

the spin

BC PARAPLEGIC ASSOCIATION

WINTER 2012

Guitar Man

Whether he's rescuing a neglected guitar or handcrafting a new one, luthier Mike Trelenberg is on the job





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Reference: 1: Christensen P, et al. Gastroenterology 2006; 131:738-747

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Luthier Mike Trelenberg working on a custom Riversong guitar in his Kamloops workshop.

A glass half full.

The holiday season is a time to reflect on the year past—and contemplate the year ahead. As we complete our first year of publishing the new *The Spin*, we felt it was time for us to do the same for this magazine.

With every issue, we receive overwhelmingly positive feedback from readers who thank us for sharing new information, ideas and inspiration. But the feedback isn't always positive, and a recent email from a reader with SCI is a case in point. This individual says she has felt increasingly depressed by the positive nature of the stories we've presented, and that the achievements and activities described in those stories wasn't possible for her or many others. This reader felt we were mistakenly trying to empower our readership by telling them that they can "do it all" and that this was actually leading to the opposite effect of "causing disappointments when regular people with SCI can't meet these ideals."

When we launched *The Spin*, we decided that we would present stories that informed and inspired, highlighting some of the many challenges of living with SCI, but also showing how people have overcome them, or what's being done in the world of research and technology to address them. Through our 57 years of service, we know that life with SCI and related physical disabilities isn't always filled with good news stories. We know that not everyone who reads our magazine will be able to or interested in doing everything we report on; that there are many challenges and barriers that either inhibit or prohibit some of our readers from participating in the same activities or achieving the same results as the people we feature in our stories.

But we believe that one of the central objectives of *The Spin* is to help our readers see what is possible. True, not everyone can afford to travel the world, and not everyone can play sledge hockey or start their own business building bikes. But the intent of our stories isn't always about the specific example. Instead, it's to create a broader understanding for some of our readers that maybe there's more potential and quality in their lives than they might appreciate.

The magazine is also about letting readers know about the value of connecting with our Peer activities and Information services, which, like *The Spin*, are provided for free (or at a minimal cost) to our members. The goal is to connect you with others who can offer experience and wisdom.

Life with SCI is far from easy. Our promise is not to sugarcoat it in *The Spin*. But we will continue to take the "glass is half full" approach. We won't hide the nasty bits—but neither will we stop telling you how others deal with them. In one short sentence, BCPA Peer Jurek Golas, who we've featured in a short story on sledge hockey on page 12, sums up our approach: "...when I get there, I'm in pain and feeling a bit negative—and when I'm finished I feel uplifted and positive."



Chris McBride
Executive Director, BCPA



thespin

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The Stevens Pool Ladder is a practical alternative to expensive powered pool lifts. Wheelchair users enter a pool by sliding out of their chair onto the platform, and then down the gently-graded padded steps that float and lower with the users' weight. Each step has its own set of hand grips. When fully submerged, the ladder's lowest step rests about two feet under the water's surface. The Stevens Pool Ladder is constructed from stainless steel and can be coated. More information can be found at www.stevenspooladder.com.

GLOBAL ACCESSIBILITY MAP

In the last issue of *The Spin*, we told you about wheelmap.org, a user input website based in Europe that allows visitors to provide location-specific wheelchair accessibility ratings for facilities and services around the world. Recently, the Rick Hansen Foundation launched its Global Accessibility Map, which offers the same functionality—but allows for more specific ratings and details about accommodations, facilities, businesses and other public spaces around the world. The tool is designed to allow all people to make informed decisions on everyday activities such as where they eat, shop, work, play and access services. It's based on a five-star ratings system and is similar in concept to the consumer reviews commonly found on many travel websites, but with a focus on accessibility criteria. At the time of writing, there were 1,247 reviews on the site, with the majority of those describing accessibility at Canadian locations. As with wheelmap.org, there is also a version specially designed for mobile devices. For more information or to submit your accessibility reviews—positive or negative—visit www.rickhansenglobalaccessibility.com.



Innovations

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



THE PUMP

Emptying a leg bag without assistance is a challenge for many people with SCI—particularly those with quadriplegia. A new power wheelchair accessory called The PUMP allows people to independently empty their leg bag into a toilet or urinal at a touch of a button. The PUMP attaches to the outlet of the leg bag and directs the flow of urine out through the tip of a flexible wand. An ultra compact 12-volt lithium polymer battery powers The PUMP for up to five days with an overnight charge. It installs easily and quickly on most power wheelchairs. Once the urinary leg bag is full, the user maneuvers their wheelchair within arm's length of a toilet or urinal, extends the wand, and presses the switch twice to begin pumping. When the bag is empty, the user presses the switch once to turn off and return the wand to its stowed position. A cleaning kit is included. For details, visit www.wheelchair-freedom.com.

NUBRELLA

Viewers of ABC's *Shark Tank* might be familiar with the Nubrella, which is worn over the head and shoulders and leaves the hands free—perfect for West Coast wheelchair users. In 2010, owner/inventor Alan Kaufman presented the product to the Sharks, and agreed to an investment. The deal eventually fell through, but the exposure helped propel sales. Nubrella has shoulder straps that keep it off the top of your head, and a strap that attaches in front to keep it from blowing off or tipping back in strong winds. It's spring-loaded and pops open with the press of a button. Like a regular umbrella, it folds up when not in use. The clear polyurethane is treated to keep water-beading to a minimum, and lightweight aluminum alloy ribs provide strength and durability. It weighs just over a kilo, and includes a lightweight, over-the-shoulder carrying case. Visit www.nubrella.com for details.





