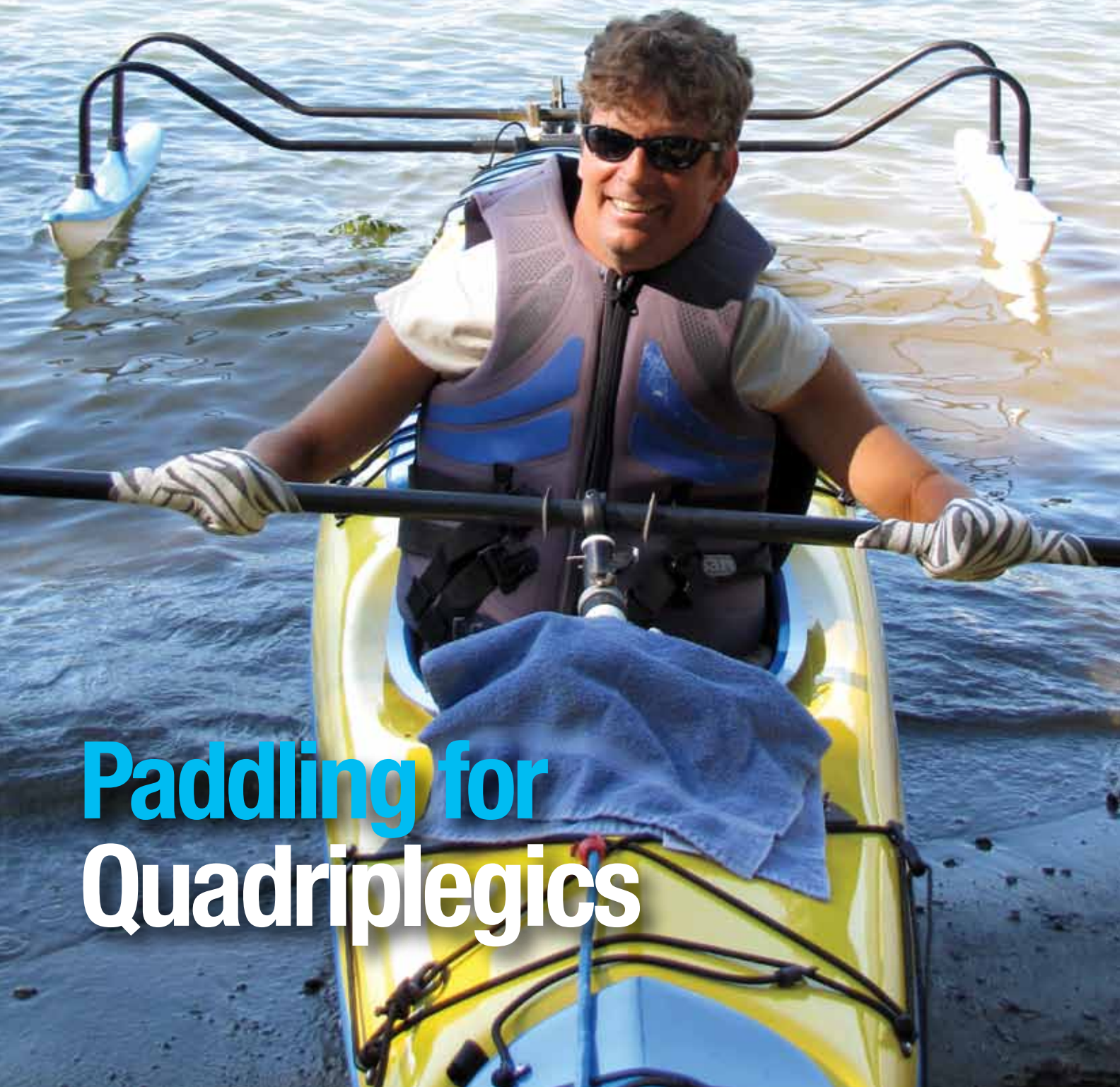


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BRITISH COLUMBIA PARAPLEGIC ASSOCIATION

SPRING 2011



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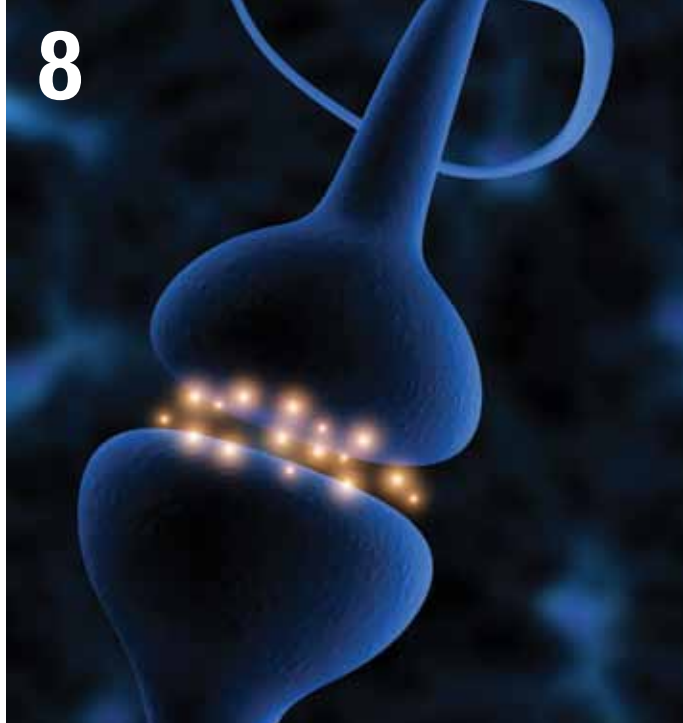
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Comox's Jim Milina takes a spin in a kayak adapted for quadriplegics on BC's Sproat Lake. Photo by C. Gailloux.



Welcome to *The Spin*

THERE'S SO MUCH GOING ON IN THE WORLD OF SCI that it's hard to keep up. It seems that every day, new technologies and devices appear, new services are developed and delivered, and exciting developments in research take place. There are also so many great stories about people with SCI and related disabilities who have found ways to succeed and make a difference in their lives and the lives of others.

With so much inspiration and information, how does one stay connected and informed? Well, it's not easy, but we think we can help with *The Spin*, our newly revamped quarterly magazine. We believe you'll find *The Spin* to be an entertaining and valuable way to learn about what's new in the world of SCI, share information about the wisdom and strategies BCPA Peers have gained and developed, and inspire you to learn more—and enhance your connection with the SCI community.

BCPA is here to help people with SCI and their families adjust, adapt and thrive, by providing information and answers, and relating positive community experiences. *The Spin* now takes on an even greater role as we strive to accomplish our work. Importantly, *The Spin* complements our existing services, such as our Peer Program, InfoLine and SCI Information Database, and will contribute to our ongoing efforts to develop a vibrant and engaged SCI community through both social media and established relationships with our members, supporters and partners.

This inaugural issue of *The Spin* will give you a sense of what to expect to receive on a quarterly basis. Each of the four issues we will publish each year will include information on the successes and challenges of people living with SCI, new research, health and wellness information, and new technologies, services and strategies. This information will come not only from British Columbia, but from across Canada and around the world.

