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WINTER 2014

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The Neil Squire Society's Dr. Gary Birch explains why emerging information and communication technology is often inaccessible—and what can be done about it



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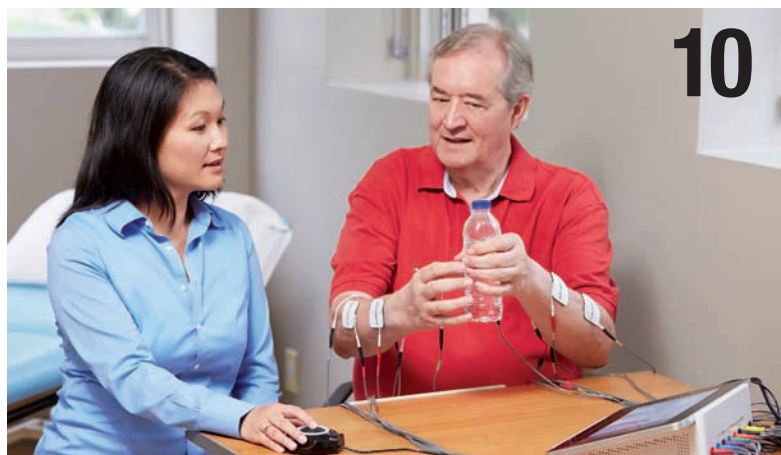
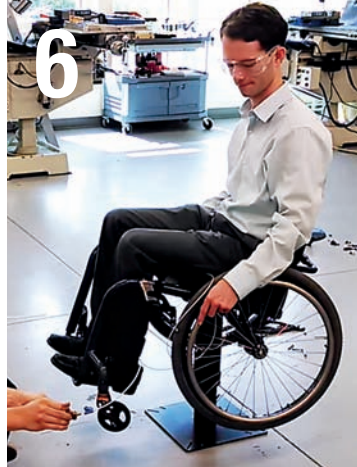
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Cover Photo by Maya Pankalla



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## "It's not about a cure. It's about quality of life."

Never have so few words in our communications created so much discussion!

This phrase was at the bottom of a poster we created earlier this year. The poster has lots of stats and facts relating to living with an SCI and SCI BC's services. It was well-received by people who saw it. But when we posted it on our Facebook site in September, a bit of an international online maelstrom broke out.

All of the furor was over that small line of text at the bottom.

I'll concede that, when we created the poster, we wondered if the phrase might be misinterpreted. But we didn't anticipate the level of reaction it generated.

It wasn't all negative. In fact, the response was overwhelmingly positive. But some interpreted the phrase as meaning SCI BC does not support the quest for a cure. Negative posts were written at [www.StemCellsandAtomBombs.org](http://www.StemCellsandAtomBombs.org) and [CareCure.org](http://CareCure.org), including some by SCI BC members.

We clearly touched a nerve. So I was most pleased to receive a letter from Stem Cells and Atom Bombs founder Dennis Tesolat, asking for clarification on SCI BC's position on cure research. The online correspondence I had with Dennis can be viewed on his website and on the CareCure forum.

I was appreciative of the opportunity to clarify that SCI BC is most supportive of the need for ongoing research that will lead to meaningful functional improvements and ultimately a cure for SCI. But I also emphasized that SCI BC is passionate about promoting the ways in which people with SCI can adjust, adapt and thrive, and the need to reset the balance of investment in both the types of research being conducted (cure vs. functional and quality of life improvement), and between research and the invaluable community services that allow people with SCI to maximize their potential and quality of life today.

Having been involved in SCI research for over 22 years, I am aware of the frustratingly slow pace of discovery. I understand why Dennis and others like him campaign for a greater focus on finding a cure. But I also know that too much focus on a cure can be detrimental, and that some people with SCI focus too heavily on the fact that they need a cure to be whole. It's important to have a balance in one's perspective and not let the focus on a future cure prevent anyone from finding ways to maximize their potential and quality of life right now.

In hindsight, we might have chosen our words a little differently. "It's not just about a cure" might have been a better choice. But your words matter, too, which is why Dennis and I agreed that this is an opportunity for people with SCI to let us know what they think might be an ideal phrase—a phrase that promotes the possibilities for people with SCI without negating the importance of cure-based research. I'm sure there will be good suggestions from the international online communities engaged in the discussion, and I'll post a survey on the SCI BC website for input from SCI BC's members and online audience.

I appreciate that the end result may not satisfy everyone. But I hope readers will at least understand SCI BC's position: while finding a cure for SCI is a priority, we believe where it fits on people's priority list varies greatly.

The discussion that this short phrase has generated has been healthy. It's forced a lot of thought on the topic, and reminded us that words really do matter.

I wish you and yours the best of the season.



— Chris McBride, Executive Director, SCI BC



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## AIRSHELLS

If you're a traveller who's had a wheelchair damaged before, during or after a flight, you'll want to check out Airshells—protective baggage for manual wheelchairs that you rent for as long as you need. Since 2005, the company has rented their baggage to European travellers at 70 airports across Scandinavia, the UK, Ireland, Portugal, France and Spain. Recently, the Danish company brokered a deal with United Airlines, and you can now rent the protective luggage for use on domestic United Airlines flights at airports across the USA as well as Canadian airports serviced by United Airlines, including Vancouver and Victoria. There are four sizes that will accommodate most manual chairs and some scooters. All weigh in at about 3.5 kilograms, and have a hard-wearing outer fabric, a high-quality zipper and a custom foam lining. All you do is go to the website, choose your product (as little as \$25 for the first week and \$12 each week after) and then input your travel specifics. Airshells will overnight the bag to your departing airport, where you pick it up and use it. Visit [www.airshells.us](http://www.airshells.us) for more details.

# Innovations

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

## LEVATÉ

If you're a manual wheelchair user who often wants or needs access to items high above what you're able to reach, have a look at Levaté—a lightweight lift that attaches to the bottom of a manual chair and uses compressed air to boost the user and user's chair 12 inches. Levaté was created by a team of students at the University of Oklahoma. It's currently in a developmental stage, with the team working on various proof-of-concept versions. The goal is to develop a product that is stable, weighs less than five kilograms, and is commercially viable—all by late 2015. For more information, check out [www.levatelift.com](http://www.levatelift.com), where you'll find some great videos of the device in action.



## PANTHOOK

The PantHook allows you to keep your pants on—and out of the way so that you can more easily self-cath. The PantHook is a discrete black panel about the size of your palm. It slides under your chair's cushion. Once in place, you pull the connected hook up to snag your pants and underwear, keeping them out of the way while you cath. The simple but effective device is the brainchild Mark Van Linden, a T10 paraplegic from Grand Rapids, Michigan. He came up with the design in desperation after two years of using what he describes as a “hideous-looking thing with surgical tubing” that he'd been given in rehab. For more info, go to [www.panthook.com](http://www.panthook.com) where you'll find an excellent YouTube video that illustrates how the device is used.



## CRYTICO MOBILITY REVIEWS

Crytico.com, which launched a few months ago, is an interactive website that's dedicated to gathering and sharing consumer-submitted reviews of mobility products and services, and the companies that provide them. Crytico's financial model is based on mobility dealers paying regular fees to be featured, much like TripAdvisor business listings for hotel and restaurant owners. But any visitor can submit a review, and all reviews are intended to be independent and impartial. There are four main categories of reviews: mobility dealers, mobility vehicle products, personal mobility products and home mobility products. The site is getting some traction with consumers, as various reviews have been submitted.

# If a picture is worth a thousand words, video must be priceless.



Introducing SCI BC TV, a short-form YouTube series that explores and celebrates innovative stories from the spinal cord injury community.



Join host Kirsten Sharp as she keeps viewers informed, engaged, and up-to-date with the latest in SCI—from adaptive sports and recreation, to community events and research.

Through its mini documentary/community news format, SCI BC TV motivates others to realize their potential, challenges perceived barriers, and opens minds to new experiences and information. Episodes cover informative, edgy topics, with an emphasis on humour and human connections.

Our host has already learned the ins and outs of wheelchair rugby, used her wheelchair to “drop in” at the local skate park, and even walked again for the first time in 23 years with the help of an exoskeleton.

“There’s a whole world out there—come experience it with us!” says Kirsten.

## [www.sci-bc.ca/tv](http://www.sci-bc.ca/tv)





### Don't save the date.

No hair to style, no shoes to shine, and no need to hire a sitter. Join Northern BC's movers, shakers and socialites at the biggest non-event of the year. The fabulous Ugly Tie No Show Gala, coming to Prince George on March 26, 2015, is a unique twist on a typical fundraiser: in exchange for an online donation, attendees are cordially invited to stay at home and relax. A real auction and door prizes will round out a perfectly uneventful evening. Email [kmarshall@sci-bc.ca](mailto:kmarshall@sci-bc.ca) or visit us online at [www.sci-bc.ca/events/no-show](http://www.sci-bc.ca/events/no-show) for details.



