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Photos of Summer Peer Events

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What Happened to the Paralympics?

ACCESS AND INCLUSION. These are important concepts for the disability community, and they have been at the heart of SCI BC's mission since 1957. On the surface, they seem necessarily linked—after all, without access, it's very hard to achieve inclusion.

However, we must be careful about what we mean by access. And we must not assume that, because we are a province and nation that has often led the way in improving the accessibility of our communities, that BC or Canada is a leader in inclusion. Case in point: the Paralympics and Canada's inexcusably pitiful television coverage of the Games.

The Paralympics have become a powerful symbol of achievement and possibility for people with disabilities. Through sport, we witness the triumph of the human spirit in overcoming physical and societal obstacles, and through this, society moves toward greater inclusion for all.

Too bad, then, that the Canada's Olympic Broadcast Media Consortium, which held the broadcast rights to the 2012 Paralympics, chose not to dedicate TV time to the Paralympics. Too bad that the Consortium's sports networks barely covered highlights from the games. Too bad that they missed the opportunity to push the stories of triumph and disappointment on their websites or smartphone apps. Yes, there was online coverage, which is some consolation, but based on the level of overall coverage, it's clear that Canadian broadcasters do not deem disability to be important. They are not supporters of inclusion.

Contrast this with coverage in Great Britain, a country not known for the accessibility of its cities and infrastructure. I had the good fortune of passing through London on the closing day of the Olympics and again on day three of the Paralympics. I witnessed the equal excitement the city had for both. They fully embraced the Paralympics—in spirit and on TV, where full coverage of the Paralympics was provided daily.

This drove home the rather obvious fact that simply making our communities physically accessible is not enough to create full inclusion. Access to the stories and events that can change societal attitudes and remove perceptual barriers is just as, if not more important for enhancing inclusion for all.

I hope that all of the people who have complained to me about the lack of Paralympic coverage here in Canada send their complaints to the TV networks that failed to provide it. I hope that by the time the Winter Paralympics roll around in 2014, that I can turn on the TV and see Paralympic curler and SCI BC Peer Coordinator Sonja Gaudet competing for Gold and inspiring even more people with disabilities to take up curling or other forms of sport or active living.

It's only through broader access to important and culturally significant events like the Paralympics that we can truly leverage the relative accessibility of our physical infrastructure to become a true leader in inclusion.



— Chris McBride, Executive Director, SCI BC



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eyeCAN EYE MOUSE

Operating a computer via an eye-controlled interface isn't new technology, but many of these devices have carried high price tags. Recently, Samsung announced it was open-sourcing its eyeCan technology, developed by five engineers

as a side project to their main work. The engineers modified an existing drawing tool called eyeWriter (designed for paralyzed artists) into a new device intended to allow people with high level paralysis to control a computer through eye tracking. They've been testing it and posting videos of it in use on YouTube over the last few months. Samsung isn't actually selling the eyeCan; it provides the software and instructions on how to make the device from readily available components costing around \$50. For more information, visit www.eyecanproject.wordpress.com/english.

Innovations

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

KENGURU ELECTRIC CAR

The Kenguru (pronounced "kangaroo") is an electric car designed for wheelchair users. The tiny vehicle can travel up to 45 kilometres an hour and has a range of 60 kilometres. Its rear hatch opens so the driver can wheel right into it. Once inside, the wheelchair is locked down and the driver steers via a motorcycle-style handlebar. The Kenguru's Hungarian owners couldn't afford to bring it into production. Enter Texas attorney Stacy Zoern, who discovered it while searching for her own ride (she has spinal muscular atrophy). She was so impressed that she went into business with the company and opened a manufacturing facility just north of Austin. The first models rolled off the line in January. The Kenguru is classified as a scooter in the USA, so a driver's license isn't required. Head lamps and turn signals are built in, so it can be driven on city streets. However, like all scooters, it can't be driven on the highway. For more information, visit www.kenguru.com.



CURSUM STROLLER

The Cursum stroller was designed specifically for parents who use wheelchairs. The Cursum is the perfect height for someone sitting in a wheelchair. It also has smaller wheels and an overall smaller wheelbase than regular strollers so that it can be positioned right in the front of your wheelchair, where it locks firmly in place. Once locked in place, the stroller/wheelchair combination is easily manoeuvred, since the front wheels swivel 360 degrees. There's a storage space underneath the seat at about knee height, and the stroller's handlebar is placed at an optimal height for pushing. Handle height can be further adjusted to fit the parent's requirements, as can the seat. The entire stroller is constructed of lightweight aluminum, and it folds to a compact size for travel with the click of a button. The Cursum is the brainchild of Swedish industrial design student Cindy Sjöblom. For the moment, there are no commercialization plans, but that should change at some point given the practicality of the design and a clearly unmet need. You can see a video of the Cursum in action by searching for it on Vimeo.



GENNY MOBILITY

The Genny 2.0 utilizes the self-balancing base of a Segway PT. With just two wheels, it can rotate on the spot, as well as negotiate a wide variety of difficult terrain. There are no joysticks, accelerators or brakes. When the user leans forward, the chair moves forward; when the user leans backward, the chair moves backwards. Five gyroscopic sensors keep the chair perfectly balanced all the while. Moving the handlebar to the left or right provides turning or rotating on its own axis at slower speeds. Two self-levelling legs, activated by the user or automatically when any type of a problem is sensed, park Genny safely on any kind of terrain. Power is provided from rechargeable lithium-ion batteries. The chair also comes standard with a modular Tarta seating system, which adapts to the specific needs of each user. At the moment, we couldn't find out what level of ability is required to safely operate Genny. Visit www.gennymobility.com for more information.





Have a coffee on us.

In September, SCI BC's peer program kicked off five new coffee shop group gatherings in North Vancouver, Burnaby, Richmond and two different places in Vancouver. It's a great, informal opportunity to share wisdom and support, develop friendships and build social networks. The coffee groups are facilitated by a Peer Mentor and the cost of the first coffee is covered by us. The gatherings happen once a month with a different date and time at each location. Visit www.sci-bc.ca to get the latest details on the nearest coffee group gathering near you.



The uglier, the better.

SCI BC's second annual Ugly Tie Campaign runs November 5th to 9th. Employees at participating businesses wear ugly ties to raise awareness and raise funds for SCI BC peer events and information services. Sign up as an "Ugly Tie Captain" to represent your business or organization, and we'll provide you with everything you need to succeed. The campaign culminates in the 'Ugly Tie Affair', on Thursday, November 8th, with a casual evening of food, drinks, networking and of course, ugly ties! For more information, email gsteves@sci-bc.ca.



Aneurism & Stroke Group.

