuables.

**Do you feel you have to terminate a caregiver?** There are a number of issues to consider, and a documented process to follow. If you haven’t already, we suggest downloading and reading the appropriate section of SCI BC’s CSIL workbooks, developed in partnership with the BC Ministry of Health and with support from a grant from the Law Foundation of BC. You can find the workbooks at [sci-bc.ca/choice-supports-independent-living/](http://sci-bc.ca/choice-supports-independent-living/)



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# Push Button Release

New research from UCLA raises hopes that a wearable electronic stimulator could soon restore significant bladder function in many people with SCI

**W**hen it comes to what kinds of research we choose to pass along to readers of *The Spin*, we have a loosely-defined policy to guide us: basically, we publish news about research that we believe has the possibility of improving the quality of lives of people living with SCI, particularly within a reasonable time frame.

In other words, you won't read much about the elusive search for an outright cure (think stem cells), or even research about acute care interventions—those that are aimed at improving outcomes when provided in the first few hours after injury. What you will find, on the other

hand, are stories about research that we believe might have a positive impact for our readers within their lifespans.

That's why we're so keen on all the work being done in the field of electrical stimulation as a tool to restore function in people living with SCI. In particular, we're really fascinated with the work being done in the lab of veteran UCLA researcher Dr. Reggie Edgerton. In our last issue, we told you about Edgerton's team's success with a non-invasive (no surgery required) electrical stimulation device, used in conjunction with a short-term rehab exercise program, to restore a surprising amount of hand function in people with high level quadriplegia.

In this issue, we're pleased to report that Edgerton's lab recently achieved similar success using the same type of stimulation device to restore a significant amount of bladder function in a small group of people with SCI. Clearly, further research is needed to confirm the benefits. But we believe it's possible this work could, in the foreseeable future, result in a relatively inexpensive, wearable device that would allow people to fill their bladders without fear of leakage, and then urinate on demand—all without the need of catheters. And we know this would be a game changer for the majority of our readers.

The research results were summarized in a paper titled *The Non-invasive Neuromodulation of Spinal Cord Restores Lower Urinary Tract Function After Paralysis*, published in the June issue of the journal *Frontiers of Neuroscience*. As with the hand function study we told you about in the last issue, the lead author was Dr. Parag Gad, assistant researcher in Edgerton's lab.

In the paper, Gad and his fellow team members describe how SCI wrecks havoc on the complex bodily function of storing and releasing urine—and how their technique, which they call TESSLA, seems to restore that function by applying electrical stimulation at a carefully-chosen location on the skin above the spinal cord.

TESSLA, by the way, stands for Transcutaneous Electrical Spinal Stimulation for LUT functional Augmentation. And LUT is the acronym for lower urinary tract. (Yes, scientists love acronyms.)

TESSLA represents the evolution of a good deal of previous studies using electrical stimulation to restore function after SCI. Notable among these are two studies that we wrote about four years ago. The first, which took place at the University of Louisville, saw four young men with SCI regain some walking function—and also experience some secondary improvements in bowel and bladder function. That same year, we also told you about the Edgerton lab's success in restoring bladder function in paralyzed rats using

electrical stimulation. The key difference is that those projects relied on stimulation using surgically-installed devices.

That's roughly the time Edgerton and his team got to work examining the possibility of achieving the same results through a non-invasive device—one that would provide electrical stimulation to the appropriate nerves in the spinal cord via electrodes attached by gel to the skin at a carefully-chosen location. The device has evolved continuously since then. A more current prototype was successfully used in the hand function study we told you about in last issue, and also in this bladder function study. It's currently being fine-tuned and commercialized by NeuroRecovery Technologies, a corporate offshoot of Edgerton's lab.

### Understanding the Problem

Normally, the LUT allows for storage of urine without leakage and timely emptying without urine retention. Working behind the scenes are both motor nerves and sensory nerves. The motor nerves carry commands to the LUT—one set supports bladder contraction and voiding, another set promotes bladder relaxation and bladder neck contraction, and yet another drives closing of the external urethral sphincter (EUS). In a healthy state, bladder and EUS activity are coordinated, with the EUS closing and the bladder relaxing during urine storage, and the reverse occurring during urination. This coordination is controlled in the brainstem, in response to signals sent by sensory nerves from the LUT (for instance, when the full bladder sensation is sent to the brainstem, it in turn issues the commands to relax the EUS while contracting the bladder).

An SCI disrupts communication between the brainstem and the LUT, and causes two big problems. First, the bladder and the EUS become uncoordinated, which is known as detrusor-sphincter dyssynergia, or DSD (the detrusor is the primary muscle in the bladder). DSD can be particularly dangerous: as the bladder contracts while EUS remains closed, it generates increased pressure, which can

### Acronyms at a Glance

TESSLA: Transcutaneous Electrical Spinal Stimulation for functional Augmentation

LUT: lower urinary tract

EUS: external urethral sphincter

DSD: detrusor-sphincter dyssynergia

DO: detrusor overactivity

lead to bladder and kidney injury, loss of bladder flexibility, and dangerous autonomic dysreflexia. The second problem is unwanted bladder contractions, which result in incontinence—a condition known as detrusor overactivity, or DO.

Based on the previous studies involving surgically-implanted devices, and the successful results of a 2017 study to test the feasibility of using external stimulation to activate bladder emptying in uninjured monkeys, Gad and his teammates set out to design a human clinical trial using TESSLA to restore bladder function in a small group of people with SCI.

"We hypothesized that TESSLA could activate the spinal neural networks that are active in controlling LUT function," says Gad. "The traditional view has been that bladder function is controlled primarily in the brain and brainstem. However, over the past few years, we have performed a series of experiments in animals and humans, and have shown that, along with these regions in the brain, there are networks in the spinal cord that also contribute to control of bladder function. So we wanted to see if, by stimulating these specific regions of the cord, we could restore some bladder function."

### How the Study Unfolded

Once the study had received the blessing of an ethics committee, the team recruited seven participants—four men and three women. All were injured at T11 or above (five with paraplegia, and two with quadriplegia). All used clean intermittent catheterization to manage their bladder care. Each subject had a stable SCI that occurred at least one year prior to study initiation.

Six of the participants were tested three hours a day, for two days. The

first day involved a mapping process to determine the ideal location to place the electrodes on the skin above the spinal cord (T11 turned out to be the best location), as well as the appropriate intensity of stimulation. On the second day, the participants underwent urodynamics testing—their bladders were filled with a catheter and subsequently emptied while Gad and his colleagues observed and recorded how well the bladder, sphincters, and urethra held and released urine. The first urodynamics tests were performed without any stimulation in order to determine the baseline function for each participant. Subsequent tests were then carried out in the presence of TESSLA.

"There are two types of stimulation patterns that we used," explains Gad. "First, low frequency (1Hz), which is used to initiate voiding. This pattern of stimulation is initiated once the bladder is full, to initiate voiding. The second protocol is high frequency (30Hz), which is turned on before the filling begins. This higher frequency tends to increase activity in the sphincter, and reduce activity in the bladder, thereby allowing us to increase the overall capacity of the bladder."

