

# the spin

SPINAL CORD INJURY BC

WINTER 2012

## big hills... big thrills

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# contents

WINTER 2012



## features

- 8 Long Distance Voyager**  
Ben Goodridge has been flying high since moving from England to Vancouver a few months ago.
- 10 Bladder Cancer**  
Learn about the warning signs and preventative measures you can take to lower your risk.
- 14 Big Hills, Big Thrills**  
Josh Dueck finds freedom with a sitski in deep powder—and he wants you to do the same.
- 16 Progress Report: Smart-e-Pants**  
Smart-e-Pants, the underwear with built-in electrodes designed to combat pressure sores, has passed an important test.
- 19 Have Wheelchair...Will Travel**  
How to survive a hostage-taking and other great travel tips.

## departments

- 4 editor's message**  
When it comes to SCI in the media, sometimes, reporters get it right—and they should be applauded for it.
- 6 gear & gadgets**  
New products, devices and aids to daily living that might make a difference in your life.
- 7 events**  
Important dates for your calendar.
- 12 working**  
Connecting employers & jobseekers with disabilities.
- 22 last word**  
Peers from across BC get together for some sky high adventure in Kelowna.

## cover

Sitskier extraordinaire Josh Dueck carves up a treed slope at Golden's Chatter Creek. Photo courtesy Paul Morrison Photography.



## What's Happening Online

An Accessible Travel Series

**You Tube** [youtube.com/SpinalCordInjuryBC](http://youtube.com/SpinalCordInjuryBC)

2012 Ugly Tie Affair photos and recap

**facebook** [facebook.com/SpinalCordInjuryBC](http://facebook.com/SpinalCordInjuryBC)

Great photos from our summer peer events!

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# Disability in the News

People with disabilities are largely underrepresented in the media and popular culture, but when they are, they are too frequently covered in a way that is patronizing, demeaning or disappointingly cliché. Trite expressions such as “having the courage to keep going,” “inspirational,” and “overcoming obstacles” are interspersed with outdated and politically incorrect terms like “handicapped” and “wheelchair bound” to create a narrative that is supposed to tug at the heartstrings but diverts the reader from what is actually important or interesting about the story—about personal achievement or the impact an individual or organization is having on the lives of others.

Why does this type of cliché storytelling persist? I’m not entirely sure, but I suspect that in today’s pressure-packed environment of fast-paced reporting, it is the easiest way to cover disability-related events and human interest stories. It’s the easiest angle for reporters and editors, who don’t have the time to truly understand the issues related to the story, to take. It becomes the default.

We try to avoid such reporting pitfalls in *The Spin*. Granted, we have the advantage of 55 years of experience working within the disability community. But that’s only part of it. We believe that people with disabilities are people first and that our readers will be inspired, motivated, or informed by the stories we tell, not because we told them that they should feel that way.

As disappointed as we often are by the media in their reporting of disability-related stories and issues, it is not always bad news. And, when the media gets it right, they should be acknowledged for doing so. This is how we can help promote change.

Take, for example, a recent story in the *Vernon Morning Star* (“Group Provides Support”, October 10, 2012). This informative piece, written by reporter Andre Lodder, describes the impact our Peer Program is having for people in Vernon and Kelowna. His article hit all the right points without resorting to patronizing language or clichés about how brave and inspirational the people he describes are. It was one of the best news articles I’ve read on what our programs are all about and what kind of difference they make in helping people with SCI and related disabilities adjust, adapt and thrive.

Another excellent story recently written by Canadian Press reporter Sheryl Ubelacker made great strides in debunking many myths surrounding sex for people with disabilities. The story appeared in many newspapers across Canada with different titles—in the *Vancouver Sun*, it ran with the title “Let’s talk about sex (and people with disabilities), say advocates”. It was articulate, sensitively-written, and accurate—all without resorting to cliché or patronization.

So, kudos to Mr. Lodder and the *Vernon Morning Star*, and to the Canadian Press’s Sheryl Ubelacker. Let’s hope we see more stories like these. And when we do see them, we must be sure to reward their authors and publishers, because, as in so many aspects of life, the carrot is often a more effective instrument of change than the stick.

- Chris McBride, Executive Director, SCI BC



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### LIFTKAR STAIR CLIMBER

The Liftkar PT Uni, made by Austrian company Sano, is a rechargeable battery-powered device that allows anyone in a wheelchair to ascend or descend stairs. The user simply wheels into place on the Liftkar's platform, activates the lock, and applies the wheelchair brakes. The Liftkar requires an assistant to guide and control the device, but all of the heavy lifting is done by the motorized stair-climbing mechanism. It folds compactly for quick and easy storage or transport. Other Liftkar models have integrated seating. Visit [www.sano-stairclimbers.com](http://www.sano-stairclimbers.com) or search for demo videos in Youtube.



### LP PAD Xbox 360 CONTROLLER

The LP Pad is a wireless controller that allows people with quadriplegia or anyone else with little or no fine finger control to keep up with the latest XBOX games—particularly the latest shooter games. The LP Pad and its buttons are large, so that they can be easily controlled by a palm, knuckle or edge of hand. Along with the laptop controller, there is a standalone chin stick which the gamer can use to direct the action. For more information or to see a video of the LP Pad in use, visit [www.lpassibletechnologies.com](http://www.lpassibletechnologies.com).



# Innovations

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### WHEEL BLADES CASTER-MOUNTED SKIS

Wheel Blades are lightweight mini-ski attachments that clip onto your wheelchair's front wheels or casters to provide better movement over snow, ice and frozen ground. They mount easily with an adjustable clamp that fits wheel widths from one to six centimetres. The wide base of the blades evenly distributes the weight of the wheelchair and its user to prevent sinking in snow. Like a castor, the skis always face in the desired direction since the mounts are located in the front portions of the skis. Two tracking channels on the underside ensure you stay on course. Visit [www.wheelblades.ch](http://www.wheelblades.ch) for more information.



### High Tea.

Hold the date! On Saturday, February 2, join us for a day of high tea, entertainment, and some much-needed pampering. The annual SCI BC Women's Tea aims to provide women with SCI and other disabilities with an opportunity to come together as a group. Last year we highlighted women with creative talents like poetry, writing, singing, music, and dancing. This year's theme will be announced in January—be sure to check [www.sci-bc.ca/events](http://www.sci-bc.ca/events) for more details on this and other Peer events.



### Smart Money.

On Saturday, March 16, SCI BC hosts an SCI forum on financial literacy at Vancouver's Blusson Spinal Cord Centre. Taxes, savings, estate planning, vacations, retirement planning and the Retirement Disability Savings Plan (RDSP) are all topics that will be addressed. Guest speakers will connect attendees with the resources and the tools that they need to achieve their financial goals. In addition to presentations, there will also be interactive workshops. For more information, visit [www.sci-bc.ca/events](http://www.sci-bc.ca/events).



