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Paying our respects to "the Quadfather".

Cover Photo by Candice Vallantin









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#### editor's message

## **Investing: Research vs. Community**

**Investments are tricky.** What do we invest in that we need today versus what may pay off in the future? We all face this question in our personal lives. But it's also a question that must be considered when balancing community services for people with SCI and other disabilities versus research. Indeed, it also needs to be considered when deciding how much to invest in research that will have an impact in the near term versus what may be a very long term prospect of a cure.

These investments are more than financial in nature—they also involve time, energy, expertise and emotion. There is only so much of each to go around, which is why we must make careful, well-considered decisions when allocating such investments. A balance between addressing the urgent needs of today with the potential, future results of research must be struck.

Unfortunately, I don't believe we have the balance right. In recent years, investment in research has increased while investment in essential and vital community services has steadily decreased. Today, the amount invested in SCI research dwarves that of community services.

Both research and community services are essential. However, investing in research is a calculated gamble, and any benefits that result from it won't typically be realized in the short term. The benefits of community services, on the other hand, typically have an immediate and long lasting impact, keeping in mind that their direct economic benefits can be harder to quantify.

In the 21 years since I started my SCI research career, there have been important improvements, particularly in the areas of rehabilitation and assistive technologies. Some of these have had direct, positive impacts for people with SCI. Still, research has a long way to go to realise the types of functional and economic outcomes it promises. In contrast, the services provided by SCI BC and our BC SCI Community Services Network partners have an incredibly positive impact in the lives of people we serve, each and every day.

Part of the problem may be that those of us in the community sector aren't that good at telling our success stories. These stories are as powerful as the sensational research headlines we often see. They're just more complicated to tell. We're trying to do better. For example, read about the incredible difference SCI BC and our partners have had in the lives of Brent Worrall (page 10) and Dustin Paul (page 16). And next time you're online, have a look at our new Impact YouTube playlist and let us know how we are doing.

Ultimately, research and community services will maximize their impacts when working together. SCI BC is proud to be working with ICORD, the Rick Hansen Institute, SCI Action Canada, and other researchers to improve the quality of both research and community services.

To achieve this, there must be continued investment in research and community services. In fact, there needs to be more invested in both. However, even as a former SCI researcher, I think there must be a reset in the balance between what's invested in research versus community service—more money must be directed to

helping people with SCI and their families adjust, adapt and thrive throughout their lives. This is a wise and safe investment that will have a lasting benefit in years to come.



- Chris McBride, Executive Director, SCI BC

## thespin

The Spin is the quarterly magazine of Spinal Cord Injury BC. An online edition of *The Spin* is available on the SCI BC website www.sci-bc.ca.

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Free subscriptions are available for BC residents and health professionals:

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Advertising rates and a publishing calendar for *The Spin* are available online at www.sci-bc.ca, or by contacting: Gary Steeves E: gsteeves@sci-bc.ca T: 604.326.1210

SUBMISSIONS

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Publications Mail Agreement #: 40684573 ISSN #: 1922-9445

Return undeliverable Canadian addresses to: Spinal Cord Injury BC, 780 SW Marine Drive Vancouver, British Columbia V6P 5Y7 T: 604.324.3611

To update/change delivery address, email thespin@sci-bc.ca or call 604.324.3611.

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SCI BC acknowledges the financial support of the BC Gaming Commission, the Rick Hansen Institute, and the BC Paraplegic Foundation.

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#### **KICKSTART ORTHOSIS**

Kickstart is a wearable device that can help people with weakened muscles or disabilities regain mobility. Kickstart uniquely stores and releases a user's own energy to provide walking assistance and improved stability for people living with partial paralysis from incomplete SCI, strokes, and other conditions that affect mobility. Unlike robotic devices, there are no batteries, motors, electronics or noises associated with its use. It is a simple and lightweight device that provides a boost of energy return to help swing your leg forward for each step, reinforcing correct walking motions so your legs advance smoothly and naturally. Visit www.cadencebiomedical.com for more information







#### DIY HANDCYCLE

Klaus Rausch is a German paraplegic and handcyclist who believes every wheelchair user should have the opportunity to cycle, regardless of where they live in the world or how much money they have. In fact, he believes handcycles are superior to wheelchairs in many parts of the developing world—they can extend a person's living range, pass easier over poor roads at greater speed, and create more independence. So he developed a simple DIY handcycle design that requires a wheelchair, an old bicycle, and some labour. The concept is surprisingly simple—the bicycle's front wheel and front portion of the frame are cut off. What's left is flipped over and attached to a wheelchair, which is also flipped over. Rausch has made the entire concept open source—you can see the details, examples and videos at www.santa66.net.

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#### events



#### Tea...and much more.

Join us on February 16th, 2014, for the 11th Annual Spinal Cord Injury BC Women's Tea at the elegant Heritage Hall ballroom in Vancouver. This one day event celebrates all women, regardless of physical ability. Come for a day of high tea, delicious treats, primping and pampering. Leave revitalizeed with some great memories and new friends. This event is entirely free! To RSVP, contact Marnie at mdevries@sci-bc.ca.



#### Flaunt those ugly ties.

From March 10 to 14, 2014, wear your ugliest ties with pride! Throughout the work week, businesses and individuals throughout the province are invited to take part in our annual Ugly Tie Fundraiser to show their support for Spinal Cord Injury BC. To find out more about our wacky campaign, send Gary an email (gsteeves@sci-bc.ca) and he'll send you all the tools you need to get ugly while raising funds and awareness for SCI BC.



#### Hell on wheels.

The BC Wheelchair Sports Association and the BC Wheelchair Rugby Association invite you to the 2014 Vancouver Invitational Wheelchair Rugby Tournament, taking place from March 14 to 16 at the Richmond Olympic Oval. Come out and watch the best club teams from across North America battle it out in the hard-hitting sport of wheelchair rugby. Email lisa@bcwheelchairsports.com for more information.

#### Vancouver bylaw makes new homes more accessible & adaptable

On September 25, Vancouver City Council approved changes to its building codes that will make all new homes more accessible and adaptable for seniors and people with disabilities. The changes will come into effect in March 2014.



Jill Weiss, the chair of Vancouver's Persons

with Disabilities Advisory Committee, told the *Georgia Straight* that the changes are "vitally important."

"This means that we will be able to operate in houses in the city of Vancouver...that the housing will be for everyone," she said in an interview. "So I can't say how important it is."

The city is now working on an 18-month study on the feasibility of insisting that new homes have at least one accessible path to a ground level entrance.

"An accessible path to an entrance on all new houses has been in place in England for 14 years," Weiss told the *Georgia Straight*. "Since 1999, it cost virtually nothing, and it works just fine. So it's fine that they're going to study it, but the evidence is overwhelming that it makes sense to do, and it's not expensive."

The building codes were also changed to improve water and energy efficiency, and to allow developers and building owners to build gender-neutral washrooms.

Vancouver is the first city in the country to set mandatory adaptable housing standards. "I hope other cities will follow suit," said Mayor Gregor Robertson. So do we.

#### Participate in our Housing Survey!

Spinal Cord Injury BC is conducting a survey to study accessible housing in the Lower Mainland. By understanding the accessibility needs of housing seekers and the barriers they face, we can better direct our efforts to address the situation.

This survey will take less than ten minutes to complete. You can find it online here: www.surveymonkey.com/s/accessiblehousing.

Your answers are completely confidential and no identifying information will be used when we publish our research results. You can choose to complete the survey anonymously if you prefer.