We're pleased and excited to be launching this new magazine and hope that you find it to be an entertaining, inspiring and informative publication that you look forward to receiving and reading. Thanks to the support of our donors, funders and advertisers, there is no cost for anyone in BC who wishes to receive *The Spin*. If you know of someone who could benefit from *The Spin*—a person with SCI or one of their family members, a doctor or clinician, or a researcher—please have them contact our office and sign up for a complimentary subscription.

Chris McBride
Executive Director, BCPA



The Spin is the quarterly magazine of the British Columbia Paraplegic Association (BCPA). An online edition of *The Spin* is available on the BCPA website www.bcpa.org.

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

Return undeliverable Canadian addresses to:
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To update/change delivery address, email thespin@bcpa.org or call 604.324.3611.

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IZ COLLECTION

The IZ Collection is an adaptive ready-to-wear clothing line created by award-winning Canadian fashion designer Izzy Camilleri. Each of the collection's pieces have been designed for the sitting position of a wheelchair user. This allows each item to follow the line of the seated body, eliminating fabric bulk and bunching from the front, sides and back. For women, offerings include pants, blazers and suits, tops, skirts, dresses, jackets and coats, evening wear, bridal wear and more. The men's line includes jackets and coats, pants, tops and robes. Many of the items are made with ingenious features which make dressing much easier for both wearer and assistant—for example, the women's tailored blazer is constructed as two separate pieces that zip at the high back for easy dressing, and pants feature invisible zippers for catheter tubing. Visit www.izadaptive.com to view an online catalogue along with details and examples.

Innovations

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



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sturdy, stained timber and is designed to fit standard grow bags. For more information, visit www.hi-grow.co.uk.

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Because the capacitive touchscreens of the iPad, iPhone or other capacitive touch devices require conduction from direct skin contact, most mouthsticks won't work as a stylus. One answer is the Stylus Sock II kit, which includes two solutions that give high level quadriplegics a proper experience with their touch device. The first is a fully conductive aluminum mouthstick with a Stylus Sock (a conductive fabric) on the tip—this allows your body's energy to flow through to the touchscreen. The second is a separate Stylus Sock that you can wrap around your own mouthstick and connect to the iPad body (the energy from the iPad itself activates the touchscreen). Neither of these approaches require a wire in the mouth. For more information, visit www.etsy.com/shop/shapedad.





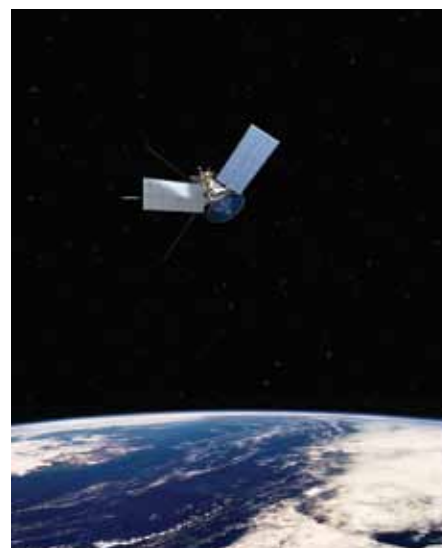
Celebrating 40 Years.

On February 5th, the BC Wheelchair Sports Association (BCWSA) kicked off its 40th anniversary. To celebrate, BCWSA held a photo contest and released the top 40 BC wheelchair sports stories from the past four decades in its “40 Years. 40 Stories. 40 Days.” initiative. You can check out the winning photos and all 40 stories by visiting www.bcwheelchair-sports.com. BCPA was pleased to be a partner in the photo contest—only fitting, as former BCPA employees and volunteers Doug Mowat, Doug Wilson and Stan Stronge (that’s Stan in the photo above) helped BCWSA founder Harry Beardsell achieve non-profit incorporation back in 1971. Happy birthday, BCWSA!



Evening at the Empress.

BCPA is holding “A New Era Gala” at Victoria’s Fairmont Empress Hotel on Friday, April 15th. Prominent Victoria lawyer Michael O’Connor and philanthropist extraordinaire Eric Charman have joined forces to co-host this affair. The evening will feature popular show band The Timebenders taking guests on a musical journey through the decades, while they wine and dine on culinary delights prepared by the Junior Culinary Team Canada. All net proceeds from Gala tickets and silent and live auctions will allow BCPA to continue its Vancouver Island regional services. To purchase tickets or become a sponsor, contact Tami Tate at tate@bcpara.org or call 250.595.8381.

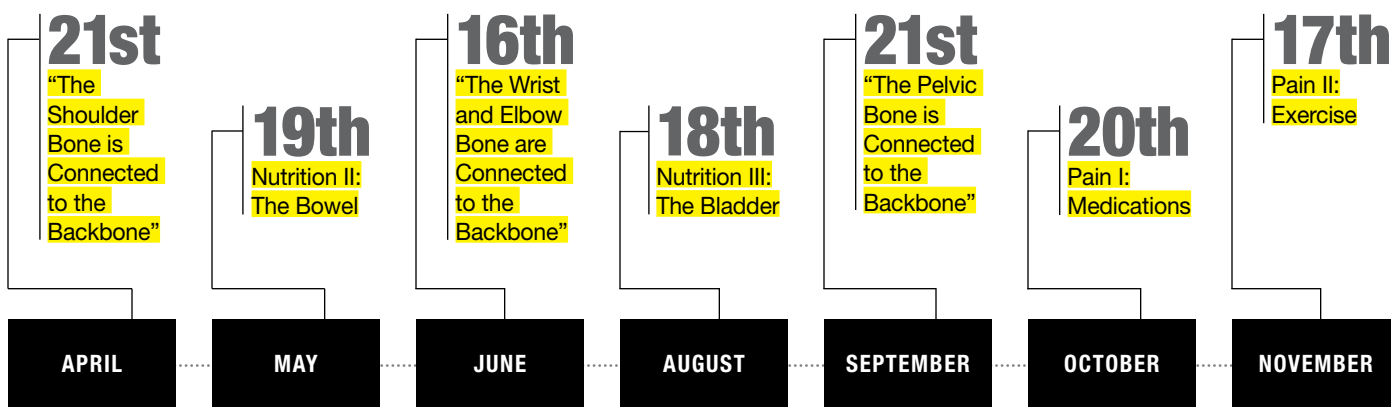


Tune into Telehealth.

Telehealth is the video conferencing system used by the BCPA Peer Program to allow people across BC to participate in monthly education sessions held at GF Strong Rehabilitation Centre. Participants can listen and watch presenters, and take part in discussions. Sessions take place on the third Thursday of every month, excluding July and December. Contact your local BCPA Peer Associate in advance and they’ll arrange for you to take part using the telehealth equipment at your local health unit or hospital. Note that, if you live in the Lower Mainland, you only need drop in to GF Strong (registration isn’t necessary). See the remaining 2011 schedule below, or visit www.bcpara.org for more information.

Balance of 2011 Telehealth Schedule

(Note: all events take place from 3 to 5 PM. Schedule subject to change—check www.bcpara.org for the most current dates. The BCPA website also has a full schedule of BCPA Peer Program social and information events around the province.)