### Learn Online.

Tune into SCI BC's Winter Webinars from the comfort of your own home. On January 21, learn about Get In Motion, a free telephone fitness consulting service provided by SCI Action Canada. On February 17, get the scoop on SCI University, which just released a series of videos aimed at helping people who are dealing with a range of SCI secondary health problems. These webinars are a great opportunity to talk to someone live and ask questions about these online resources. Visit us online at [www.sci-bc.ca/events](http://www.sci-bc.ca/events) for details.

# Make an impact.

Life with a spinal cord injury has its share of challenges. But over 55 years of experience tells us that they can be overcome—and that the best advice is often from someone who's already been there. That's why we're committed to creating peer-to-peer opportunities and making information resources available throughout BC. Your financial support makes it happen. Please consider making a donation online at [www.sci-bc.ca](http://www.sci-bc.ca), or get in touch with us to learn about other ways you can make your own impact.



# Long Distance VOYAGER

Ben Goodridge has been flying high since moving from England to Vancouver a few months ago



“Flying,” says Ben Goodridge, “has given me a freedom that most people, pilots or otherwise, could never understand. Growing up as a paraplegic was demanding and somewhat constricting. Learning to fly gave me freedom in the sense that it took me out of the chair and into the sky—not a bad trade, really.”

Goodridge was injured at the age of two when he was struck by a car. His ticket to fly came via his father, an avid pilot in the UK where Goodridge grew up. Among the airplanes that the elder Goodridge regularly flew was a Yak-52, a Russian two-seater that offered the chance for father to train son.

“I think it was flying the Yak that ultimately gave me the flying bug,” says Goodridge. “A lot of fun it was, especially trying to get into the plane in the first place!”

As Goodridge grew up, flying became more important in his life. By the age of 18, he had his pilot’s license. Eventually, flying became a career focus. In 2010, at the age of 32, he owned his own hand control-equipped Ikarus C42E ultralight airplane, and had achieved his certification as an ultralight flying instructor.

His goal was to train students at a flight school in Swindon, where he lived in the UK. But post-recession England limited his customer base.

“As work was slow and finances were pressing, I was considering my future as a pilot and how I could somehow extend my career in aviation,” says Goodridge. “I had heard that BC was very active in aviation and had a colourful flying culture as opposed to Europe, where it’s seen more as a luxury than a source of transport and way of life. As I have dual citizenship, I sold the C42E and decided on a vacation to visit a family friend in Vancouver—and to



seek out an ultralight school for a work or career opportunity.”

During his visit, Goodridge met with Arnold Klappe, manager of Surrey’s King George Aviation Flight School. He explained his vision of becoming an instructor for Klappe’s company, focusing on promoting flying for other people with disabilities. “I received a really positive reaction to the idea,” says Goodridge. “Without hesitation, I returned to the UK, had a cup of tea and prepared to move. A couple of weeks later, after several farewells, I made the move and became a new BC resident.”

The next step was to find another aircraft. Based on his own experience and how well how it was respected in the ultralight community, Goodridge settled again on the Ikarus C42. This one was located in Florida, where he quickly flew on a commercial flight to purchase it. Ten weeks later, the plane had been approved for Canadian certification and registration. The only question was, how to get it back from Florida?

“Just fly it back,” he was told by his new colleagues at King George Aviation.

Although he’d owned the same aircraft in England, Goodridge had never flown more than 300 miles from his home airport. “So the thought of flying diagonally across North America was, in a word, daunting,” he says.

Klappe introduced Goodridge to an experienced pilot, Jim Stevens, who offered to share the flight and workload. “He was a super chap, an experienced conventional and ultralight instructor, a well-versed bush pilot and, most importantly to me, he had done this flight before,” says Goodridge.

Goodridge and Stevens departed Florida on August 21st. Their route to Vancouver from Florida took them across Alabama, Louisiana, Texas, New Mexico, Arizona, California, Oregon, Washington, and finally up to BC, where they received a warm welcome at King George Airpark.

“The flight took us a total of 40 hours over seven days,” says Goodridge. “Two days were desert flying—pretty

## Tribute to Ben Stam

Canada’s first paraplegic pilot passed away on August 23 at the age of 72. Ben Stam, who was from Chilliwack, was injured in a fall at the age of 17. The late 50s was a tough time to have an SCI, and physical and attitudinal barriers were everywhere. SCI BC (then CPA BC) was there to help out, helping Stam secure his first job at Lenkhurt Electric.

Stam, however, had loftier goals—literally. In the 60s, he set his mind on becoming a pilot. He initially got the go ahead from the Vancouver Transport Canada office, but Ottawa nixed his application, claiming he was “medically unfit”. Over the course of three years, and with SCI BC’s assistance, Stam forged ahead, providing documents to Ottawa that showed paraplegics pilots were flying in the US. In 1970, after completing a practical test in a Piper Cherokee, Stam was finally granted his pilot’s license.

“My initial flight was absolutely beautiful,” Stam recently recalled. “I’ll never forget the freedom. And I’m so pleased that together with (SCI BC), we paved the way for other paraplegics to experience the wonder of flying.”

Ben’s legacy lives on in a display at the Canadian Museum of Flight, located in Langley. He is survived by his wife Ria, daughter Ingrid and son Clarence.



tiring overall. We would fly daily legs of about 250 nautical miles, leaving us a 45 minute fuel reserve. Then we’d land, taxi to pumps, refuel, fly another 250 miles cruising at 100 miles per hour, then land, grab a taxi, get to the nearest motel, eat, sleep, and do it all again the next day. It was absolutely unforgettable.”

Goodridge concedes he would have had a difficult time making the journey without Stevens. Along with BC’s entire flying community, he was devastated when Stevens died in a freak float plane training accident just a few weeks after their return.

“Jim was an all round gentleman and a scholar,” he says. “I felt privileged to have been able to share the flight with him. The aviation knowledge he passed onto me will never be forgotten, and will be passed on to my future students.”

Since bringing his airplane to its new home, Goodridge has been working to convert his UK instructor rating to a Canadian rating. He’s also been working on modifying the C42 with a fully Transport Canada-approved dual hand control system that will allow him to instruct able-bodied and disabled pilots.

“What makes the system unique is that the rudder control will work with the throttle,” he says. “The throttle

works like a motorcycle’s twist grip, and the rudder bar will be all linked as one piece to the throttle bar. We’ll have that on both sides of aircraft.”

He estimates he’ll have completed both of these tasks early in the new year. And that’s when he and King George Aviation will officially kick off the new instructional program to teach other paraplegics to fly ultralights.