If you'd like some help with your housing search, you can visit www.accessiblehousingbc.com, call our InfoLine at 1.800.689.2477, or leave your contact information at the end of our survey to have one of our staff get in touch with you.

If you have any questions or comments about this study, contact Heather at 1.800.689.2477 ext. 2, or email hlamb@sci-bc.ca.

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Brent Worrall is back at the motocross track, thanks to a winning attitude, support from his family and the motocross community, and a boost from SCI BC's Peer Program.

#### It was a horrific crash.

On August 18, 2011, Brent "Airmail" Worrall was one of the favorites to win the Walton TransCan, in Walton, Ontario—the biggest race of the year on the Canadian motocross circuit. Worrall, a former Canadian champion and once the 10th ranked rider in the world in his class, got off to a slow start but quickly moved up to fourth place. That's when he hit the track's biggest jump at top speed. In the blink of an eye, everything would change.

"As soon as I crested the jump, my bike hit neutral," recalls Worrall, who grew up in Chilliwack before making Vernon his home. "I flew 120 feet and landed on my head. The bike fly-swatted me and bent me in half backwards, breaking T-3,4,5,6,7,8 as well as my L1 and L2 vertebrae. I also broke all my ribs—yes, every one—in many pieces, and my sternum and collarbone."

Worrall was rushed to the London Health Sciences Centre, where doctors put him into a coma and waited to see if he would survive. "My heart stopped four times, and doctors told my wife I would be a quadriplegic if I lived," he says.

Days later, he defied the odds and regained consciousness. But his days as a motocross racer were over, as he was left with T-3 complete paraplegia.

Today, just over two years after his crash, Worrall has his life back on track. His health is improving, his outlook is positive, much of his independence has been regained, and he's once again involved in his beloved motocross community—he's the track announcer for Canadian Motocross Federation events, and the host of his own weekly online motocross radio show.

"The thing that has helped me get this far is just living each moment as it comes and trying to be the best person I can be in that moment," he says. "Mentally, I'm as strong as I have been in a long time in my life, even pre-injury."

The journey hasn't been an easy one, however. The extent of Worrall's injuries meant that he had to remain hospitalized for the first nine months after his injury—first in Ontario, and then in Vernon. His recovery was slow and riddled with complications from blood clots and numerous bladder infections. His health struggles were exacerbated by the prospect of moving back to a home that was inaccessible, and by the London Health Sciences Centre, which added insult to injury by hounding him for \$28,000 for his air ambulance flight back to Vernon from



Ontario despite the fact that he had been assured there would be no cost to him.

One by one, hurdles dropped away. The London Health Sciences Centre, no doubt feeling the pressure brought by widespread media coverage of Worrall's plight, backed down on its \$28,000 bill. When he checked out of hospital in August 2012, his long-time friend, Dan Martell, renovated the condo's ensuite, installing a roll-under vanity and a rollin shower. And eventually, thanks to a grant from BC's Home Adaptation For Independence program (HAFI), an elevator was installed in Worrall's condo. More independence was regained earlier this year, when he got his driver's license and started to get back out into his community. And most importantly, his health steadily improved, with the turning point being Botox injections into his bladder.

"That has been life-changing, to say the least," says Worrall. "Prior to Botox, I had 16 bladder infections in 20 months. It's only been since I stopped getting infections that I've really felt like I'm starting to move forward with my recovery."

Looking back, Worrall credits the sport of motocross for giving him the resolve he's needed during his recovery.

"Motocross has been my life-long passion, and it pretty much defined my character and shaped and prepared me for what fate laid ahead," he says. "I believe the fortitude I needed to compete at the top level gave me the strength I would need to re-create myself post-injury."

But he's quick to add that he couldn't have done it by himself.

He's grateful for the support of his family—particularly his wife, who, as luck would have it, is a trained professional caregiver and was undaunted by the task ahead. "Gisela actually had to bump me up and down 16 stairs for the first year,"

#### THEN AND NOW ....

Right: Brent Worrall racing at the Walton Trans Can in 2009. Left: Worrall track announcing during a recent arenacross event in Chilliwack. Middle: Nova Scotia rider Tyler Medaglia is interviewed by Worrall for an upcoming edition of his weekly online radio show. Photos by Clayton Racicot. says Worrall. "I have a beautiful soul mate in Gisela, as well as two beautiful girls and a son in England, and a threeyear-old granddaughter who makes life really special for both Gisela and I."

Support—financial and otherwise—also came from Worrall's friends and fellow competitors in the tight-knit motocross community. "Fortunately for me, I was blessed with having many, many friends and acquaintances throughout the great sport of motocross—they supported my family and I on many levels post injury. The sport and the community wouldn't allow me to let go of my passion, and I made it my mission to one day give back what was so unconditionally given to me."

The opportunity came earlier this year when Worrall was asked by Future West Productions to come out and try his hand at track announcing. "I said I would give it a go, as I was going to be at the races as a spectator anyway," he says. "They pretty much hired me on the spot, and today I'm very honoured to be able to share my passion for the sport through the microphone. It's given me a special connection with my moto community and a purpose within the sport I truly love."

The indoor motocross season takes place in the Lower Mainland with Future West Kawasaki Arenacross events throughout the winter. That's where you'll find Worrall, announcing and interviewing participants for the BC Moto Show, his weekly online radio broadcast another opportunity to reconnect with and contribute to the community that was offered to him by the sanctioning body.

"It's been a lot of fun—it's nice to be able to be a part of a sport where risk is a factor and yet feel safe," he laughs.

Worrall also praises the support and friendship he's found at SCI BC's Okanagan Peer Support Program. For the past year, he's been connecting with his peers during weekly group meetings and events, which are organized by Sonja Gaudet, Paralympic curler and SCI BC's Vernon Peer Coordinator.

"I can tell you that, two years ago, I didn't think that the life I'm living today would be possible," he says. "I remem-



PEER RIDE: (left to right): Sonja Gaudet, Brent Worrall, Daniel Shermeto and Shawn Baxter

ber being in GF Strong and being very afraid of what life would be like once I left that safety net."

It was during his stay in rehab that Worrall was encouraged to get involved with his peers. "It was not an easy step to make, but once I did, I wished I had reached out sooner," says Worrall. "I feel an honest, unconditional connection with each and every individual I have met through my peer group. I can honestly say I have not felt that with any other group, and my motocross family is pretty tight. I have never left a peer gathering wondering why the heck I went. Not only have my peers opened my eyes, they've opened doors for me that I probably couldn't have opened myself. To all of them-and they know who they are-I am happy and proud to call each and every one of you my friends. I would not advise anyone to deprive themselves of the wonderful opportunities that a para peer connection provides."

Worrall is so grateful for the Okanagan Peer Support Program that he recently took it upon himself to give something back to it. Working with SCI BC organizers, he played key roles during two fundraisers in October—one at the Kelowna Dirt Bike Club, and one at the Laurel Packing House in Kelowna. Both events were well-attended and hugely successful. "We raised over \$13,000, and it was so rewarding to watch and participate with both my para peers and motocross friends as we worked towards a common goal. With the money raised, I'm hopeful that there will be many more peer outings and endeavours."

Looking to the future, Worrall is taking things one step at a time. He's back on a bike, albeit an unmotorized one—with encouragement from his peers, he's become passionate about handcycling, which provides him with much needed cardio exercise. And he's looking forward to getting out to his peer group meetings and even trying some wheelchair sports over the winter months ahead.

