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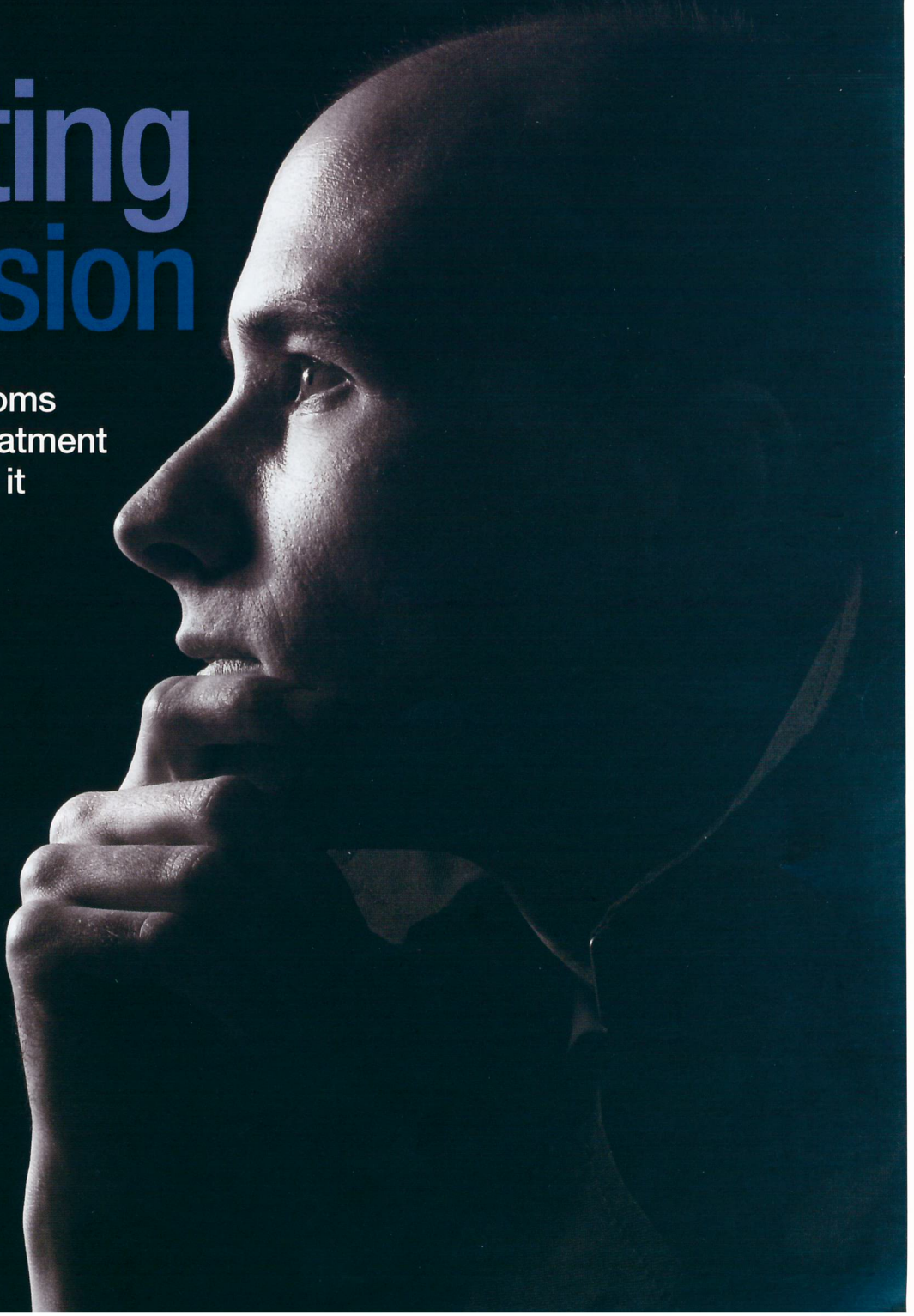
SPINAL CORD INJURY BC

SUMMER 2012

Defeating Depression

Recognizing the symptoms and finding effective treatment strategies to move past it





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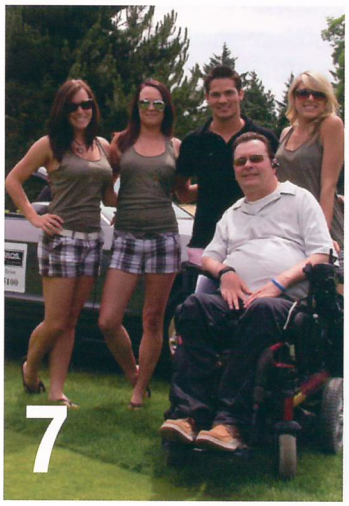

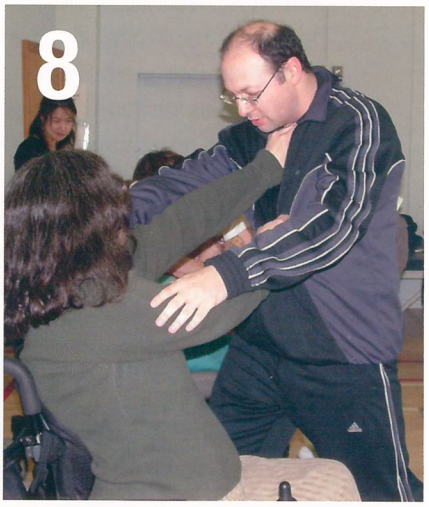







editor's message

What's in a Name?

OCTOBER 27, 2011 WAS A HISTORIC DAY for the Canadian Paraplegic Association, the BC Paraplegic Association, and other Canadian Paraplegic Association provincial divisions. Following a broad stakeholder engagement process, extensive research and thorough deliberation, representatives from each provincial CPA division voted unanimously to rename the national body Spinal Cord Injury Canada.

The majority of the provinces agreed to do the same, substituting our provincial name for Canada. On May 3, 2012, BCPA started doing business as Spinal Cord Injury BC. Note that, for the near future, our legally incorporated name remains Canadian Paraplegic Association (BC).

Why was change needed? There are many reasons, but inclusivity was one of the most important. CPA was founded by spinal cord injured veterans returning home from World War II. At that time, there were only paraplegics, since quadriplegics didn't survive for long. Today, advances in science and medicine have improved the survival and outcomes for both paraplegic and quadriplegics, who are now represented in almost equal numbers in BC.

So the term paraplegia no longer represented the SCI community. It also led to confusion. Our team would regularly be asked by families of newly injured quadriplegics if their loved one could access our services, or if they were for paraplegics only. We also heard that the term paraplegia was too medical.

Thus, we chose a name that was inclusive of our core membership and common to each of our service mandates—one that was clear and recognizable to all. Thanks in large part to the awareness raised by Rick Hansen over the past 25 years and to the many other difference makers across this country, the term spinal cord injury and what it means is understood by everyone.

What might not be so obvious to everyone is what the term includes. Most often, SCI conjures up traumatic injuries. But almost half of SCIs result from non-traumatic causes, such as cancer or infection. SCI also refers to spinal disorders such as spina bifida. In other words, the term is not just inclusive of different levels of injury, it's inclusive of a wide variety of causes as well.

However, it's important to emphasize that the name is all that changes. For Spinal Cord Injury BC, our programs remain the same and who can benefit from them doesn't change. People with related physical disabilities such as MS are still welcome and eligible to participate in our Peer Program and Information Services. We are as inclusive as always.

Change can be a challenge and we know it will take time for people to get used to our new name—and to recognize it when they see it. However, we think the time was right for the change, and judging by initial responses from members and the broader stakeholder community, the decision was a good one. We'd like to hear what you think about our new name—let us know by mail, email, Facebook, Twitter or our website.





– Chris McBride, Executive Director, SCI BC

thespin

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Innovations

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

PARAGOLFER

BC's golf courses and length of golfing season are the envy of Canada. Yet opportunities for BC golfers with mobility disabilities are abysmal compared to those in provinces such as Alberta and Saskatchewan. Perhaps Ottobock's ParaGolfer, now available in Canada, will change the situation. In just seconds, the ParaGolfer can position a user in a fully upright stance where he or she can swing a club with two hands. An all-terrain design allows the player to move effortlessly across the course without damaging the greens. A low profile provides stability and secure footing when in standing mode. The ParaGolfer easily conquers grades of up to 30 percent. If the maximum values are exceeded, the ParaGolfer automatically turns the vehicle back to a safe position. For more information, visit www.ottobock.ca.