SCI BC and the Victoria Disability Resource Centre invite new and old aneurysm and stroke survivors to a newly formed support group. The group will be led by SCI BC Peer Support Specialist Scott Heron, and aneurysm survivor Sarah Kendall. The goal is to provide support and encouragement to people struggling with recovery and adjustment. Meetings take place at the Disability Resource Centre at 817A Fort Street. For details and times, or to reserve a spot, contact Sarah Kendall at sarahkendall321@gmail.com.

Finally, a Craigslist just for you.

In September, SCI BC launched two new online resources for people with SCI or related physical disabilities: Accessible Housing BC (www.AccessibleHousingBC.com) and Accessible Employment BC (www.AccessibleEmploymentBC.com).

Both sites are free to use and operate much like Craigslist. On Accessible Housing BC, housing providers can post photos and information of homes they want to rent or sell, while housing seekers can search for properties by region or accessibility features, or by selecting only subsidized or co-op housing. Accessible Employment BC works the same way: employers can post job opportunities, and job seekers can post their resumes online and search for employment in their regions. The site also has links to various resources for potential employees and employers.

The websites are the first online resources of their kind.

"Finding housing and employment are two of the biggest challenges people with SCI or related physical disabilities face in British Columbia," says SCI BC executive director Chris McBride. "That's why SCI BC created these two new websites. We wanted to help people meet these challenges head on, with the support and resources they need at their fingertips."



Battling Fatigue

Research is making it clear that overwhelming fatigue is a big and poorly understood problem for many people with SCI—perhaps even the majority of us. ICORD researchers are collaborating to better grasp the causes of SCI-related fatigue and find new approaches to bring relief to those who suffer from it.

It's safe to say that, in the past, the healthcare community and perhaps even people with SCI didn't pay that much attention to fatigue. The prevailing attitude seemed to be that fatigue is just a part of growing older, SCI probably speeds up the onset of fatigue for some individuals, and there are more immediate and pressing SCI-related health concerns and research priorities.

Several recent studies, however, make it clear that fatigue is a much bigger problem than originally thought. For example, a British study involving almost 300 people who had lived with SCI for more than 23 years found that more than half reported exhaustion and other fatigue-related symptoms. The study also made a clear correlation between fatigue and poor past and future health of those who participated. In other words, poor health contributes to fatigue which, in turn, leads to even poorer health.

Closer to home, several researchers at ICORD, many of whom who are also clinicians at GF Strong Rehabilitation Centre, have also been shedding new light on the prevalence and nature of fatigue in people with SCI. In a 2008 qualitative analysis, these researchers described

a chart review at GF Strong which "found that 57% of outpatients with SCI of greater than one year duration reported fatigue of sufficient severity to interfere with function." Armed with this knowledge, the ICORD researchers worked with the SCI BC (at that time, we were the BC Paraplegic Association) Peer Program and recruited 21 participants with SCI. Of these, 16 were determined to suffer from significant fatigue (as determined by the internationally accepted Fatigue Severity Scale, or FSS). These 16 then described the nature of their fatigue, with the researchers hoping to come to an understanding of the root contributors.

As it turned out, there were no easy answers.

"This small, exploratory study provides qualitative evidence indicating the complex nature of fatigue following SCI," concluded the researchers. "Rather than constituting a simple, physical phenomenon, fatigue following SCI was perceived to have cognitive, emotional and physical dimensions that require a broad range of responses. Further, participants in this study contended that fatigue is closely connected to hopelessness, pain and depression and is affected by sleep problems, spasticity and reduced motivation, which fatigue also effects.

The impact of fatigue upon the everyday lives and quality of lives of people with SCI who already struggle with severe physical impairments is significant and constitutes a problem deserving significant research attention."

Even before that paper was released, several of its authors had joined with other ICORD specialists to form F2N2—the Fatigue and Function; Neuromuscular and Neurological Team. "Given that advances in medical care have led to an increased life expectancy, prevention and treatment of secondary conditions such as fatigue is necessary to ensure optimum quality of life of the disabled population who reside in BC and beyond," reads the introductory page of the team's website at www.fatiguefunction.icord.org.

The F2N2 team members are working on several projects to better understand the nature of SCI-related fatigue and develop strategies to alleviate it. One of those is a pilot study being led by Dr. Andrea Townson, medical site lead and an attending physician at GF Strong Rehabilitation Centre, and Clinical Associate Professor and Head of the Division of Physical Medicine and Rehabilitation at UBC. Along with co-investigators Dr. Hugh Anton and Dr. Bill Miller, Townson has initiated a study titled *The Effects of L-Carnitine on Fatigue in Spinal Cord Injury (SCI)*.

L-Carnitine is a naturally occurring nutrient normally obtained from the fat from meat and dairy products. In mammals, it promotes fatty acid oxidation of muscle, thereby promoting efficient energy production. Once refined into a supplement product, it has been shown to alleviate mental, physical and muscular fatigue.

"We wanted to look at possible treatments for fatigue and thought that L-carnitine would be a good treatment to explore," says Townson. "Existing research has demonstrated a link between low blood levels of L-Carnitine and fatigue, and L-Carnitine has successfully decreased fatigue in numerous other medical conditions including cancer chemotherapy induced fatigue, multiple sclerosis, chronic

fatigue syndrome, celiac disease, and certain chronic neurologic conditions. While the causes of fatigue in persons with SCI may result from many factors, successful use of L-Carnitine in MS-related fatigue in particular suggests it may have a role in SCI."

The supplement is widely available in oral

form in Canada. "However," says Townson, "it has never been studied in people with SCI. Even though L-Carnitine is already available in Canada, it's important that we study the effects of this supplement in a scientific manner. Just like pharmaceutical drugs, supplements can have important benefits and potential side effects."

Townson and her colleagues are currently recruiting participants into the study. They're seeking SCI outpatients or individuals living with SCI in the community with moderate to severe fatigue. Participants will receive four weeks of treatment, followed by three weeks of follow-up. An initial interview and three subsequent visits to GF Strong will take less than an hour each; treatment and weekly follow-ups can be done from home. The treatment consists of 990 milligrams of L-Carnitine oral supplement twice daily.

This study has a single subject design, which means each subject acts as his or her own control.

Participants can be men or women who are either paraplegic or quadriplegic, and at least one year post-injury. Additionally, they must have clinically significant fatigue as measured by the FSS.

Study results aren't expected until next year. Meanwhile, Townson cautions that even excellent results will not mean L-Carnitine will become a cure-all for SCI-related fatigue.

"When we're looking at fatigue following spinal cord injury, we're looking at the entire phenomenon of fatigue with its physical, cognitive and emotional components. A complex problem such as this will likely require a number of complementary strategies. In the interim, there are lots of things that people can try, such as practicing energy conservation and pacing their activities throughout the day, seeking treatment for pain or depression if present, reviewing their medications—including non-prescription medications—with their physicians to see if any of them could be contributing to their fatigue, and remaining active."