"I feel I'm on the right track, and I look forward to my 'new normal' being a little more comfortable in the days ahead. I still deal with a lot of pain and have good days and bad days. I'm hopeful that, in time, I will have more pain-free days, but I know it'll take time. I broke a lot of bones when I was racing, and the pain always eventually went away. This crash was huge, so it might just take a little longer!"

Worrall has some hard-earned advice for anyone that is newly injured or is just home from rehab and not sure what lies ahead. "I would recommend, if you're able, to get out in your community. I remember Walt Lawrence, my counsellor at GF Strong, saying to me, 'Brent, I know you're going to do the right thing." I said, 'Walt, what's that?' He said, 'Get out and be involved in your community. You need your community, but more importantly your community needs you.' Walt, so true! Our communities need us to be who we are and what we are, no matter what our purpose on this broad and all inclusive journey is. We have absolutely nothing to be afraid of-in my opinion the toughest days are in the past."

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# **Bionic Bladder**

British researchers have developed a neuroprosthetic system that restores bladder control in paralyzed rats. So what are the chances of a human version being developed?

n October, we saw widespread media coverage about technology that could one day restore bladder function to people with SCI. The system, developed by researchers at the University of Cambridge in Britain, has been successfully tested in spinal cord injured rats.

While the public and media remain focused on a "cure" for SCI, we know the

> powerful, positive impact that restored bladder function would make in our readers' lives. Even those who have successfully used Botox to con

trol neurogenic bladder report incredible improvements in their health and quality of life. In addition to the obvious benefit of eliminating embarrassing accidental leaks, these people report significantly lowered incidence of UTIs. In turn, emerging research is making it clear that eliminating UTIs and bladder issues results in fewer bouts of autonomic dysreflexia, which allows our immune system to stay stronger in the long term.

With all this in mind, we set out to find out more about the neuroprosthetic bladder and its potential for human use.

In a nutshell, an SCI blocks signals that the bladder attempts to send to the brain to let it know that it's full and needs to be drained. Meanwhile, even when the brain knows the bladder is full (for example, if you drank four cups of coffee in two hours, you'd probably realize it was time to void even if your brain didn't get the signal from your bladder), the SCI would block the brain's command to release the bladder once you were at a toilet.

The device developed by the researchers was described in a recent issue of the journal *Science Translational Medicine*. It consists of a set of electrodes that are wrapped around the sensory nerve fibres coming from the bladder. A "full" signal from the bladder is picked up by the electrodes and sent to a control unit on the outside of the rat's body. The control unit is then manually activated, sending a signal back into to the body to other nerves which control contraction of the bladder and opening of the valve to release the stored urine.

There has been at least one other method devised to electric-

ally stimulate the bladder to empty—the Brindley Procedure. But what makes this new device so compelling is that, unlike the Brindley Procedure, it doesn't require surgical destruction of the sensory nerve fibres coming from the bladder.

"Sparing and making use of sensory signals from a filling bladder adds a welcome degree of sophistication to elective voiding whilst retaining other functions normally lost such as erectile function a distressing consequence of current methods," lead researcher Dr. Daniel Chew told the BBC in October.

Most importantly, according to Chew and his colleagues, the device was "very effective" when tested with rats.

So what is the potential to develop a human application of this technology?

Chew stated in the BBC interview that he believes it is possible to modify and surgically implant the necessary technology in people with SCI. This technology would be used conjunction with a handheld controller that would buzz when users need to void, and when they're ready, they just press a button to start emptying their bladder.

But he also added the caveat that he and his colleagues are now "limited by miniaturisation of the technology." While the internal electrode array could conceivably be modified for human use, the external controller portion is now a two meter high stack of equipment.

We wanted to know more about the potential for human application, so we contacted Chew. The first thing we wanted to know was what kind of surgical procedure would be required to implant the electrodes in the human body. "This would involve a laminectomy, typical for implantation of a SARS (sacral anterior root stimulator) device, plus manipulation and implantation of the dorsal roots into an additional device for recording neural activity," says Chew. "Surgically, it is challenging to dissect the dorsal roots into the fine rootlets/ fascicles required for implantation."

What does this mean in plain speak? Chew is first describing the procedure required to implant the technology that would stimulate the bladder to void. It involves removal of a portion of the vertebra to provide access to the appropriate nerves. This procedure has already been used to implant the SARS device—the type of device that's been used with the Brindley Procedure that we described on the previous page. In fact, the SARS device currently used in the Brindley Procedure could, in theory, be modified for use in the new neuralprosthesis.

"We're trying to refine the current SARS device, which has lost appeal in the clinic because of the requirement for transection of dorsal roots and insensitive approach to stimulation," explains Chew.

As for the other part of the system, recording and sending the "bladder full" signal to the controller outside the body, Chew is saying that another module of electrodes would need to be surgically connected to nerve fibres at the base of the spinal cord, or dorsal root.

How would they be powered?

"We're working with engineers at University College London to design a 'telemeter' device that uses magnetic induction to power the implanted recording module," says Chew. "This is external and can be applied to the skin of the abdomen. This is wireless and does not

Dr. Daniel Chew

#### AD a Threat During Urological Tests

Most readers are regular visitors to their urologist, and many will have undergone one or both of the comprehensive urological tests—urodynamics and cystoscopy. These common procedures allow urologists to assess how well the bladder is functioning.

It turns out that mild or silent bouts of autonomic dysreflexia (AD) are a concern during these tests. While there are no clear numbers about how often this occurs, a recent study by ICORD's Dr. Andrei Krassioukov sheds some light on the problem.

Krassioukov and his colleagues studied the charts of individuals with SCI who had blood pressure monitoring during these procedures. They found a total of 21 people with SCI who underwent both procedures and developed episodes of AD. At 86 percent, the majority of individuals were quadriplegic. Their average age was about 49, and the



Dr. Andrei Krassioukov

time elapsed since their injury was about 15 years.

They found that cystoscopy (the insertion of a tiny camera through the urethra and into the bladder) results in more episodes of AD than urodynamics (filling the bladder and then measuring the ability and speed of voiding). They also found that the elevated blood pressure response during episodes of AD was more pronounced in individuals with more than two years since injury, during both urodynamics and cystoscopy.

Krassioukov concludes that cystoscopy presents more of a risk because "stimulation of the urethra/prostate/internal sphincter region probably is a more potent stimulus of AD than just the filling of the bladder."

Regardless of the procedure being used, Krassioukov believes urologists and people with SCI need to be aware of the risk. "Considering the high incidence of silent episodes of AD during the urological procedures, it is recommended that monitoring of cardiovascular parameters during these procedures be routinely performed," he says. "We strongly recommend blood pressure monitoring during both procedures—at VGH, it is already standard clinical practice to monitor blood pressure and watch for other signs of AD."

He adds that the goal now is to educate urologists throughout the province and beyond about the findings and the need to monitor blood pressure during these procedures involving people with SCI.

need an implantable battery. The SARS is also wireless. We're currently exploring these design options in clinical SCI pet dogs with veterinary collaborators at University of Bristol and Iowa."

That leaves development of an external controller that both receives the "bladder full" signal and, in turn, is activated by the user to send the signal back to the SARS device to contract the bladder and initiate voiding. Chew would not speculate about what that development might entail. Obviously, with the present controller requiring a two meter-high stack of equipment, a great amount of work will be required. The bottom line?

