

the spin

SPINAL CORD INJURY BC

SPRING 2013

No Apologies

Jessica Kruger has found friendship, mentoring and thrilling competition in the male-dominated game of wheelchair rugby





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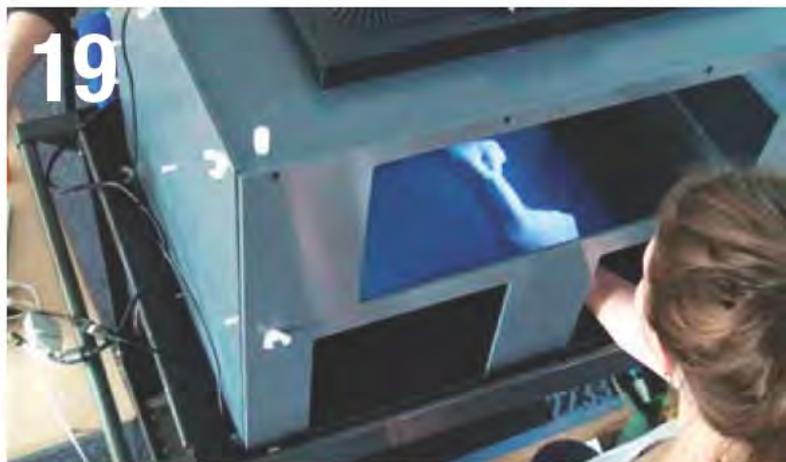
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Jessica Kruger has found friendship, mentoring and competition by getting involved with wheelchair rugby. Photo by Candice Vallantin.



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Stocks up. Common sense down.

In mid-February, when StemCells Inc. released an update on the company's Phase I/II clinical trial in chronic SCI, the company's stock price shot up by over 25 percent. But does that mean a cure for SCI is around the corner?

The goal of the trial is to determine the treatment's safety and preliminary efficacy. Conducted in Switzerland, it will study 12 individuals who have sustained a thoracic (T2-11) level injury between 3 and 12 months before the start of the treatment. So far, three individuals with complete injuries have completed the trial. The remaining nine participants will have incomplete injuries.

Clearly, this is not a big trial. Although a decent indication of the treatment's safety can likely be determined, its ability to lead to improvements will be a little harder to interpret. So why did StemCells Inc. stock prices surge after it released results on the first three participants? I guess it's because investors were buoyed by what they perceived to be encouraging results on two of the three participants. If I was an investor, I'd be a little more cautious.

StemCells Inc. reports that two participants showed improvements in sensory function, with one converting from a complete injury to an incomplete injury. In particular, this conversion sounds rather remarkable.

But wait a second. Many people undergo spontaneous conversion from complete to incomplete classification. Granted, when it happens, most experience it within the first three months after injury, but it can happen within the first year. So the conversion could have happened without the treatment at all. In addition, because the trial is not a controlled one (in which a group undergoes the same treatment, except that they have a placebo injected into the spinal cord instead of the stem cells), we can't really know if it was the stem cells or some other aspect of the treatment, such as physiotherapy, that led to the improvements observed. Until more subjects go through the trial, we shouldn't get too excited.

StemCells Inc.'s President and CEO made a statement that appeared, at first, to provide similar caution—but fell far short. "While we need to be cautious when interpreting data from a small, uncontrolled trial, to our knowledge, this is the first time a patient with a complete SCI has been converted to a patient with an incomplete injury following transplantation of neural stem cells," said Martin McGlynn.

I guess he's right—it's probably the first time someone receiving stem cell treatment has converted from complete to incomplete SCI. But remember, this is far from the first time someone has experienced this kind of conversion. It happens with some regularity. The StemCells Inc. trial doesn't yet provide any credible evidence that the company's stem cell treatment is directly responsible for either the improvements in sensation or the conversion.

Some may complain that I'm overly cynical or pessimistic. Maybe, but as a former SCI researcher, I've learned to become an optimistic cynic (or maybe a cynical optimist). There is great value in the research that companies like StemCells Inc. and Neuralstem (which we cover in this issue of *The Spin*) are doing. At the very least, they're figuring out how to conduct trials safely and determine if a treatment-based effect occurred. These are huge, costly and risky undertakings and they will ultimately help move the field closer to a cure—some day.

However, with the stakes so high, there is a tendency toward prematurely interpreting results—and sometimes over-interpreting them to boot. That's why we all need to employ a bit of cynical optimism.

So while StemCells Inc. investors appear eager to bet that the company is on the verge of curing SCI, I'll wait for more convincing data before I risk my money on it.



- Chris McBride, Executive Director, SCI BC

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TETRALITES

Being lower than other pedestrians, wheelchair users at crosswalks are sometimes not noticed by motorists—particularly at night. TetraLites, created by Tetra Society of North America volunteers, helps solve the problem. TetraLites feature rows of high-power LED lights in Plexiglas tubes, which mount to the sides and rear of a wheelchair or scooter. They draw a negligible amount from power chair batteries, and can be connected to rechargeable batteries for use on a manual chair. This ingenious solution was created in response to a request by Burnaby's Eric Molendyk, who was struck by a vehicle while using a crosswalk in 2008. "When I'm crossing a road, I always try to make eye contact with drivers, so I know they've seen me," says Molendyk. "Now that I'm using the TetraLites, I notice that they see me sooner. I also use them when I'm waiting for a bus to make sure the drivers notice me—most bus drivers comment on how effective they are." For information on TetraLites and other adaptive technology solutions engineered by Tetra volunteers, visit www.tetrasociety.org.

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Innovations

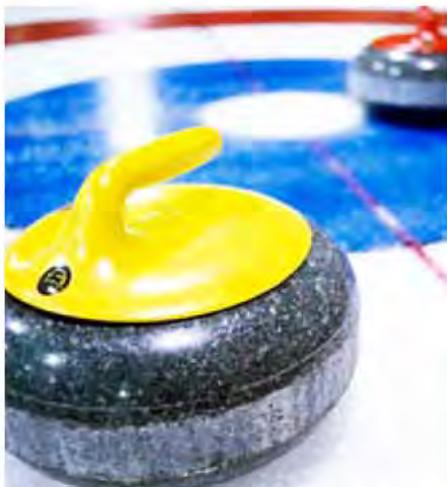
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Hurry Hard to Richmond.

It's BC vs. the best club curlers from all over the Pacific Rim, including Australia and the United States, during the 14th annual Pacific International Cup, from April 17th to the 21st at the Richmond Curling Club. All proceeds raised will support SCI BC events and programming across the province. A big thanks to the PIC committee, the Richmond Curling Club and all the participating curlers, audience members and event supporters. For more information, point your browser to www.picup.ca.



Make Your Voice Heard.

The SCI BC Annual General Meeting will be held on June 20, 2013 at 780 SW Marine Drive, Vancouver. Registration and a reception begins at 6:15 PM, with the meeting following at 7:00 PM. Registered in BC as Canadian Paraplegic Association (BC), SCI BC previously operated as the BC Paraplegic Association. Please RSVP to Maureen Brownlee at 604.326.1225 or via email mbrownlee@sci-bc.ca. A voting member is defined in the Association's Bylaws as a member who has paid an annual fee.



Walk 'n Roll With Us.

The SCI BC Walk 'n Rollers are at it again for this year's Scotiabank Charity Challenge and we're looking for people to join our team! Last year, 22 team members had a blast as they walked and rolled five kilometres around the Stanley Park seawall, raising a total of \$15,000 for our peer program and information services. So register with your friends and family to join our team today! Contact Brad Jacobsen at bjacobsen@sci-bc.ca or 604.326.1236 if you'd like to walk or roll for our cause.

Make an impact.