Additionally, one participant agreed to spend a third day undergoing a different test—a uroflow test in the absence and presence of TESSLA.

### Assessing the Results

The results were impressive. Urodynamics revealed that TESSLA delivered at a low frequency (1 Hz) resulted in im-



proved voiding efficiency, increased rate of urine flow, decreased residual volume, and improved coordination between the bladder and sphincter.

“This stimulation is needed for about 60 to 120 seconds to initiate voiding,” says Gad. “This essentially means, if a person knows their bladder is full and uses a catheter to empty their bladders, instead, they could turn on the stimulation for a couple of minutes which will lead to them voiding.”

Meanwhile, TESSLA delivered at a high frequency (30 Hz) resulted in reduced DO during urine storage, along with increased bladder capacity. Like the low frequency stimulation, it also improved bladder-sphincter coordination during voiding.

“This allows the patient to hold larger quantities of urine in their bladder, leading to fewer incontinence episodes, longer duration between voids, and overall better quality of life,” says Gad.

As for the single participant who underwent a uroflow test, the results

were again significant. The participant was initially asked to void in the absence of TESSLA, and subsequently in the presence of TESSLA.

“The uroflow test reflects the real life situation—emptying a naturally-filled bladder, several times a day,” says Gad. “We demonstrated that, by stimulating at 1Hz, a person can empty their filled bladder within a couple of minutes of turning on the stimulation. Again, this is important since it reflects a real life scenario. A person could turn on the stimulation several times a day to empty their bladder into a urinal, and eventually ween off the catheter.”

As for safety, TESSLA was well tolerated by all subjects with no change in blood pressure, heart rate, spasticity, or skin irritation. None of the participants reported episodes of increased incontinence during the days following the sessions. And since urodynamics are known to trigger episodes of autonomic dysreflexia (AD) due to overfilling of the bladder, care was taken to ensure the

bladder was not overfilled and did not induce symptoms of AD.

## Looking Forward

Gad says he and his team are increasingly excited about TESSLA's potential to improve the lives of people with SCI in a realistic timeframe.

“The study shows that TESSLA represents a first-of-its-kind method to improve bladder function using a completely non-invasive approach—one that has three key features: increased bladder capacity, improved coordination between bladder and sphincter, and ability to void on command. This means fewer incontinence episodes, thus benefiting users' health and self-confidence. It also means lowering the risks of high pressure voiding, loss of bladder compliance, and kidney injury. And our finding that TESSLA mediates recovery of bladder-sphincter synergy suggests this coordination can occur at the spinal cord level, thus challenging the dogma that it's facilitated solely by the brainstem and the brain.”

## Another UCLA Study Reports Success with Restoring Bladder Function

Just prior to this issue of *The Spin* going to press, another group of researchers at UCLA reported success in restoring significant bladder control in five men with SCI. This project, led by Dr. Daniel Lu, associate professor of neurosurgery at UCLA's David Geffen School of Medicine, is unrelated to the electrical stimulation work led by Dr. Parag Gad.

Like the study at the Edgerton lab, this study involves “awakening” the dormant abilities of the spinal cord to improve bladder function. The difference is in the mechanism used—while Gad's study used electrical stimulation, Lu's study involved the use of a magnetic device placed at the lumbar spine.

“Most SCIs are not anatomically complete; the spinal cord retains a weak, residual connection with the brain,” Lu says. “We are restoring bladder function by amplifying these faint signals and enhancing the spinal circuits' ability to respond to them.”

Each participant underwent 15 minutes of weekly stimulation for four months, but it only took four sessions to see positive effects.

“All five of the men regained the ability to urinate on their own during stimulation,” says Lu. “In one case, the patient was able to completely stop using a catheter and empty his bladder sev-

eral times a day, up to four weeks after his last treatment.” He adds that the benefit persisted from two to four weeks for all participants, and the ability to urinate at will improved in each patient. Four of the men still had to use a catheter at least once

a day—but that was still a significant drop from their average of more than six times a day before the treatment. The treatment improved the men's quality of life by an average of 60 percent, according to questionnaires they completed before and after the study.

Lu and his colleagues are now planning a larger study in order to confirm the benefits and get a better understanding of how magnetic stimulation alters neural activity in the spinal cord.

The same approach has been used in the brain to treat conditions ranging from depression to migraine. The magnetic stimulation device is FDA-approved for use in humans.

We asked Lu if there was any link between his study and the electrical stimulation work being done by Gad and his team.

“There is no overlap between the two studies,” says Lu. “The targeted mechanism is likely different.”

The findings were published in the journal *Scientific Reports*.



Dr. Daniel Lu

Gad also recognizes that one of most important features of the TESSLA technology is the non-invasiveness—it could ultimately be easily used for a number of different purposes—for example, improving hand and grip strength, as we told you about in the last issue of *The Spin*.

“You could easily move the electrodes,” says Gad, “and then could undergo rehab for hands and arm, trunk, legs and bladder using a single device, in a single day.”

However, while he believes the device could be commercially available in a realistic time frame, he cautions that larger studies are needed to confirm benefits and safety.

“The next key step is to look at the long term effects of stimulation on overall bladder function. It’s important to note that these results were observed within a few days of the stimulation.”

We’re as intrigued as you are about the potential of this research, so rest assured we’ll report any new developments as they happen. ■

## Fecal Incontinence Treatment Gets Boost from the FDA

In the Fall 2016 issue of *The Spin*, we told you about RDD-0315, a first-of-its-kind topical cream being developed and tested for the treatment of fecal incontinence in people with SCI. At the time, RDD Pharma, the Israeli company behind the treatment, had received orphan drug status in Europe based on promising results from its Phase 2a clinical trial. Recently, RDD Pharma received FDA clearance for its Investigational New Drug (IND) application for RDD-0315.

“This allows RDD to begin clinical studies in the US,” says Jason Laufer, RDD Pharma CEO. “We will examine safety and the pharmacological properties of three doses of RDD-0315. This study will be conducted as a standard Phase 1 study in human subjects. The study commences in August and will conclude before year end 2018.”

The active ingredient in RDD Pharma’s compound is a variation of the drug oxymetazoline, which has been used safely for decades in medications such as Dristan nasal spray and Visine eye drops. Oxymetazoline promotes smooth muscle and blood vessel constriction. In the case of RDD-0315, it’s placed into a cream and applied manually to the inner anal rim, where it signals the smooth muscle in the sphincter to contract, thereby helping to prevent accidental leaks. Results from the company’s Phase 2a clinical trial in Europe indicated a reduction of approximately 25 percent in fecal incontinence.

The same trial demonstrated the treatment’s safety, so future trials will focus on increasing the dose with the goal of getting even better effectiveness.

“Drug development requires focus, determination, patience and financing,” says Laufer, adding that a best case scenario for full sale approval would be 2021.

