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AUTUMN 2013

AD and Immunity

New research is shedding light on the connection between autonomic dysreflexia and your immune system



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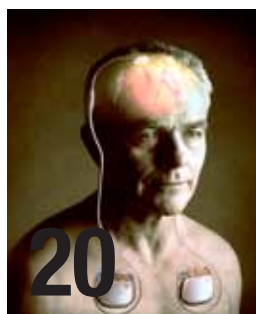
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Basic Necessities

What's the number one reason that people call our toll-free InfoLine service? Accessible housing.

That's not particularly surprising. Access to functional and affordable housing is a fundamental need for everyone. For those with a physical disability, however, finding such housing can be an incredibly daunting, frustrating and often impossible task. This is particularly true in BC, where any housing—rental or owned—is incredibly expensive, and where there's a limited stock of accessible or easily adaptable homes.

Meanwhile, the need for accessible housing is growing. The demographic bulge of the aging baby boomers alone is creating this need.

However, housing is a complex issue, and availability of accessible housing is just one aspect. Affordability is another, particularly for all those facing economic barriers and challenges resulting from their disability.

Can we count on charity, goodwill or a sense of moral obligation to change the situation? I don't believe so. But I do believe that builders, developers and even individuals are beginning to understand that building accessible, visitable and/or adaptable housing today will give them a competitive advantage in the near and long-term, as the base of potential buyers or renters will be greatly expanded.

Change of this nature is always too slow, but at least there are encouraging signs that change is taking place. As reported on the SCI-BC.ca blog, the City of Vancouver announced this summer that it's introducing a bylaw requiring the interior of all new housing to meet new accessibility standards.

Spinal Cord Injury BC has also launched a website to connect accessible housing seekers with housing providers, and created a list of resources to help all stakeholders in the housing game. This service, found at AccessibleHousingBC.ca, recently caught the attention of researchers commissioned by the Real Estate Institute of BC to undertake a scoping study on the need for a provincial registry of accessible and adaptable housing in BC. This led to a half-day, multi-stakeholder forum to further explore interest in creating such a registry. There was unanimous support for the need of such a registry, with SCI BC's housing board on the table as a potential option to be that registry. This initiative will continue to move ahead and we hope a registry will be implemented soon.

The registry, however, is only part of what has been exciting about this process. The willingness of realtors, certification bodies, developers, city planners, community groups and researchers to get together and tackle this issue is where the real magic lies. It's only through this type of collaboration that access to accessible and affordable housing will be improved.

In an ideal world, we wouldn't talk of visitable, accessible or adaptable housing. We would be talking about inclusive housing that works for everyone, regardless of ability. Maybe we'll get there someday. In the meantime, we need to keep making steps toward enhancing access to housing that maximizes independence and quality of life for those with physical disabilities.

- Chris McBride, Executive Director, SCI BC



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

Return undeliverable Canadian addresses to:
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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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gear & gadgets



Innovations

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WALKING CHAIR

You certainly can't call this prototype mobility device a wheelchair. Developed by Martin Harris, a 21-year-old British college student, the Walking Chair moves via 12 steel legs working in pairs. The design enables the user to cross terrain wheelchairs can't—for example, snow, sand, mud, and modest slopes (unfortunately, it doesn't climb stairs). It's powered by standard power wheelchair motors and batteries, and operated with a standard power chair joystick. Martin based the Walking Chair on the work of artist Theo Jansen, a sculptor who created the Strandbeest, a mechanical steel creature with legs. The Walking Chair moves smoothly at speeds up to seven kilometres per hour. Is it an oddity or does it have a place in the world of seated mobility? Only time will tell. Visit www.walkingchair.co.uk for more details, and search YouTube to see a video of the chair in action.



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ICON WHEELCHAIR

The Icon wheelchair is an adjustable, lightweight, everyday chair that has the benefit of suspension. Adjustments can be made easily with minimal tools, so you don't need to worry about having to choose permanent settings that can never be changed once a chair is built. Change your back angle when you're sitting at your desk, or change your seat height when you change your cushion—the Icon's geometry changes with you. The suspension allows the user to navigate bumps like raised doorframes and curbs easily and without fatigue, but can be locked when not needed. The modularity of the Icon offers flexibility to change every component, including wheel sizes. Parts can be swapped out for new or different ones at will for different terrain or as the user's body changes. At the helm of Icon are two Canadian wheelchair users with many years of experience in the industry: Christian Bagg, an accomplished machinist, and Jeff Adams, a champion Paralympic track athlete. They have teamed together to create a chair that is lightweight, versatile, and aesthetically pleasing. For more information and to find out where to purchase, visit www.iconwheelchairs.com.





Great Gatsby at the races.

Peers, family, friends & donors are invited to join Spinal Cord Injury BC on September 28 for a day of horse racing at the Hastings Racecourse. This year we're celebrating the races in style with a Great Gatsby theme. Come in your best 1920's attire and enjoy a day of thrilling racing, betting, a silent auction, food, drinks, costumes and more! The Hastings Racecourse is wheelchair accessible and served by TransLink. To RSVP, please contact Marnie at mdevries@sci-bc.ca or 604.326.1233.



Free Yoga workshops.

Spinal Cord Injury BC is partnering with Mary-Jo Fetterly to offer free yoga workshops at the Blusson Spinal Cord Centre in Vancouver. There are two workshops: September 25 from 7 to 9 PM, and October 19 from 1 to 4 PM. Mary-Jo is a high-level quadriplegic who has more than a decade of yoga teaching experience. No previous yoga experience is necessary and the workshops are open to anyone with an SCI or other physical disability. To RSVP contact Marnie at mdevries@sci-bc.ca or 604.326.1233.



Okanagan fundraiser.

On October 24, Spinal Cord Injury BC will host its very first Okanagan fundraiser at Kelowna's Laurel Packinghouse, a heritage landmark which is home to the BC Orchard Industry Museum and the BC Wine Museum & VQA Wine Shop. Tickets are \$30 and admission includes refreshments, entertainment, and an opportunity for donors to meet our Okanagan Peer staff and learn how their donations will impact their local community. For more information, contact Shelley at smilstein@sci-bc.ca or 604.326.1222.

New videos illustrate the impact of Spinal Cord Injury BC



"What do you do, anyway?"

It's a question people often ask about our organization. We could respond by trying to explain how people with SCI have benefited from our Peer Program and our Information Services. But on reflection, we decided that our Peers could tell the story on video in a much more powerful way.

In July, we released two new short videos featuring Peers explaining the impact Spinal Cord Injury BC has had in their lives.

The first video tells the story of Kelowna's Paul Gifford, who has lived with a high level quadriplegic injury for almost 35 years. Check out www.MeetPaul.ca to watch how Spinal Cord Injury

BC helped Paul climb a mountain, and see the effect this had on him and his family. That's a screenshot from the video to the left.

The second video stars Scott James, who went from being angry and isolated after his injury to becoming an athlete and a support to other Peers in the Okanagan, thanks in part to his involvement with Spinal Cord Injury BC. A screenshot from that video is shown below.

More videos are on the way. To watch our Peers and their family members tell their story, or to learn more about what we do, visit www.youtube.ca/spinalcordinjurybc and look for our Impact playlist.



AD and Immunity

A new study sheds light on the relationship between autonomic dysreflexia and immune suppression, two well-known secondary health complications of SCI

As most readers well know, people with SCI are repeatedly warned

during rehab about the causes and dangers of autonomic dysreflexia (AD)—abnormally high blood pressure that can lead to pulmonary embolism, stroke and, in severe cases, death. And, either during rehab or at some other point in their post-injury life, people also learn that their SCI can somehow compromise their immune system, making it difficult for them to fight off a multitude of dangerous infections.

But it appears there's a connection between these two secondary health complications—one that's only now emerging, thanks to groundbreaking research led by Dr. Phil Popovich of The Center for Brain and Spinal Cord Repair at Ohio State University.