“Flying,” says Goodridge, “is a great way to experience one of the ultimate freedoms in life. You see the world with new vision and passion. No matter what our mobility issue is, we can all be as one and enjoy what aviation has to offer. It puts everything in perspective. You can leave your troubles on the ground and rise above them, with dignity and pride.”

For Goodridge, 2012 has been quite a voyage—one that he says he couldn’t have completed without help. “I need to thank my mother for all her moral support and helping to push me to pursue my dreams. She’s like a rock in my life. Also, I dedicate the trip from Florida to my father, who passed away last year.”

For details, contact Ben Goodridge via Facebook or his cell phone (604.218.6275), or visit King George Aviation online at [www.kinggeorgeaviation.com](http://www.kinggeorgeaviation.com). ■

# bladder cancer

This insidious disease represents a significant risk people with SCI. Learning about the warning signs and preventative measures you can take can lower your risk.

**E**arlier this year, Scottish singer and actress Kerry McGregor died after a protracted battle with bladder cancer. Star of the British version of the *X Factor*, McGregor was a paraplegic since the age of 13. She was just 35 when she died. Closer to home, many friends of SCI BC have died from the same disease, including one of our founders, Doug Mowat, and Scot DeWolf, our long-time North Okanagan regional consultant.

All of these sobering deaths remind us that bladder cancer is a concern for people with SCI.

## Understanding the Risk

Some studies suggest bladder cancer could be more than 100 times more prevalent in people with SCI compared to the able-bodied population. A commonly accepted figure is that three percent of all people with SCI will develop bladder cancer.

Heart and respiratory diseases like pneumonia are far bigger threats for people with SCI. But if three percent of us are going to experience it, then we should all know what the signs are, what factors increase the risk, and what actions we can take to minimize those risks.

Research has shown that people with SCI at the greatest risk are those with a long-term history of bladder irritation—repeated urinary tract in-

fections (UTIs) and bladder stones, tissue trauma from poor intermittent catheterization techniques, and especially tissue trauma from long-term indwelling catheters.

UTIs appear to increase the risk by changing the bladder's chemistry. In contrast, catheter use causes physical or mechanical irritation—it's not uncommon to see tumours growing at the exact site of this irritation on the inside of the bladder walls. The worst culprit is the indwelling catheter. In a study of 2,660 of people with SCI at Denver's Craig Hospital, indwelling catheters were found to increase the risk of cancer 3.8 times, compared to other drainage methods. That same study concluded that the longer indwelling catheters are used, the greater the risk.

Dr. Daniel Rapoport, a urologist at Richmond Hospital and clinical in-

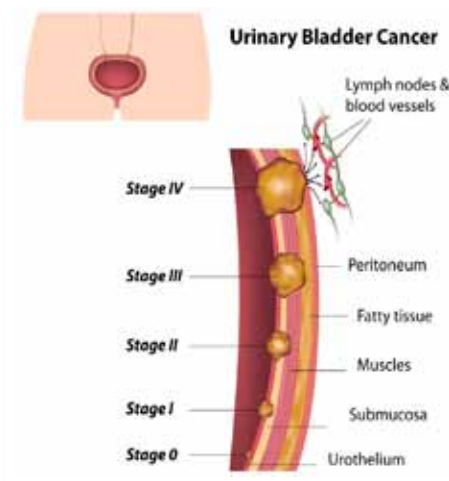
structor with the UBC Department of Urologic Sciences, says cancers caused by indwelling catheters are of greatest concern. "This is mostly because the types of cancer that can develop in patients with chronic catheters—squamous cell cancer—are more aggressive than the usual type we see in the general population," says Rapoport. "And the signs and symptoms may be much more obscure, leading to later diagnosis."

## Signs, Symptoms & Diagnosis

"One of the main problems with diagnosing bladder cancer in people with SCI is that the signs and symptoms can be subtle—or attributed to other common issues such as UTIs or a stone," says Rapoport. "Blood in the urine is the main symptom to watch for. Other symptoms are usually non-specific and may include weight loss, loss of appetite, night sweats, or UTI-like signs."

Any of these signs, says Rapoport, warrant an examination by a urologist as soon as possible.

A urologist visually examines the inside of the bladder using a cystoscope—a catheter with a tiny camera on the end which is inserted through the urethra. During the cystoscopy (often a simple outpatient procedure), the urologist looks for any suspicious areas or growths. If any are found, the urologist may opt to perform a biopsy—scraping away a small piece



of the suspect area. The biopsy, which is often done at the same time as the cystoscopy, is rarely painful.

The tissue extracted during the biopsy is carefully examined by microscope to determine a cancer diagnosis.

## Treatment

Like any cancer, the earlier it's diagnosed, the more options there are for treatment and the better the prognosis is for a cure, says Rapoport.

He explains that, once diagnosed, treatment depends on whether or not the cancerous tumour is noninvasive (present on the surface of the bladder lining) or invasive (extending into the tissue or muscle of the bladder).

"In general, many superficial or noninvasive tumours can be treated and cured by resection, which is when we use a scope to remove a tumour from the bladder lining," he says. "Sometimes we use medications or chemotherapy solutions placed into the bladder in addition to this. With invasive tumours which are not yet spread

beyond the bladder, we sometimes need to perform surgery to remove the entire bladder. The kidneys are then diverted to a piece of small intestine which is brought out the abdominal wall or what is known as a 'urostomy'."

In general, Rapoport says, cure rates are dependent on the severity of the tumour, with the highest likelihood of cure in those detected in the early stages. "Cure rates are still reasonably good for the more aggressive tumours with major surgery," he adds.

## Lowering the Risk

Because early diagnosis is critical, Rapoport says regular screening is the best way to lower the risk—particularly for people with SCI who are at the top of the risk scale.

"We currently recommend annual cystoscopy for those with indwelling catheters," he says. As for people who use intermittent catheterization, Rapoport says that an annual cystoscopy is recommended for the first five years after injury. "If there are no

issues, this can be extended to every two years or so."

He adds that people with SCI need to be proactive about their urological care and avoid being complacent, even if they've gone for a long period of time without significant problems. "If they have not seen a urologist in over two or three years, they should probably request a referral to either a local specialist or one here in the lower mainland. The need for testing and a follow-up plan can be sorted out by the urologist depending on the specific issues of the person. The main reason for a person with SCI to keep in touch with a urologist is to screen for and manage the possible urological complications of SCI which can include incontinence, retention, UTIs, stones, and kidney disease. Bladder cancer is a rare but significant issue that would be addressed as well."

What about other steps people can take to lessen the risk? "There's not really one specific recommendation that can be applied to all people with SCI,"

# HEART OF A DRAGON



The major motion picture inspired by Rick Hansen's Man in Motion Tour to China and the Great Wall is now available in DVD.