When it comes to battling fatigue yourself, another F2N2 team member has seen success in a group approach involving other disabilities such as MS.

Dr. Susan Forwell, Associate Professor at the Department of Occupational Sciences and Occupational Therapy at UBC's Faculty of Medicine, reasoned that a similar group approach might work with SCI-related fatigue. With assistance from SCI BC's Peer Program, she developed and recently completed testing of a self-help, energy management group program.

"The goal is to assist participants to better manage and understand their fatigue, and thus to enable improved



"In recent years, we've started to recognize the importance of fatigue for people who are living with SCI. Fatigue after SCI is very common. Research suggests that 57-65 % of the population living with SCI experience fatigue." – ICORD researcher Dr. Andrea Townson

participation in work, meaningful activities, and other life roles,” says Forwell. She explains that group participants learn about their fatigue and self-help strategies within five two-hour weekly sessions.

“Preliminary research testing of the program suggested a beneficial decrease in the impact of fatigue that was retained over a six month follow-up period,” she says. “However, we were unable to determine if this beneficial change was as a result of the program, or due to group effect. As a result of the initial work, future research will involve a control group to see if we can better pinpoint the exact reasons why the approach seems to work.”

For more information about enrolling in the L-Carnitine study, contact Bitá Imam by phone at 604.714.4108 or by email at Bitá.Imam@vch.ca. Watch for updates on Dr. Forwell’s group fatigue program in future issues of *The Spin*. ■

SCI-Related Fatigue: What Do I Do?

Unfortunately, medications are rarely used for physical fatigue unless they specifically treat a particular physical problem like headache or muscle pain.

These are some things that one physician-writer says he might suggest:

- Rearrange your schedule and place important activities at peak energy times; rest during the low times.
- Reduce your physical demands by getting more help, a lighter or power-drive wheelchair, or by cutting out some nonessential activities. Your physician can advocate for you and help you justify the necessary changes to your insurance company.
- Increase the amount of rest you get.
- Consider whether exercise, diet, sleep, and/or stress management might be helpful. Physical activity is necessary no matter how bad the fatigue gets; otherwise, you’ll get even more out of shape, lose more strength, and the problem will only get worse.
- Focus on quality of life. Set goals for yourself, and put your energy into the things that are most meaningful and rewarding to you. Is dressing independently really more satisfying than spending time with your friends, family, grandchildren?
- If you’ve lived with SCI for a fair number of years and fatigue is a part of your life, make your physician, your other health care providers, and those around you take you seriously. Most important, you need to take your fatigue seriously. Following through on the changes that are needed to reduce your fatigue will be up to you. Only you can halt what could otherwise prove to be a predictable downward spiral.

— from the website of Craig Hospital, Denver, CO

Movie Review: *The Intouchables*

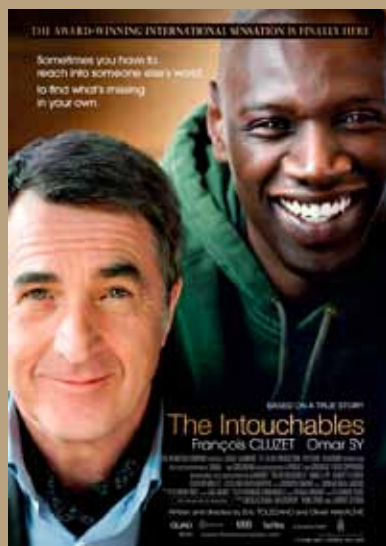
Inspired by a true story, *The Intouchables* is a comedy-drama centered on the close friendship that develops between Philippe, an affluent quadriplegic living in Paris, and his caregiver Driss. When Philippe interviews for a new caregiver, Driss—a down-on-his-luck street thug—applies for the job but is only going through the motions for the sole reason of retaining his welfare benefits. Philippe, however, is intrigued and hires Driss. There follows a series of interactions that make light of almost every aspect of spinal cord injury; at first the comedy is at the expense of Driss, but later Philippe is just as often the target. Over time the relationship—and the film—transitions from that of quadriplegic and caregiver to two friends. Huge changes in both men’s lives are brought about because of that friendship.

François Cluzet is very convincing as a quadriplegic and especially compelling as Philippe considering he is acting only from the neck up. A person who is familiar with SCI will immediately spot the humour in the interactions between Driss and Philippe, and for an able-bodied person it is Cluzet’s believability that makes the comedy part of the film work. When Driss taunts Philippe about not being able to use his hands, it’s only humorous because Philippe finds it funny

and is so convincing. Cluzet was nominated for Best Actor in the French Cesar Awards for his performance. Omar Sy is likewise very credible as Driss (winning the Cesar award for Best Actor), and when things turn serious both men are as adept at the dramatic aspects of the film as they are the comedy.

It seems contradictory that a movie about a quadriplegic and his caregiver could be a comedy-drama, but filmmakers Olivier Nakache and Eric Toledano have done just that with *The Intouchables*. The movie is quite humorous throughout yet tells a touching story that anyone—able-bodied or disabled—can relate to.

Little wonder *The Intouchables* has broken box office records in France and is considered to be in the running for next year’s best foreign language film Oscar.



- *The Intouchables*
- comedy drama, 112 minutes
- french, with subtitles
- inspired by true story, 2004 documentary “A la vie, a la mort”

Review by Andrew Trevitt, SCI BC volunteer, C6-7 quadriplegia

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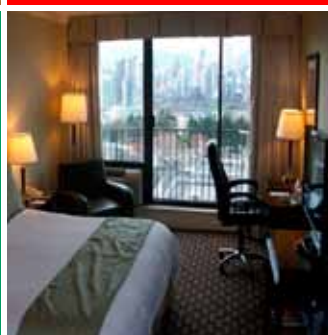
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Reflections on the career of a hard-working assistance dog—and a woman's best friend



By the time his brief career was over, he was more cultured than most Vancouverites. He had seen countless theatrical presentations, lounged in restaurants across the city, and travelled thousands of kilometres—in cars, on trains and once in a helicopter. He was even a successful abstract painter whose work had fetched thousands in an auction for a local charity.

"I was heartbroken when he left," says Sherry Caves.

Caves, a T4 paraplegic, isn't talking about her husband or son. She's talking about Athens, a ten-year-old golden retriever—her former assistance dog.