### Make some noise.

The 2015 Canada Winter Games, featuring 19 different sports and competitors from across Canada, are coming to British Columbia! From February 13 to March 1, Prince George and Northern BC will play host to 2,400 amateur athletes ranging in age from 12 to 35 years old, and to thousands of volunteers and visitors. Come out and support BC's wheelchair basketball team, as well as other Para-Sport athletes competing in the Games. For more information, head to [www.canadagames2015.ca](http://www.canadagames2015.ca).



### Lap up the luxury.

Ditch the winter coat, grab a cocktail and get pampered in tropical style at our 12th Annual Spinal Cord Injury Women's Tea. The February 15 event, held at Vancouver's historic Heritage Hall Ballroom, will celebrate, spoil and unite a variety of women, regardless of physical ability. Take an elegant tropical vacation without ever leaving the city: join us for hair styling, salsa lessons, live music, finger foods, tropical drinks and more. Email Marnie DeVries at [mdevries@sci-bc.ca](mailto:mdevries@sci-bc.ca) to RSVP for this free event.

# NO ICE BUCKETS.

Just the warm fuzzy feeling that comes from knowing you've done a good thing.

That's what we promise you when you make a donation to Spinal Cord Injury BC this holiday season. Your generous donations help us to ensure we can continue to deliver our powerful information and peer services that support and improve the quality of life of British Columbians who live with SCI. Even a modest donation helps to offset the cost of publishing and delivering this magazine free of charge to thousands of readers. It's easy to make a donation online at [www.sci-bc.ca](http://www.sci-bc.ca), or you can call us at 1.800.689.2477 to learn more about how you can have an impact.



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## Balance

Life is a balance between being active and staying healthy. Mobility Mount can help with that.





# Getting a better Grip

More than a decade of innovation and research by Toronto's Dr. Milos Popovic has led to the development of MyndMove, a promising therapy for improving hand function in people with SCI that's now commercially available in Canada

**IF YOU'RE SOMEONE WITH QUADRIPLÉGIA**, you already realize how important every little bit of hand function can be. Eking out the slightest improvement can sometimes make the difference between dependence and independence. To reinforce the point, we'll remind you that large scale surveys of people with quadriplegia have made it clear that restoration of hand function is a top priority.

Enter MyndMove, a promising therapy for the treatment of arm and hand paralysis caused by SCI or stroke. In October, the therapy was introduced to Canadians by medical technology company MyndTec Inc. MyndMove has full approval by Health Canada and is now being commercially rolled out across Ontario, with other provinces soon to follow.

On a simple level, MyndMove therapy works by stimulating the nerve pathways engaged when executing a desired movement over and over. Electrodes are attached at key points on the skin of the hand and arm of the patient. Functional electrical stimulation (FES) is provided via the electrodes at the precise time that the patient "practices" a movement. Research has confirmed that, when this is repeated, specific hand functions can be significantly and permanently improved.

During MyndMove therapy, the patient is instructed to actively envision and attempt to engage their muscles in a desired



movement—for example, reaching for and grasping a glass. As the patient attempts the movement, their therapist triggers the MyndMove device, which then delivers electrical stimulation to the muscles involved in the movement. The muscles respond by sending a signal to the brain. When repeated, this coordinated effort eventually creates a new pathway for the intended movement—in other words, the nervous system “learns” a new way of allowing that movement to be permanently repeated, long after the therapy is finished. The entire therapy is based on the concept of neuroplasticity, which is the brain’s ability to reorganize itself by forming new neural connections to compensate for injury and disease.

As you can see in the photo above, the MyndMove stimulator is a compact device with an easy-to-use 11.6 inch touchscreen user interface. The device has eight

channels, which allow up to eight distinct muscle groups to be stimulated via electrodes, in the order and with the duration necessary to complete sometimes complex natural movements. In fact, the MyndMove stimulator has many pre-programmed stimulation algorithms. Each is designed to stimulate specific muscles in the correct sequence to create natural movements for activities of daily living—for example, holding a cup or pen, or bringing your hand to your mouth.

The mind behind the MyndMove belongs to Dr. Milos Popovic, Toronto Rehab Chair in Spinal Cord Injury Research and a Professor at the Institute of Biomaterials and Biomedical Engineering at the University of Toronto. Popovic started his career as an aerospace engineer, switched to designing prosthetics, and eventually discovered the enormous potential of electrical stimulation to reawaken the nervous system and restore voluntary movement in people with par-

alysis. Today he’s recognized as one of the world’s leading authorities in FES.

MyndMove is the culmination of numerous randomized controlled trials in the FES field led by Popovic over the last decade. The entire system is now licensed to MyndTec Inc., a company that Popovic co-founded in 2008 to develop and commercialize innovative medical devices designed to improve function, maximize independence and enhance quality of life. Popovic is no longer involved in the day-to-day operations of MyndTec, but remains the company’s Chief Technology Officer and a director.

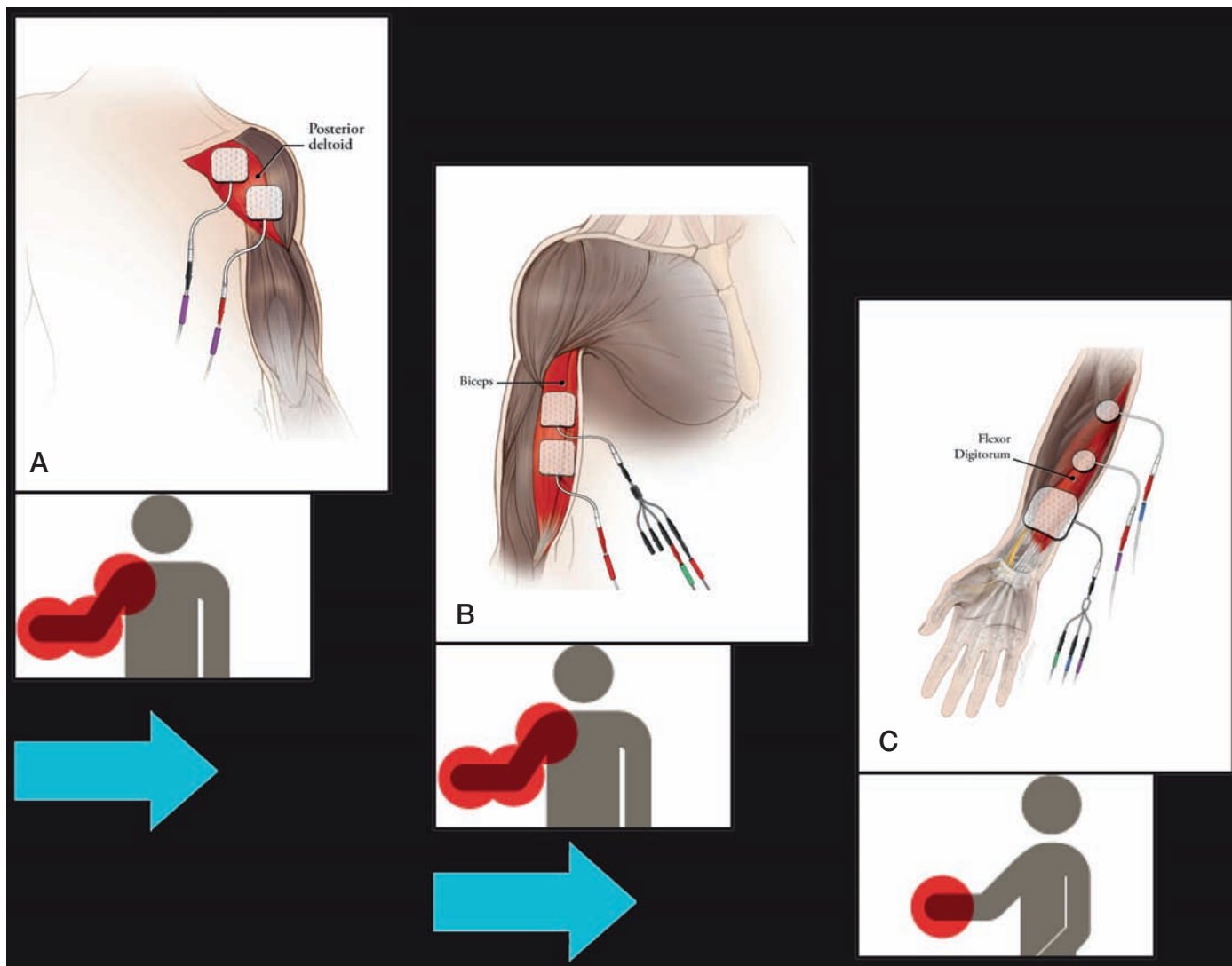
He explains that the therapy has rolled out in six clinics in Ontario, and the company is in active discussions with many more clinics in Ontario and other Canadian provinces.

