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*Cover Photo by Candice Vallantin*
White Paper: A Golden Opportunity

What would it take to make BC the most progressive place to live for people with disabilities? The Government of BC wants to know, and they asked for your help to answer the question. Through the Ministry of Social Development and Social Innovation’s Disability White Paper Process, British Columbians have been invited to submit their ideas on how government, businesses and communities can increase accessibility and decrease barriers for people living with disabilities. The consultation phase started in December 2013 and ended on March 11, 2014. It involved community consultation sessions in cities and towns throughout the province, an online discussion forum, and direct submissions to government.

SCI BC contributed to the process in many ways, including as Community Champions who helped facilitate several community consultation sessions throughout the province. We also submitted our ideas about how to decrease barriers, increase accessibility, and enhance community participation.

Sound underwhelming? Maybe, but a White Paper can be an important foundation for changes in government policy and action. How? Wikipedia describes a White Paper as “an authoritative report or guide helping readers to understand an issue, solve a problem, or make a decision.” They are tools for participatory democracy, helping government incorporate public opinion into their policy.

At the outset, it sounded like a bit of stretch to think the process would be a meaningful one. After all, how many times does the disability community need to be consulted before any meaningful changes are implemented?

However, I, along with other members of SCI BC’s staff, were pleasantly surprised by the disability community’s willingness to be constructive contributors to the process. Sure, there was some griping at the consultation sessions (how could there not be?) but overall, people were eager to contribute ideas for change.

The catch with all of this is that any changes that do result from the process will be those that do not require new money to be thrown into the pot—government has deficit and debt challenges that suggest this will not happen. Instead, changes will see money used more effectively to meet the challenges.

What are those changes? Who knows, but we think there can be wins with respect to easily addressed policies relating to the province-wide adoption of an accessible housing building code for all new construction, individualized funding for supports that are more secure and portable, and better options that support independent community living.

It’s naïve to think that the Disability White Paper process will lead to all the changes needed for making BC the most progressive place for people with disabilities to live. That would require a massive deconstruction and rebuild of our structures and systems. However, it’s not unreasonable to think that some positive change will arise out of the process. SCI BC will continue to help push for that and so should all British Columbians.

It’s early in the process. The White Paper itself will be developed and there will be a Summit in June during which short, medium, and long-term strategies and action plans will be developed. Sound like a lot of talk? Yes. But at least there is talk, and at least it has involved talk from the disability community. Now, the key question is: has there been enough listening?

Chris McBride, Executive Director, SCI BC
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WHILL TYPE-A
Designed by a Japanese team of former Sony, Toyota, and Olympus engineers, the Whill Type-A is a fresh take on the power wheelchair. The startup company based its design on interviews of 150 American wheelchair users, concluding that they wanted stability, nimbleness, and a less-clinical look. The finished product allows users to sit in different positions—for example, one position allows users to look and feel like they’re riding a motorcycle. Special front wheels that incorporate rollers give the chair an impressive 28 inch turning radius, while still allowing it to navigate rough terrain. Atsushi Mizushima, Whill’s director of business development, says he hopes the Whill Type-A will ultimately be “the iPhone of mobility devices.” The chair will be available in the USA later this year. Visit www.whill.jp for more details.

PDG ELEVATION
The Elevation wheelchair, designed by Vancouver’s Dr. Jaimie Borisoff, uses a unique hydraulic system to elevate users for better interaction or reaching ability. Borisoff, a Paralympian basketball player and SCI researcher, spent four years designing and researching Elevation. Recently, Vancouver’s PDG Mobility completed its purchase of the Elevation technology, and the chair is now commercially available. You can learn more about it at www.pdgmobility.com. You can also read more about Borisoff and his views about the role technology can play in improving life for people with SCI on page 16.

MOBILITY MOUNT
After he was injured in a 1995 workplace accident, SCI BC board member Gerry Price began creating wheelchair mounts for various purposes. His latest product is the Mobility Mount, which uses an under-seat base constructed from anodized aluminum, which is connected to a multi-table with a nonslip surface that holds whatever you need held, including your iPad or other tablet. The system can also hold a camera mount, an umbrella, a shopping basket, and fishing rod holders. For more information on the Mobility Mount and other wheelchair mounts and holders, visit www.mobilitymount.com.

CONVERTASTEP
ConvertaStep is an incline wheelchair lift that offers an easy, instant, construction-free ramp alternative for any raised entrance, inside or out. Constructed of heavy, weather-coated steel, the ConvertaStep can smoothly lift wheelchair and user up to 350 kilograms. It comes in three sizes to offer an adjustable height range from 11 to 33 inches. The highest model lifts to 33 inches in less than 15 seconds, and moves the user forward to span from one to five standard steps. It’s 31 inches wide, and can therefore accommodate most manual and power chairs. The lift is inconspicuous and can be painted to blend easily with any home decor. Each unit comes with two remote controls, and runs on a 12 volt battery which is maintained through a charger which plugs into a standard 110 volt outlet. This American-made product is sold in Canada by Wolfe Mobility—visit www.wolfemobility.ca for more information.
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Join SCI BC’s Walk ‘n Rollers on June 22 for our third annual Scotiabank Charity Challenge. We’ve been selected as a Featured Charity this year and we need you to help us make an impression! Whether you want to walk, run or roll in a manual or a power chair, we’re excited to have you and your friends and family join our team. Contact Kirsten at ksharp@sci-bc.ca or 604.326.1259 if you’d like to walk or roll for our cause.

Fashion statement.
Three of our peer members will wheel down the catwalk on April 24 at the River Rock Casino in Richmond during the graduation show of Kwantlen Polytechnic University’s fashion design program. Designer Kaylyn MacKenzie is dedicated to making functional and beautiful adaptive apparel, and our peers are excited to present her work to the world. Contact Kirsten for details: ksharp@sci-bc.ca or 604.326.1259.

World-class rugby.
From June 19 to 21, the world’s best wheelchair rugby players will compete in the 2014 International Wheelchair Rugby Canada Cup at Richmond’s Olympic Oval. The top ten teams in the world will vie for top honours, including defending Canada Cup champion USA. Spinal Cord Injury BC usually has a few extra tickets on hand, so get in touch if you would like to attend. Visit www.canadacupwcrugby.com for details.

Disability Parking: Some Perks You Might Not Know About
If you have a valid disability parking permit, you’re obviously well within your rights to use disabled parking stalls at shopping centres, and a variety of public buildings and facilities. But did you know that the City of Vancouver has other parking benefits for people displaying a valid parking decal?

For example, you can park for three hours for free at parking marked “Resident Permit Parking” or “Resident Parking Only” even if you don’t have a residential parking permit.