Neuropathic Pain: Is It All In Your Head?

Dr. Min Zhuo and his University of Toronto team believe that the best way to provide relief to people with severe neuropathic pain is to switch it off in the brain.

DON'T TRY TO TELL AJ STAR that the pain is all in his head. The Kelowna resident suffers from excruciating bouts of neuropathic pain as a result of an incomplete T-2 through T-6 SCI that he sustained in 2006.

"I have a diffuse pain, mainly burning and a buzzing sensation in my buttock, hamstrings, calves and bottom of my feet," says Star. "The pain changes regularly in severity. From the moment

I open my eyes until I doze off to sleep at night, I'm dealing with pain. The worst is waking out of a deep sleep in spasm with nerve pain. Sometimes I'm unable to get out of bed. I've been taking maximum doses of Baclofen and gabapentin, and 400 milligrams of morphine, every 24 hours just to make it through each day since my accident. It has severely impacted my daily life, as the pain dictates how my day will go."

Star is far from alone. According to the US National Institutes of Health (NIH), two thirds of people with SCI report neuropathic pain, and a third of those rate their pain as severe. The NIH also provides the grim reality in terms of treatment: “There is no...uniformly successful medical or surgical treatment to prevent or reduce (neuropathic pain). The mainstays of neuropathic pain treatment are antidepressants and anticonvulsants, even though they are not uniformly effective.”

Little wonder, then, that people with SCI rate neuropathic pain as one of their most pressing issues. For example, the Rick Hansen Institute recently conducted an online poll asking which secondary complication of SCI is most important to focus research on. Neuropathic pain was the second highest response, behind only bladder function/urinary tract infections.

Researchers have been listening—not only to people with SCI, but to others who suffer from related types of neuropathic pain from other causes, such as amputation or diseases such as cancer. Around the world, scientists are now engaged in hundreds of research projects aimed at understanding the mechanisms of neuropathic pain and finding ways of treating it effectively.

One of those researchers is Toronto’s Dr. Min Zhuo, Professor of Physiology at the University of Toronto’s

Faculty of Medicine, Canada Research Chair in Pain and Cognition, and Michael Smith Chair in Neurosciences and Mental Health. For more than ten years, Zhuo has theorized that there must be a way of “switching off” neuropathic pain in the brain—a considerable departure from the approach taken by most researchers, which involves blocking the pain at the level of the offending nerve cell.

In a paper published January 12 in the journal *Science Translational Medicine*, Zhuo and his team described how they’ve developed a new drug called NB001 which does exactly that: switch off neuropathic pain directly in the brains of mice.

In the paper, titled *Identification of an Adenylyl Cyclase Inhibitor for Treating Neuropathic and Inflammatory Pain*, Zhuo and his team explained how their new drug, NB001, produced powerful pain-killing effects in mice by blocking a particular enzyme known as type 1 adenylyl cyclase (thankfully shortened to AC1). This enzyme, says Zhuo, plays a key role in allowing neuropathic pain to take place.

“It all started more than ten years ago,” says Zhuo. “In 1998 or 1999, we found that many neurons in the cortex of the brain, including the anterior cingulate cortex, responded to injury at the peripheral level. We believed at that time that such long-term changes in the brain may play important roles in long-lasting chronic pain.”

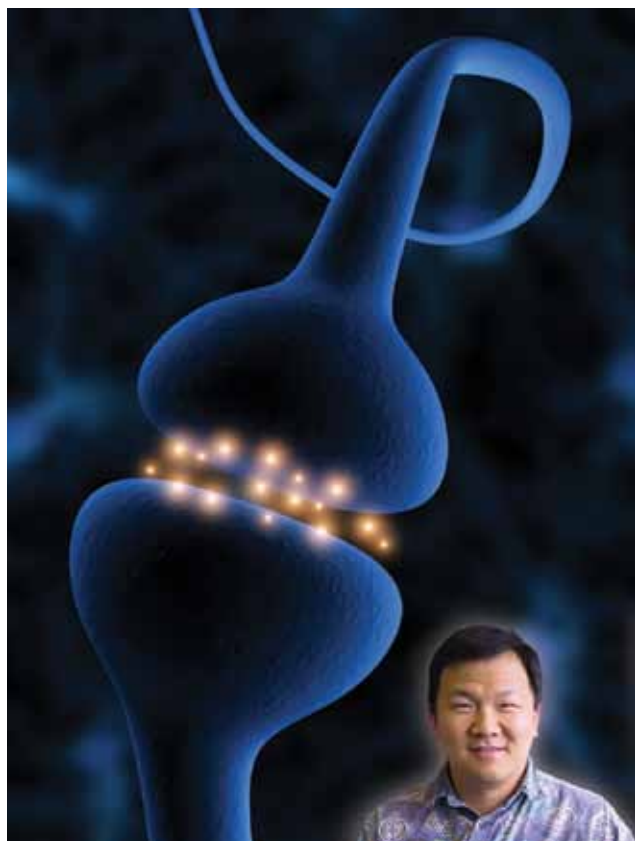
Zhuo explains that neuropathic pain begins with a constant barrage of inappropriate pain signals originating at the beginning of the pain pathway—nerve cells called nociceptors that were initially altered by injury such as SCI or by diseases such as cancer. Over time, this barrage of pain signals leads to changes in the section of the brain that’s responsible for perception and memory. It’s here that brain cells become hypersensitive, the result of connections (called synapses) between these cells being strengthened and the pain signals becoming amplified.

The culprit that leads to this hypersensitivity is AC1. “AC1 contributes to long-term potentiation (strengthening) of sensory synaptic responses in the brain, or what you may call ‘pain memory,’” says Zhuo. “Such enhanced cortical activity may directly cause chronic pain in patients.”

In previous studies, Zhuo and his team have demonstrated the role of AC1 in mice by removing the gene responsible for its production. This resulted in neuropathic pain be-

“I believe that NB001 or future generation inhibitors of AC1 will help to reduce chronic pain in patients with SCI.”

Below: A digital illustration of a synapse occurring between two brain neurons. Dr. Min Zhuo (inset) and his team have developed a drug that limits inappropriate synapses in a specific area of the brains of mice, which leads to a reduction or elimination of neuropathic pain. The challenge now is to move this promising drug into human clinical trials.



ing significantly reduced or eliminated. Importantly, the mice retained normal sensitivity to acute pain—the type needed for survival.

Armed with this knowledge, a new goal emerged for Zhuo: find a drug that could selectively prevent formation of AC1 in the affected region of the brain. The team used a cell model to screen for compounds that could do this. One of these compounds, NB001, appeared to work well. The next step was to test it on mice. Lo and behold, it powerfully reduced neuropathic pain.

Gradually, other important facts emerged about NB001. It only seemed to work well in the target region of the

brain, and didn't affect AC1 (or other isoforms of adenylate cyclase) in other parts of the body. Only low doses were required for it to be effective. It did not significantly affect acute pain sensitivity (the "good" pain), or cause cognitive or physiological side effects. In short, NB001 seemed to have promise as an effective treatment for neuropathic pain in humans, including people with SCI.