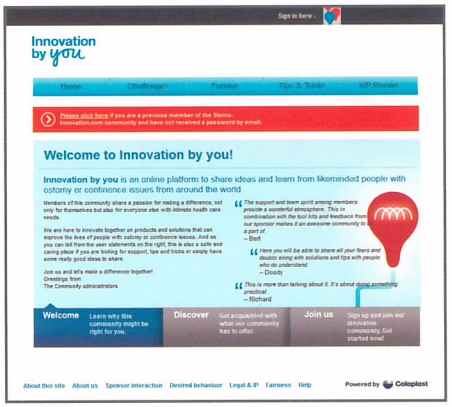
SIDESTIX

If SideStix sounds familiar, perhaps you saw the company's owners (who hail from BC's Sunshine Coast) successfully pitch their innovative crutches on a recent episode of CBC's *Dragons' Den*. What makes the product unique are its integrated shock absorbers and interchangeable feet suitable for a variety of terrains. In addition to the internal shock absorber, the SideStix's arm cuffs are padded to prevent chafing, while ergonomically designed hand grips provide maximum support. The angles incorporated into the design of the crutches also put the arms and wrists in a neutral position. All of these features, according to the company, combine to provide superior joint protection, minimal vibration to the hand, and maximum comfort and safety for the user over the long distance. SideStix also feature rotating, articulating feet that remain flat against the ground throughout an entire stride, or when gripping a slanted surface. Interchangeable foot types include the snowshoe and sandshoe feet which spread the user's weight more evenly on soft surfaces, and the ice pick feet which feature a stainless steel spike in the middle surrounded by a rubber sole. Visit www.sidestix.com for details.



INNOVATIONS BY YOU

Coloplast has created a new online community called Innovation By You. Here, community members with common challenges can freely and privately share their experiences and advice, while taking an active part in creating the health care devices of tomorrow by interacting directly with Coloplast's product engineers, with the goal of improving existing products and developing brand new medical devices. The community's members can influence all of Coloplast's new products, and the company will also support the community in developing the co-created products that Coloplast doesn't currently have the capacity to bring to market. Innovation By You is a growing community that has already attracted 2,400 members globally. Visit www.innovationbyyou.com to learn more.





Tennis, anyone?

BC Wheelchair Sports Association hosts the ITF 3 Wheelchair Tennis Tournament from July 19 to 22 at the Stanley Park Courts in Vancouver. The tournament attracts international and local athletes competing in both the Open and Quad divisions. It will also feature the USA's Steve Welch, the top ranked Men's Open player, and Canada's top ranked player, Joel Dembe, who will compete in one of their last matches before heading to the London 2012 Paralympic Games. Come out and watch some competitive matches in a beautiful setting. For details, email holly@bcwheelchairsports.com.



Bus Stop Hop.

The Bus Stop Hop is SCI BC's signature Peer event in Metro Vancouver, showcasing accessible transportation options for people who use wheelchairs. Teams of four (two able-bodied and two people with mobility disabilities) race around the city, answering trivia questions and scoring points as they hit all the hot spots using everything Translink has to offer. Teams are going green for 2012 with sustainable transportation tips and eco-friendly finds! The event will be held August 18, 2012. Get onboard the Bus Stop Hop and register your team today at www.sci-bc.ca.



Golf & Support SCI BC.

The annual Doug Mowat Memorial Golf Tournament returns to the Point Grey Golf & Country Club on July 16, 2012 in support of the BC Paraplegic Foundation (BCPF). Participating golfers in this premiere fundraiser event compete for excellent prizes while helping British Columbians with SCI adjust, adapt and thrive post injury. Proceeds allow the BCBF to provide annual scholarships and bursaries for people with an SCI to pursue post secondary education, and support SCI BC in its provision of vital provincial programs. For more information, visit www.mowatmemorial.com.

Congratulations!

The BC Spinal Cord Injury Community Services Network congratulates Rick Hansen on the successful completion of his 25th Anniversary of your Man In Motion World Tour! We'd also like to congratulate all of our staff, volunteers and members who participated in the Rick Hansen 25th Anniversary Relay and related activities. Together, we are making a difference for people with SCI and related disabilities.

Neil Squire Society

Sam Sullivan Disability Foundation

BC Wheelchair Sports

Spinal Cord Injury British Columbia

BC wheelchair basketball

A New Name for a New Era.

Spinal Cord Injury British Columbia

The BC Paraplegic Association (BCPA) is now Spinal Cord Injury British Columbia (SCI BC). Here's why we changed:

- There are as many quadriplegics as paraplegics in BC
- SCI results from a broad range of causes, not just trauma
- More and more older people are sustaining SCIs
- Our focus is not just SCI—it's also related physical disabilities.

Only our name has changed. SCI BC continues to provide answers, information and unique community experiences to people with SCI and their families throughout BC through our Peer and Information Services Programs. Learn more at:

www.sci-bc.ca **InfoLine: 1-800-689-2477**

SCI BC is an operating name formally registered as Spinal Cord Injury Organization of BC, recorded as a partnered name with its legally incorporated charitable entity, Canadian Paraplegic Association (BC).

Defend Yourself

Vancouver's Master Michael Sirota believes everyone can benefit from the martial arts, regardless of ability or disability.

In November of 2010, Vancouver's Larry Skopnik became an overnight Internet sensation when a security camera video of him subduing a would-be thief in a Commercial Drive grocery store was posted online. Skopnik, a paraplegic, grabbed the suspect in a headlock and held him there until help arrived.

Not surprisingly, Skopnik was both hailed as a hero and criticized for risking harm to himself. Regardless of which camp you're in, you have to admit that Skopnik challenged the general public to rethink the misconception that everyone who uses a wheelchair is helpless.



Vancouver's Master Michael Sirota agrees—and he's keen to help people with SCI and other disabilities learn how to defend themselves while reaping the many other benefits of learning martial arts skills.

Sirota is the owner of Sirota's Alchymy Martial Arts & Life Skills Centres, one located in Richmond and the other in downtown Vancouver. If you're curious about the word alchymy, it's another spelling of alchemy—the practice of transformation.

"It's my vision to facilitate personal transformation via martial arts training," says Sirota. "I use martial arts as a tool to assist our students grow in body, mind and heart."

Sirota's personal foray into martial arts began when he was a child. "I started martial arts training to develop self-confidence, self-defence and the ability to stand up for myself," he explains. "It's been a transforming journey."

Skill, desire and hard work helped Sirota become a world-renowned Taekwondo expert and instructor. In 1992, he opened Sirota's Alchymy, where he's since trained thousands of people in the ways of martial arts. But he's viewed it as much more than a business—he's always seen martial arts as a platform to develop and offer programs for the betterment of individuals and the communities they live in. His work includes introducing martial arts as a tool to enhance positive life skills and character development in children, operating a high school martial arts course for at-risk youth, and leading the Canadian University Taekwondo Program to the world stage.

He's also been recognized as the pioneer and leader of martial arts programs for individuals with various disabilities. "About 13 years ago, I started a small class for children with developmental disorders," says Sirota. "At that time, it was my way of making a small difference in our community and returning positive energy to others. Since those very humble beginnings, I have made the work I do in this area a significant part of my life, introducing martial arts and self-defence programs for people living with various disabilities—visual, mobility, and intellectual."

Sirota estimates he's trained about 50 people with mobility disabilities, including people with SCI, spina bifida, cerebral palsy and polio. Although he

doesn't rule out anyone with a disability joining a regular training program, his preference is to train people with disabilities within disability-specific classes. "This way," he says, "our instructors can create programs that are best suitable for that disability group. However, I also believe that everything is possible."



Sirota's Alchymy teaches two martial arts systems—Taekwondo and Hapkido. "Taekwondo is the world's most popular martial art with millions of practitioners in over 200 countries," explains Sirota. "It's an Olympic sport, and it's my vision to see it also become a Paralympic sport. Hapkido is a self-defence system using various joint manipulations, locks, throws and takedowns. Hapkido is an integral part of the self-defence curriculum that we teach when we offer programs for people with mobility disabilities."

He adds that one of the main goals of training for people with mobility disabilities is to gain the confidence to defend themselves in the face of conflict. "We offer training against all attacks, including punches and grabs of the body," he says. "We also educate practitioners how to use their chair as a self-defence tool. The more students attend the classes, the greater the knowledge they will acquire."

But Sirota is quick to point out that acquiring the ability to defend one's self is only one benefit of martial arts training.

"I have witnessed tremendous changes and improvements in students' overall state of being. Self-confidence and self-esteem are the two areas where I've witnessed the greatest changes. This confidence carries beyond the martial arts training into the practitioners' daily lives. I also teach martial arts from a therapeutic perspective, where individuals develop greater mobility, strength, coordination, balance and various other physical attributes."

Sirota is currently working with SCI BC and other community disability organizations with the hope of establishing long-term relationships that lead to short-term courses and ongoing training opportunities for individuals with SCI and other mobility disabilities. He's also striving to work with the BC Taekwondo Federation in order to promote Para-Taekwondo as sport for individuals with disabilities.