“I’m not in a position to tell you exactly when MyndMove therapy will be available in BC, but I can tell you that there are ongoing discussions between MyndTec and potential clinic partners in BC to bring this therapy to your province in the near future,” says Popovic. “The company intends to expand across Canada during 2015. The best way for you readers to accelerate expansion to



*“This is actually the most rewarding thing I have ever experienced...Being able to say that one of my team’s ideas and inventions became a product which will help many people with SCI is extremely exciting.”*

– Dr. Milos Popovic



*The MyndMove therapy system is capable of stimulating up to eight channels, meaning that it can create some complex activities of daily living. For example, it could first (A) stimulate the muscles in the shoulder to move the entire arm, then (B) stimulate the muscles in the upper arm in order to raise the forearm, and finally (C) stimulate the muscles in the forearm to move the fingers into a grasping position. All of this is done at the same time as the patient attempts to will the same movements, and as this is repeated, a new neural pathway is eventually created.*

BC is to send an inquiry email to [info@myndtec.com](mailto:info@myndtec.com). This email address is monitored by the MyndTec team regularly, and they will promptly respond to the inquiry. Our focus is to connect with clinics that primarily deliver other neurorehabilitation therapies—they are our priority for forming partnerships.”

Expansion into the US and abroad, adds Popovic, will only be contemplated when MyndMove has been successfully rolled out in all Canadian jurisdictions.

As for cost, MyndMove isn’t cheap—clinics charge about \$175 per hour, and most patients need about 20 to 40 hours of therapy to achieve meaningful gains. While a \$4,000 cost might initially seem high, it begins to make much more sense

when you consider that therapy might result in perhaps six hours less personal assistance required per week for a particular patient. Taken over a lifetime, the \$4,000 clearly starts to look like an investment rather than an expenditure.

“At the present time, MyndMove is available to clients whose insurance provider is willing to pay for the therapy, or clients who themselves are able to pay for the therapy,” says Popovic. “But the company understands the need to build a compelling case in order to have more insurers see the benefits of providing coverage for their clients. MyndTec is collaborating with the MaRS EXCITE program in Ontario with the objective to conduct a multisite randomized control

trial that would provide economic and clinical evidence that provincial health care providers could use to justify their decision to cover MyndMove therapy.”

Unfortunately for DIY types, purchasing a unit and performing therapy by yourself isn’t an option. “MyndMove is not envisioned as a system that patients would take home and use themselves,” says Popovic. “This device needs to be used by highly-trained and skilled physiotherapists or occupational therapists. MyndMove therapy generates the best results when both therapist and patient are working synergistically and use MyndMove as a tool to help retrain the brain to relearn how to reach and grasp objects again.”

With the hard work of launching the therapy behind him, Popovic now has time to reflect on the success. He's understandably proud of MyndMove and seeing his work actually begin to benefit those who he set out to help—an achievement that the vast majority of SCI researchers never get to see during their careers.

"This is actually the most rewarding thing I have ever experienced," says Popovic. "Getting something from an idea to a full product that is available on the market is not trivial. Being able to say that one of my team's ideas and inventions became a product which will help many people with SCI is extremely exciting. In my previous professional lives, I helped design systems for airplanes and robots, and while it was very exciting to watch our airplane take off, nothing can be compared to the satisfaction one gets from seeing a patient improve or get better. This is why I decided to stay in this field 15 years ago."

For more information on MyndMove, visit [www.myndtec.com](http://www.myndtec.com). ■

## More Details About MyndMove Therapy

In order for people to benefit from MyndMove, they must be medically stable, able to actively participate in therapy sessions, and able to communicate with the therapist during treatment. All types of stroke and C3-C7 SCI patients can be treated with MyndMove therapy.

You enroll in MyndMove therapy by subscribing to a minimum of 20 therapy sessions. A typical therapy session is one hour in length. During each session, a MyndMove-trained occupational therapist (OT) or physiotherapist (PT) will lead you through various stimulation protocols, each designed to produce a different purposeful movement.

During each session, patients will have electrodes placed on the skin over the muscles that require stimulation.

Patients participate by envisioning and actively attempting the desired movements, with therapists guiding the timing and quality of the desired movements. The MyndMove device delivers FES to elicit the movements—this will result in a mild tingling sensation while the device electrically stimulates the muscles.

An integral component of MyndMove therapy is the MyndMove-trained therapist. OTs and PTs complete an intensive multi-day training course provided by MyndTec or a partner institute in order to qualify as MyndMove Therapists. Your therapist will work with you to identify appropriate goals and desired movements, correctly place electrodes on your skin and optimize muscle stimulation, adjust stimulation levels to ensure appropriate muscle contractions, ensure you're comfortable during therapy, identify your responses to MyndMove and ensure you receive optimal therapy.



### YVR: MAKING TRAVEL ACCESSIBLE TO EVERYONE

Vancouver Airport Authority is proud to support Spinal Cord Injury British Columbia.



# Stimulating Relief

UCLA researchers have confirmed that an electrical stimulus can trigger the bladder to empty in animals with SCI. The result could pave the way for an implant to restore this critical function in people.



**T**he mainstream media had a field day in October, when UK researcher Dr. Geoffrey Raisman reported that a Polish surgical team had apparently succeeded in using a technique he'd developed—transplanting nasal cells to the SCI site—to restore some lower body function and sensation in a Bulgarian man who had sustained a near-complete severing of his spinal cord four years earlier.

The result is intriguing, but clearly it's far from the outright cure that it's often been presented as in the media (see sidebar on the facing page). Little wonder that veterans of SCI, long weary of cure claims through the decades, were quick to voice their skepticism—and remind the world that it's solutions for the secondary complications of SCI that are most needed.

This was neatly summed up by Mike Mackenzie, a prominent British paraplegic, in a guest editorial in the November 1 issue of London's *Thame Gazette*. "The loss

of bowel and bladder control, the loss of sensation, often resulting in pressure ulcers, and loss of sexual function are all the devastating hidden horrors of your future life (with SCI)," wrote Mackenzie. "It is the sincere wish of almost all of those with a spinal cord injury to have the restoration of these basic and vital functions. Not being able to walk becomes more of an inconvenience than a major loss and is compensated for by the technology of modern wheelchairs."

Far from the controversy and the media spotlight, research into the restoration of these basic functions is, in fact, underway. One such project is taking place in Dr. Reggie Edgerton's lab at UCLA and involves electrical stimulation of the spinal cord to restore bladder function.

We're largely preaching to the choir, but we'll remind you that bladder issues are huge for people with SCI. Beyond the sheer inconvenience of having to figure out how and when to void, there's a myriad of potentially

serious complications when things go south—bladder infections, kidney damage, bladder cancer and autonomic dysreflexia. So the concept of an implantable device that would allow you to void using your own plumbing, wherever and whenever you want, is intriguing to those in the know.

You may recall that, in the Summer issue of *The Spin*, we told you about the four young Americans who had received an implant that provided electrical stimuli at key locations on their spinal cords. Using a combination of stimuli and training, all four subsequently developed some lower extremity sensation and the ability to “walk” on a treadmill while being supported. But the researchers involved also reported that the four subjects experienced measurable improvements in a number of key secondary areas—autonomic function, blood pressure regulation, bowel function, sexual function, and bladder function.

Dr. Claudia Angeli, a senior researcher at the University of Louisville in Kentucky who co-leads the ongoing project, gave us the details of the improvements. “These changes seem to be long-lasting since they don’t require the stimulation to be on, but they gradually improve as the individuals start and continue training with the stimulation,” said Angeli. “These changes are very gratifying to see, and are very important for the research participants because they have a direct impact on their quality of life.”

Across the country in California, Edgerton and his team at UCLA had long been collaborating on aspects of that research. They’d also branched off their own electrical stimulus work to explore its potential in resolving specific secondary complications. Of these, the team has recently published its success in using electrical stimulation to restore bladder control in rats with SCI.

Edgerton’s team studied 10 paralyzed rats that were trained daily for six weeks with epidural stimulation of the spinal cord. Epidural stimulation means that tiny electrodes were placed at precise locations in the epidural space, directly

## Unrealistic expectations?

Unless you’re living in a vacuum, you’ll have recently seen a lot of media coverage of a Polish surgical team’s compelling claim to have restored some lower body function and sensation in a Bulgarian man who had sustained a partial severing of his spinal cord. Front and centre in that coverage was UK researcher Dr. Geoffrey Raisman, who researched and developed the technique to transplant specialized nasal cells into the injured spinal cord—the technique used by the Polish surgeons.

Raisman, the head of University College London’s Institute of Neurology, was jubilant about the result, declaring in a statement that it was “more impressive than man walking on the moon.” And here’s what he told *The Guardian* newspaper: “We believe that this procedure is the breakthrough which, as it is further developed, will result in a historic change in the currently hopeless outlook for people disabled by spinal cord injury.”

We’ll ignore that Raisman believes that people with SCI have a “hopeless outlook” and instead tell you how some of his colleagues (who are some of the world’s most respected SCI scientists) reacted in the days and weeks that followed the announcement.

Dr. Simone Di Giovanni, Chair in Restorative Neuroscience at Imperial College London, wrote in a statement that a single positive outcome “cannot represent any solid scientific evidence to elaborate upon. In fact, there is no evidence that the transplant is responsible for the reported neurological improvement...Extreme caution should be used when communicating these findings to the public in order not to elicit false expectations on people who already suffer because of their highly invalidating medical condition.”