"Indeed, one of my research projects was funded by the International Spinal Cord Research Foundation, and we are planning to test the effects of NB001 on SCI-triggered cortical changes," says Zhuo. He and his team now have a patent on components of NB001, and are

actively looking for industrial and investment partners to move NB001 into clinical trials.

He adds that pre-clinical toxicity tests and others experiments are needed before permission is granted to conduct human trials. In particular, because AC1 is present in other parts of the brain that process memories, such as the hippocampus, it needs to be ensured that NB001 does not affect this type of functioning. Keep in mind that no side effects of this type have shown up in the mice experiments.

On a personal level, this work is one of Zhuo's major research interests. "I believe that NB001 or future genera-

NEUROPATHIC PAIN: A PRIMER

To understand the significance of Dr. Zhuo's discovery, let's back up and take a look at what neuropathic pain is—and what it isn't.

NEUROPATHIC PAIN vs. ACUTE PAIN: Neuropathic pain shouldn't be confused with acute pain—for example, pain in the shoulders from overuse. Generally, acute pain is considered "good pain" in that it serves a purpose, letting you know something's wrong with your body (think of putting your hand on a hot frying pan). This type of pain also responds well to traditional medications including aspirin, ibuprofen and stronger painkillers. And if it's due to injury, this type of pain disappears once the injury has healed.

Neuropathic pain is generally accepted as pain that results from functional changes in neurons, which makes them hyperexcitable—that is, they begin firing intense pain signals to the brain for little or no reason. This type of pain clearly has no benefit.

SCI NEUROPATHIC PAIN: In the case of SCI, neuropathic pain can be further broken down into two categories.

Pain can be at the level of the injury, due to damage to the actual nerve roots or to the spinal cord itself. Doctors may refer to this as "segmental deafferentiation" or "girdle zone pain". A common place for this pain to appear is from your stomach around to your back, at the level of your injury. This can develop during the first few weeks after initial injury, or more slowly over time.

Diffuse pain below the level of injury appears to be due to actual changes that have occurred in the central nervous system—the interruption of nerve pathways and the formation of abnormal connections within the spinal cord near the site of injury. It's this type of pain that is usually the most intense—people have described it as tingling, numbness, aching, throbbing, burning, or squeezing. It often occurs in specific body regions, on either side of the body or both, and may be constant or intermittent.

CURRENT TREATMENT OPTIONS: Regardless of the cause, neur-

opathic pain responds poorly, if at all, to the wide range of treatments that exist—from medications and acupuncture, to spinal or brain electrical stimulation and even surgeries (DREZ, or dorsal root entry zone; rhizotomy; or cordotomy). Treatments that do have modest benefits for neuropathic pain often dull acute pain—the type of pain that has a very useful role to play in our survival. Add to the limited benefits a large number of risky side effects and the possibility of a raised level of paralysis, and it's little wonder why there's such a critical need for continued research into neuropathic pain.

THE CURRENT STATE OF RESEARCH: Not surprisingly, a great deal of neuropathic pain research has focused on stopping pain at the source, in the specialized pain-signaling nerve cells known as nociceptors. In an uninjured nervous system, nociceptors only do their job during a normal painful encounter. With neuropathic pain, nociceptors go on a rampage, firing intense pain signals to the brain without any external pain stimulus or injury. The active mechanism in nociceptors are "voltage-gated sodium channels" (VGSCs). Sodium-channel-blocking drugs appear to have promise as a treatment. However, VGSCs contribute to more than just pain processing; they are vital for the proper functioning of many organs such as the brain and heart. Existing sodium-channel-blocking drugs—for instance, gabapentin—are only partially effective and poorly tolerated—they target all members of the VGSC family in the body, and at doses sufficient to reduce pain, they can cause confusion or interfere with vital organ functioning.

And so the search is on for sodium-channel-blocking drugs that target only the specific VGSCs involved in neuropathic pain. However, success in this area is proving to be elusive, which is why Zhuo's apparently successful focus on the receiving end of the pain conduit, the brain, is so intriguing.



tion inhibitors of AC1 will help to reduce chronic pain in patients with SCI," he says. "I believe that understanding changes in brain areas related to pain is the key to help us to design better drugs for controlling SCI-related chronic pain and chronic pain induced by other injuries and cancer. Seeing many patients suffering from chronic pain and my desire to help those patients are the major driving forces for my work. I have received many emails from patients' wives, daughters, sons and friends requesting information about NB001. This just makes me feel that I am working in the right field."

Meanwhile, AJ Star and a legion of other sufferers of neuropathic pain wait for further breakthroughs, often less than patiently. "This pain has completely changed my life," he says. "I feel as though I am surviving everyday instead of living a life. Hopefully sometime in the future, medicine will grasp a better understanding of the subject and how to deal with it." ■

You're Not Alone...

A new report, commissioned from the Urban Futures Institute by the Rick Hansen Institute, synthesizes data from across the country to come up with what appear to be accurate estimates of SCI incidence and prevalence (how many people are living with SCI). The report also breaks down the health care costs of various types of SCI, and takes a look at the future of SCI in Canada.

Some of the numbers are eye-opening. For example, the total number of people living with SCI in Canada is estimated at 85,556 (about six thousand more than the population of Victoria) with 4,259 new cases of SCI each year. Of those living with SCI, 48,243 people are quadriplegic and 30,324 are paraplegic. Roughly half of all SCIs are due to traumatic injury, with motor vehicle collisions being the leading cause. Other leading causes include diseases such as cancer and ALS.

The costs of SCI are also alarming: the lifetime medical costs of a person with quadriplegia exceed \$3 million; for a paraplegic, \$1.6 million. The total yearly economic cost of traumatic SCI is \$3.6 billion a year. Of this, \$1.8 billion is in direct medical costs, of which a large portion is not related to paralysis, but instead to medical complications such as UTIs, pneumonia, pressure ulcers and depression.

"Until this report, we really didn't have a reliable baseline from which to justify research or service expenditures," says Dr. Chris McBride, BCPA Executive Director. "These are sobering figures that reinforce the need to enhance the reach, scope and quality of our services and why it is important to fund them."

The authors predict that the number of people living with SCI will increase sharply in coming years, reaching 121,000 in 2030. This is due largely to the aging population: older people fall more and suffer disproportionately from illnesses such as cancer.

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Heavy Duty

BCPA members have never failed to impress us with their career paths, and Port Alberni's Joe Hawkins is no exception.

■ Photos by Keri Sculland

JOE HAWKINS HAS WRENCHED himself a Western Canadian reputation as a problem-solving diesel mechanic.

"My business is very successful," says Hawkins, who works at his own modern home-based shop and business, Off Road Diesel. "I have vehicles coming from all over the island and as far as Alberta with owners wanting repairs completed. Diesel engine repairs are my area of expertise. I've been at this for many years, focusing specifically on diesel engines."

Hawkins comes by his love of mechanics honestly. "My father owned an off-highway trucking company when I was growing up," he says. "So I've always been interested in mechanics."

At the age of 22, Hawkins' career was well underway in the marine industry, where he specialized in engine rebuilds.

