

thespin

SPINAL CORD INJURY BC

FALL 2014

From Patient to Practitioner

Physiotherapy played a huge role in Victoria Feige's recovery after SCI, so she decided to pay it forward





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Our theme of incomplete injuries in our last issue clearly resonated with our readers.

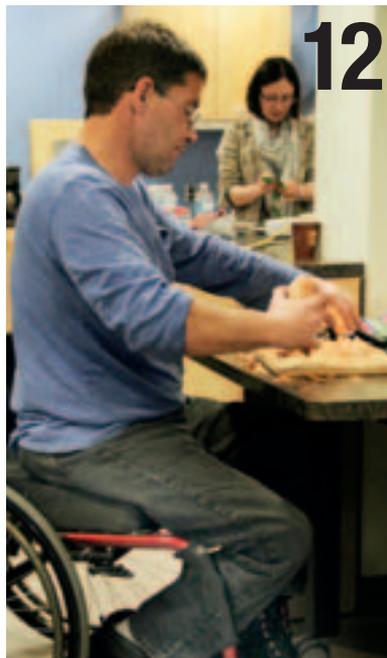
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SCI BC Peers recently converged in Whistler for an adrenalin-fuelled weekend of adventure and friendship.

Cover Photo by Maya Pankalla



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Snotty spine: a good investment?

A recent headline caught my eye: "Nasal Cell Transplant Leads to Snotty Spine." The *medpagetoday.com* article described the development of spinal cysts that actually produced mucous in a 28-year-old woman who had received olfactory stem cells to treat her SCI sustained ten years earlier. The treatment did not lead to any benefits, and now appears to actually have done harm (more on page 15).

This and similar reports of stem cell treatments leading to tumour formation and other health issues should send up a warning flag to those hoping to receive similar, unproven treatments. Not only will these treatments require large sums of your money, they involve real health risks. And they've never been proven to lead to meaningful improvements in function after SCI.

It should also give researchers pause before rushing new cell-based and drug treatments into human trials. Most researchers will admit that SCI treatments currently being trialled in human subjects, and those in the pipeline, are unlikely to lead to significant improvements. But they add that these trials are critical for establishing better research processes, so that when more promising treatments are developed, they'll be better able to quickly evaluate their effectiveness.

Is this a valid reason to be rushing treatments into clinical trials? What is the cost to people who are expecting more significant benefits of the research? Also, a lot of money is being invested in these trials—is it well spent?

Readers may remember my recent call for a resetting of the balance between research funding and services that improve aspects of daily living. I also believe we need to reset the balance of funding within the continuum of SCI research. Yes, basic research is critical—we need novel interventions, technologies and practices that will have long and medium-term impacts for people with SCI. But there is much more to research than stem cells and drug development.

That's why we're proud community partners with many leading research centres, such as ICORD and the Rick Hansen Institute, with which we're involved in projects ranging from improving cardiovascular health to developing better information resources and practices concerning perinatal issues for women with SCI. We're also partnering with the research team at McMaster University's SCI Action Canada group to investigate the important role of peer mentorship and leadership in enhancing community participation and quality of life for people with SCI.

We're very proud of our role as a lead investigator on a new \$2.6 million project funded by Canada's Social Sciences and Humanities Research Council. Over the next seven years, we'll seek to understand the best ways to enhance the quality and quantity of community participation amongst Canadians with disabilities, with a specific focus on employment, mobility and physical activity. This project, led by Dr. Kathleen Martin Ginis at McMaster University, engages over 20 researchers and 20 community service organizations throughout Canada in research that will lead directly to positive social and economic benefits, not only for people with disabilities, but all Canadians.

No, it's not a cure. And yes, research may eventually lead to a cure, and we need to continue to support it—but not at the expense of research that can have more immediate impacts. I've heard from many of my friends with SCI that they need not be cured to be whole. So true. But there is a lot research can do to enhance opportunities and wellbeing for people with SCI. Perhaps this is a better investment than a snotty spine?

- Chris McBride, Executive Director, SCI BC



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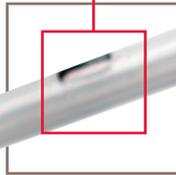


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CHAIRIOT SOLO

The Chairiot Solo is an electric “neighbourhood” car designed specifically for wheelchair users. Using a key fob, the driver opens the little car’s hatchback, wheels up a short entry ramp, locks the chair into place, and drives away. The car can be charged from a standard 110-volt outlet in about six hours at a cost of about 70 cents, and it can go up to 80 kilometres on one charge. The Solo is classified in the USA as a low-speed vehicle that can only be driven in neighbourhood streets with speed zones of up to 60 km/hr, but it can cross through intersections with higher-speed streets. It must be registered and licensed as a motor vehicle. It’s constructed from a unitized fibreglass shell attached to a welded steel chassis. Power comes from twin hub motors built into the rear wheels. Other features include four-wheel hydraulic disc brakes and simple hand control operation. The Solo is made by Changzhou Greenland Vehicle Co. Ltd. in China for Riverside, California-based Chairiot Mobility. For more details, visit www.chairiot-mobility.com.



BRUISING PANTS

Students at Imperial College London and the Royal College of Art recently unveiled a pair of athletic pants that uses pressure-sensitive film and dye packs to help wheelchair athletes see injuries in areas of their bodies where they have no pain sensation. The system, known as Bruise Injury Detection, uses a special pressure-sensitive film developed by Fuji. The film is installed in the pants’ pockets that are located at common injury sites. When one of the films is hit, it blooms red—the more vivid the intensity of the colour, the stronger the impact. The films can be replaced after use. The team would like to develop the concept into a full bruise suit, and then into a product line. For more details on this sporting innovation, visit www3.imperial.ac.uk and search for “bruising”.



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Innovations

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

EYE-CONTROLLED WHEELCHAIR

Researchers at the Imperial College London have developed powerful yet inexpensive technology that allows wheelchair users to navigate using eye movements. Unlike existing eye-tracking solutions which restrict the user from looking around while moving, the system developed by Dr. Aldo Faisal and colleagues analyzes subtle eye movements to distinguish between when a person is looking around and when they actually want to move. The prototype, which appears to be a little cumbersome, uses two cameras that observe eye movements and pass that information into a laptop computer, which determines if movement is actually desired and then works out where to go. The system’s response time is virtually instantaneous. Testing determined that users were able to steer through a crowded building faster and with fewer mistakes than with current technologies. The system, which won’t be for sale for at least two years, will cost about \$100. More detail can be found at www.faisalab.com.



RIFTON TRAM

The TRAM, developed by USA-based Rifton, strives to combine elements of a standing frame with some of the functionality of an exoskeleton. The result is a device that is more than a patient lift system—it offers users assistance with sit-to-stand transfers and seated transfers, but also provides an opportunity to experience the benefits of gait training. TRAM, which won gold at the Medical Design Excellence Awards in 2013, is capable of lifting and transferring patients of varying abilities and body types. It features an innovative, patent-pending support system that secures the patient with a simple buckle, enabling the caregiver to quickly prepare the user for a safe transfer. At just over 30 kilograms, the TRAM’s compact, ultralight frame is manoeuvrable in small or confined areas, and simple to transport or store. Quickly adaptable to multiple caregivers, the TRAM’s intelligent engineering significantly reduces back strain and stress, providing a smarter and safer environment. More information is available at www.rifton.com.

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Be well.

Project EveryBody, Spinal Cord Injury BC and other community partners are pleased to present a Sport, Recreation and Wellness Fair, October 5, at Creekside Community Centre at Vancouver's Olympic Village. It's a great opportunity to learn how you can get active and reach your health and fitness goals. Watch live demonstrations, connect with experts and professionals, learn about programs that can improve your health and wellness, and join the fun. Details at www.projecteverybody.ca.



Get a job.

The Neil Squire Society's Job Fair is exclusively for job seekers living with a disability. It will feature employers committed to hiring a representative workforce, including BCIT, City of Burnaby, City of Vancouver, ICBC, and the Royal Bank. It takes place from 12:30 to 3:30 PM on October 23 at the Firefighters Banquet & Conference Centre in the Burnaby Metrotown Complex. There's no need to pre-register. To learn more, visit www.neilsquire.ca or call Anirudh Rayas at 604.637.3577.



Strike a chord.

Spinal Chord is a gala evening in support of ICORD and the Vancouver Cantata Singers. It's a chance to get dressed up, hear an award-winning choir in the spectacular atrium of Vancouver's Blusson Spinal Cord Centre, enjoy fabulous hors d'oeuvres, and bid on an array of uncommon silent auction items. The sixth annual Spinal Chord takes place on the evening of Saturday, November 1. Doors open at 6:45 PM. For ticket information, call 604.675.8844 or order online at www.spinalchordgala.icord.org/tickets.

David Parke's Journey

On June 27, Vancouver's David Parke marked the end of a long, personal journey when he rode into the GF Strong parking lot, where he was surrounded by supporters and cameras. As we told you in our last issue, Parke tackled a grueling cycling trip from Dease Lake to Vancouver to raise awareness of SCI and funds for SCI BC. After three weeks and many challenges on the road, an exhausted and emotional Parke arrived home, having pedalled an incredible 1,800 kilometres and raising \$6,000 for our programs.

"We'd like to congratulate David and his supporters," says Chris McBride, Executive Director of SCI BC. "The fact that David, who lives with incomplete SCI that resulted from a cycling crash, got back into the saddle for such a challenging journey is amazing. That he did it to raise funds for SCI BC makes it even more special."



THAT'S ONE BIG CHEQUE! David Parke (standing left) presents a cheque for \$6,000 to SCI BC staff members Kirsten Sharp (sitting left), Richard Peter (sitting right) and Gary Steeves. All funds will be used to support SCI BC's Peer Support Program.