[www.heartofadragonmoviestore.com](http://www.heartofadragonmoviestore.com)

says Rapoport. “Specific urological management and prevention recommendations depend on the particular SCI and the associated urinary tract dysfunction type and severity. I would encourage those with SCI to educate themselves about their injury and associated urinary issues and make sure they understand the treatments recommended to them and the potential issues they may face in the future. Thankfully, I find most people with SCI are very proactive and well-informed, which really helps in their care.”

We’ve scanned the internet and, from credible sources, have assembled a list of measures that may apply in your situation and help you lower your personal risk. See the sidebar at right.

### Should you change programs?

Given that people with SCI who use indwelling catheters are at the highest risk, and that the type of cancer generally associated with indwelling catheter usage is the most aggressive, should you consider switching your drainage program?

If you could empty your bladder as easily with an IC program, and you wouldn’t lose independence and quality of life in the process, it’s an easy decision. But it’s rarely that simple.

### Bladder Cancer: Lower Your Risk

- If you use an indwelling catheter, move your legbag to alternating legs other every day—this changes the location of the catheter’s tip inside your bladder
- Be meticulous in all aspects of your bladder management program—drink plenty of water, and avoid overfilling and stretching your bladder
- Use the newer, less irritating hydrophilic catheters
- Change catheters as often as recommended
- Use plenty of catheter lube to avoid irritation to the urethra and urethral
- Be diligent in taking any physician-prescribed medications for bladder relaxation or UTI prevention
- Closely follow your prescribed urological exam/cystoscopy schedule.
- Get to your doctor immediately if you experience fever and chills, cloudy or smelly urine, drainage around the catheter, unexplained autonomic dysreflexia, and, in particular, pinkish or bloody urine
- Eat a healthy diet high in fruits and vegetables.
- Don’t smoke or use any type of tobacco—there is a clear link to bladder cancer
- Learn more about antioxidant vitamins—Vitamin C, Vitamin B6 and Vitamin E and others—which may reduce the effects of cancer-causing agents in the body

To make an informed choice, you’ll need to commit yourself to some careful research specific to your own situation. Seek advice via SCI BC’s peer program from others who have similar situations. Discuss your choices with your urologist. And ask yourself some key questions: How many years have I used an indwelling catheter? Does the increasing risk of cancer outweigh my indwelling catheter’s convenience? Will another program significantly re-

duce the risk? How much help would I need with another program? Can I live with needing to rely on that help?

The choice to have your indwelling catheter removed in favour of a different drainage program is ultimately yours. So, armed with solid information, answer these questions honestly and to the best of your ability. The key lies in knowing your own risks and tolerance of any trade-offs in independence and quality of life. ■

## Connecting Employers & Jobseekers with Disabilities

In 2006, BC Stats found that the employment rate for those with a disability was less than 60 per cent, compared to 74 per cent for the general population. For those with severe disabilities, the findings were even worse: only 47 per cent were employed.

To create a link between job providers and job seekers with disabilities, SCI BC created the Accessible Employment Board ([www.AccessibleEmploymentBC.ca](http://www.AccessibleEmploymentBC.ca)).

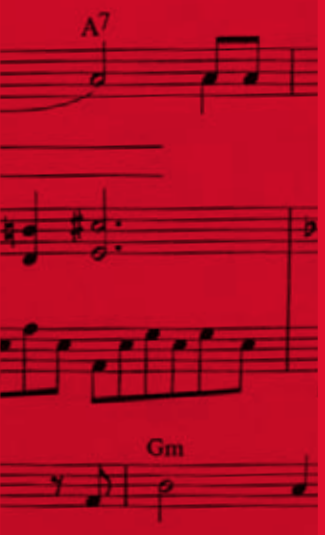
It’s the first online resource in BC dedicated exclusively to helping people with disabilities find employment opportunities.

Accessible Employment BC is entirely free to use. Job seekers with disabilities can look through job postings online and employers can sift through resumes to find potential candidates.

The site is also a resource portal. Job seekers can access information to help them with resume and cover letter writing, and improve interview skills. Employers can also find resources relevant to them, such as “Myths and Facts about Hiring and Working with people with Disabilities”.



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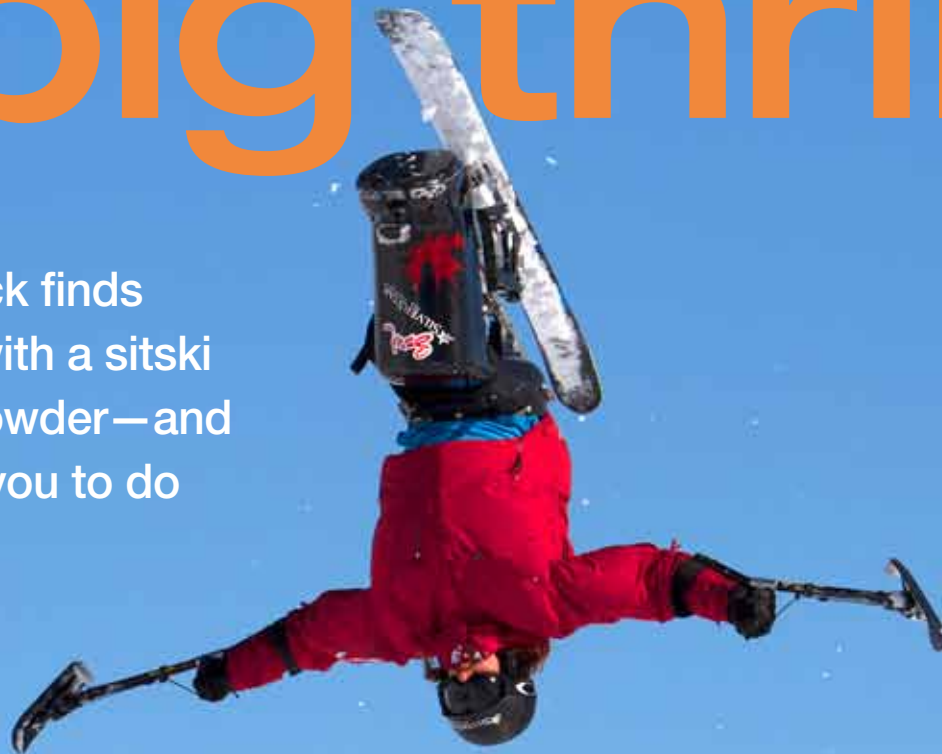
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For more information about the Advance Plus Intermittent Catheter contact your sales representative or call 1.800.263.7400.