"We are optimistic," says Chew, "but there is a long way to go on the engineering and biocompatibility side. A commercial system is, unfortunately, a long way off."

We believe Chew and his research colleagues are to be commended for their work to date. But clearly, a human application remains an ambitious goal. Nevertheless, we can't help but wonder how fast a human version could become a reality if some serious funding were to be applied to it—the kind of funding that is currently only seen in the realm of "cure" research.

Vancouver's Dustin Paul explains how breaking ambitious educational and career goals down into small steps turned into his ticket to success.

ovember was a big month for me. After three years of law school and a total of seven years of higher learning, I passed the bar exam and joined one of BC's leading law firms, Bull, Housser & Tupper, to complete my articles and become a lawyer. It's the culmination of a journey to secure a brighter future and financial self-sufficiency for myself post-injury. It's rarely been easy, but I'm starting to get the feeling it'll all be worth it.

I know some readers might be thinking, "Geez, that's just simply beyond me—I wouldn't even know where to start, and there would just be way too many hurdles to overcome." I used to think the same way, and sometimes I still do. It usually happens when I'm admiring someone's accomplishments from afar, without considering the simple steps that I could take to accomplish something similar. At first glance, even the smallest undertakings can appear to be overwhelming for those of us with SCI.

When I feel that way, I force myself to focus on the individual steps that can bring me closer to my goals, rather than looking at the enormity of the entire undertaking from the outset. I start with the smallest steps and quickly find myself on the way. If you try this yourself, I think you'll find your goals are rarely beyond you.

In 2007, three years after my injury, I was a 22-year-old with high-level quadriplegia, no money and barely a high school education. I was faced with a dwindling number of friends, massive insecurities, and depression so deep I couldn't see the light of day. Somehow, through the fog, it dawned on me that higher learning was my only hope. No one from my family had ever gone to university. But I reasoned that whatever I would face in college couldn't be any worse than what I was already going through. I was lost and my goal was simply to find a life worth living again. So I woke up one day, asked myself, 'What do I have to lose?' and set out to focus on the small steps I needed to take to get there.

I had learned about the Neil Squire Society during rehab in GF Strong. I reached out to the society with a blank slate, hoping they could help me figure out an educational program that would work for me. The society's staff worked with me over the course of a few months to help determine my interests and how they might mesh with some programs with tangible job opportunities down the road. We settled on the Criminal Justice Program at Langara College. Not only did the Neil Squire Society help me apply and get accepted, it agreed to help fund my first two years.

The next step was figuring out how a guy with no use of his hands was supposed to get through a day at school. How would I get there in time for classes each morning? How would I take my coat off? How would I eat lunch? Who would help me get my books out of my bag? How would I take notes? Those were just a few of the questions churning through my mind.

I soon discovered that most postsecondary institutions in BC have a disability resource centre, and I immediately began to work with Langara's to find answers to my questions. To my surprise, the centre had all the bases covered-from note-taking and scheduling, to in-class accommodations and even attendant care. I found out that that a fellow student could be hired as a note-taker, that I qualified for extended time on exams, and that I could write them in a private room using voice recognition software. I discovered that I qualified as a full-time student at a reduced course load, and that there were funds available to help pay for attendant care services and assistive technology.

Before I knew it I had a fresh new lap-

top and was in the front row of a class of 30 strangers listening to a lecture about something called Marxism, wondering what the hell I had gotten myself into. I was so scared to fail—and so certain that I would—that I think I had read eight chapters of the textbook a week before the first day of class.

Then something shocking happened. I began to enjoy myself. I found great pleasure in interacting with my colleagues and meeting new friends who knew me only for who I was post-injury. Without immediately realizing it, going to class became therapeutic. It gave me a reason to leave the house and took my mind off my problems for at least a few hours a day to focus on something positive that would help me move forward.

The fact that I was enjoying it so much created a positive feedback loop. Because I enjoyed school, I did very well. And because I did very well, I enjoyed school even more. In fact, I was utterly crushing my courses—straight A's across the board—and the scholarships, including an award from the BC Paraplegic Foundation, started pouring in. That was it—I was hooked. I went seven years without taking a single semester off.

#### **Education Resources**

- The Neil Squire Society has a variety of initiatives to help you identify potential education and employment opportunities (www.neilsquire.ca).
- The BC Paraplegic Foundation, administered by SCI BC, offers awards of up to \$3,000 each fall to post-secondary students with SCI (www.sci-bc.ca).
- The financial aid department and disability resource centre at your educational institution should have a list of privately-offered disability-related scholarships.
- The federal and provincial governments offer a variety of grants and bursaries to students with disabilities (https://studentaidbc.ca/explore/grants-scholarships).
- If you qualify for federal student loan funding and have a disability, you may also qualify for up to \$20,000 per year for attendant care services, technical aids, note-takers, tutors and interpreters. The disability resource centre at your educational institution can provide more information.
- The following post-secondary institutions in BC have disability resource centres: BC Institute of Technology, Camosun College, Douglas College, Langara College, Simon Fraser University, Thompson Rivers University, University of British Columbia, University of the Fraser Valley, University of Northern BC, and University of Victoria. Visit each institution's website for more information.

I graduated from Langara College in 2009. Hungry to learn more, I enrolled at Simon Fraser University on an entrance scholarship to study Criminology. During my time at SFU, I developed a passion for the law and began to see the legal industry as possibly a good fit for someone like myself with limited physical capabilities but a strong mind. I decided to attend the UBC Faculty of Law and I'm proud to say that I just graduated this past May-with no student loan debt, no pressure sores, and no infections. Instead, I had acquired a first-rate education, a well-paying job, great friends, accepting colleagues and a future with endless possibilities.

What initially seemed like insurmountable obstacles now look like minor speed bumps in the rear-view mirror.

I've now been exposed to the legal industry in some form or another for about four years. I've been thrilled with how receptive it has been, both in academic and professional settings. No matter what help a person with SCI receives from friends, family and community agencies, it's tough (if not impossible) to make it anywhere in the professional world without the support of one's colleagues. The legal industry has been outstanding in this respect. I summered with Bull, Housser & Tupper in 2012 before recently rejoining the firm for my articles, and I've never felt out of place with the firm for one moment. My colleagues have been proactive at every stage about addressing my needs and giving me the resources I need to be successful. They've accommodated my needs by providing simple things like special cutlery in the lunch rooms, to adjusting the height of my desk, to ensuring I have an ergonomic workspace, and even by installing automatic doors. No request has been off-limits for discussion. But most importantly, I've simply felt like just another member of the team.

In closing, I want to emphasize that I'm not putting my story forth as a prescription for success. As we all know, success means different things to different people, and there is no one way of getting there.

Nevertheless, there was a time in my life when I avoided reading *The Spin* and similar publications because they somehow left me feeling like I wasn't doing enough when I read about all the wonderful things that other people with SCI were accomplishing. But somewhere along the line, I realized what all those before me had been trying to drill into my head—that everyone has their own path and their own timeline for travelling down it. And so I simply wanted to share my story in the hopes that I could help even just one reader reach the same conclusions.

Post-secondary education and a subsequent career in your chosen field may seem like an impossible challenge. But the opportunities are real, and so too are the supports to help you along the way. Remember—start with the small steps, and the big challenges will fall one by one.

Interested in writing about a topic that's important to you? Your guest submissions to The Spin are welcome—email Candice at cvallantin@sci-bc.ca for guidelines.