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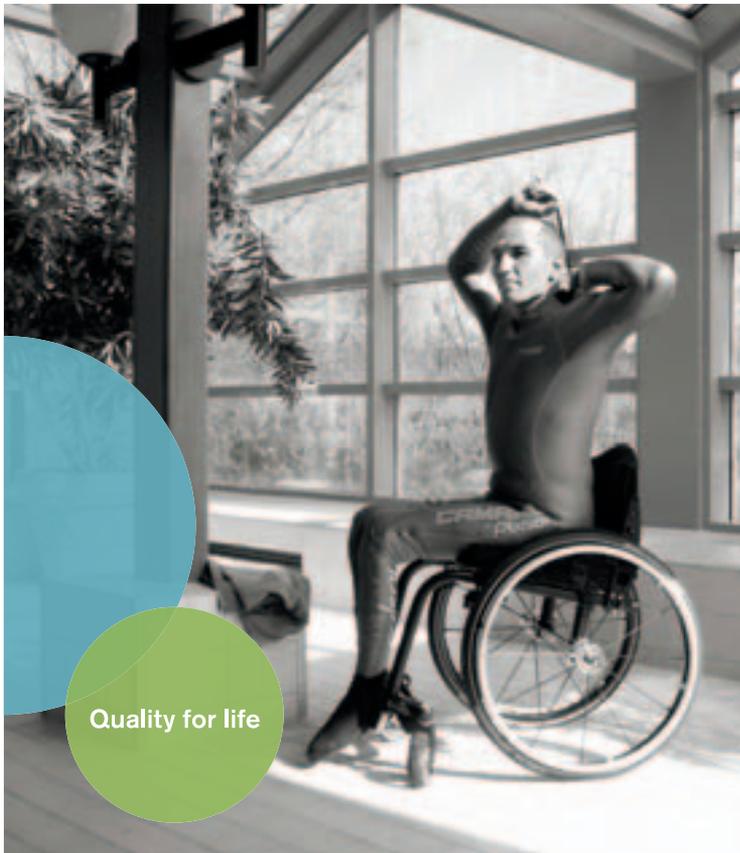
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The Incomplete Issue: Bullseye!

Here at SCI BC, we always get great feedback from the stories and issues we present in *The Spin*. But the reaction to the last issue's focus on incomplete injuries was off the charts. Clearly, Denver writer Richard Holicky's moving account of his life with incomplete quadriplegia resonated with you, as did the insightful, introspective looks at their own challenges with incomplete injury that four of our peers so graciously provided.

When we prepared last issue, we had a hunch that many of our readers with incomplete injury not only deal with very significant challenges, but also live their lives in relative isolation, believing that many of their issues are unique to them. We hit the nail on the head, because the essence of the feedback we received was, "Wow! There are others just like me!"

If you need even more reinforcement that you're not alone with the challenges of incomplete SCI, we included some of the feedback we received below. Meanwhile, rest assured that we're doing everything we can to ensure our peer and information services become even more relevant for people with incomplete injury.

I read the cover of this month's *The Spin* with delight. I have a C5-6 incomplete spinal injury of 32 years duration. I was 39 when I was injured in a car accident.



I relate totally to the issues of fatigue and depression, feelings of not being quite a quadriplegic whilst still dealing with all the problems of

mobility, sensation, temperature regulation, bowel and bladder dysfunction, neuropathic pain, spasms and limited hand/arm function. And I am still working with all the questions. When is it better to use different mobility aids that give me greater support? How to balance function and energy conservation? Should I still be striving to improve my gait? I am very aware that, when I walk with two crutches and leg braces, my eyes are on the ground figuring out where my feet are, and I am hypervigilant in case I fall. When I use a scooter, I am relaxed, smiling and able to hold a conversation. However, the limited

ability I have to stand and walk is such a bonus and helps maintain my body and spirit.

Because I spend a great deal of my time standing and walking with aids, falls have been a part of my life for 32 years—I think I average four a year, so that makes 128 falls. I fall very well and have only injured myself a handful of times apart from grazed elbows and bruises. But I am now unable to pick myself off the ground, and recently I began using a life line which took a whole new level of acceptance.

Two years ago I was diagnosed with temporal arteritis. The major concern with this condition is catastrophic loss of sight. I lost some peripheral vision before diagnosis and I realized how much I use my sight to maintain balance. To combat the temporal arteritis, I was prescribed large doses of prednisone which caused increased muscle weakness and, in turn, began to compromise some of my daily activities.

As I age, I watch my life growing smaller and my commitment to maintaining myself larger. Looking after myself is a full-time job and I wonder about that. And yet I want to



do it all. It's extremely important to me to maintain as much independence as I can. But I notice some fatigue setting in around living in this disabled body for so long, trying to figure out how to do things and how to live well and wisely.

My life in my quadriplegic body has been rich and entertaining and it has given me an opportunity for extensive reflection on the human condition and to look at the gifts of living in the slow lane. Acceptance still comes and goes. Thank you for the articles about people from my tribe—it's good to hear from others with similar issues.

—Karin Watson, Courtenay, BC

I would like to thank you for "An Incomplete Affair" in *The Spin*, Summer 2014. I

can readily identify with the problems discussed—particularly having an invisible injury.



I worked as a sole charge physiotherapist until I was 43 years old. I am now 72 years old. I injured myself catching a falling patient when I was 37. I had two nurses with me but they were slower and shorter. I felt my back snap (one of the nurses told me later that she heard it).

I managed to work for six years after the injury, with time off for two failed surgeries. Fortunately, I was hurt at work and had an open claim with the WCB for ten years, then I received a 75% loss of earnings pension for life. So money is not a issue.

Constant daily pain has led to chronic depression. The more depressed I am, the more I notice the pain. I have weakness in both legs, paraesthesia and pain in both feet, proprioceptive problems, and neurogenic bladder and bowel. However, I can walk short distances with the aid of a cane, as long as the surface is level and there are no hills. I cannot walk uphill without severe back pain.

In the town where I was injured, too many people asked why I wasn't working or if I having a good holiday. It took my mother 25 years to realize that I would not get better.

As I became unable to do simple household tasks without pain, it was difficult not to feel that I was being lazy.

– Lynn Mackenzie, Terrace, BC

When I read about incomplete injuries in our latest *Spin* magazine, I kept thinking that finally someone has written about the issues I've been hearing about on the SCI BC InfoLine.

I often hear people say that they feel alone in their situation or that they shouldn't complain because at least they can walk when so many can't. We know that members of the public often don't understand the secondary complications of SCI, and when someone doesn't need to use a wheelchair, it's even harder for others to understand what the person might be experiencing. When I read the stories, I felt like cheering because the issues are explained so well by people who have been there. This is exactly the sort of resource that I have wanted to give to people who are newly injured or who feel isolated in their experience.

I have already forwarded the articles to a number of people who have contacted me over the past few months, in hopes that know-



ing others have been through similar experiences will ease their own journey a little bit. This has been met with very enthusiastic and appreciative responses.

InfoLine received a number of other positive messages as well—more than we normally get for a *Spin* issue. Comments include:

“I didn't know others were dealing with that.”

“So I'm not the only one?”

“I can readily identify with the problems discussed.”

When people call InfoLine for information, I sometimes hear hesitation when disclosing an incomplete injury, especially for those who say they “look normal” to the casual observer. I think people wonder whether they belong in our organization if they can walk post-injury. The reality is that our members represent every possible outcome of SCI and related physical disabilities. Everyone is welcome because everyone has something to gain and to give.

Our members, and the public, need this forum to better understand the challenges and opportunities for those with incomplete injuries. Please encourage everyone you know to read these articles and learn about incomplete injuries, along with all aspects of SCI, to increase awareness and help make things just a bit easier for our members. In the meantime, we hope that anyone struggling after injury will connect with both our Peer and InfoLine programs.

– Heather Lamb, SCI BC Information Resource Specialist

Your feedback is always welcome...

The Spin is your magazine. If you'd like to comment on anything you read in it, make a suggestion for a story, or even try your hand at writing a guest story, please don't hesitate to get in touch with us. You can email our editorial staff at thespin@sci-bc.ca or send your comments by regular mail to: Assistant Editor, The Spin, Spinal Cord Injury BC, 780 SW Marine Drive, Vancouver, BC, V6P 5Y7.

Girls, we love this website!

Every once in a while, we stumble across an impressive online resource that we think readers might like. In this case, it's www.wheelchairmommy.com, created by 33-year-old Priscilla Hartman Hedlin of Austin, Texas.

In 1999, Hedlin was injured in a car crash that resulted in L1-2 paraplegia. Since then, the 33-year-old has lived large. She married her husband Charlie in 2002, and their first son was born in 2004. Two more boys followed in 2008 and 2011.

Raising her sons is clearly the focus of her life, and www.wheelchairmommy.com contains dozens of informative posts about her experiences being a mother with an SCI. But being a committed stay-at-home Mom hasn't stopped Hedlin from exploring her many other interests, including style and fashion for wheelchair users, homeschooling, food and cooking, and decorating.

Fortunately for all of us, Hedlin is also a tireless blogger, and has written hundreds of entries about all of her interests and passions.