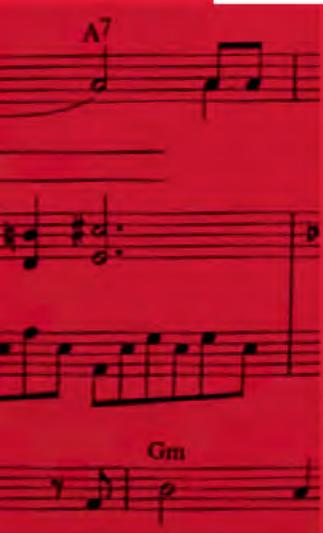
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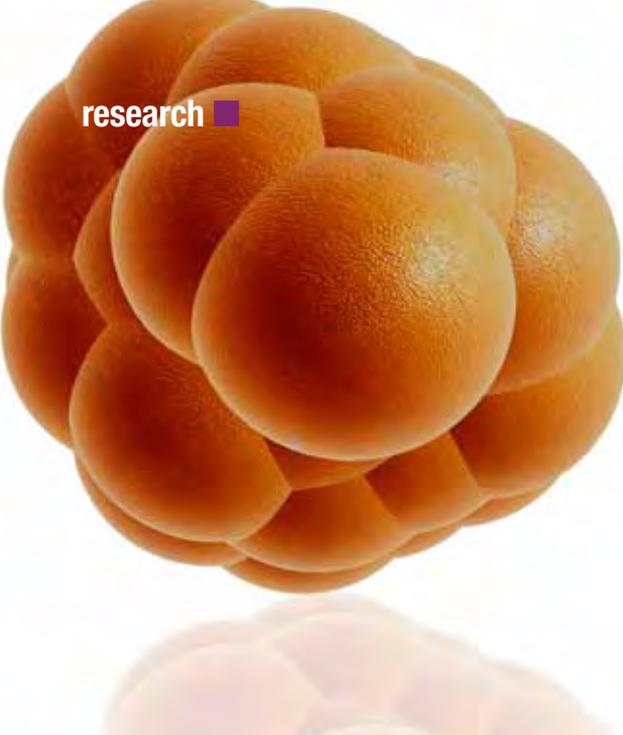
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Stem Cell Research

US biotech company Neuralstem is attempting to restore some legitimacy to SCI-specific stem cell research.

SCI stem cell research hit a low note last year, when California-based biotech company Geron abandoned its stem cell human clinical trial research. In a world rife with highly questionable, unscientific and even fraudulent stem cell research and therapy schemes, Geron's research was seen as a rare example of stem cell research that was legitimate, due in large part to the fact that it had met rigorous standards imposed by the US Food and Drug Administration.

Attempting to fill the void is Rockville, Maryland biotech company Neuralstem. On January 14th, Neuralstem announced that it had been granted FDA approval to test its NSI-566 neural stem cells in people with chronic SCI.

The study will enrol up to eight people with complete paraplegia (T2-T12) who have had their injuries for between one and two years. All participants will receive six injections of neural stem cells in or around their injury site. The first four patients will receive 100,000 cells per injection, and the second four patients will receive 200,000 cells per injection. After the procedure, all patients will also receive physical therapy and immunosuppressive therapy, a technique to prevent rejection of the transplanted cells. Each participant will be carefully monitored for six months.

Ultimately, it's hoped that the transplanted stem cells will grow into neurons within the spinal cord, where they will thrive and help restore communication across the injury site.

But the primary goal of this study is not to see if the therapy works. Instead, it's to determine the safety of the procedure. Other goals are to evaluate the survival rate of the transplanted cells, evaluate the tolerance and effectiveness of transient immunosuppression to help boost the survival rate, and explore methods of measuring the efficacy, or effectiveness, of the procedure—methods that could then be used in future phases, provided safety is proven in the first phase.

The study is scheduled to begin this summer in a number of US centres, which haven't yet been announced.

The FDA's clearance appears to be based on several factors. First, Neuralstem has proven it can consistently create high quality neural stem cells. These stem cells all continue to be replicated from neural stem cells that were harvested from brain and spinal cord tissue of a seven to eight-week-old, legally-aborted foetus that was donated more than a decade ago. The age appears to be critical—at seven to eight weeks old, the stem cells have all the information they need to become

neurons, yet they can still be easily divided. Over the ten years that's elapsed since the original donation, Neuralstem Chief Scientific Officer Dr. Karl Johe has developed and patented techniques for extracting, multiplying and transplanting these cells.

Second, the company's stem cells appear to work in an animal model of SCI—albeit a very specific one. Last August, in the peer-reviewed journal *Cell*, independent researchers provided compelling evidence that Neuralstem's cells can “bridge the gap” and return function in rats with transected (severed) spinal cords. The transplanted neural stem cells turned into neurons that, in turn, grew multiple axons which extended above and below the injury site. The rats then regained movement in all lower extremity joints.

Third, the company's stem cells have already been tested in humans—last year, Neuralstem conducted an FDA-approved Phase I trial in 18 people with ALS, or amyotrophic lateral sclerosis, with the same stem cells being injected into the spinal cords of participants. The results demonstrated safety, which, like the upcoming SCI trial, was the primary goal. But several of the study's participants seem to have shown signs that the disease

is no longer progressing. It's vitally important to keep in mind that the study's lead investigator, University of Michigan neurologist Eva Feldman, says it's too early to know if the result from such small number of patients is meaningful.

Finally, Neuralstem's approach of using the exact same cells and procedures for multiple conditions might be comforting for FDA regulators. This approach would seem to allow for a layering of results and knowledge—and applying the net knowledge to different conditions as the company moves forward. This year, in addition to ALS and chronic SCI, Neuralstem has plans for human clinical trials with the same neural stem cells in acute SCI and paralysis from stroke.

"This is another critical milestone for the company," said Richard Garr, President and CEO of Neuralstem, which trades publicly on the American Stock Exchange. "We believe the FDA approval of a trial for a second indication for our NSI-566 cells demonstrates an increasing level of comfort at the FDA with our technology and acknowledges the positive strides being made in the ALS trial."

But there are scientists in the field who are concerned that the trial is premature. That includes two prominent SCI experts here in BC—Dr. Brian Kwon, a VGH spine surgeon and ICORD neuroscientist; and Dr. Wolfram Tetzlaff, a UBC professor and ICORD researcher who specializes in neuronal reconnection after SCI.

Kwon and Tetzlaff's primary concern is that pre-clinical testing of Neuralstem's cells in animal models was limited to transected (surgically severed) rat spinal cords. "Further testing to demonstrate the efficacy of the cells in contusion/compression models and models of chronic SCI would be desirable," says Kwon, "since that is the type of injury that will be studied in the human clinical trial."

Tetzlaff agrees. "There are no rat data—or any animal data—in support

of success (of Neuralstem cells) in a chronic model and, as Brian pointed out, none in a contusion model either. What's more troublesome is that the (Neuralstem rat) study stated that only with a cocktail of 11 factors and fibrin did they see survival of the cells after the transplant—and they are only now pinpointing which factors are needed. So transplanting just the cells will very likely not succeed."

Many people with SCI are understandably fatigued by stem cell hype and jaded by the confusing myriad of unethical, pseudoscientific and even criminally fraudulent stem cell projects and therapies that abound in less regulated, less developed parts of the world (see "Risky Business" in the Spring 2012 issue of *The Spin*). So why should people with SCI care about Neuralstem and its work with neural stem cells?

To start with, there is chance that

the company's research may, in time, lead to a safe and effective therapy. But what's perhaps more important, at least in the short term, is that the company's work, and its endorsement by the FDA, signals that this promising research avenue is again being investigated in a way that is far more legitimate and ethical than what's taking place in other areas around the world.