In a study recently published in *The Journal of Neuroscience*, Popovich and his colleagues provide compelling evidence that AD is a direct cause of immune suppression in animals and people with SCI.

"Our research offers an explanation for why people with SCI develop a condition referred to as central immune depression syndrome," says Popovich. "Their immune systems, which are required to fight off infection, are suppressed due to damage or malfunction in regions of the spinal cord that help control immune function."

The implications can be a compromised ability to fight bladder infections, pneumonia, and even infected pressure ulcers—all of which can have deadly implications.

Fortunately, it's not all bad news: Popovich's study also concludes that immune suppression in spinal injured mice can be restored through drug treatment, suggesting that this also may be possible in humans. It also suggests that any method of reducing or eliminating bouts of AD in people with SCI could have a real benefit in terms of boosting their ability to fight off common infections.

Popovich and his colleagues began unravelling this mystery years ago as they strived to understand how neuron survival and axon growth after injury are affected by immune cells—a range of cells that include white blood cells produced by the body to fight bacteria, viruses and other pathogens.

"At the site of injury, immune cells are prevalent, and they persist for a long time after injury—yet they're not found in the uninjured spinal cord," says Popovich. "Because it's well known that the tissues that generate and store immune cells are hardwired into the nervous system, we suspected that SCI would affect communication between the nervous and immune systems. Understanding how might allow us to improve repair in the nervous system."

Popovich also noted that SCI is a "physical stressor" that stimulates release of an abnormally high level of hormones, including glucocorticoids, that can suppress immune function throughout the body. While studying this in mice, he and his colleagues also discovered that the immune organs—for example, the thymus gland, spleen and lymph—were abnormally small, indicating some type of atrophy or cell death was occurring. And, when they tested the ability of immune cells to respond to a threat, they found that the immune response was suppressed in these mice.

He reasoned that such a profound and wide-reaching effect of SCI on immune function was sure to dampen the body's ability to defend itself against infection. "Importantly, these data supported various older clinical reports in human SCI where there was evidence that the immune system is suppressed for prolonged periods after SCI," says Popovich.

But up to that point, there was no apparent connection between AD and immune suppression.

"The link between autonomic dysreflexia and immune suppression was a bit more complicated and built during several years of work," Popovich says.

Up to that point, all Popovich's findings were obtained from studies of mice with acute, or very recent, injuries. Logically, he assumed that the abnormal reaction of high levels of glucocorticoids and the subsequent immune suppression response was the result of the stress response and compromised communication

between the nervous and immune systems immediately following injury. It was also logical to assume that normal immune function would resume with healing over time.

"However, when we started looking at the immune organs of mice with more chronic SCI several weeks post-injury, we found that they were even smaller and more dysfunctional than at earlier times post-injury," says Popovich. "Something was actively causing long-term immune suppression. Since AD is a common problem after high level SCI, and because the spinal circuitry that triggers AD also affects immune function, we set out to explore whether there was a direct relationship between these post-injury complications."

That brings us to the most recent study, again involving spinal injured mice. As explained in detail in *The Journal of Neuroscience* article, the results confirmed Popovich's theory about AD. He and his colleagues showed that AD not only develops spontaneously, but becomes more frequent as time passes. They also demonstrated that AD directly triggers the release of glucocorticoids and another hormone, norepinephrine.

"We've shown that these hormones synergize to kill white blood cells, or leukocytes, which are the primary frontline defense mechanism of the immune system," says Popovich. "These hormones do not discriminate. All white blood cells seem to be affected. We're not quite sure yet how long this lasts; however, since AD does not resolve and, in fact, may get worse or more frequent with time, there is a constant recurrent source of these hormones that bombard the immune system. This may explain why immune suppression is a chronic phenomenon, especially after high level SCI."

As Popovich and his colleagues were working on the mice studies at Ohio State University, another component of the study was being undertaken by Dr. Mark Nash, a colleague of Popovich's at The Miami Project to Cure Paralysis. Nash's goal was to demonstrate that Popovich's findings with mice were relevant in humans. An individual with a high level SCI agreed to participate in a pilot experiment. After establishing baseline measurement of both hormones and white blood cell counts, Nash and his team triggered a mild bout of AD in this individual. As with the mice, they found that this brief bout of AD caused a significant "storm" of immune suppressive hormones in the blood stream, and also a significant reduction in white blood cells.

"We need to repeat this in a larger cohort of individuals to definitely prove cause-effect,"

"I see this as a potential way to boost immune function for those who suffer from recurrent infection or for individuals who have frequent AD and need to receive immunizations. Without a properly functioning immune system, protective vaccines, including those designed to fight off influenza or pneumonia, may have little effect." – Dr. Phil Popovich



says Popovich. "But the results are consistent with what we see in our controlled animal models of SCI."

The findings that AD triggers immune suppression is even worse when you factor in emerging evidence from Popovich and others that simple, everyday occurrences that activate normal spinal autonomic reflexes, such as having bowel movements or emptying the bladder, become hyperactive and mildly dysreflexic in people with SCI—particularly in those with higher levels of injury. In other words, AD and its subsequent immune suppression response is occurring often.

But, as we told you earlier in this article, there's a promising aspect to this research. In the study, Popovich and colleagues were able to restore immune function in mice using Mifepristone and butoxamine, drugs that inhibit glucocorticoids and norepinephrine respectively. Mifepristone has been widely used in humans as the active ingredient in the "morning after pill" and for treating cancers. Butoxamine is a beta-blocker that

isn't widely used in people.

Clearly, a great deal of testing for safety and efficacy is required before these or any other drugs could be used with humans. But Popovich believes their efficacy in mice means that there's a possibility that a immune boosting treatment could be developed for people after SCI. "I see this as a potential way to boost immune function for those who suffer from recurrent infection or for individuals who have frequent AD and need to receive immunizations," he says. "Without a properly functioning immune system, protective vaccines, including those designed to fight off influenza or pneumonia, may have little effect."

Popovich also points out that similar results could result from any treatment developed to reduce or eliminate AD—for example, deep brain stimulation, the subject of a study beginning this month at The Miami Project (see page 20).

"If the deep brain stimulation also helps restore a semblance of normal communication between autonomic

neurons in the spinal cord and the immune system, there may be less immune cell death in response to AD. Boosting immune function or minimizing the effects of AD should improve immune function, which is of paramount importance in fighting any type of infection." ■

What is autonomic dysreflexia?

Autonomic dysreflexia (AD) is a potentially life-threatening complication of SCI at T6 or above. It's caused by various painful or irritating stimuli below the level of the injury. This in turn triggers blood pressure which may rise dangerously. The most typical cause of AD is a distended bladder. Other causes could be overfull bowel, constipation or impaction, pressure sore, sunburn, ingrown toenail, skin irritant such as rivet on jeans, infection, tight clothing, or fracture. Symptoms may include headache, sweating, flushed face, anxiety, or lowered pulse rate. Treatment is to remove the cause. Once the cause is removed, blood pressure will return to normal.

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A Sport is Born

When the rapidly developing sport of floorball started being played by wheelchair athletes around the world, a long-established team of BC floor hockey players was ready to embrace it



In 1989, Adam Frost, Hilary Brown and Jaimie Borisoff were three young wheelchair athletes looking for a way to break a sweat in the summertime. So they did what any bunch of Canadian-bred buddies might do: they started a floor hockey drop-in session.

"We had 12 to 15 people show up pretty regularly I guess, and it was just something that we did in the summer to stay in shape," says Frost, who has since made a career in sport and is today coach of both the BC Wheelchair Rugby Team and Japan's Wheelchair Rugby

Team. "I wouldn't even say there were any rules—you just couldn't high-stick."

For the most part, the same group of guys have been shooting pucks at each other for almost 25 years. Aside from competing in a few tournaments in California, they've stuck to themselves, as the game never gained traction globally.

Little did they know that, at the same time, a new sport was being born in Europe. It was called floorball, and it blended aspects of hockey, soccer, basketball, and lacrosse.