# big hills... big thrills

Josh Dueck finds freedom with a sitski in deep powder—and he wants you to do the same



**J**osh Dueck has been a one man headline in the past couple of years.

It began at the 2010 Whistler Paralympics, when the 31-year-old Vernon native turned in a silver medal performance in slalom. That was followed by a gold medal in mono skiercross at the 2011 Winter X Games. Shortly after that, Dueck was the subject of the critically acclaimed, award-winning documentary *Freedom Chair*, in which filmmaker Mike Douglas showcased Dueck absolutely shredding the incredibly steep backcountry at Chatter Creek in Golden, again and again taking huge air over stunning rock faces and dropping light as feather into deep powder.

If all that wasn't enough, Dueck stared down his own demons at a backcountry ski ramp in Whistler this past February. In 2004, while coaching the

Silver Star Freestyle Club in Vernon, Dueck misjudged a jump at a similar ramp, breaking his back and becoming a paraplegic in the process. Eight years later, he executed the first ever back flip by a paraplegic skier. And it wasn't just any flip—Dueck gracefully soared about 20 metres (about 10 metres high off the snow) and nailed the landing. The video of the event went viral, and he ended up on *The Ellen DeGeneres Show* shortly after. More recently, *National Geographic* chose the feat as one its 10 Adventures of the Year.

"Life in general has picked up quite a bit since the release of *Freedom Chair*, then the flip came along and that just kept things spiralling upwards, which has been sweet," says Dueck. "The opportunities for new adventures have been abundant, plus I've got to meet some great people along the way."

At the core of Dueck's success—

before all the medals, feats and accolades—is an incredible passion for skiing and reverence for the winter alpine.

"Skiing has always given me freedom," says Dueck. "When I was a little kid, it was the greatest adventure every time we went to the hill. As I grew older it became an incredible creative outlet for me. And now it's healthy blend of all the above. I love to explore the environment around me and myself through the experiences that being in the mountains provides."

Nothing would make Dueck happier than seeing more sitskiers on the slopes this year. Granted, he is an incredible skier—among the planet's elite, able-bodied or otherwise. But he's quick to point out that his brand of extreme and competitive skiing is just one of many ways to enjoy the sport.

"It's important to find an outlet to



*FACING PAGE: Josh Dueck in the middle of his stunning back flip—the first ever by a paraplegic (photo courtesy Paul Morrison photography). LEFT: Dueck on the podium after winning silver in slalom at the Whistler Paralympics (photo courtesy Canadian Paralympic Committee/Kevin Bogetti-Smith). ABOVE: Dueck shredding treeline pow during filming of the award-winning documentary Freedom Chair, which showcases his unbelievable free form powder sitskiing and how it has helped him in his recovery after SCI (photo courtesy Paul Morrison Photography).*

express yourself, however you see fit,” says Dueck, who was back on the slopes within a year of his accident. “Some people play music, others create art, some play sports and others tune into nature...it’s important to give everything a go and see how it resonates with you. For me, nothing compares to the freedom that skiing has provided, the constant challenge of finding new ways down and the exhilaration of doing something for the first time. When I strap into my sit ski, my disability simply fades away.”

He says there are lots of great programs available to learn how to ski. “My humble beginnings were thanks to the Disabled Skiers Association of BC (DSABC). It was a lot of fun to hang out with other people learning something new, doing something outside our comfort zone and scaring ourselves—it was truly a magical experience.”

DSABC and its community-based partner programs are making it easy for anyone with a SCI to have a go at skiing this year—see the sidebar for more information.

As for Dueck’s present and future, he’s back in training mode these days, getting in some early season skiing before winter really hits, and already

thinking about the 2014 Paralympics in Sochi, Russia.

“This time of year is pretty fun, with lots of new things to test out and the anticipation and wonder of what the season will bring,” he says. “I still enjoy sliding around on snow, so I imagine I’ll do this for a while yet. The goal is to ski fast in the races and find lots of

interesting adventures during my days in the deep stuff.”

To follow Dueck’s career or to read about any of his other endeavours—for example, he’s a sought-after speaker and works closely with the Live It Love It foundation that promotes adaptive adventure for people with disabilities—visit [www.joshdueck.com](http://www.joshdueck.com). ■

## Sitskiing: Have a Go with DSABC

The Disabled Skiers Association of BC (DSABC) is a registered Canadian Charity, established in 1973, that works with hundreds of volunteers to provide opportunities for all British Columbians with a disability to enjoy the freedom and therapeutic benefits of skiing and snowboarding, both competitive and recreational. DSABC recognizes and works closely with community-based disabled skiing programs throughout the province:

- Kamloops: Adaptive Snow Sports at Sun Peaks, Sun Peaks Resort
- Kelowna: Powder Hounds Adaptive Ski Club, Big White Ski Resort
- Kimberley: Kimberley Alpine Resort
- Invermere: Panorama Mountain Resort
- Prince George: Caladonia Adaptive Snow Sports
- Rossland: Red Mountain Resort
- Vancouver: Vancouver Adaptive SnowSports, Mount Seymour
- Vancouver Island: Vancouver Island Society for Adaptive Skiing, Mt. Washington
- Vernon: Silver Star Adaptive Snow Sports, Silver Star Mountain Resort
- Whistler: Whistler Adaptive Sports Program

For more information, contact DSABC by telephone at 604.333.3630 or visit DSABC online at [www.disabledskiingbc.com](http://www.disabledskiingbc.com).

# PROGRESS REPORT: Smart-e-Pants

Smart-e-Pants, the underwear with built-in electrodes designed to combat pressure sores, has passed an important test. So when can you expect to be able to buy a pair?

It's a made-in-Alberta innovation that has garnered a great deal of media interest, not to mention hope within the SCI community, since it was first unveiled almost three years ago.

Developed at the U of A by a team led by Dr. Vivian Mushahwar, Smart-e-Pants look at first glance like cycling shorts. Closer examination of the prototypes reveal an integrated transmitter pack and pockets that contain strategically-placed electrodes. The electrodes deliver small electric signals to stimulate contractions in paralyzed butt muscles at regular intervals. This appears to redistribute pressure, promote blood flow around vulnerable areas and prevent pressure sores—devastating and even life-threatening ulcers that threaten people with SCI and other at-risk people, while costing our health-care systems immense sums of money.

Recently, Smart-e-Pants passed a critical test, moving the product a small step closer to commercial viability.

On October 15th, during the annual meeting of the Society for Neuroscience in New Orleans, the University of Calgary's Dr. Sean Dukelow and his assistant, research nurse Robyn Warwaruk Rogers, reported results from the most recent study of the Smart-e-Pants system—a small feasibility trial involving 37 at-risk patients at the Foothills Hospital in Calgary, and the Glenrose Rehabilitation Hospital and the Allen Gray Continuing Care Centre in Edmonton. The participants, who had conditions including SCI, hip fractures, diabetes and MS, wore the

underwear for 12 hours per day, four days per week for four weeks.