"It's far too early to make any conclusions about the effect that NeuralStem's trial will have on re-establishing credibility and legitimacy to SCI-specific stem cell efforts," says Kwon. "But a FDA-regulated trial is welcomed in the field in terms of it at least providing us with valid information about whether the cells have any effect—positive, negative, or neutral."

As always, we'll report any developments—positive or negative—in future issues of *The Spin*. ■

SCI BC Staff Member Awarded Diamond Jubilee Medal

Pat Harris, Spinal Cord Injury BC's Information Service Manager, was one of 70 Olympic and Paralympic athletes, coaches and builders who were awarded Queen Elizabeth II Diamond Jubilee medals in Vancouver and Ottawa on January 25th.

The medals are being distributed to celebrate Queen Elizabeth II's 60-year reign, and provide an opportunity to honour exceptional Canadians for their contributions to their fellow citizens, communities and country.

Pat was nominated by BC Wheelchair Sports Association (BCWSA) in recognition of his many years of service as an athlete, a volunteer, a coach and a leader. In addition to his long career with SCI BC, Harris has been a member of the BCWSA Board of Directors for 18 years, serving as President for the past 12 years.

"For the past 30 years, Pat has dedicated himself to helping people with disabilities in Northern BC to lead active, healthy lives," says BCWSA Executive Director Gail Hamamoto. "We're so pleased that his dedication has been recognized."

When Pat moved to Prince George with his wife Nancy in 1980, he began laying the foundations for wheelchair sports and accessible infrastructure in Northern BC.

In the mid 1980's he founded the Prince George Titans wheelchair basketball program. Since then, he has tirelessly created awareness of sport for people with disabilities, and nurtured countless new athletes, many of whom have gone on to high levels of competitions.

Congratulations from all of your coworkers and colleagues at Spinal Cord Injury BC, Pat.

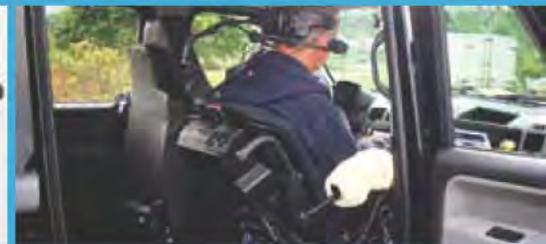


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Back in the Saddle

“There’s nothing so good for the inside of a man as the outside of a horse,” once said Ronald Reagan. SCI BC peers Lynn Turner and Terry Forster wholeheartedly agree.



Lynn Turner and Terry Forster live in different corners of the province, and while they’ve never met, they have a lot in common—they’re both quadriplegics who have rediscovered a long-lost passion for horses, albeit in two different ways.

When Turner was a young girl, she knew the value of one hour on a horse. It cost her exactly six hours of babysitting, but it was worth it.

By her mid-thirties, Turner didn’t have to save up loose change to go riding anymore. She had her own horse, an Arabian Welsh pony-cross named Feathers. Coasting on his flanks, she rode the trails of the East

Kootenays whenever she had the chance, soaking in the amazing scenery.

Then, in her early 40’s, a motorcycle accident turned her life around. It would take a decade before she rode again.

“I knew it was possible, but the further you move away from the hub of most injured people, the further away you are from all that equipment, from all those opportunities,” says Turner, who lives in Quesnel.

Then, last summer, Turner saw a poster for the Cariboo Hoofbeat Assisted Activity Program Society (CHAAPS), a non-profit organization focused on animal-

assisted therapy. CHAAPS had never worked with anyone with quadriplegia before, but after a few emails, they invited Turner to Pen-Y-Bryn Farm to plot a strategy to get her back in the saddle.

It took a couple visits and a homemade wooden horse, hand-crafted by Paul Nichols, the co-owner of the farm, for Turner to comfortably and safely mount the saddle. But by September, she was back on a horse.

"It was the most amazing thing in my life," she says. "I was now planning absolutely everything around my riding lesson."

At first, Turner was accompanied by volunteers on either side of her horse while she rode, but after four or five lessons, she was riding on her own.

"It opened my horizons—it made me think that someday I might not just be in the arena, I might be back on a trail," says Turner. "I was just overwhelmed by the size of the gift these people were giving me."

For Turner, the benefits of getting back in the saddle have been plentiful. "It helps you with all sorts of things, emotional and physical. It helps with spasticity. Physically, it's helped me with my balance, and emotionally, it helps me through the connection I get with the animal. The feeling of, 'he's so big and strong', and suddenly I'm not so small and weak in a chair anymore. I'm tall. I'm moving without having to wheel somewhere. It's a different perspective."

Turner had to stop riding in October after the first snowfall, but knowing that she'll be riding again in the spring has helped her get through a tough Quesnel winter. "It got me back into the gym to get in shape so I could do this," she says. "It was my carrot."

Turner encourages others to seek out riding opportunities in their hometown, and says if you live near Quesnel, it's worth giving CHAAPS a call. "They're really trying to expand

their program. I think these people are just amazing and the gifts they give to people, they're so healing."

Unlike Turner, Forster found his love for riding later in life. He was already 56 years old when he discovered horses during a charity event. One ride was all it took for Forster and his wife Gale to quit sailing and devote themselves to learning everything they could about horses.

They found a ranch in Merritt owned by "a horse whisperer kind of guy" who agreed to share his wisdom in exchange for their time. Undeterred by the commute from their home in Delta, they volunteered on weekends through the winter and as much as possible in the summer. They also volunteered at another dude ranch in Langley. "It was a total commitment," says Forster. "We were hooked. Our friends thought we were crazy, but I was always happy to be in a barn somewhere, to be outside."

Then, in 2000, a horse threw Forster over the fence from the ring and onto the concrete. For a few years following his rehabilitation, riding was

Facing page: Lynn Turner gets a helping hand from CHAAPS volunteers before enjoying a turn around the corral. Below: Terry Forster aboard a fully accessible carriage.



the furthest thing from his mind. But eventually, he started returning to some of the barns he used to know. "It wasn't the same, not being able to be involved," says Forster. "I felt like a flower pot, watching."

A couple of years ago, Forster was browsing online and discovered carriage driving. As he learned more, he found that, while carriage driving was a well-established sport for both able-bodied and disabled people across the United States and Europe, it was only just gaining interest in Canada. He was disappointed to learn that there were no accessible carriage driving opportunities in British Columbia—yet.

That's when Forster made a chance connection with Simon Roseman and Marceau LaRose, two well-known Canadian carriage drivers who had recently joined the Professional Association for Therapeutic Programs (PATH). Roseman and LaRose had a horse and a wheelchair accessible cart—they just needed a student. And

then Forster called. When the trio met, they had instant chemistry.

"The coaches are just fantastic," says Forster.

Still, the search wasn't over. Now they needed somewhere to practice. After cold-calling therapeutic ranches all over the Lower Mainland, Forster finally found a ranch that was willing to give accessible carriage driving a shot—the Valley Therapeutic Equestrian Association (VTEA), in Langley.

The entire process, from discovering carriage driving online to the day he succeeded in making it all happen, took Forster two years to accomplish.

"When we finally did my first ride in the ring, there were a couple tears," says Forster. "I had a lot of trouble in the first several lessons, getting the setup right so I could keep my body up. We're still going through adjustments."

While it's been a tough trail, Forster says it's been more than worth it. "The first time I went outside (of the ring) and on these trails, there was

that sense of freedom, and I never ever thought I would have that feeling again, so it's pretty powerful. I don't have my legs to communicate with the horse, but I can use my arms, my hands and my voice. I think when you achieve that level of communication, that's the magic moment."

Despite the magic, Forster's dream is only half-complete. He won't rest until the sport of accessible carriage driving gains popularity in BC. "Now we just need drivers," he says. "It's a challenge, but anybody can learn. You can even compete with able-bodied people if you're good enough. There's absolutely no difference between the two."