If you're interested in martial arts training, Sirota urges you to visit his website (www.sirotasalchymy.com) where you can learn more about the opportunities he offers and find contact details for him and his staff. ■

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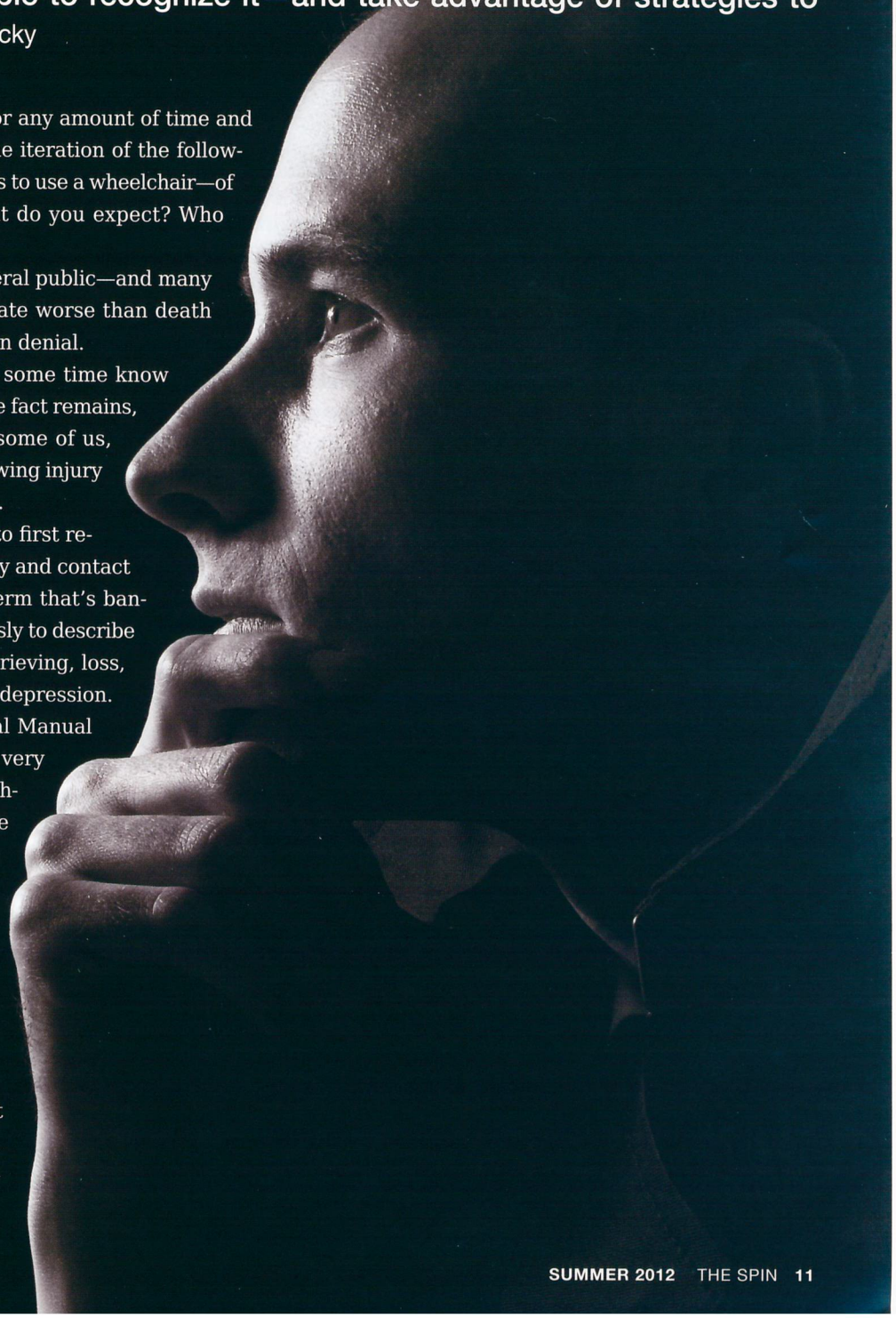
Defeating Depression

Contrary to public opinion, depression doesn't go hand in hand with SCI. But if does show up, you've got to be able to recognize it—and take advantage of strategies to move past it. ■ By Richard Holicky



Hang out at a rehab hospital for any amount of time and you'll probably overhear some iteration of the following: "He's paralyzed and needs to use a wheelchair—of course he's depressed! What do you expect? Who wouldn't be depressed?"

The social construct of SCI that the general public—and many wheelers—buy into is that paralysis is a fate worse than death and, if you're not depressed, you must be in denial.

Most of us who have lived with SCI for some time know these misconceptions for what they are. The fact remains, however, that depression is an issue for some of us, whether it's experienced immediately following injury or rears its ugly head years down the road.

To understand the issue, it's important to first remember that depression is often like beauty and contact lenses: in the eye of the beholder. It's a term that's bandied about and used cavalierly and generously to describe moods ranging from the blues to serious grieving, loss, anxiety, bereavement, despair and clinical depression.

"The DSM IV—Diagnostic and Statistical Manual of Mental Disorders—doesn't really apply very well to SCI," says Lester Butt, the head psychologist at Craig Hospital, an SCI acute care and rehab facility in Denver, Colorado. "So many of the criteria normally used to define depression—especially the physical variables such as weight loss, fatigue, loss of energy, psychomotor retardation—are symptoms that most everyone experiences immediately following SCI. Some symptoms may be tied to medications. Clinical depression is very different from loss, grief or bereavement. As a result, I look for cognitive markers such as helplessness, hopelessness and worthlessness,



***KEITH SACKIN** credits a combination of counselling and anti-depressant medications for relieving his clinical depression during rehab.*

all of which, I've found, are far more indicative of significant clinical challenges."

Hopeless, as in nothing will ever change and things will always be this bad; helpless, as in I have no power to change things and make them more tolerable; and worthless, as in this is all my fault and I probably deserve it.

So given all this, just how prevalent is depression after SCI?

"Figures vary," says Toby Huston, another psychologist at Craig Hospital. "But if you mean clinical depression, somewhere between 11 percent and 30 percent. If you're talking about grief and mourning masquerading as depression, then it's more like 85 percent."

And depression can show up at any time: in rehab, several years post-injury or decades later. Think of depression as a gift that SCI can keep on giving.

But in the same thought, keep in mind that there are tried and tested ways of dealing with it and treating it. Just as it's time to put to rest the misconceptions about life with SCI, it's also time to dispel the widespread myths regarding mental health therapy: it doesn't work, it's for the weak, and drugs don't do any good either.

Depression Following Injury

Keith Sackin was diagnosed as clinically depressed while in Shepherd Center in Atlanta for his initial rehab 10 years ago, following a fall from a third floor balcony.

"I couldn't sleep, had night sweats and regular panic attacks, and next to no energy," says Sackin, a 30-year-old T10 paraplegic and professional photographer. "I felt like I was grieving. I had lost a huge part of my life and it felt absolutely earth shattering. I was constantly worried about the future, how I would take care of myself, how I would do in the world."

His situation was complicated by chronic pain and the medications he was taking to deal it.

Sackin says the first three months were the most difficult for him and credits a combination of meeting with hospital psychologists and a regimen of SSRI inhibitors—basic anti-depressant and anti-anxiety medications—with taking the edge off the worst of it. Once out of rehab, he traded the Percocet and Darvocet for ibuprofen, Neurontin and relaxation exercises.

"After rehab, I continued in the Shepherd Day Program," he says. "I learned how to drive and began running errands. I gained more control of my life. I also continued to see a therapist."

Sackin says he stayed in therapy for a couple years, as he found talking about his feelings to be helpful.

"Toward the end I began to slack off, not going as often, and eventually decided that everything was good. I had some anger issues at first; a lot of it directed at myself. I blamed the injury on my own carelessness in slipping and falling over the railing. Initially I was in a bad mood, but not toward others; mostly it was self-directed."

Many people may be reluctant to see a therapist, either believing that doing so is a sign of weakness or being uncomfortable sharing intimate life details with a stranger. Having been a psych major at the time of his accident, Sackin says he had no issues with the intimate aspects of therapy.

The Harder You Fall

Nick Pearce had the world by the tail in the fall of '09. He was a middleweight mixed martial arts/cage fighting champion with a girlfriend on his arm until he broke his neck during a training session in South Dakota. He showed up at Craig Hospital in Denver a couple months later with a nasty bed sore that hampered rehab. That's when his girlfriend left, leaving with no explanation other than what he calls, "the obvious."

"I spent about six months in the dark alone healing that sore," says Pearce. "I went from being a middleweight champion with a girlfriend to being alone and paralyzed in a hospital bed. I actually went online and ordered Nyquil and Tylenol PM in order to try to finish myself off."

Because the Nyquil bottle broke during shipping, the package had a recognizable odour when it arrived at the hospital and his plan was foiled.

"I was truly in the depths of despair. I kept looking at that overhead lift in my room, thinking of ways to end my misery. It's scary to be thinking those thoughts.