Also, with a valid permit, you can park in City of Vancouver designated disabled parking zones, and accessible parking meter spots.

You can also park for 30 minutes while actively loading or unloading people or materials in regular loading zones, passenger zones, and no parking zones.

The Social Planning and Research Council of BC (SPARC BC) issues parking permits for people with disabilities who are residents of BC. To learn more about applying for a permit and what it entitles you to, please visit www.sparc.bc.ca.

For more information about Vancouver’s exemptions for valid disability parking permit holders, visit www.vancouver.ca/streets-transportation accessible-parking.aspx. And if you don’t live in Vancouver, contact your local city hall to see if your community has any such exemptions.

Meanwhile, we know that abuse of designated parking spots for people with disabilities continues to be a hot issue. SPARC BC is working on the problem, and has set up a new hotline that you can call to report violations in Vancouver and throughout BC.

The hotline number is 604.718.7734. When you report a violation, SPARC BC will in turn contact the appropriate authorities and attempt to have the violator ticketed.

One final note: remember that tourists visiting our province can use their legally-issued handicapped parking permits while in BC. Tourists are encouraged, however, to carry proper documentation to verify ownership of a parking permit, since they vary from country to country and aren’t always recognizable.

There’s a great alternative for visitors who want to avoid any problems. SPARC BC issues temporary parking permits for visitors with disabilities. For details, visit the SPARC BC website at www.sparc.bc.ca, call 604.718.7733, or email info@sparc.bc.ca.
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**WEB:**
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Regular readers of The Spin know that we like to write about pain. Life with any type of level of SCI is no picnic, but to have severe neuropathic pain as a constant companion to paralysis, as is the case for many of our readers, just seems like a gross injustice. That’s why we’re always on the lookout for promising research in this area.

Late last year, we learned about some fascinating results from a decade-old research effort led by Dr. Riyi Shi, a professor of neuroscience and biomedical engineering in Purdue University’s Department of Basic Medical Sciences, School of Veterinary Medicine and Weldon School of Biomedical Engineering. The results were published in the November 29th issue of the Journal of Neurochemistry.

The essence of Shi’s work is that a well-known neurotoxin called acrolein appears to be one of the culprits behind the
often excruciating neuropathic pain that many people with SCI live with. Additionally, and perhaps more importantly, a drug already approved by the FDA neutralizes this neurotoxin, reduces the neuropathic pain, and is therefore a potential treatment.

A word of caution: as with a great deal of SCI research, this body of work has been conducted only in animal studies. But it’s still promising, and because the drug involved is already being used successfully and safely for other conditions, it may be possible to move it quickly into human clinical studies for a neuropathic pain application.

So what is acrolein? It’s a highly toxic compound that can be found all around us in the environment, and also inside of us. For example, it’s produced when many foods such as vegetable oils and animals fats are heated, and it’s also in cigarette smoke and vehicle exhaust. Industrially, it’s actually produced in large quantities, often for use as a herbicide to control water-based weeds and algae. Scientists have also known for some time that acrolein is produced inside the body as the result of a process called oxidative stress.

We couldn’t live without oxygen—our bodies combine it with the food we digest to essentially power vital life functions. But where there is oxygen, there is also the possibility of oxidation. When you see rusting iron, for example, you’re actually viewing oxidation in action—the process by which free oxygen radicals “steal” electrons from the iron atoms and damage them in the process. This process also occurs in our bodies throughout our lifetime—it’s one reason why we age. Inside our bodies, we refer to this process as oxidative stress.

Oxidative stress is largely kept in check in a healthy person by antioxidants. But it can be accelerated by elevated levels of free radicals. When this happens, it can have devastating results. Research to date implicates oxidative stress as a contributing factor in more than 70 well-known diseases, including heart disease, cancer, Parkinson’s, diabetes, and Alzheimer’s. And there’s long been an acknowledgement that elevated levels of oxidative stress increase the severity of an SCI in the days and weeks that follow the initial trauma, which leads us to Shi’s research.

“It’s well known that oxidative stress and free radicals are important pathological mechanisms related to SCI,” says Shi. “However, strategies aimed at reducing free radicals alone have only demonstrated marginal benefits. This is why we were motivated to identify more important targets for therapies in oxidative stress.”

Shi and his team knew that acrolein was produced by a specific type of oxidative stress known as lipid peroxidation. Lipids are molecules that our bodies use for a variety of purposes, including forming cell membranes. During lipid peroxidation, free radicals “steal” electrons from lipids in cell membranes. Not only does this cause damage to the cells, it results in the production of acrolein.

They also knew that trauma to nerve cells has been demonstrated to trigger lipid peroxidation, and, in turn, produce acrolein. And they recognized that acrolein causes a chain reaction of biochemical events thought to worsen the injury’s severity, perpetuate the oxidative stress, and produce even more acrolein—truly a vicious biochemical circle. Therefore, they set their sights on better understanding the role of acrolein in SCI.

In a series of experiments with rats, they confirmed that the quantity of acrolein present in the body increases by an astonishing 300 percent immediately following an SCI. But they discovered much more.

“It turns out that acrolein is a very important compound behind neuropathic pain,” Shi says.

Their findings suggest that the increased levels of acrolein bind to and activate pain receptors called TRPA1, which are contained in pain-sensory nerve fibers of dorsal root ganglia located alongside the spine. In fact, the elevated levels of acrolein after an SCI resulted in a three-fold increase in the number of TRPA1 channels.

“The amplification of pain can be exacerbated in SCI due to acrolein’s direct activation of pain receptors, as well as acrolein-induced inflammation that further intensifies pain sensation,” Shi says. “Sometimes you have pain even without stimulation. You can have excruciating pain just sitting there.”
With new evidence that acrolein is at least in part responsible for neuropathic pain following SCI, Shi and his team then moved on to finding some way of limiting it after injury. They focused on hydralazine, a drug that was already known to be an “acrolein scavenger.”

“The reason we tried hydralazine is because other scientists have already shown it could bind and neutralize acrolein, particularly in liver cells,” Shi explains. “It turned out to work very well.”

Shi’s work with hydralazine involved measuring a treated rat’s reaction to stimulation, and demonstrated a significant reduction in neuropathic pain that corresponded with the reduction in acrolein. And there’s more—they also discovered that hydralazine treatment also resulted in significant reduction of post-SCI tissue damage and motor deficits.

All of this might sound like hydralazine is effective only in the short period of time after injury—the acute phase of injury. But Shi says it also has promise as a treatment for neuropathic pain in people who have been injured for some time.