If you're interested in learning more about accessible carriage driving, Forster would love to hear from you—email him at horsecart@eastlink.ca. You can also visit www.vtea.ca or call 604.857.1267 to schedule a session. To learn more about CHAAPS, visit www.chaaps.ca call 250.747.2416, or email chaaps2@gmail.com. ■

TRAVEL ACCESSIBLE BC: STRATHCONA PROVINCIAL PARK

If you're planning on being one of the hundreds of thousands of tourists that visit Vancouver Island this year, consider a visit to Strathcona Provincial Park, located just a short drive from Comox and Courtenay, and about three hours north of Victoria.

Designated in 1911, the park is the oldest in BC. It's a rugged mountain wilderness comprising more than 2,500 square kilometres of mountains, lakes, streams and alpine tarns. If all of this sounds slightly inaccessible, take heart—the recently-completed barrier-free Centennial Trail loop provides access for all to the park's Paradise Meadows sub-alpine area.

The two-kilometre loop makes use of hard compacted gravel sections and well-constructed boardwalk sections in order to offer all visitors who use wheelchairs and other mobility devices the opportunity to take in the beauty of this unspoiled area. A visit in late summer or early fall is particularly rewarding, when you'll see a splendid display of mountain heather and other sub-alpine flowering plants, and perhaps have a close-up encounter with one of the countless critters that make the area home, including whiskey jacks and the occasional black bear.

The Strathcona Park Wilderness Centre, located at the trail-head, is fully wheelchair accessible. More information is easily found online.

The Strathcona Provincial Park Centennial Trail is just one of 40-plus accessible Vancouver Island travel destinations listed in the 2013 Vancouver Island Travel Planner, published by the Accessible Wilderness Society, based in Campbell River. The travel planner also lists accessible accommodations and other accessible businesses, including gas stations that offer full service, located on Vancouver Island. Once published in May, you'll be able to find the travel planner at any BC Tourist Information Centres. You can also visit www.awsociety.org for more information.





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beating the bladder blues

Like many other SCI BC peers, Paralympic hopeful Caleb Brousseau is hoping Botox can improve his bladder program and quality of life.

When Caleb Brousseau was injured in 2007, he barely paused before jumping back into the great outdoors.

Brousseau compressed his spine at L1 while landing a big air back flip at Shames Mountain, just outside of Terrace where he grew up. Soon after discharge from rehab, he discovered that the incomplete injury he sustained was low enough to leave him with more than enough trunk strength to take up whitewater kayaking—a sport in which he quickly excelled. And when he finally got back on the slopes in 2009, it was immediately apparent that competitive sit-skiing was another natural fit. He steadily climbed the ranks of Canada's Paralympic alpine program, and last year, he made the national world cup B-team. In his first full season with the team, he recorded two top ten finishes at IPC World Cup events. Little wonder that he's regarded as one of the team's stars of the future and a strong contender to make the Canadian team for the 2014 Sochi Paralympics.

Mastering a bladder program, however, has been much more of a challenge for Brousseau, who is now 24.

"Ever since my injury, I've struggled with having to cath," he says. "I really didn't like the thought of it. The doctors warned me I should use intermittent catheters, but I would still have to wear a condom catheter anyway because of leaking. So I didn't cath often, and when I did I got sick—I didn't know how to cath cleanly because it had been a while since I was shown."

In 2011, Brousseau got the mother of all UTIs. "It was at that point that I'd had enough," he says. "I needed to do something about it, so I learned how to cath cleanly and started to look into fixing the problem. I tried to go without a condom catheter for a while, but then found that when I did, I would still have random leaks. I expected leaks if I let my bladder get too full, but I could just be sitting around five minutes after using a catheter and have a leak of 50 mils come out. So I would go cath and only end up with another 100 mils. It

became clear that, if I wanted to go without a condom, I would have to cath at least upwards of ten times a day. And that just didn't work for me."

Brousseau spoke with the team doctor, who referred him to urologist Dr. Mark Nigro in Vancouver. After a thorough assessment, Nigro concluded that Brousseau was a good candidate for Botox—the trade name given to botulinum toxin type A by the company behind it, Allergan. Botox is a powerful, bacteria-produced neurotoxin which, when injected into the smooth muscle of the bladder, results in relaxation of the bladder, an increase in bladder capacity, and prevention of neurogenic detrusor overactivity, or NDO.

NDO is the spasming that inappropriately contracts the urethral sphincter and leads to the type of leaks that Brousseau and countless others with SCI experience every day.

Brousseau is due to have the procedure on March 15th, just as this issue of *The Spin* is scheduled to be on the printing press. "If everything goes as planned, I'll be able to sleep through the night free of a condom and soiled sheets, be able to ski without a leg bag, and paddle where I want and pull over when I need and have a pee break like everyone else I paddle with," he says.

In theory, the quality of life boost he'll experience will be in addition to long-term health benefits. If he responds well to the treatment and remains diligent about his cathing program, he'll be at much lower risk of UTIs and even bladder cancer, mainly due to lower cathing frequency throughout the day. And research also indicates that, since Botox reduces high bladder pressure resulting from NDO, it will provide some protection against damage to his upper urinary tract and renal system.

We first told readers about Botox in the Autumn 2011 issue of *The Spin*. At that time, Allergan had recently completed worldwide clinical trials that provided solid evidence that Botox was both safe and effective for treating NDO in some people with SCI and MS. It had already been successfully used for muscle spasms, migraine headaches, upper motor neuron syndrome, and, of course, cosmetic procedures. So it wasn't surprising that the American Food and Drug Administration (FDA) approved Botox for use in neurogenic bladder resulting from SCI and MS on August 24, 2011.

Four months later, Health Canada followed suit, approving Botox for the treatment of Neurogenic Detrusor Overactivity resulting from SCI and MS.

Ever since, there's been growing interest in the treatment by both urologists and patients, according to

Wendy Cox: Positive Outcomes

In the summer issue of *The Spin*, we're going to ask Caleb Brousseau to tell us about the results of his Botox treatment, which he's scheduled to receive on March 15. Meanwhile, we asked another SCI BC peer to share her Botox experiences with readers.

Wendy Cox, a 37-year-old who makes her home in Victoria, has an incomplete injury at C5,6,7. A few years ago, she heard about Allergan's study, which had included Victoria as one of its international sites.

"My bladder controls my life," says Cox. "It can hold only a small capacity and the sphincter is weak so I can't 'hold' it very long. I wouldn't go kayaking, camping, on long drives, or do any activities that weren't within minutes of an accessible bathroom. Botox sounded wonderful! Fortunately, I fit the criteria."

Cox describes the procedure as "only slightly uncomfortable." The study included a placebo, so she couldn't be absolutely positive she'd actually received Botox. But she was pretty sure she did. She experienced upper body weakness, which was one of the side effects. After two or three weeks, she had less incontinence and her bladder capacity had almost doubled.

"This had a huge, positive impact on my life," says Cox. "I could be away from an accessible bathroom for several hours without worry. I started doing things I had never done, like kayaking and camping. I could enjoy a wine while out to dinner. I could eat at restaurants that didn't have an accessible bathroom! Honestly, it was such a big life change. I hadn't realized how

much my bladder was holding me back. My quality of life improved, I was more active—which created a healthier me—and incredibly happy. Not only did it improve my leisure life but it improved my work life. I was able to put in more time actually working than being in the bathroom. There weren't any trips home during the work day to clean up and change. And I could go on those work trips that I wasn't able to before."

Cox concedes that she found the upper body weakness concerning—she had difficulty steering her van and wheeling up slopes. That wasn't enough, however, to discourage her. "It lasted a few weeks but it was worth it—so much so that I had the opportunity to get more injections and I jumped at the chance."