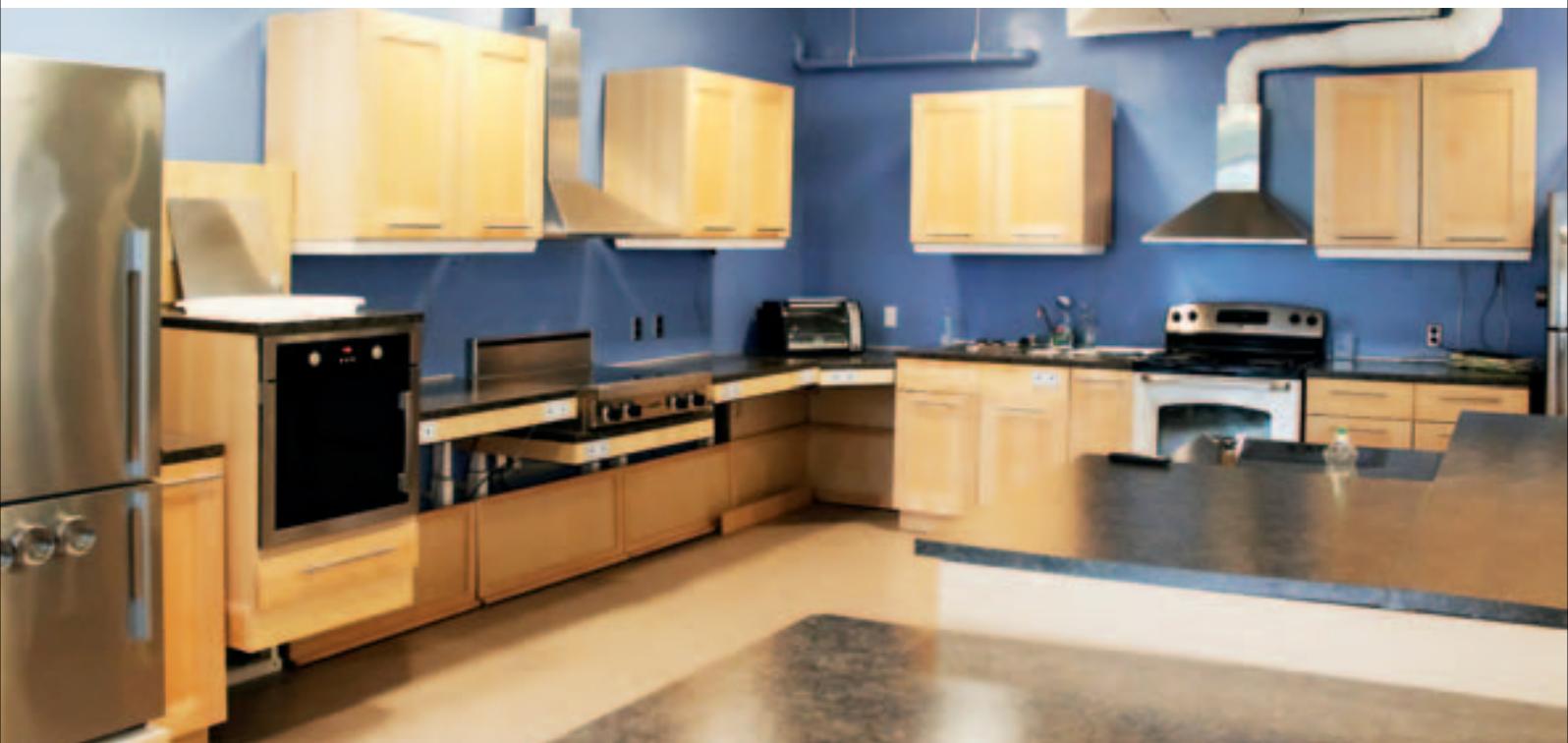
All are well-researched and well-written pieces aimed at imparting her hard-won knowledge to the site's visitors. She's also created dozens of YouTube videos about her interests.

Want to know the best vacuum for a wheelchair user, and how to use it? How about how to change baby's diaper? What about

the most flattering clothes and styles for wheelchair users, or how to make homemade laundry soap? Or how to make the best BBQ chicken pizza? All this and much more can be found at www.wheelchairmommy.com, and it's all presented in a friendly, entertaining, yet entirely professional manner, complete with excellent photos or video.

Perhaps you're thinking that Hedlin's blog site sounds a little too traditional for your tastes. We know that not everyone will relate to her emphasis on stay-at-home motherhood. But

there are so many other superb facets to her blogging—her many entries on wheelchair fashion alone make the site worthy of a visit.



KITCHEN CAPERS

ICORD's kitchen is a showcase for accessibility—and a perfect home for SCI BC's cooking classes.

Step or wheel into ICORD's accessible kitchen, and you'll find it looks like any working kitchen—even though it was designed primarily as a research lab.

The state-of-the-art cooking facility, located on the ground floor at the Blusson Spinal Cord Centre, hosts SCI BC's monthly cooking classes, as well as a variety of accessible kitchen demos and workshops.

"About five years ago, when we completed construction of the Blusson Spinal Cord Centre, we wanted to incorporate an aspect of research that looked at accessibility issues," says Dr. Lowell McPhail, Managing Director at ICORD. "So our accessible kitchen has two main components: one is a completely accessible high-cost, high-tech version, and the other is more of a low-tech version of what's in a standard kitchen—a control to see how you can adapt a regular place."

Kitchen Accessibility: 10 Great Tips

Without renovating:

1. **Get into gadgets.** From touch can openers to hands-free salad spinners and two-handed slicers, small contraptions can make a huge difference. Buy them from catalogues, or ask your OT for do-it-yourself adaptation ideas.
2. **Rearrange.** Put away the foods and cookware you use most into waist to shoulder-level locations. Lacking storage space? Use decorative canisters or baskets on your counters.
3. **Use mobile storage.** Opt for lazy susans on counters and in cabinets to help you access those hard to reach places. A rolling utility cart can also be a huge help.
4. **Mind the heat.** Hang a slanted mirror above stove burners to oversee your pots and pans from a seated position. Line the front of hot surfaces with foam tubes or, if using an oven is unsafe, switch to a quality microwave or toaster oven.
5. **Bring in a corner table.** If counters are too high, consider using a lower corner table with a pedestal base for easy wheelchair access as a moveable food prep station.

Accessible kitchens are gaining in popularity—not only for people with mobility disabilities, but for the large population of baby boomers hoping to age in place.

Purchased from a specialized Swedish manufacturer, the kitchen at Blusson cost about \$150,000.

Throughout, mechanical cantilever devices are operated by buttons or remote controls to raise and lower the counters, cabinets and appliances. Convenient? Absolutely, but not cheap: the mechanisms, along with proper backing to bear the weight, can add up to about \$10,000 per device.

Sensor pads ensure the cupboards will stop lowering before squashing your tea kettle or toaster. The devices move slowly, but if they went any faster, your now-easily-accessible dishes would most certainly fly out.

The fridge can move up or down to facilitate ease of access, and the freezer is conveniently located at the bottom. Users can slide the shelves out and even completely remove the fridge containers. Similarly, the dishwasher drawers pull out, putting the dishes within reach without the obstacle of a protruding swing-down door.

Unlike a standard oven, ICORD's oven is height-adjustable and has a side-opening door.

Directly above, the vertically-mobile stove allows for easier and safer access. By shifting the stovetop to counter level, cooks can easily transfer dishes between both surfaces. Height-adjustable counters can be especially handy if you're living with someone who is able-bodied.

Meanwhile, the stove controls are large, easy to manipulate, and located on the front, eliminating any reaching hazards.

Unconventionally, the kitchen sink is installed sideways with a single handle on the right to take the wet 'n' wild out of

With renos:

6. **Swap the knobs.** Select a stove with knobs running along the front, and ensure that high cabinets have door-pulls near the bottom. To help with limited hand function, switch up round cabinet and drawer knobs for loop handles.
7. **Install pull-out surfaces.** Put in counters, cutting boards, drawers and other work surfaces that pull or glide out. Sliding shelves and pull-out drawers are great in fridges, too.
8. **Create knee space.** Remove cupboards and cabinet doors to make room for knees beneath the sink and other counters. A plumber can help you relocate troublesome pipes.
9. **Move the sink forward.** Install the sink closer to the front of the kitchen counter or save on counter space by turning it sideways. For ease of use, go with a single lever control faucet and a sink that is 5 ½ inches or shallower.
10. **Reposition the plugs.** Hire an electrician to relocate electric switches and plugs into kitchen counters, the island, or the front part of the lower cabinet face.

dishwashing. The basin is shallow, and the entire sink moves up and down to create extra clearance underneath.

True, the mechanisms that raise and lower each kitchen feature are pricey. But the actual cupboards, cabinets and counters are from Ikea—another Swedish manufacturer, though one that’s quite reasonably priced.

Over on the low-tech side of the kitchen, ergonomics meet aesthetics. A cutout below a standard sink allows wheelchair users to slide in underneath, while tasteful cabinets hide the gaping hole.

The kitchen is also equipped with a series of ergonomic knives and adapted cooking tools, but some SCI BC cooking class participants choose to bring in their own favourites: from hand-made tools to custom-ordered utensils and convenient finds from Ikea.

Launched late last year, the Blusson-based cooking classes have already proven to be very popular. SCI BC partners with a nutritionist for the monthly courses with the goal of promoting



Vancouver’s Alexis Chicoine gets cooking at the ICORD accessible kitchen.

healthy eating specifically for people with SCI. (And yes, you get to eat the food—and even take it home with you.)

“We try to make the recipes that we bring to class easy, especially for people with dexterity problems,” says Alfiya Batalova, SCI BC Programs Administrative Coordinator. “I think our participants get

excited because they can make something healthy and delicious in a way that’s not very complicated.”

For details about how to get involved in SCI BC’s cooking classes, email Alfiya at abattalova@sci-bc.ca. You can also see ICORD’s accessible kitchen in action at www.sci-bc.ca/tv. ■






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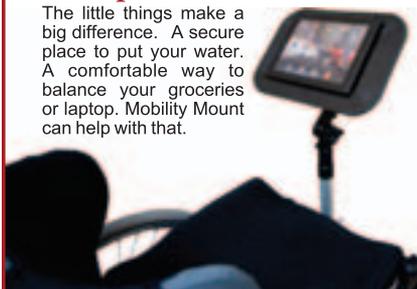
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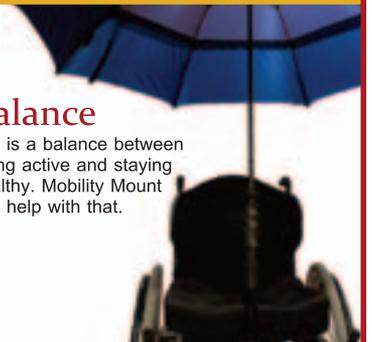
Participation

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.