"Floorball grew out of the need to

have a gymnasium sport, a hockey sport and a safe sport," explains Greg Beaudin, a board member and founder of the BC Floorball Federation. "The history of floorball is a bit muddy, but basically, floor hockey was developed in the '50s and '60s in the USA and Canada, and some Swedish recreational professionals took floor hockey sticks to Sweden and reengineered them. They made them shorter, made them lighter, and made them more hollow, so they're more versatile and developed for an indoor gym."

The International Federation of Floor-

ball celebrated its 25th anniversary last year, and Beaudin says that there are now participants in 60 countries playing the sport around the world, from Malaysia to Brazil, Jamaica to Sierra Leone and South Africa to Finland. In 2010, floorball was even approved as a summer Olympic sport, but we won't see it at the Olympics until it gets accepted by the hosting country of 2020.

The secret to the sport's success, says Beaudin, is the gear—or lack of it. "It's growing quite rapidly and it's all due to the easy, light-weight nature of it. With ball hockey, there's too much equipment needed. You need gloves and shin guards and helmets if you play with kids. With floorball, you don't need any protective equipment. No gloves, no helmet, no shin guards. When you're talking about a country like Mozambique, you can bring a bag of sticks, 20 balls, you can run a clinic and 'Bam', they learn a new sport."

Because of the lightweight gear, floorball has also become increasingly popular among wheelchair athletes around the world, so Beaudin was eager to get a wheelchair floorball team started in Canada. "My sister is in a wheelchair and that's how I got interested in wheelchair sports," he says. "When I started playing floorball and saw the inclusivity part of it, I thought, 'Wow, this is a great opportunity to bring a great sport to the wheelchair community.'"

When Frost and other members of his wheelchair floor hockey team met Beaudin and got to know floorball, they were immediately onside. "Floorball is for everybody," says Frost. "The stick is light enough that it can work for quads, it can work for kids with disabilities, it can work for anybody who can push a manual wheelchair."

Frost and his team learned the rules of the game and started practicing twice a week this summer. So far, they've adapted to it well—after all, it's a simple game, says Frost. "You have to put the ball in

the net to score. The biggest difference compared to floor hockey is that when you check somebody, you have to attack the ball before making contact with their stick. It's like soccer in that way. And it's like hockey in that your stick can't go above your wheels. It's also like lacrosse because the sticks are curved in such a way that you can pick up the ball on your stick and whip it around."

The best part of the team's transition to floorball is that they have instant competition. In fact, they're been invited to represent Canada this October at the Para Games Breda in the Netherlands. "We're looking forward to playing competition other than ourselves," says Frost. "We've played the same group for more than 20 years! It will be nice to play with other teams for sure."

Although they've only been playing the game officially for one summer, Frost and his teammates aren't intimidated by the competition, which includes teams from at least seven other countries. "How can I say this nicely? We don't expect to lose, let's put it that way. Even though the sport is new to us, our many years of ball hockey experience will allow us to be competitive."

So far, six players have committed, and Frost is hoping to recruit a few more. "We have a couple of ringers, so we should compete well. One of them is Pat Anderson, who is arguably one of the best para athletes in the world. He's won three gold medals in wheelchair basketball."

As for the Europeans, they're elated

to have a Canadian para team on board. Frost says the BC Wheelchair Sports Association has already been approached to host an international floorball tournament, but for now, the association is focused on spreading the game locally.

BC Wheelchair Sports is only planning on hosting the sport in the summer months and during early fall, because once the ice goes back in the rink, players tend to go back to wheelchair rugby or wheelchair basketball. However, if there's enough interest, Frost says the association will try to find a way to keep floorball games going.

He adds that anyone who can push a manual chair is welcome. "We wouldn't turn anybody away, but we are a manual wheelchair floorball league right now."

As for Beaudin, he's just happy to have more opportunities to watch the sport being played. "There's a lot of playmaking and magic that goes on," he says. "You can have a lot of creativity because of the lightness of the stick and the ball. It's very fast, it's pretty poetic."

If you're living in the lower mainland and would like to learn more about floorball or join the only Canadian wheelchair floorball team currently in existence, email Adam Frost (adam@bcwheelchair-sports.com).

If you live elsewhere in BC, Adam is still the man to get in touch with.

"If there's a community champion who would like to start something locally where they live, we're certainly happy to support them any way we can." ■



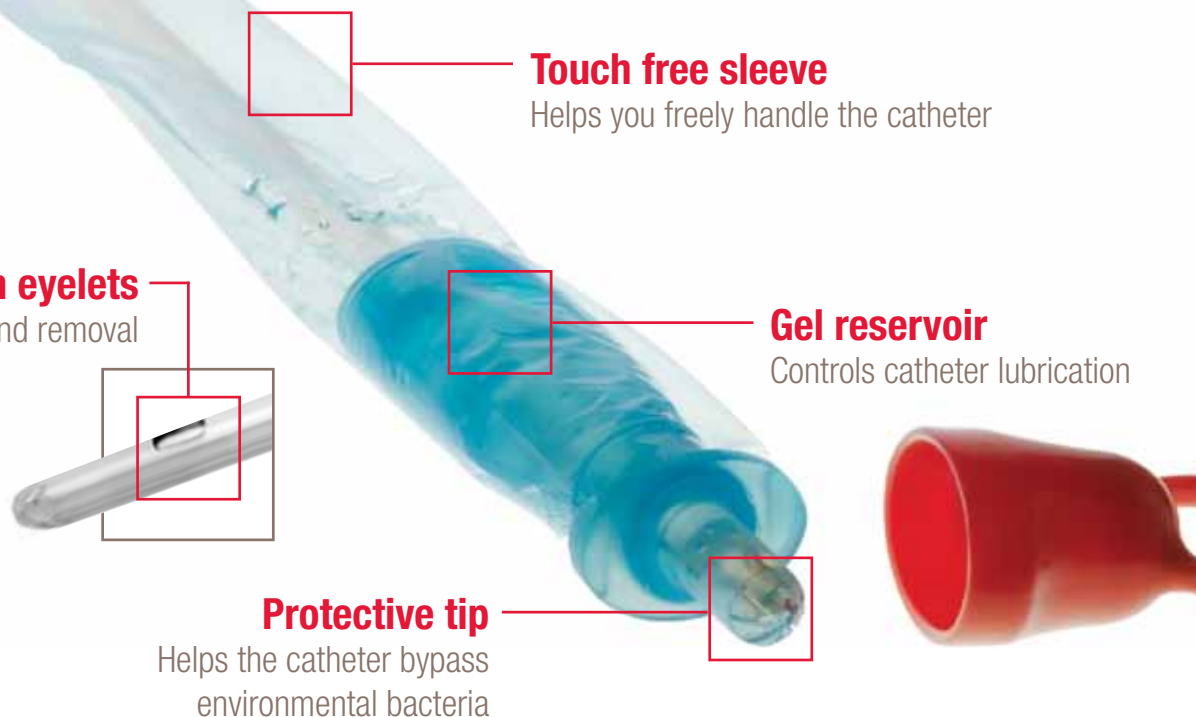
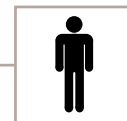
Facing page: Adam Scott (left) and Doug Brown battle for the ball. Right: Jaimie Borisoff fends off Paul Finkbeiner.

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Belt it out!



Singing might improve your respiratory health, not to mention your frame of mind

Since she started working as a registered music therapist, Dr. Jeanette Tamplin has worked with numerous patients with quadriplegia who had difficulty projecting their voices. One treatment she's employed for these patients is a music therapy singing program—an approach that has often produced surprising improvements.

"After anecdotally seeing many patients improve their voice projection, I decided that it would be good to try to quantitatively measure the effect of singing training on a range of areas for people with quadriplegia," says Tamplin,

who specializes in neurorehabilitation of people who have sustained an SCI or other neurological injury or disorder.