For seven years, Athens almost never left Caves' side. He pulled her up hills. He picked things up for her. He carried her groceries. He was even the house butler. "He would hear the phone ring for the door—it would be a double ring instead of a single ring—and he'd get up, go open the door and wait for the person

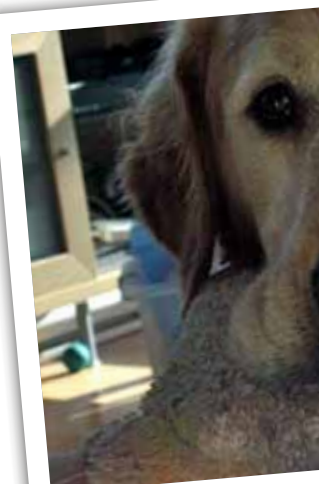
to come up the elevator," says Caves, an SCI BC volunteer and

Peer Mentor.

Used to shadowing her every move every day for years, Athens became an extension of Caves' body. He was her ghost limb. "He felt that my spokes were part of me," she says, "and he just needed to be near me, touching me, all the time. He could anticipate all my moves and he never got in my way. Eventually, you become one. He was my appendage."

Then last year, tragedy struck. Athens and Caves were hit by a car as they were crossing the street. Athens went under the car's front tire, and his hips, shoulders and chest were injured. His pulling days were over. "There were days he couldn't get up because he was so sore, and I couldn't leave him because he's never been left alone, so I had to cancel appointments," says Caves, who sustained only minor injuries. "That's when we knew he was ready to retire."

In November he was adopted by a semi-retired couple in



Salmon Arm. Nine months later, Caves is still getting used to living without Athens by her side. "It was a fun relationship, we just made everything work. It was a huge loss to our family and friends when he retired."

Changing the perception of disability

When Caves and her family first considered getting an assistance dog, their first stop was the Pacific Assistance Dogs Society (PADS), the only certified assistance dog organization in British Columbia.

PADS executive director Laura Watamanuk says assistance dogs can help people with a lot more than just mobility and companionship. "Dogs also break down barriers in regards to other people's perception of disability," she says. "They make some clients feel safer, and their dogs can be a real communication ice breaker."

That's one of the things Caves misses the most about not having Athens around. "Independence, quickness and mobility—that's what he was all about. It deflected a lot of my disability, because when people were seeing me, they were seeing my dog, not my chair."

To illustrate her point, she recalls the many instances in which complete strangers have rushed to provide unwanted help, pushing her up a hill or along a sidewalk without asking. "It really shocks you," she says. "I've spilled my coffee. I've fallen out of my chair. That happened all my life, then I got Athens and it never happened again. I got a reprieve. Now it's back—it happened again on the SeaBus ramp the week Athens left."

No walk in the park

Despite the many benefits of having an assistance dog, Watamanuk and Caves are quick to point out that it's not all roses. "I just want people to know that it's work," says Caves. "Sometimes, with your disability, it's exhausting. But you get even more exhausted by hitting the dog park and doing all the things you need to do for the dog."

The hard work starts even before an assistance dog arrives. During an intense vetting process, applicants must provide details about all aspects of their lives—level of ability and medical history, how much they work, the kind of home they live in, their main form of transportation, and the kind of tasks they need canine assistance with. Potential candidates also have to write a brief autobiography.

Watamanuk explains that this process helps trainers figure out what kind of dog to match clients with. "It's a real evolved process to determine who is placed," says Watamanuk. "It's very important that the dog and client are a strong match."

Fortunately for Caves, the bond

between her and Athens was instantaneous. "It was love at first sight," she says. But that didn't make the two-week team training period that followed any less grueling.

"During team training, you take that dog home with you on a leash and you don't let the leash go for two weeks. You can let it down while you're in the washroom but that dog is in the washroom with you. That's what forms the bond. But it was very draining. You're with the trainer all day, taking in tonnes of information. I was exhausted."

Even once the training was over, Caves says keeping Athens happy and healthy was a lot of work. "They have to go to the dog park to be socialized and the parks often aren't accessible. They have to be clean. They have to have their teeth brushed. They have to get their nails clipped. You're taking them to public places, to restaurants, so they can't smell like a dog."

Caves was lucky, as her husband and son helped with Athens' grooming and poop duties. But not everyone has a family to make it work. Fortunately, Watamanuk says PADS is also there throughout the dog's life to help clients with if they need assistance caring for their dog.

Ultimately, Caves says caring for Athens was a lot like caring for a toddler. "A big, handsome, hairy toddler," she adds with a smile.

When your best friend retires

If your chair breaks down, you can always get a new one. But if your assistance dog is suddenly out of commission, the decision to replace him or her is not a simple one.

Nine months since Athens' retirement, Caves says she's still not ready for a new assistance dog. "My heart is still mending," she says. As a result, it often takes her a lot longer to get around. "I have to think carefully about the routes I take, whereas with Athens I never thought about it. Now I drive more and sometimes I take the Canada Line one stop to avoid hills. You just accommodate."

To honour Athens' legacy, and in recognition of PADS, which spends an estimated \$30,000 in training and care over the course of each assistance dog's lifetime, Caves decided to sponsor the training of a new puppy.

"Because this woman who hit us took one dog out of service," says Caves, "I wanted to put one back in service. Her name is Willow; she's with a puppy raiser out in Mission. She's a yellow lab and she's so cute!"

Caves has no plans to adopt Willow as her new assistance dog, but she likes getting updates on her progress. Meanwhile, she's created a coffee table book of photos to document Athens' life with her and her family. They stay in touch, whenever possible.

"We reunited at Easter and he was so all over me, he knocked me over!" says Caves. "We're so much in love. I'll always be his Mom." ■

For more details on the Pacific Assistance Dogs Society (PADS), visit www.pads.ca.



Partners for Pleasure

A new non-profit organization is teaming up with a new sexual coaching agency to provide companionship and sexual fulfillment opportunities to people with disabilities.

“Sex,” once commented Marilyn Monroe, “is a part of nature. I go along with nature.”

Monroe offered that as if we all have a choice. But with all due respect to the blond bombshell’s memory, sexual desire is not an optional add-on in human beings. We’re all sexual creatures who, to varying degrees, crave sexual intimacy and fulfilment. And that goes for everyone—even people with the highest levels of SCI.

The science of the matter is that our sexuality is controlled in our brains, not by organs between our legs that may or not function normally after SCI. Sexual thoughts and desire, along with other emotions, impulses and desires, are all the results of neurochemical activity that takes place in the limbic system, an ancient part of the brain that lies beneath the cortex. Think of the limbic system as the part of your brain that works tirelessly to keep you alive and reproducing. It does this by helping you avoid pain, and by strongly encouraging you to repeat anything that provides pleasure. Quite frankly, your rational being doesn’t have choice—no matter how hard you try, your limbic system is in full control of your feelings and emotions, including how, when and with whom you fall in love—or lust—with.

On the simplest of levels, denying the limbic system’s continuous demands for companionship, intimacy and sex can lead to loss of well-being, to more extreme depression and a host of other mental and even physical problems.