“Even if we delay administration of hydralazine we can still reduce the pain, meaning not only acute but chronic pain might be reduced by acrolein-scavenging treatment,” Shi says. “In addition to the elevated acrolein level immediately following SCI, the expression (activity) of the TRPA1 is elevated long after the injury. This means that the sensory neurons remain sensitive to acrolein. So acrolein may produce neuropathic pain even after the acrolein level is normalized. Therefore, it’s likely that acrolein can not only contribute to pain in acute SCI, but also to chronic pain in SCI long after the acute stage. One piece of evidence to support this is the very fact that, in our animal experiments, treatment with hydralazine not only reduced pain in the acute stage post-SCI, but also in sub-acute and chronic stages post-SCI.”

All of this leads us to ask, “So what is hydralazine?” It’s a drug known as a “smooth muscle relaxant” that has long been approved by the U.S. Food and Drug Administration to treat high blood pressure, or hypertension. In this role, it works by relaxing blood vessels so blood can flow through the body more easily. Its ability to “scavenge” acrolein has been known for some time, but it’s only recently that studies like Shi’s are finding specific applications for this ability.

“We are making efforts to push hydralazine to the clinical usage,” says Shi. “It is FDA approved, so there is a history of several decades of safety data regarding hydralazine. Meanwhile, the dosage to lower acrolein is at least a magnitude lower than that needed for reducing blood pressure, making it safe to use in SCI. Since it is FDA approved, this will be a repurposing drug, just like aspirin was repurposed from a pain medication to a blood thinner. So we could likely skip phase I trials to test safety, and go directly to phase II clinical trials, to see if it is effective in humans. This would significantly expedite the approval process.”

As for side effects of hydralazine, the most concerning is hypotension, or a dangerous drop in blood pressure. “However,” says Shi, “since the dosage to scavenge acrolein would be lower than that used for hypertension, the risk of hypotension will be minimal. In addition, in the animal studies, the dosage at which hydralazine could effectively lower acrolein did not cause any significant hypotension.”

Interestingly, we did find someone in a popular online SCI consumer forum who claims to have recently started taking hydralazine for neuropathic pain. When we told Shi that, he understandably expressed concern.

“At this point, I need to make it clear that hydralazine has not been approved for SCI or as an analgesic medication,” he cautions.

Shi is also researching the role of acrolein in multiple sclerosis, where he believes it is one of the agents responsible for the breakdown of myelin, the protective sheath found around neurons. Watch future issues of The Spin for developments about hydralazine and Shi’s research as they become available.
I’ve been an accountant for almost two decades. During that time, I’ve prepared hundreds—even thousands—of returns for clients, many who have an SCI. I also happen to have an SCI. As a result, I’m pretty comfortable with how Canadian tax law relates to people with SCI and other disabilities.

In the past, I’ve offered tax tips to SCI BC members and peers in Paragraphic, the predecessor of The Spin. But it’s been a while since we’ve done that. Laws have changed; The Spin has many new readers. So we decided to prepare something for this issue—some disability-focused tax tips that will inspire you to maximize your 2013 personal tax return, which is due on April 30th. I know it’s hard for anyone but an accountant to get excited about tax season, but there are strategies that you should get enthused about—strategies that can save you and your family a lot of money if you’re not presently taking advantage of them.

What follows are my top ten tax tips. Note that these are general, practical tips—important, overarching knowledge that you need to be up to speed on before you prepare your return, or before you see a professional about preparing your return.

1. **Everything starts with your application for the Disability Tax Credit (DTC).** If you’re a person with an SCI or a related permanent disability, you absolutely need to get your doctor to fill out form T2201, the Disability Tax Credit Certificate, and have it submitted to the Canada Revenue Agency (CRA). As a person with an SCI, having your T2201 approved by CRA is a foregone conclusion. Once you’ve been approved, you can apply for the actual Disability Tax Credit (more on that below). But maybe you’re thinking, “I have no income, so I don’t need to apply for the DTC.” Wrong! You may be able to transfer your DTC to someone else. Not only that, having your T2201 approved is really important for more than just applying for the DTC. It qualifies you for other government benefits, the most important being the Registered Disability Savings Plan (RDSP), and some of the major...
medical expenses such as attendant care. Again, more on this in the points that follow below.

2 Once your T2201 is approved, claim the DTC. Simply put, the DTC reduces the amount of income tax you have to pay. The bottom line savings can be up to approximately $1,600 per year. If you have little or no income and can’t make use of the DTC yourself, it may be possible to transfer it to a spouse or a relative who is providing care or financial support. And if you’ve been injured for some time, and somehow have never clued into the DTC, take heart—you can apply for the credit retroactively, potentially going back up to 10 years (see 9 on the next page).

3 Claim Allowable Medical Expenses. This is a major section of potential deductions that may be available to people with SCI or their caregivers. For people with SCI, there are many allowable medical expenses—expenses for products and services prescribed by a doctor that you’ve paid for out of pocket, above and beyond what’s been provided to you by government programs or private insurance. The most important of these is probably attendant care—if you paid any amount to someone other than your spouse to help you with your daily care, you can probably claim what you paid as an Allowable Medical Expense. Once again, an approved T2201 is necessary to claim attendant care expenses.

4 Be aware of other possible benefits, credits and deductions. In addition to the two biggies I’ve mentioned above, there are other credits or deductions that you might be able to take advantage of. Some of the most important ones are listed below, but keep in mind there are others. For more information on all of these, visit the CRA website.

- The Caregiver Amount (Caregiver Tax Credit): A commonly missed tax credit is the Caregiver Amount or Caregiver Tax Credit. If, at any time in the year, you were a dependant of someone who maintained a dwelling where you both lived, that person may be able to claim this credit, resulting in savings of up to $600.
- Family Caregiver Amount Tax Credit: If the person who received the Caregiver Tax Credit above is your spouse, partner or other family member, and provided any type of care to you, he or she may be able qualify for this credit, resulting in additional bottom line savings of up to $300.
- Disability Supports Deductions: If you pay for supports to enable you to perform the duties of an employee, business owner or student, you may be able to claim them on your taxes.
- Working Income Tax Benefit (Disability Supplement): If you qualify for the DTC, are employed or own a business, and earn between $1,150 and $19,867, you may qualify.

5 Don’t delay—open a Registered Disability Savings Plan. This is just too good of a deal to pass up. First of all, the government will match any contributions you make by up to 300 percent, to a maximum of $3,500. Can’t afford to make a contribution? It doesn’t matter—open an RDSP anyhow, because, depending on your family income, the government may give you the Canada Disability Savings Bond of $1,000 a year regardless of whether or not you make personal contributions. In addition, you can carry forward unused government grants and bonds as far back as 2008. So if you qualify for the bond and have for some years, simply opening an RDSP in 2014 will get you up to $7,000. What are you (or your financial advisor) waiting for?