Tamplin assembled a specialised research

team and successfully applied for a grant to conduct this research where she works at the Royal Talbot Rehabilitation Centre in Melbourne, Australia. The study, which was conducted during 2009 and 2010, involved two phases.

The first phase compared the respiratory and vocal function of people with quadriplegia to an able-bodied control group. As expected, results showed that participants with quadriplegia exhibited respiratory impairments, and also perceived problems with their voice. When compared with able-bodied people, they recruited more accessory respiratory muscles when speaking and singing—especially when louder. They also had reduced dynamic range (the difference between the quietest and loudest passages they were able to vocalize) and maximum phonation length (the length they could hold a note or speak without needing to breathe).

The second phase was a randomized controlled trial which saw participants with quadriplegia randomly assigned to either 12 weeks of a group therapeutic singing program or a group music appreciation and relaxation program. Following 12 weeks of singing, people with quadriplegia demonstrated clear improvement trends in respiratory function and strength, and significant improvements in voice projection and endurance when compared to the music appreciation control group. Both programs, however, had a positive effect on mood.

Tamplin and her team concluded that most people with quadriplegia can speak and sing adequately, but employ unusual techniques to compensate for the respiratory compromise that their injury causes. More importantly, they concluded that, while the magnitude of the improvement is uncertain and further research is needed, singing training



can facilitate improvements in respiratory and vocal function.

"After the singing training, one person reported being able to shout at the football game again," says Tamplin. "Another said he was able to call out to someone in the next room if he needed help. Some participants became very good at singing long notes. And some of the people with C4 quadriplegia said that, aside from being enjoyable and rewarding, singing was one of the only things they could do completely independently."

So is it possible that taking singing training, and then continuing to sing regularly, could help people avoid some serious respiratory illnesses?

"We definitely think this is possible," says Tamplin. "This was one of the key motivators for my research. We thought that, if singing can improve respiratory function, then hopefully it can help people to cough, reduce the incidence of respiratory tract infections, and reduce respiratory-related hospital admissions."

Tamplin adds there were also some unexpected outcomes—for example, peer support and friendships that developed out of the music therapy groups. "People also found the experience motivated them to get out of the house and socialise, not only in the music therapy groups, but also in other areas of their life, such as going to the gym or walking the dog," she says.

She believes that even one-on-one singing lessons (necessary to learn proper technique) followed by a daily regimen of singing would be beneficial for people with quadriplegia.

"I think that this is a great idea. Any type of singing is good, both physically and emotionally. Singing lessons that emphasise respiratory support in a way that's accessible for people with quadriplegia would be particularly beneficial. The benefits of group singing, however, also add the elements of social connection and mutual satisfaction derived from a shared pleasurable experience."

Tamplin's next goal is to replicate this study with one that involves a larger number of people. She concedes that one of the impeding factors to participation in the group approach is distance and the difficulties relating to travel. One solution might be a tele-health study using online singing groups who meet online via Skype, and Tamplin is currently exploring the feasibility of this approach.

Tamplin presented the results of her work as her PhD thesis, completed in 2012. Not only was it accepted, it resulted in her recently being awarded a University of Melbourne Chancellor's Prize for excellence.

"I've always been passionate about music, and when I discovered music therapy as a career path it seemed like the perfect marriage between music and health," says Tamplin. "I've been working in neurorehabilitation ever since I graduated nearly 15 years ago, and I still love it!" ■



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The Perfect Garden

As Burnaby's Anna McLeod explains, the painstaking process of creating a visually stunning garden resulted in an unexpected epiphany.

For the past few years I've been on a journey—one that I wasn't initially aware that I was on, strange as that may seem. It gradually dawned on me that there was something compelling and pushing me, but I couldn't quite put my finger on what it was.

Of course, I reasoned that it must partially stem from the fact that my life had changed in the most drastic way possible when I became quadriplegic and dependent on a wheelchair. Months of recovery and years of rehabilitation were needed to recover the smallest movements that I previously took for granted. Anyone who has been through a similar situation will understand the long, hard road that must be travelled just to regain a tiny fraction of the life you once knew.

But it was more than that. As the years passed (faster than I thought possible after seemingly endless days in hospital and rehab), a new feeling started to nibble at my subconscious. It was faint at first, but its intensity grew like a runaway snowball as more time went by.

Looking back, I suppose it began not long after rehab

as I struggled to adjust to everyday life, which was completely overwhelming at times. After awhile, I started to be able to manage better. But I'm not sure this was necessarily a good thing—now I had more time to think about my fate, and where I was headed in life. Sometimes it was a very bleak picture, which would throw me into periods of deep depression. There were times I was in that void so deep and so dark that I was sure there was no way out. Those were terrible days.

Then I began to think, "I must do something useful. I need to be a useful member of society, a contributing member to my family, and a good friend to my supportive husband and loyal friends." It became clear to me that everyone, regardless of ability, needs to have a sense of purpose and to feel they're contributing in some way. The problem, of course, was how to do that without the use of my arms and legs, with severely limited mobility, and in the midst of the usual post-injury medical complications.

I no longer had my career, and many of the things I used to excel at could only be fleetingly enjoyed vicari-



Anna and her husband Terry

ously through the experiences of others. I was determined to build on this. I started small by rediscovering my love of hosting—prior to my injury, I loved cooking, trying different cuisines and staging elaborate dinners. It took me seven years to teach my assistant to be an extension of me in the kitchen and dining room—cooking complicated dishes, setting a table, opening a bottle of wine, and learning other aspects of entertaining. I received plenty of compliments, some incredulous stares and much praise.

After a while, that wasn't enough. Almost anyone can teach someone else to cook. There was little personal satisfaction there. So I turned my attention to gardening—something that turned out to be substantially more difficult to teach and enjoy vicariously through another's experiences. How do you show someone how to pull a weed without physically demonstrating—how you have to pull gently, wait for the right tug, then pull it up slowly so as not to disturb the root system of the surrounding plants, and yet pull firmly enough to ensure you

remove the entire root structure of the weed? In particular, how do you impart this knowledge to someone who's never even gazed on a garden, except at a park? How do you explain the fragility of a seedling ready to be transplanted, or how to check the soil with your finger to gauge moisture? Deadheading, fertilizing, dividing and much more—it's difficult to explain without being able to demonstrate. Then what to do when, after you've taught the basics over a period of years, your assistant decides to move on, and you have to start from square one with your new assistant?

After many years of trials and tribulations, mistakes, and yes, some blood, sweat and tears, I finally got to the point where my efforts began coming to fruition. I received many compliments from neighbors, friends, and family. My thoughts and dreams started to run rampant, and I began to think bigger. "Maybe you'll enter your garden in the local contests, maybe the international contests," I thought. The possibilities become endless when I started dreaming.

Then, one sultry July afternoon, as I sat in my perfectly manicured masterpiece surrounded by lush growth and blooms of brilliant colors, finally able to sit back and breathe after all the hard work over the years, I had my "aha" moment that simultaneously made me squirm with embarrassment and yet see my world with stunning clarity. This moment will always stay with me.

In a flash, I realized it's not about planting and designing the perfect garden per se. Nor is it about driving yourself harder and pushing the people around you to achieve your dreams. Instead,

it's about finding a place where you fit, where you feel wanted, where you feel safe and comfortable. It's about willingly and freely sharing yourself, your ideas, and your dreams with others. "Share your knowledge with others, for it will make you immortal," the Dalai Lama once said.