Yes, we all know that SCI often results in erectile dysfunction and other lovemaking roadblocks. But as most readers know, there’s many alternate roads to Rome, and the ability to achieve an erection or an orgasm is just one aspect of intimacy. No need for a lesson on these pages—the nuances of alternative love-making for men and women with SCI are readily obtainable online, through GF Strong’s Sexual Rehabilitation Service, and through peer-to-peer insight via SCI BC’s Peer Program and other sources.

The pressing question is, what if you’re a person with SCI or another disability who doesn’t have a loving, understanding partner who can help you explore your sexuality?

In Vancouver, two unique organizations—one a not-for-profit advocacy and education organization, the other a for-profit sexual coaching service—are teaming up to help create better access to sexual and intimacy opportunities for people with SCI and other disabilities.

EASE, which stands for Equitable and Accessible Sexual Expression, is a new organization with decade old

roots, according to one of its founders, Dave Symington. “Sam Sullivan and I originally discussed the idea around 2002 to help address the needs of younger adults who were injured before ever experiencing dating, relationships and other forms of intimacy,” says Symington, a counsellor and disability rights activist who is quadriplegic. “Of course, we soon realized that this also applies to some adults who have never experienced relationship or physical intimacy.”

Terry LeBlanc, a SCI BC board member who is also quadriplegic, got involved in the discussion. “Dave and I had been experiencing feedback from peers who felt that telehealth sessions on sexual health were almost painful because of a lack of intimate touch in their lives,” says LeBlanc. “Sexuality seems to be stripped from you with the onset of a sudden disability. And it predominantly happens to young adults in the prime of life.”

Over the next few years, Symington continued working on the concept. He wrote reviews of the existing kinds of sexual services available—for example, tantric massage, escort agencies, and massage parlours—and researched sexual surrogacy and facilitation success stories that had been emerging for people with disabilities in other countries. Finally, in 2009, Symington and

LeBlanc achieved critical mass when they were joined by a group of influential and knowledgeable volunteers, including Vancouver madam and sex worker rights activist Scarlett Lake, BC Compassion Club Society co-founder Rielle Capler, and sex trade educator and human rights activist Kerry Porth. A committee was formed and the organization slowly but surely eased into formal existence, with partnerships soon forming with other agencies, activists and advocates. Advice was also sought from like-minded organizations around the globe that have been in existence for some time—for example, the TLC Trust in the UK and Touching Base in Australia (see sidebar).

“The fundamental principle or philosophy behind EASE is that persons with disabilities are recognized as sexual beings and that sexuality is a vital part of everyone’s identity,” explains LeBlanc. “We’re based on the premise that meaningful and caring touch and intimacy are important contributors to our happiness,” adds Symington.

EASE’s founders had always envisioned the organization playing an advocacy and education role. But that wouldn’t be enough—the central premise was somehow to actually connect people with disabilities to trained, disability-sensitive sexual surrogates, coaches and escorts. In a stroke of synchronicity, just as the organization pondered the considerable work needed to get such a service off the ground, Symington and LeBlanc learned of Sensual Solutions—a fledgling sexual coaching agency in Vancouver that was developed to specifically provide companionship and intimacy coaching to people with disabilities.

A meeting with Trish, Sensual Solutions owner and “Director of Pleasure”, was quickly arranged.

“The relationship with Sensual Solutions came about at the exact time we were debating how to get a similar service off the ground,” says LeBlanc. “Trish had identified a niche not being filled by regular escort agencies.”

“It was clear to us,” says Symington, “that Sensual Solutions was on the same wavelength, in terms of awareness and sensitivity to disabilities, function, and alternate forms of pleasure.”

The idea for Sensual Solutions germinated as Trish was working part-time doing bookings for a Vancouver escort agency. “I noticed that some gentlemen with disabilities would call us to book an escort,” says Trish. “While some of our escorts would see these clients, most were concerned that they could not provide adequate service. The gentlemen who called would tell me horror stories about their experiences in the past with working girls who would rob them, or have their boyfriend rob them, or collect money from the client and then take off—terrible, terrible scenarios that just tore at my heart.”

Trish saw an opportunity to make a difference. The agency she worked for wasn’t interested in focusing on that particular market segment, so she forged ahead with some research. She assembled a focus group of men

with disabilities to find out about their experiences and desires. And she searched online for success stories. “I found some good examples of similar services happening around the world—one in Israel, one in Germany and one in Australia—of forward-thinking people who are doing similar work,” she says. “It was evident that the time has come—there is a shift in thinking and it’s all very exciting.”

Earlier this year, she launched Sensual Solutions, which she describes as “a business devoted to provide coaching and education to men, women, and couples with physical challenges and disabilities.”

A quick tour of the company’s website at www.sensualsolutions.ca provides an overview of the services provided and their costs, the company’s ethos, and the “sensual coaches” who work for the agency—at the time of writing, five women and one man who is comfortable working with women and men.

“The fundamental philosophy behind Sensual Solutions is that every human

Scarlet Road

Scarlet Road is an Australian documentary that showcases the powerfully beneficial aspect of sex work as it relates to disability. It chronicles the career of Rachel Wotton, an Australian sex worker who specializes in working with clients with disabilities. The film focuses on Wotton’s conviction that human touch and sexual intimacy are highly therapeutic and necessary for all human beings regardless of ability, and the two clients who are also profiled in the film, Mark and John, provide powerful testimonial of Rachel’s impact in their lives.

John, who has high level paralysis from MS, has regained body movement and self-esteem that he thought was lost forever. Mark, who has severe cerebral palsy, had long-dreamed of an intimate relationship, something that has been difficult to achieve. Through therapy provided by Wotton, he has achieved fulfillment and self-love.

“I don’t have a girlfriend,” Mark says in the film, “so I can’t share my feelings with just one person. Rachel makes me feel like I have a girlfriend.”

In following Wotton’s work with John and Mark, the film illustrates her commitment to increase access to sexual expression for people with disability—and to gain rights for sex workers and end the social stigma that surrounds their occupation. The film also deals with Wotton’s pursuit of a Master’s degree in Sexual Health from the University of Sydney, and her work to help establish Touching Base, a charitable institution based in Sydney that seeks to connect people with disability and sex workers.

For more information on *Scarlet Road*, visit www.scarletroad.com.au. For more details on Touching Base, visit www.touchingbase.org.



being has the right to experience self-love, intimacy and pleasure regardless of injury or challenge," says Trish. "Our branding message is, 'Enjoy your whole life!'"

She says that the response has been good right out of the gate. "Our clients have been lovely gentlemen who have told us that the concept is refreshing and needed. Their challenges have ranged from SCI to stroke and cerebral palsy. Meanwhile, I have been contacted by sexologists who are very enthusiastic to see this new service available, and by very interested body work practitioners who are also delighted with the concept. Everyone says the same thing: 'It's about time.'"