# Driving your way.



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# EventFull



## “What did you do on your summer vacation?”

Remember when you went back to school every September, and that was the burning question every one of your friends asked you as soon as you saw them? Maybe you even got to give your entire class the lowdown on your summer adventures in a show and tell session. Well, in the next couple of pages, we’re going to give you a peek into some of the experiences shared by the nearly 2,000 Peers who joined Spinal Cord Injury BC for our annual summer events. With the assistance of our committed volunteers and funders, we hosted more than 125 awesome events and meetups that offered our Peers the chance to learn a new sport or activity, see some incredible scenery, reconnect with old friends, and forge new connections throughout the province.



## PEERS AT PLAY

(from left to right in each photo)

- 1 Vince Miele and Terry LeBlanc share a chuckle at the annual Guys' Garage in Vancouver.
- 2 SCI BC staff Ryan Clarkson, Shelley Milstein and Micaela Evans may hate running, but they love the yearly Multi-Sports Day & BBQ.
- 3 Ron and Yuko Holmberg hit the water with their son at Alice Lake during SCI BC's first ever "Learn To Camp" trip.
- 4 SCI BC Kootenays Peer Coordinator Josh Dueck turns up the heat after a day of Peer paddleboarding at Paul Lake near Kamloops.
- 5 Pat Danforth and Glenda Gain swap stories and laughs at the Women Only group in Victoria.



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- 6 In memory of Bayan Azizi, Nika Aziza and Louisa Bridgman join Team Walk 'n' Rollers for the Scotiabank 5k race along Vancouver's Seawall.
- 7 Bhavyn Sandhu and her family enjoy paddling together at SCI BC's Whistler Weekend.
- 8 Fist bump! Mitch Garrett conquers new heights at SCI BC's action-packed Whistler Weekend.
- 9 Codi Punnett and her family take a break from the surf during a Power To Be surf trip in Tofino.
- 10 John Chernesky, Richard Peter and Aidan Love take the adaptive mountain bikes out for a spin with the gang on Whistler's Trainwreck Trail.

**PREVIOUS PAGE:** Codi Punnet and her boys prepare to catch some waves with Power to Be in Tofino.



10

# ask the SPIN DOCTOR

Heather in Creston writes, “I want to exercise in a gym, but I don’t live in an area where there is a truly accessible facility. I think there are some local gyms that might work, but I’m a little intimidated and not sure how to approach them. Do you have any advice?” Our thanks to Dr. Jasmin Ma, adapted personal trainer and researcher in Health and Exercise Sciences at UBC Okanagan, for stepping in to answer this question.



I love getting this question. I believe, where there’s a will, there’s always a way we can adapt a space for everyone.

I start by answering three questions: Who can help? How can we best adapt the facility/equipment that’s available? And what are the alternatives to the gym?

At the gym, the most likely people who can help are staff. Don’t be intimidated—most gym staff I’ve encountered are enthusiastic about helping everybody get fit.

Start by asking if there are any staff who have knowledge about working with people with disabilities. Sometimes being specific about the areas you might need assistance with can give staff a better sense of how they can help (for example, needing grip assistance, or enough space at a piece of equipment for your wheelchair). However, don’t be surprised if the gym doesn’t have disability-knowledgeable staff. Most will be willing to help, so think of it as a mutual learning opportunity. Also, often times you can request to have an assistant, such as a friend or caregiver, come in with you (most times for free).

Also ask if there is any equipment that can be or is adapted. Again, the gym might not have specialized adapted equipment (or even an answer), but it doesn’t hurt to ask. I’ve posed this question to many gym managers and often received a positive response—either asking how they can learn to make their space more accessible or expressing a willingness to source some adapted equipment.

As for how to best adapt the facility/equipment, this question requires some creativity and trial and error—which is the fun part! There are several pieces of equipment that are typically found in any gym that can easily be adapted.

For example, free weights (or dumbbells) can often be used by anyone, disabled or otherwise, for bicep curls, shoulder presses, bent over rows, and straight arm overhead rotations. Free weights are especially advantageous for engaging stabilizing muscles and can add a challenge to the core for those that have the activation. Also, pulley machines are a common staple in the gym, and often allow anyone to do exercises such as lat pulldowns, tricep push downs, shoulder abduction/adduction/flexion/extensions, seated rows, and more.

If you’re a manual wheelchair user, I always recommend “pull” exercises with pulleys to help counteract sometimes over-developed chest muscles and strengthen back muscles.

There are some additional considerations.

The first is grip. For those who need a little extra help with grip, try Active Hands ([www.activehands.com](http://www.activehands.com)) or have an attendant help you wrap tensor bandages around the hand while gripping the equipment. Note that this adaptation can be a bit time consuming, so I’d typically only recommend it if you’re using cardio equipment like an arm ergometer, where an extended amount of time is spent using the machine. Wrist hooks are another option and are a common accessory gyms will already have—these are especially helpful for supplementing your grip when using the pulley or bar.

Second is specialized equipment for people with disabilities. These pieces may be hard to find, but can sometimes be added to a gym if you (and others) keep asking for them! These include an arm ergometer or arm bike (my favourite piece of cardio equipment), rowing machine with an adapted seat, medicine balls with wrist straps, cuff weights, and weight machines with removable seating.

As for alternatives to the gym, there are days when the weather, traffic, or motivation is less than ideal and a home workout can help alleviate these barriers. Here are some equipment and exercise ideas to make your own home gym:

- resistance bands (you can do almost any exercise you would do with a machine with these bands—check out Active Homes at [SCIActionCanada.ca](http://SCIActionCanada.ca) for ideas)
- body weight exercises (push-ups, scapular retractions, modified plank)
- household items for weights (cans, soap jugs, almost anything you buy from Costco)
- free weights, which can be purchased inexpensively online at Amazon or Canadian Tire (\$5-\$25 depending on the weight)
- Yoga and stretching exercises (great for helping to tame spasticity)
- wheeling (listen to your body and avoid overuse injuries)
- dance (one of my former clients has a blast holding dance parties with her kids).

As a goal, the *Spinal Cord Injury Physical Activity Guidelines* recommend at least 20 minutes of moderate to vigorous aerobic activity twice a week, as well as strength training incorporating all major functioning muscle groups twice a week. Regardless of where or how you do it, you should enjoy your exercise—it’s a lifestyle. If it’s not the gym, maybe it’s handcycle rides with family, sports with friends, exercise classes, wheels on the track, or dancing like nobody’s watching—the goal is to get your physical activity in a sustainable and enjoyable way.