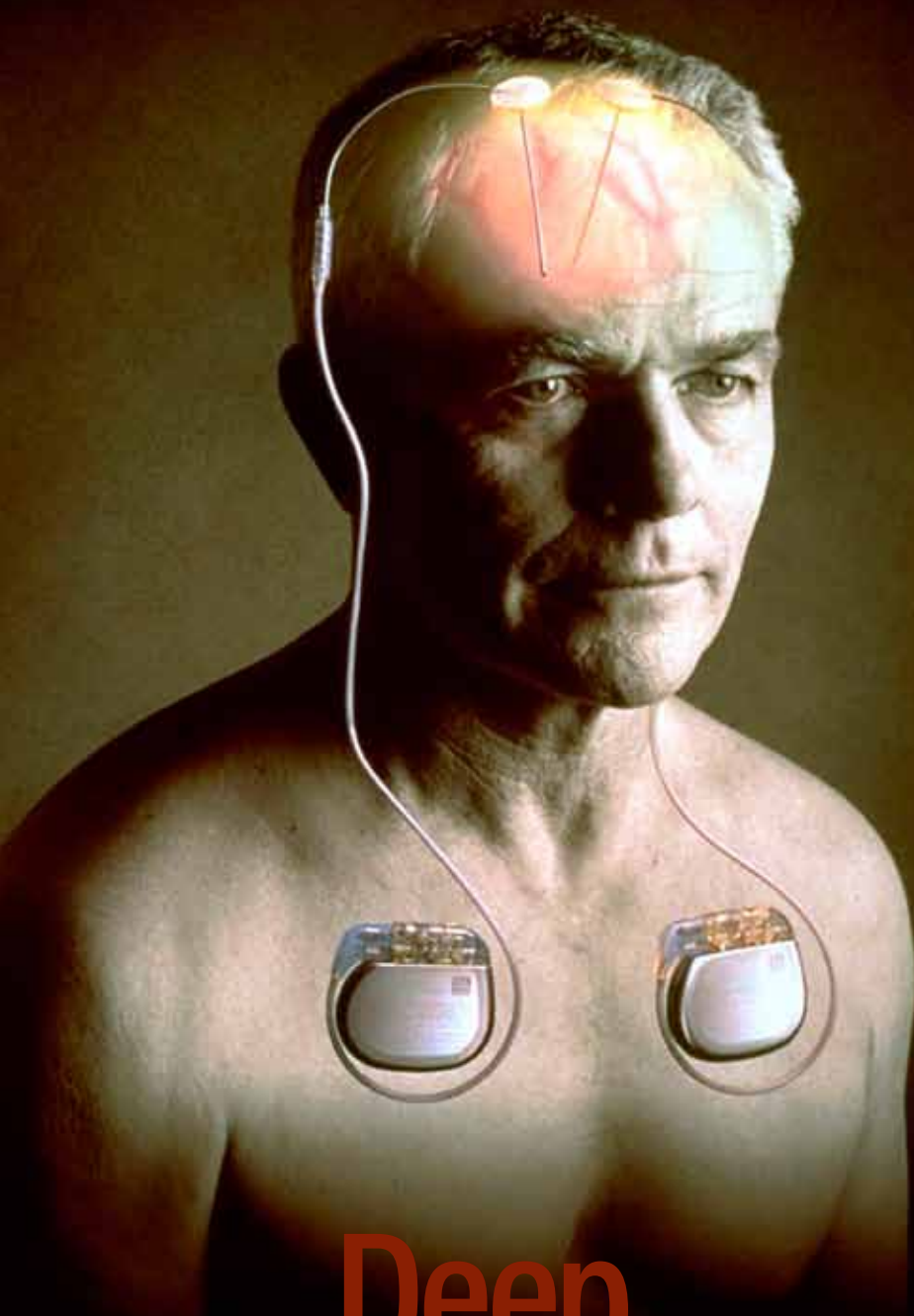
Unconsciously, in the garden, I was carving a little piece of the world for myself where I could feel safe and protected; a place where I could temporarily forget all the turmoil and uncertainties in my life. When I had completed this transformation to the garden, I discovered that the most important things to me were not what I could accomplish. Instead, I realized that what I prized most were my family, my friends, my assistants, and my husband, who had been there every step of the way to catch me when I fell—figuratively and literally. Equally important was the peace of mind that I'd found inadvertently along the journey.

Everyone struggles to find their place in life. Some find it early. Some never do. Many, I believe, are like me: they discover their place after a great deal of life experience, highs and lows, and soul searching.

It's all about finding a place for yourself where you can clear your head, still your soul, and let peace and serenity bathe you in its warmth. Some people may find this in yoga, hiking, or meditation. For me, that place is my garden. ■

Anna McLeod lives in Burnaby with her husband Terry and their new puppy, Presley Peanut. She sustained a C4,5,6,7 SCI in April 1994. Your guest submissions to The Spin are welcome—email Candice at cvallantin@sci-bc.ca for guidelines.





Deep Stimulus

Dr. Ian Hentall and his colleagues at The Miami Project to Cure Paralysis are poised to begin testing deep brain stimulation as a method of reducing chronic pain and autonomic dysreflexia in people with SCI

Borrowing a treatment strategy proven to work for Parkinson's disease, a team of researchers at The Miami Project to Cure Paralysis will begin a clinical trial this fall to see if electrically stimulating the brains of people with SCI can reduce their pain and episodes of autonomic dysreflexia (AD)—perhaps even permanently.

The groundbreaking study is being led by Dr. Ian Hentall, research associate professor of neurological surgery, and Dr. Jonathan Jagid, M.D., associate professor of neurological surgery.

Hentall, Jagid and other collaborators will use a technique known as deep brain stimulation, or DBS. This involves implanting a “brain pacemaker” that sends electrical pulses to a specific region of the brain to alter its activity. The devices have been successfully implanted in some 100,000 people with Parkinson's disease to control some of their most disabling symptoms.

The team has already obtained approval from the Food and Drug Administration (FDA) to implant and test the Medtronic Activa PC DBS device in up to 12 participants with SCI.

“One of the things that makes this Phase I clinical trial so promising is that we will use a well-established method and apply it to SCI,” says Hentall. “In other words, we don't have to invent a new device. If this works, we can translate it to the clinical setting relatively quickly. It's not a cure, but it may well ease the pain that many people with SCI live with, and could even benefit some of their other symptoms.”

In addition to safety and efficacy already confirmed in people with Parkinson's, Hentall's DBS trial no doubt received FDA because of the substantial testing and success he's had in animal models of SCI. In particular, Hentall and his colleagues have reported that stimulating certain regions of the brains of rats for a few weeks after spinal injury reduces sensitivity to pain, improves motor performance and results in healthier spinal cord tissue near the damage. They have also completed unpublished studies

showing improved digestion, restored insulin levels, and less development of AD.

In other words, the DBS study is far from a random shot in the dark—it's based on a great deal of good science that began years ago with Hentall pondering the mysteries of the body's repair mechanisms.

"My thinking went like this," he explains. "The body has evolved mechanisms to repair any recent brain or spinal cord injury that isn't too severe. This involves a lot of different actions and numerous genes. For example, metabolism must change, debris must be removed, and blood vessels need to be renewed, on top of the obvious need for nerve growth and reconnection. So I was led to believe that adaptive repair systems must be centralized, in order to activate and coordinate these various processes. The brain is good at centralized control, unlike most other organ systems that restore themselves. The different inputs that can indicate a recent injury, which may include pain, hypothermia, blood loss and the circulating chemical products of damage, must come together in some brain center in order to help initiate a repair response."

Based on detailed published studies of many investigators, Hentall theorized that specialized brain cells known as raphe nuclei seemed to be ideal candi-



Dr. Ian Hentall with collaborators Melissa Carballosa Gonzalez, Ph.D. postdoctoral scientist (right) and Catalina Martinez, MS, bioengineer research associate (photo by Rob Camarena)

dates for this job of orchestrating repair. "From a few discrete locations in the brain, their axons cover the entire CNS, and they can release certain growth substances—serotonin or neuropeptides—at any injury site," he says.

He set out to test his theory with DBS, but realized that the location of the raphe cells posed a real problem. They're located in the hindbrain part of the brain stem of animals and humans, an area where it would clearly be extremely risky to attempt to place electrodes within.