Then came the accident that left him with a T9 - T10 SCI. While the injury was incomplete and he





regained some ability to walk using leg braces and forearm crutches, he had doubts about whether he could continue as a mechanic.

"It was a friend who owned a trucking company that asked me to come to work for him, but I wasn't sure," says Hawkins. "He said, 'Let's try and see what happens.'"

Hawkins did more than try. He overcame the challenges of working in a shop designed for able-bodied mechanics, and ended up working for his friend's company for the next 15 years. But as you'd expect from someone who truly loves his trade, Hawkins also put in extra hours in his own shop, working on his own vehicles and equipment, and slowly taking on more work from paying customers. Then, in November of 2010, he made the decision to quit his job and focus exclusively on his own business—a decision he says has worked out incredibly well.

"I enjoy working for myself and the freedom that it allows me to be flexible in my schedule," he says. "The biggest thing is that you can work around your conditions. If my back is sore, I can take

time off work to rest. And, of course, you can write a lot off when you operate your own business."

Hawkins is also more than a mechanic—he's expanded his business to include excavation contracting. "I have nine excavators at this time, which are located all over the island," he explains. "I run these excavators myself when I can—when I can find the time in my busy schedule. I also have some very reliable, dependable operators running them as well."

Amazingly, Hawkins juggles his expanding business with the responsibilities of being a committed single father to two sons, ages 12 and 14. "I coach my oldest son's football team, and we travel a lot for their karate. We love to camp when we can, and ride quads and wakeboard when the weather is warmer. I really encourage my children to be very physically active. It's a lot of work trying to find time to balance everything, but my family and friends are pretty understanding of my time constraints with work commitments and looking after my kids."

Would he recommend mechanics as a career for other people with SCI—

even full-time wheelchair users? "Yes, I would say that it's a good vocation if someone wants to work on engines at a bench if they want or need to stay in their wheelchair," he says. "If you really want to return to work you can overcome just about any problem if you really want to. You definitely have to be ready and willing to make some sacrifices, and you should find people who will support you and provide access to resources."

Hawkins extends his "adapt and conquer" philosophy to most areas of his life. "If you really want to do things, you have to adapt yourself and possibly your thinking, making them work for you. For example, I loved motorbike riding, but now I have to use a quad that has an automatic transmission. I loved water skiing, but now I ski biscuit. So...if you want to do something, do it by finding ways to make it work for you. Don't give up." ■

Off Road Diesel is located in Cherry Creek, just outside of Port Alberni. If you've got a diesel vehicle needing repairs, or need excavating done on Vancouver Island, you can reach Joe Hawkins at offroaddiesel@yahoo.com



Taking Care of The Old Ball and Socket

■ By Amy Mackinnon

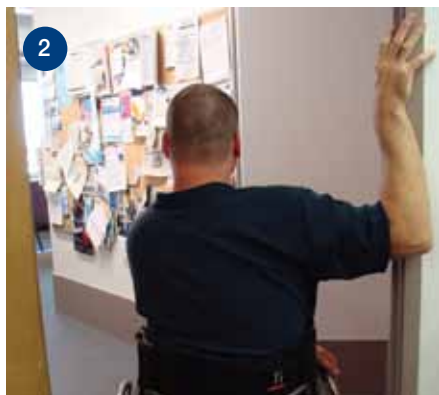
INDEPENDENCE. For manual wheelchair users, its loss is not usually the result of the old ball and chain, but rather the old ball and socket. Ball and socket joints tend to be very stable because typically the socket is large and the ball half is able to fit in nicely. However, in the shoulder, the ball is larger than the socket, making the shoulder more susceptible to injury. This is why it's important to maintain the health of the muscles, tendons, and ligaments surrounding the shoulder joint. As a wheelchair user, having healthy shoulders equates to independence.

The shoulder is designed for reaching and carrying, not for repetitive movements such as pushing a wheelchair, transferring and lifting things overhead. For many wheelchair users, this puts the shoulder at risk of overuse which, in turn, causes injury and pain. Some common shoulder issues include rotator cuff injuries, bursitis, shoulder joint instability, frozen shoulder, degenerative joint disease and osteoarthritis.

However, there are many things you can do to help keep your shoulders in tip-top shape and decrease your chance



CPA Alberta staff member and Paralympian Ross Norton demonstrates some simple stretches and exercises that you can do in just a few minutes each day, at home or in your office, to keep your shoulders flexible and strong and decrease the chance for injury and overuse. For the two stretches (1 and 2), hold the position in each arm for at least 30 seconds to maximize the benefit. Exercises 3 and 4 are performed with a Theraband, an inexpensive elastic exercise aid that can be tied to a doorknob as required. To maximize the benefit of these two Theraband exercises, try to keep your arm as straight as possible, and move each arm into and out of the extended position with an even unhurried motion. Begin at a gentle pace and, over time, strive for three sets of ten reps each time you perform the exercises.



of developing a serious injury. An ounce of prevention is worth a pound of cure.

First, while it might seem easier said than done, maintain a healthy weight. This will decrease stress on your shoulders from wheeling and transferring.

Try to perform transfers in both lateral directions. This avoids putting constant stress on the same arm. Level transfers are also preferable whenever possible, and avoid turning the arm inwards as it can lead to impingement (the tendons of the rotator cuff muscles become irritated and inflamed as they pass through the subacromial space). Leaning forward or sideways periodically while sitting in the wheelchair also helps to relieve pressure.

Get the lightest chair possible and make sure your equipment is set up appropriately. If the wheels are too far back, you'll be reaching behind and causing unnecessary stress on the shoulders.

The elbow should be bent at around 100 to 120 degrees when your hand is at the top-centre of the push rim. Also make sure your seat isn't too low, as that will cause extra strain. And make sure to regularly maintain your wheelchair—even a slight decrease in tire pressure can cause a significant increase in the force required to push.

In terms of wheelchair technique, it's a smart move to develop an efficient wheelchair stroke. Minimize your strokes per minute by using long smooth motions instead of short and small ones. Be sure to perform a consistent semi-circular pattern when pushing as well. When you let go of the rim, your hands should fall and swing back for the next push.

Finally, there's no shortage of strength and flexibility exercises that you can easily build into a daily routine. Former Paralympian Ross Norton demonstrates

some of these on the previous page.

What to do if you already have shoulder pain? Address it as soon as possible. This can help prevent long-term damage and pain which can be difficult to manage. Don't forget to rest too. If doing certain tasks and activities cause pain, think about other ways you can accomplish the same results in a more relaxing manner. Once the pain has subsided, remember to gradually return to your normal activities. Most importantly, consult your physician who can discuss options with you. Ask if a referral to a physiotherapist or other rehabilitation specialist is appropriate. If so, make sure to follow the specialist's rehab plan closely, and you'll be sure to see results. ■

Amy Mackinnon is a Client Services Coordinator for CPA Alberta. She has a degree in Physical Education.

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kayaking for quadriplegics

Over the years, paddling has become an increasingly accessible sport for paraplegics. Now, thanks to a few pioneering individuals and new technology, people with quadriplegia are getting out on the water.