6 Be informed. A quick Google search will yield a ton of hits and a lot of great information, but I suggest going straight to the horse’s mouth—CRA itself. Gone are the days that CRA spoke in the kind of gibberish that only accountants could understand. CRA’s guide for people with disabilities, available online or in printed form which CRA will mail to you, is excellent. It contains every possible nugget of information that CRA has on the benefits and credits you may be able to access as a person with SCI. Not only that, it’s written in plainspeak and shows just how far CRA has come in this regard. Here’s the direct link: www.cra-arc.gc.ca/E/pub/tg/rc4064/README.html.

“Are you one of the thousands of Canadians with a disability who have given the government thousands—and maybe millions—of dollars in taxes unnecessarily?” asks Walter Gagen. “If so, don’t despair.”
Get help if you think you need it. While Canada’s tax benefits for people with disabilities are, for the most part, pretty impressive, wading through every step to maximize your return can be difficult. A professional might be able to save you both money and grief in the long run. Even for those who are determined to DIY their taxes, seeing a professional to help with the first return after the onset of disability might make it a lot easier for you to be self-sufficient in years to come.

Be organized and accurate. Take your yearly tax return seriously. Never submit incomplete or incorrect information. Even though you don’t have to submit receipts for medical expenses when e-filing, you can be asked for them at any time—so make sure you have them in an organized, safe place.

Get back taxes that you should never have paid. Recently, a prominent Ottawa accountant who works with many people with disabilities estimated that only about 50% of people who are entitled to the Disability Tax Credit and the Caregiver Tax Credit are actually claiming it. Are you one of the thousands of Canadians with a disability who have given the government thousands—and maybe millions—of dollars in taxes unnecessarily? If so, don’t despair. You can claim the DTC from this year onward and potentially for up to 10 years in the past, under the Taxpayer Relief provisions. In addition, caregivers can also claim as far back as 2002 for the Caregiver Tax Credit. The result could be a windfall tax refund of $10,000 or more.

Get your gas rebate. My final tip isn’t really an income tax tip, but if you qualify for BC’s Fuel Tax Refund Program for People with Disabilities, tax season is a great time to get your annual rebate application submitted. Basically, if you’re a person with an SCI, and use a vehicle, you can apply to this program and receive a rebate of up to $500 per year for all the tax you paid as part of your annual fuel expenses. And if you qualify for this benefit, you may be eligible for other discounts—for example, insurance (check with your insurance agent). A great starting place to learn more about this is the SCI BC website’s SCI Information Database—visit www.sci-bc-database.ca and search for “gas tax rebate.”

Good luck!

Walter Gagen is a Vancouver-based SCI BC peer and an accountant. For more information about Walter, the services he provides, and how to contact him, visit www.gagen.ca.
Better Living Through Engineering

Dr. Jaimie Borisoff on the evolution of assistive and mobility technology—and why Robocop isn’t in our future.
Jaimie Borisoff doesn’t just solve problems, he does it with panache. When he and his wife had their first child, he added a gas spring and pivot to the front wall of the crib. The wall would then smoothly open up and out “like the door of a Lamborghini” to provide Borisoff with easy access to his son.

The husband and father of two is also a Paralympic wheelchair basketball champion, and he plays ball hockey on his off time. But Borisoff doesn’t want to talk about any of that. Instead, he prefers to speak about innovation and how technology can enhance his own quality of life, and that of others with SCI.

And he has the credentials to do just that. Borisoff is the Research Director and the Canadian Research Chair of Rehabilitation Engineering Design at the British Columbia Institute of Technology (BCIT). He’s also a Principal Investigator at ICORD, and Adjunct Professor at the University of British Columbia. This is a man who has a wealth of big ideas to talk about.

Recently, Borisoff completed the sale of his revolutionary Elevation wheelchair to PDG Mobility Technologies, which is now marketing and selling it. Borisoff sat down with The Spin to discuss the Elevation, his current work, and the exciting developments in his field of rehabilitation engineering.

Update us on the Elevation wheelchair. How is it different?
One area of my lab at ICORD and at BCIT is really thinking about equipment and technology for people with disabilities and impacting quality of life, health, function and that sort of thing.

This wheelchair was designed so that you can change your position throughout your day at any time, to suit whatever activity you want to do. You can change your seat height so you can have a lower centre of gravity and a better wheeling position to get around your community, or you can sit a bit higher at a desk or at a table, and you can also sit even higher if you want to reach a shelf, interact with people at eye level, or do whatever it is that you might want to do.

You can also change your backrest position easily to match your activities and maintain your comfort. For instance, if you move it forward, you’ll find it easier to wheel up hills or ramps. You can also make it recline so it’s easier and safer to go down ramps.

It’s very quiet and simple. It’s all mechanical. That’s the key to the design. The goal was to make it very simple and natural to use. You have to have some hand or arm function or enough to move yourself. You have to put a bit of strength into it—it’s not going to do it all for you.

What’s next for the Elevation?
It’s now owned by PDG, which is quite exiting as PDG is a successful Vancouver-based wheelchair manufacturer. I also have an ongoing role with PDG, helping to direct their expansion into high performance products. The Elevation is now available commercially in Canada. It’s not yet being heavily marketed in some provinces, where coverage isn’t yet in place. But we are pursuing this, and we’re also going through the FDA approval process for USA sales.

With the Elevation now complete and commercially available, what are you working on these days?
One area that I’m really excited about right now is exercise equipment. What we have downstairs (in the Blusson Spinal Cord Centre) is the Physical Activity Research Centre (PARC). The Centre has adaptive equipment, and volunteers are available to help anyone, regardless of disability, learn to use that equipment.

One of the things I’m doing with my grad student, Jacqueline Cragg, is looking at the major issues in SCI that cause poor health and reduced life spans. People with SCI typically don’t live as long or stay as healthy as someone without it, and one of the reasons is cardiovascular health and fitness.

It’s hard for someone with SCI to stay fit and healthy, so we’re taking a closer look at the benefits of regular use of arm and leg bikes. In particular, we’ve found that moving your legs passively in conjunction with your arms can be hugely beneficial with a very simple piece of equipment. We just did a case study with ICORD’s Dr. Chris West about this, which we’ll hopefully publish soon.

This is ongoing work taking place in several labs, but it’s becoming clear that moving your legs—even passively—is beneficial to spasticity, circulation, cardiovascular health, maybe even bowel and bladder function, and a whole host of other things.

If you’re using your legs while standing with exoskeletons, that might even improve your body composition, weight loss, and bone density. So yes, that whole area is very fascinating.