"Fortunately, we were able to show in rats that stimulating a midbrain zone known as the periaqueductal gray, or PAG, which

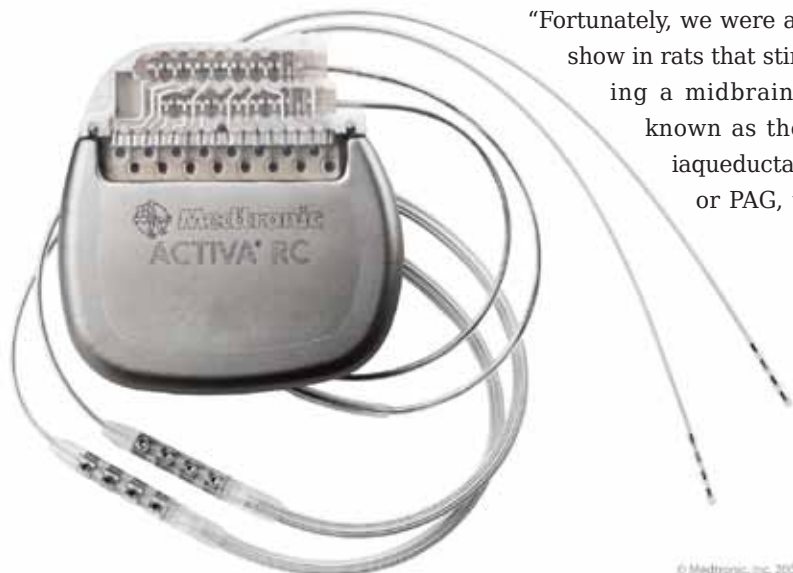
connects strongly with the hindbrain raphe and has been targeted before in humans, generates benefits after SCI similar to those of the raphe," says Hentall. "This offered an obvious way forward."

He and his team set out to test whether artificially enhancing raphe activity via electrical stimulation in the PAG improves recovery from traumatic brain or spinal injuries or SCI, including older or more severe injuries for which the repair system doesn't normally seem capable of fixing. The length of time that stimulation was applied ranged from days to weeks. True to theory, DBS in this area of the brain produced results.

"The research has been quite successful so far," says Hentall. "Diverse deficits are reversed, not just the obvious motor problems in the case of SCI, but also AD, the rate of gastric emptying and blood insulin levels, for example."

As for the mechanism behind the improvements, Hentall and his colleagues believe it's likely that DBS alters the various cellular signaling pathways that enhance growth in the damaged spinal cord. As a result, he believes that DBS not only suppresses SCI pain, but

Medtronic's Activa DBS device



© Medtronic, Inc. 2009

enhances the pathway that promotes repair. He and his research team already have found that this brain pathway increases the presence of a key repair molecule, cyclic adenosine monophosphate (cAMP), in the injured spinal cord.

But will success in animals translate into human improvements? That's the question that leads us to the upcoming study, during which up to twelve participants will have the Medtronic DBS device implanted under their skin near the collarbone, with an electrode threaded into the midbrain.

It's not the first time that DBS has been used to treat chronic pain—Hentall says that hundreds of patients with ongoing, drug-resistant chronic pain have had the procedure. "This has produced relief in about two thirds of cases," he says. "But very few cases of clear-cut SCI pain have been treated in this way. As a result, the question of whether deep brain stimulation can effectively reduce SCI-induced pain remains unanswered. Moreover, nobody has looked at the permanent

benefits of this stimulation after SCI, or at symptoms other than pain."

The primary goal of the study is to confirm safety while identifying the best method of using DBS for SCI pain—for example, the best target in the midbrain, the ideal duration and pattern of stimulation, and the injury type and level which responds best.

The second goal is to see if long-term or permanent changes can be produced, meaning that the pain is less or absent for a long time after the stimulation is turned off. Improvements in other symptoms, including reduction of AD, will also be studied.

"We'll select participants with chronic pain that is not well controlled with drugs," says Hentall. "The presence of AD in participants would tell us more about the potentially beneficial effects of the treatment, but it's not a strict requirement for enrollment. However, we will be studying higher injuries only, to increase the yield of AD cases."

As far as participants' time since injury,

Hentall says the intervention probably works best when given within a few days of injury. "But since it's hard to imagine asking a patient to undergo experimental brain surgery just after the life-changing event of an SCI, we first need to demonstrate good outcomes and safety in a solid proportion of chronic cases."

In terms of duration of the treatment, Hentall says the plan is to stimulate for 40 weeks. "Some of our unpublished work in rats suggests that, the longer the stimulation, the better the outcome, including when we start the treatment many weeks after injury. So if a patient does well, there's no reason why the stimulation can't continue indefinitely for acute suppression of pain, or until long-term improvements stop accruing."

The promising study has been funded by a three-year \$750,000 grant from the U.S. Department of Defense. Look for updates on outcomes in *The Spin* as they become available—keep in mind that published results aren't expected for at least two years. ■

ask the SPIN DOCTOR

John from Vancouver Island asks, *"Any suggestions for chronic pain? Drugs don't work, and I don't like being stoned, so cannabis is out. What are my options?"* To answer this question, we turned to Dr. Michael Negraeff, an anesthesiologist and pain specialist at Vancouver General Hospital who also has an SCI.

"Pain sucks! Just as you're figuring out how to live with this spinal cord injury, you realize you might have to deal with this pain arising from it for a long time. It's like your nervous system has forgotten to take the foot off the gas pedal, or has the volume on the amplifier stuck on 10. At least that's how I felt.

Here's the deal. We have drugs, but they're not always great. At most, you can expect 20 to 40 percent pain relief from drugs, and you'll likely have some side effects like fatigue, foggy head, or dizziness from them. We're still waiting for the Star Trek gadgets that will tell us what exactly is going



on and how to fix it—there are some promising developments, but we're not there yet. So what do we do?

Well, better than any drug we have is the power of that thing between your ears—yep, your brain! You need to learn how to dial that in to reduce your pain and increase your sense of control. It can make its own morphine!

One example is mindfulness-based meditation research. There's good evidence that even short-term practice with this technique can help you reduce pain levels and emotional distress. And the real gains come with commitment to a longer-term practice.

Yoga should also be considered—it combines mindfulness, breathing and gentle movement techniques to reduce pain, as

shown in an accumulating body of evidence.

Check out Pain BC Society, www.painbc.ca, or on Facebook, for webinars and other tools on how to start using that brain to your advantage."



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A Win/Win Workout

ICORD's new Physical Activity Research Centre offers Vancouverites with SCI the opportunity to workout in a state-of-the-art facility while contributing to a great research cause

It's often been said that the best things in life are free. For anyone with an SCI who values a great workout, proof of this can be found at the Physical Activity Research Centre (PARC), located on the ground floor of Vancouver's gleaming new Blusson Spinal Cord Centre.

PARC is a spacious, state-of-the-art workout facility that's been designed specifically for people with SCI. It operates as a program of ICORD (International Collaboration On Repair Discoveries), the Vancouver-based research

collaboration of clinicians and scientists dedicated to "the development and translation of more effective strategies to promote prevention, functional recovery, and improved quality of life after SCI."

PARC is the brainchild of ICORD rehabilitation researchers seeking to study physical activity outcomes in people with SCI. Their vision was a community facility where people could freely participate in exercise and physical activity, while contributing their experiences and suc-



cesses to a growing body of knowledge about the benefits of exercise for people with SCI. The vision became reality this year, thanks to a Canada Foundation for Innovation grant and matching funding from the British Columbia Knowledge Development Fund and the Rick Hansen Foundation. Together, these grants allowed ICORD to purchase the facility's equipment. Additional funding for PARC staff and operations then arrived in the form of generous contributions from the Vancouver Cantata Singers/ICORD annual Spinal Chord Gala, SCI BC, and HAL Industries.

The facility opened its doors on May 1st. Since then, membership has grown from five to almost 50. But there's room for many more to take part, according



to PARC supervisor Megan Brousseau.

"Anyone with an SCI who is at least 19 years old is welcome to join," she says. "The people are friendly, and the facility is beautiful, community-oriented and free. What more could you ask for?"