## ask the SPIN DOCTOR

This issue's question comes from Scott in Vancouver, who asks, "Can you tell me about any dangers and consequences of mixing pharmaceutical medications with street drugs and alcohol?" To answer the question, we turned to Dr. Patricia Branco Mills, a Physical Medicine and Rehabilitation Specialist at GF Strong Rehabilitation Centre.

"Many people with SCI require the use of pharmaceutical medications to manage problems such as pain, spasticity, and mood disorders. Some of these individuals also use street



drugs and drink alcohol while on medications. If you're one of these individuals, it's important to understand the potential consequences that may have profound and lasting effects on your body.

Although there are many potential consequences, I'll limit this discussion to a few of the potential effects on your central nervous system, your liver, and your cardio-vascular system.

First, the central nervous system, or CNS. Recreational substances work by changing the balance of chemicals in the CNS. Medications that are used for treatment of common conditions after SCI also act by affecting chemicals in the CNS, such as medications for pain or spasticity. When these types of drugs are used with recreational substances, the combined effect can cause dangerous imbalances in the CNS. For example, cocaine taken with Nortiptyline can cause increased risk of seizures, as can the use of the painkiller Tramadol with heroin. Taking cannabis with fluoxetine (Prozac) might cause you to feel irritated, nervous and jittery. Alcohol taken with narcotics and anti-anxiety medications including lorazeparm (Ativan) has been known to result in coma—and even death.

Now the liver. Alcohol is processed through the liver. Many pharmaceutical medications, including commonly used anti-spasticity drugs such as baclofen and tizanidine, are also processed through the liver. When the liver has to process alcohol and these drugs at the same time or in large quantities, severe and even irreversible liver damage can result.

Finally, the cardiovascular system. Using cannabis while taking the blood thinning agent warfarin (Coumadin) might increase the chance of bruising and bleeding. And amphetamines taken with certain anti-depressants can cause a sudden and severe rise in blood pressure, which is especially dangerous if the individual is also at risk for autonomic dysreflexia.

Many people with SCI have turned to medicinal cannabis as a treatment for many secondary health complications such as pain and spasticity. Regardless, all of the contraindications listed above apply whether or not you're using cannabis recreationally or medicinally.

These are just a few examples of how recreational substances can cause significant harm when taken with pharmaceutical medications. It's best for your safety to avoid using recreational substances, but this is especially true if you're also on pharmaceutical medications. However, if that's not an option for you, I recommend that that you tell your doctors so that they can help you minimize your risk. Also, please do not stop using any pharmaceutical medications without first talking to your doctor, as sudden withdrawal of medications can also cause significant harm."



## Make Your Home Safe for Independent Living

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

Do you have difficulty performing day-to-day activities?

Does your home need to be adapted to meet your changing needs?

If so, you may be eligible for financial assistance under the **Home Adaptations** for Independence (HAFI) program.

**Find out today if you are eligible** and if you meet all of the requirements as a low-income homeowner or as a landlord applying on behalf of an eligible tenant.

Home Adaptations for Independence To apply or learn more, visit www.bchousing.org/HAFI You can also contact BC Housing: Phone: 604-646-7055 Toll-free: 1-800-407-7757 (ext. 7055)

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HOUSING MATTERS

#### health

# Botox for Spasticity

When we think of treatments for spasticity, baclofen usually comes to mind. But for certain types of spasticity, Botox may provide better results without major side effects.

n recent issues of *The Spin*, we've told you about Botox and its increasing popularity as a treatment for neurogenic bladder. The number of our readers who have experienced a real life improvement from this treatment continues to grow—for example, former motocross star Brent Worrall raves about the difference Botox has made in his life on page eleven of this issue.

But when it comes to SCI, Botox has another potential use—spasticity. In fact, Botox been available in Canada as a spasticity treatment for several decades. Despite this, it's not well-known for this use, and there seems to be a little confusion about what specific types of spasticity make good candidates for the treatment.

As we set out to learn more about Botox, we contacted Dr. Heather Finlayson, a physiatrist at GF Strong Rehabilitation Centre who is also the champion behind the centre's relatively new Interdisciplinary Spasticity Management Clinic.

"Botox has been used much more frequently over the past ten years as we have gained greater understanding of the potential benefits when used appropriately, and research studies have demonstrated efficacy," says Finlayson.

To understand how Botox works with

spasticity, it's probably a good idea to revisit what exactly it is. Botox is actually a trade name used by pharmaceutical company Allergan for its formulation of botulinum toxin type A, a neurotoxin produced by the bacterium Clostridium botulinum. In addition to SCI, Botox is being successfully used in a number of other medical and cosmetic applications.

"Botox works by temporarily blocking the connection between nerve and muscle," explains Finlayson. "After it has been injected into a muscle, the Botox spreads to points where the nerve-tomuscle connection normally causes muscle contraction. By blocking this connection, the muscle's ability to contract is reduced."

Because Botox is injected in minute amounts into the affected muscles, it's ideal for focal spasticity. "This means that the spasticity is in a specific or 'focused' area of the body," says Finlayson. "For example, a tight elbow that bends up involuntarily may make it difficult for a person to reach for objects or get dressed, or it may lead to pain and skin breakdown around the elbow. In this case, injection of Botox to the overactive elbow flexors—muscles such as the biceps that bend the elbow—would be appropriate. In the lower body, some people have very tight hip adductors, which are the muscles that pull the legs together. This tightness may make it difficult to perform peri-care and catheterizations, and may interfere with sexual function. Botox injections to these muscles can help ease the tightness and make it much easier to bring the legs apart."

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Finlayson adds that these are just two examples of focal spasticity, but it can occur anywhere in the body. The important point is that Botox is used in a very targeted way, as opposed to treating generalized spasticity—spasticity that affects a number of areas or almost the entire body.

"In this case, Botox injections wouldn't be appropriate as there are simply too many muscles to inject and the maximum dose would be exceeded, with a risk of significant side effects and a huge financial cost," says Finlayson. "In this situation, the use of other treatments such as oral medications or intrathecal baclofen is more reasonable."

But she adds that some people have generalized spasticity as well as focal spasticity. "An example is a person with widespread spasticity in addition to very tight hip adductors that are affecting their function as described above," she says. "This person would be a candidate for Botox injections to the hip adductors as well as oral medications for their generalized tone."

But why not get "blanket coverage" by using baclofen? "Side effects (of baclofen) include drowsiness and grogginess, which can be a significant limitation, particularly when many people with SCI or other neurological conditions already suffer from fatigue," says Finlayson. "Baclofen is metabolized by the liver so there is a small risk of liver damage and blood work has to be checked regularly. As baclofen affects the whole body, it can cause generalized weakness, including weakness in muscles that a person with spasticity may use to help stabilize themselves for activities such as transfers."

In contrast, Finlayson explains that Botox doesn't cause drowsiness, grogginess, or liver damage. "There are potential side effects of Botox, including those related to the needle poke for the injection-bleeding and infectionas well as a very small risk weakness outside of the injected muscles. However, the frequency of side effects with Botox is far less than those associated with baclofen. The fact that it's injected into the spastic muscles means that treatment can be targeted to maximize looseness in the problematic muscle groups, while sparing other muscles groups that may benefit from increased muscle tone to assist with activities such as standing and walking."

#### The GF Strong Interdisciplinary Spasticity Management Clinic

The GF Strong Interdisciplinary Spasticity Management Clinic began providing service to patients with spasticity in 2010. It's called an "interdisciplinary" clinic because clients/ patients are assessed by a team of health professionals, which includes a physiatrist, a physiotherapist, an occupational therapist and a nurse. An orthotist is also available for consultation and fabrication of braces or splints as needed. The entire team works together with the client/patient to asses the spasticity-related problems and how they can best be addressed.