Despite the fact that it's been a few years since her last treatment, Cox says her bladder is still better than it was before the Botox injections. If BC PharmaCare decides to provide coverage, Cox will seek additional treatments.

"I do wholeheartedly endorse this treatment for those with incontinence issues," she concludes.

Cox's experience with Botox is no doubt a best-case scenario, and not all people with SCI who receive the treatment will experience the same dramatic benefits.



Dr. Daniel Rapoport, a urologist at Richmond Hospital and clinical instructor with the UBC Department of Urologic Sciences.

"It's a little difficult to know exactly how many patients have received Botox treatment for NDO both in Canada and BC," says Rapoport, who has provided many Botox treatments. "However, according to Allergan, between 150 to 200 injections for NDO have been provided in BC, which would be approximately 130 to 150 patients. Allergan also tells me that 17 urologists throughout the province are providing Botox, and that figure will increase in 2013."

Rapoport adds that Allergan is currently creating a referral list for physiatrists and rehab physicians so they'll know which urologists provide Botox.

As for the procedure itself, injections into the bladder sounds complicated. But the process is generally quite simple and routine, according to Rapoport.

"The procedure can be done under local anesthetic in the cystoscopy clinic or, if needed, in the operating room with sedation," he explains. "The injections are given through a long needle that runs inside a cystoscope, a special instrument that a urologist uses to see inside the patient's bladder. The patient will be given either a general or a local anesthetic depending upon where the procedure is being done. The Botox is administered across numerous sites in the bladder and the procedure takes approximately fifteen minutes."

He explains that, while some patients may feel some slight discomfort, the procedure is not usually painful. "The procedure is typically very quick and painless. And on follow up, we find it has a good rate of effectiveness." We've included the experiences of one SCI BC peer on the previous page.

If you're reading this and wondering if Botox could be beneficial for you,



here are some other things you should know about the treatment.

First, efficacy— to what degree does Botox work? Without getting into the details (which you can easily find yourself online), there's

been a significant amount of highly credible research delving into this question. One of the first studies, published in 2011 in the journal *European Urology*, concluded in this way: "(Botox) significantly reduced incontinence and improved urodynamic parameters (for example, bladder capacity) and (quality of life) in patients with (urinary incontinence) secondary to NDO." In plain speak, Botox helped study participants hold more urine longer without leakage, while reducing bladder pressure levels at the same time. Subsequent studies, including a study published in January that analyzed the long-term safety and effectiveness in people who have had up to five treatments of Botox, confirmed the *European Urology* study. But it's important to note that not everyone experiences the same benefits, and that Botox effects are not permanent—in ideal candidates, the benefits last between eight to ten months, although some people have experienced longer-lasting effects.

Second, there's the question of who is eligible. The main criteria for treatment is that you are able to perform clean intermittent cathetering. There's no benefit for anyone using an indwelling catheter. As well, you must have tried using antimuscarinic therapy (anticholinergic drugs) to rule out the potential of receiving the same benefit without using an invasive procedure.

Third, there are potential side-effects—UTIs from the procedure, insomnia, constipation, increased spasming, painful urination, sweat-

ing and upper body weakness are all possibilities. But studies alluded to above, including the long-term study, demonstrated that any side effects are generally short-lived and that Botox is typically well-tolerated.

Finally, there's the matter of who pays? It's a great question, considering that the cost of a single treatment is about \$700. Across Canada, several provinces are already footing the bill: Alberta has both hospital formulary coverage as well as provincial coverage; Saskatchewan has special authority provincial coverage; and Ontario has just granted limited use formulary status for Botox for NDO.

"In BC, the submission for coverage with Pharmacare has taken place and is currently being reviewed," says Rapoport. "My understanding is that the Pharmacare application is in the final review stages and we are very optimistic it will be approved for NDO use of Botox. We're expecting an answer very soon. Meanwhile, in some Health Authorities, Botox is covered on hospital formulary and is therefore provided to patients free of charge. And third party coverage is provided by almost all private insurance companies. For now, however, without private coverage or hospital coverage, the cost would be paid by the patient."

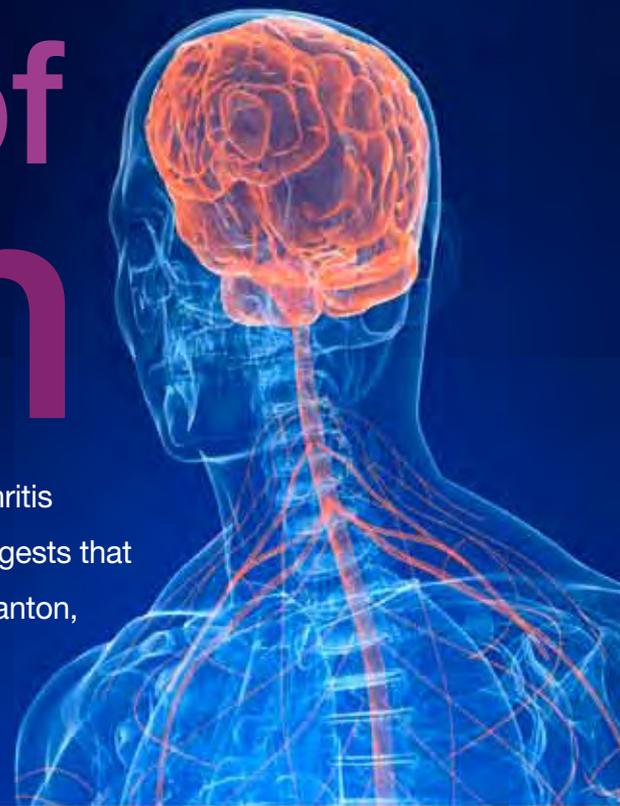
Given the quality of life and long-term health benefits experienced by Botox patients, SCI BC is optimistic that BC Health will make a positive decision about coverage in the near future.

"Studies from the US show that the cost of treating a single catheter-related UTI is almost \$3,000," says Chris McBride, SCI BC Executive Director. "We believe Botox treatment for NDO will, over the long term, provide not only a tremendous quality of life boost to many of our members, but also a substantial cost savings to our provincial health care system."

For more information about Botox treatment for NDO, please ask your family physician for a referral to a participating urologist. ■

the power of illusion

Recently, British researchers stumbled upon a way to reduce arthritis pain through video illusions, adding to existing evidence that suggests that the key to relieving chronic pain resides in the brain. Dr. Tasha Stanton, a Canadian researcher in Australia, believes the discovery could someday play a role in relieving SCI neuropathic pain.



At SCI BC, we try to feature pain research in The Spin for two reasons. First, pain is a top issue for people with SCI, and in a world that often seems to be obsessed with “cure” research, we believe it’s important to generate more support for SCI pain research and the researchers involved in it. Second, we believe we have an obligation to keep our readers—many of whom suffer greatly from neuropathic pain—informed of any new developments in the field of pain management. This story provides an overview of fascinating research, but we want to make this disclaimer: it’s not going to lead to any type of treatment or breakthrough in the short term. We do, however, believe the longer term implications are important.

Many of mankind’s greatest scientific and medical discoveries have come via a combination of chance and astute observation. Of these, the discovery of antibiotics stands out. In 1928, Scottish physician and researcher Alexander Fleming left a culture plate smeared with *Staphylococcus* bacteria on his University of London lab bench and went on vacation for two weeks. When he returned, he discovered that the bacteria’s growth had been stopped dead in its tracks by the arrival of a fungus. The fungus was penicillin, and it and other antibiotics have been saving lives ever since.