So what exactly does Sensual Solutions provide? And is it legal? "Firstly, let me say that Sensual Solutions does not sell sex," says Trish, pointing out that Sensual Solutions, similar to escort agencies, is lawfully licensed by the City of Vancouver. "Selling sex is illegal. However, prostitution is legal in Canada—a person can be paid for sex. The illegal part is everything surrounding the transaction, which includes pandering, advertising, communicating, living off the avails of, operating from a location—a common bawdy house."

She explains that sensual coaches are only available by booking via telephone or internet for visits in the client's own home or hotel room. This is known as an "out-call" and doesn't break any laws, since the booking doesn't constitute public communication and the client's home is not a bawdy house because it isn't "regularly" used as one.

Trish points out that the fundamental difference between Sensual Solutions and an escort agency is the nature of the services offered. "While an escort is paid to provide expensive social companionship which usually leads to consensual intercourse, a Sensual Solutions coach works with the client to explore and discover new ways of self-pleasure. It's about learning through trial and error how to rewire the brain so that the client experiences pleas-

ure in non-traditional ways. It's about firing off endorphins and dopamine and all that good brain stuff through new techniques. And it's fun!"

She concedes that consensual sex may be a possibility, but if it happens, it's beyond the scope of Sensual Solutions. "If anyone wants to purchase intercourse then that is something between the two adults involved and is outside the realm of our services," she says. "All our coaches choose their own form of work, and what they will do or not do in any given session. There is absolutely no way to guarantee any specific activity; however, the goal is to bring each client to an oasis of pleasure."

Central to the company's approach is its staff. "To be a Sensual Solutions coach, he or she goes through an application process and interview. I want adult women and men who have empathy first of all, and then I look for a health care background such as a personal care aide, nurse, or nursing assistant, or body work background such as a tantric practitioner, massage therapist or social escort. I am amazed by the number of applications I receive from people, who are not sex workers, and who have such compassion and enthusiasm for this service."

Trish says there is currently no formal training or certification provided, but she is discussing possibilities with GF Strong's Sexual Health Department. And she also sees a great deal of potential with her company's new relationship with EASE.

"The ongoing role of EASE in relation to Sensual Solutions is still in the brainstorming phase but we have discussed having EASE as a resource for us—for example, to provide orientations for our coaches and possible training for those coaches who would like to feel more at ease with some scenarios like spasticity, colostomy bags, and so on."

And it's training, says, LeBlanc, that is critical. "During our initial information gathering roundtable with sex trade workers, we heard from working girls who balked at dates with persons

with disabilities," he says. "I can only imagine how the clients must have felt. This should not happen if the worker is properly screened and trained."

While Symington and LeBlanc are enthusiastic about the potential of working closely with Sensual Solutions, they point out that the relationship is not exclusive. "I see the role of EASE as linking potential clients with screened and trained sex workers—and of course making sure that the workers are not exploited," says Symington. "Sensual Solutions is not the sole provider, and instead is just one resource. We will continue exploring partnerships with other like-minded services with the goal of providing safe choices for the people who come to us seeking assistance."

What about criticism? So far, neither EASE or Sensual Solutions has had any type of negative responses.

"We haven't had anyone say that physically disabled adults shouldn't be allowed to experience personal pleasure and self-love," says Trish. "But I'm sure someone will say it at some point. The service we are providing comes from a place of educational and experiential, with respect and dignity—it's allowing adult men, women, and couples the opportunity to realize their full humanness. There is so much research showing the positive health benefits of pleasure and brain function and potential health care cost savings. How can this be a bad thing?"

"There are people with disabilities who would never get to explore their sexuality, or revisit their sexuality, if not for the men and women who work in this field," says LeBlanc. "EASE will endeavor to make it safer for everyone by providing training and screening. Our SCI peers need to have an open mind. If it's not for you, it's not for you. It's certainly not for everyone, but all things considered, it's great to have choice." ■

For more information about EASE, visit www.facebook.com/easecanada?ref=hl or email easecanada@gmail.com



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WORK SAFE BC

The Blusson Spinal Cord Centre: In Praise of Centralized Care

We're told by many of our peers that Vancouver Coastal Health's Blusson Spinal Cord Centre and its Brenda and David McLean Integrated Spine Clinic have greatly improved their lives.

One of these peers is Lori Slater, Fort St. John Volunteer Peer Program Coordinator. "The Blusson Spinal Cord Centre has made things so much easier for me and many other people with SCI living outside of Vancouver," says Slater. "They really understand SCI and work together with you to come up with the best plan for you."

Slater was born with spina bifida. In 2005, she was told that she would have to become a full-time wheelchair user. At that time, travel to Vancouver to receive medical care became a regular event for Slater and her supportive husband, Bob.

"Because of my condition we have to travel to Vancouver at least five times a year for medical care," says Slater. "But the Blusson Spinal Cord Centre has made things so much easier for us, as we no longer have to travel all over town. Now, when I come to Vancouver I usually get my appointments all in a single day as the staff do their best to make it work for us."

Not only has the Blusson Spinal Cord Centre cut down the amount of travel Slater has to do, it's also

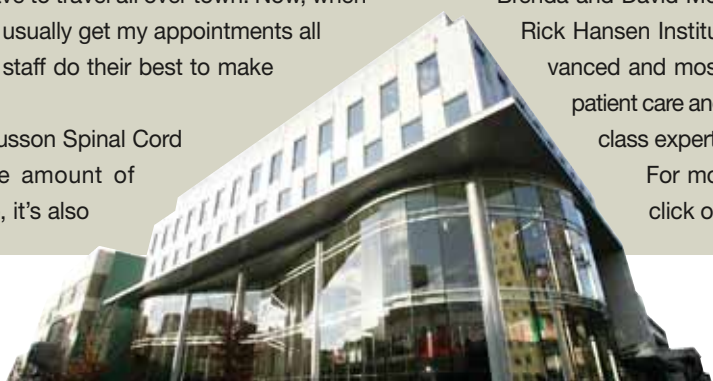
reduced the cost of her trips as the couple no longer needs to stay as many nights away from home.

Another positive for Slater are Blusson's doctors and clinicians. "The staff at the Centre are wonderful. My last visit down was to see one doctor, but after all was said and done, I was able to see three! I credit that to the doctors all being in one place and being able to quickly consult with each other as well as with me."

Slater recommends others to embrace the services provided by the Blusson Spinal Cord Centre. "I am so glad it's there," she says. "It makes life so much easier for people with SCI, especially those travelling from out of town. Keep up the great work."