The clinic is intended for anyone with spasticity—the uncontrolled increase in muscle tone or "tightness" caused by SCI, stroke, traumatic brain injury, MS, cerebral palsy and any other condition.

People must be referred by a physician, either a GP or specialist. Often, community therapists such as physiotherapists or occupational therapists help to initiate a referral if they're working with a client and realize that assessment in the spasticity clinic would be appropriate. In this case, the therapist may liaise with the physician to recommend a referral. Referrals are sent to GF Strong Rehabilitation Centre.

In addition to Botox for focal spasticity, prescribed treatments may include stretches and exercises, braces/splints, adaptive devices, oral medications, and/or phenol injections.

For more information, visit www.vch.ca/403/7676/?program\_id=12910.

If you think you might be a candidate for Botox treatment for your focal spasticity, the first step is to speak with your physiatrist, or seek a referral to the GF Strong Interdisciplinary Spasticity Management Clinic (see sidebar above).

Once you've had your referral, you'll visit the clinic for an initial assessment from the clinic's team to determine if Botox is an appropriate treatment. If that's the case, the team will pinpoint the most important muscles to target and an appropriate dose.

Botox will then be injected into the muscles that have been identified as targets. The injection(s) will be done by a physician. In most cases, the needle will be attached to a machine that listens to and stimulates muscle activity so that the physician can be certain that the correct muscle is being targeted-particularly important when the small and deep muscles in the forearm or lower leg are targeted. Additionally, physicians are increasingly using an ultrasound machine (similar to those used for looking at babies in utero or the heart) to get an image of the muscles and determine where the needle needs to go. It's only

Dr. Heather Finlayson

in the case of large, easy-to-see muscles, such as the calf or hamstrings, that no special techniques are required.

It takes about seven to ten days for the anti-spastic effect to take place.

The only downside? Unfortunately, the benefits are not often permanent.

"Repetitive treatment is usually necessary in people who have a permanent neurological condition such as SCI," says Finlayson. "The Botox typically wears off in three months. Some people want to have the injection repeated right away as they find that their spasticity becomes bothersome again as soon as the Botox wears off. Other people are able to stretch out the time between injections. It's never essential to have the injection repeated if a person doesn't like the effect or doesn't find it helpful, and remember, there are no permanent effects or risk of withdrawal."

Fortunately, as with Botox for neurogenic bladder, Botox for focal spasticity is approved under BC Health's Pharmacare Special Authority plan. Keep in mind that a specialist physician needs to request special authority approval in order to ensure it will be covered.

Our thanks to Dr. Heather Finlayson for her assistance with this story.

# GirlTalk

"Wouldn't it be cool to figure out how to meet all our dreams and goals and aspirations together?" asks Jenna Reed-Cote, our new Women's Group Coordinator he's the kind of person who celebrates the day she was born by doing something that scares her. For her 21st birthday, Jenna Reed-Cote pushed herself up the 853-foot peak of Mount Douglas in greater Victoria with some friends.

Flying in the face of fear and challenging the limits of her endurance—both physical and emotional—has always been a big part of Reed-Cote's life.

Born with spina bifida, Reed-Cote has been in and out of the hospital since she was born. She's undergone more than a dozen surgeries for her feet, her spine, her colon, her bladder and even her brain. Although she's relatively healthy now, just a simple cold or flu still has the potential to push her body out of equilibrium.

But Reed-Cote has transformed what started out as a weakness into a source of strength. She started training in karate with her family when she was only four years old, and she didn't stop until she was 17.

"It's great to feel strong when everybody sees you as disabled in a very physical world," says Reed-Cote. "I got my first degree black belt in karate about one month after brain surgery.

"My karate school was one of the few places where I felt like I was strong growing up. I was the only one in a wheelchair and there were a lot of students, so it's not like it was a school that had built a name for itself in adaptive karate. Right away, the teachers didn't treat me any differently. They decided to figure out how I could do it, not if I could do it."

The unwavering patience, dedication and strength she learned from her karate community helped Reed-Cote get through the difficulties of growing up in and out of a hospital setting. Although the medical community tended to her physical needs, it was the emotional support

from her extended karate family that got Reed-Cote through those tough early years.

"It's hard for me to look back on my life as a patient and not feel that it represents negativity," she says. "In karate there was just as much focus on having a strong spirit as there was on having a strong body. Without a kickass medical team tending to you, having to deal with medical challenges can threaten to crush your spirit—and the spirit is the last show of strength."

That's why Reed-Cote is today working hard to help others navigate the difficulties of growing up with a disability. After completing her bachelor's degree in social work at the University of Victoria, Reed-Cote moved to Vancouver where she volunteers at the Spina Bifida Clinic at BC Children's Hospital, and at Canuck Place, where she helps children and families by sharing her experiences.

Her goal is to become a child life specialist, which is a non-medical professional who works in a hospital setting to help patients mitigate the negative effects of hospitalization. When she's certified next year, she'll be 24 years old.

"These kids want a break from dealing with the harsh reality of living in a hospital, and if you come into it with an open mind and just follow their lead, they will have that ability to play," she says. "If they can learn from my experiences, then that's good."

Since she's finally come into her own as a confident woman with a disability, Reed-Cote has taken on another project that's close to her heart: in October, she started co-hosting GirlTalk, SCI BC's new women's group in Vancouver, with Kristina Shelden, who was injured in a car accident. The group meets monthly at the Murphy Battista Personal Injury Resource Centre, and is open to all women with any kind of disability.

"I want it to be a place where you leave feeling more empowered and more in control of your life, and just knowing that you're not alone," says Reed-Cote. "Sometimes you can be really embarrassed about having a little element of your condition coming up, but if you have an opportunity to talk about it with other women who won't judge and who can just laugh about it with you, then you can move on with your day and not waste energy thinking about it."

She says the focus is positivity through togetherness. "We don't want to get together to feel like victims, but wouldn't it be cool to figure out how to meet all our dreams and goals and aspirations together? Because we'll get there, we're getting things done, we're just doing things differently. It's about picking up tools from other people so you can feel more in control and conquer the day."

Deepa Gajjar is an elementary school teacher who has lived with paraplegia for 16 years. The second GirlTalk meeting was the first peer support group she's ever attended.

"It went really, really well," says Gajjar. "It was nice to have that kind of support and people to talk to who know exactly what you're talking about.

"I talk to my friends about a lot of stuff but no matter how hard they try they could just never completely understand and that's why I was starting to poke around to find a peer support group. I think that there's just a level of comfort that comes with a women's group that might not come with a coed group. Sometimes you can just meet a woman and become friends with her so quickly and divulge information so quickly that way. It feels like such a safe place to go and talk, and to talk about everything, not just injury related things."

Co-hosting GirlTalk, along with her other endeavours, would be enough to keep most people busy, but Reed-Cote is already working on her next two big projects. She has an iPhone app in the works, and is trying to put together a clothing line for women that accommodates their medical conditions in a functional, stylish and sophisticated way.

"It all keeps me on my metaphorical toes," she says. "I just don't want to be inspirational for getting out of bed in the morning."

If you'd like to learn more about the monthly GirlTalk meetup groups or how to set up a local peer group in your own community, visit www.sci-bc.ca/events or contact Jenna Reed-Cote directly by email (jcote@sci-bc.ca).