Dukelow, a physiatrist and neuroscientist who led the study, explains that, typically, about 10 to 30 percent of people with these conditions would be expected to develop pressure sores. But all of the study's participants remained pressure sore-free.

"Most of them wanted to keep the device after they were done," says Dukelow, who was recruited by Mushahwar because of his clinical rehabilitation expertise, needed to properly evaluate the innovation.

The study results were presented as a poster during the Society of Neuroscience meeting, which is attended annually by up to 30,000 health professionals. "The poster was pretty well received," he says. "We had a steady stream of researchers coming past the poster over our four-hour presentation slot. This is probably not surprising as a number of people at the conference interact with individuals with neurological disorders who are at risk of pressure ulcers."

"Well-received" might be an understatement. The presentation was among those that clearly stood out among the hundreds of other posters on display in an area the size of three or four football fields. This became evident when many global news organizations, including ABC News, CBS News and BBC News, aired stor-

ies about Smart-e-Pants in the days following the meeting.

"It has been interesting, that's for sure," says Dukelow. "This project has gotten a considerable amount of media attention, and certainly a bit more than many of the other projects that my lab is involved with. I spend far more time dealing with media people, individual patients or family members emailing requests to be included in the study, or requests to buy the device than any other project we're running. Unfortunately, we're not quite there yet."

That's because testing efficacy—proving conclusively that the system prevents pressure sores—was neither a goal or an outcome of the study.

"The study that we've done is relatively simple—looking at safety and feasibility," he says. "Our data on subjects to date shows that the device seems to be safe and our nursing staff is able get it on and off pretty easily. The bottom line is that we needed to show that we weren't going to cause any harm with the device. This is an important step in the regulatory process that most governments demand."

With safety and feasibility confirmed, the focus now moves to efficacy. Clearly, this will be an important question

*"If we can't answer the question around efficacy, then we would be no better than any of the other devices out on the market that claim to do something, but have never really been properly tested." – Dr. Sean Dukelow*





to answer for doctors prescribing the device, people using it, and insurers such as provincial health care plans providing coverage for it.

“If we can’t answer the question around efficacy, then we would be no better than any of the other devices out on the market that claim to do something, but have never really been properly tested,” says Dukelow.

But he cautions that an efficacy study, which is only in the preliminary planning stages, will take much more effort.

“If I was to hazard a guess, because it is a prevention study, it will likely need to be very large—potentially several hundred subjects, if not a few thousand. Again, this all depends on the sample size calculation, which we are currently assessing—so this is only a best guess at this point. The study we’ve just presented and some research over the next 12 months we’re conducting will help us to iron out the population we would want to include. I’d also guess that it will need to be more broad-ranging than just SCI, because all individuals with reduced mobility or sensation are at risk and we would like to demonstrate that Smart-e-Pants would work for this wide population.”

With the team’s current grant expiring in 2014, there is the problem of funding. “One of the big challenges we will face in trying to conduct an efficacy study is identifying funding for what has the potential to be a large and quite expensive study,” says Dukelow. “And who funds the study has an impact on timing, locations, and more.”

All this means you will won’t be wearing Smart-e-Pants anytime soon.

“I empathize with individuals who are at risk of developing pressure sores or who have developed pressure sores—I wouldn’t be involved with this particular project if I didn’t,” says Dukelow, who has debrided his fair share of what he describes as “particularly terrible” pressure sores.



Dr. Vivian Mushahwar (RIGHT) and Dr. Ming Chan (LEFT) of the University of Alberta explain the Smart-e-Pants system. (Photo courtesy Canada Foundation for Innovation)

“However, I think that many people fail to realize how much time, effort and manpower goes into a project like this. The process requires continuous effort and what amounts to thousands of hours of collective work from many individuals. We have to write and obtain grants to fund the research, write ethics proposals so we can conduct the research, deal with administrative red tape, seek regulatory approvals, and conduct the kind of carefully controlled scientific research to ensure that no one is harmed by a new device—and that the device actually works.”

The “we” Dukelow is referring to is actually a small team of researchers and clinicians. “For perspective, we are not a major corporation with tens of thousands of employees, trying to churn out the ‘next best’ version of a cell phone or automobile with a few incremental improvements over last year’s model. Trying to make significant changes in treating pressure ulcers—or most health care issues, for that matter—takes a lot of time. Believe it or not, if I compare this particular project to other

technologies or medications that have been shown to ‘work’ in rehab, we’re actually moving along quite quickly.”

If and when Smart-e-Pants comes to market, what would the price tag be? About \$300 plus monthly costs for disposable electrodes, says Dukelow. However, given the incredible cost of pressure sores and potential health care savings of \$1.7 billion in Canada alone, the hope is that Smart-e-Pants would be covered by insurance.

Visit [www.smartneuralprostheses.com](http://www.smartneuralprostheses.com) for more information. ■

## The Staggering Cost of Pressure Sores

On an individual level, pressure sores take a terrible toll, ranging from a few days of bed rest to weeks or months of lost productivity, and even death (Christopher Reeve was just one of many people with SCI who have died from pressure sore complications).

But what about the collective, direct health care costs to treat pressure sores?

Last year, the Rick Hansen Institute took a stab at answering this question in a paper titled *Reducing SCI-Related Complications and the Potential for Associated Cost Avoidance*. Not surprisingly, the numbers are staggering.

People with SCI, write the authors, have “up to 80% lifetime prevalence of pressure ulcers.” Furthermore, the authors assert that, of all secondary complications of SCI, pressure ulcers “represent the most burdensome complication in terms of direct costs”, well ahead of UTIs and neuropathic pain.

In Canada alone, the cost of treating those pressure sores is \$355.4 million annually. But remember, that’s just within the SCI population. The study’s authors estimate that there are 148,902 new pressure ulcers annually in Canada within the entire population, including people with SCI. The annual cost estimate is \$1.73 billion.

Developing a method to prevent even just a fraction of these pressure sores annually should clearly be a priority for health care insurers and governments across Canada.