"They had me try many different anti-depressants while in the hospital. I'm not sure if the pills worked, but the psychologist I saw there sure helped a lot. He understood the injury as well as anyone who's not in a chair can. Having someone to talk to helped a great deal. He didn't judge me and he let me vent and talk about my fears."

Pearce says the hardest thing was going from being a physic-

ally fit, macho fighter to living in a chair and trying to be around other men.

"So many of these guys in rehab were doing so well and acting like being in the chair didn't bother them; for me, being in a chair was all I was thinking about."

Today he's slowly putting his life back together: he's playing rugby, living with a new girlfriend, and started attending college last fall.

"I don't want to go back to that (mental and emotional) place. I've put in too much work to give up now. I've found something valuable in my life to live for. Having someone who's a professional to talk to was really helpful and made a difference."

Pearce's experiences speak to the common myth that only psychological weaklings succumb to depression. They also put to rest the assertion that counselling doesn't help.

When Reality Catches Up

Sam Gardner struggled for close to five years following injury in a violent crash in which his friend was killed.

"I spent those years drinking and drugging, trying to medicate away the pain and guilt I felt for surviving a trip I had talked him into taking," says Gardner. "I always believed that things eventually turn out okay, but gradually over that five years my hope simply evaporated and the drugs and booze would no longer take away the pain. Then I lost the girlfriend that I'd had since before I was injured and everything totally unravelled: my self-identity crumbled, I got sick, I went through a weird drug experience that slammed me to the ground and I simply lost hope."

Gardner spent about six months in the ditch of depression that Butt defined as helpless, hopeless and worthless. "I felt like I was in a deep pit with no escape. Something physiological happened when I took that dive; I experienced the feeling of being without energy that others describe in a very palpable way, and it was like nothing I've ever experienced before. I was almost catatonic at one time."

Eventually, Gardner says, he realized



***DEBORAH KROTENBERG** suffered from serious depression when she reached the limits of her functional recovery two years post-injury.*

he either had to move on or do himself in, which he "dismissed out of pure fear." He looked up the psychologist he had seen in rehab, sought some counselling and began to see some glimmer of hope. Looking back he's unsure as to the effectiveness of the counselling sessions ("I saw the guy three times and made the decision that seeing him more wouldn't help.") or the pills that he prescribed ("I took them for about a week, and didn't feel any different, so I quit.").

It seems likely that his finally hitting rock bottom and accepting the reality of his situation with a clear mind is what Gardner really needed to move forward.

Gardner's experience of impacting the wall of reality several years out of rehab is not all that uncommon. Whether it's using drugs and alcohol, obsessing over small improvements in physical function that finally plateau, or believing that a financial windfall from a legal settlement will make everything better, the result is too often the same: reality eventually catches up. When it does, you discover that you're still on wheels, still doing bowel programs and still looking for accessible parking spots. That, in turn, often leads to depression.

A Black Cloud Out of the Blue

Fourteen years ago, Deborah Krotenberg, then 30 and two years into living with a C5-6-7 injury, was working full time and quite proud of her progress. Then, one day while driving along the highway next to the concrete median barrier, it occurred to her how easy it would be to flick her wrist, hit the barrier and take herself out.

"I didn't know where the hell that came from," she says. "I spoke to my sister, who's a school psychologist, and she told me to tell the therapist I'd been seeing—quickly!—and suggested I get on an anti-depressant."

Krotenberg's psychologist immediately suggested a drug regimen of the anti-depressant Zoloft. "About two weeks later, the black cloud lifted and I began to feel a bit better," she says.

She remained on Zoloft for a couple of years before switching to a different anti-depressant, which she continues to take.

"At first I resisted an anti-depressant because I figured that the drugs would make me go around with a smile pasted on my face, but that hasn't been the case," says Krotenberg. "My sister suggested that I was questioning her experience, education and professional training, so I gave the drugs a try. I didn't even realize that black cloud was there."

Krotenberg also made the decision to begin counselling, which she continued for several years. "I'm not a crier, so the sessions served as my safe place to go and mourn. Therapy taught me a great deal about myself and gave me tools. The biggest one was learning to not blame everything on the injury."

Looking back, she recognizes that it was reaching the limits of functional recovery that triggered the black cloud. "Up until then I was getting stronger, gaining more independence and generally improving. Then I pretty much plateaued and realized that this was it."

Though Krotenberg was never formally diagnosed with clinical depression, thoughts of suicide or self-harm are a key indicator. Other signs include feeling sadness throughout the day, nearly every day; loss of interest or enjoyment in favourite activities, feelings of worthlessness, excessive feelings of guilt, or trouble concentrating.

Recapping the Options

Some may feel that depression will run its course and they just need to "get over it." The reality is that, untreated, depression

can severely affect a person's ability to function in day-to-day life. It can make pain worse and sleep difficult, sap energy, take enjoyment out of activities, and lead to poor physical health and higher incidence of suicide. Untreated depression can last as long as 12 months or more.

But that's not to say time isn't important. Time has always been called the great healer for good reason. In the case of SCI, as people gain more control and essentially "learn how to be disabled," they gain self-efficacy and self-esteem, and their mood elevates as they gain more confidence and control of their lives.

"To be honest, I've been underwhelmed with the effectiveness and utility of the sole usage of psychoactive drugs."

While everyone and every situation is different, it seems safe to say that time combined with some sort of therapy is the best approach. But what kind of therapy is best: pharmaceutical or counselling, as in talk therapy or cognitive behavioural therapy (CBT)?

Our duo of psychologists from Craig Hospital see a role for drug therapy, but neither believe it's the panacea that people are often led to believe it is.

"To be honest, I've been underwhelmed with the effectiveness and utility of the sole usage of psychoactive drugs," Butt says, asserting instead that talk therapy, or talk therapy used in conjunction with drugs, are far more effective in bringing about emotional stability. He goes on to describe therapy following SCI as "coaching people to access internal strengths and external resources, along with teaching some fundamental skills."

He says that people often hide their true feelings of despondency from loved ones, whom they're trying to be strong for. That, he says, makes talk therapy with a professional so powerful. "One's willingness and ability to verbalize concerns within the context of a trusting therapeutic relationship is where the effectiveness lies," he explains.

Huston agrees. "People may be filled with doubts and uncertainty but don't want their families to see that, or to hear them say 'Maybe I'd be better off not being such a burden. Maybe it would be better if I wasn't here.' They can feel safe and get some relief saying that to a therapist."

But both also point out that there are other options to consider—namely, information support to help with the problems and difficulties brought by SCI, particularly during the first few years after injury; and peer support—learning the ropes from people who wheeled down the same path a long time ago.

Figuring out how to navigate the system, accessing resources, connecting with peers, finding support, identifying funding sources and getting transportation in place—these are all issues that can see a person slide into depression when left alone to deal with them.

So perhaps people would be just as well off getting some case management support as going to a therapist?

"Possibly," says Huston. "It depends on the person—some need treatment for depression, some need the connections a (case support worker) can provide, and some need both."

"We're not wired to tolerate ambiguity," Butt says.

"And that intolerance of ambiguity," adds Huston, "leads to a good deal of anxiety."

Depression and Aging

People's vulnerability to depression extends far beyond those first few years and well past any plateau stages. I still vividly recall a conversation with my wheelchair guru a couple years after I sat down and listened to him tell me, "I went through two periods of depression; one shortly after I was injured and another, about 20 years post injury."

How to account for depression so long after injury? Theories abound, but it's safe to say that depression is part of the human condition and we're all susceptible, some more than others. Aging adds numerous issues and challenges to life separate from disability. Life on wheels consists of an ongoing negotiation process, a bargaining back and forth over what's possible and what's not.

"People get worn out," says Kathe Hulse, an outpatient counsellor at Craig Hospital. "They have to deal with all the aging issues non-disabled people do, plus the complications of a spinal cord injury. They get tired of feeling dependent or like a burden to others; some are weary of the ongoing hassles of maintaining home health care, others have to face the fact that parents can no longer provide care, some run out of the necessary energy or are dealing with too much chronic pain to work full-time."

Couple these with new health issues, such as heart disease, cancer, skin issues, worn out shoulders and chronic pain, and it's easy to understand why people again experience the feelings of anxiety, fear and loss not felt since injury's onset.