## What are you reading this holiday season?

If you've enjoyed The Spin magazine throughout 2013, please consider making a donation to help keep it going in years to come. It costs us \$20 to send you The Spin four times per year. You can make a secure donation online at www.sci-bc.ca or by phone—call 1.877.324.3611. We thank you for your support, and wish you the best of the season!



Spinal Cord Injury British Columbia



# Reaction

A training regimen designed to suppress abnormal reflexes appears to modify the nervous system in people with incomplete SCI, significantly improving their ability to walk

p until a few decades ago, scientists believed that the structure and wiring of the brain and central nervous system were fixed and permanent once a person aged beyond childhood. That view changed when research confirmed the existence of neuroplasticity—the ability of the brain to modify its connections as required throughout life.

Researchers in New York recently published details of a study in the *Journal of Neuroscience* that builds on previous neuroplasticity research to significantly improve the walking ability of some people with incomplete SCI.

Dr. Aiko Thompson and Dr. Jonathan Wolpaw, both researchers with the New York State Department of Health and the State University of New York in Albany, conducted the study with 13 participants with incomplete SCI whose ability to walk was impaired by spasticity.

During the first two weeks of the study, all participants received weak electrical stimulation of the nerve controlling a calf muscle, which produced a knee jerk-like reflex. The size of the reflexes were measured to form a baseline for each participant.

During 30 additional sessions over the next ten weeks, nine participants viewed the size of their reflexes on a monitor and were encouraged to suppress them. Meanwhile, four control group participants also received stimulation, but weren't given visual feedback or encouragement to suppress the reflex. The walking speeds of each participant were measured before and after training sessions.

Among the nine participants who were encouraged to suppress their reflex, six learned how to do just that. The result? A 59 percent average increase in walking speed, along with a more symmetrical gait. These improvements weren't seen in the three participants who were unable to suppress their reflexes, or the four participants in the control group.

Wolpaw describes the therapy as "targeted neuroplasticity." To understand how it works, it's important to distinguish between conscious movements and spinal reflexes. Ordinarily, when you want to move a part of your body, your brain sends signals that travel through the spinal cord to the appropriate muscles. Spinal reflexes, on the other hand, provide a way for the body to react and move quickly without a conscious decision from the brain—for example, a spinal reflex allows you to jerk your hand away from a hot stove before your brain has registered the pain, so that you don't get severely burned.

With incomplete SCI, some reflexes may be weakened and others exaggerated, or hyperactive. These hyperactive reflexes can cause spasticity during movement. In this study, it's hyperactive reflexes in the lower leg that participants

A man with an incomplete SCI learns to adjust his spinal reflexes, with help from Dr. Aiko Thompson. (Helen Hayes Hospital photo) learned how to suppress, improving their walking ability in the process. But how did they do this?

Wolpaw explains that, by showing the participants a positive "reward" (a green bar on the screen, as opposed to a red bar) on the video monitor when they were successful at suppressing the reflex, they gradually rewired their nervous system.

"The observation from human and animal studies is that, over the course of the training, about 75 or 80 percent figure out something to do to suppress the reflex," he says. "Now, people say different things—they may say they're meditating, they may say they're trying to anticipate the stimulus or not anticipate it, they may say they're concentrating on not reacting when it occurs. But what people say they're doing may have very little relationship to what's actually going on in their nervous systems."

He explains that all reflexes operate within a range in the spinal cord, and may change within this range from moment to moment. "All of a sudden, when we start providing this feedback, one end of that range is getting rewarded and the other one isn't," he says. "When something gets rewarded, you do it again, and if it doesn't get rewarded, you don't do it again."

"You're being rewarded whether you consciously know it or not, for providing the correct descending activity in your



spinal cord," says Wolpaw. "So that's what's being rewarded—you're setting the descending control at the correct end of its available range. That changes the reflex in the correct direction, and over time, this gradually changes the spinal cord. We're strengthening or weakening connections in the spinal cord."

While this study didn't attempt to observe anatomical or physical changes in the participants' spinal cords, Wolpaw and his colleagues have studied the spinal cords of animals before and after similar training, with anatomical changes being visible under the microscope.

The next step is a larger trial, and Thompson and Wolpaw have already applied for funding. "This was a small trial—the results are highly significant, but it's still a small trial," he says. "We'd like to look at many more people, do more function measures in a completely blinded fashion, and do more follow up months later to see if the benefits persist."

Another goal is to make the system more robust and easier to use, so that

other clinicians could eventually start using it in a rehab setting to complement existing therapies.

"After SCI, changes to the central nervous system occur normally and improvements take place. But you don't often get back to normal function, and the reflex pathway is one of the things that often remains abnormal—it causes

spasticity. While standard rehabilitation therapy does produce plasticity, there's no guarantee that the best pattern of plasticity is going to be produced. And often it isn't—you wind up with an overactive reflex pathway. By doing this targeted training, we get change that often appears to be widespread—even the other leg function improves. You've enabled the nervous system to wind up in a better place. It's still not normal, but functionally it's in a better place than it was before."

Wolpaw says the types of improvements and standardization that are required for widespread clinical use will take years. And, while he cautions it's even further in the future, he en-

Dr. Jonathan Wolpaw

visions a day when people with incomplete SCI can use the technology in their own homes. "In theory," he says, "this entire unit could be automated in a unit that a person at home could strap on to his or her leg, and have a screen

in front of them, and they would be led through the entire process in an automated fashion. Therapists from the clinic could oversee it remotely via the internet—it could be very cost effective and very clinically effective."

A final note: the study, which was partially funded by the National Institute of Neurological Disorders and Stroke (NINDS), does not attempt to explain why only two-thirds of the participants were able to suppress their reflexes and benefit from training. However, Wolpaw says he has found similar response rates in people and animals without SCI.



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Mike Webb (left) and Dexter Assoon at work at Mike's Quality Body Works & Refinishing in Richmond

# **Working Together**

## The Neil Squire Society's newest program provides some powerful incentives to help employers hire people with SCI and other disabilities

uring his 20-year career as a jockey, Dexter Assoon competed in at least 5,000 races, and won 455 of them. But in 2010, his luck took an unexpected turn. He was riding a horse named Bright Star during a race in Kamloops when it happened.

"I was going into a turn, the saddle slipped, and *boom!*, that was the end of that," says Assoon.

He landed on his head, breaking a bone in his skull. He hasn't been able to raise his left hand above his shoulder ever since.

In the three years following his accident, Assoon struggled on income support, trying to upgrade his skills to find a new place for himself in the workforce. In early 2013, thanks to a government skills training grant that paid for his entire tuition, he completed a six-month auto refinishing painting course at Vancouver Community College (VCC).

It was a serendipitous opportunity. "My family used to be in the painting business a long, long time ago," says Assoon. "But instead of going into the painting business, I went into the horse business. Since I couldn't race anymore, I thought I would go back into painting." Unfortunately, after he completed his course, Assoon's progress ground to a halt. "I did really well in this course at VCC, but I only got so far," he says. "There were other courses I could have taken, but it was money I didn't have."

That's when he heard about the Neil Squires Society's new Working Together program, which is designed to help people with disabilities find meaningful work opportunities.

Funded by the Government of Canada's Opportunities Fund for Persons with Disabilities, the Working Together program is completely free for participants, and is open to any Canadian who is unemployed and living with a selfdeclared disability.