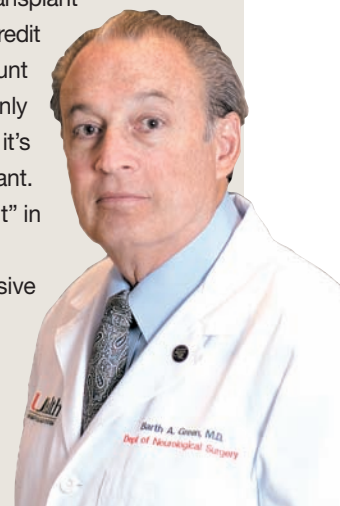
Similar cautions were issued by Dr. Mark H. Tuszynski, Director of the Translational Neuroscience Unit at the medical school of the University of California in San Diego. “It is premature at best, and at worst inappropriate, to draw any conclusions from a single patient,” he told *The New York Times*. “You can see surprising improvements in patients engaging in rehab, even long after the injury. The problem with concentrating on one case is that people living with these injuries feel that they are missing out on something life-changing, when that is extremely unlikely to be the case.”

Yet another cautious voice was heard from Dr. Barth Green, Professor and Chairman of Neurological Surgery at University of Miami Health System, and co-founder of The Miami Project to Cure Paralysis. “They’ve got one patient who did well and that’s wonderful,” Green told CNN. “If you can’t reproduce it, it’s not real...The question is, is it all the physical therapy, or the cells he’s getting? I’m not convinced that this is a breakthrough. It definitely isn’t the answer for everybody—or even everybody with the same injury—until we have more examples with more than one patient.”

Finally, and closest to home, ICORD neuroscientist and VGH spine surgeon Dr. Brian Kwon offered similar thoughts. “The investigators did indeed provide a very careful and comprehensive documentation of the patient’s function prior to transplant and after the transplant, and in this regard, one should give them credit for really trying to provide the community with a detailed account of what happened before and after,” Kwon told us. “But it is only one patient with a very atypical type of spinal cord injury, and so it’s impossible to interpret the true effectiveness of the cell transplant. And in this regard, the portrayal of this type of “n of 1 experiment” in this fashion is quite misleading, particularly for the public.”

In other words, it’s an interesting result—but a very inconclusive one at this point.

*“If you can’t reproduce it, it’s not real...The question is, is it all the physical therapy, or the cells he’s getting? I’m not convinced that this is a breakthrough.”* – Dr. Barth Green, University of Miami



onto the surface of the spinal cord. An additional five rats formed the control group—they were untrained and did not receive stimulation.

The bottom line? The combination of training and epidural stimulation allowed the rats to empty bladders more fully and in a timelier manner than those in the control group. The researchers also filled the rats' bladders with saline, and when they turned the stimulator on, urine was released within 90 seconds. The full results were published in the online journal *PLOS ONE*.

"The big deal here is the immediate effect," says Edgerton, a professor of Integrative Biology and Physiology, Neurobiology, and Neurosurgery at UCLA. "There may be a way that when people have bladder problems, you can turn the stimulator on and they can release urine at will. This strategy could have a major impact in improving the quality of life and longevity of human patients. We're not saying it will restore this part of their lives to normal, but we think it will lead to a significant improvement in quality of life."

As with the four young men we told you about in the Summer issue, the underlying premise is that the circuitry in the spinal cord is remarkably resilient, even after injury, and can be "woken up" with accurately-delivered electrical impulses. "Once you get them up and active, many physiological systems that are intricately connected and that were dormant come back into play," explains Edgerton.

No doubt, all of this leaves you asking the same question: when will we see this tested in people with SCI?

"We are looking forward to testing the potential of this technology in human subjects," says Parag Gad, an assistant researcher in Edgerton's lab, and lead author of this particular study. "However, it may take another two to three years to get to that point."

Gad adds that one of the reasons for the delay is that the team needs to complete testing and development of a fully implantable, miniaturized stimulus system that's safe and more appropriate for this particular task (the system used with the rats was a combination of an external transmitter attached to the internal epidural electrodes).

While he urges caution and patience, Gad is also enthusiastic about the potential of this line of research. "I think this technology has great potential for controlling various autonomic functions," he says. "The work that we're involved in is very, very satisfying; the improvement in quality of life that this technology has so far demonstrated is path-breaking. The clinical implications of this technology are substantial and could have a major impact on improving the quality of life and longevity of patients, reducing reliance on caregivers, while simultaneously dramatically reducing ongoing health maintenance after a spinal cord injury."

You can follow all of the research taking place in Edgerton's lab by visiting [www.ibp.ucla.edu/research/edgerton](http://www.ibp.ucla.edu/research/edgerton). ■

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# The Inside Scoop

If they haven't already, Frozen Coconut's dairy-free desserts are coming soon to a supermarket near you. Frozen Coconut co-founder Kevin Carta reveals the inspiration behind the company's products, why Ice Cream University was a wise investment, and how success has given him a new lease on life.

Kevin Carta abandoned a blossoming career in ballet. His garage-band music label folded before it ever really took off. And, if the single-car accident that left him a T10 complete paraplegic at age 20 wasn't enough, less than a decade later he found himself in another collision—this one involving a second car and his own family of passengers, and leaving him with severe post-traumatic stress.

By his 30th birthday, it seemed as though life had handed Kevin Carta a whole lot of lemons.

Fortunately, life also granted Carta a zest for entrepreneurial adventure along with a like-minded friend, Ryan Geni, who had recently been laid off.

On account of his pregnant wife's lactose intolerance and his own vegan preferences, Geni had learned to make a mean homemade coconut ice cream. When Carta hosted a small birthday soiree at his Kelowna house, Geni brought over a bucket of the creamy, dairy-free dessert. It was a hit, and Frozen Coconut was born.

"I'd always been kind of a big dreamer," says Carta. "But I think that after my accident, I needed something that was a little more adventurous than the typical office job to draw me out."

The duo began selling the organic, lactose-free coconut concoction at the Kelowna Farmer's Market, first in single-serve cups, then in plain one-litre tubs. But after two successful summers, and with coconut still on trend as



a “superfood” and customers asking about home delivery options during the farmer’s market’s off-season, the pair realized they’d reached a tipping point—they needed to go big, or go home.

They got their product into a few supermarkets—but they realized that, before they could knock on doors in earnest, they’d need some real credentials. And Geni had a plan.

“At first I laughed,” says Carta. “I said, ‘Ice Cream University? Is that right next to Clown College?’”

But Geni was serious. Located in New Jersey, Malcolm Stogo’s Ice Cream University gives its students the opportunity to study with frozen dessert enthusiasts from around the world in a classroom-kitchen setting. Geni and Carta signed on, and over five intensive days, they honed techniques in non-dairy ice cream production and strengthened their existing product under the guidance of the university’s namesake president and professor—a repeat author, inventor of the chocolate-dipped waffle cone and a veritable celebrity in the world of frozen delights.

Despite a few setbacks near the end—the duo just narrowly avoided getting stranded by Hurricane Sandy—the trip was a delicious scholarly success. Armed with new confidence and knowledge, Carta and Geni arrived home and quickly transitioned their lovely bunch of coconut ice creams into a budding business.

Success came in a flurry. Frozen Coconut swapped out its faceless white container for a blue and neon splash of the tropics, with different coloured lids to match its six island-inspired flavours: Classic Coconut, Chocolate Mint, Mixed Berry, Orange Cream, Lemon Meringue and Chocolate. “We designed it as more of a refreshing treat,” says Carta. “It’s not super decadent, so we purposely avoided doing stuff like caramels, peanut butter, chocolate chunk, that kind of thing.”

Retailers embraced their creation. Today, the tropical tubs of melt-in-your-mouth goodness are sold in over 100



stores across Western Canada, including Urban Fare, Cooper’s Foods, Save-On-Foods, and Dad’s Organic Market.

Carta, now 33, recently moved from Kelowna to Vancouver to be near his vendor base and the company’s Richmond manufacturing facility, which is where we caught up with him.

The well-lit, simply-stocked and modestly-sized room is a far cry from the kind of manufacturing plant you associate with modern-day food labels. And, like its facility, Frozen Coconut’s production process is refreshingly minimalist.

Raw, fair trade coconut milk, sourced from Thailand, allows for a taste and texture that’s creamy, not oily. The balanced sweetness comes from agave syrup, and a touch of sea salt rounds out the flavours. Frozen Coconut contains no dyes or additives. And because it’s organic, lactose-free and nut-free, it’s truly a product that everyone can enjoy—a completely inclusive dessert, if you will.

“A lot of it stems from my own situation,” says Carta. “Nobody likes to feel like they’re not included in something. Nobody likes to go to places that they can’t get into, so we try to have that in our business model as well. We try to include everyone.”

That same inclusiveness extends to the brand’s business model: always say yes; add value, not competition. However, Frozen Coconut draws the line when it comes to trade secrets—recently,

the company’s new brand manager not-so-gently advised Carta to keep details of six new tropical flavours, set to launch in the Spring of 2015, a corporate secret.