What do you think are some of the challenges faced by people with physical disabilities that can be solved through engineering?
When I think about the challenges we face, I’m not thinking in terms of finding a cure. I’m more interested in terms of quality of life with SCI, and having the fullest and healthiest life you can lead, for the longest you can live. It’s more about participating in the community and the activities of daily living.

This sort of technology can definitely have an impact. We hope it can have an impact on general health with exercise equipment. With better wheelchairs you can have better participation in the community—you can get anywhere you want, and do the activities you want, wherever it is that you want to do them. That’s where technology can have a big impact.

Why did you decide so early in your career to focus on quality of life as opposed to finding a cure?
Life isn’t so bad. We’re pretty lucky where we are. Spinal Cord Injury BC is a great example: there are some people who are living some pretty good lives regardless of their level of injury. We
At this point it’s certainly a therapeutic device, in that exoskeletons can help you get standing and walking your legs passively. It’s very expensive, however.

So that’s what I’m interested in right now—comparing cost to effectiveness. I’m interested in the impact of exoskeletons, but I also want to know if there’s something that’s more accessible, say like an elliptical machine, which is a thousand dollar device that anyone can buy for their own home. We haven’t shown that these machines have the same benefits as an exoskeleton, but potentially they might have similar effects as well as exercising cardiovascular health—really two birds with one stone, so to speak.

That’s the path that’s happening right now, so it might be overhyped, but it’s still very exciting and interesting.

Tell me about some of the big technologies that have a lot of hype right now in this field, and what you think is overrated.

I think exoskeletons are a bit of both. If we think of equipment and technology for SCI, this is going to be one of the major pieces of technology we will continue to hear about that’s coming down the pipeline in the future.

ICORD just bought one, which you might have seen on the news recently. It’s a state-of-the-art walking exoskeleton that’s available commercially for clinical and research use only.

Exoskeletons are overhyped because the media and the public see this as a mobility device. They see people up and walking in them and think, “That’s awesome!” But in reality it’s not a mobility device; it’s only a therapeutic device.

It’s not a mobility device because it’s very, very slow. It takes a very long time to get from A to B so mobility is actually hampered, not enhanced. It’s very difficult to get in and out of it. It hasn’t been shown to be safe in the community at all.

If you talk to the companies making exoskeletons, they’ll say these are designed specifically for inside use in institutions right now, under supervision. They acknowledge that it’s not a mobility device at this point. Of course, they want to get to that, so maybe we should throw some money at it because it could evolve into a mobility device over the years—maybe.

At this moment, we think of equipment and technology that have a lot of hype right now, so it might be overhyped, but it’s still very exciting and interesting.
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Vancouver Airport Authority is proud to support Spinal Cord Injury British Columbia.
New research reveals just how much at risk people with SCI are for sleep disorders—and, given the serious health implications, suggests how important it is that they be carefully assessed and treated.

Over the past two decades, there’s been a smattering of research efforts that concluded people with SCI are at risk for sleep apnea and other sleep disorders. But most of these have just scratched the surface of the problem, and answers have been scarce when it comes to details about the prevalence and types of sleep disorders experienced by people with SCI—and more importantly, what can be done about them.

Dr. Abdulghani Sankari, a physician scientist at Detroit’s John D. Dingell VA Medical Center and Wayne State University School of Medicine, has been working on answering those questions for the past four years.

“I became interested in studying sleep and breathing disorders in SCI during my pulmonary fellowship and as I was completing my PhD in physiology of sleep and breathing in 2009,” says Sankari. “I noticed that patients with SCI have very little information on why they have poor sleep and quality of life. I met with my research mentor, Dr. Safwan Badr, and decided to focus my career development and research investigation on this challenging area to understand the mechanism of disease and explore other options for treatments.”

Sankari and his team recently completed two lengthy research projects that provide a much more robust understanding of the problems.

The first study used a battery of tests and questionnaires to compare sleep-disordered breathing in people with quadriplegia against people with paraplegia—a comparison that hasn’t ever been attempted.

“We studied 26 consecutive people—15 quadriplegics, 11 paraplegics, and 6 able-bodied controls,” says Sankari. “We found that those with SCI were at a significantly higher risk of sleep apnea, with a higher rate of central apneas and a lower rate of obstructive apneas.”

The second study focused on the prevalence and types of sleep disorders experienced by people with SCI, using a combination of self-report questionnaires and objective sleep assessments.

“We found that a significant number of people with SCI report symptoms of insomnia, sleep disorders, and restless legs syndrome,” says Sankari. “We also found that people with SCI have a higher prevalence of psychiatric disorders, which can exacerbate sleep problems.”

Sankari and his team are now working on developing targeted interventions for people with SCI to improve their sleep and quality of life.

“We are currently developing a comprehensive intervention program that includes education, cognitive-behavioral therapy, and medication management,” says Sankari. “We are also working on developing a mobile app to help people with SCI track their sleep and monitor their progress.”

Sankari and his team have also established a network of researchers and clinicians to collaborate on future studies and develop new treatments for sleep disorders in people with SCI.

“We are excited about the potential to make a real impact on the lives of people with SCI,” says Sankari. “We are committed to finding new and effective ways to improve their sleep and quality of life.”
and 11 paraplegics—who have lived with chronic SCI for more than a year,” explains Sankari. “We found that nearly everyone we studied had poor sleep quality. More importantly, we found that 77 percent had confirmed breathing disorders during sleep—sleep apnea or sleep disordered breathing.”

Perhaps the most revealing result of the study was the significant difference in the prevalence and type of sleep disorders Sankari and his colleagues found in people with quadriplegia versus those with paraplegia.

“We were very surprised to find that sleep apnea prevalence is much greater in those who have injury at the neck level—more than 90 percent—versus those at the high back, or thoracic level, which was around 50 percent,” says Sankari.

He adds that the nature of sleep disorders in people with SCI is complex, with a high occurrence of both obstructive and central sleep apnea. And the occurrence of central sleep apnea, which requires special consideration in diagnosis and treatment, was more common in quadriplegics than paraplegics.

The results of that study appeared in the Jan. 15 issue of the Journal of Clinical Sleep Medicine, published by the American Academy of Sleep Medicine.

In the second project, Sankari and his team delved deeper in an attempt to understand if quadriplegia has a different effect on breathing during sleep than paraplegia—and how both compare to non-disabled people.

“In this study, we looked at 32 subjects—eight quadriplegics, eight paraplegics, and 16 non-disabled people,” says Sankari. “We were surprised to find a striking difference in the tendency to stop breathing due to a faulty signal from the brain—central apnea—in the quadriplegic group, compared to the paraplegic group, which acted similar to the non-injured participants.”