Feedback has been exceptional. "The equipment, which is state-of-the-art and designed specifically for wheelchair users, is the biggest draw," says Brousseau. "Most of the equipment can be used from your wheelchair—you can wheel directly in. Or you have the option of transferring onto the equipment if you're able. This is the case for both strength training and cardiovascular equipment."

For strength training, participants can use adaptive equipment made by Finland's HUR. The various HUR machines utilize compressed air for resistance instead of the traditional weight stacks or plates—this helps to provide a more consistent resistance throughout the range of motion. Smart Card technology enables participants to monitor their progress and automatically follow individualized programs. Each machine provides on-screen guidance, including the level of resistance and repetitions of the individualized training program as well as exercise technique instructions. Some of the strength machines have dual functions to help minimize the number of transfers, and many have



hand grips to assist when transferring.

For cardio, the facility offers wheelchair accessible SCIFIT upper and lower body bikes and GameCycle ergometers, which offer users the experience of playing a challenging video game as part of their exercise regimen. "They're very popular," says Brousseau.

She adds that PARC is already expanding its programming beyond its impressive variety of strength and cardio machines. "Lately, we've been able to offer yoga classes taught by Mary-Jo Fetterly," she says. "We're now looking to offer complimentary tai chi classes as well, and there's also other public interest in offering nutrition classes."

How can you get involved? Brousseau says it's as simple as having your family doctor fill out a form that acknowledges you're able to safely take part in physical activity and exercise. And, in order to use the facility, you'll also need to agree to participate in PARC's research component.

"The research study we're conducting now is considered a pilot study to examine the effects of physical activity and fitness on those with an SCI and to look for trends in the data for future studies," says Brousseau. "We perform baselines assessments at the time of enrolling and then every six months after. Beyond that, however, participants can come when they want during hours of operation, as often as they want and for as long as they want. Using built-in tracking software, we keep track of their workout data anonymously, which is also a bene-

fit to users as they can see their own progress, print progress reports and load a prescribed program from either their trainer or therapist onto the system. It's truly a win-win."

Chris McBride, Spinal Cord Injury BC Executive Director, couldn't agree more. "PARC is another positive sign that Blusson Spinal Cord Centre is steadily becoming the one-stop shop for SCI treatment, research and community involvement that was initially envisioned by its founders," he says. "With PARC and other community initiatives moving under one roof with ICORD, the Brenda and David MacLean Integrated Spine Clinic, and the Rick Hansen Institute, we're seeing a strengthening of the relationship between the community of people with SCI and the researchers and clinicians who strive to improve their quality of life."

"We are definitely making every effort to create an all encompassing SCI community by constantly asking for

and responding to the feedback of our participants," adds Brousseau. "For example, we have a research board in PARC that lists other ICORD research studies happening in the building so that participants can see, and have the opportunity to participate in, other exciting initiatives taking place within Blusson. PARC participants are also invited to ICORD community events such as the popular Cafe Scientifique evenings, which offer an opportunity to learn more about different aspects of SCI research. The dialogue is growing and amazing to be part of."

PARC is currently open daily from 9 AM to 6 PM (staff would like to expand the hours, but PARC can only be accessed through the main doors of the Blusson Spinal Cord Centre, which is only open daily until 6 PM). Free parking is available onsite. For more information or to learn how to join, call 604.675.8814, email parc@icord.org, or visit www.icord.org. ■

Physical Activity Guidelines

How much exercise should you, as a person with an SCI, try to get? What types of activity are best? These are the types of questions answered by the *Physical Activity Guidelines for Adults with Spinal Cord Injury*, developed by SCI Action Canada, an ongoing, collaborative endeavour bringing together university-based researchers, knowledge mobilization specialists, support networks, service groups and community members focused on advancing physical activity, knowledge and participation among Canadians living with SCI. Check out the guidelines and find out what types and amount of physical activity are right for you—you can find them on our website at www.sci-bc.ca. The guidelines are also part of the *SCI Get Fit Toolkit*, which can be downloaded free at the SCI Action Canada website (www.sciactioncanada.ca).

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Peristeen: Number Two Relief

Is your bowel program leaving you unrelieved? If so, you're not alone: estimates suggest that as many as half of all people with SCI suffer from moderate to severe neurogenic bowel syndrome. The results range from occasional discomfort to accidents, mental distress, autonomic dysreflexia, and even death. Little wonder that surveys of people with SCI conclude that finding methods of improving bowel function is a top priority.

Sometimes, medications and suppositories are enough to improve the situation—but not always. An alternative that seems to work for some people is transanal irrigation and, more specifically, the Coloplast Peristeen TAI system.

The system consists of a rectal balloon catheter, a manual pump, and a water container. The catheter is inserted into the rectum and the balloon inflated to hold the catheter in place while a warm water enema is delivered with the manual pump. The intermittent, rapid pulses of warm water break up stool impactions and stimulate peristalsis. The water is then evacuated into a toilet together with the content of colon and rectum.

The system, shown in the image, can even be used independently by some people with quadriplegia.

While it's only been available in Canada since 2011, the Peristeen TAI system has been used by people in other countries for more than a decade. As a result, there's been a considerable

amount of research to test the safety and effectiveness of the system. Every study we could find supports the system's overall safety and effectiveness.

The most recent study, completed in 2012 in Dublin, Ireland, involved 11 people and echoed previous results. "There was a significant decrease in bowel problems...indicating a significant improvement in bowel function from using TAI," concluded the authors.

"No serious adverse events occurred during the study. TAI is an effective treatment option for the management of neurogenic bowel dysfunction."

Less scientific but equally compelling are the many anecdotal accounts of the system provided by real individuals on various SCI forums around the world. For example, in April, brockit79 wrote this on UK's popular www.apparelyzed.com forum: "I use it and it has transformed my life! It took some

getting used to in order to use it correctly but your community continence advisor/nurse and/or spinal rehab place ought to be able to advise. The reps are good too."

However, as the forums make clear, not everyone has found it effective, and it's not a fix-all—it seems to work best for those with good dietary habits, for example.

Use of the Peristeen TAI system requires an examination and prescription from your doctor or specialist. For more information, visit www.coloplast.ca.



Make an impact.

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





Water Access

Two Vancouver Island ecotourism companies have taken great strides to ensure their marine adventure cruises are accessible to everyone

EACH YEAR, millions of tourists visit Vancouver Island. One of the draws is the island's diverse and beautiful marine ecosystem—its waters and shoreline are some of the best places in the world for viewing whales and other marine life in their natural setting.

Two Vancouver Island companies deserve a shout-out for their efforts to ensure that people with SCI and other wheelchair users can experience the majesty of Vancouver Island's coastal waters: EcoCruising Tours and Transport based in Victoria and Sydney, and Tofino's West Coast Aquatic Safaris.

EcoCruising Tours and Transport (see photos above) is a family business owned by long-time Victoria area residents and retired biologists Brian and Roxy Smiley, and their son Matt. The company operates a fleet of three unique vessels—28 foot commercial pontoon boats with custom-built solarium domes for all-weather comfort. The vessels are powered by quiet, efficient four-stroke outboard motors, and are certified to carry 12 pas-

sengers and their skipper-guide.

The vessels' shallow draft allows close approach to the scenic coastline for excellent wildlife viewing, and even short stops at remote beaches for intertidal exploring. A convenient bow door enables guests to simply step or wheel out onto the sand or a dock. That same door, along with a safe, wide ramp, allows easy access for wheelchair users. Inside, guests find themselves in a warm livingroom atmosphere complete with soft sofas perfect to enjoy the spectacular panoramic view.

Two of the vessels are based at Sydney, close to the BC Ferries terminal at Swartz Bay. The third vessel is based at nearby Brentwood Bay—note that the dock is not accessible at this location.