Balance

Life is a balance between being active and staying healthy. Mobility Mount can help with that.



Stem Cell Therapies: Real Risk

More cautionary stories about unproven stem cell therapies highlight the risk of stem cell tourism

For years, debate has raged about stem cell tourism—Canadians and people with SCI from other countries travelling abroad for unproven stem cell therapies in the hopes of a miraculous recovery. Those not in favour include most Western scientists and organizations including SCI BC, citing the fact that stem cell technologies are unproven and too often motivated by hope-based profit. Arguing on the pro side of the debate, people seeking these treatments often seem to disregard facts and warnings, instead adopting a “What have I got to lose?” attitude.

The reality is that people with SCI may have a lot to lose beyond their savings. That point was made clear in July, when researchers published a case study in the *Journal of Neurosurgery: Spine* in which they documented the case of an American woman who developed a painful tumour in her spine eight years after having what’s believed to be an unsuccessful stem cell treatment.

The woman, who remains unnamed, travelled to Portugal where she took part in a clinical trial that saw researchers extract olfactory stem cells from her nose and transplant them into the injury site in her spine. The hope was that these cells would develop into neural cells and help restore function in the woman’s spine.

The woman, who was 18 at the time of the procedure, was forced to have a three-centimeter tumour removed from

her spine last year at a hospital in Iowa. The tumour, composed of nasal tissue, bits of bone, and tiny nerve branches that hadn’t connected to any spinal nerves, turned out to be benign. But it was causing a lot of pain for the woman, likely the result of “thick copious mucous-like material” that it was secreting.

This isn’t the first time that a tumour has been reported as being the result of stem cell treatment. Other reports include a 50-year-old man with Parkinson’s who developed a teratoma, an Israeli teenager who developed brain and spinal tumours, and a woman who developed kidney tumors after receiving stem cells to treat kidney failure.

But it is the first time such a tumour has resulted from a stem cell clinical trial carried out at a reputable, Western-based mainstream hospital—in this case, the Hospital de Egas Moniz in Lisbon.

George Daley, a stem cell researcher at Harvard Medical School who has helped write guidelines for people considering stem cell treatments, told *New Scientist* that the news is sobering. “It speaks directly to how primitive our state of knowledge is about how cells integrate and divide and expand,” said Daley.

Another expert, stem cell research analyst Alexey Bersenev, told *New Scientist* that the case shows that, even when carried out at mainstream hospitals, experimental stem cell therapies can have unpredictable consequences. “We

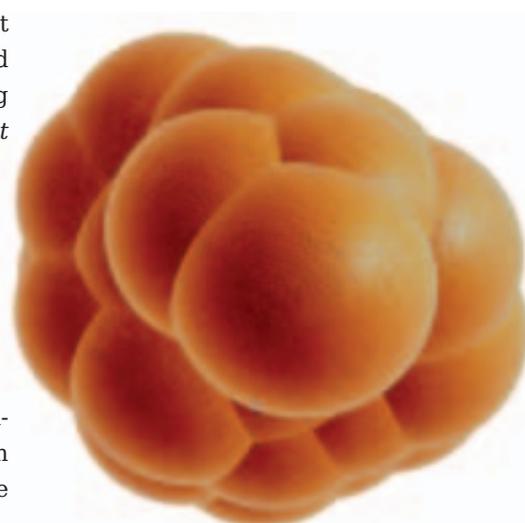
have to realize complications can also happen in a clinical trial,” he said.

In 2010, the Lisbon researchers published their results using this method on 20 participants. They reported that 11 experienced some modest recovery of movement or sensation, one person’s paralysis got worse, one developed meningitis, and four others experienced minor adverse events. It’s not known if the woman from the US was part of this trial, or if the improvements in those that experienced them were a result of the stem cell treatment or the active therapy they received after the transplant.

In a more recent case, an Australian woman died after stem cell therapy in Russia. On July 19th, Brisbane mother-of-two Kellie van Meurs received treatment in Moscow for a rare neurological disorder known as stiff person syndrome. She died from a heart attack while undergoing the controversial treatment.

Her death, and the continued marketing of stem cell tourism in Australia, has renewed criticism of these types of unproven therapies.

Stem cells have often been hailed as the future of medicine. But it’s clear that their ability to multiply carries an inherent danger. Here at SCI BC, we take a cautious stance: stem cells may yet hold promise for therapies in the distant future, but the worldwide body of knowledge in the area is primitive. Until we have long-term efficacy and safety established, people should clearly be informed that there is considerable risk involved. ■





Get Some Leverage

Tired of pushing, but not quite ready for a power chair? An ICORD research project concludes that two lever-operated systems might be an alternative.

It turns out that pushing a manual wheelchair is largely a wasted effort. In fact, pushing on standard handrims is less than ten percent efficient. Is there a better way?

That's the question that ICORD researcher Dr. Bonita Sawatzky and Jordon Lui, one of Sawatzky's graduate students, asked themselves after looking at two commercially-available wheelchair lever drive systems—the Willgo and the Wjijt.

"Jordon and I came up with the idea," explains Sawatzky, an Associate Professor at UBC's Department of Orthopaed-

ics and Principle Investigator with Vancouver-based ICORD (International Collaboration On Repair Discoveries). "We wanted to know exactly what impact the two devices had on energy expenditure. The devices had some significant differences in design which made them intriguing to study. Was one more efficient in the end than the other? And how did they compare to conventional propulsion?"

With those questions in mind, Sawatzky and Lui recruited UBC kinesiologist Dr. William Sheel (co-lead investigator along with Sawatzky) and several other ICORD researchers and students.

The team first obtained the equipment—the Willgo and the Wijit. Both systems share the same general concept—operating the levers moves you forward. But there are differences.

The Willgo is a complete wheelchair that features two integrated levers that, when pushed forward, engage a belt and pulley transmission that generates propulsion. The levers are retracted in a passive phase in preparation for the next push. In contrast, the Wijit is a standalone system that can be installed on most manual wheelchairs. It features levers that are connected to the hub of each wheel. Users push the levers to engage a roller clutch mechanism in each hub to generate propulsion. The Wijit can be switched easily into reverse (the levers are pulled rather than pushed when reversing).

Unlike the Wijit, the Willgo's levers can't be used to reverse the wheelchair—you have to use the handrims to move backwards. Both systems have

the ability to be disengaged in favour of using the handrims.

With equipment and an approved protocol in place, the team recruited ten healthy, able-bodied men with no prior manual wheelchair experience. Each of the recruits was taught how to use the two systems, both on the ground and on a treadmill. Then they participated in two sessions that occurred on different days, randomly being selected to try four scenarios: lever propulsion system using the Wijit, lever propulsion system using the Willgo, handrim propulsion with the Wijit with the lever system disengaged, and handrim propulsion with the Willgo with the lever system disengaged.

In all scenarios, the wheelchair was mounted on a treadmill and connected by a cable to measure the drag force. Participants wore a ventilator and were connected to heart-monitoring equipment to gather cardiopulmonary data.

Each trial consisted of three four-minute exercises at five-minute intervals.

The treadmill was set at a constant speed. For the first exercise, the treadmill was level. For each subsequent exercise, the slope was increased by one degree.

As the participants exercised, the researchers measured energy expenditure, along with heart and lung response.

“The comparisons revealed significant differences at all three workloads,” explains Sawatzky. “The difference became greater as the slope of the treadmill increased. With the treadmill perfectly level with no incline, we observed an eight percent drop in effort using levers compared to handrims, with both systems. The reduction was even more significant as we raised the incline of the treadmill to simulate pushing up slight slopes. At both one and two percent grades, there was an 18 percent reduction in effort required. This doesn't seem like a lot, but pushing with levers results in a significant saving of force and energy.”

Sawatzky adds that there was no significant difference between the results



FACING PAGE: Dr. Bonnie Sawatzky (right) puts a student volunteer using the Willgo through her paces on the treadmill in the ICORD labs. LEFT: The Willgo is a complete system with the lever drive integrated into a manual wheelchair. More information on the Willgo can be found at www.willgowheelchairs.com. BELOW: The Wijit system can be mounted on most manual wheelchairs. Visit www.innovationshealth.com for more details.



of the Wijit and Willgo—both had similar ratings for mechanical efficiency and physiological response.

The bottom line? These two lever drive systems are significantly more efficient than standard handrim propulsion.

It should be pointed out that the researchers investigated only mechanical efficiency and cardiopulmonary response. They did not measure joint movement, steering, comfort, safety and related personal and biomechanical factors. Therefore, even though both manufacturers claim that their respective systems lead to fewer shoulder and arm injuries, this study didn't confirm that.

"Measuring a reduction in injuries is extremely hard to do," says Sawatzky. "It would require a long-term study where one can control many variables. The difficulty with wheelchair users is that wheeling isn't the only factor. Transferring, reaching and lifting activities also play a significant role in risk of injuries."

As well, the study examined able-bodied men—but Sawatzky is confident that the results would be similar with actual wheelchair users.

"This was an undergraduate project with a student who had only one year to complete it," she says. "If we studied those who use wheelchairs, we would need a large sample to adjust for varying ability levels. Yes, the application transfer to those with SCI is always in question with any able-bodied research, but at least we leave out the big variables of lesion level and completeness. It's tricky."

As for her impressions of the two systems, Sawatzky says both have their advantages. "The Willgo might look a bit clinical while the Wijit has more cool factor. They both add weight to the chair. The Willgo is a complete chair, not an add-on, so adding unique seating arrangements is more difficult. The Wijit can be put on almost any chair. The Willgo is a bit more efficient, but not statistically significant. It's all give and take."

The complete results of the study were published in the March 11, 2014 issue of the *Journal of Rehabilitation Research & Development*, and can be found online.