These days, Carta is experiencing sweet success, but it’s never far from his mind that life before Frozen Coconut was a rocky road. True, his post-injury stays at both the Vancouver General Hospital and GF Strong Rehabilitation Centre had been fortuitously brief (in high school, Carta had broken both of his legs snowboarding and was somewhat accustomed to maneuvering a wheelchair). But a couple of years after his injury, Carta fell

into a pattern of depression, anxiety and isolation. It took several more years for him to get back to a place of confidence and focus. And just when he did, he was thrown into a second car collision.

“This business has actually been kind of like a mask for me in a lot of ways—like a shield, if you will,” he admits. “Because I got it in my head that I was cursed after that accident—you know, I don’t need to be told more than a few times that something’s wrong or that I should just stop trying.”

For two years, he stayed in his house with a girlfriend who was happy to do the same.

And then, a pact from the past caught up to him. Nearly a decade earlier, Carta and a friend from rehab had made a deal that, when they were ready and medicine had advanced enough, they would travel abroad for experimental surgery. Now Carta’s friend was eager to go (though it was questionable whether or not medicine had truly advanced).

Alone, he would never have elected the surgery or a trip to India, but Carta isn’t a man who backs out of a deal. So he and his friend travelled to New Delhi. And although the success of the epidural surgery was limited, the trip itself helped Carta address his anxiety and withdrawal.

“Honestly, if it wasn’t for me going to India, I wouldn’t be this far in the busi-

ness right now," he says. "Just being in a place like that with so many people, so much chaos, and nothing bad happening. There are a million people honking and driving around and they're not constantly bumping into each other. I saw that you can go out in the world and not have bad things happen."

With the weight of his curse lifted, Carta returned to Canada and narrowed his focus: from small business to health food to coconut ice cream. And the rest is history.

He concedes that entrepreneurship can be demanding. "It's not just physical challenges, but the emotional aspect of it. You have to put on a nice shirt, comb your hair, shave, go out and be the face of the product. And sometimes you really do have to dig deep for that."

As for his SCI, he admits that it does impose limitations. Loading ice cream pallets and vending carts will always be a job more easily done by Geni. And hours of driving between Kelowna and Vancouver, and of popping in on vendors, does

get exhausting. But he also recognizes that having an SCI sometimes gives him a leg up on his competitors. "For anything that's more challenging, there are also certain doors that open because of it," says Carta. "A lot of people are very quick to make the connection, 'Oh, this guy's very serious about what he's doing or else he wouldn't be here.' They can see that, just for me to get there, it took a little more effort. It's been a very interesting kind of social experiment."

It helps that Carta believes strongly in putting out a clean, socially responsible product—particularly when you compare it to what he describes as the "dirty business" of mainstream ice cream. "It's a product for kids," he says, "with a lot of ingredients you can't name, food colourings, processing techniques and just absurdities that nobody would really, when they sat down and thought about it, give to a developing child."

Currently, Frozen Coconut has a handful of competitors in North America. But with sales tripling between this past

April and June, more than 100 stores already carrying the product in Canada, and a lofty but realistic goal of adding another 500 vendors by next summer, Frozen Coconut's momentum won't be thawing any time soon.

"Frozen Coconut—that's what's really gotten me back into being an active member of society," says Carta. "I'm going to push it as far as I can, and it's going to pull me the rest of the way. So for me to keep going and to keep challenging myself, the business needs to keep growing. If the business were to suddenly slow down or if we were to be content, then it just wouldn't work for me because then the adventure would stop."

It's been said that when life gives you lemons, make lemonade. It's only fitting that one of Frozen Coconut's most popular flavours is Lemon Meringue. ■

*Want to know more about Frozen Coconut? Check out the company's website at [www.frozenscoco.ca](http://www.frozenscoco.ca).*

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# Access Denied: When Technology Excludes



**Information and communication technologies are expanding at light speed—so much so that the individuals and companies developing and rolling them out often fail to consider how to make them truly accessible for people with SCI and other disabilities. We asked Dr. Gary Birch, Executive Director of the Neil Squire Society and ICORD researcher, to shed some light on the problem and offer some solutions.**

Birch has some strong opinions about information and communication technologies—ICT for short—and how they're often rolled out in a manner that excludes people with disabilities from benefitting from it.

His opinions are well-informed. For two decades, Birch has been the Executive Director of the Neil Squire Society. In that capacity, Birch has led the Society in its quest to empower Canadians with physical disabilities from coast to coast to become more independent with technology and knowledge. Not only that, he is an Adjunct Professor at UBC's Electrical and Computer Engineering Department and is internationally recognized for his research in brain computer interfaces. He's also an Officer of the Order of Canada. And if those credentials aren't enough, he also has the personal life experience of living with quadriplegia since 1975.

Birch's passion for making ICT usable by people with high level SCI and other disabilities has led him to be a credible advocate for standards and approaches that ensure accessibility becomes the norm—he's written papers on the subject and provides input wherever and whenever he has the opportunity. He was quick to accept our request for an interview in this issue of *The Spin*.



**In the last 50 years, ICT has made a tremendous impact in the lives of people with SCI, and there's great potential for many more benefits in the future. Can you give us a couple of examples where you've seen ICT benefit people with SCI?**

The most obvious example would be the personal computer and the related assistive technologies that have made these computers accessible to people with high level SCI. These are technologies like alternative mice—for example, Jouse and HeadMouse—and voice dictation software. Effective access to computer technology has opened up opportunities for employment as well as participating in many other aspects of life that are becoming Internet-based.

A second and much more recent example would be the emerging option to interact with health care professionals—doctors, specialized nurses, physiotherapists, etc.—by distance using computer video technology, and

now often even smart phones, with software like Skype or more dedicated applications like Medeo. The convenience and timeliness of getting medical support through this growing method of access can be a significant help to persons with SCI.

**Can you give us a couple of glaring examples where emerging ICT has created barriers for people with SCI?**

One of the best examples is one what happened many years ago. When personal computers first came out, they were based on DOS. Soon after, assistive technologies were developed that allowed persons with even high level SCI to fully access these computers. When the graphical user interfaces—Windows being a common example—became the standard, many users with disabilities were left without access to computers.

The situation was eventually resolved when alternative mice were developed

that enabled persons with high SCI to fully control the graphical user interface. But during the interim period, the ramifications were devastating for many of these users, as they no longer had access to this technology—I know of some who actually lost their jobs.

Another, more recent example would be the growing prevalence of smart phone technology. Again, because accessibility for those with high level SCI has not been taken into account, most of these individuals can't use this ICT without the help of an able-bodied assistant or an aftermarket modification.

**In papers you've written about this subject, you've said that retrofitting new ICT for accessibility is not the answer. Can you explain why, perhaps through an example?**

Many years ago, when ICT was emerging at a much slower pace, retrofit solutions were eventually developed for people with high level SCI or similar

disabilities. During the time it took to develop these solutions, people with disabilities were left out in the cold, but at least when they became available, they were often viable for several years.

A much better approach is when designers and manufacturers of ICT take accessibility needs into account right from the beginning. When this happens, access solutions are available, either because the new technology is inherently accessible, or the technology has been designed in such a way that existing assistive technologies will work without any new specialized effort. For instance, smart phones are really just small personal computers. If they had come equipped with interface ports, such as fully supported USB ports, then existing assistive technologies for persons with high SCI could have simply been plugged into them with the possible addition of some simple software provided by the manufacturer.

**You've indicated that ICT is advancing at a much more rapid rate today—does that compound the problem? Is a speeding up**

**of the change and obsolescence cycle making accessibility more difficult?**

Indeed, this is a huge part of the current problem. As I've said, in years past, inherent delays in coming up with retrofitted solutions were a problem, but at least the solutions, when developed, were viable for a while. When you speed up the rate of emerging ICT, the retrofit solutions can't keep up, and we're seeing ongoing gaps in new technology where good solutions for persons with high SCI are simply not available. We need accessibility to be thought of in the initial design phase—not as an afterthought.

**What are the best strategies for ensuring new ICT is accessible from the onset?**

In addressing this problem, I usually talk about three key strategies: working with the ICT industry, working with government regulatory bodies, and promoting accessibility to today's students—the designers of future ICT.

An example of working with a member of the ICT industry is when we, or others in this field, convince them that when they're developing a new service

or product, they need to conduct user focus groups and user trials which would include people with high SCI so that they can learn firsthand the issues and solutions that various users require to use technology effectively. We've done some of this work on a small scale, leading to some positive results. I hope that we can do it on a much larger scale with many manufacturers. The huge upside of this approach is that the manufacturer, once they understand the problem, is in the best position to provide elegant solutions for all users with disabilities.

In terms of government regulation, one of the best examples can be borrowed from the deaf community. Several years ago, the US Federal Communications Commission (FCC) required that any television set sold in the US must have a chip incorporated into it that would allow the decoding and displaying of closed captioning. At the time, the cost of the device that had to be connected into the television to show closed captioning was quite expensive. Because the US market is so large, all television manufacturers incorporated this chip into their television sets, which allowed anyone who wanted closed captioning to turn it on. Due to the huge scale of demand for these chips, they became very inexpensive. The ripple effect is that all television sets available in Canada also have this chip, and the end result is a seamless accessibility solution for persons who are deaf and hard of hearing. This kind of initiative would have never happened without regulation forcing the manufacturers to meet this standard.