# Make Your Home Safe for Independent Living

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

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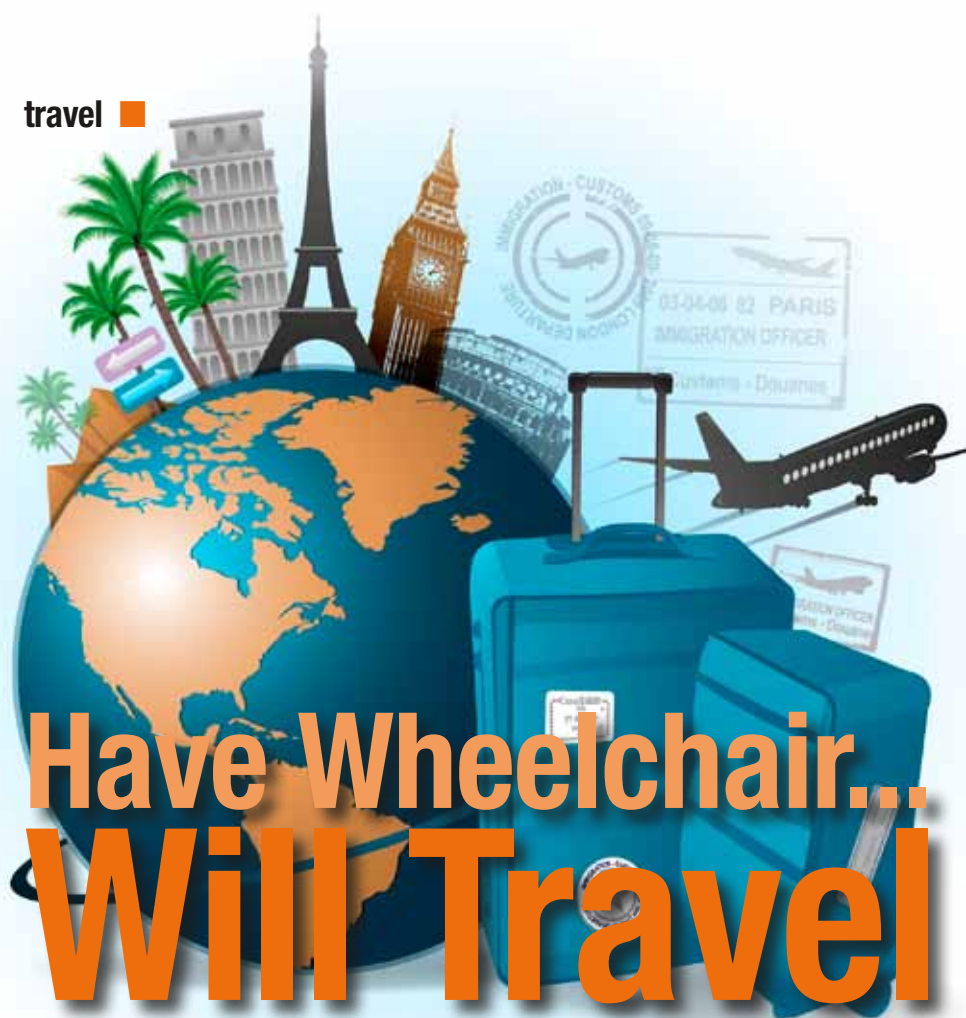
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**HOUSING MATTERS**



## How to survive a hostage-taking and other great travel tips

**T**ravelling with a wheelchair can be a daunting proposal—especially for people who have recently been injured. Fortunately, there are many trail-blazers in our midst who have dared to go where no man or woman on wheels have gone before. The stories from their journeys are sometimes problem-free, sometimes catastrophic, often hilarious, and always educational.

If you pay attention to the knowledge they've earned, and learn about the steps the travel industry is steadily taking to adapt to the needs of wheelchair users, you'll find that taking a long-distance voyage can now be a relatively smooth experience.

That's why SCI BC has partnered with the Vancouver Airport Authority to share our peer's wisdom far and wide with our Accessible Travel Series.

Starting this month, you can visit our YouTube page to watch several short

video tutorials which illustrate step-by-step what happens once you get to the airport. You can also watch videos of different people with disabilities sharing their best travel stories and the travel tips they learned along the way.

To start off our Accessible Travel Series with a bang, we talked to Roger Jones about his first trip to Latin America in 1988. His ten-day vacation had more ridiculous plot twists and misfortunes than a National Lampoon flick. You can watch him tell all on camera at [www.YouTube.com/SpinalCordInjuryBC](http://www.YouTube.com/SpinalCordInjuryBC), but here's a preview to whet your appetite for more.

Jones' adventure started over a glass of wine at a restaurant with his friend Dan MacLellan. Jones had been a quadriplegic for just over three years when he suggested the two go on vacation.

"We can't travel!" said MacLellan incredulously with wide eyes. "Where would we go?" Dan had been a quadriplegic for about 20 years at the time and

had never travelled abroad post-injury.

Jones spotted a pamphlet one table over. He was drawn in by the palm trees, the white sand beach and the crystal clear ocean. There was one word typed in bold print: Venezuela. "I had no idea where it was, but I decided that's where we'd go," says Jones.

The two buddies travelled with two able-bodied friends, but aside from that they were completely unprepared. This was the late '80s, and Venezuela had absolutely no accessible infrastructure.

Their tragic-comic ordeal began as soon as their plane hit the tarmac in Caracas. As they were getting off the plane, Jones' power chair was confused with a bomb and completely dismantled. A few days later, during a day trip to the city market, Jones and Dan attracted a huge crowd as they wheeled around in their power chairs—technology that, apparently, no one had ever seen before. The military was called in to disperse the crowd, and the bewildered duo was escorted out of town and sent back to their beachfront resort.

By the time they were seated on their flight home, Jones and MacLellan were relieved. "What else could possibly go wrong?" they thought. Then the unthinkable happened. Their plane was surrounded by military tanks. Everyone was removed from the aircraft at gun-



**NO STRANGER TO DANGER:** Roger Jones, intrepid traveller

point—everyone except for Jones and MacLellan, of course, who struggled to explain their predicament in Spanish to angry armed men who had probably never encountered two quadriplegics before.

They were held hostage for about 8 hours—Jones tied up with rope on a chair because he couldn't keep his balance—before they were finally sent home. It wasn't until they landed safely in Toronto that they learned that they had been caught in violent riots resulting from tough new economic measures imposed by the government. Hundreds had died that day in Caracas.

You might assume that the pair's epic adventure would dissuade them from travelling abroad again. In fact, it had the opposite effect.

MacLellan became a prolific traveller. He's been to Japan, the Caribbean and eventually moved to Costa Rica. "After that trip, he never stopped!" says Jones.

As for Jones, he's since travelled across North America as a motivational speaker, and says that first trip had a profound effect on his outlook on life.

"I still think fondly of Venezuela," he says. "I had just come out of rehab so being able to get out there and learn what I was capable and not capable of, that was a great experience for me. A lot of what I've done in life, a lot of it comes back to that trip. The worst that could have happened, happened to us during those ten days. I think that really helps me put all the fears, the challenges and the obstacles I take on in life into perspective."