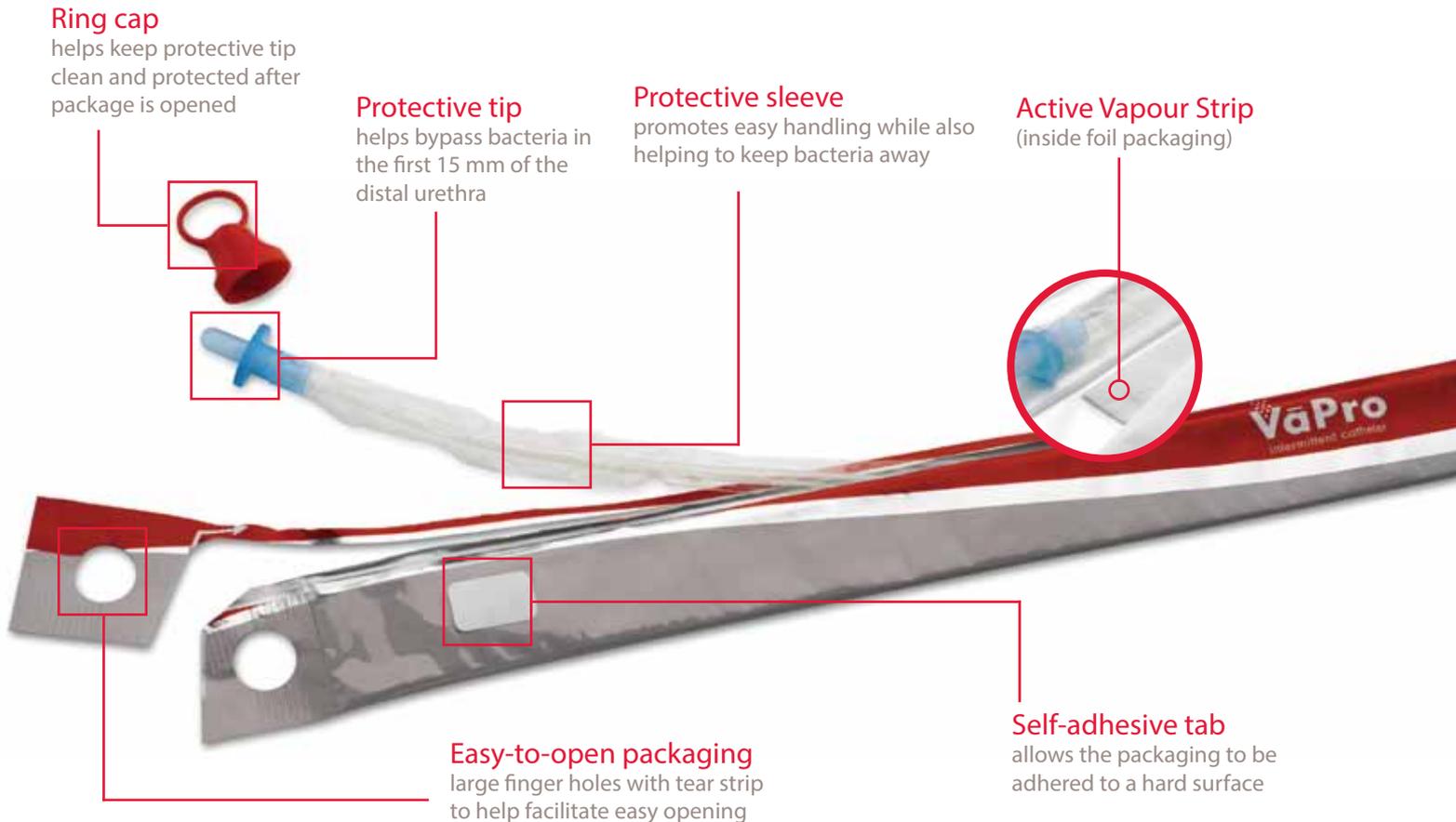
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# access & allies

**Rolling Gonzo In Europe With C6  
Quadriplegia – and Killing It** *by Murray Siple*





## Thanksgiving night, 1996.

I met friends at a pub and ended up a passenger in their sports car. In a fast kilometre we reached a 100km/hr. That's when I found out my mates had been partying all day. We hit a barrier and the car launched 40 feet into the air, landing roof first. Hello, quadriplegia.

You might think it was an insane decision—to get in a car in that situation. But in the six years leading up to that night, I'd been travelling the world, snowboarding and skateboarding with professional extreme athletes. I had been in many more insane situations than getting into that car.

In rehab at GF Strong, I was thrown into a new world. I had plummeted from extreme sports to spending my days trying to roll over on a mat while hearing about bowel and bladder issues. Thankfully, one day there was a travel talk for people with SCI held by wheelchair rugby legend Duncan Campbell, who had wheeled as a C6, without assistance, from Amsterdam to Paris. So, if I learned to pull my pants up myself, could I eventually graduate to travelling again? Absolutely. Thank you, Duncan. You inspired and launched me back out into the actual real world.

If you travel and use a wheelchair, don't forget to pack a sense of humour. It'll get you up, down, over, and across barriers that have kept you meandering the same path for too long. Plus, when wheelchair travel goes feco-ventilatory on a trip—and it will, BTW—that sense of humour might be the best wingman you've ever had. I learned this quickly

during my first adventures in Europe as a wheelchair user. I've been around the world since, but those first few travels in Europe taught me a sack of tricks that inspired me to never give up. They gave me the confidence to be bold in my ventures, not to mention a suitcase full of stories—and isn't that the point?

## London: Old...and accessible.

My first trip to London as a wheelchair user was solo. I landed at Heathrow Airport, which had flooded from a rainstorm. Long after my fellow passengers had disembarked, I sat alone for an hour, waiting for assistance because the gate staff were dealing with rising water in the terminal. As the cleaning staff began vacuuming around me, a sympathetic pilot dodged them and handed me a whisky (flight staff are unable to assist you off the aircraft; only ground crew can).

Once off the airplane, it became apparent to me that London is surprisingly accessible. All the city's iconic black cabs can accommodate a manual wheelchair. Although you're not strapped down, you'll be preoccupied with London's fascinating street scenes flashing by. I gawked at mobs of people of all ethnicities, and at historical locations made

famous by album covers and movies—who needs tie-downs? There are other options for wheelchair transportation (for starters, wheelchair taxis and buses) but I found hailing a black cab the most convenient and best use of my short time in the big city.

I visited St. Paul's Cathedral (1400 years old), and it had an elevator. Rooftop restaurants all had elevators and incredible views. Both banks of the Thames had massive wheelchair-accessible paths. The art galleries and museums are not only free, but also entirely accessible. But don't always take accessibility for granted in an old city like London. One rainy night, I had to rely on friends in dress shoes to carry me up four stories of glass stairs to a party, then back down.

I stayed at the Ace Hotel London Shoreditch. Most Ace Hotels are retrofitted historic buildings, and have accessible rooms with a small living space, micro kitchen, a music system, street art, and vintage industrial furniture. They also have bars frequented by local artists, writers, and musicians—a great place to find out what's happening. A dishevelled man with a ball cap pulled tightly down over his eyes took a seat at my table. Turns out he was the Ace Hotel





co-founder, Alex Calderwood. Stressed from the explosion of success of his hotel chain, he found solace in disguising himself. I bought us a round of pints and complimented him on the hotel designs, fun vibes, and accessibility.