Finally, there's the strategy of influencing our next generation of ICT innovators and creators. If students across a number of disciplines, including engineering, software development and business, can be educated about accessibility issues and actually be exposed to working with individuals with disabilities including those with high SCI, they will naturally consider and include accessibility issues right from the very beginning of the design of a new product or service. This is happening

## Touchscreens for Everyone

If you're a high level quadriplegic or anyone who has limited arm and hand function that prevents you from using touchscreens, the Tecla Shield DOS could be your solution. The Tecla Shield DOS is a new product that allows you to use your power wheelchair's controller, or any compatible external switch, to access iOS and android phones and tablets, along with PCs and Macs. Once installed, you can use the device to make phone calls, surf the Internet, send and receive emails and texts, read, operate your environmental controls, and use apps or play games. It can be configured for use with up to six switches, to provide you with the customized setup you require. It offers system-wide voice assistance, allowing you to use your voice to enter text into any text box—no more typing your e-mails or text messages, just speak your mind

and let your device do the typing for you. As well, it allows

for totally hands-free and independent access to Siri on your iPhone, iPad and iPod Touch using as little as a single switch. The device is compact and connects via Bluetooth wireless technology, so it's completely portable and can be easily used away from your home environment. Visit [www.gettecla.com](http://www.gettecla.com) for more information and technical specifications.



in a number of universities and schools across North America. A great example is graduate studies offered at OCAD University in Ontario, where students from a variety of backgrounds get an excellent education, both from experts and from individuals with disabilities, around the importance of inclusive design—which is just another way of saying designing with accessibility integrated as a key part of the design process.

**What are some of the most critical areas of ICT that need addressing immediately?**

I think the most critical area is the explosion of smart phone technology and how that technology is being used ubiquitously in almost all facets of our life—work, play and obtaining services. In particular, I'm seeing a gap in accessible solutions for persons with high level SCI, and without some of the strategies discussed above, I'm not hopeful that robust sustainable solutions for these individuals will be available. This will leave these individuals at a distinct disadvantage, as using smartphone technology as an everyday tool becomes more and more prevalent.

**Is there a role for *Spin* readers to play, in terms of achieving change?**

I believe that, when *Spin* readers come across glaring accessibility problems with new smartphones and other ICT, the best thing they can do is go to the CRTC (Canadian Radio-television and Telecommunications Commission) website ([www.crtc.gc.ca](http://www.crtc.gc.ca)) and find a way to register a complaint with them. I believe they have made several options available such as email, letters or phone calls for people to express their concerns. The more complaints that the CRTC hears from individuals who are experiencing these kinds of difficulties, the more they will be inclined to find mechanisms that will force manufacturers and service providers to ensure accessibility solutions are available for persons with high SCI.

**Thank you for speaking with us.**

It's been my pleasure. ■

## ask the SPIN DOCTOR

*Joe from the Okanagan asks, "Why does it seem like many of my friends with SCI manage their bowel systems better than I do, with fewer accidents and less constipation?" To answer this issue's question, we turned to Dr. Rhonda Willms, Medical Manager of the Spinal Cord Injury Program at GF Strong.*



Few areas of post-SCI life are so difficult to manage. For many, neurogenic bowel results in leakage, chronic constipation or both. The anxiety this creates sometimes leads to social isolation and depression. Poor bowel management can also lead to serious health issues, including autonomic dysreflexia, pain, increased spasticity or even bowel obstruction.

There are two types of neurogenic bowel: reflex and flaccid bowel. They're distinct and require different management. Typically, if your injury is above T12, you'll have reflex bowel, meaning you'll probably not be able to detect when your rectum is full, and the reflex to empty the rectum can happen anytime when it's full. If your injury is below T12, you'll have flaccid bowel—your sphincter may relax and stay open.

There are excellent online resources to learn more about the two types of neurogenic bowel and how to manage them. One is SCI-U, a series of 10 multimedia courses about living with SCI. Visit [www.sci-u.ca](http://www.sci-u.ca) and follow the links for "bowel".

Fortunately, there are ways to improve bowel management after SCI, regardless of which type of neurogenic bowel you have. Diet is one way to see improvements.

Spicy, fatty, or greasy foods may lead to diarrhea. Other diarrhea culprits are caffeine from coffee, tea, chocolate and soft drinks. Chocolate and caffeine can also cause constipation, as can dairy products, red meat and bananas. Keep a record of what and when you eat. As for what you should eat, a diet rich in fibre from cereals, fruits and vegetables will help keep things moving through your system. But any increases in fibre should be introduced with more water and other fluids in your diet. You'll need to experiment to find the right amount of fluid to consume each day to make sure your stool is not too hard or too soft.

Consistent timing can also help. Choosing a regular time for your program helps retrain your body for better results. In general, bowels move better after a meal because of your stomach's reflexes. Your type of neurogenic bowel, along with your diet and other factors, will determine how often to evacuate.

Positioning during bowel movements is another important factor. Using a commode or toilet (rather than lying in bed) can increase the frequency of bowel movements and reduce the amount of time needed for bowel care.

Digital rectal stimulation increases the peristaltic activity (waves of muscle movement) of the colon that push stools through your system. Using a finger to make a circular motion in the rectum also causes the anal sphincter to relax.

Regular exercise has also been shown to improve bowel programs. And, to avoid accidents, it's important to make sure you're empty at the end of your program.

As for pharmaceutical assistance, there are different types of bowel medications that you can ask your doctor about, including lubricants, laxatives, prokinetics and several types of suppositories. Anal irrigation systems such as Coloplast's Peristeen can be an effective way to soften stools and help prevent leakage.

We recommend an annual bowel health checkup at which time you can also have your health care team review and adjust your medications or prescriptions. Any issue such as ongoing rectal bleeding needs to be addressed by a doctor ASAP.

*Email your questions for the Spin Doctor to Brad Jacobsen, our SCI BC Peer Program Coordinator ([bjacobsen@sci-bc.ca](mailto:bjacobsen@sci-bc.ca)). Any advice given is general in nature and is not intended to replace advice specific to your personal situation provided by your family physician or SCI specialist.*

# Adversity into Opportunity

Frustrated with trying to navigate the medical system to deal with my complex and ongoing health care needs, I vowed to create a tool that would help me be more organized and more in control. The result is Phoenix Attitude, and now I'm pleased to offer it to the world.

— by Jenna Reed-Cote, SCI BC Vancouver GirlTalk Peer Group Volunteer Leader

*“Change will not come if we wait for some other person or some other time. We are the ones we’ve been waiting for. We are the change that we seek.”*

— President Barack Obama

I was tired of coming out of doctors’ appointments dazed and confused. I was tired of feeling like my health care providers were patronizing me when I had finally built up the courage to talk openly about my concerns. I was tired of them not giving me credit for knowing my own body until it became clear to them that there was no other option but to give my “theory” a try. I was tired of trying to explain to those around me, who couldn’t be in the hospital or clinic room with me, what had happened during my most recent appointment. I was tired of fighting for support as I figured out what to do next. I wanted more control. I wanted to feel organized. I wanted to be an integral part of my medical team.

Sound familiar?

Nearly 24 years of practice as a professional patient with spina bifida in the medical system had not made me perfect. It had worn me out.

Three years ago, I hit rock bottom. I was dealing with my umpteenth UTI (urinary tract infection), powerful antibiotics that led to c-difficile (a bacterium that can cause symptoms ranging from diarrhea to life-threatening inflammation of the colon), a ruptured colon, sepsis, emergency surgery in my ICU room, and, as a result of all of the above, PTSD. Yes, that’s right—post-traumatic stress disorder as the result of dealing with all of the above. Go big or go home, right?

But you know what they say about what doesn’t kill you. I was down but not out. And as I healed, I resolved to find a way of being more in control in the future. I turned adversity into the motivation I needed to imagine and create a new way for people like me to navigate the medical system.

My goal was to somehow empower myself and others—to give all of us a tool that would allow us to say, “I got this. I can be a part of the conversation and decisions about my health. There’s no better expert on me than me!”

My solution is Phoenix Attitude (think Phoenix rising from the ashes). Phoenix Attitude is a mobile-friendly website that will give you the power to take more control of your life as a person with ongoing medical needs, without making you feel like a victim or a number.

Phoenix Attitude’s Medical & Motivation account is an essential and powerful online tool that you can get working for you for the modest one-time cost of just \$3.99 plus applicable taxes. For less than the price of a Starbucks latte, you’ll get a Medical & Motivation account that’s accessible on your smartphone, tablet and computer.

Simply explained, Phoenix Attitude’s Medical & Motivation account gives

people with ongoing medical needs a powerful, yet easy-to-use way of taking control of their critical health information. It helps them make their doctor or hospital visits more efficient and error-free, express their needs and desire to play an essential role in their own health in a clear way to members of their medical team, capture precisely what happened at their medical appointments, and instantly review and share their critical health information with anyone who also has an account, at any time.