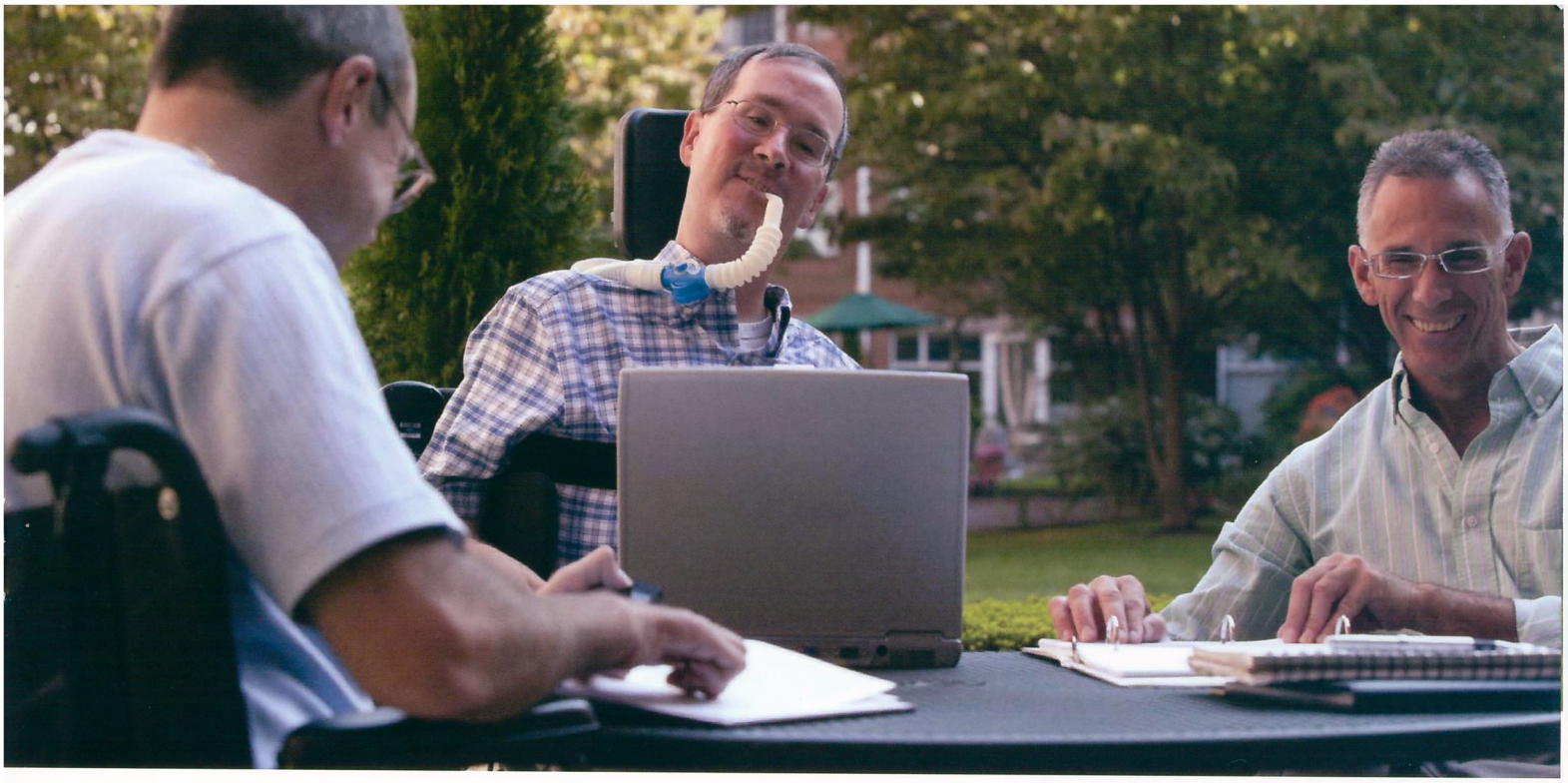
The bottom line is that we all have to be vigilant for depression throughout our lives.

But the good news is that rates of depression actually decrease as people age, quite possibly adding some credibility to the adage of wisdom coming with age. Certainly experience plays a large part. People with disabilities usually learn to be masters of coping and resourcefulness.

"Forty-five years in a chair have given me an almost perverse sense of confidence about being able to deal with what life throws at me," says Don Dawkins, a disability advocate and long-time paraplegic who lives in Florida. "I know I can ride the whitewater." ■

Richard Holicky is a writer, researcher, and paraplegic who lives in Denver, Colorado.

SCI BC urges readers to learn about the symptoms of depression, see your family doctor immediately if you're experiencing any of these symptoms, and learn about the many ways you can prevent the onset of depression through a healthy and active life.



Take the Spinal Cord Injury Community Survey today!



Over 1,400 Canadians have completed the SCI Community Survey – the largest of its kind ever conducted in Canada – **but we still need your input!**

Take this opportunity to voice your opinions.
As an individual living with SCI, participating in the SCI Community Survey will provide you with a unique opportunity to further describe your most critical needs and help guide how the Canadian health and social services system could better meet those needs. All survey participants will receive a **$25 gift card** upon survey completion.

Your participation makes a difference!

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The survey is supported by the Rick Hansen Institute and the research team is led by Dr. Luc Noreau at the Université Laval. Surveys are conducted by the Mustel Group, a professional market research firm.

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Growing Big in small places

Jeanette Andersen says you don't need lots of space or experience to nurture your green thumb.

THERE'S BARELY ENOUGH ROOM for Jeanette Andersen to roll onto her south facing balcony, but that's just how she likes it. A lilac tree dangles from the ledge, pots full of chives, parsley and rosemary clutter her balcony floor, and a blooming vine grows up along the wall, as if reaching up to choke the wind chimes.

"So far I've just got some things from last year," she says, "but I'd still like to plant some leafy greens. Kale maybe. I still can't get over the Swiss chard from last year—it was amazing what grew!" She looks at the bucket stuffed with tools, pots and gloves leaning near the sliding glass door leading to her balcony, making a mental note of what she'd like to plant next.

"For some reason, when you're growing [herbs or vegetables] yourself, they taste so much better," she says. "My chives, they're just delicious."

Gardening has played a role in Andersen's life since she was just a little girl, thanks to her mother, who was a passionate gardener. "It's such a pleasure," says Andersen. "You get to see things grow and come to fruition. It's like life on a smaller scale."

Anderson was paralyzed with polio when she was 16 and made her home at the George Pearson Centre for the next 30 years. When David Tarrant, the host of CBC's *Canadian Gardener*, began giving monthly gardening workshops to residents, she became one of his most loyal followers.









Need More Visual Encouragement?

A picture is indeed worth a thousand words. If you'd like to see more excellent photos and ingenious examples of how wheelchair users are exercising their green thumbs, point your browser to Google Images and search for "accessible gardening" or "wheelchair gardening". You'll be amazed at the number of results.

"He would give talks on all kinds of gardening subjects and take us out to his events, at the VanDusen Gardens and other places," says Andersen. "He got my interest going and from there, it just grew."

She hasn't looked back since. When Andersen moved to a housing co-op 20 years ago, she put Tarrant's lessons into action. She planted a balcony garden and became the chair of her co-op's garden committee, a position she's held for 17 years. "I can't do the hands-on stuff so I learn what I need to learn and direct other people so they know what to do," she says.

Under her helm, her co-op built its first rooftop garden, complete with a small blueberry bush, a strawberry patch, a rose bush and a four-foot tall apple tree, which she says produces an abundance of excellent apples.

"I just love the way people react when they see the blueberry bush and the strawberries. They're always so surprised and excited," says Andersen, who always tries to plant what people like best.

For the past three years, she's also served on the board of the Disabled Independent Gardener's Association (DIGA), so she knows all about the challenges other gardeners with disabilities face, especially those who live in condos and apartments. But Andersen says there are solutions.

For those in Vancouver, DIGA offers workshops, one-on-one support, volunteer help and fully accessible plots in two community gardens. Thanks to Tetra, another organization made up of volunteer engineers and technicians, custom-designed assistive devices such as adapted hand tools, garden stools and devices to transfer from a wheelchair to the ground are provided to DIGA members whenever possible.

Of course, you don't have to live in Vancouver to nurture your green thumb. "It's just like when you're dealing with a disability; you just have to start small and keep going," says Andersen. "Work towards something bigger and don't give up."

Andersen recommends novice gardeners start with perennials—plants that come back each year. "Then slowly go beyond that. If you've got a balcony, gradually grow your favourite vegetable and your favourite flower."

When it comes to pots, she suggests going for plastic instead of clay. "It's more durable, it's lighter and the plastic holds the fluid better."

Finally, if you do have a yard, Andersen recommends you have someone help you build a deck or a raised container up to three feet high, so you can work more easily from your wheelchair.

Most importantly, Andersen says people should try reaching out to others in their community. "Find a local garden club and see if they'll help you set something up. Most people who enjoy gardening, they love it. Even if they can give you only a couple hours a week you can actually do quite a bit. Just go for it." ■

Dig It With DIGA

If you live in the lower mainland and want to see what accessible gardening is all about, the Disabled Independent Gardeners Association is the place to turn to. DIGA offers accessible plots for people with disabilities who can't garden where they live, along with a bushel of support from volunteers and other passionate gardeners with disabilities. DIGA has plots at two community gardens—one at Pandora Park in the Hastings Sunrise area of Vancouver, and Pearson Community Gardens, located at Cambie and 57th Avenue. Both have raised beds, wheelchair-accessible pathways, and integrated irrigation systems. Volunteers are on-hand to help with weeding, thinning out and harvesting, and to provide support, encouragement and advice. Visit www.disabilityfoundation.org/diga for more information.