Two weeks later, I learned Alex had passed away.

### Paris: Not So Much

I arrived in Paris on the wheelchair accessible Eurostar train, which rockets from city to city via the Channel Tunnel in less than two hours. I stayed in Montmartre, hoping to see neighbourhoods where Picasso, Van Gogh, and Matisse once lived and worked. Unfortunately, I arrived with the flu and spent the first few days in my room recovering. Hotel rooms in Paris are usually extremely small. Mine had just enough room to just wheel into—I had to back into the bathroom’s roll-in shower just to turn around in order to leave the room.

Once I was mobile, a friend invited me out for *Nuit Blanche*, the dusk ‘til dawn art festival that holds the entire city in its thrall. We first had to travel by non-accessible taxi (no wheelchair van taxis in Paris at that time) to the outskirts of town to meet his friends, and the plan was to walk and roll through the art displays all night. My friend and his comrades loaded up on magic mushroom tea and wine as we discussed the art we anticipated experiencing. I was okay with them on mushrooms, but I personally avoid hallucinogenic drugs because my muscle spasms turn me into Elvis.

Getting underway, we began to encounter the many bridges or “passerelles,” over the canals. Most had stairs that I had to be carried up by new friends



with slowly-melting brains. Adventure is everywhere, I guess; I made it without being dropped or tipped into a canal. But by the time we reached downtown, *Nuit Blanche* was over.

The next day, I wheeled alone along the Seine, past Notre Dame and to the Eiffel Tower. The tower’s elevator, of course, was under repair.

Paris sidewalks are too narrow for wheelchairs, so I fought my way through the middle of side streets where dog excrement is a constant reality. I asked numerous people for a little help, and “Why are you here?” was a typical response. Paris is many things, but it’s not London, especially for those using a wheelchair. After a few photos, I left, hoping to find better accessibility and friendlier faces in Barcelona.

### Barcelona: Mediterranean Magic

Some of my optimism faded as I contemplated the grim reality of the non-accessible night train from Paris to Barcelona. I was carried grudgingly by staff to a car devoid of other passengers. But my peace and quiet soon disappeared as the train stopped to gather late-night commuters: a drunk mad at his wife for cheating; a woman in a torn gown who frequented the bathroom often and crawled out (heroin?); a small group of excited Japanese teens. I put a blanket over my head and managed to doze.

I woke up in Barcelona, where no staff were willing to carry me off. I hollered at

a few tourists for help, and fortunately, a few came to my aid. I had made it to Spain, and although physically burnt out from train travel, I was stoked to explore everything that glistened in the bright morning sunshine. Beckoning me were beaches, long seawalls, architecture, art, culture, and culinary adventures—all in one concentrated area of a city that quickly became my favourite.

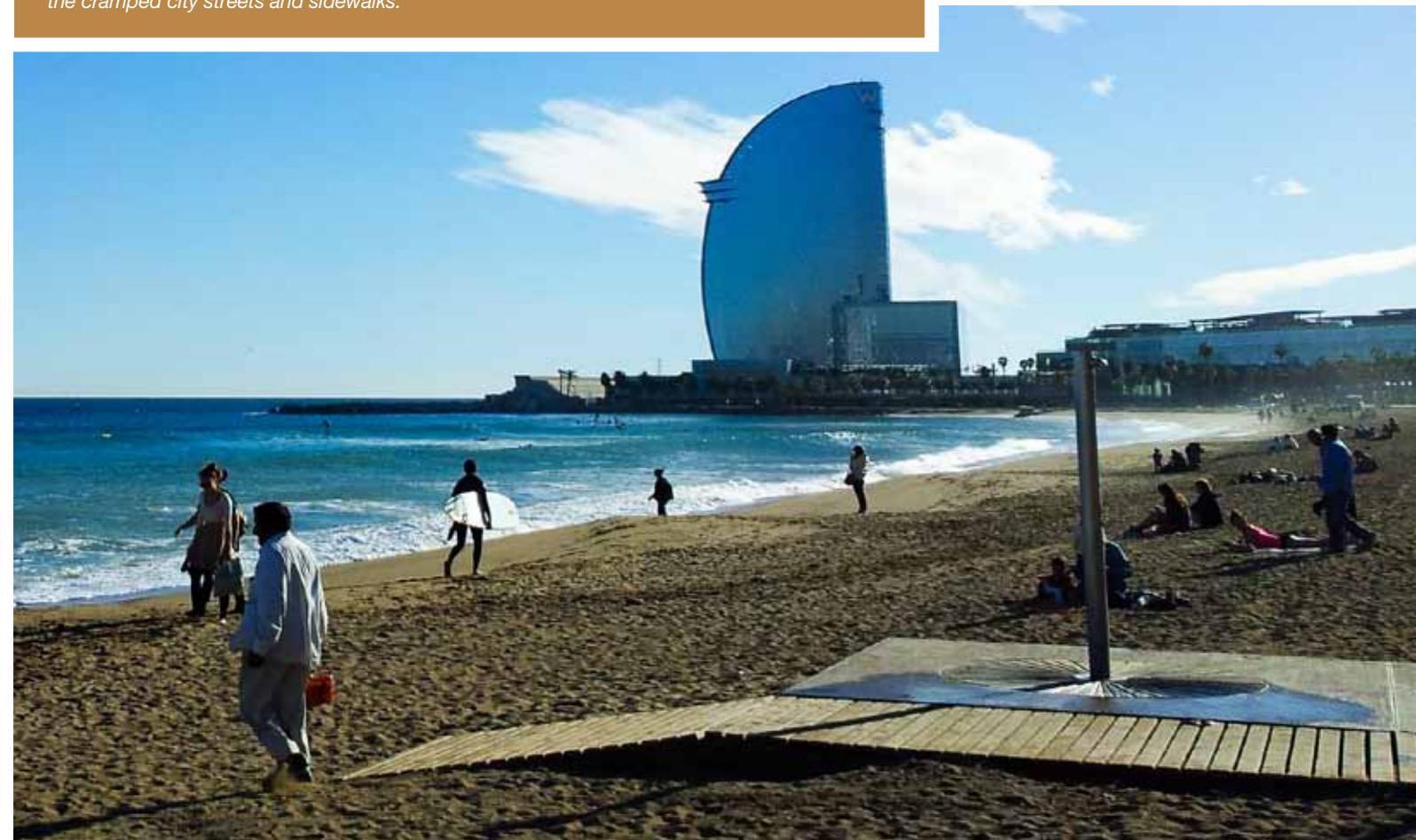
I discovered that navigating Barcelona in a wheelchair is relatively easy. For example, the curb cuts are designed so that when you roll down one, it gives you enough momentum to cross the street and roll up the other—genius. Even the beaches are highly accessible with ramps, hard paths, and change rooms with beds.