To help these individuals find work, the program provides prospective employers with a minimum of six months' subsidized wages, along with worksite accommodations and assistance with paperwork if necessary. And it also provides ongoing support for both the employee and the employer for the duration of the contract.

"There's no model like ours anywhere in the country," says Greg Pyc, national operations manager for the Neil Squire Society. Pyc says that the program is unique because of its four core components. "We have an awareness component to educate employers through our business liaison facilitator," he explains. "We have a job developer who matches clients with employers, we have a case manager who makes sure that our clients have a reasonable back to work action plan, and on top of that, we even have workplace accommodation if needed."

For Assoon, the program couldn't have come at a better time. He connected with one of his instructors from VCC, Mike Webb, who also owns Mike's Quality Body Works & Refinishing in Richmond. The rest is history, as Mike and Dexter became the Working Together program's first success story in BC.

"I thought it was an excellent program," says Webb. "I might have hired Dexter without it—I liked Dexter, and he was a really good student—but yes, it definitely made it a lot easier to do."

Assoon started working at Webb's shop in October. "Things are going really well,"

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he says. "I don't lose interest, I don't get bored, I don't watch the clock. I think as long as you're doing that, you're on the right track for doing something that's fulfilling to you and to other people."

He says that, without the Working Together program, he might have put his career on hold, or perhaps never have made the leap from class to career. "I couldn't afford to take more classes, so I really needed this opportunity to get more in-depth and more professional at what I was doing," he explains. Pyc says that since the program launched in October, demand has been growing. The goal is 200 new work placements this year through the program, and there are already dozens of clients who have called looking for work.

Although the Neil Squire Society only have staff in Burnaby and Penticton, the Working Together program is offered throughout the province, and Pyc says he and his team will do everything to accommodate clients regardless of location.

"The logistics are difficult, but we wouldn't turn anybody away in the other regions," he says. "We just recently matched a client with an employer in Campbell River."

People with disabilities aren't the only ones who are clamoring to sign up.

"When you engage employers, they realize that there's a huge reason to hire people with disabilities," says Pyc. "Once you get to the (business) owner, and they realize that they can get valued employees who can really benefit their business, they're sold."

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# Welcome to the Jungle

#### Victoria Butterfly Gardens gives visitors a fully accessible rainforest experience

nyone who lives in Victoria or has been a tourist in the city knows about Butchart Gardens. This world famous group of wheelchair accessible floral display gardens, located just outside of Victoria in Brentwood Bay, receives more than a million visitors each year.

Located just five minutes away, Victoria Butterfly Gardens isn't as well known but it might be soon.

Butterfly Gardens is a 12,000 square foot, climate-controlled indoor facility that lets visitors experience the sights, sounds and scents of a tropical jungle. They can wander along paths through lush tropical rain forest vegetation, including vanilla on the vine, papaya, bougainvillea, orchids, and more. Along the way, they can get up close and personal with flamingos, parrots, ibis, frogs, lizards, geckos, turtles, koi, and other tropical fish. And, of course, there are the butterflies—up to 75 exotic species from around the world are represented in the gardens. All of the butterflies and other creatures live freely within the facility—there are no cages or tanks.

Victoria Butterfly Gardens is a completely green facility that embraces recycling, organic cultivation, biological pest control as opposed to pesticides, and a zero-use policy when it comes to synthetic cleaning products.

Best of all, Victoria Butterfly Gardens is committed to accessibility. "We have accessible washroom facilities and it's easy to get around the gardens and the building in a wheelchair," says general manager David Roberts. "Wheelchair accessibility is important to me personally, as my dad suffers from MS and uses a wheelchair. I look at this through his eyes and would want him and everyone in that situation to enjoy our little piece of paradise. This is a place where you can lose yourself in the warmth and beauty that surround you. The thought that someone would not be able to get that experience just because of their inability to walk is not acceptable to me. As we move into

the winter this becomes even more important to all of our guests."

While Victoria Butterfly Gardens is entirely accessible inside, Roberts explains that some visitors with higher levels of disability may need assistance with the entrance doors. "We do not have automated doors, as this would allow our butterflies and creatures a chance to escape," he says. "We are, of course, happy to help in any way that we can."

Victoria Butterfly Gardens was recently awarded the 2013 Certificate of Excellence from TripAdvisor, and was also the winner of Where Canada's 2012 award for "Canada's Best New or Improved Attraction." It's located at 1461 Benvenuto Avenue in Brentwood Bay, about 20 minutes from the Swartz Bay BC Ferries terminal. Check it out online at www.butterflygardens.com.

Interested in promoting a wheelchair accessible British Columbia travel destination or attraction in The Spin? Email cvallantin@sci-bc.ca for details.

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# Paying our respects to... The Quadrather

Duncan Campbell receives the Paralympic Order for his role in developing and promoting the incredibly popular game of wheelchair rugby.

n 1976, Duncan Campbell and four buddies in Winnipeg were thinking outside the box before that term ever became popular. Through trial and error, they developed a game that would become a passion for wheelchair users around the world and a highlight of Paralympic competition.

On November 23rd, during a ceremony in Athens, Greece, Campbell was presented with the International Paralympic Committee (IPC) Paralympic Order—the highest tribute a person connected with the Paralympic Movement can achieve—for the role he has played in the development and promotion of wheelchair rugby.

Campbell, affectionately known as "the quadfather", is acknowledged as the creator of the game which was originally named murderball. But he's quick to point out that it took a team effort to develop this highly competitive, high impact and hugely popular team sport.

"I am extremely appreciative of this award and it means a ton, but I look back at all the other people who contributed to this happening," says Campbell. "Initially, five individuals tried all sorts of things, and everyone inputted to some degree. I feel I'm kind of a figurehead for hundreds of people who worked hard since 1976 to create and develop this sport from a rehab game to a Paralympic competition with more than 30 national teams worldwide."

While Campbell makes it clear that it took a team to invent and develop the



*Five pioneers in 1976:* From left to right, Jerry Terwin, Duncan Campbell, Randy Dueck, Paul LeJeune and Chris Sargent

sport, it must be acknowledged that no one has worked harder in the past 37 years to elevate the game to the huge popularity it enjoys today. He's been a member of Canada's national team, promoted the sport tirelessly, personally introduced it to thousands of participants, and mentored some of our country's greatest players such as Garett Hickling and Ian Chan.

And he's far from done. These days, in the Canadian Wheelchair Sports Association offices in Vancouver (located in the same building as us at SCI BC) Campbell works as Director of Development for Wheelchair Rugby Canada and the National Coordinator of CWSA's Bridging the G a p program, which introduces wheelchair rugby and several other sports to thousands of wheelchair users each year. He wears numerous other hats, including that of a member of the International Wheelchair Rugby Federation board of directors. And of course, he's still a passionate player of the game.

It's been a journey that, when he looks back, Campbell still finds amazing.

"We kind of knew that other quads would love to play the game once we got a semblance of how to play and the rules, but we never thought it would

get to this," he says. "It was really not our intent to develop a Paralympic Sport—in fact, the Paralympics, as they are today, did not exist back in the 70's. We just wanted to play a team sport and had an idea that other quads would too. It's an understatement to say I'm amazed at where it has gone and continues to go."

He adds that wheelchair rugby has given him much more than he could ever give to it. "Through wheelchair rugby, I have travelled the world, and made friends around the world. It's even provided gainful employment. The sport has kept me fit and healthy

for a long time and I'm sure it will continue to. I can't imagine my life without this sport." ■



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