The \$45 million Blusson Spinal Cord Centre was officially opened in November 2008. The Centre is a unique facility dedicated to advancing world-leading integrated research and care for people with SCI. The Blusson Spinal Cord Centre is home to ICORD, The Brenda and David McLean Integrated Spine Clinic, and the Rick Hansen Institute. It is the world's largest, most advanced and most comprehensive facility dedicated to patient care and research—patients can access world-class expertise in all fields within the one building.

For more information, visit www.vch.ca and click on the "locations & services" tab.



Lady of the Rings

Vernon curler extraordinaire Sonja Gaudet is already dreaming of 2014 and a third Paralympic gold. In the meantime, she's doing all she can to get other wheelchair users out on the ice.



Sonja Gaudet is one of Canada's most celebrated Paralympians. As lead of Canada's wheelchair curling team, she played a huge role helping our rink capture gold medals in the 2006 and 2010 Paralympic Games. She and her teammates added gold medals in the 2009 and 2011 World Championships.

Along the way, she refined a game-changing piece of equipment—a self-designed “balance post” made from aluminum that's attached to her wheelchair and allows her to sit up straight when she delivers her rocks, greatly improving her accuracy. The innovation earned her the nickname of “The Brain” in curling circles.

But Gaudet, who became spinal cord injured in 1997 during a horseriding accident, is hardly resting on her laurels.

She recently kicked off her annual eight month intensive training regimen consisting of three ice sessions and two gym sessions per week. This year, she'll average about 40 days away from her husband and two teenaged kids to participate at training camps and international competitions.

“Right now, I'm one of twelve athletes who are trying out for a spot on the national team for our world championships in 2013, which will be in Sochi, Russia,” says Gaudet. “The hope and plan is to secure my spot as lead on the team right through to the Paralympics in Sochi 2014.”

High level competition, however, is only one of Gaudet's curling passions. She's also deeply committed to promoting the sport and encouraging other wheelchair users in the Okanagan and across the province to grab a rock and get in the game.

“Last year, with funding through Curl BC and the Canadian Curling Association, we held three novice wheelchair curling clinics across the province,” says Gaudet. “The results were great. We had good numbers attend each camp and from those camps we now have individuals very interested and enrolling in their community leagues and getting out on practice ice. A group in the Okanagan are very keen and I'm sure we'll see them entering the provincial playdowns in 2013.”

Gaudet adds that there are plans to continue with clinics this season. “Not only will we offer a ‘day one’



novice clinic, but we're excited about taking the participants from last season into a 'day two' clinic," she explains.

What makes curling so unique in the world of wheelchair sports is that integration is so easy, says Gaudet, who, along with her national teammate Ina Forrest, curl on able-bodied teams in regular leagues at the Vernon Curling Club.

"If you're a sport enthusiast and you're looking for something to do—to get out, have fun, get active and get involved—try the sport of wheelchair curling. It's a sport that you can enjoy together with your friends and family. As an individual, you can participate in the able-bodied curling leagues in your community—you don't have to wait around for three other people in wheelchairs to form a team. One person in a wheelchair can play on a team with their able-bodied teammates with minimal adaptations. Of course, if you have a team of four wheelchair curlers, by all means enter as a team and challenge the others!"

SCI-BC is pleased that Gaudet has brought her leadership abilities and other skills to a part-time position as Regional Peer Coordinator in Vernon. Visit our website at www.sci-bc.ca to stay abreast of peer events in Vernon, and in other regions throughout the province. Meanwhile, for more information on wheelchair curling opportunities, visit:

- Curl BC - www.curlbc.ca
- Canadian Curling Association - www.curling.ca
- Canadian Paralympic Committee - www.paralympic.ca ■



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Wasted Opportunity?

Canada's Registered Disability Savings Plan is almost too good to be true. Despite that, reception and uptake has been lukewarm to date.

When the Registered Disability Savings Plan—RDSP for short—was introduced in 2008, SCI-BC and many other organizations that provide services for Canadians with disabilities were ecstatic. It was immediately clear that this tax-assisted, government-sponsored savings plan could really make an impact and provide some financial security for people with SCI and other disabilities as they age.

Almost four years later, we're wondering what's gone wrong. The latest statistics (March 31, 2012) show that only some 56,000 Canadians have taken advantage of the RDSP—at best, not much more than ten percent of the people who qualify. Meanwhile, the average plan value sat at just under \$10,000.

This is a sad situation, because this program is incredibly generous—particularly for people with low incomes or low family incomes. For example, if you're in this category, you can contribute just \$1,500 a year and the federal government will kick in a grant of \$3,500. Not only that, if you're in the lowest family income bracket, the federal government will sweeten the pot with a \$1,000 Canada Disability Savings Bond—that's \$4,500 in grants and bonds for just a \$1,500 yearly contribution. And if you can't afford to make any contribution in a given year, you'll still receive the \$1,000 bond. Note that all federal contributions must remain in the plan for ten years.

What's the catch? Well, there isn't one. This is made clear in a comment by a reader responding to a CBC News story on the RDSP which aired last December. "(I've gone) from \$0 to nearly \$26,000 in four years in my RDSP," wrote Gravff Itti. "The magic number is \$1,500 per year. No more, no less and this will give you the maximum in government bonds and grants. If one

can save, scrape, scrimp, borrow \$125 per month and reach \$1,500 per year, that \$1,500 turns into \$6,000 with government bonds and grants. I now have more money saved than at any time in my working life. Nothing on earth gives a return on investment like the RDSP. And being disabled, I totally get how hard it is to come up with \$125 per month, but it's well worth it."

When it comes to the point where you'll be taking money out of an RDSP, the news is equally good. Only the portion of the withdrawal derived from grants, bonds

What is an RDSP?

An RDSP is similar to an RESP (Registered Education Savings Plan), in that contributions to the plan are not tax-deductible, but the income inside the plan is allowed to grow on a tax-sheltered basis until funds are withdrawn. The RDSP allows any Canadian citizen who is under the age of 60 and eligible for the Disability Tax Credit to invest up to \$200,000 in savings. Family members and friends can also contribute to that person's plan. These contributions are further bolstered by federal grants and savings bonds that provide up to \$4,500 a year of direct assistance to a lifetime total of \$90,000, depending on income. The money can really add up: for example, assuming a modest 4% annual yield, a low-income family contributing \$1,500 a year for 20 years and receiving the maximum \$90,000 of federal grants and bonds in that time could have \$400,000 after 30 years (remember, all federal contributions have to remain in the plan for 10 years).

More information on RDSPs is available from financial institutions, the Canada Revenue Agency website, and various advocacy groups including www.plan.ca.

and growth is taxable. The part derived from contributions is not taxable. More importantly, payments do not reduce the beneficiary's entitlement to any federal income-tested benefit, such as the child tax benefit, the federal sales tax credit or the Guaranteed Income Supplement. And, like most provinces, BC has a full exemption of RDSP income and assets from provincial income-tested support programs.