By the first evening, I had met a local artist who guided me to the Plaça Sant Felip Neri where young people were drinking wine, writing poetry, and playing guitar. At that moment, under the starlit Mediterranean sky, all my efforts to get to Spain were justified. I’ll concede, however, that the night suddenly became darker when my guide pointed out bullet holes on the walls and doors of the church, left as reminders of Franco’s atrocities less than 80 years ago during the Spanish Civil War. My guide’s words, “That’s where they killed children,” will haunt me forever.

Barcelona has wheelchair taxis, one of which I hired to get up the dauntingly steep hill to Park Guell, home to some



*ABOVE: Barcelona's incredible Sagrada Família, scheduled to be completed by 2025—more than 140 years since construction started. RIGHT: I found exceptional accessibility at the amazing monastery of Santa María de Montserrat, outside of Barcelona. BELOW: Barcelona's beautiful beaches offer exceptional accessibility. That's the famous Hotel W Barcelona towering in the background. FACING PAGE, LEFT: Sharing pints with new friends in a typical London pub. FACING PAGE, RIGHT: Paris' iconic landmarks, such as the Eiffel Tower, are difficult to reach via wheelchair on the cramped city streets and sidewalks.*



of the most significant works of sculptor Antoni Gaudí. My plan to explore the park failed when, barely 100 meters in, I realized the trails were either gravel, dirt, or hot asphalt. I had no water, it was 38 degrees, and the friend I was to connect with bailed on me. I had no choice but to call the police. What else does a person with quadriplegia in this predicament do? When the Guardia arrived, they took me through the park and down the trail like angry tour guides, and hailed me a cab.

Initially, I wanted to find a rental apartment in Barcelona. This turned out to be a challenge—in Spain, it's common to have three steps up to the elevator. After days of blowing my budget on hotels, I started to give up hope for staying longer. That's when I stumbled upon Pere Pueyo's ground-floor rental apartment.

Pere, like me, is a filmmaker. Travel luck! His eco-friendly studio had a roll-in shower, and a courtyard lined with banana trees. The entry had one step; I rented it anyway. After a day of exploring, I came home to find Pere had designed,

built and installed a shining aluminum ramp I could deploy as needed.

From my base at Pere's now fully-accessible apartment, I wallowed in the sights, sounds, tastes and smells of Barcelona for days. Throughout it all, I marvelled at how the city and its citizens design so incredibly well, then commit to the finishing of projects. Gaudí died 100 years ago, yet work continues on his visionary Sagrada Familia—a cathedral that enralls believers and non-believers alike.



This past winter, I traded in air travel for long-distance driving, and ended up in a small village near Puerto Vallarta, Mexico. But I'll always cherish my rough European adventures, experienced in the first years after my injury—even when they didn't unfold perfectly (think Paris). The exoticness of the Old World destinations was one reason, but I think these journeys also restored my confidence as a traveller—something that had waned in the dark days following my injury.

Travelling as a wheelchair user should not leave you on a beach where you can't roll anywhere, at a pool you can't dive into, or on a tour bus removed from the local vibe. Life is short; if someone is vacuuming around you while you sit and do nothing, or you can't find anything new on Instagram, at least be in a foreign country with a drink in your hand. ■

*Murray Siple is a 48-year-old filmmaker who studied at the Emily Carr University of Art And Design. When he's not rolling gonzo in an exotic destination, he lives in North Vancouver, where he's painting, editing experimental films, designing sculptures, putting the finishing renovation touches on his fully-accessible 50s-era rancher, and researching new adventures to locales where he's not supposed to go.*

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# ELECTRIFYING

It's always been hard to keep up to SCI BC Peer James Telep, but his new custom-made electric bike makes it even tougher.

**G**oing fast—and finding unique ways to do it—have always been constants in James Telep's life. Even a snowboarding accident that left him with paraplegia 20 years ago did little to dampen his need for speed, or his love of getting his hands dirty, twisting wrenches in his garage.

"I'm a very hands-on kinda guy with a high drive to do unique things in life," says Telep, who has lived most of his 40 years in Maple Ridge.

As just a few examples of what he refers to as "my madness," Telep owns three hovercraft (which he's completely rebuilt), a 1968 Corvair street trike he's in the process of restoring, 14-foot aluminum jet sled river boat, an insanely fast Yamaha Banshee ATV, and a modified wave ski.

"Every sport I do requires custom equipment, so I love creating stuff me and my fellow paras can use," says Telep.

Four years ago, he decided the only thing missing in his man cave was an electric bike that would allow him to ride both streets and trails with friends and family.

"So me and a friend came up with a concept while we were brainstorming and trying to think outside the box about how anyone disabled could get back out and enjoy being on the trails again," he explains. "I looked at many ideas and concept bikes that were being built in other countries, and found them all way over-engineered. So I kept my design as simple as I could make it, using existing electric bike technology and creating my own one-off design to use it on."

He knew he needed to begin with thoughtful design, so his first task was to learn how to use 3D computer-assisted design software. He settled on a four-wheel concept for stability, with rear wheel drive. The software allowed him to visualize the concept and prove it could work before attempting to build it.

And build it he did. But the project wasn't without its challenges, and his family life and career as an office manager for an electrical contractor often took precedence.

"It took me over four years to get this bike right," Telep

says. “From idea to creation, this bike has been a hard, hard, uphill battle with many sleepless nights.”

Among the challenges were sourcing the various parts that were available commercially, and then fabricating those that simply weren’t available for purchase. Many parts had to be expensively cut on CNC machines (CNC is short for computer numerical control), and Telep also learned some additional skills such as aluminum welding. From there, it was trial and error, with many important parts needing strengthening and redesign.

Along the way, the friend who had been part of the project since the beginning moved to England. So Telep paid him for his investment in the project and forged ahead by himself.

This year, he put the finishing touches on what he now calls the Enduro Bike.

“I finally have it nailed down and get to enjoy all my hard work,” he says.

The finished result is an impressive piece of engineering. The bike has full independent air ride suspension, front disk brakes, thumb throttle, LED safety lights, and individual electric rear hubs that are powered by 52-volt, 13-amp lithium ion batteries. It’s capable of speeds up to 57 km/hr, but it can be programmed to limit the speed to 50 km/hr, which keeps it legal as an electric bicycle. Range is about 40 to 50 kilometres per charge.

“For me, this electric bike has brought endless freedom back to my life,” says Telep. “I find I’m riding it, on average, three to four times a week, and I’ve even started riding it to and from my work. I take it to the rivers and fish, and I explore all over the local trails and dyke systems in our area. On July 1st, for my 40th birthday, I challenged myself to do the Okanagan trestles tour with a few lady friends—it was an 80 kilometre ride from Kelowna to Penticton along the old Kettle Valley Railway system. It was awesome—I did it in just over five hours and the bike ran flawlessly. I wanted to prove my design could handle it, and it did.”

But Telep is not one to rest on his laurels. Keen to share the experience with his peers, he’s already started building an additional ten bikes based on his prototype.