Because of their vessels' all-weather comfort, the company offers a diverse range of services year-round—guided eco-cruises, gourmet picnic and sunset cruises, group tours for seniors centres, special event cruises, and water taxi. Destinations include the Sydney water-

front, the Saanich inlet, and nearby islands. The tour routes stay near the shorelines in protected waters, ensuring a smooth, stable ride. Passengers cruise quietly amongst the coastal islands, passages, and wildlife hotspots rich with seal pups, orca whales, porpoises, nesting eagles, oyster catchers and purple seastars. The onboard ecologist offers fascinating insight along the routes.

For more information, visit www.ecocruising.com.

Meanwhile, some four hours from Victoria lies world-renowned ecotourism destination Tofino. That's where you'll find West Coast Aquatic Safaris (see photos opposite). The company operates two vessels, but its flagship NANUQ—an all-weather, high-speed 36-passenger cruiser—is accessible to wheelchair users, offering them an opportunity to experience the spectacular, rugged beauty of the Pacific side of Vancouver Island.

The Nanuq is capable of high speeds, thanks to its two powerful diesel engines. A catamaran design offers speed



and stability on the open ocean. Passengers board the Nanuq via a wide, wheelchair accessible gangway. There are some limitations for wheelchair users onboard—for example, while most passengers can choose from a variety of indoor and outdoor seats, most wheelchair users will have to sit in the back end of the vessel. This area, although covered, is still open to the elements, so you'll want to dress warmly or cruise on a beautiful day. As well, the bathroom isn't accessible.

Limitations aside, Nanuq provides incredible opportunities for wheelchair users to see Esowista Peninsula and the islands of the outer Clayoquot Sound. The company offers a variety of specialized tours, with the most popular being bear watching, whale watching, sheltered fishing, and seasonal expeditions year-round. Of these, whale watching is the most popular—at various times of the year, these waters are home to gray whales, orcas, and humpback whales. No matter which tour you take, you're also likely to see bald eagles, Stellar and California sea lions, harbour seals and porpoises. It's little wonder that the company gets rave reviews on Tripadvisor.

Dan Bauer, president of the Vancouver Island-based BC Accessible Wilderness Society, has taken three trips on the Nanuq and offers his own rave review. "My wife Judy and I had a blast," reports Dan, shown aboard Nanuq in the bottom photo below. "The folks at West Coast Aquatic Safaris are all very friendly and informative, and they also seem very comfortable working with people with disabilities. The biggest highlight for me was actually getting out again on the ocean—there's a sense of freedom doing that, and I thoroughly enjoyed that feeling. A whale-watching adventure was always on my bucket list—I now realize that it's actually something I want to keep doing whenever I get a chance."

For more information about West Coast Aquatic Safaris, visit www.whalesafaris.com. ■

Pat Harris, SCI BC Manager of Information Services, and Heather Lamb, Information Resource Specialist, assessed the Universal Boardwalk prior to its official opening



Accessible BC: Ancient Forest Gets New Life

The Ancient Forest, located in the BC interior some 113 kilometres east of Prince George, is a unique temperate rainforest. In fact, being located so far inland, it's the only one of its kind on our continent. The highlight is the forest's spectacular, towering cedars, which range in age from 800 to 2,000 years old.

Thanks to local volunteer Nowell Senior, members of the Caladonia Ramblers (a group of outdoor enthusiasts), and other volunteers and donors from surrounding communities, a sizable portion of the Ancient Forest can now be accessed by wheelchair users. For three years, volunteers worked tirelessly on the construction of the Universal Boardwalk—an undertaking requiring more than 6,000 hours of labour, 56,000 kilometres of travel time, 60 tons of lumber (carried by hand), three tons of hardware, and 11 tons of rock, cinder blocks, gravel and paving stones. In addition to the actual trail and boardwalk, the site now features accessible parking, an entrance ramp and a wheelchair-accessible outhouse.

Pat Harris, information services manager with Spinal Cord Injury BC, toured the boardwalk before it was officially opened to make sure there weren't any outstanding accessibility issues. "The boardwalk is very special, it's an attraction," says Harris. "This is a unique opportunity for people with disabilities to access a really special and pristine part of our province."

The Ancient Forest Trail is located on the south side of Highway 16 near Slim Creek. The trailhead is marked by a large sign on the right hand side of the highway (heading east). Pull into the trailhead parking lot and spend an hour or two walking or wheeling through one of BC's best kept secrets. The trail is an easy-to-moderate hike marked with interpretative signage.



new name... same game

The Disabled Skiing Association of BC is now BC Adaptive Snowsports—a name that reflects just how far the organization has come in four decades

It's often been said that great things come from humble beginnings.

That's certainly the case with the Disabled Skiing Association of BC, which was renamed BC Adaptive Snowsports as part of the organization's recent 40th anniversary celebrations.

The organization was formed in Vancouver in 1973 to promote skiing for amputees and people with other disabilities. It became relevant in the lives of British Columbians with SCI in the early 80s, when the first sit-ski technologies were introduced. Since then, hundreds—if not thousands—of British Columbians with paraplegia and quadriplegia have tapped into BC Adaptive Snowsports programming to experience or re-experience the thrills of downhill skiing.

Today, BC Adaptive Snowsports is a truly all-inclusive organization that strives to make all people, regardless of ability, feel welcome on the slopes of our province's spectacular winter resorts. From its new offices in the SCI BC building in Vancouver, the organization oversees 11 adaptive snowsport clubs located around the province. It serves as an entry point for recreational skiers and snowboarders with disabilities, and as the overseer of high performance disabled skiing in our province—it's the umbrella organization of the BC Para Alpine Ski Team.

Jim Dixon, BC Adaptive Snowsports Executive Director, explains that an increasingly diverse membership made the name change necessary. "We felt BC Adaptive Snowsports was far more appropriate given we now serve members with cognitive, physical, visual and audible challenges," he says. "The programs delivered by our clubs and provincial staff



are truly adaptive, be it through modified equipment or teaching practices. We therefore feel BC Adaptive Snowsports is inclusive of all these things."

The new name was rolled out during the organization's 40th anniversary gala, held on June 15 at Vancouver's Sheraton Wall Centre. The event was attended by staff, volunteers, funders and many standout disabled skiers.

"It truly has been a remarkable 40 years," says Dixon. "Our anniversary gala gave us the chance to reflect on what we have achieved and provided us with motivation and drive to further improve our reach and services."

As part of the anniversary, BC Adaptive Snowsports has been hard at work developing a new website and online resource centre for its existing and potential members. "Our hope," says Dixon, "is that the site will help provide a greater awareness of our association. We know there are so many people out there looking for opportunities to participate in adaptive snowsports but perhaps lack the knowledge of how to access programs or the support available to them through our provincial and club programs. The new website will help to create this awareness."

He adds that, although the name is new, the focus remains the same. "A lot

of what we do will not change—we are here to serve our members, support the development of programs provincially, and offer advocacy to our growing network of clubs."

Dixon says that it couldn't be a better time for SCI BC peers to learn more about adaptive snowsports and the work of BC Adaptive Snowsports.

"We welcome new members, and I would encourage any member of the SCI BC community to contact BC Adaptive Snowsports—we will gladly point you in the right direction. There are clubs in almost every community in BC, so I'm positive we can assist all interested SCI BC members and introduce them to a life on the slopes. The development of adaptive snowsport equipment is moving at a staggering pace; there truly are so few barriers in your way. Our network of affiliated clubs will gladly support you, providing you with instruction and equipment to utilize while you're getting introduced to the joys of skiing. I can tell you that, as an avid skier myself, there truly is no better feeling than the freedom a mountain can offer you—so get out there and give it a go!"

BC Adaptive Snowsports membership re-opens in early October, coinciding with the launch of its new site (www.bcadaptive.com). In the meantime, you can learn more by visiting the existing website at www.disabledskiingbc.com. ■



Paralympian Josh Dueck and Candice Drouin, Head Coach of the Canadian Para Snowboard Team, were among the enthusiastic guests at the anniversary gala.

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