Pain & Pregabalin

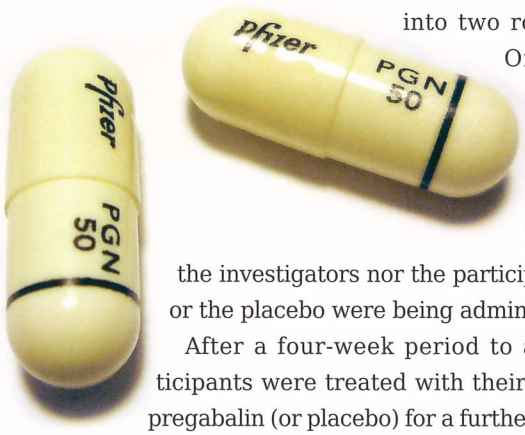
A new study appears to provide more evidence that pregabalin, also known by the trade name Lyrica, is an effective option for treating SCI-related neuropathic pain. Will it work for you?

IF YOU'RE ONE OF the estimated 40 percent of people with SCI who struggle to deal with the crushing burden of central neuropathic pain, and if you've never tried or been prescribed pregabalin as part of your pain management program, read on.

On May 2, during the 2012 Annual Meeting of the American Academy of Neurology, pharmaceutical giant Pfizer released results of a study it had funded to further test pregabalin in people with SCI central neuropathic pain.

"Pregabalin achieved rapid and meaningful relief of neuropathic pain and related sleep interference associated with spinal cord injury," said Dr. Luis Sanin, the Pfizer representative who presented the study.

The study took place over 17 weeks and involved 220 participants from ten different countries. All were adults who had a complete or incomplete SCI between C2 and T12, and all had central neuropathic pain—long considered the most difficult type of neuropathic pain to treat.



The participants were randomly placed into two roughly equal groups. One received a daily dose of pregabalin, while the other group received a placebo. The study was double-blind, meaning neither the investigators nor the participants knew if the drug or the placebo were being administered.

After a four-week period to adjust the dose, participants were treated with their optimal fixed dose of pregabalin (or placebo) for a further 12 weeks. Afterward, they were tapered off the drug over a one-week period.

Throughout the treatment period, participants were evaluated with the two standardized tests: the Daily Pain Scale and the Daily Sleep Interference Scale. The average changes in pain and pain-related sleep interference scores were significantly better for those who received pregabalin instead of the placebo. The percentage of patients who achieved clinically meaningful pain relief (at least a 50 percent decrease in mean pain score) at the end of the study was also significantly greater in those who received pregabalin.

As with previous studies, the drug was generally well-tolerated. The most common side effects were drowsiness and dizziness.

The study appears to confirm results from an earlier Australian study.

So what does this mean for people with SCI? In the United States, pregabalin has never had approval for use in SCI. It is, however, approved as a treatment for seizures, and for neuropathic pain from fibromyalgia and shingles. It's also approved as a treatment for neuropathic pain from diabetic neuropathy, although its future in that area is now murky—a few days after Pfizer released the positive SCI results, the company admitted failure in a trial for diabetes, as well as a trial for HIV-related pain.

It seems likely that the company, armed with its positive data from the SCI trial, will pursue FDA approval for treatment in SCI-related neuropathic pain.

Meanwhile, here in our country, Canadians with SCI have had access to pregabalin for some time, since it was indicated for SCI on a conditional basis by Health Canada

in 2006. Across the country, pain specialists have been prescribing pregabalin for pain sufferers with SCI since then.

One of those pain specialists is Dr. Michael Negraeff, who works with patients at Vancouver General Hospital's Spine Program, helping them deal with pain from acute and chronic spine conditions. He's also a principal investigator with ICORD (International Collaboration on Repair Discoveries); a Clinical Associate Professor with UBC Department of Anesthesiology, Pharmacology and Therapeutics; and chair of Pain BC, a non-profit society committed to improving British Columbians' access to the best possible pain resources.

Negraeff also brings the unique perspective of being paraplegic to the field of pain medicine.

His view of pregabalin is based on years of experience prescribing it to patients, and hasn't been significantly changed by these new results.

"Yes, I would agree it appears to be effective in this condition for many people with SCI-related neuropathic pain—but not all," he says. "I'd say the results are moderate. Probably half the time it doesn't work well enough for the patient to be happy staying on it because of side effects. The rest have a similar result to the study."

In addition to sleepiness and dizziness, Negraeff says another side effect he's seen with pregabalin is significant swelling in the hands and feet, along with weight gain.

And because there is no provincial prescription coverage for pregabalin, he often initially prescribes its older cousin, gabapentin.

"It's hard to say if (pregabalin) is any better than gabapentin. There are no head-to-head trials. I often find if gabapentin doesn't work, then pregabalin doesn't either, or maybe only a little better. There are definitely some patients, though, where pregabalin works well and gabapentin doesn't. But I start with gabapentin as it is covered by the province and thus cheaper for the patient. So if it works, then we're all happy. If not, I try pregabalin if they can afford it or have (third-party insurance) coverage."

The bottom line, says Negraeff, is that pregabalin is not a panacea for neuropathic pain. Instead, he says, it's a "useful drug for the toolbox." Most people, he adds, will need to continue to work with their pain specialist to find a multi-pronged approach to chronic pain that works best for them—one that includes pharmacologic approaches such as pregabalin, in combination with non-pharmacologic approaches that include physiotherapy, exercise, goal setting, sleep hygiene, mental health for mood balance, relaxation, meditation, and breathing exercises.

As a pain specialist and as a person with an SCI, Negraeff knows better than most how devastating neuropathic pain can be. Understandably, he's realistic about the prospects for a cure-all. Nevertheless, he is encouraged by some new research avenues—for example, using virtual reality games and devices. "This is novel and quite interesting. It's so totally distracting that you can use it for doing very acutely painful procedures like changing a burn victim's dressings without any morphine. Where it fits into chronic pain, we're not sure yet, but there is some research going on. We might even try for a project on SCI patients, but this is very preliminary."

Meanwhile, he urges people with SCI to be vigilant in seeking out all the help and resources available to help them deal with neuropathic pain. A good place to start, he says, is the Pain BC website at www.painbc.ca. ■

WHAT IS PREGABALIN?

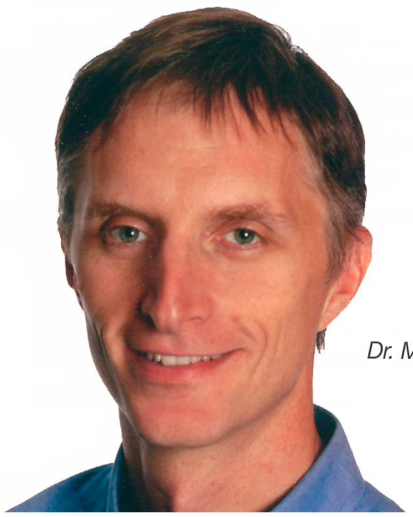
Pregabalin, marketed by Pfizer with the trade name Lyrica, belongs to a class of drugs known as anticonvulsants, which have been long used to treat seizures in conditions such as epilepsy.

The best known of these drugs is probably gabapentin. In the 1990s, gabapentin began to be used as a treatment to control neuropathic pain from many conditions. These include SCI, although it's never been scientifically tested specifically with SCI-related neuropathic pain. It's marketed in North America under the trade name Neurontin by a Pfizer subsidiary, and is also available in generic form.

Pregabalin was developed to be a successor to gabapentin, but that hasn't happened yet. Pregabalin is related in structure to gabapentin, but appears to be more potent and absorb faster. Higher potency means that less of the medication is required for the same effect, but this doesn't necessarily result in fewer side effects.

Researchers have not been able to absolutely determine the mechanism by which these drugs reduce chronic pain. Here's how Wikipedia describes pregabalin: "Like gabapentin, pregabalin binds to the (alpha2delta) subunit of the voltage-dependent calcium channel in the central nervous system. This reduces calcium influx into the nerve terminals. Pregabalin also decreases the release of neurotransmitters such as glutamate, noradrenaline, and substance P (Australian Medicines Handbook)."

In plain speak, it appears that pregabalin binds to receptors in overactive or damaged nerve cells and decreases the ability of those cells to send pain signals.



Dr. Michael Negraeff (courtesy ICORD)



Lasting Relief

The Finetech-Brindley Bladder Stimulation System has been a life-saver—perhaps even literally—for Golden's Tom Coughlin.

What if there was a product out there that, once surgically implanted, would allow you to empty your bladder with the push of a button?