Meanwhile, Sawatzky encourages readers of *The Spin*—particularly those in the Lower Mainland—to consider getting involved in other ICORD studies.

"Without more studies using people who use wheelchairs daily, we won't get the 'real' results. We'll always be extrapolating from able-bodied to SCI folks. We love hearing new ideas people have when they come to participate in research and I have actually implemented research based on input. I am currently studying the impact of using a whole-body vibrator to improve various aspects of quality of life—spasticity, strength, bowel routines, and pain. I hope I listen to the people affected by an SCI, not just study them."

Visit www.icord.org/research/participate-in-a-study to learn about how you can get involved in ICORD research. ■



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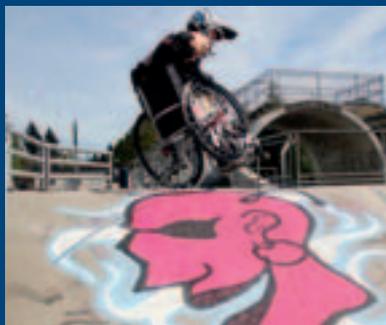
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If a picture is worth a thousand words, video must be priceless.



Introducing SCI BC TV, a short-form YouTube series that explores and celebrates innovative stories from the spinal cord injury community.



Join host Kirsten Sharp as she keeps viewers informed, engaged, and up-to-date with the latest in SCI—from adaptive sports and recreation, to community events and research.

Through its mini documentary/community news format, SCI BC TV motivates others to realize their potential, challenges perceived barriers, and opens minds to new experiences and information. Episodes cover informative, edgy topics, with an emphasis on humour and human connections.

Our host has already learned the ins and outs of wheelchair rugby, used her wheelchair to “drop in” at the local skate park, and even walked again for the first time in 23 years with the help of an exoskeleton.

“There’s a whole world out there—come experience it with us!” says Kirsten.

www.sci-bc.ca/tv



From Patient to Practitioner

Physiotherapy played a huge role in Victoria Feige's recovery after SCI—so much so that she decided to pay it forward and become a physiotherapist herself.

Can a person with an SCI become a successful physiotherapist? As Vancouver's Victoria Feige has clearly demonstrated, the answer is a resounding "yes."

Growing up, physiotherapy wasn't even on Feige's radar. Ten years ago, at the age of 18, she had set her sights on a career involving political science, and was immersed in first year arts and sciences studies in an undergraduate program at Colorado College in Colorado Springs.

All that would begin to change when she was injured at a Colorado ski resort.

"I had a decade of snowboarding experience, but I overshot a jump and landed badly," says Feige. "I fractured T12 and sustained an incomplete SCI."

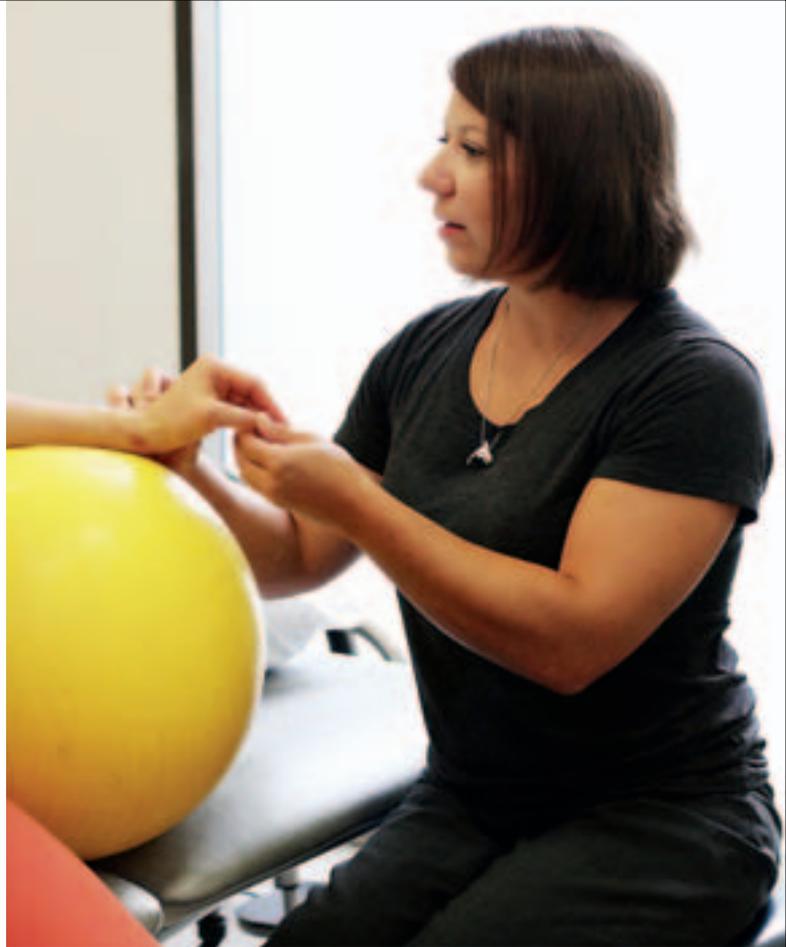
As Feige completed her rehab, first in Colorado and then at GF Strong, she regained some lower extremity movement. "I could do some standing and stepping in parallel bars with my arms, and transfer out of my wheelchair independently," she says.

"After discharge, I wanted to maximize my recovery. And I wanted to be sure that I had tried to make the most of it."

Her first priority was finishing her degree in Colorado. But during school breaks spent back in Vancouver, Feige got serious about making the most of her abilities. She learned about Libby Swain, a private physiotherapist with a great reputation in neurophysiotherapy—working with people with neurological impairments to maximize their functional recovery.

"Working with Libby turned out to be a transformative experience," says Feige.

"I improved from the physiotherapy



sessions; I got significantly stronger. I could stand unassisted for about 15 minutes with ankle braces, and walk up to a kilometre with forearm crutches and ankle braces. I could stand to reach something high on a shelf. I still used the chair 95 percent of the time, but I could stand to play foosball with my friends.”

Feige continued her sessions, and continued to get stronger. Five years post injury, she was still making small but useful functional gains.

“I could stand and walk in my small kitchen to put away the dishes,” she says. “I could get up stairs and drag my chair up to my friends’ second story walk-up apartments. I could cross-country ski on easy terrain with ski poles and ankle braces. Libby helped me figure out all these things in a way that prevented pain and utilized what muscles I did have. I would bring my goals and ideas, and she helped shape them to be workable.”

As it turned out, Feige found herself getting much more from Swain than just therapy. “I like to ask questions, and I discovered that she likes to teach. I learned so much from her

about human anatomy, neuroplasticity, open and closed chain exercises, sensation—the list went on and on. It was so neat! I loved it, deconstructing all my compensatory movement strategies and unmasking strengths. I loved the analysis of movement. And I learned so much about the biomechanics of walking and the kinetic chain that I began to do gait analysis on pedestrians walking in front of my car!”

Intrigued with the science, Feige began to wonder if it was possible to become a physiotherapist herself. But she had doubts.

“I didn’t seriously consider the career for years,” she says, “because I didn’t think I could physically manage the necessary skills.”

The dream wouldn’t die, however, and she gradually formed a plan.

“My family was hugely supportive,” she says. “Libby was also very supportive at every step of the way. We brainstormed all the various obstacles, such as patient safety, protecting my own body, finding a university department, getting placements, inquiring

about the national exam, and of course, clinical skills—how I would transfer patients, walk them down a hallway, teach and demonstrate exercises.”

She pushed forward, applying to UBC’s physiotherapy program. To her surprise, she was accepted.

While the UBC faculty staff were supportive, they also made it clear to Feige that she wouldn’t receive any special treatment. “They made it clear that there were no guarantees—I might not last six months in the program; I might not last three,” she says. “A few people did suggest I should have a good backup plan. I do think the ability to stand and transfer easily made the profession more possible, but even I wasn’t certain I would be successful in the program when I was accepted. My attitude was, ‘you never know until you try,’ but I also did a lot of preparation.”

Once immersed in her studies, she quickly discovered that her professors, teaching assistants and classmates were incredibly supportive when she needed assistance. “But mainly, I didn’t need extra help or any extra time. I found I could

perform the vast majority of skills with little or no adaptation.”

She recognized that the onus was on her to make it work physically.

“It was all about planning and problem solving,” she says. “Occasionally, I did put in extra study time, had consultations with experienced physiotherapists, brought equipment that would help me, and used my creativity and stubbornness to make it work. When I had to adapt something, often it was going from standing beside the bed to sitting on a stool. If I could manipulate the equipment and environment to give my body or the client more support, I found I could just focus on the hands-on work. Overall, I found my experience in the physiotherapy program was similar to any other student’s. The program was rigorous, but I loved it.”

In 2012, Feige graduated from UBC with a Masters in Physiotherapy. In the process, she became what many believe to be North America’s first physiotherapist who uses a wheelchair.

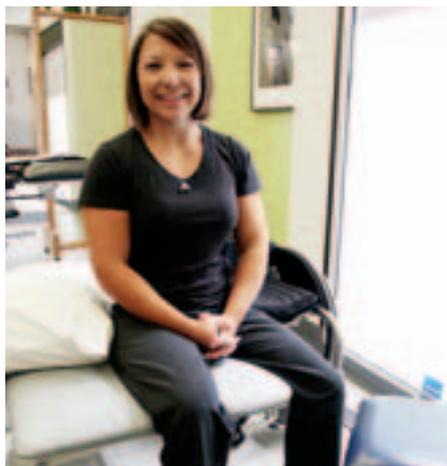
The question then became, how to put that great education to work?

Once again, Swain would play a significant role in Feige’s life. In 2011, Swain had joined forces with three other physiotherapists to establish Vancouver-based Neuro-Ability—a practice that focuses on treating people with neurological conditions such as SCI, stroke and brain injury. Neuro-Ability provides one-on-one physiotherapy, yoga-based exercise classes, individualized gym programs, and rehabilitation assistants who work under the direction of a physiotherapist. The clinic also has a body weight support treadmill training system to maximize client recovery.