Tea Time.

BCPA is holding its 9th Annual Women's Tea event on Sunday, February 19th at the Heritage Hall in Vancouver. This year the event will include a talent showcase as well as the usual fabulous mini make-overs and extra tasty treats. Right now BCPA is looking for talented female performers with a disability to audition for the "In the Spotlight" talent showcase. Whether it's singing, acting, dancing or playing a musical instrument, BCPA would love to hear from you. For more information on the 9th Annual Women's Tea or to arrange an audition (prior to January 20th, 2012) contact Lydia Walczak at lwalczak@bcpara.org or call 604.326.1230.



Cafe Scientifique.

The Canadian Institutes of Health Research (CIHR) Café Scientifique program presents *It's not rocket science, it's harder: past successes and current challenges of spinal cord research*. Join an expert panel of ICORD researchers for refreshments and lively discussion about how discoveries in the lab translate into treatments that affect lives now, as well as the inherent challenges in that process. It takes place on Thursday, January 19, from 7 to 9 PM, at the Blusson Spinal Cord Centre Atrium. There is no charge to participate in this event but registration is required. RSVP to cafe@icord.org. Space is limited!



P.G. Resource Centre.

You're invited to our Prince George office on Wednesday, January 25th, from 12 PM to 5 PM, to help us launch our new SCI Resource Centre. The Centre will be open to the public Monday to Friday from 9 AM to 5 PM, and will offer information on living with a physical disability, peer support, an accessible computer workstation, and teleconference facilities. This is BCPA's first SCI Resource Centre and is part of a wider BCPA initiative to build a stronger presence throughout BC—our plans include opening SCI Resource Centres in Victoria and Vancouver in 2012. For more information, contact the BCPA InfoLine at 1.800.689.2477.

BCPA's New Website: Making Your Life Easier

We're pleased to announce the launch of our new and improved website.

"The new bcpara.org isn't just another website, it's a powerful, easy-to-use tool and resource for people living with SCI or related physical disability and their families," says BCPA Executive Director Chris McBride. "People can go online to get the information they need, they can share that information or offer new information, and they can find the support they need."

The site includes a new and improved SCI Information Database where information on everything relating to living with a disability—for example, housing, recreation and funding sources to name a few—can be found. Another improved feature is the Swap N Shop, a "craigslist" type of service for people selling SCI-related equipment.

New features have been planned for the coming year, including a Housing Board displaying accessible housing opportunities and a Job board for job listings. BCPA is also launching a blog, with Peer Coordinator Brad Jacobsen and Executive Director Chris McBride regularly blogging on a wide range of topics relating to the world of SCI.

Go online today and check it out www.bcpara.org.





the Scuba (re)Connecti

Could scuba diving offer clues to improve function for people with SCI? Cody Unser thinks so, and a recent research study appears to confirm this.

“FROM BIRTH, MAN CARRIES THE WEIGHT OF GRAVITY ON HIS SHOULDERS,” once wrote the legendary Jacques Cousteau. “He is bolted to earth. But man has only to sink beneath the surface and he is free.”

For Cody Unser, this passionate quote from the father of scuba is incredibly meaningful.

Unser, the daughter of two-time winner Indy car driver Al Unser Jr., became paraplegic at the age of 12 after an acute attack of transverse myelitis—a neurologic syndrome caused by inflammation of the spinal cord. When she was 15, she discovered scuba. She quickly revelled in the freedom, strength and independence she felt undersea. But she noticed something else—a tingling and return of feeling in her legs and bladder when she went diving.

Unser, now 24, became convinced she was experiencing

a physiological benefit from diving. With help from family and friends, she established The Cody Unser First Step Foundation to further paralysis research. She approached two of her physicians, Dr. Adam Kaplin and Dr. Daniel Becker, and told them what she had been experiencing while diving.

Kaplin, an assistant professor of psychiatry and behavioral services at the Johns Hopkins University School of Medicine, admits he was skeptical at first, but he became intrigued when Unser brought him to a scuba training session in Pennsylvania to talk to other wheelchair users who reported similar responses while diving.

Unser, through her foundation, offered to sponsor a pilot study to attempt to confirm the benefits she and others had been experiencing. Kaplin and Becker accepted, and this

on

past May, a group of 19 participants—10 veterans with SCI and nine able-bodied “buddies” who acted as a control group—gathered in the Cayman Islands for four days of testing while they achieved their open water diving certification.

Before the dives, Kaplin and Becker conducted a series of neurological and psychological tests on all 19 participants, including spasticity, motor control and sensitivity to pinprick and light touch. Then the participants underwent scuba certification, which included nine dives up to depths of 30 metres over the course of four days.



LEFT: Cody Unser and her boyfriend Beaux Barfield diving in the Cayman Islands. ABOVE: John Supon, one of the veterans with SCI who took part in the study, diving in the Caymans' Sting Ray City. (Photos provided by The Cody Unser First Step Foundation)

The results, according to Kaplin and Becker, were “dramatic” and included an average 15 percent reduction in muscle spasticity, 10 percent increase in sensitivity to light touch, and five percent increase in pinprick amongst the veterans with SCI. In fact, in some individuals, the improvement in tone, sensation or motor function was between 20 and 30 percent. The able-bodied control participants experienced no neurologic changes. Two of the 10 paraplegics were unable to complete the dives.