EVERY SUMMER, THOUSANDS of British Columbians take to the water in kayaks, enjoying our province's countless and spectacular inland and coastal waterways. As both a sport and a recreational pursuit, kayaking in BC continues to experience explosive growth, and in recent years it's become increasingly accessible to people with disabilities, thanks to some minor equipment adaptations and some forward-thinking individuals and organizations.

However, if you're a person with quadriplegia, you've probably been watching all the action from the shore. You could be excused for this—after all, balancing a kayak requires good trunk control and hand strength. Or does it?



Jim Milina had plenty of assistance when he tested the waters the first few times.

■ Photos by C. Gailloux

Jim Milina is one quadriplegic who has discovered this is no longer true.

Milina, who lives and works as a graphic designer in Comox, has always been an outdoorsman. A provincial free-style skiing champion at the age of 17, he was injured one year later, becoming C4 - C5 quadriplegic doing the sport that he loved. His thirst for adventure, however, remained undiminished. This is clearly evidenced by the fact that, in 2002, he became the first quadriplegic to reach the peak of Africa's Mount Kilimanjaro (he and his fellow climbers accomplished this with a TrailRider from the BC Mobility Opportunities Society—visit www.bcmos.org for more information).

Last year, he set his sights on a new outdoor challenge—kayaking.

"Having been injured in 1981 when I was only 18 years old, kayaking was something I had yet to experience,"

he says. "And, seeing as it always looked so peaceful and enjoyable, it was one of those things that I've wanted to do for a long time. Now, after trying it a few times, I find it's really an exhilarating experience. The most rewarding and unexpected part is being out of my wheelchair and yet still 'mobile', albeit on the water."

What's made it possible for Milina to take up paddling is an ingenious, accessible kayak designed by Nanaimo inventor Bruce Fuoco. "Bruce is the man responsible for providing us with all the technology necessary to modify the kayak for people with disabilities," says Milina. "Bruce sustained a stroke several years ago, but his disability did not prevent his pursuit of the dream of returning to a sport which he loved prior to becoming disabled."

After his stroke, Fuoco was left with only the use of one arm. Over the course of five years, he and some friends built eight different kayak prototypes before finally coming up with a design that's versatile enough to accommodate a wide variety of disabilities.

The kayak, purchased from Seaward Kayaks of Chemainus and modified by Fuoco, has outrigger pontoons on both sides that can be raised, lowered and extended outward to increase or decrease the amount of stability needed. It also has an adjustable oar holder that locks in place and, with the use of a pivot, allows the kayak to be rowed with just one arm. For quadriplegics like Milina, who aren't able to firmly grasp the paddle, a special glove and grip combination is added (see cover photo). And the seating can be augmented with foam supports as needed by people with limited trunk control.

Milina and others with similar abilities in the Comox Valley are now able to paddle in one of Fuoco's creations on a regular basis, thanks to generous local donors who contributed to the area's annual Rick Hansen Wheels In Motion event. Unfortunately, this national event was cancelled after 2010, but it left a lasting legacy in Comox, where a portion of funds raised were used last year to purchase the kayak.

"I went out three times last year," says Milina. "As it was my first time in a kayak, we thought it better to try it in a lake first as opposed to the ocean in and around Courtenay and Comox. Being a quadriplegic, it was a fairly daunting challenge and intricate process to get my 6'2" body into the cockpit and stable enough to feel comfortable. I required two strong and willing partici-

"Once snugly in the cockpit, I could relax and concentrate more on my paddling and not worrying about my balance."

pants to lift me out of my chair and set me on a spare cushion placed on the top of the kayak, just behind the front cockpit. Once safely seated there, a third person held my body steady and balanced while the other two repositioned and got ready to place me down and into the cockpit. Keep in mind that this became much easier each time it was performed.”

Once in the cockpit, sponge yoga blocks were fitted between Milina’s trunk and the sides of the cockpit, and he donned special gloves which are easily attached and unattached from the paddle.

“The learning curve appeared fairly steep,” says Milina. “But by my third trip out I was powering the kayak on my own—which was a very satisfying experience. I was amazed at how proficient I had become after only three sessions in the boat.”

Milina concedes that safety was a concern, but he was quickly satisfied that ending up “in the drink” wasn’t in his cards. “Feeling secure was the biggest challenge for me, as my balance is always an issue. Once in the boat, I discovered

there was no physical way I could fall out of the boat, as the sides of the cockpit were too far up my rib cage. I could fall over if not adequately braced, but there was no way to fall out and into the water. And there was no way that the boat could tip, thanks to Bruce’s adaptations.”

The added pontoons on either side of the rear of the boat make it virtually untipable—Bruce demonstrated this point to Jim by standing up in his kayak to show how stable the vessel really is due to the adaptations. “Once snugly in the cockpit,” says Jim, “I could relax and concentrate more on my paddling and not worrying about my balance.”

He adds that it’s important to always paddle with someone who is experienced, not only in paddling but also in safety and emergency situations. “That’s just common sense,” he says.

Milina is now looking forward to a full summer season of paddling,

“The kayak is currently in storage for the winter,” he says. “However, once the nice weather of spring arrives, it will again be available to users through-

out the Comox Valley. We’re currently working on a website which will handle booking the kayak as well as provide some explanation of the logistics and intricacies of using the boat.”

Milina encourages other quadriplegics in the area to give it a try. “I had no idea that there was an accessible option when it came to kayaking—I just assumed it was like many things and inaccessible to people with a disability such as mine. Well, accessible kayaking is available in many communities in BC, and the number is growing each year. The biggest obstacle to overcome is between your ears, and once you overcome that, anything is possible, including kayaking.” ■

Jim Milina is eager to offer advice or assistance to anyone looking for more information—you can reach him by email at jim@littlerivermedia.com. He also recommends visiting www.interfit.ca (North Vancouver) and www.powertobe.ca for more information on accessible kayaking.

Bits & Bytes

BCPA Connections Lead to Van Donation

During BCPA’s recent holiday dinner event in Prince George, our staff learned that a local peer, Mel Marchewka, was having a hard time qualifying for funding for a basic wheelchair accessible van. Right around the same time, our Vancouver office staff were asked if they knew of a suitable recipient for an accessible van being donated by Betty Charles, the widow of recently deceased BCPA member Don Charles. Bert Abbott from our Vancouver office sent Betty’s generous offer out across the BCPA network, where it was quickly seen by Brandy Stiles from our Prince George office. Days later, Marchewka was the new owner of a fine lift-equipped Ford Windstar. Our thanks to Betty for her generous gift, and congratulations to all BCPA staff who helped make this connection.

RDSP: Positive Changes

The Registered Disability Savings Plan (RDSP), the Canada-wide registered matched savings plan specific for people with disabilities, has some positive changes for 2011.

As you probably know, the federal government provides two big incentives for using an RDSP. Through the Canada Disabil-

ity Savings Grant, Ottawa matches contributions based on the recipient’s income, or family income in the case of minors. The grant amount ranges between 100 percent for recipients with income of more than \$81,941 to 300 percent for recipients with income below \$23,855. For those with income below \$40,970, there’s also the Canada Disability Savings Bond, which provides up to \$1,000 a year, regardless of whether they contribute any of their own money to their RDSP.