“It’s simply life-changing for me, as no other bike gets me all the places I have gone with such minimal wear on my body like this one has,” he says. “So I want others to share and have the same feelings I get every ride from getting my freedom back to explore again. I’ll make a touring edition (like his prototype) and a more off-road version with electric hubs designed to provide more torque, so it can hill-climb a little better.”

While he says the bike is very easy for anyone with paraplegia to transfer into, he’s hoping to incorporate a swivel seat in his next round of bikes.

“I have a few friends who are quads, and they’ve given me a few ideas on how seats could swivel and lock, and also for sorting out a better (quad-friendly) brake handle,” he says. “It’s all very doable in my eyes.”

He estimates that he’s about halfway through his next round of ten bikes.

“Funding is my biggest hurdle,” he concedes. “All my pieces needs to be CNC-machined, which isn’t cheap. I’m just starting now to look for grants, as I have really proven my concept over the last year of my ventures. For now, I’m self-funded.”

His future plans are to form a company to market the product. He’ll keep two of the bikes currently under construction as test or display units for the company, and another for him and his kids to use. He hopes to sell the remaining seven, with the goals of recouping some of his costs. In addition to Peers with SCI, he’s had expressions of interest from some seniors he knows, as well as some fellow hunters who like the quietness of the electric propulsion system.

If you’re interested in the bike, or would just like to talk about the possibilities of getting back out and on the trails, Telep says feel free to get in touch with him.

“This is my goal—to help others get back out again. I know all too well how depressing it is when you’re stuck indoors and not able to explore. Even just riding down to the end of the block and back can be huge. But this machine takes it to a whole new exciting level—that’s for sure!” ■

*You can reach James Telep by email at [mrwheelz@hotmail.com](mailto:mrwheelz@hotmail.com).*



Photo by Crystal Smith, All Things Crystal Photography



Photo Courtesy: Fohan O'Doherty/Quesnel Cariboo Observer

# Peer Shoutouts

**1** Congratulations to Quesnel's **TREVOR ADELMAN** (above) for capturing his first ever WESCAR Series main event. Trevor beat out 11 competitors to win the main event at Prince George's Billy Barker Days Stock Car Race on July 21, battling from the fourth row starting position to the front of the pack where he stayed. The victory is even sweeter given that three weeks prior, he was involved in a nasty crash that resulted in his hand-controlled car needing extensive repairs. Trevor is well-known to many readers of *The Spin*, as he's a Paralympian sledge hockey player, and also the front man for the well-known country rock band Rockin' Chair. He was injured in a car crash in 2004.

**Are you an SCI BC Peer who has something to shout about? Or do you know a Peer who has recently accomplished something noteworthy? Send the details to [info@thespin.ca](mailto:info@thespin.ca).**

**2** It's great to see Vancouver's **CODI DARNELL** (bottom left) acknowledged for her incredible blogging of her life as a woman with an SCI. Recently, Vancouver Mom ([vancouvermom.ca](http://vancouvermom.ca)) announced that Codi was the winner of its 2018 Top Blogger award. Codi, who is a wife and mother of three kids, beat out 30 other finalists to take home the coveted prize for her blog *Help Codi Heal* ([www.helpcodiheal.com](http://www.helpcodiheal.com)), which she passionately uses to provide readers with honest (sometimes painfully so) insights into her life as a woman with SCI. Readers might recall that we published one of Codi's poignant blog posts (Deconstructing a Panic Attack) in the last issue of *The Spin*. Write on, Codi!

**3** **JAISA SULIT** (bottom right) returned to Toronto last year, but she is well known by many of our Peers for sharing her insightful, holistic approach to healing after SCI during the two years she called our province home. Sulit, a rehab occupational therapist, sustained her own SCI in 2010 in a motorcycle accident. Since then, she has studied mindfulness as a tool to use in her own battle with chronic pain, anxiety and depression (she shared some of that knowledge two years ago in a feature here in *The Spin*). Recently, she published the book *Purpose in Paralysis: From Chronic Pain to Universal Gain*, which is getting rave reviews on [amazon.ca](http://amazon.ca) and other book selling websites. We miss you, Jaisa!



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# Strawternatives

As you read on page 7, not everyone agrees that plastic straws should be banned. Regardless, the anti-plastic straw movement is gaining momentum. For those who want to be prepared, here are seven innovative, eco-friendly alternatives. You can find many more online with the help of Google and Amazon.



## Bunkoza

The Bunkoza Eco Straw Classic is made of stainless steel, and comes with its own pouch and cleaner.  
[bunkoza.com](http://bunkoza.com)

## Titanium Straw

The Titanium Straw is advertised as the world's strongest and most durable straw.  
[snowpeak.com](http://snowpeak.com)



## Aardvark Eco-flex

Disposable paper straws that are safe, food grade, durable and biodegradable; available in a variety of sizes and colours.  
[aardvarkstraws.com](http://aardvarkstraws.com)



## Simply Straws

The Classic Single Sleeve Set from Simply Straws includes one straight glass straw, a sleeve, and a cleaning brush.  
[simplystraws.com](http://simplystraws.com)



## FinalStraw

A reusable, collapsible straw that comes with its own case and squeegee cleaning tool.  
[finalstraw.com](http://finalstraw.com)



## Bambu

Bambu creates hand-crafted reusable straws from real whole bamboo stalks. They come in package of six with a sisal cleaning brush.  
[bambuhome.com](http://bambuhome.com)



## Softy Straws

Eco-friendly, BPA free, reusable straws made from food grade silicon, available in a range of sizes.  
[softystraws.com](http://softystraws.com)



# 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.

## Comparison of Pain Response in Able-bodied People

**Overview:** Researchers in Dr. John Kramer's lab are investigating the brain's response to different painful stimuli: contact-heat and radiant-heat. The brain's response will be recorded using electroencephalography (EEG). These stimuli are currently used in clinical applications to diagnose nerve-damage (neuropathies); however, no direct comparison between them has ever been done. We therefore aim to characterize their effects in able-bodied participants with no history of neuropathy or chronic pain. Response to both stimuli will also be investigated in a neuropathic-pain setting, modelled by application of topical capsaicin to the forearm. Capsaicin-related sensation is temporary and will be resolved within 24 hours of application.

**What to expect:** In this study, you will be asked to wear an EEG head-cap while undergoing approximately five minutes of stimulation at each appointment. You will rate each stimulation on a scale of 0 - 10/10. Your response to multiple pinpricks will also be recorded at each experimental session. The study will take a total of six hours to complete (four 90-minute sessions). No compensation will be provided but refreshments (coffee, tea) will be provided after each session.

**Who can participate:** You may be eligible to participate in this study if you are between 19 and 45 years old, proficient in English. You may not be eligible to participate if you are pregnant, have taken any psychoactive medication, alcohol or other drug in the 24 hours before testing, have any neurological condition, are hypersensitive to light in the near-infrared wavelength region, take any prescribed medications other than birth control, have a personal history of skin cancer, have had previous negative reactions to topical capsaicin application, or have skin disorders or tattoos in the area of testing.