As the participants with SCI were all injured veterans, post-traumatic stress disorder (PTSD) symptoms were also measured, with dramatic reductions experienced as well.

“This is just a pilot study, but to see such a restoration of neurological function and significant improvement in PTSD symptoms over such a short period of time was unprecedented,” says Becker, head of Pediatric Restoration Therapy at the International Center for Spinal Cord Injury at Kennedy Krieger Institute.

“What we saw in the water strongly suggests there is some scuba-facilitated restoration of neurological and psychological function in paraplegics,” adds

Kaplin. “It’s very provocative.”

The researchers stress they can’t say conclusively if the benefits are reproducible or long-lasting. Nor can they explain why the benefits occurred. But they do have a theory: because of pressure at greater depths, more nitrogen is dissolved into blood and body tissues, which leads to a large increase in serotonin production in the brain and spinal cord tissues. Many researchers believe that serotonin, a neurotransmitter found in the central nervous system, kickstarts the central pattern generator in the spinal cord, which acts like a microprocessor and may activate dormant pathways, restoring some function in the process.

The benefits wore off after a few weeks. But the researchers say treatment at regular intervals may lead to more and longer-lasting improvements and even true repair of broken spinal cord pathways—permanent life improvements such as greater sensation, improved bladder control, and relief from depression or pain are all possibilities.

Kaplan and Becker both agree that larger, scalable studies are now needed to confirm results and tease out specific research angles.

"The response of the study has been overwhelming and very exciting," says Unser, who has been travelling the country to publicize the findings (you may have seen her recently on the *CBS Evening News*). "I knew what I was personally feeling under the ocean in my legs and bladder was strange back in 2002, but I didn't know to what extent the effects of scuba diving could have on the paralyzed body, both psychological and neurological. This study does confirm on paper and in numbers and graphs that scuba diving provides not only a therapeutic gateway but also a whole realm as to what a future treatment may look like for SCI."

Unser says that the focus now for everyone working for her foundation and on its behalf is to take this pilot study and promote it to the world, in order to raise funds for a larger study.

"I'm very excited—it's been a dream of mine since I started having sensations under the ocean's surface to study these effects and really bring this sport—this therapeutic, life changing experience—to a whole new level," she says. "And I think

that's what this study and hopefully many more of them does and will do. In terms of treatment, that is the dream, but many more studies and funding will get us there."

For more information on the scuba study and The Cody Unser First Step Foundation, visit www.cufsf.org. ■

Want to experience firsthand what diving is all about? There are plenty of BC opportunities for people with SCI to learn scuba. Check the peer listings at www.bcpa.org for 2012 scuba events, and learn more from these web resources:

- Handicapped Scuba Association – www.hsascuba.com
- New World Diving – www.newworlddiving.webs.com
- Access Diving on Gabriola Island – www.accessdiving.ca
- Freedom at Depth Canada – www.freedomatdepth.ca
- Pacific Northwest Scuba Challenge Association – <http://members.shaw.ca/gsingler/scuba/scubainfo.html>

What to make of Geron's abandonment of its SCI stem cell trial?

For years, embryonic stem cell transplantation has been touted as one of the more promising research avenues for SCI. In simple terms, the theory is that stem cells obtained from embryonic tissue could be cloned, coaxed into becoming specialized nerve cells, and transplanted into the injury site where they would restore function.

While many expensive stem cell therapies are currently available to people with SCI in many foreign countries, no such therapy has ever been scientifically shown to be effective—or, for that matter, safe. Enter Geron Corp., the California biotech company that has been viewed as a pioneer in stem cell-based therapies.

Based on some success in animal studies, Geron became the first American company to receive critical FDA approval to conduct clinical trials involving embryonic stem cell transplantation in humans with acute (within 14 days) SCI. In October of 2010, with great fanfare and massive amounts of publicly-raised funds, it began its phase 1 trial to study the safety of such a treatment.

Just over a year later, on November 14, Geron released results of the phase 1 study—and dropped a bombshell in the process. The therapy does appear to be safe, as none of the four participants had any significant adverse reactions. But despite that, officials announced the company is abandoning the research.

The reason given by Geron is increasingly heavy costs. But the company concedes that none of the four participants showed any sign of benefits or improvements that had been seen in rats that had been given the therapy.

It seems likely that if any positive results had been demonstrated in the phase 1 human trial, Geron would have proceeded with phase 2 trials designed to test efficacy.

Geron's decision comes as a blow to many BCPA members and many others with SCI around the world, who were looking for the company's research to legitimize human stem cell therapies for

SCI. But Dr. Michael Fehlings, a senior stem cell scientist at the McEwen Centre for Regenerative Medicine, says it's not a death knell for SCI stem cell research.

"It's disappointing that Geron has elected to stop its stem cell research program," Fehlings told CTV's *Canada AM*. "But it's hardly a fatal blow to the field. The whole area of stem cell research is certainly taking off. There are a number of other studies that are underway in the U.S. and internationally looking at the application of stem cells to treat a number of disorders including blindness and SCIs."

Meanwhile, in the absence of any conclusive evidence of safety and effectiveness of any of the myriad of stem cell therapies offered around the globe, BCPA urges readers to resist unrealistic claims and restrain from participating in treatments that promise only a high cost instead of any real benefits or guarantees of safety.