The new rules now allow you to carry forward unused government grants and bonds starting from 2008. So for those who qualify for the bond, simply opening an RDSP in 2011 will get them up to \$4,000 in government bonds. And beginning in July, the proceeds from a deceased individual’s registered retirement savings plan, registered retirement income fund or registered pension plan can be rolled over into the RDSP of a financially dependent child or grandchild with a disability, without triggering taxes and probate fees. It’s a simple, tax-efficient way to leave an inheritance.

Keep in mind that the RDSP is exempt from most provincial disability and income assistance benefits. It does not get clawed back and it does not reduce disability benefits payments. For more information, visit www.disabilitysavings.gc.ca.

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“like”

Social networking offers BCPA Peers and others with SCI an excellent opportunity to connect and learn.

■ By Jennifer King

WHEN IT COMES TO social networking, Canadians are heavy users. More than 70 percent of Canadians say they regularly use social networking platforms such as Facebook. The beauty of these platforms is that they enable you to network without needing physical access or physical proximity to others in your online community—particularly important in a country as vast as Canada.

For British Columbians living with an SCI, and particularly those who already stay connected as part of BCPA's Peer Program, free social networking tools can be like a modern lifeline—they enable you to regularly connect, share and learn without leaving your home, eliminating barriers such as inaccessibility, transportation and cost.

That's why BCPA sees the value of connecting with peers, as well as connecting peers with peers, using social networking tools. We're already using Facebook, Twitter and YouTube, and we're looking to expand the range of social networking tools we use and ramp up communication via these platforms in the near future.

Brad Jacobsen, BCPA Peer Associate and our "Social Media Man", is helping to lead this charge. "Social networking not only keeps me up-to-date with what's going on in our peers' everyday lives, but it also allows me to provide them with information regarding education, upcoming events and resources," says Jacobsen. "I'm also able to connect individual peers together so that they can

offer some one-to-one advice or assistance. And in my personal life, social networking allows me to keep myself immersed in the vibe and flow of what's going on in my everyday world with family and friends."

Jacobsen also feels that the ability to share and glean information on social networking sites such as Facebook is a much richer and less superficial experience than many people realize. "People can gain an amazing amount of information simply from another's interest or need in a certain area and their subsequent actions in posting that info on their profile or page," he says. "The spontaneity of it all is magical in its ability to enlighten and enrich."

Jacobsen also points out that social networking isn't always about two-way communication. For example, YouTube, the video sharing website, has proven useful to the SCI community by visually teaching self-management skills. Search for "how to apply make-up in a wheelchair" and "how to transfer from a wheelchair to a bed" for some examples of this.

And when it comes to really connecting, few would disagree that online dating networks have been a real asset for people with SCI. "Dating websites allow people to meet and form relationships that might never present themselves otherwise because of some of the psycho-social barriers that exist," explains Jacobsen.

If we've painted too rosy a picture, don't worry—we recognize that social networking has some pitfalls. One concern Jacobsen has is that people might immerse themselves into a virtual world of friendships and community, completely isolating themselves from society and the opportunities that exist outside their online networks.

"Lack of interaction with the outside world can lead to depression, lack of sleep, obesity, secondary health issues, loss of confidence and, in general, decreased quality of life," he says. "There needs to be a balance; a healthy lifestyle both on and off the computer."

Another concern is that people could end up sharing too much personal information—particularly health-related information—without considering the consequences. For example, details about people’s health listed on social networking sites could be used against them by potential employers or insurance companies who see this information. BCPA is currently looking at ways to address this concern. One possibility is to establish our own social network so that Peers have a safer, more personalized environment to share their health information and everything that goes along with it. TYZE (www.tyze.com) is one company that provides specialized social networks that allow people to collaborate with their friends, family and support network in a private online space.

The bottom line is that BCPA encourages Peers to use social networking tools—but to do so wisely. They’re a great way to stay in touch with fellow Peers, family, friends and organizations such as BCPA. The tools act as a social lifeline, especially when you’re unable to get out and about as much as you’d like. BCPA is definitely seeing more and more useful ways to use social networking tools and we’re looking to adopt more of these as we go.

In the meantime, make sure you’re connected with us on Facebook, Twitter and YouTube. Visit www.bcpara.org to get started. ■

BCPA’s Super 5 Social Networking Tips

Tip 1: Pump up your profile. Your profile is representative of you, so make it about you. Post your favourite photos, and share with people what you’re passionate about, what you do for fun, what you find funny, and the list goes on...

Tip 2: Get your gang together. To find Peers online, try going to where they congregate such as the BCPA Facebook page or the BC Wheelchair Sports Facebook page. Once you find one, you usually find many as they’ll most likely be connected with other Peers.

Tip 3: Share and share alike. Share your ideas, questions, and answers with others. Chances are that they’ll share theirs with you.

Tip 4: Keep it fresh. Update your profile regularly—give people a reason to follow you or visit your page. Just a quick status update or a tweet once or twice a week is often all it takes to stay fresh.

Tip 5: Don’t go overboard. Be aware of your security settings and only share your information with people you trust. Some conversations should be saved for face-to-face meetings at Peer Events or with your support team.

Disability? There’s an app for that.

The Christopher & Dana Reeve Foundation recently published a *Guide to the Best Apps for People Living With Paralysis*, the first online consumer’s guide of its kind. The guide features descriptions of 67 SmartPhone applications for iPhones, iPads, Blackberrys and Androids. Some were created specifically for wheelchair users, while others were developed for general use, yet have particular applicability to those living with SCI.

“SmartPhones offer a whole new level of independence and connectivity for people living with spinal cord injury, impaired mobility and paralysis,” says author Rob Gerth, the Reeve Foundation’s Director of Digital Media. “We’re offering a user’s guide to the coolest and most beneficial apps available.”

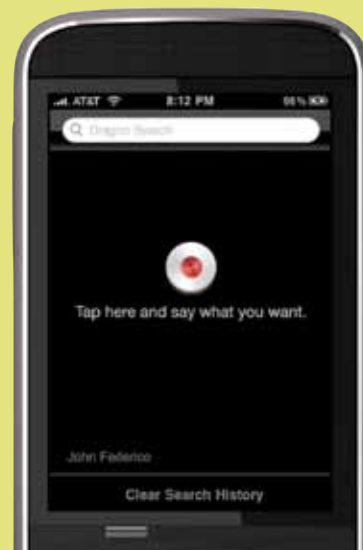
The apps are organized in nine different categories. Here are a few examples:

- CitiRoller (developed in partnership with the Reeve Foundation) enables users to instantly locate accessible transportation, restaurants, cafes and restrooms. While it currently only offers service in New York, Washington, D.C., Boston, Chicago and San Francisco, it is fully scalable internationally, so major Canadian cities could be added in the future. Its social media function permits users to nominate, rank and comment on specific locations.