With a growing reputation and client base, the owners of Neuro-Ability looked to expand. In 2013, they hired Feige.

“Victoria was one of several applicants that Libby and myself interviewed,” says Catherine Eustace, one of Neuro-Ability’s owners and a physiotherapist herself. “For us, it was clear Victoria would be an excellent addition to our team. In the time she’s been with us, she’s proven herself to be a skilled, car-

ing, dedicated clinician. She’s highly professional, and dedicated to ongoing learning. She seeks to empower her clients and to understand their priorities, needs, abilities and limitations.”



“I was elated to join Neuro-Ability—it’s the dream job,” says Feige. “I wanted to work at Neuro-Ability because in my mind it’s about excellence in physiotherapy, and the whole team is on the same page. For me, it’s about combining professional experience, clinical expertise and the latest neuroscience research to provide the best care for those with SCI, stroke, brain injury, MS and other neurological conditions.”

As one of the clinic’s newer therapists (most of their team has 10 or more years of experience), Feige’s role is to treat clients while continuing her already extensive professional development.

“There are real limitations and I have to respect them,” Feige explains. “I personally only treat clients that can transfer independently, as lifting the full weight of someone isn’t safe for me or them. I use an adjustable height plinth and a rolling stool, but that’s standard physiotherapy equipment. So far, working at the Neuro-Ability has been a wonderful success.”

Eustace says that one of Feige’s core strengths is the empathy that’s resulted from herself being the beneficiary of neurophysiotherapy. “Victoria has been ‘on the other side’ and she knows the experience of being the patient. And in terms of SCI, Victoria has knowledge that other physiotherapists in the practice don’t have. For me, there’s no

question that Victoria has transformed her injury into something beneficial for others. I see patients watch how she overcomes her own physical challenges as she provides treatment. One minute she’s in her chair carrying a piece of equipment she needs, the next she’s on her feet providing hands-on treatment.”

Eustace adds that Feige views herself as being successful with patients if she can change how they engage in life. “For some clients, this may mean reducing pain so they’re able to venture back into the community; for others it may involve strength and balance training to then reintroduce them to previous recreational activities such as skiing or fishing. Victoria works with her patients to ensure their life outside the clinic has changed for the better.”

With her career blooming, Feige is in a good place these days. Of course, work isn’t everything for her. “I love the mountains,” she says. “I’ve been a sit ski instructor with Vancouver Adaptive Snow Sports for the past six years, and I’m now a program co-coordinator. It’s a great organization. I love teaching students and new instructors as much as I love skiing powder. In the summer, I swim, kayak, surf and try to get outside as much as possible with my boyfriend. When the weather doesn’t cooperate, I like to watch Jon Stewart or play guitar.”

She’s also participated in the Tough Mudder event in Whistler for the last two years, relying on friends, a rickshaw wheelchair and an affinity for physically grueling challenges.

But physiotherapy is more than just a job for Feige—it’s one of her loves.

“I really do believe that good physiotherapy can change people’s bodies, how people think about their bodies, and how they function in their lives. An ideal day for me is going to work and helping people understand their bodies better, move better, and perhaps live a little better as a result. And then skiing in the evening!” ■

For more information on Neuro-Ability, visit www.neuro-ability.ca.

Hope or Hype?



We first told you about exoskeletons in our Summer 2011 issue. Three years later, exoskeletons are once again back in the headlines. But just who is creating the hype—and is it justified?

Exoskeletons are again a hot item. One reason is the publicity generated during the symbolic kickoff of soccer's World Cup in São Paulo, Brazil. Juliano Pinto, a Brazilian paraplegic, created a worldwide buzz when he kicked the ball while wearing an exoskeleton during the ceremony at Corinthians Arena. Pinto wore a cap lined with electrodes which picked up and magnified the faint electrical signals of his intention to kick the ball from his brain. The signal was then transmitted on to his exoskeleton, which was created at Duke University. Some 984 million viewers from around the globe tuned in.

Even more recently, there's been a spate of exoskeleton publicity. On July 1, the US Food and Drug Administration (FDA) approved the Israeli-developed ReWalk for sale to consumers, making it the first to market. Here in our country, Health Canada followed the FDA's lead later in July, and it's now theoretically possible for Canadians to buy the unit.

Meanwhile, the company behind that exoskeleton, ReWalk Robotics, made headlines again when it filed an initial public offering (IPO) on the NASDAQ stock exchange. The company's goal is to raise \$58 million.

Other companies looking to cash in on their own exoskeleton designs include REX Bionics of New Zealand (the company had its IPO on the UK's AIM market in May), and Ekso Bionics. The Ekso exoskeleton, already listed on the OTC

(over the counter) exchange in the USA, is making inroads throughout the rehab community in Europe, and seems a likely candidate to follow ReWalk with FDA approval at some point in the near future.

The idea of a bionic mechanical suit that can restore walking movement to someone with an SCI is indeed fascinating, at least at first glance, and certainly to the easily-influenced general public. But is the hype—and the hope—realistic?

Here at SCI BC, we see this technology in the same light as we see stem cell research: we believe that these devices may have potential, some of which is already being realized in rehab settings. But we also believe it will take a great deal of time, effort and investment before they become viable for everyday home use—if they do at all.

The first hurdle is the technology itself. To put it bluntly, it's awkward and cumbersome. All of the devices available today are very slow, and users need to understand that falling is a real possibility. To underscore this, we remind you that ReWalk's FDA and Health Canada approval comes with the caveat that every purchaser must have a caregiver willing to take training to provide assistance, and that assistant must be present at all times while the exoskeleton is being used. While the companies involved are quick to point out that studies show there are health benefits from using an exoskeleton (they do allow standing and weight bearing, for example), most

people with SCI, including people with high level quadriplegia, would wheel circles around a peer in an exoskeleton with their manual or power chairs.

Second, there's the exorbitantly high cost. The ReWalk's price tag is about \$75,000. The Ekso currently sells to rehab centres for more than \$130,000. And the REX exoskeleton, which is the only design that's able to be operated by quadriplegics, sells for about \$150,000. How many can afford this? Is it likely that we'll see any public or private insurers cover the cost? We don't believe it is.

And yet we continue to sometimes see unbridled enthusiasm about exoskeletons. So where does it come from, given that research suggests that people with SCI don't rank walking as a top priority?

For starters, the mainstream media is quick to report stories that combine tech and disability. So it's not surprising that they've glommed onto the exoskeleton.

Last year, *Time Magazine* called the ReWalk exoskeleton one of its 25 Best Inventions of the Year 2013.

"It looks like something straight out of the pages of a comic book or sci-fi TV show and sounds just as strange," reported *BBC News* on July 16. "A robotic exoskeleton that helps paralysed people to walk again. But, this bionic suit is real and has already helped people across the world to take their first steps in years."

"This Computerized Exoskeleton Could Help Millions of People Walk Again," declared the headline in the July 22 issue of *WIRED*.

And in a June 26 online story, CNET made this dubious statement: "The ReWalk exoskeleton has helped countless paraplegics be able to walk again."

Countless paraplegics? Really?

The media, in its zeal to sell advertising, can be excused for being a little too enthusiastic. For their part, the compan-



The Ekso Bionics exoskeleton (the ReWalk is shown on the previous page).

ies behind these exoskeletons are no doubt happy to see this type of publicity and are no doubt the catalysts behind it—not surprising, as all of these ventures are commercial in nature, and all require capital to move forward.

The logical place to seek investment would be the world's stock markets, and as we said earlier, ReWalk Robotics is leading the way with its NASDAQ IPO filing with the SEC in July. At a valuation of \$250 to 300 million, ReWalk is seeking to raise \$58 million when it goes public. Last word is that the IPO will proceed in September. It will be interesting to see how enthusiastic investors will be.

But what about you—an average person living with SCI? Are you hyped about the ReWalk and other exoskeletons? Can you really see forking over \$100,000 or more for one of these bionic suits? Can you see yourself abandoning your trusty wheelchair in favour of strapping yourself into an exoskeleton at the beginning of each day? In short, does the hype meet actual customer interest and demand?

We searched two of the world's most popular online communities for people with SCI—Apparelyzed (www.apparelyzed.com) and CareCure (www.sci.rutgers.edu) to see if we could gauge consumer interest and response. We found that the flavour of most exoskeleton threads pertaining to consumer practicality was largely negative, although there were some posts that were positive (see sidebar to the left for examples).

We leave the last word on the subject

Exoskeletons: What People with SCI Say

"The scope and practicality of these suits is minimal and they are promoted exclusively by private companies looking to profit." – *Tayberry, CareCure, June 19, 2014.*

"I walked with ReWalk and would never buy it." – *wesmaister, CareCure, June 19, 2014.*

"Come on, this is not walking...I can do more with my manual wheelchair." – *manouli, CareCure, March 21, 2013.*

"(The first cars and airplanes were) clunky and almost useless...With development of new materials exoskeletons will become lighter and more useful to the point when they will replace wheelchairs as a...mobility device." – *comad, CareCure, June 19, 2014.*

"Expensive short cut...not interested in looking or feeling like Robocop in or out (of) the house...definitely not that desperate to walk." – *cable guy, CareCure, March 31, 2013.*

"I worry that it ties into the mobility = walking myth and is a diversion from the real solutions. The current cost of an (exoskeleton) would probably make an entire small town wheelchair accessible...As a student of disability history it reminds me of the 'normalisation' fervour of the 19th and early 20th century where looking normal in callipers (leg braces) was seen as a better solution to functioning than a wheelchair-accessible environment." – *Tinbasher, Apparelyzed, June 18, 2014.*

"Will exoskeletons ever be a practical solution to mobility? The short answer is NO, and the longer, more accurate answer is, HELL NO! It is a 'feel good' device which has only one real purpose, and that is to attract grant money for 'research and development'...It will NEVER be a mainstream mobility device, any more than the flying cars they spoke of in the 60s are today..I'll keep rolling, thank you very much!" – *edlee, Apparelyzed, on June 18, 2014.*

"...The problem is that exoskeletons are so incredibly far from actual walking, that (they) would make one considerably less mobile than a wheelchair (specifically for someone with paralysis)." – *tomsonite, Apparelyzed, June 18, 2014.*

"Only time will tell but I think there is a lot of potential for exoskeletons." – *Sam, Apparelyzed, June 18, 2014.*

to three BC experts: SCI BC's Kirsten Sharp, Dr. Jaimie Borisoff, and Dr. Gary Birch. All three live with an SCI. Sharp is our Peer Support Specialist & Communications Liaison, and she recently test drove the Ekso Bionics exoskeleton at ICORD. Borisoff and Birch are scientists with an extensive background in engineering mobility solutions.