"Perhaps the most important lesson from the Geron experience is that it simply takes a lot of time and effort to determine the safety, let alone the effectiveness, of these stem cell therapies for spinal cord injury," says Dr. Brian Kwon, Vancouver Coastal Health spine surgeon and ICORD scientist. "Given the hype that was generated—both intentionally and unintentionally—around the enrolment of the first patient in the Geron trial, the public could hardly be faulted for thinking that they were just a few months away from proving that these cells were a 'cure' for SCI."



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Ice TIME

Vancouver finally has a much-needed option and venue for sledge hockey, and BCPA Peers like Jurek Golas are taking full advantage.



One of the most popular events during the 2010 Paralympics in Vancouver was sledge hockey. With TV coverage and crowds in excess of 5,000 at the UBC Winter Sports Centre, the tournament provided excellent exposure for the sport, despite Team Canada finishing a disappointing fourth in the final standings.

What's surprising is that, at the time, Vancouver offered no options for anyone interested in playing recreationally (although there was a program in place in Surrey).

Enter the newly-completed Hillcrest Community Centre at Riley Park and its much-needed sledge hockey program. In September, the Centre's Olympic-sized rink opened its doors and began offering novice and intermediate programs every Friday night from 5:15 to 7:30. Led by enthusiastic volunteers and instructors, the program is a perfect opportunity for people with disabilities of all ages

and abilities to get on the ice.

One of the program's new recruits is Jurek Golas, a T3 paraplegic.

"I started this year in September," says Golas. "I needed some winter recreation to replace ball hockey and that's why I tried it. Some of the guys on my ball hockey team played it out in Surrey, and when the program was finally offered in Vancouver, I decided to give it a try."

At 48, Golas admits he's a late comer to the sport. "There are people of every age group, from maybe teens up to the senior person—which is me," he says. "But when we're on the ice, age and disability seem to disappear."

Golas loves the fact that it's a recreational program aimed at having some healthy fun, and that he gets to try all positions as a result.

"We're just a group of people with different disabilities who come together and have fun," he says. "I feel abso-

lutely great and invigorated when I'm out there. I get to meet people of all levels of disability, and when I'm on the ice I feel a good sense of belonging with everyone on the team. Another benefit—really the major one, I think—is that when I get there, I'm in pain and feeling a bit negative—and when I'm finished I feel uplifted and positive. Aren't those endorphins great?"

Not surprisingly, Golas has become an ambassador for the sport. "I definitely would encourage others, and we keep trying to get more people to come out. We even have able bodied people come out to play or volunteer." ■

For details about the Hillcrest Community Centre's sledge hockey program, visit www.hillcrestcentre.ca. For more information about sledge hockey at the Surrey Sport and Leisure Complex, visit www.sportabilitybc.ca. For information about sledge hockey in Kelowna, visit www.kelownasledgehockey.com. For more information on other opportunities, visit www.bchockey.net.

Get 'em when they're young...

That's the philosophy of the Let's Play Program, operated by the BC Wheelchair Basketball Society (BCWBS) with funding from the Rick Hansen Foundation and the Province of BC. The program strives to help kids with physical disabilities become active early in life so that they can experience life-long benefits.

The program is directed at BC kids who are eight years of age and under, along with their parents, teachers and recreation/sport coordinators. It provides the equipment, fundamental skills, knowledge and abilities needed to confidently participate in play, sport and physical education with their peers.

The program offers qualifying kids a specially-designed RGK sports wheelchair, as well as equipment for the wheelchair—for example, cushion and straps. It also provides adapted equipment for program facilitators, some limited funding for improving the physical accessibility of program facilities, expertise and guidance for organizations that want to deliver inclusive physical activity programs, and training and a best practices guide for teachers, parents, recreation programmers and other facilitators.

In October, BCWBS launched the Let's Play Program official website and teacher's resource. LETSPLAYBC.CA is designed to help parents, teachers and program coordinators by providing skill descriptions with video footage, ideas on how to modify and adapt activities to be more inclusive, and examples of inclusive games and activities. The Let's Play teacher's resource also highlights this key information in a hands-on user friendly format that can be used in the classroom or gym.

Visit the new website or contact BCWBS at 604.333.3530 for more details.



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When it comes to guitars, few are as finely tuned in as Kamloops' Mike Trelenberg

Guitar

FOR MIKE TRELENBERG, a post-injury hobby morphed into a passion for guitars—first as a player, and then as highly skilled luthier.

Today, Trelenberg handles all repairs at Kamloops' largest music store, Lee's Music on Battle Street. Repairs, however, are just one aspect of his job—he's also the innovator and builder of a highly sought-after line of custom handmade acoustic guitars.

Trelenberg's story began after a 1998 motocross bike crash in his home town of 100 Mile House. He was 14 at the time, and the result was T6 complete paraplegia. Not surprisingly, the first years following the injury were a challenge. One Christmas, his parents bought him a guitar. It proved to be a sound investment, as he quickly mastered the instrument. Bigger things would follow.

"After playing guitar for a few years, I started thinking of the possible careers in the music industry," says Trelenberg. "I saw an advertisement for a lutherie school, and began researching. It seemed like a good fit."

In 2004, he applied to the renowned Summit School of Guitar Building and Repair at Qualicum Beach on Vancouver Island. He was accepted into the intensive one year Masters program beginning in January, 2005. A \$1,500 bursary via the BC Paraplegic Foundation Scholarships and Bursary Program helped him realize his dream, and he soon found himself in a small class with a high teacher/student ratio.