- Proloquo2Go turns a SmartPhone into a sophisticated text-to-speech voice synthesizer for those who can’t speak.
- Physiotherapy Exercises plays over 600 exercises for people with SCI and other neurological conditions. You can filter the search through a variety of categories such as condition, body part, equipment available and age categories. The purpose of this app is to improve strength, flexibility and fitness. It was created to promote an independent lifestyle by creating exercises that do not require manual handling from physical therapists.
- Quick ADA provides easy access to the Americans with Disabilities Act’s standards and regulations for doors, stairs, hallways, plumbing and parking accessibility. At first glance, perhaps this isn’t relevant in Canada, but why not? The ADA’s standards are among the best in the world. Use this app to see how we measure up.

Other featured apps and accessories allow users to dictate email and text messages, track medications, “shake to dial” or mount their SmartPhone on a wheelchair.

To see the entire app guide, visit www.ChristopherReeve.org/apps.



The Ulu Effect

Looking to be better, faster and safer in your kitchen? Consider buying an Ulu, a traditional Inuit skinning knife.

■ By Cory Parsons



At the age of 23, Nanaimo's Cory Parsons was in a serious diving accident that left him quadriplegic. Today, Cory is a world class chef, celebrity, and author (Cooking with Cory, Whitecap Books, \$29.95). Below he shares his story of how he discovered the Ulu, some tips on using it, and how it helped inspire him to get back in the kitchen after SCI.

AFTER MY ACCIDENT, I was dependent on others for meal preparation. Occasionally I would try and participate by duct-taping my regular heavy chef's knives to my hand, but not only was this extremely dangerous, it just wasn't the same. I was disappointed, sad, frustrated, angry, and I began to wonder if I would ever again be able to work in the kitchen. I was devastated.

My participation in the kitchen was kept to consumption and giving directions until my father took a trip to Alaska. It was there he learned of the Ulu knife, and he immediately thought it might be what I needed.

The Ulu is an Inuit skinning knife with a rounded double blade and horizontal handle. When I tried the Ulu for the first time I immediately felt comfortable. It inspired me to begin creating some of my favorite dishes again.

Soon after I discovered the Ulu, I decided to prepare a special dinner for a new girlfriend. I planned the menu and even wrote it out to make sure I didn't miss a thing. Shopping was another fearful task to overcome at this time, as were the logistics of transportation to and from the market. But I was highly motivated, so these obstacles didn't deter me. I wanted my partner to know how special she was to me and I knew she would appreciate the effort.

Here was my must-have list: groceries and supplies (including wine, cheese & crackers—just in case dinner was a total failure!); my trusty Ulu knife, newly sharpened; and Band-Aids (just in case).

And so I began chopping, slicing, and mixing. I had decided to make a dish that I previously whipped up in about

20 minutes—not the case this time! Everything takes a lot longer post-injury. Four hours later, one bottle of wine down and all the cheese & crackers gone, I had a dish that slightly resembled what I was striving to prepare. Thank goodness my girlfriend was patient!

But in the end I had the most amazing sense of accomplishment I had ever felt in my life. And I didn't need a single Band-Aid! In fact, I have never cut myself with my Ulu knife in the ten years I've been cooking after my injury. From that day forward I was hooked.

I began planning meals for my girlfriend each week and gradually honed my skills to where I am today. I'm very comfortable working in the kitchen and I have become very adept with the use of all my kitchen tools. In fact, my previous home had two kitchens, and once a month my friends and I would have an Iron Chef challenge. I'm currently the reigning champion and have yet to lose a battle.

The Ulu was the tool that I needed to get back in the kitchen. The horizontal method of its use and the design of its handle provide excellent control and great contact with your ingredients, which makes for very efficient and safe use.

However, there are some ingredients that pose a greater challenge. Things like large yams, watermelon and cantaloupe are difficult to chop because their depth exceeds the depth of the Ulu blade. A simple solution is to cut from each side. With yams and potatoes, once you've started your cut, you can pry the blade sideways carefully and split it along your cut.

Smaller foods such as garlic, ginger, mushrooms and chilies can also be tricky. My best advice to anyone is to be very careful and attentive, and always use a sharp knife. Believe it or not, most knife cuts in the kitchen occur with a dull knife. A sharp knife will do what you ask of it with minimal pressure or force. A dull knife takes more effort and generally speaking has a tendency to "slip" instead of cut, increasing the likelihood of a serious injury.

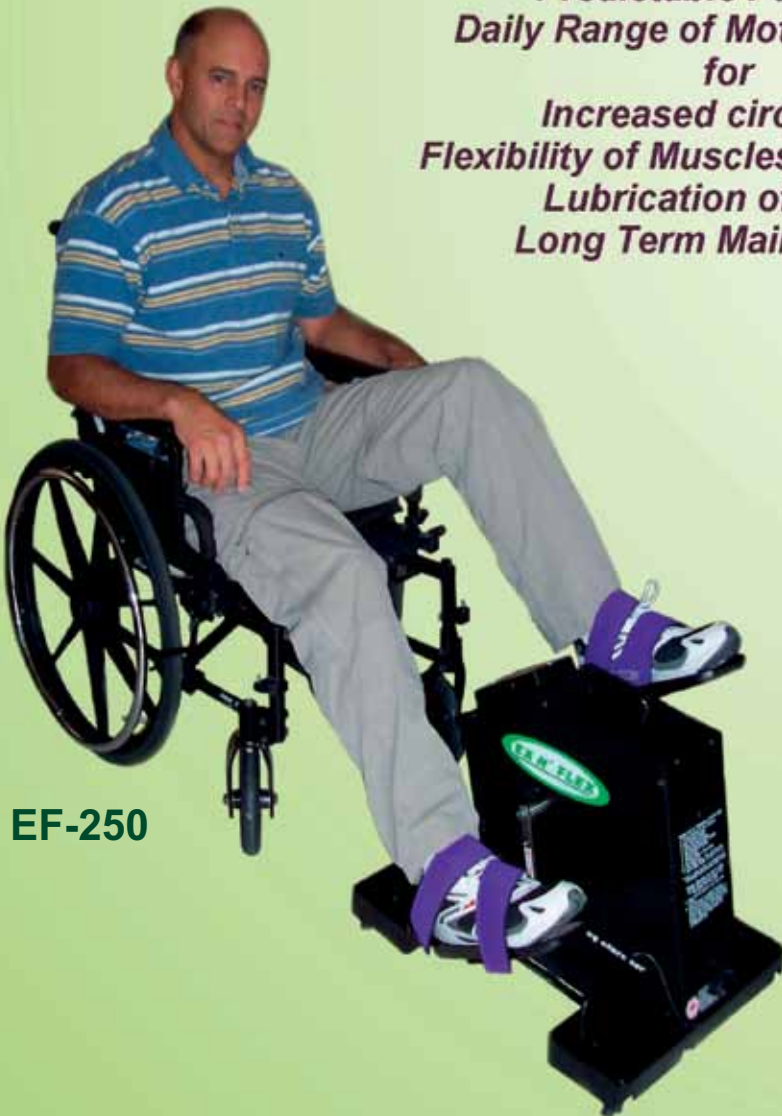
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Thank you to Wheelchair Basketball Canada for the action shots of Chantal Benoit, white, and Kendra Ohama, black above. More information is available on these two veterans of the women's National Program in Canada on the web site at wheelchairbasketball.ca