Specifically, Sankari and his team found that 63 percent of participants with quadriplegia had central sleep apnea, compared to only 13 percent of patients with paraplegia. They also found that the quadriplegic participants with central apnea required less carbon dioxide in their blood to trigger a bout, compared to paraplegics. And the efficiency of the respiratory system in quadriplegic participants was lower, with shallower breathing, than those with paraplegia.

Results of this study appeared in the October 2013 issue of the Journal of Applied Physiology.

“Sleep apnea: just what exactly is it, anyhow?”

Sleep apnea is the most common and the most serious of sleep disorders. People with sleep apnea stop breathing during their sleep, sometimes hundreds of times. The result is that the brain and the rest of the body may not get enough oxygen during sleep. This can lead to sleep deprivation and, more importantly, many serious health risks.

There are two types of sleep apnea: obstructive sleep apnea, or OSA; and central sleep apnea, or CSA. OSA, which is far more common in the general population, is caused by a blockage of the airway, usually when the soft tissue in the back of the throat collapses during sleep. With CSA, the brain fails to signal the muscles to breathe due to a compromise in the respiratory control centre.

A person can also experience a combination of OSA and CSA—this is sometimes called complex sleep apnea.

Sleep apnea can affect anyone at any age, but those at higher risk are men who are over 40; are overweight; have a large neck, tonsils or tongue; have a family history of sleep apnea; and have nasal congestion from a deviated septum or allergies. Additionally, the new research outlined in this feature suggests that people with SCI are at higher risk than others.

Treatments can range from simple weight loss to dental appliances that eliminate the obstruction and machines that increase air pressure in the throat so that the airway doesn’t collapse.

If left untreated, sleep apnea can result in poor performance in daily activities, motor vehicle crashes, high blood pressure, stroke, heart failure, diabetes, depression, and even death.
Sankari says that both studies have important implications for people living with SCI.

"First, as we learned from the first study, the majority of people with SCI have poor sleep quality and sleep disorders that can be missed if not evaluated early on in specialized centres such as in-lab sleep study clinics," he says. "The second study gives us a better understanding of the causes of disease and targets for new therapies. Specifically, the second study showed that injuries in the neck level have a greater tendency to stop breathing and develop unstable breathing immediately after falling asleep. In turn, these trigger a cascade of events of dropping oxygen levels and multiple awakenings. Therapeutic measures can alleviate this chain of events, using mechanical treatments such as positive airway pressure with or without oxygen and possibly drugs that stimulate and stabilize breathing via actions on the central nervous system."

Sankari’s message to those of you who think you’re not sleeping well is to stop procrastinating and get assessed for a sleep disorder, because there’s a lot more at stake than simply being tired and sleeping every day.

“There’s strong evidence that links sleep disordered breathing to higher rates of mortality and morbidity from cardiovascular disease and stroke,” he says. “People with SCI are more vulnerable to these adverse consequences, as many of them have respiratory disorders and weak respiratory muscles. In addition, many people with SCI suffer from autonomic and cardiovascular disorders related to their injury. These, combined with very poor sleep and frequent drops in oxygen levels at night, lead to a perfect storm that can affect directly the lives of many people with SCI.”

And, while new treatments are being studied (including two new drug therapies by Sankari and his team), Sankari says the best option remains CPAP (short for continuous positive airway pressure) or, in the case of central apnea, BiPAP—the bi refers to bilevel airway pressure. Unfortunately, he concedes that even after his patients with SCI know their diagnosis and the implications of not using one of these machines, they often do just that.

“Nearly two thirds of SCI patients who were identified to have sleep apnea did not start treatment despite formal notification. A few subjects stopped the mechanical treatment due to intolerance or interference with their quality of life, and one subject refused any treatment for his severe sleep apnea—he died within a year. We are assessing these barriers more systematically to identify responsible factors for these observations.”

Upper Airway Stimulation Offers an Alternative to CPAP

For some people with obstructive sleep apnea, wearing a CPAP mask nightly is a hard sell. A new technique, Inspire Upper Airway Stimulation (UAS) therapy, might be one solution.

The device is surgically implanted. It has three components: a stimulation electrode placed on the hypoglossal nerve that stimulates the muscles of the tongue; a sensing lead placed between rib muscles to detect breathing effort, and a neurostimulator implanted in the upper right chest. When the sensing lead detects abnormal breathing effort during sleep, it signals for stimulation of the nerve of the tongue, thereby enlarging and stabilizing the airway and improving control of breathing.

Results of a multi-centre trial of the therapy involving 126 people with moderate to severe OSA were recently published in the New England Journal of Medicine. After one year, participants using the device had an approximately 70 percent reduction in sleep apnea severity, as well as significant reductions in daytime sleepiness.

“While CPAP is a successful treatment when used on a regular basis, as many as half of the patients who have been prescribed CPAP are unable to use it regularly, largely due to discomfort with the mask and/or the lack of desire to be tethered to a machine,” says lead author Dr. Patrick Strollo, professor of medicine and clinical and translational science at the University of Pittsburgh School of Medicine. “The results of this trial show a huge potential for a new and effective treatment that can help millions of patients.”

“My short-term memory has improved significantly, and the surgery has made a huge difference in my quality of life,” reports Kathy Gaberson, one of the study participants who used the Inspire therapy. “My apnea episodes went from 23 times an hour to just two.”
Sleep Apnea: Three Success Stories from SCI BC Peers

Ken Legros, C5 – C6 complete, Prince George
I’ve been in a wheelchair for 27 years due to a car accident back in August 10, 1986. I was told by family members that I was snoring very loudly, and that I stopped breathing when that happened.

I was assessed back in 2006 by VitalAire—the outcome wasn’t very good, as I stopped breathing for three minutes several times. I was then set up with a CPAP machine that I wear every night.

The treatment has been a success, as I sleep through the night and wake up feeling rested. Prior to that, I woke up several times per night from the snoring and shallow breathing. My quality of life has improved 90 percent—it helped with weight loss, and I’m no longer sleepy or lacking energy during the day.

“The only difficulty was getting used to having a mask on your face, but after a while you get used to it. I recommend getting treated as it will improve your day-to-day living and result in way better sleeps.”

Dave Dawson, C7 incomplete, Vancouver
For several years, I hadn’t been sleeping well at night and had been experiencing extreme bouts of fatigue during the day. I would generally wake up with a headache every morning. I didn’t really think anything of these symptoms until last February when I started having difficulty breathing and shortness of breath in the daytime. This got worse over a period of several months until I began waking startled in the middle of the night with shortness of breath.

One morning in May I was having such difficulty breathing that we called an ambulance. When the paramedics arrived my oxygen levels were so low that they actually thought their equipment was malfunctioning—my body was getting so little oxygen I should not have been conscious.