Recently, another case of scientific serendipity in jolly old England has changed the way many researchers

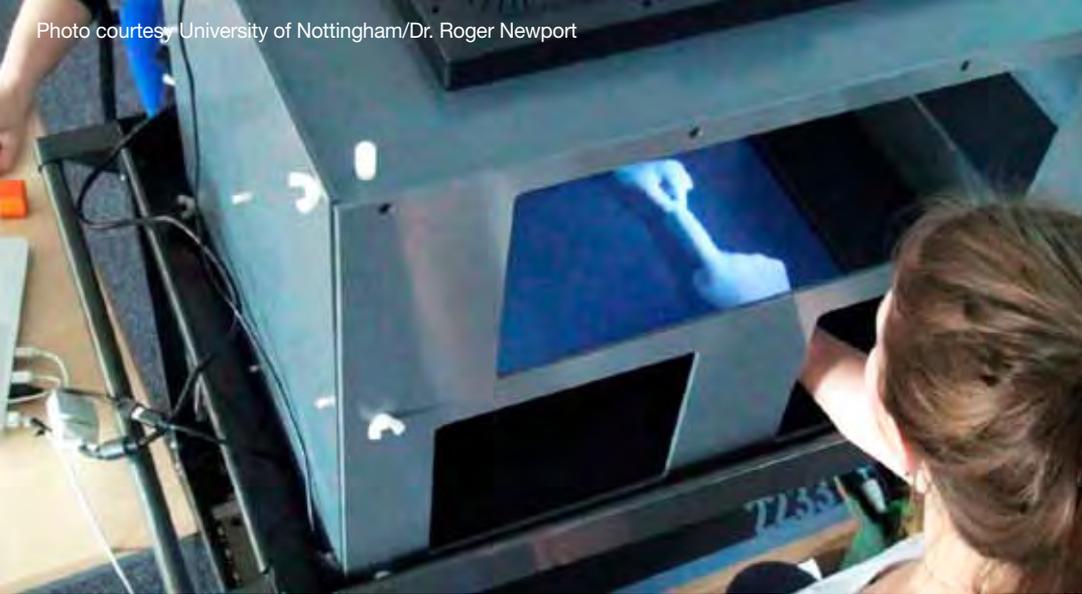
are thinking about chronic pain—pain that is persistent for long periods of time. The discovery revolves around a device called the MIRAGE—a kind of virtual reality box that uses a system of cameras and mirrors that the subject inserts their hand into. When the subject looks down to see their hand, they see a real-time video image of their hand reflected in a mirror. This video image appears to be in the same location as their actual hand, which is hidden below the mirror.

The video image can then be distorted—for example, the fingers can appear to be stretching or shrinking. At the exact same time as the distortion takes place, an assistant sitting on the opposite side of the device applies a gentle pull or push to the subject’s fingers from within the box. The result is a combination of tactile and visual stimuli that can be extremely convincing for the subject.

This powerful bit of multi-sensory trickery was originally developed by Dr. Roger Newport of the Nottingham University’s School of Psychology. He believed the device would help him study the way our brains put together what we see and feel happening to our bodies.

In 2010, during an open house at the university, researchers were busy demonstrating the device to some school children. A grandmother of one of the students wanted to try the device. But she cautioned the staff to be gentle, explaining that she had painful osteoarthritis in her fingers.

During the demonstration, the woman stunned



the researchers with a simple pronouncement. “My finger doesn’t hurt anymore,” she said. And she asked whether she could take the machine home with her.

The researchers flew into action to find out if the result could be replicated. They recruited 20 volunteers, all around the age of 70, and all with osteoarthritis and arthritic hand pain.

The results were striking: 85% of

the participants reported immediate and significant reduction of their pain, and almost a third reported that their pain had completely disappeared. The researchers also determined that the illusion only worked when the painful part of the hands was being manipulated. And follow-up suggested that, at least for a small number, the effect had some staying power—some reported still feeling less pain as they were leav-

ing, and one even reported feeling less pain weeks later.

Since that time, the researchers have been developing more rigorous experiments with MIRAGE that will help them rule out placebo effect or other causes beyond what they’re really hoping is happening—that the brain can be influenced to turn pain off, or not turn it on at all in the first place. Along the way, they’ve generated quite a buzz worldwide, with many researchers seeking to play a complementary role and contribute to this new and emerging

body of knowledge.

Among them is a transplanted Albertan who now lives and works in Australia—Dr. Tasha Stanton. Stanton is a Canadian Institutes of Health Research Postdoctoral Fellow who investigates pain neuroscience at both the University of South Australia in Adelaide and Neuroscience Research Australia in Sydney.

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Once Stanton completed her PhD, she focused her research interests on the neuroscience behind chronic pain—how the brain processes painful stimuli and decides something is painful, and other factors that influence pain. In fact, much of her postdoc research focused on the use of illusions to evaluate the brain's role in pain, as well as the use of illusions as a targeted treatment for chronic pain. So when her supervisor, Professor Lorimer Moseley, saw Newport demonstrating the MIRAGE at a conference in 2011, he saw a perfect opportunity for collaboration, with Stanton taking the lead in Australia.

Neuroscience Research Australia completed the purchase of a MIRAGE, and in January, 2012, Stanton flew to England to train with Newport on the device. When she returned, she brought the new MIRAGE home, so that she and her colleagues would have hands-on access to the device and begin actively collaborating with Newport and his team in England.

There are many aspects to the work—confirming through more rigorous tests the results that have already been witnessed, and learning about how illusions can influence reactions in the body that we can't consciously control—for example, temperature, which is relevant because people with certain types of chronic pain have impaired temperature control of the painful body part. Stanton is enthusiastic about all of this work, but she hopes that MIRAGE ultimately brings the field closer to understanding how illusions reduce chronic pain.

"In order to talk about how we might think illusions work, we have to talk about why chronic pain occurs," says Stanton. "There are two main 'brain' theories regarding why people have chronic pain. The first relates to a problem with our brain getting faulty information. With this theory, when different parts of the brain talk to each other, one part has faulty information and one has correct information. And

this mismatch is thought to cause pain."

The mismatch, says Stanton, may be related to faulty 'maps' in the brain.

"Your brain has a map, or representation, of your entire body—this is how we know where we're being touched," she explains. "In people with chronic pain, these maps are altered. We're not sure why—it may be from not moving the body part very much or other more complex reasons that involve our immune system. The problem—and the pain—is thought to occur when we move. If you want to move your hand, the area of your brain that controls movement activates, and then you actually move your hand. Importantly, the movement centre makes a copy of that movement command and sends it to another area of the brain, just to say, 'Hey, this is what we just did, so this is where you should expect our hand to be.' However, if the movement command centre based its information on the faulty brain maps, then where you expect your hand to be is not where



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it actually is. It's thought that this incongruence may cause pain."

She adds that illusions may work by temporarily 're-setting' those faulty brain maps so that, suddenly, where you expect your hand to be is where it actually is. "Many people with osteoarthritis respond best to the illusion where the fingers or hand are stretched and then appear longer than normal," she says. "Preliminary work suggests that many people with osteoarthritis seem to perceive their hand as smaller than it actually is, suggesting that their brain maps for that hand are altered. Thus the stretching illusion may work by temporarily 're-sizing' the brain map for the hand."

The second theory, says Stanton, relates to how our brain analyses incoming information. "The brain's role is to interpret all the incoming information about a specific body part or area, and then make a decision on whether or not this information warrants a pain response in order to deflect further damage—real or perceived—to that body part. In other words, our brain evaluates how much threat something poses to us. In the case of chronic pain, we believe the brain is wrongly assigning increased threat value to incoming information."