So what's the problem? Lack of awareness is a huge hurdle, says Joel Crocker, Director of Planning at the Planned Lifetime Advocacy Network, a Vancouver-based non-profit group that played a major role in lobbying for the creation of RDSPs. "We still regularly meet people with disabilities and their families who have never heard of the RDSP, or know very little about it."

Other problems, adds Crocker, include a lack of money to save, the program's complexity, misconceptions



surrounding loss of other benefits if the program is applied for, and lack of incentives for financial institutions to promote the RDSP. "We have heard feedback of bank staff in fact discouraging opening, giving misinformation and even not knowing about RDSPs at all," says Crocker.

He believes there are a number of ways uptake could be improved, with a focus on information and awareness being key. For example, he thinks that the federal government should increase and promote RDSP informa-

tion sessions, and that government and financial institutions should more aggressively market the RDSP. "So far," he says, "there have been little or no TV ads."

He also believes that a great deal of red tape could be cut out of the application process for both the disability tax credit and the RDSP, and that people with disabilities should have more resources in place to support their applications.

Here at SCI-BC, we agree with Crocker's assessment. We're going to do our part to help promote awareness of the RDSP (thus this article).

As if you needed more to act on this golden opportunity, here's one final kick in the pants. Ottawa also allows a 10-year carry forward of unused grant and bond entitlements. This means that, even if you've been missing the boat for the past four years, you can claim unused grant and bond money going back to 2008.

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Cranberries Revisited

It turns out that cranberries' benefits for urinary health aren't just another old wives' tale

Consuming cranberry products can reduce the risk for urinary tract infections (UTIs), according to a recently released meta-analysis.

Dr. Chien-Chang Lee of the National Taiwan University Hospital and colleagues studied data from nine trials involving 1,175 individuals. Studied as a whole, the data reveals that cranberry consumption could reduce the risk for UTIs by 38% overall and by 51% in women, according to the researchers.

"Cranberry-containing products tend to be more effective in women with recurrent UTIs, female populations, children, cranberry juice drinkers, and people using cranberry-containing products more than twice daily," say Lee and his colleagues.

The authors found that cranberry juice was more effective than cranberry supplements. They suggest that this could be due to better hydration practices in those consuming juice, or that there might be an as of yet unidentified substance in cranberry juice that's not found in supplements. But they concede that capsules might be a better option for anyone with diabetes avoiding sugar, or for anyone who experiences negative gastrointestinal side effects from consuming large volumes of juice.

The authors also caution that their analysis is limited by the fact that the products used in the trials differed significantly in form and dosage. More importantly, they say that only three studies reported the A-type proanthocyanidin (PAC) content, a flavinoid that is thought to play a significant role in any beneficial effects of cranberries.

The exact mechanism by which cranberries can prevent UTIs is unknown. However, PACs have been clinically demonstrated to attach to E. Coli bacteria (responsible for most UTIS), preventing the bacteria from attaching to the walls of the urinary tract or bladder.

Lee and his colleagues suggest that in future PAC contents should be specified in trials to differentiate their effects. They also call for more dose-response studies to determine optimal dosing. One such study is currently underway.

Results of the meta-analysis recently appeared in the *Archives of Internal Medicine*. "The results of the present meta-analysis support that consumption of cranberry-containing products may protect against UTIs in certain populations," conclude the authors. "However, because of the substantial heterogeneity across trials, this conclusion should be interpreted with great caution."

So what does this mean for people with SCI? Well, none of the studies included in the meta-analysis dealt with SCI. So there's nothing conclusive to be gleaned from all of this. But it seems reasonable to conclude that cranberry useage may have some beneficial effects.

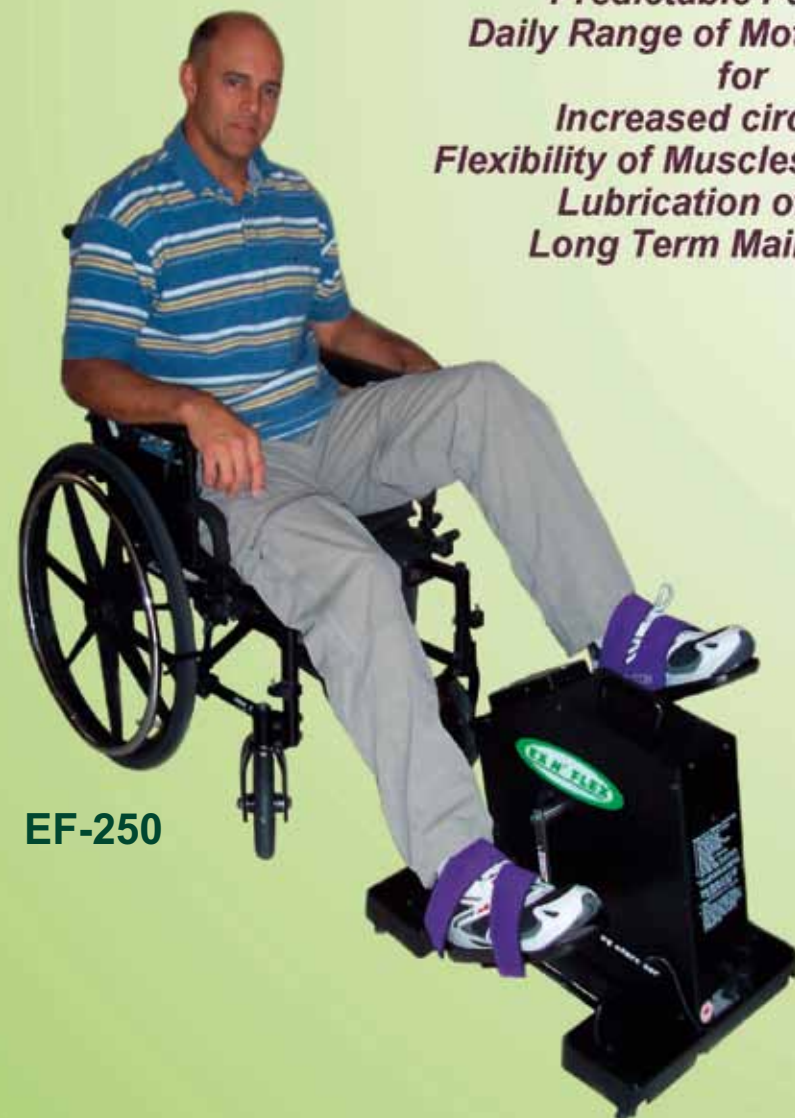
And given that cranberry juice is a healthy, refreshing drink for those who have no dietary issues with sugar, why not consider adding a glass or two a day to your daily fluid intake? ■



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