The first thing you notice when you visit [www.phoenixattitude.com](http://www.phoenixattitude.com) is that it’s not your typical medically-focused website. Instead of reminding you of the white sterile walls of the hospital, we purposely use vibrant colours to make you feel alive and to ignite your drive to persevere and take control.

With my Medical & Motivation account, I feel confident. I can reflect on what’s working for me and what’s not. It keeps my medications, doctors, past surgeries and procedures, symptoms and vital information organized and at my fingertips. I can use it to prepare for my scheduled appointments, and it’s an equally powerful ally when I need to take those surprise visits to the ER which just happen to always take place at midnight

when I'm tired/in pain/anxious/distracted and basically not at my best.

With a few touches or keyboard taps, I can make sure I have the information I need when scheduling and preparing for appointments. My account reinforces the need for me to ask questions and

insist on getting real answers. It helps me highlight and remember the more subtle points about my appointment that can get overlooked in the moment when I'm tired or sick. There's nothing like being surprised with a

cystoscopy because I didn't know it was part of the appointment!

One of the features of the Medical & Motivation account I'm most proud of is the ability to upload audio and video recordings of your appointments with your practitioners that can be easily made with a smartphone. Once uploaded, these stay in one convenient location—the appointment file. I always ask my practitioners for permission to record my appointments, and I've learned that they see the value in it. In particular, they see that I can stay in the moment and ask relevant questions, instead of being focused on writing down important details in notes. And they recognize that it's a great way for them to avoid the inevitable post-appointment phone call to go over information that's been given to me, but I haven't remembered in any meaningful way. In other words, they recognize that allowing me to record my appointments is hugely efficient for both of us.

This isn't just a tool that benefits you as you negotiate the medical system—your loved ones benefit as well. If I come to my appointment alone, I may eventually want to enlist support from my

family members to help me sort through and pick out the information that's going to make the most impact in my life. With my Medical & Motivation account, I can send the information about my appointments to anyone else who has an account, securely and easily. This way, anyone I choose can hear a firsthand account of what happened during the appointment, support me more effectively, and help me to feel more comfortable with the next steps I may have to take.

There are some appointments that I get so nervous about that it's hard to stay in the present when I'm finally sitting in them. My emotions can take over and leave me with a completely different impression of what was actually said or intended. So I take advantage of being able to listen to appointment-specific recordings as often as I want—usually when I feel calmer and am in my safe place. It shocks me every time how my perspective changes, and how I can see things more clearly with every new listen. More often than not, I feel more competent in making the best decision for me when I have a well-rounded understanding of the situation at hand.

I strongly believe that physical health and mental health are interconnected, and that you can feel better when you nurture both (it must be the social worker in me). To give Phoenix Attitude's Medical & Motivation account some personality, I designed it to give you easy access to content that motivates you whenever you need it—for example, during an ER visit, prior to surgery, as you sit in a doctor's waiting room, when you're dealing with test results, or when you're laid up in bed. The goal is to cheer you up when you're feeling like you might never crack a smile again. It gives you an opportunity to let you see how others are coping with the same thing, and the ability to pick up some tips or tricks to help make daily life easier, whether you have spina bifida, SCI or some other chronic condition. The collection of content becomes more expansive every day.

One final and very important note about Phoenix Attitude: in a day and age

where privacy is paramount, we've gone to great lengths to secure your information (you have enough to worry about already). We've chosen a data centre that's ranked among the top in the world to host the website. Our data centre provides 24/7 secured access with motion sensors, video surveillance and security breach alarms to safeguard your data against intruders. We've also engaged the services of a top firm to implement necessary security and privacy measures within the portal itself. For more information, you're more than welcome to contact us!

Phoenix Attitude began life as an attempt to help me feel in control again, at a time when I felt like I had nothing to lose. I realized that the concept could help so many others, and the project quickly snowballed. I found myself putting my money where my mouth was and getting a team of experts together to help me build a tool that would resonate with many more people than just myself.

The days that stretched into the wee hours of the morning working on this (while volunteering at BC Children's Hospital and Canuck Place, and co-facilitating a support group for women with disabilities) may have led to a few more grey hairs than I would like. But if it helps you as it's helped me, it was all worth it—and if it turns into a way to make a living doing something I'm passionate about, while honouring the obstacles I've overcome, all the better. I'm glad that I've found a way to learn from my experiences and give them purpose by hopefully making you feel a little more confident, a little more in control, and a little more organized when it comes to your own ongoing medical needs.

In doing so, I hope you can go out and make an amazing mark on the world, turning your own adversity into opportunity.

For more information on Phoenix Attitude Inc. and its inaugural dream tool, Medical & Motivation, please visit us at [www.phoenixattitude.com](http://www.phoenixattitude.com), on Facebook, or on Twitter @PhoenixAttitude. ■

**“Phoenix Attitude began life as an attempt to help me feel in control again, at a time when I felt like I had nothing to lose.”**

# Getting a Better Sleep

A recent research project in Australia suggests that people with quadriplegia might get a better night's rest by taking a common melatonin supplement.

**P**eople living with SCI—particularly quadriplegia—have long reported poor sleep quality. Obviously, poor sleep and lack of sleep can severely impact quality of life.

In recent years, compelling evidence has emerged that one of the main culprits for poor sleep after high level SCI is an inability to produce melatonin, a vital hormone secreted by the pineal gland located deep within the brain. Melatonin plays a major role in the timing of circadian rhythms—physical, mental and behavioral changes that follow a roughly 24-hour cycle, responding primarily to light and darkness in a person's environment. Simply put, melatonin is created by the body when it's dark. In turn, melatonin signals the body that it's time to sleep.

"When you have a spinal lesion higher than T1, the path-

ways that connect your eyes—which sense daylight—and the part of your brain that produces melatonin are interrupted," explains Dr. David Berlowitz, Lead Investigator of the Sleep Health in Quadriplegia program at the Spinal Research Institute in Melbourne, Australia. "Previous research had shown that people with complete quadriplegia have essentially no circulating melatonin and no normal melatonin rhythm over the 24-hour cycle. Normally, melatonin goes up as your core body temperature goes down; both of these are important triggers for your body to get ready to sleep. We wondered if giving people supplemental melatonin two hours before sleep would help with restoring the 'normal' rhythm."

Berlowitz and his colleagues knew that timed, daily administration of melatonin appears to improve sleep in



able-bodied and functionally blind people with insomnia. They also knew that another recent study of nightly melatonin supplementation in people with complete quadriplegia had produced some positive results, with participants reporting that their sleep quality improved—in other words, there was a subjective improvement. And the researchers involved in that study were also able to see a scientifically measurable increase in stage 2 sleep—an objective improvement.

Based on all this, the researchers set out to complete a proof of concept study that would further explore the effect of melatonin supplementation to see if it was safe, and whether or not it would confirm subjective and objective sleep improvements for people with complete quadriplegia.

Unlike the previous study, this project would use a randomized, blinded, placebo-controlled, crossover design. At different times in the study, some par-

ticipants would randomly be chosen to receive a placebo, while others would be given melatonin—but none of the participants or the investigators would know what each participant was receiving.

Eight participants with quadriplegia were recruited. Of these, seven completed the study. Their average age was just under 50, and they'd lived with SCI for an average of about 17 years. For six participants, the research was conducted in their own homes in Melbourne, while the seventh completed the study at Melbourne's Austin Hospital Sleep Laboratory.

Each participant was given either three milligrams of melatonin or a placebo for the first two weeks, nothing for the next three weeks, and, in the final three weeks, the opposite treatment (melatonin or placebo) of what they had received during the first two weeks.

Testing took place over the course of the study. Objective testing included the collection of urine and blood samples to measure melatonin levels circulating in the body, and full polysomnographies—comprehensive recordings of the biophysiological changes that occur during sleep, including brain activity (EEG), eye movements (EOG), muscle activity or skeletal muscle activation (EMG) and heart rhythm (ECG) during sleep. Subjective testing included completion of questionnaires to assess mood, sleep symptoms and health-related quality of life, as well as an ongoing sleep diary.

Melatonin circulating in participants' urine and blood was clearly present in those who were given the supplement—and non-existent in those taking the placebo. As far as objective results (that is, scientifically measurable), polysomnography showed

a significant increase in light sleep with melatonin. Subjective results, as measured by the self-reporting questionnaires, were also positive following melatonin supplementation—in particular, participants self-reported that their duration of sleep per night and psychological well-being both improved. The placebo didn't appear to improve sleep as measured subjectively or objectively.

There were no adverse reactions or side effects from taking the melatonin.

"These results suggest that increasing melatonin in people with complete (quadriplegia) is beneficial, especially for subjective sleep," wrote Berlowitz and his colleagues in their study results, which were published in the journal *Spinal Cord* this past June. "Nightly supplementation with three milligrams of melatonin successfully elevated circulating nocturnal melatonin levels in a system where it was otherwise absent. Melatonin improved subjective sleep with participants reporting faster sleep initiation, having longer sleep duration and improved psychological well-being. The results of this preliminary study appear to show that melatonin may have a role in promoting sleep in (quadriplegia)."