In this theory, brain maps are again involved. "The maps help us localize where information is coming from on our skin. However, to be able to move around in the world, our brain also has to know where our body part is in space, in relation to our body. In order to do this, our brain has to combine the information coming from our skin with information about the space surrounding the body. This is a complex process. Perhaps illusions work by giving us visual information that is different from the actual information coming from our hand. For example, in the MIRAGE, our eyes tell us our fingers are being stretched, but our fingers are telling us they haven't. It's possible that this conflicting information is difficult to process and reduces

our brain's ability to produce pain. Or because our vision is giving us 'faulty' information about our hand, perhaps our brain disregards all the incoming information from the hand because it can't be trusted, and thus the threat value is reduced, and pain is also reduced. Yet another possibility is that illusions may work because we may 'disown' the body part involved—the vision doesn't match how our hand feels, so it must not be ours, so let's ignore incoming information from it."

Stanton concedes that illusions may also just work via distraction—we're paying less attention to the painful body part and so pain decreases.

"However," she says, "if this is the case, we would expect an illusion to decrease pain in a painful hand even if we did the illusion on a non-painful body part. We don't see this in our experiments."

Regardless of which theory proves to be correct, Stanton and her colleagues believe that control of chronic pain lies in the brain, as do many other scientists. "The difference is that our aim is to target pain via rehabilitation strategies instead of pharmacological strategies," says Stanton. "The brain's role is to interpret incoming information and, at the end of the day, decide whether or not this information should be painful. Thus, if we can target this faulty analysis of incoming information—which one would argue is present in people with chronic pain—then we may be able to influence pain levels."

She adds that it's important to remember that targeting the brain isn't about improving the pain sufferer's willpower or ability to bear the pain better. "Rather, it's about treating an improperly working nervous system," she says. "One might argue that instead of trying to get the brain to turn pain off,

we're trying to avoid having the brain inappropriately switching pain on."

So where does SCI come into the picture? Stanton and her colleagues believe that SCI neuropathic pain at or below the level of injury appears to be an ideal model of chronic pain to study with illusion-based research techniques.

"I think because SCI pain is so resistant to various forms of treatment, both drugs and invasive surgeries, it makes good sense to follow up avenues that aim to determine the role of the brain in maintaining and potentially generating pain," she says. "And I think this is where the MIRAGE and illusions in general fit perfectly, since there is altered sensory information going to the brain for the body parts below the level of the lesion, which then likely results in altered brain maps of the body."

There's another reason why SCI neuropathic pain could become a targeted area of study: there's already been some success testing the power of illusions for pain relief in people with SCI. That work was done in 2006 by none other than Professor Lorimer Mosely, Stanton's supervisor.

Mosely's experiment created the illusion of walking for five people with paraplegia. The participants sat with their lower bodies concealed, facing a mirror stacked on top of a projector screen. The mirror reflected the participant's upper body and head, while a perfectly-aligned image of legs walking was projected onto the screen below.

One participant withdrew from the study just 45 seconds into the test—the illusion was emotionally overpowering.

Dr. Tasha Stanton



But for the four remaining participants, the results were quite dramatic. It was found that ten minutes of watching this illusion decreased pain intensity and duration compared to performing control activities—watching a funny comedy movie and performing guided imagery of an enjoyable, painless activity. Furthermore, repetition appeared to improve results. After 15 days of ten minute training sessions, pain intensity levels decreased by 50%, duration of pain relief significantly increased (up to two hours in one participant), and the total area of pain also decreased.

When he published his work, Mosely conceded that there were many variables and possible explanations for the pain-relieving effect. But he also felt that the results warranted further investigation. Stanton agrees, adding that the MIRAGE could play a role.

“In the MIRAGE’s current form, an

SCI study wouldn’t be possible given the size of the device. But there are some adaptations that we can make that will allow us to apply similar type illusions without needing to use the whole MIRAGE equipment set-up. However, we don’t have any direct plans to follow this up in SCI yet. The priority is more preliminary work to try to understand how the MIRAGE might actually work to decrease pain—for example, using electroencephalography to measure brain activity during the illusion.”

But she adds that any MIRAGE research has the potential to ultimately benefit every person with chronic pain, regardless of the source. In the short term, it could lead to confirmation of the brain’s role in controlling chronic pain, which could prompt more funding and more research about how it does that. In the longer term, all of this could lead to discovering how chronic pain for

many conditions can be switched off in the brain, and ultimately, development of a therapy or therapeutic device based on the MIRAGE could be developed for SCI and other causes.

“Even without the addition of the MIRAGE to SCI research, illusions have provided us with a unique opportunity to understand and evaluate how the brain can influence pain,” says Stanton. “We’re in the early stages of understanding exactly how the brain does this, and in the next decade or so, I have high hopes that we will make great strides forward with this knowledge.”

On a personal note, Stanton says her work down under is incredibly gratifying. “To target pain in a body part without really doing anything to that body part itself is just plain cool,” she says. “And it opens the door for so many treatment possibilities if we can understand why this happens!” ■

ask the SPIN DOCTOR

Welcome to the first regular instalment of The Spin Doctor. In each issue, we’ll ask one of our BC-based SCI medical experts to address our peers’ most pressing medical issues. Our first instalment is provided by Dr. Rhonda Willms, Medical Manager of the Spinal Cord Injury Program at GF Strong Rehabilitation Centre in Vancouver.



Many people with SCI are prescribed spasticity medication, and it’s important for these individuals to have a clear understanding of how to manage this medication for maximum benefit and safety. Here are some tips on managing your spasticity medication.

Baclofen, the most common spasticity medication, is metabolized (broken down) by your liver, and in some individuals it can be irritating to the liver. Talk to your family physician about having your liver enzymes and liver function periodically checked by a blood test. Typically, this would be done two to three times per year.

The “half-life” of any medication is the time that it takes your body to metabolize half of the dose that you have taken. If you take your medications in such a way that all of the medicine is out of your system before you take the next dose, your blood levels of the medication are on a bit of a roller coaster. Taking your medications as directed will help to keep the blood levels

more even, which will hopefully allow you to have more consistent symptom control. For example, the half-life of baclofen is about four hours, which is why it is typically prescribed to be taken three or four times per day.

Tizanidine (Xanax) is another medication used to manage spasticity. It has a drug interaction with another commonly prescribed antibiotic called ciprofloxacin (Cipro). These medications should not be taken together as the ciprofloxacin will increase the blood levels of tizanidine, making its side effects such as fatigue or weakness much more pronounced.

Never suddenly stop your dose of baclofen. It works by mimicking an inhibitory neurotransmitter. In other words, it helps to suppress the (overactive) nervous system. If you suddenly take away suppression, the response is excitation. Excitation of the nervous system can mean agitation, a sudden increase in spasticity, confusion or even seizures. With this in mind, always taper down your dose of baclofen gradually—you can ask your physician for help in how to do that. And if you are admitted to the hospital, make sure that your baclofen is ordered for you.

Got a question for The Spin Doctor? Email it to Brad Jacobsen, our SCI BC Peer Program Coordinator (bjacobsen@sci-bc.ca), who will recruit the most appropriate SCI expert to provide an answer. Remember, the advice provided is general in nature and is not intended to replace advice specific to your personal situation provided by your family physician or SCI specialist.



Practice is Perfect

After his injury, Dr. Rex Hawthorne couldn't wait to get back with his staff and patients in his busy Okanagan dental practice

Like many people with incomplete injuries, Dr. Rex Hawthorne deals with ongoing neuropathic pain. "But," he says with a smile, "it never hurts when I'm working."

Work has been a tonic for Hawthorne ever since he sustained a fracture at T12-L1 in a 2005 mountain biking accident at Silver Star Mountain Resort. Getting back to his busy dental practice in Vernon was one of the first things he thought about in hospital as he grappled with his new reality.