"The technology is amazing," says Sharp. "But would I use it to walk down the street? No, for so many reasons. It was like trying an exciting new sport and after my limited sessions I felt immediate benefits in all areas of my health. And it's exciting when technology can get to a place where a robot can mimic human behaviour, but is it at the cost of projecting to society that the only desire of an individual who uses a wheelchair is to walk? And, in turn, that using a wheelchair is a lesser mode of transportation?"

"As a researcher, I'm very interested in the health benefits possible from using an exoskeleton that have been recently reported," says Borisoff, who is the Canadian Research Chair in Rehabilitation Engineering Design at BCIT, an Adjunct

Professor in the Department of Occupational Science and Occupational Therapy at UBC, and a Principal Investigator at ICORD. "However, these benefits have occurred with exoskeleton use in a clinical setting, under the supervision of a therapist at all times. Two significant issues faced by companies as they strive to deliver a device for personal home use are cost and safety. I expect that the cost of these devices has much room for improvement, and perhaps with the support of the funding bodies, this issue can be overcome—although it remains to be seen what level of funding support will be available for exoskeletons in the near future. But I have seen little if any work done on the overall safety of these devices for personal use, other than the FDA's and Health Canada's caveat that the devices must be used under the supervision of a trained able-bodied person at all times. Falling remains an issue with all designs, and until unsupervised safety is demonstrated by many users, it may be difficult for exoskeletons to be adopted for everyday practical use."

Borisoff says that if cost and safety

issues are overcome, exoskeletons may be a useful health-promoting device, and ideal for occasions where standing and walking trump efficient mobility. "But," he adds, "as a replacement for a wheelchair for basic daily mobility? I don't see this happening in the foreseeable future."

Birch, an expert in Brain-Computer Interface (BCI) technology who is Adjunct Professor in UBC's Department of Electrical and Computer Engineering, Executive Director of the Neil Squire Society, and a Principal Investigator at ICORD, is even more cautious about the future of exoskeletons.

"Research on exoskeletons for persons with mobility impairment has been going on for probably over half a century," he says. "Over that time, there's been some major progress. However, I'm still not aware of any existing or pending robust, practical and safe exoskeleton solutions for these individuals to use on a daily basis. Although continued research and development in this area still hold promise, my best estimate is such a solution is still a long way off, as there are many practical challenges yet to overcome." ■

Meet Harper, Archie's New "Friend"

The long-running *Archie* comic book continues its socially progressive stance.

In 2010, *Archie Comics* introduced an openly gay character, Kevin Keller. This June, main characters Archie, Reggie, Betty and Veronica were joined by another contemporary character, Harper Lodge. Harper is the beautiful and stylish cousin of Veronica, and just happens to use a blinged-out wheelchair. She joins Betty and Veronica as a love interest of Archie's.

Harper debuted in *Archie* #656, which was released on June 18. The character is based on and inspired by Toronto children's author Jewel Kats, who has a disability.

Kats, herself a long-time *Archie* fan, is the author of the *DitzAble Princess* comic series, about "a zany quirky woman with a disability." She met writer and artist Dan Parent at Fan

Expo in Toronto last August, and challenged him to include a character with a disability. To her surprise, Parent agreed—and then modelled Harper based on Kats.

"She is beautiful, she's fashionable, she's eccentric and she's very smart," Kats recently said in an interview with Matt Galloway

of CBC Radio Toronto's *Metro Morning*. "The difference about her is that she uses a wheelchair. She still looks like a Barbie, but just not your typical Barbie in a toy box."

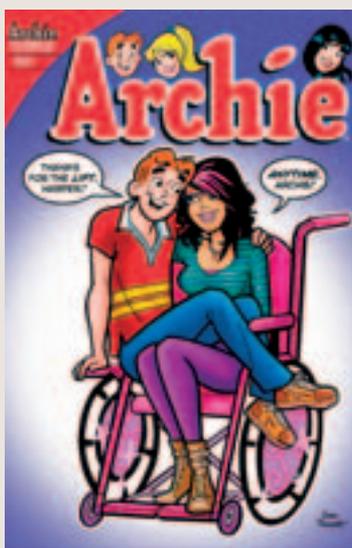
"Harper is, first and foremost, a funny, fashionable and witty teenager," said *Archie Comics* publisher Jon Goldwater in an official statement. "The fact that she's disabled is only one part of her story, and we're excited to welcome her to Riverdale and *Archie Comics*."

Harper uses a wheelchair as the result of an incomplete SCI sustained in a car crash.

And by the way, Archie is still alive and well—at least in the original *Archie Comics* version. While it's true that he died in the July 16 issue of *Life with Archie*, that series took place

in an alternate timeline, and his death (he took a bullet intended for his gay friend) concluded that series.

For all the latest Archie news, visit www.archiecomics.com.



Cold Weather Workouts

Staying in shape over the colder months can be a challenge for wheelchair users. Here's a couple of ideas to help.

Winter in BC really puts a cramp on anyone seeking to stay fit in the great outdoors. In the Lower Mainland and across Vancouver Island, wet and rainy weather makes outdoor fitness impossible for all but the hardest of wheelchair users. And they have nothing to complain about, considering the plight of others throughout the rest of the province who deal with a harsher winter.

So what can you do to stay fit?

For those in greater Vancouver, consider joining the ranks of those already using PARC (that's short for Physical Activity Research Centre), ICORD's spacious and well-equipped fitness facility located on the ground floor of the Blusson Spinal Cord Centre.

PARC offers state-of-the-art equipment for both strength training and cardiovascular exercise. The facility's HUR adaptive strengthening equipment utilizes compressed air for resistance instead of the traditional weight stacks, providing more consistent resistance

throughout the range of motion. Smart Card technology enables participants to monitor their progress and automatically follow individualized programs. Meanwhile, wheelchair accessible SCIFIT upper and lower body bikes and Game Cycle ergometers are also available to increase cardiovascular fitness.

Since it opened, PARC has had stellar reviews from Peers—but they've also complained that the hours are so limiting that it's been difficult for anyone working to take advantage of it. That's now changing, thanks to a \$350,000 investment by the BC government.

"With this funding, we can now make the gym more accessible by extending our hours into the evening and weekends," says ICORD researcher Dr. Tania Lam. "The funding will also allow us to build on research results to create and evaluate strategies to enhance participation in exercise and physical activity in the SCI community."

The funding announcement took place

on July 14, with BC Minister of Children and Family Development Stephanie Cadieux on hand for the ceremony.

"As someone who lives with a spinal cord injury, I appreciate the work that the researchers at ICORD do to support British Columbians living with this type of injury," said Cadieux, a former SCI BC staff member. "This new funding will build on existing work, improve accessibility and support continued research into new rehabilitation strategies."

Anyone with an SCI who is 18 years of age or older can sign up for PARC. Visit www.icord.org/parc for more details.

While PARC is a great opportunity for people in the Lower Mainland, it leaves people elsewhere in the province out in the cold. One solution is home-based fitness. And that's where the Canada-wide Get In Motion program can help.

Operated by SCI Action Canada, Get in Motion is a free telephone-based physical activity counselling service for Canadians with SCI. When you enrol, you have access to the information and support you might need to set and reach your personal physical activity goals. You'll also receive a free physical activity toolkit that includes two therabands and information on physical activity for people with SCI.

The program has been in hiatus since January, but is scheduled for relaunch in early October.

"The service has been in hiatus simply because our team is moving towards broadening the scope of the service from an SCI-exclusive service towards helping adults with other types of physical disabilities," says Dr. Kelly Arbour-Nicitopoulos, Get In Motion's Managing Director, and Assistant Professor at the University of Toronto's Faculty of Kinesiology and Physical Education. "Over the past eight months, we've been working on refining our resources and service manual, hiring and training new counselors, and rebranding the service."

One of the most exciting changes is that Get In Motion is working cooperatively with many provincial organizations in order to have locally-based counsellors with disabilities and a fitness



ICORD's PARC (Physical Activity Research Centre) at the Blusson Spinal Cord Centre

background provide the actual service. Here in our province, SCI BC is pleased to be that partner. And our counsellor is none other than newly-appointed SCI BC staff member Richard Peter, a proud member of the Cowichan Tribes of Vancouver Island, and a repeat Paralympic gold medallist in wheelchair basketball. Richard will divide his time between his duties as Peer Coordinator and Get In Motion counsellor.

“Richard is our counsellor for the West—BC, Alberta, and Saskatchewan,” says Arbour-Nicitopoulos. “In the past, we’ve had one counsellor who is based out of Ontario. Over the years, we’ve realized our capacity to reach potential clients in other provinces is limited. It

has also been a challenge to provide counselling to clients in different time zones. So we’re thrilled to have Richard on board as our West Coast counsellor, given his many contacts within the BC SCI community.”

Another counsellor based in Ontario services Manitoba and eastern provinces.