A challenge quickly emerged: a lutherie workshop is equipped with table saws, other power tools, and work benches, all built to accommodate a standing craftsman. "It became apparent that I needed to adapt myself to the tools, and not the other way around," says Trelenberg.

He found a surprisingly simple answer at Advanced Mobility's Nanaimo location—a LEVO LAE standing wheelchair. Back in the school's shop with his new chair, Trelenberg found he could easily push himself from a sit-



Man



ting position into a standing position (and any point in between) by simply using the elevating armrests with their integrated gas springs adjusting to his weight.

The solution was perfect, and over the course of the next 12 months, Trelenberg would immerse himself in an intensive curriculum ranging from basic repair to advanced lutherie and building custom guitars.

Soon after completing the course, he landed the job at Lee's as a guitar repairperson. Manager Mike Miltimore was willing to modify Trelenberg's workshop area for accessibility, but it turns out nothing was needed—the Levo chair was the only solution required.

As Trelenberg became comfortable with his new career and living in Kamloops, he started dreaming of owning an exceptional guitar. But he was discouraged by four digit price tags, and reasoned he could build the calibre of instrument he desired for much less, afterhours in his home workshop.

One day, he brought one of his creations in for his boss to see. Miltimore was impressed, and that was the beginning of Riversong Guitars.

Trelenberg began taking custom orders from discriminating buyers, carefully and lovingly handcrafting each solid-topped instrument with specialty woods and strict attention to detail and quality.

Today, Trelenberg finds himself with a growing backlog of orders. Prices begin

at \$1,400 and can go as high a customer's imagination and budget will allow. Multi-more recently committed an additional 2,000 square feet of workshop area and new equipment, and plans are in the works for a Riversong production model.

As his reputation as both a repairman and a builder grow, Trelenberg now finds himself busier than he's ever been. "Repairs are always priority," he says. "Once they're complete, I move on to building. I usually have time to do both each day."

Is there a downside to success? "I'm not playing as much as I'd like to," he concedes. "It's hard to find time between work and home life."

Despite that, Trelenberg wouldn't

change a thing.

"Being a luthier is rewarding," he says. "It's nice to see planks of wood become a beautiful instrument and fixing people's guitars so they can make music again. It's a very rewarding career that beats sitting in front of a computer all day. If you have patience and like to create, go for it. Don't let your injury hold you back. If you have a career in mind, there's always a way to make it work." ■

Lee's Music is located at 1305 Battle Street in Kamloops. The company also has a Kelowna location. For more information, call 250.374.6683, email infokamloops@lees-music.net, or visit www.leesmusic.net.

Pedals Make the Piano Player

Paralegic piano or keyboard players seeking to use pedals for a fuller musical experience now have a viable option. The TouchMIDIpedal device consists of brass rod that attaches just below the keys, an electronic box with a processor, and two MIDI cables. The pedal function is generated as soon as the player touches the rod lightly, either with any part of the palm or any finger, as the player continues to play with both hands. The function continues as long as any part of the palm touches the rod, and ceases when the palm is lifted. The technique is easily learned. The rod is easy to mount with plastic fasteners, and there's no need to for it to be permanently fixed. The device doesn't affect the normal



foot pedal, as both function independently of each other. The electronic box is connected to the brass rod. The MIDI cables go from the electronic box to the MIDI IN and OUT terminals of most digital pianos or keyboards. For more information, visit www.touchmidipedal.se.

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Syrinx Alert

Vigilance and fast action are critical when it comes to posttraumatic syringomyelia.

TERRY LEBLANC HAD ENJOYED ENVIABLE GOOD HEALTH during the 33 years that had elapsed since he became a C4 quadriplegic in a diving accident.

"During those thirty-some years I had worked at BCIT, BC Hydro, and the GVRD in CAD and digital mapping," says LeBlanc. 'Life goes on' was my mantra post-injury and, because I was lucky enough to be injured in Vancouver, my quality of life was excellent."

But a blip on the radar appeared almost overnight this past September. "Approaching my late 50s, naturally I had aches and pains from too few muscles doing too much work," he says. "But suddenly I lost all strength in my right arm and developed a very sore shoulder from the trapezius down through the shoulder blade. It was a pain I'd never felt before. All of this happened within a couple of days."

LeBlanc remembered that a small syrinx—a fluid-filled cavity or cyst in his spinal cord—had been spotted in an MRI taken back in 1988. "I remembered the doctor telling me that, if I ever had a sudden loss of function, to get into the ER. Despite this I foolishly hesitated to go into emergency for several days hoping against hope that it would go away on its own. I finally took a good book and parked myself in emergency at Vancouver General Hospital for two days. On the second day, the MRI confirmed that the previously stable syrinx had suddenly gotten much larger."

What LeBlanc had developed was posttraumatic syringomyelia (sear-IN-go-my-EE-lia)—PTS for short. PTS occurs at the site of the initial SCI, in an estimated three percent of people with SCI—mainly those with upper thoracic or cervical injuries. It can develop any time after SCI—sometimes in just months after injury, sometimes taking years to show up. It begins with formation of a syrinx, usually the result of tethering—a condition where scar tissue binds or "tethers" the spinal cord to the dura, the soft tissue membrane that surrounds it. A small syrinx may never become a problem, or it may remain stable for years. It may grow slowly over many years, or grow rapidly.