"Your life gets turned upside down," says Hawthorne, who grew up in Vernon and started practicing dentistry there in 1995. "I had a family that I had to come back to; my son was just going into kindergarten and my daughter was just going into grade two. I was fairly motivated to do whatever it took to come back."

He recalls an email he received on day three from Dr. Brian Clark, the owner of the other dental practice in the building. "It said, 'Yeah, Rex, we got it all figured out—you're coming back.' In dentistry, we use a foot-operated rheostat like a gas pedal to work the drill. He had a photo of himself with a napkin wrapped around the rheostat, and the rheostat in his mouth."

The email brought some comic relief, but it was also a subtle message from his staff and colleagues. "I guess it was always assumed that I would come back," says Hawthorne. "It really wasn't a question if I would be able to do it. It was a question of how to do it."

Turns out it wasn't that complicated.

"We built the building—I guess it was 12 years ago now—to be accessible. Never in a hundred years did I think that we'd be building it for myself. As it turned out, it worked really well." The only change made to the building was the installation of an elevator to get from the main floor dental suites to second floor offices and staff room.

"The rheostat was the big thing—how I could work the drill," continues Hawthorne. "One of our suppliers was really good—they actually came up with a hand rheostat for me. And I did grapple with a number of different wheelchairs. On a dental stool, your feet touch the floor. In a wheelchair, I'm too high up."

The answer was a wheelchair that Hawthorne found on ebay. "My dad and I basically dismantled it and changed the design of it. We modified how the front wheels are attached, so that the footplate is only a quarter inch off the ground—

it's tight to the floor. That works really well, and it's also got a little arm rest just like my dental chair used to have."

Three weeks after his accident, Hawthorne flew back home for a visit.

"It was pretty good," he recalls. "I had my family waiting for me, and I spent the weekend with them. On Monday I spent the morning at the office, seeing my orthodontic patients and trying to figure out what's going to work. It was sort of the first step to realizing, 'You know what? This is very doable.'"

Hawthorne's staff—the dentists, hygienists and assistants he employs—smoothed the transition.

"I've got an amazing staff," he says. "They really had my back from day one. It's probably a little more challenging for them—I can't reach for tools as well as I used to. You can't spin a wheelchair around to grab something off the counter like you can a dental stool while keeping your hands sterile. 'Rex is a little bit more high maintenance' is the joke in the office. But they all step up to the plate."

As for his patients, Hawthorne was pleasantly surprised to receive a box containing hundreds of get well cards delivered to him in GF Strong. "The support was amazing," he says.

Today, eight years into his post-injury life, work is far from being Hawthorne's only passion. His two older children, along with new twins that his wife Melissa recently gave birth to, are central in his life. He was also a high level athlete in a variety of outdoor sports—water skiing, alpine skiing and cycling—before his accident, and he's since found ways to enjoy all these sports and more, at a very high level. For example, search YouTube for "paraplegic kiteboarder" and you'll see just how gifted and ingenious he is as an athlete.

But work is hugely important to Hawthorne—to provide for his family, and for a number of other reasons.

"I think everybody likes to feel a sense of accomplishment or a sense that they're contributing to something beyond themselves. You know, it's just nice to not be dependent on someone else and to actually be able help other people out. For me, at the end of the day, it feels like I'm not in a wheelchair, I'm still the same Dr. Hawthorne that I was before my accident. It's peace of mind; my own mental sanity. I don't know what I'd have if I didn't have work."

Would he recommend dentistry to others with an SCI?

"Absolutely. There's obviously obstacles that would need to be overcome. But I think dentistry is a great career. I enjoyed it before my accident, and it's equally as gratifying now as it was then—maybe even more so." ■

For more information about Dr. Rex Hawthorne and his Cornerstone Dental Group, visit www.cornerstonedental.ca.

Kickstart Your Education

The BC Paraplegic Foundation (BCPF) provides bursaries to individuals with a SCI to support them with their post-secondary education. Awards vary in amounts up to \$3,000. The BCPF is now accepting applications for the 2013 Bursaries. The application deadline is May 24th. To learn about past winners and criteria for consideration, or to download the entire application package, visit www.sci-bc.ca/about-sci-bc/spinal-cord-injury-bc-foundation. While you're there, check out the other scholarships and bursaries for British Columbians with SCI and other disabilities.



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No Apologies

How wheelchair rugby helped one girl get her groove back

The incredibly popular game of wheelchair rugby has an unwritten rule: don't apologize after you hit someone. For Coquitlam's Jessica Kruger, one of only ten female wheelchair rugby players in Canada, it took a while to figure that out.

Thanks to her merciless mentor Duncan Campbell, one of the inventors of the sport that's since become a global phenomenon, Kruger is finally catching on. "She's gradually gotten a lot more aggressive and she now puts some impact into her hits," says Campbell. "She also does a lot of other things like bringing cupcakes to practice, which everyone appreciates."

Aggressiveness and baking aren't the only skills Kruger has picked up since she started playing five years ago. She might be the youngest female player on the BC provincial team, but Campbell and her teammates have always pushed her hard. "I remember one time I saw her transfer out of her chair," says Campbell. "It was a really messy transfer, and I gave her hell. 'You have to lift! No wonder you can't transfer, you have to lift!' I don't think an OT in rehab would tell her that."

It's that kind of mutual support and no-nonsense attitude that kept Kruger coming back for more. "The first year I was so painfully slow and weak," she says. "But it's totally a community of friends and they're so encouraging—I came out just to be around people who were experiencing similar things to me. Then I started coming more and more because I started to love the game. But for sure I stayed at the beginning because I loved all the people."

After five years of playing, Kruger is glad to finally be training competitively



on the provincial team. Since September, she's been working out five days a week at the Richmond Oval. One of her long-term goals is to one day make the national wheelchair rugby team.

"That's the hope," she says. "I'm a long ways off right now, but in the next few years, I hope to get to that point."

Campbell says Kruger has lots to learn, but that "she's improved tons" since she started. "She can carry the ball now, she can beat people every once in a while, and she's learned to move in the right way," says Campbell. "But she has to make quicker decisions. That comes with playing at a higher level. It gets faster and it gets harder."

In the mean time, Kruger keeps herself busy, coming into her own as an athlete, a part-time cupcake entrepreneur, and a student—she attends night classes at Simon Fraser University, where she's three years into completing a degree in literature. She's also an avid traveller, who has already been to 43 countries—six of those in a chair. She credits a lot of her ambition and independence to her participation in wheelchair sports.

"It's through sports that you find that community of people. You see them travelling as a sports team; you see what all those people are doing and it's super inspiring. In the beginning I didn't realize that people in wheelchairs played sports and travelled and did all those things. At first I was devastated; I thought I would lose all that. It wasn't until the third or fourth year (after my injury) that I came to accept that this is how my life is going to be, and it doesn't necessarily mean that my life is over. It's an ongoing process and I'm still figuring it out."

Campbell says that mutual mentorship is an essential element in wheelchair rugby. "It's a huge part of the game because quads, those who play rugby, are on the verge of being independent and not being independent. And if they don't work at it, they may not become independent. They learn how to travel, they learn how to transfer, they learn how to adapt. That's why I like to call the sport the mentor rather than the individuals who contribute to it. It never ceases to amaze me how this thing that was supposed to be fun has turned out to be what it is." ■

Wheelchair Rugby: Your Chance to Get in the Game

BC Wheelchair Sports Association (BCWSA) will visit community centres and schools in Smithers, Terrace and Prince Rupert this May during the second leg of a northern tour. In an effort to engage new participants in wheelchair sports, BCWSA will be giving demos on various sports, including wheelchair rugby and wheelchair basketball. For more information, or to learn how you can get involved in wheelchair sports in your community, visit www.bcwheelchairsports.com or contact program director Kevin Bowie at kevin@bcwheelchairsports.com or 604.333.3520.

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