**Why participate:** There are no direct benefits to participants from participating in this research study, but the researchers hope that the information gained can be used in the future to help others receive a more accessible and timely diagnosis of neuropathies, including spinal cord lesions.

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

**For more information or to sign up to participate:** Please contact the study coordinator, Carson Berry, by email ([carson.berry@alumni.ubc.ca](mailto:carson.berry@alumni.ubc.ca)) or call 604.675.8876.



## Assessing Pelvic Floor Muscle Function in Individuals with SCI

**Overview:** The pelvic floor muscles (PFM) are situated under the bladder and play a crucial role in bladder control by facilitating the voluntary retention and voiding of urine. In the able-bodied population, training programs to strengthen these muscles are a common treatment in fighting bladder problems, including leakage and overactive bladder symptoms. However, we have yet to apply these training programs to individuals with SCI because we do not know how the PFM function post-injury. Researchers in Dr. Tania Lam's lab want to determine how and if the PFM work in people with SCI using two different techniques.

**What to expect:** In this study, you'll be asked to come to the lab for one visit that will last two and a half hours. Once you arrive, we will place small markers on your skin that record different types of muscle activity. We will also ask you to complete some questionnaires about your injury, overall health, and current bladder function. After this, two small experiments will be conducted (see [icord.org/pfm-function-sci/](http://icord.org/pfm-function-sci/) for details).

**Who can participate:** You may be able to participate in this study if you are between 19 and 60 years of age, and incurred an SCI at least 12 months ago that is above the level of L1 AND is motor-complete (i.e., you have no movement below your injury level but may still have sensation). To see a list of reasons why you may not be considered eligible to participate in the study, please visit the study's webpage on the ICORD website ([icord.org/pfm-function-sci/](http://icord.org/pfm-function-sci/)).

**Why participate:** Research suggests that more than 80 percent of individuals with SCI experience some form of bladder impairment post-injury. However, current bladder management techniques are limited and pose other health concerns (e.g., bladder infections from catheter use). Our hope is that by demonstrating how the PFM function after SCI, we can aid in developing new and non-invasive rehabilitation methods to improve bladder function and overall quality of life for those with SCI. You will be compensated \$50 for your participation.

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

**For more information or to sign up to participate:** Please contact the study coordinator, Alison Williams, by email ([awilliams@icord.org](mailto:awilliams@icord.org)) or call 604.675.8815.



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](http://www.icord.org/research/participate-in-a-study)



# WEED 101

Many SCI BC Peers tell us they've successfully tried cannabis to improve their quality of life, either with or without Health Canada medical approval. But we also know of many who haven't, with legality and stigma often being the barriers. On October 17, everything will change. So, for anyone late to the party who is now determined to take advantage of weed's impending legal status, we offer this little primer.

## What does weed offer people with SCI?

For many, simply getting high is an enjoyable reprieve from the daily grind. But it's clear that, for people with SCI, there are therapeutic benefits. The pot prohibition has made it difficult to conduct research on the health benefits of cannabis. But the smattering of research that has been done, along with a few decades worth of anecdotal evidence, suggests that, for people with SCI, weed can be effective for managing pain, spasticity, depression and anxiety, and insomnia.

## Are there different types? Which is good for me?

There are two main types of cannabis plant: sativa and indica (there are also hybrids of the two). Regardless of the type, cannabis plants contain varying amounts of the two important active ingredients, or cannabinoids: THC and CBD. THC gets you high, but doesn't offer many therapeutic benefits. CBD is the stuff that tames spasticity, reduces pain and anxiety, and counter-balances the "high" effects of THC. It's generally accepted that sativa is THC dominant, while indica is CBD dominant. Indica, therefore, is most recommended for therapy.

The rule of thumb is that, for most people with SCI, weed with a three or four to one ratio of CBD to THC is ideal—it provides therapeutic benefits without getting people too high. Producers will be required to list the CBD/THC levels on packaging, but it remains to be seen how accurate this labelling will be. Most experts agree that trial and error, along with good advice from a reputable store or dispensary, will be necessary to find what works best for you.

All cannabis has a third notable cannabinoid: CBN. If insomnia is a big problem for you, CBN is a key ingredient. Essentially, CBN is degraded THC—it accumulates in cannabis that's been left to age (ideally in sunlight) for an extended time. Not many producers pay attention to CBN content at the moment, so if you want to experiment with it, you'll probably have to age your own weed to maximize CBN content.

## How do I use it?

Cannabis is mainly consumed in three forms: dried flowers, oils and extracts, and edibles and tinctures. Dried flowers, or bud, is the most common, but smoking it isn't recommended. Fortunately, for a modest cost, you can buy a vaporizer that heats the flower up just enough to release the vapour containing the active ingredients—and not the carcinogenic smoke. You can also vape oils and extracts. Edibles (like cookies and candies) and tinctures are popular, but they will not be legally available until next year (however, you can still make your own from your legally-sourced weed). Inhaling vapour gives the quickest results, while edibles provide more long-lasting effects. Regardless of method, dosing is important. Start low and go slow—experiment with a small quantity and gradually increase the amount until you get the benefits you're seeking.

## Where will I be able to buy it?

Starting October 17th, anyone 19 or older in BC will be able to buy cannabis online, and from private and government stores (exact locations are not available at the time of writing). Adults will be also allowed to grow up to four plants per household, but be warned this is a lot more difficult than simply planting a seed.

## Where will I be able to use it?

Obviously, you can consume on your own property. You can carry up to 30 grams when in public, and you can consume it in most public places where smoking cigarettes is allowed. But you won't be able to consume in recreational areas, parks, enclosed public spaces, bus/ferry stops, or near children. And it goes without saying that you can't consume in your car.

## Is there anything I should be worried about?

Every province will have different rules for buying, so check those regulations before you travel! While legal in Washington State, it's NOT legal to take it across the US/Canada border. In fact, you could be banned for life from the US for even telling a US border guard that you've consumed weed at any point in your life! Also, remember weed isn't for everyone. It can cause disorganized thoughts, confusion, agitation and paranoia. It can impair your balance and stability, along with your memory and judgment. Above all, do not drive under the influence—this is not only highly illegal, it's just plain stupid.

## Where can I get more information?

First, don't consider this page as a definitive guide. If you're a weed newbie, you definitely need more knowledge before proceeding. But don't expect to get much information from your family doctor.

By and large, Canadian doctors have chosen to distance themselves from weed, despite a growing body of evidence that it has many medical benefits. If you want more information (and there's far more to know than what we can include on this page), Google is your friend—but as always, make sure you're getting credible advice and not fake news. ■



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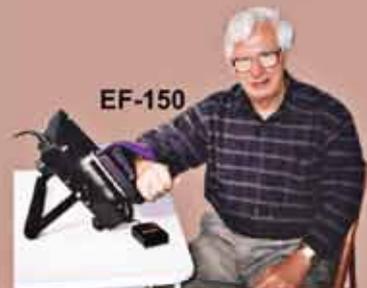
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