The tethering prevents the spinal fluid from moving freely around the spinal cord. Pressure may increase, forcing more fluid into the cord and the syrinx. As spinal fluid leaks into the cavity, pressure builds and the cavity expands, damaging nearby nerve fibres. The result is full-blown PTS.

The results can be devastating. Progressive deterioration of the spinal cord, progressive loss of sensation or strength, profuse sweating, spasticity, pain and autonomic dysreflexia (AD) can all result. More serious yet is the possibility of new levels of irreversible neurological damage—and corresponding new levels of disability.

The only treatment option is surgery, according to Dr.

Scott Paquette, one of two spine surgeons at Vancouver General Hospital who deal with the majority of PTS cases in BC.

"Treating a syrinx is never easy," says Paquette. "Just like every person is unique, every damaged spinal cord has unique issues as well. These operations are very delicate as every blood vessel and nerve is potentially vital. We tend to use a surgical microscope for these operations to see even the smallest detail of anatomy. The average surgery usually lasts anywhere from four to six hours."

Paquette explains that current surgical practice is aimed at restoring a fluid pathway down the spinal canal. "Often," he says, "this can be accomplished by opening up a narrowed spinal canal or releasing any scar tissue (untethering) in order to recreate a path for the spinal fluid to flow around the cord as the first option."

Surgery usually leads to stabilization, improved strength and reduced pain (although it doesn't always bring back lost sensory function). But Paquette concedes that the first surgery isn't always successful.

"Sometimes the scar reforms and we need to re-operate or opt for other options such as shunting the spinal fluid elsewhere in the spinal canal or even di-



LEFT: Terry LeBlanc, BCPA board member and enthusiastic sailor. RIGHT: this large syrinx at C7 is clearly visible in the highlighted area of the MRI.



verting that fluid to another area of the body," he says. "Also, shunts are mechanical devices that can fail, block, break or slip out of the correct position."

Other possibilities during surgery may include placing a small graft at the tethering site to fortify the dural space and decrease the risk of re-scarring.

In LeBlanc's case, a gradual narrowing of the spinal column at C3 was the reason his long-stable syrinx had begun to expand. Just above his injury site, the column had begun filling in with bone and compressing the cord.

This restricted the spinal fluid flow, and it finally infiltrated the cord itself, rapidly leading to PTS.

"My surgeon (Dr. Paquette) told me that decompressing the spinal cord was the only solution," says LeBlanc. "A laminectomy was needed on the back of my spine to give the spinal cord some breathing room, so to speak. I'm not ashamed to say I was very concerned about the procedure. I have a couple of friends who have had to have syrinxes shunted with resulting loss of function and many complications. It crossed my

Travel Accessible BC: NAKUSP HOT SPRINGS

Many people believe the Nakusp Hot Springs have healing properties. These enthusiasts have been travelling there for decades, claiming that improved circulation, respiratory health and skin condition are among the benefits of immersing in the sulphate and bicarbonate-rich water.

Maybe it's true, but there's certainly no doubt that taking a leisurely dip in perfect 38 degree water is great for relaxation and stress relief—particularly in the middle of winter.

The Nakusp Hot Springs, operated by the Village of Nakusp, is fed by a spring just above the Kuskanax Creek, nestled between the Monashee and Selkirk Mountain ranges in the West Kootenay district of South Central BC. The 55 degree water is filtered and cooled before it enters the round amphitheatre-shaped pool facility, which features an accessible change room with heated floors and a Aquanaids Mark 11 pool lift for wheelchair users (providing access to the largest of two pools).

The facility charges a modest fee for both a relaxing soak or an all-day pass. Winter hours are 1 PM to 9 PM, seven days a week.

Lodging is available on site at the Nakusp Hot Springs Chalets, but

wheelchair accessibility is limited. In the summer, riverside camping is available for RVs and tents. If you're looking for true accessibility and a little more luxury, there are several hotel, motel and B&B options in the charming Village of Nakusp, about 12 kilometres away.

Note that there is another hot springs facility nearby, but unlike Nakusp Hot Springs, Halcyon Hot Springs doesn't have a pool lift.

Nakusp is easily accessed from the Trans Canada Highway at Revelstoke (take Hwy 23 south) or from Vernon (take Hwy 6 east). On both routes, you'll have to take one of BC's free inland ferries.

For more information, visit www.nakusphotspings.com.



mind several times to cancel the surgery, even when I was in pre-op."

Despite his misgivings, LeBlanc proceeded. The surgery took place on September 29, one week after LeBlanc checked into emergency.

"When I awoke from surgery, the shoulder pain was gone," says LeBlanc. "And the arm function returned to C4 level the day after the procedure. I was told that as soon as the laminectomy was done, ultrasound showed the spinal fluid resuming normal flow. In total, I spent eight days on the Spine Ward at VGH. Some four weeks later, I'm still stretching and combating muscle stiffness but I'm euphoric at how successful the surgery was."

Since the surgery, LeBlanc has heard of several others who have had the same outcomes. "It was an eye-opener because, before the procedure, I'd only heard about the ones with multiple complications. But I've also heard from others who put off the surgery too long. When the surgery was finally performed, it was suc-

cessful, but the function never returned."

For this reason, early detection is critical. "I would advise any readers to listen to what their body is telling them," says LeBlanc. "Any sudden onset of weakness shouldn't be ignored. When presenting at emergency, ask to speak to a neurosurgeon. Most importantly, be patient. It's very easy to get upset with the glacial pace at the ER and to refuse to go or to leave prematurely."