At the hospital I was diagnosed with severe pneumonia—and sleep apnea, which had contributed to development of the pneumonia. I was assessed in hospital with various BiPAP machines. When I was stabilized, the hospital referred me to a lung specialist, along with a company to provide me with my own BiPAP machine to be used at home. The company’s staff came to our home to set me up, and train my wife and care aids.

These days, I sleep much more soundly. I no longer wake up at night or have any bouts of fatigue during the day. I also no longer wake up with headaches every morning. In fact, I now really can’t even sleep without the BiPAP machine.

The only difficulty for me personally is that I am unable to take the mask on and off myself due to limited hand functionality. The other downside is if we’re travelling, we have to be sure to take the machine with us. However, it’s quite small and compact—about the size of a shoebox. We have adapted pretty easily considering we usually need so many other medical aids when travelling anyway!

If you’re experiencing any difficulty sleeping at night, headaches in the morning or extreme bouts of fatigue during the day, please don’t hesitate to see your doctor and enquire about the possibility of apnea—if I had done this sooner I would not have ended up with severe life-threatening pneumonia.

Dean Stone, C7 – T1, Vancouver
In the mid 90s I found I was constantly feeling very fatigued. I was sent to the sleep clinic in Richmond Hospital to do an overnight study, and I was assessed as having sleep apnea.

I tried a CPAP machine for about a week, and didn’t like it at all. I had better success with a custom dental appliance that moves the lower jaw forward a bit which keeps the airway open (like when CPR is performed).

I began to feel more energetic in the day and my quality of life improved. I wore it for several years. After losing quite a bit of weight, it seemed like the apnea had subsided so I stopped wearing it.

In 2007, while I was in GF Strong after my accident, my roommate threw a pillow at me one night to wake me up because I wasn’t breathing. I did a few more tests, which showed my apnea had returned with a vengeance—I would stop breathing about 400 to 500 times per night. I got fitted for another dental appliance, which brought down the episodes to about 50 or 60 per night. I have been wearing it since.

It takes a bit of getting used to, but it’s not uncomfortable and not hard to stick to the treatment once you get used to it. The bottom line is that getting a good quality sleep at night is especially important to those of us with SCI.
“It seems like I haven’t had a good night’s sleep since my injury. My wife says my snoring is intolerable, and that I sometimes seem to stop breathing while asleep,” writes John in Surrey. “Is it possible I have sleep apnea? What should I do about it?”

To answer this issue’s question, we turned to Dr. Jeremy Road, a Professor of Medicine at UBC, Respirologist at Vancouver Hospital and UBC, and Medical Director of the Provincial Respiratory Outreach Program and the Vancouver Hospital Lung Function Laboratory.

It is possible that you have some form of sleep apnea. It’s a potentially serious condition, so you shouldn’t delay in seeking answers. Your first step is to speak to your family physician, who will in turn refer you to a specialist qualified to diagnose and treat respiratory sleep disorders including sleep apnea.

Your referral to the specialist will include an overnight stay in a hospital or sleep clinic, where you’ll be assessed for sleep apnea using polysomnography, a test that electronically transmits and records specific physical activities while you sleep. Your “sleepover” will be conducted in a natural, comfortable setting.

If you’re diagnosed with sleep apnea, the goal of treatment is to restore natural breathing throughout the night, resulting in a return of daytime energy and alertness. The treatment that is prescribed to you will depend on what type of sleep apnea is involved.

If you’re diagnosed with obstructive sleep apnea (OSA), and you’re overweight, losing some of that weight can sometimes be enough to reduce apnea. As part of your body’s weight reduction, elimination of excess adipose tissue around the upper airway makes it that much easier to breathe while you’re asleep. Avoidance of medications and drugs—including alcohol—that relax the muscles in the upper airway can also be a simple solution. Failing that, an oral appliance custom-made by a specialist dentist can often reduce or eliminate mild to moderate OSA—these devices move the lower jaw forward during sleep, which prevents the tongue from falling into the airway. However, the standby treatment for more severe cases of OSA remains CPAP, or continuous positive airway pressure. With CPAP, a soft mask is worn during sleep, with positive air pressure delivered by a small, quiet machine.

You may also be diagnosed with central sleep apnea (CSA), or a combination of CSA and OSA. As emerging research is demonstrating, people with quadriplegia are at an increased risk for this type of apnea. With SCI, there are a variety of positive pressures machines for treating this combination of OSA and CSA. These machines are more sophisticated (and hence more expensive) and are designed to minimize hypoventilation, which can occur when breathing during sleep is not deep or regular enough. Hypoventilation is associated with an elevation of carbon dioxide levels in the blood, which can produce symptoms of headache and sleepiness in the morning.

These types of positive pressure devices are called BiPAP, a trademarked abbreviation for bilevel positive airway pressure. They are designed to prevent hypoventilation. Like CPAP, BiPAP involves a mask and a machine to maintain air pressure. The “bilevel” component refers to the fact that there are two alternating pressures—higher pressure when you breathe in, and slightly lower pressure that allows you to breathe out.

There are some existing surgical options, but these are only considered in unusual circumstances, since success rates are not high.

You may be wondering who pays for all of this. Here in BC, the entire sleep apnea assessment process is paid for via your standard BC Health coverage. Unfortunately, treatment is a different matter—there is no BC Health coverage for any type of treatment. Sleep disorder specialists in BC are working together with our Ministry of Health to change this—for example, we have prepared a study which points out that providing treatment coverage is less expensive than the combined cost of motor vehicle collisions, workplace accidents and serious health complications associated with untreated sleep apnea.

For the moment, you’ll have to bear the cost of treatment by yourself. We urge you not to let this get in the way of getting assessed and, if you’re diagnosed with sleep apnea, finding out your personal risks that may result from failing to have it treated.
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Vancouver’s Greg Rodgerson is thriving after his injury, and so is his drywall & steel stud business.
ver the years, we’ve seen firsthand proof that the sky’s the limit when it comes to careers for people with SCI.

Ingenuity and perseverance—two traits that many of our readers seem to have in abundance—have led them down some professional paths that are both fascinating and stereotype-challenging.

Even so, we were intrigued when we learned about Greg Rodgerson and his business, Rufus Enterprises Ltd—a Vancouver-based commercial drywall and steel stud contracting outfit. We caught up with Rodgerson at his company’s latest project at the historic Beth Israel Synagogue on Oak Street and 27th Avenue. Inside, we found him supervising his crew (who affectionately referred to him as “Boss”), hard at work installing steel studs and drywall as part of a complete remodel of the synagogue.

“I began the business in 1984 as a way to simplify taxes and legitimize my employment,” says Rodgerson, who got into the trade after finishing high school. “I started out doing warehouse improvements, and moved on to retail stores in malls. Slowly, we built a reputation for being able to complete jobs efficiently and with quality.”