As some readers know, that product actually exists—in fact, it's been around for three decades. It's called the Finetech-Brindley System (or Vocare in the United States), and it was developed in the UK in 1982. It consists of a stimulator, similar to a heart pacemaker, that's placed under the skin of the recipient's belly. Wires are attached to the stimulator and run through to the lower spinal cord, where they're connected via electrodes to the sacral nerves going to and from the bladder.

After a successful installation, the recipient holds a small handheld device, similar to a television remote, next to the receiver and presses a button. The receiver then sends electrical impulses to the electrodes attached to the nerves, which in turn stimulate the appropriate bladder muscles into a cycle of contraction and relaxation.

A few pushes of the button allows the recipient to empty the bladder into a toilet or urinal at will—all without catheters, condoms, leg bags and, most importantly, urinary tract infections (UTIs).

In addition to dramatically reduced incidence of UTIs, studies have also shown that recipients get improved bladder capacity, less incontinence, improvement in bowel function, the ability to have an erection, and, ultimately, greater independence and quality of life.

Despite all this, only about 1,600 people worldwide have received the system. This is no doubt due to the complexity, finality and cost of the surgery involved. In addition to the task of installing the receiver under the skin just below the ribs, it requires a laminectomy—removing bone in the spinal column to provide access to the nerves that carry information to and from the spinal cord to the bladder. It also requires a rhizotomy, whereby the sensory nerves from the spinal cord to the bladder are cut and divided to allow the system to get complete control over the bladder. All in all, it's a serious surgical procedure that can only be done by highly trained surgeons, takes up to

eight hours to complete, and requires up to a week of hospital recovery time.

But for some people with SCI who suffer relentlessly from UTI after UTI, the system can quite literally be a life-saving final option. Tom Coughlin is one of those people.

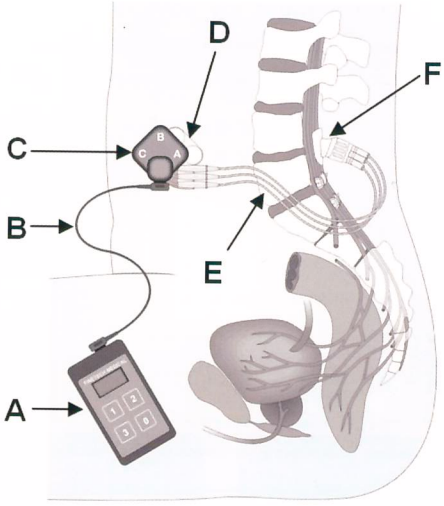
Coughlin sustained a complete C6/C7 SCI in a 1990 logging accident just outside his home town of Golden, BC. Like many people with quadriplegia, serious bladder complications became his constant companion.

"After the first couple of years, I was plagued by constant, reoccurring bladder infections, whether or not intermittent catheters were done," says Coughlin. "The symptoms varied from excessive sweating to autonomic dysreflexia, upset stomach, excessive back and stomach pain, and blood pressure dropping so much that I would pass out."

In one instance, Coughlin's blood pressure dropped while he was sitting on the commode, and he passed out, fell and broke his hip in the process. Meanwhile, he was battling UTIs with large amounts of antibiotics—this created a vicious circle as the bacteria in his system became resistant to stronger and stronger antibiotics. "The resistant bugs resulted in many different outcomes, stronger antibiotics and longer duration of treatment, often with intravenous (IV) instead of oral medications," he explains. "Multiple hospital stays and compounded bowel issues from the use of antibiotics were common. Somewhere around my eighth year into the injury, I ended up on two IV antibiotics that ended up causing the lining of my bowel to shed itself, resulting in severe damage."

In the aftermath of that episode, Coughlin spent two months in the hospital and desperately began searching for answers. He came across an article about the Finetech-Brindley System which was being tested for FDA approval at the Cleveland Clinic. Taking a proactive approach, he contacted the lead investigator, physiatrist Dr. Graham Creasey.

Creasey was supportive, as was Coughlin's family physician. Both helped



The Finetech-Brindley System

A External controller (external)
B Transmitter lead (external)
C Transmitter block (external)
D Implant receiver (internal)
E Cables to electrodes (internal)
F Electrodes attached to nerves (internal)

Coughlin apply for funding approval from WorkSafeBC, which had been supporting Coughlin and his family since his injury. The application stressed the financial feasibility and cost benefits.

The funding process took about a year, and wasn't without its ups and downs. But in the end, WorkSafeBC agreed the procedure made sense from several perspectives, including cost benefits. To Coughlin's relief, WorkSafeBC agreed to fund the implant and any future costs that resulted from it.

In May of 1999, Coughlin and his wife Deb travelled to Cleveland for the procedure. "We met up with Dr. Creasey and the surgeon, and went over the basic procedure and did some bladder testing prior to surgery," he recalls. "At this point I was starting to wonder if I was making a mistake and almost turned back. But I knew that I could not continue along my previous path as the health concerns were too much and the promise of freedom from leg bags and condom catheters was great."

The surgery was performed the next day and took about eight hours to complete. It went well but wasn't without problems, as Coughlin's lungs had complications. But he pulled through and within a week he was heading home with his new hardware installed and working well.

"The first night home, I went to bed for the first time in a very long time, free of all the leg bag drainage systems," he says. "Wow—what a great feeling."

He woke up dry—but quickly realized he had a lot to learn. He had to learn to void into a urinal—not so easy given his limited hand movement and poor trunk strength and stability. He also had to keep tract of his fluid intake and the time it took for his body to process, and figure out his allowable bladder volumes to prevent leaking.

"I've found over time what different positions allow maximum voiding—and what positions are less desirable. The voiding is very much a positional action and I believe this will be different for different levels of ability. The problems that I have are holding the urinal and the external control box while pushing my hips out to the front of my chair at the same time, without spilling or accidentally voiding outside of the urinal. The key is to make sure that there is no residual when done and this takes some practice and understanding."

Although the stimulator has a cycle that stimulates bowel voiding, Coughlin was unable to benefit in this regard. He believes that this was due to the fact that his bowels were already so severely damaged from antibiotic use. He now has an ileostomy, so it's not an issue.

Thirteen years later, Coughlin remains a satisfied user and huge proponent of the system. "I believe if I hadn't received the implant, the alternatives weren't good. However, I was fortunate enough to receive the implant. It's eliminated most of my infections and given me freedom from the use of condom drainage, which in itself is huge and has given me good health, physically and mentally."

Coughlin says if he was newly injured, he wouldn't hesitate to have the procedure. "I'm not saying this lightly. The physical health and mental benefits combined with cost savings to the

health system are enormous when all of the factors are accounted for. Some people may hold back in fear that the surgery will exclude them from being able to benefit from any type of cure for SCI. I wouldn't worry about this, as I believe if a cure is found to fix a severed cord, it should also make it possible to have this surgery reversed."

Not surprisingly, he is grateful to his funder. "WorkSafeBC has been my support throughout my adventures, and overall has been very accommodating."

Keep in mind that not everyone with an SCI is a candidate for the system. Patients must have established skeletal maturity, because if the body is still growing, the electrodes may be displaced and the entire system may not be stable. Also, a complete lesion is necessary—if the lesion is incomplete or partial, some of the nerves still have a chance to regenerate and regain function, which may eliminate the need for artificial stimulants. The user must also be in a neurologically stable condition in order to manipulate the device and establish the right time to utilize it. Additionally, the peripheral nerves found in the bladder and sphincter muscles must be intact to respond to electrical stimulations. For more information, visit www.finetech-medical.co.uk. ■

Spinal Cord Injury BC
Peer Program



We've been there

It's natural for people with spinal cord injury to seek support and information from those who have been there. This is exactly the foundation upon which the SCI BC Peer Program was built and it is faithful to the origins of the organization, when veterans returning from WWII with spinal cord injuries realized that their strength came as much from others as from within.

The SCI BC Peer Program is a vibrant community of individuals with spinal cord injury and related physical disabilities, as well as their family and friends. These individuals can count on the Peer Program for answers, connections, solutions and unique community experiences.