Jones has some advice for travellers with disabilities who are nervous about heading to the unknown. "With a disability, maybe there are some things you have to adjust and plan for, but I don't think it's a barrier of any kind. I think you should plan up to your own comfort level and go from there. Travel is a great way to learn about other cultures—and everyone should just do it." ■

## More About our Accessible Travel Project

- Watch Roger tell his story and more find travel videos at [www.youtube.com/SpinalCordInjuryBC](http://www.youtube.com/SpinalCordInjuryBC)
- Download a PDF of our Accessible Travel EBook full of detailed travel tips from peers on our website: [www.sci-bc.ca/travel](http://www.sci-bc.ca/travel).
- Participate in our YVR Experience days where groups of SCI BC peers will be invited to go through Vancouver International Airport security and practice transferring onto an aisle chair and then onto a plane. We'll be hosting several YVR Experience Days throughout the year starting this January to help you learn the nuts and bolts of travelling with a wheelchair. Contact Brad Jacobsen at [bjacobsen@sci-bc.ca](mailto:bjacobsen@sci-bc.ca) to sign up in advance.
- Are you an avid traveller? Share your stories with us! Tell us the good, the bad and the ugly about your favourite destinations. You can write a blog post for us to share on our website or record your own video travel tips and share them on our Facebook page. Contact Candice Vallantin at [cvallantin@sci-bc.ca](mailto:cvallantin@sci-bc.ca) if you have a travel story to share.



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# Okanagan High



SCI BC's first ever multi-regional peer gathering was a blast

**O**n August 27th and 28th, Peers from Kelowna, Vernon, Quesnel and Prince George got together in the beautiful Okanagan Valley to experience parasailing, explore the bountiful Kelowna Farmer's Market, and tour the Mission Hill Winery.

In total, 50 Peers and their family members and friends came together for the three-day event.

One of those participants was Ken Legros, who has been part of the peer group in Prince George since he moved there in 2007. Although he attends the odd coffee group, this was the first SCI BC Peer adventure event he attended.

"I loved it," he says. "I so wish I had gone to the previous events. I've missed out on so much—I have to get out more and do things like this. Now I know what a bird feels like. All you hear is the wind. That was the nice part, it was peaceful. Just soaring around and being free."

For Legros, the event's adventure component was just icing on the cake. The real highlight was all the connections he made during the trip. "Just to interact with everybody

else and find out what they're doing—that was a lot of fun, getting to know people in chairs from around the province and talking to them. You learn something that they do differently that you can try."

That's exactly the result that Brandy Stiles, the Northern BC Peer Coordinator who led the event's organization, was hoping for.

"Trying to organize multiple groups is difficult, but it's broadening our horizons a little bit," says Stiles. "I think people find it quite refreshing. They create new connections, and it starts in a nice way when you have a face-to-face meeting. People find and connect with each other on the internet these days, but it's quite difficult and can be limiting. These events are one of the best benefits of the peer program."

For Legros, this parasailing trip is just the first of many adventures to come. "I'm definitely going to try not to miss anymore events if I can. The event was so well organized. The volunteers and everyone really did an amazing job. I'm hooked now after going on that first trip." ■

## Paddles & Pedals

In 2001, Kelowna firefighter Troy Becker had an epiphany. After spending time with his brother-in-law, who has Down syndrome, Becker decided that everyone should have access to the same outdoor activities he takes advantage of on his days off. That's how the avid hiker, rock-climber and kayaker launched the Community Recreational Initiatives Society (CRIS). Armed with donated sporting equipment and volunteer help, the organization has grown from humble beginnings over the past 11 years, and now provides multi-day outdoor adventure activities from hiking to rock-climbing for people with different levels of ability across the province.

This July, Troy and his team from CRIS met up with more than 55 Spinal Cord Injury BC peers in Vancouver and Victoria for four days of adaptive cycling, hiking and kayaking.

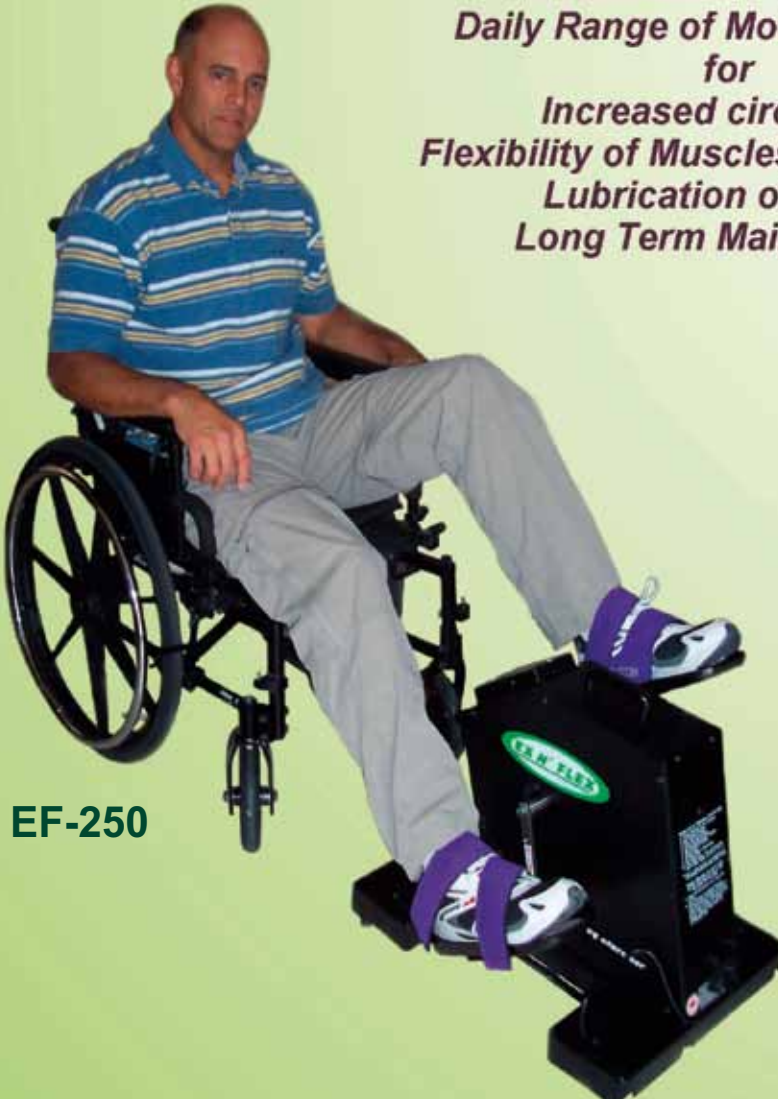
Mission's Bobby Brar (right) originally came out to kayak, something he'd never tried before. But he was elated when he discovered he would also get a chance to try adaptive hiking and cycling. "That was my first time hiking and on a bike in 20 years," he beamed later in the day.



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