Paquette agrees. "Early and correct diagnosis of syringomyelia can mean halting the progression of the disease and saving neurological function. I'd like to remind readers that sometimes the best advocate you have for your medical care is yourself. Even in a very busy general practice, a doctor may only follow a few patients with SCI and, given how rare PTS is, it's likely they've never treated a patient with it. Additionally, most syringomyelia becomes symptomatic years after the SCI. It's not likely to be the number one differential diagnosis

on the GP's mind. I tell every patient to be wary of progressive neurologic loss and to insist on an MRI if that ever happens. MRI is really the test of choice."

Paquette offers one final piece of advice. "Being fit and healthy always helps prior to, and following surgery. And while there's a lack of scientific data to prove this in syringomyelia surgery, it's preferable for patients to quit smoking prior to surgery and to be as well nourished as possible." ■

PTS: Know the Signs

Check into your closest emergency room if you experience:

- loss of feeling in the extremities
- muscle weakness
- increased spasticity
- pain that is new or different
- changes in patterns of sweating
- chronic pain and headaches



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WORK SAFE BC

Whistler High

The sky's the limit for a group of Northern BCPA Peers who recently experienced several of the tremendous adventure opportunities at Whistler and nearby Pemberton

Whistler. With its majestic peaks, clear blue lakes and breathtaking natural beauty, it's the perfect adventure destination. Little wonder that, each year, hundreds of thousands of thrill seekers from around the world head to Whistler for some unadulterated outdoor adventure.

This past summer, a group of Northern BCPA Peers decided that they would join the adventure party in Whistler. Over the course of an August week, our hardy and enthusiastic Peers feasted on kayaking, hiking and gliding.

Among them was Prince George's Jurgen Posselt. Posselt was injured in 2005 after falling from the roof he was working on. "That moment changed my life forever," says Posselt. "My first thought was that my legs don't work. That's when the panic set in. I couldn't believe this was happening to me."

Gone was Posselt's livelihood driving trucks and hauling logs for the forestry industry, along with his dream home, which he was forced to sell as he couldn't imagine caring for such a large property on his own. And also gone was his spontaneous travels and enjoyment of the great outdoors—or so he thought.

"It was a challenging time," he says. "I was in a terrible state. I didn't think I had any kind of future. I really felt like my life was over."

But all that would change.

"A young fellow from BCPA came to visit us at the rehabilitation centre," says Posselt. "He was also an outdoor nut who had become involved in disabled hiking after his own injury. It was a real eye-opener for me to see someone not only enjoying life again but continuing to do something he really loves."

For Posselt, himself a self-proclaimed "outdoor nut", this was just what was

LEFT: Jurgen Posselt, ready for a week of adventure. RIGHT: Brandy Stiles and volunteers enjoy a hike using the TrailRider.



needed to inspire him to move forward with his life. Six years on, Posselt has often taken advantage of the activities offered by the BCPA Peer Program, including the outdoor adventure trip to Whistler in August this year.

"It is all very liberating—you're able to forget about the wheelchair, forget about the tingling sensation in your feet, forget the pain, and all the other crap you put up with," says Posselt.

He participated in all three activities—kayaking, hiking (using a TrailRider), and gliding. He particularly enjoyed the gliding as it brought back memories of his childhood. "My father was a big fan of gliding when I was a teenager back in Germany," he explains. "I went up a couple of times and loved it. It was very beautiful—I reacted to it like a kid. Gliding is especially good for someone in a wheelchair as every day you're acutely aware you don't have the same movement as you did before, then all of a sudden you're flying like a bird."

Kayaking was also an enjoyable experience for Posselt, who had enjoyed canoeing prior to his injury but hadn't ventured out with a paddle since. "It's easy to fall into a lazy routine—you can spend way too much time indoors, online, etcetera, when you should be getting out there and doing real stuff. I used to always do real stuff. Well, it's all still possible. Really, the sky is the limit. It's up to your own motivation and your own self confidence. I feel proud of myself that I did this stuff here.

Visit www.bcpara.org to view some video footage of the BCPA Northern Peers' Whistler adventure. ■

Are you the adventurous type?

Summer might be over, but there's still plenty of adventure to be had in winter. It's also a perfect time to get prepared for next summer's opportunities. Here are two organizations that coordinate adaptive adventures for people with SCI:

- Whistler Adaptive Sports (www.whistleradaptive.com) provides opportunities for people with a wide range of disabilities to experience Whistler's world class recreational opportunities alongside their able-bodied peers.
- Community Recreational Initiatives Society (CRIS) Adaptive Adventures (www.adaptiveadventures.ca), based in (but not confined to) Kelowna, unites volunteers with outdoor enthusiasts with disabilities and, using adaptive equipment, provides outdoor adventures that improve quality of life for everyone.

For other outdoor opportunities, call the BCPA InfoLine 1.800.689.2477 or visit the SCI Database at www.bcpara.org.



Ryan Purves (front) gets ready to soar above Pemberton. ABOVE: Posselt and a volunteer paddling on Alta Lake.

Happy Feet

How are you thawing those blocks of ice at the end of your legs this winter?

Cold feet. Maybe you can feel them, or maybe your bed partner keeps a healthy distance until you warm up. Or maybe you instinctively know that an unnatural shade of blue can only mean trouble.