“Now that we have two counsellors, my hope is that we are able to broaden our national reach,” says Arbour-Nicitopoulos. “I’m also hoping that our new counsellors will be able to provide a unique, enriched counselling experience that comes from their own understanding of the challenges of living with an SCI and overcoming barriers to living an active lifestyle.”



Richard Peter

For details about Get In Motion, visit www.sciactioncanada.ca/get-in-motion or www.sci-bc.ca. ■

ask the SPIN DOCTOR

Daniel asks, “I get terrible headaches when we’re having sex—I know I should stop what we’re doing, but then it totally kills the mood. Any advice?” For this issue’s question, we turned to Kate McBride, a registered nurse and sexual health clinician in the Sexual Health Rehabilitation Service at GF Strong Rehabilitation Centre, Vancouver Coastal Health.



Daniel, what you’re experiencing is autonomic dysreflexia or AD, which can happen to anyone with an SCI at T6 or above. It occurs when intact nerves carry signals from specific stimuli below the level of the lesion to the spinal cord, triggering the sympathetic nervous system to respond in an uncontrolled way. The result can be a pounding headache, blurred vision, sweating, facial flushing, nasal congestion, and high blood pressure that can be dangerous.

As you probably learned in rehab, AD can be caused by many stimuli—for example, a very full bladder, a bladder infection, and pressure sores. But sexual stimulation—especially penetrative activity or penile vibrostimulation—can also trigger AD. In fact, it’s very common, especially at time of ejaculation or orgasm.

Most triggers are things that most people would like to avoid, but sex isn’t usually in this category! Some people even interpret AD symptoms experienced during sexual activity as pleasurable. And people may not wish to stop the activity because it’s disruptive to their own and/or their partner’s sexual experience. We know that the need for intimacy and desire for sexual functioning are key issues for a majority of people living with SCI. But how to avoid life threatening AD situations during sex?

The short answer is that, when AD occurs, sexual activity should

be stopped for a few minutes and your head elevated until the symptoms, such as headache and sweating, subside.

Here’s the longer answer.

- Make sure other stimuli aren’t making the AD worse—for example, a full bladder/bowel, constrictive clothing, bladder infection, or pressure sore.
- Sometimes finding a new position for penetrative or non-penetrative sexual activities can help.
- Try different types of stimulation and utilizing all senses (maximizing arousal by using taste, hearing, soft or firm or vibratory touch may help).
- Try a water-soluble lubricant, which will decrease friction that can often cause AD; it also maximizes stimulation of nerve endings so helps with arousal.
- Talk to your doctor about using a medication such as nitropaste or patch, which can be applied when symptoms start occurring but then can be removed quickly so that the medication doesn’t stay in your system. But use caution! Using any nitrate-containing medication at the same time, such as Viagra, Cialis, or Levitra, can cause a deadly drop in blood pressure.
- Finally, always talk to your partner about the possibility of AD occurring during sex and make sure they know to call for medical assistance in the case of unresolved AD.

This is an area requiring more research and understanding. For those who are more prone to AD with sex, getting to know how your body responds and finding creative solutions to enjoy sex without AD is the ultimate goal. Start by talking to your primary healthcare provider or sexual health clinician—they may be able to help.

For more information about the Sexual Health Rehabilitation Service, or how to get a referral, call 604.737.6233 or email kate.mcbride@vch.ca.

Accessible Modo

Vancouver's original carsharing cooperative hits a home run with its new wheelchair-accessible Dodge van.



Since its inception in 1997, Vancouverites have embraced Modos, a carsharing cooperative. From its original two cars and 16 members, Modos has grown steadily. It now boasts more than 10,000 “carsharers” who pay a modest membership cost in order to access some 300 vehicles—from trucks and convertibles, to hybrids and electrics.

Earlier this year, Modos added yet another vehicle to the cooperative—one with special significance to readers of *The Spin*. Unit number 521 is a 2013 Dodge wheelchair-accessible van, complete with a folding ramp, rear entrance, and tie-down straps. The Accessibility Van, which seats four passengers plus a wheelchair user, is available for pickup at the City Hall Parking Lot, just above the Broadway-City Hall SkyTrain station.

Rental rates for the van are roughly the same as all other sets of Modos wheels: from \$3 to \$7.50 per hour depending on membership type, with up to 200 kilometres included free of charge with each booking. Insurance, gas, maintenance, BCAA roadside assistance, Lower Mainland toll bridges, and resident or permit parking are thrown in free.

“The van has seen many bookings since we’ve placed it in our fleet,” says Anthony Casey, Modos’s Marketing Coordinator. “Many of the bookings are over three hours, which is a good indication of the vehicle’s popularity. We also see several regular and scheduled bookings, and

that’s encouraging because it means our members are factoring this van into their plans, personal or professional.”

He adds that, if there is sufficient demand, Modos would consider adding another accessible vehicle to the fleet.

Why the popularity? “Sometimes, a taxi or transit isn’t sufficient for your whole trip, and vans with wheelchair modifications are very expensive,” he says. “When you don’t need one all the time, it’s a heavy expense to bear. Having the option to join a carshare like Modos and have access to this van is a great solution for some people. Modos is the only carshare in Vancouver with an accessible vehicle in the fleet, so that’s helped with our usage as well. Of course, we’re still working on awareness to let as many people as possible know we have this van, so working with groups like SCI BC definitely helps.”

Casey says that the average Modos member spends about \$100 per month—considerably less than car ownership.

If there’s any limitation to the newly-added accessible van, it’s that it doesn’t have hand controls, so wheelchair users are limited to being passengers.

“Before purchasing, we looked at how we might include hand controls,” says Casey. “But at this point, it’s a liability issue preventing that. Being a carshare organization, all of our members can access any Modos vehicle on the map. Having hand controls in place could be an issue for our members who aren’t familiar with them, or don’t know how

to disengage the hand controls during their trip. With that said, it’s something we have discussed internally, and we’re open to speaking with people who might have some experience or know-how we haven’t yet considered.”

Meanwhile, Casey says Modos is proud to offer this van to its members, and hopes it increases the transportation options for people with disabilities.

“For years, Modos has been a carshare that’s helped people access different parts of the city and surrounding nature through shared mobility,” he says. “Many of our members take our vehicles to the mountains, or to beaches and lakes, or to the suburbs to visit family, in addition to using it for daily errands when you need a car. Having this van in the fleet helps us expand that offer, and we hope to grow these options in the future.”

To get started, visit www.modos.coop to choose an appropriate membership package. Once signed up, members have access to all cars in the cooperative. Cars are located in permanent spots—this means members can book the exact vehicle they need for the exact time they need it. All members get their own electronic fob. When members arrive at their car for their booking, they use their fob and onboard technology to let them enter the car and operate it. At the end of their trip, members return to the same spot and fob out. This ends their booking and disables the engine. Payment is by the hour and kilometre. ■

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Whistler High 2.0



Are SCI BC peers adrenaline junkies?

On the weekend of August 7 and 8, a gang of fearless SCI BC peers, along with many of their friends and family members, converged in Whistler to take in a weekend of adventure and friendship. The group totalled almost 80 people, with about 35 from the Vancouver area, and the rest from the Okanagan.

Many took advantage of the opportunity to get airborne on the bungee jump, and on the zipline at Cougar Mountain—it's one of Canada's longest, fastest and highest. Other activities included adaptive kayaking at Alta Lake, handcycling, a trip on the Peak 2 Peak Gondola, and, of course, some enthusiastic socializing and partying.

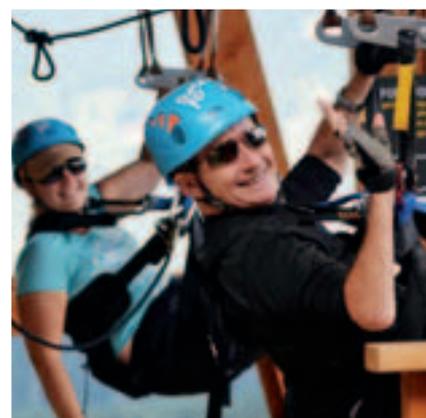
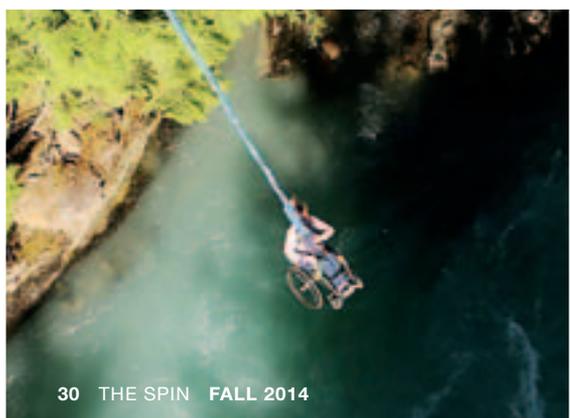
Everyone stayed at the Whistler Athletes Centre, a super accessible facility equipped with a commercial kitchen where volunteers cooked most of the meals.

"It was an amazing opportunity for us to be able to bring our Okanagan and Vancouver Peer communities together," says James Hektner, SCI BC's Okanagan Peer Program Coordinator. "It was great to have participants from these two regions there to provide support and friendship, and to share in the awesome camaraderie that was built between them. It was key in helping people to try new things, find courage, and push their personal boundaries. SCI BC events like these are so important to build the Peer networks of support that are so critical for people with SCI."

For more photos, or for information on upcoming peer events, visit www.sci-bc.ca or check out our Facebook page (www.facebook.com/SpinalCordInjuryBC).



COUNTER CLOCKWISE FROM TOP: An enthusiastic group; James Hektner, Kirsten Sharp and Trevor Zachary at the lookout; Richard Peter and David Parke paddling on Alta Lake; Kirsten Sharp takes the bungee plunge; Desiree Stiles and Mike Stiles prepare for the zipline; Anand Kannan and Sarah Thompson share a laugh.



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