The study does seem to have successfully provided

*"I think it's critical that we address the secondary disability that people with SCI are forced to live with. That's why we focus on sleep disorders. They're very common, often readily treatable and have been under-recognized and under-treated for years."*

— Dr. David Berlowitz



proof of concept—melatonin can be provided to people with quadriplegia safely, and there were enough benefits to suggest further research is warranted.

“However, with such a small, single study, it’s not wise to extrapolate too far and too fast,” cautions Berlowitz. “What we would like to do next is really establish the exact role of melatonin supplementation in SCI, and how it relates to the other important body rhythms like temperature. We need funding support for a much larger trial with multiple sites.”

Given that melatonin is a readily-available, non-prescription supplement, those of you who deal with poor sleep might be wondering if it’s worth trying right now, on your own.

“I think this is where I’m not sure what to suggest,” says Berlowitz. “Yes, melatonin is essentially safe in the able-bodied, but I have no idea how a body that has had no melatonin for, say, 20 years since injury will respond over time when it is re-introduced. It’s highly likely that the way the body responds to the melatonin at a cellular level has modified over time. I think if people want to try this, then they should talk to their spinal or sleep clinical teams.”

Berlowitz looks forward to expanding his research in this area, but concedes that funding is always an issue, and that in order to make a larger, longer study a reality, partners must be found.

“I love doing research in this area,” he says. “People with SCI are so generous with their time and knowledge, and that makes what my team and I do so rewarding. As your readers will no doubt be aware, there’s not much research done on ways to make living with SCI ‘less bad’. While we wait for a cure, I think it’s critical that we address the secondary disability that people with SCI are forced to live with. That’s why we focus on sleep disorders. They’re very common, often readily treatable and have been under-recognized and under-treated for years.”

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

## Spotlight On Chronic Pain

In November, Australian-based publisher HammondCare Media released *The Spinal Cord Injury Pain Book*. HammondCare Media describes it as “a first of its kind book that provides vital support for the two out of three people with spinal cord injury who experience chronic pain.”

*The Spinal Cord Injury Pain Book* presents the latest research on how neuropathic pain is created in the damaged central nervous system of people with SCI, and describes the specific pain challenges for people living with SCI and strategies for dealing with them—all in an easy-to-read format with more than a dozen illustrations.

Written by some of Australia’s most experienced spinal cord injury pain experts, the book also includes the personal stories of people living with SCI neuropathic pain.

Strategies discussed in the book range from medication and new technology through skills such as exercise, distraction, relaxation and meditation.

*The Spinal Cord Injury Pain Book* is the follow-up to the successful *The Pain Book* by the same authors (2013, HammondCare Media).

For more information, visit [www.hammond.com.au](http://www.hammond.com.au). Here in North America, the book can be purchased from [www.amazon.com](http://www.amazon.com).

Still on the pain front, the Global Year Against Neuropathic Pain launched on October 20. Sponsored by the International Association for the Study of Pain (IASP), the 15-month campaign focuses on education for health care professionals and government leaders as well as public awareness.

As readers of *The Spin* know too well, neuropathic pain is a common secondary health complication of SCI, and is characterized by shooting or burning pain, numbness, altered sensation, and sensations that are very difficult to describe.

Led by IASP’s Special Interest Group on Neuropathic Pain, the initiative will mobilize IASP’s 8,000 plus members and 90 national chapters, and forge partnerships with other organizations, to:

- disseminate information about neuropathic pain worldwide;
- educate pain researchers as well as health care professionals who see the issues associated with neuropathic pain firsthand in their interactions with patients;
- increase awareness of neuropathic pain among government officials, members of the media, and the general public worldwide; and
- encourage government leaders, research institutions, and others to support policies that result in improved pain treatment for people with neuropathic pain.

As part of the Global Year Against Neuropathic Pain, IASP offers a series of fact sheets for clinicians and health care professionals that cover specific topics related to neuropathic pain. The free fact sheets are translated into multiple languages and available for download. Also available on the web is a page of resources including links and free posters promoting the Global Year. Throughout the coming year, IASP and its chapters will sponsor meetings, symposia, media interviews, publications and other efforts to promote education on issues surrounding neuropathic pain.

While the resources are primarily intended for health care professionals, could it hurt to download some of them and give them to your own doctors—particularly your family doctor—during your next visit?

For more information, visit [www.iasp-pain.org/GlobalYear/neuropathicpain](http://www.iasp-pain.org/GlobalYear/neuropathicpain).



# Tools for Pain

A new, valuable online resource for managing SCI neuropathic pain recently launched in Australia, and people around the world can benefit.

Apparently, they take pain seriously. Down Under, judging by a government-funded, comprehensive online chronic pain toolkit for people with SCI launched in October.

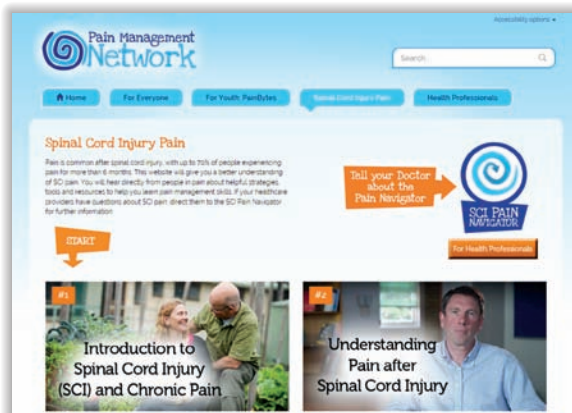
The toolkit was created by the New South Wales Agency for Clinical Innovation (NSW ACI) Pain Network, with funding provided by the New South Wales government. It's intended for both people dealing with chronic pain and SCI, and for health care professionals.

The toolkit's development began with an extensive consumer and clinician consultation process to determine what it should include.

"Many people get mixed advice or none that applies to SCI, and this project will help ensure people with chronic pain and SCI are able to access the right advice and treatment in a timely manner," says Jenni Johnson, Manager of the Pain Network. "The Spinal Cord Injury and Chronic Pain Project has found long wait-lists and lack of a standardized approach are key issues for people with SCI and chronic pain in New South Wales, and has highlighted the need for a pain management service specific to SCI."

Johnson explains that a survey of health professionals found that over 80 percent of clinicians were under-resourced to manage chronic pain after SCI, that individuals with SCI were often not able to access multidisciplinary pain clinics throughout NSW, and that, often, the only pain management tools offered to people with SCI were medications.

"We know from research that medica-



tions alone are not the answer, and that a combination of education, physical and psychological strategies, and the option of additional good medication management, is likely to achieve the best results," explains Johnson. "The new online resources are designed to help facilitate better pain management in both primary and tertiary care, with the client taking an active lead in their care."

The finished product offers a wealth of resources, including SCI pain strategies and plans, pain assessment forms, handy hints, useful links, an interactive clinical pathway for SCI pain management called the SCI Pain Navigator, and videos based on the latest evidence in pain management, which are delivered by experts in the field.

Video topics include understanding SCI and pain, getting help from health teams, pain and physical activity, pain lifestyle and nutrition, pain and thoughts, pain and sleep, pain and the role of medications, and how strategies can be implemented in daily routines of people with chronic pain and SCI. The videos are professionally produced and polished.

"The website videos specific to SCI

feature prominent clinicians led by Professor James Middleton, Director of NSW State Spinal Cord Injury Service, and individuals sharing their own personal experiences of pain after SCI," says Johnson. "Hearing the consumer voice is so important."

The SCI Pain Navigator, a clinical decision support tool based on the latest scientific evidence in the field, alone makes the entire kit worthy of pointing out to members of your own health care team here in BC.

"The SCI Pain Navigator guides clinicians through a series of phases including screening for pain, assessment of pain intensity and interference, pain types, screening for yellow flags or psychological considerations, and screening for SCI red flags or physiological considerations of major concern," says Johnson. "Clinicians are guided through any additional assessment or investigations that may be required, and suggested treatment strategies are provided with a holistic medical, physical and psychological approach."

In particular, says Johnson, the red flags screening pages are critically important, as they provide a physician with fast and easy access to important SCI-specific health information. "This is particularly important for individuals with SCI who present with an increase or change in their neuropathic pain that may be an indication of something occurring in their body in an area where their sensation is reduced or absent," she says.

While the SCI Pain Navigator is a clinician tool, one of the primary goals of the entire toolkit is to give people with SCI a powerful resource at their fingertips so that they can play an integral role in their own pain treatment.

"We know the best evidence for the most effective pain management is to arm the person who has a spinal cord injury and pain with a range of skills and self-management strategies to build into daily life and routines," says Middleton.

To see the pain toolkit in action, visit [www.aci.health.nsw.gov.au/chronic-pain](http://www.aci.health.nsw.gov.au/chronic-pain). ■

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*Richi Sahey, Montreal*

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