In the winter, or even at other times of the year, cold feet are usually the result of poor circulation. The foot is the part of the body furthest from the heart; thus, the feet are often the first to suffer from inadequate blood supply due to poor circulation. The problem is often greatly intensified with SCI. At best, cold feet can be a discomfort. At worst, they can lead to chilblains or severe skin problems.

First, see your doctor to make sure you don't have any serious circulatory issues. Given that this is ruled out, how do you keep your feet warm? We posed the question to BCPA peers on our Facebook page and got some great responses.

"Merino wool socks... light and warm... Keep your knees warm (long underwear or a knee stocking) and your feet will stay warm...Do some range of motion sometime during the day to improve circulation...Make sure your straps and laces are not too tight," said BCPA Peer Coordinator Brad Jacobsen

"Sheepskin UGG boots," countered Christie Ewen.

"I use battery powered boot warmers to prevent frost bite (when skiing)," offered Rob Gosse. "They get warm enough to take the chill off but not hot enough that they burn."

"Wool socks, fleece lined slippers," wrote Jenny Jensen.

We also looked farther afield at some popular SCI forums such as carecure.org and apparalyzed.org.

"What I sometimes use are those smallish cushions that are filled with walnut shells or rice that you can put in the microwave," wrote Eileen, a senior member of carecure.org. "That way I can make sure the temp is not too hot, then shove it under the covers and down by my feet, or directly under my feet, to help warm them up. Outside I have used those chemical hand warmers, except putting them into my shoes as long as I have nice thick socks to protect my skin."

Mike Bauer, another member of carecure.org, offered this: "I got some real high tech hunting underwear...not just the thermal K mart stuff...this is super thin, high tech material...they cost about \$75

bucks. But somehow they are amazing the way they work. They keep my legs toasty and I wear them under everything."

The SCI Nurse at carecure.org also got into the act. "Problems with circulation usually are more obvious during the day when feet are dangling down and blood and fluids pool in the legs due to gravity...Try elevating...legs when up during the day. TED hose or support hose may help..."

And finally, Tim Ripley, a contributor at www.apparalyzed.com, offered this advice: "I've been using Hottronics for skiing for years...you just need to be careful, i.e., sweating etc."

Good luck, and stay warm. ■

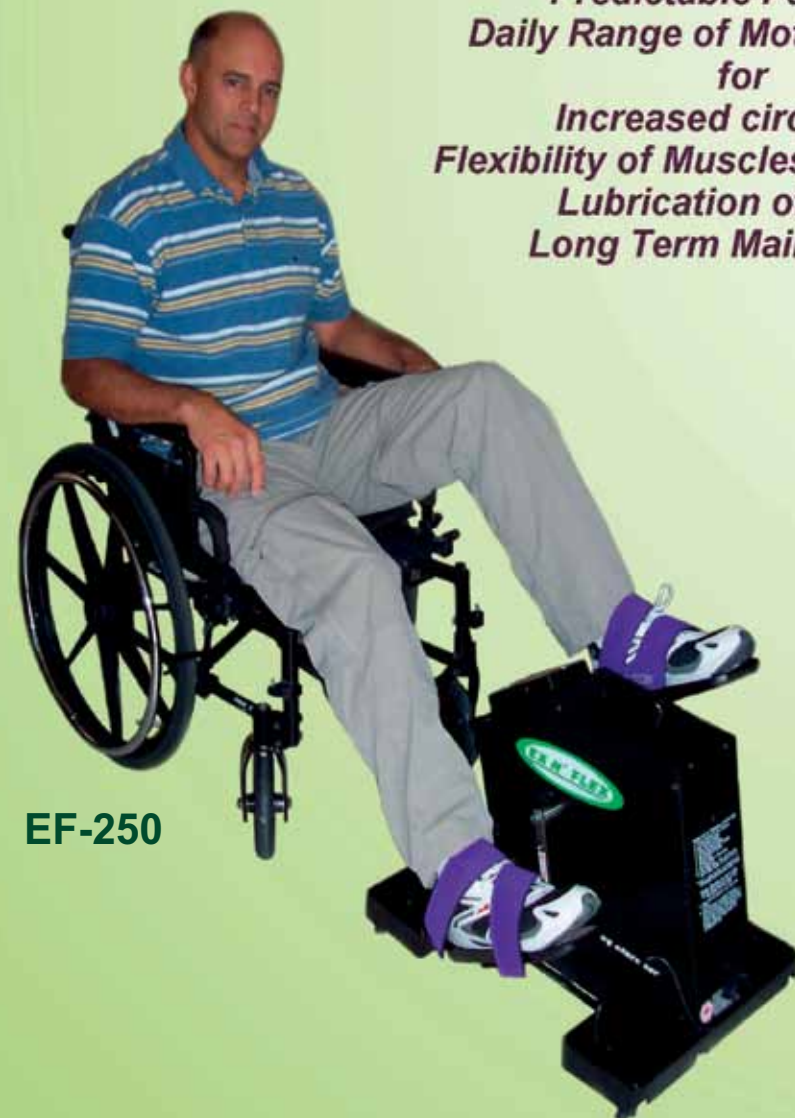


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Thank you to Wheelchair Basketball Canada for the action shots of Chantal Benoit, white, and Kendra Ohama, black above.
More information is available on these two veterans of the women's National Program in Canada on the web site at wheelchairbasketball.ca