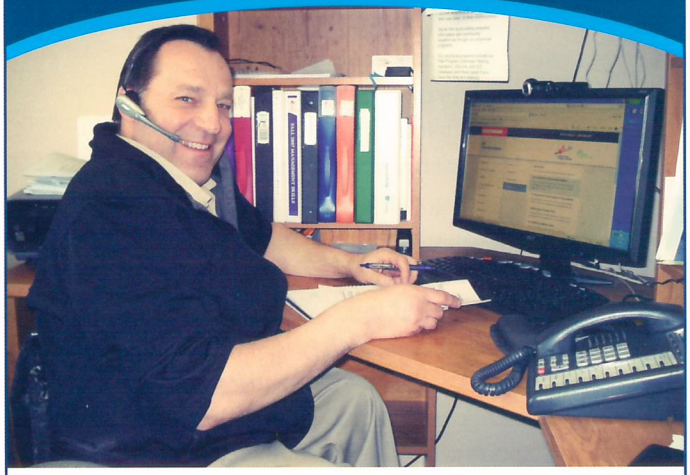
"The Peer Program introduced me to a world of opportunities that I never thought existed. They provided valuable information on issues related to my spinal cord injury and helped me meet some amazing friends." – SCI BC Peer

We have SCI BC Peer Program Coordinators located across BC - find your nearest Coordinator at **www.sci-bc.ca**

Spinal Cord Injury
British Columbia

Connect with Spinal Cord Injury Organization of BC:
www.sci-bc.ca / InfoLine: 1-800-689-2477
SCI-BC Peers SCI-BC SpinalCordInjuryBC

Spinal Cord Injury BC
Information Services



The Trusted Resource for
People with Spinal Cord Injury

SCI BC's Information Services is the trusted resource for people with spinal cord injury or related physical disability, and their support teams including family and friends, health professionals and community workers.

SCI BC's experienced and knowledgeable Information Services staff assist individuals in finding the answers or resources they need on a wide variety of topics including: accommodations, equipment, funding, universal design, recreation and leisure.

"You are a wealth of information. I was having difficulty finding what I needed, but you knew exactly where to look. And so quickly too!" – InfoLine Client

Spinal Cord Injury
British Columbia

You can access SCI BC Information Services via phone, email and web:
InfoLine: 1-800-689-2477 **email:** info@sci-bc.ca
web: www.sci-bc.ca

Connect with Spinal Cord Injury Organization of BC:
www.sci-bc.ca / InfoLine: 1-800-689-2477
SCI-BC Peers SCI_BC SpinalCordInjuryBC

Help for Housing



A new joint provincial/federal initiative will provide financial assistance to British Columbians with disabilities seeking to make their homes more accessible.

The Home Adaptations for Independence (HAFI) program, operated by BC Housing, will provide eligible homeowners and landlords with financial assistance of up to $20,000 per home in the form of a grant or forgivable loan.

Eligible renovations and retrofits include handrails in hallways or stairways, wheelchair ramps, easy-to-reach work areas in the kitchen, and grab bars and seats in the bathroom. All adaptations should be permanent and fixed to the home, except for equipment designed to give access to existing parts of the home—for example, a bath lift. The exact amount of financial assistance will be based on the cost of materials and labour necessary for the required modifications. For homeowners, where underlying deficiencies within the home require attention before adaptations can be successfully completed, further funding assistance up to a maximum of $20,000 per dwelling may be considered.

"This program is a great opportunity for our members, and a tangible step forward for our government in terms of addressing a critical shortage of accessible housing," says Chris McBride, SCI BC Executive Director. "The types of modifications supported by the program are exactly what many of our members need in order to remain independent in their own homes."

In order for grants and loans to be forgiven, owners approved for assistance must not sell their housing within the specified periods. For grants up to $5,000, grant obligations will cease after one year, while loans greater than $5,000 will be forgiven over three years. The assistance is not taxable.

We urge you to act fast—the program has limited funds, and completed applications will be reviewed on a first come, first served basis each year until the annual funding is exhausted. Applications may be made in each year, starting April 1.

More information and applications can be found online at www.bchousing.org/HAFI. If you'd like some expert assistance determining if you're eligible for this program or other forms of assistance, call SCI BC's InfoLine toll-free at 1-800-689-2477, or email info@sci-bc.ca.

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Make Your Home Safe *for* Independent Living

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

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

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

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

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

HOME ADAPTATIONS *for* INDEPENDENCE

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

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Tortoise & Hare

Claire Lomas, a British quadriplegic, captured the media's attention worldwide on May 8th when she became the first person to complete a marathon using an exoskeleton.

Lomas, 32, was paralyzed in 2007 as the result of an equestrian accident. In January, she was loaned a $70,000 ReWalk suit, the Israeli-developed exoskeleton that we told you about in the Summer 2011 of *The Spin*. Lomas set her sights on completing the London Marathon in the hopes of raising money for her charitable organization.

She achieved her goal—but her name won't appear in the London Marathon's official results, nor will she be eligible to receive a medal. That's because it took her 16 days to finish the 26.2-mile race.

Certainly, this is a noteworthy achievement for exoskeleton technology. But we can't help contrast it with Toronto's Josh Cassidy's feat just a few weeks earlier.

On April 16th, Cassidy, a 27-year-old wheelchair racer who is paraplegic due to childhood spine cancer, won the prestigious Boston Marathon. In doing so, he became the fastest person ever to complete a marathon anywhere in the world. His winning time? One hour, 18 minutes and 25 seconds. That's almost twice as fast as the runner who won this year's event, Wesley Korir of Kenya.

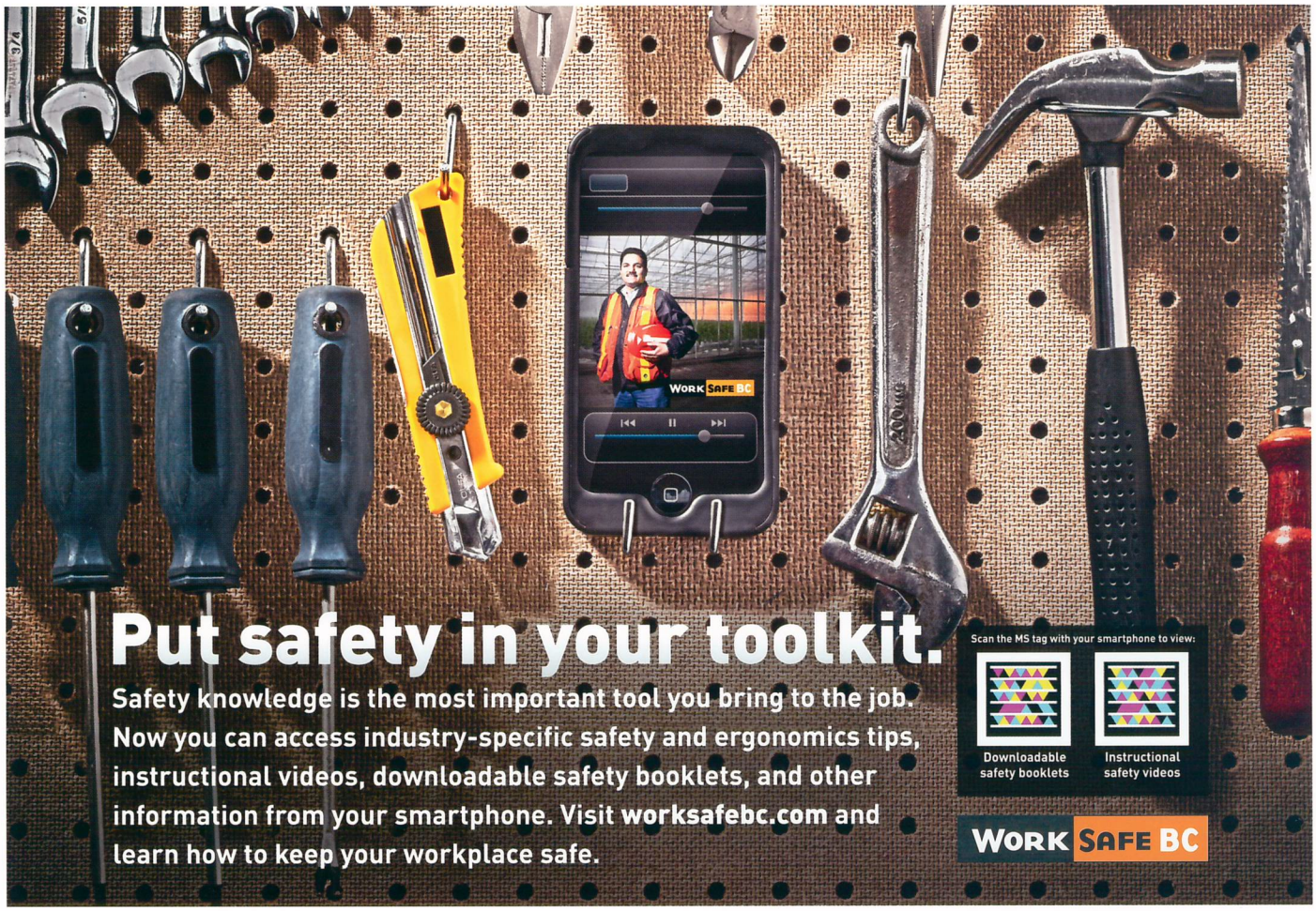
Yet Cassidy's victory received a fraction of the global newspaper and TV coverage that Lomas achieved with her two-week-plus completion of the London Marathon.

Clearly, slow and steady wins this race for the media's fleeting recognition. ■





A Tale of Two Marathoners: London's Claire Lomas (left) and Toronto's Josh Cassidy.



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