Like all contractors, Rodgerson’s company has had its share of ups and downs over the years as dictated by the economy. In the summer of 2011, business was finally looking up after some tough years. “We were involved in a hotel tower conversion, consisting of two 18-storey towers being converted to residential rental units,” recalls Rodgerson. “We had over 30 people employed at the time.”

And that’s when disaster struck. “I was riding a motorcycle on the Coquihalla, and hit some gravel,” says Rodgerson. “I drifted into the centre grass median and hit a rut. The next thing I knew, I was flippin through the air, and I landed with the bike on top of me.”

Fortunately, an off-duty paramedic was one of the first people at the crash scene, arriving about a minute after the crash. Within another minute, a doctor stopped and took over Rodgerson’s care. Within half an hour, Rodgerson was airlifted to Vancouver General Hospital. There, he was diagnosed with a C7 – C8 SCI. But, perhaps thanks in part to the rapid response of knowledgeable bystanders and the rapid air ambulance, he was left with full upper body mobility and strength.

In the blink of an eye, Rodgerson had to not only face life as a wheelchair user, but the daunting challenge of keeping a huge job on track and his company afloat.

“Being in the middle of the project, there was no room for doubt, as I stood to lose everything,” he says. “The hardest part at the beginning was communications. I was unable to do anything for over a month. I was finally able to get a laptop and start dealing with the backlog of paperwork. I mentally had accepted the new reality of my injury from the moment it occurred—I knew I would not walk again, and accepted it as a fact. That allowed me to move forward with the important stuff, dealing with the fallout within the company.”

As he healed, he began using his laptop more and more to access his home computer, answer emails, estimate extras, and even land a couple of new jobs. “During the time in the hospital,” he says, “I had terrific support from everyone working for me.”

That support, along with his own perseverance, saw him steadily regain his health and independence, while keeping the job on track and his company viable. It’s truly been a case of “what doesn’t kill you makes you stronger,” and Rodgerson says his company is now in a healthy position.

“We now do both commercial and residential projects, ranging from warehouses to residential tower projects. We’re still recovering, but we’ve seen a large spike in growth through the last year. I would say that, today, Rufus Enterprises is a successful and growing company, with eight to 12 full-time staff at any given time.”

While Rodgerson isn’t able to put the tools on anymore, he figures that’s probably for the best—it allows him to stay focused on estimating, acquiring new work, solving technical issues on the job, and working out logistics.

As for the attitude of the general contractors who hire him, there’s never been a problem. “All my clients accept my condition, after they realize that I’m extremely knowledgeable about my trade. Most just treat me just like any other contractor they may meet. I believe that our reputation is what’s growing the company, and I don’t think having an SCI is a hindrance. In fact, I think in some small way, my clients respect me more, as I’m navigating the job sites in my wheelchair.”

We asked Rodgerson what advice he would give someone who wants to get into—or back into—the building trades after an SCI.

“Well, there is life after an SCI,” he says. “Estimation is a big part of the building trades, as well as scheduling, bookkeeping, billing, and day-to-day paperwork. You can’t realistically put the tools back on, but you can do support and management work. Estimating courses are a good initial path, as well as basic accounting.”

Finally, we asked Rodgerson if he wanted to give anyone a shout-out for helping him and his company get back on track in his post-injury life.

“I have to thank Shelley Moore and JoAnne Herd for the support they gave me through the transition from legs to no legs,” he says. “I would not be where I am without their support. I would also say the support I received from Haebler Construction was instrumental to the growth of Rufus Enterprises, by seeing past my disability and accepting me as a person.”

For more information: Rufus Enterprises Ltd, 604.936.6384
Researchers at the University of British Columbia confirm concerns that SCI greatly increases the risk of heart disease and stroke.

It’s a tough pill to swallow. But here at SCI BC, we definitely think it’s a case of “better the devil you know than the devil you don’t know.”

A UBC study led by graduate student Jacque-lyn Cragg concludes that the risk of heart disease for people with SCI is nearly three times that of non-disabled people. Not only that, their risk of stroke is almost four times greater.

And, while respiratory diseases such as pneumonia still rank high, cardiovascular disease—CVD for short—is now the leading cause of death among individuals with SCI, according to Cragg.

In the past, a handful of studies shed light on the types of risk factors for CVD common in people with SCI. But those studies involved studying small groups of people with SCI, and they didn’t even attempt to determine the magnitude of the risk—in other words, how likely it is that individuals with SCI will experience CVD.

When Cragg, along with colleagues Dr. Andrei Kras-sioukov, Dr. Jaimie Borisoff, and Dr. Vanessa Noonan, were presented with a unique opportunity to determine the magnitude of risk by examining a huge slice of the Canadian population, they jumped at the chance.

“Actually, this was somewhat of an unusual study in that we obtained ethics to obtain data from Statistics Canada,” says Cragg. “Statistics Canada runs regular cycles of the Canadian Community Health Survey, and we were thrilled to find out that the 2010 cycle had data on both SCI and CVD.”

Once they had obtained the necessary clearances, the team studied health data from more than 60,000 people who participated in the 2010 Canadian Community Health Survey. Of those, 354 people reported having both an SCI and a stroke, and 356 people reported having an SCI and cardiovascular disease.

The study was completed over the past year. Cragg performed the statistical analyses, while all the team members were involved in the study design and interpretation of the results, which were published in the August 20, 2013 issue of the journal Neurology.
“The most significant finding was the increased risk of heart disease and stroke seen among individuals with SCI,” says Cragg. “We were not surprised at the findings regarding the elevated risk, but we were surprised at the magnitude of the risk.”

To put the numbers into perspective, the risk of CVD for people with SCI is similar to that of non-disabled people who smoke, have diabetes, or are obese.

There are some limitations to the study. Of these, the most significant is that the results are from cross-sectional data. “We cannot, for example, be certain if the SCI came before the CVD,” says Cragg. “However, our estimates of risk for stroke were remarkably similar to those from a Taiwanese study—this study did have confirmation that the SCI came before the CVD. Another limitation of the data is that there was not detailed neurological information (about each individual), as the data were derived from a general population health survey. We know there are a lot of differences among individuals with SCI which will affect CVD risk.”

And, to be clear, the study does not attempt to determine causes for the higher risk. But there are many established, “conventional” risks for CVD in people with SCI. And there is an ever-increasing body of evidence that implicates non-conventional factors such as poor autonomic function as a risk for CVD.

“We know that physical inactivity as a result of SCI contributes to the risk, and so do the results of physical inactivity, such as abnormal glycemic control (the ability to control spikes in blood glucose), dyslipidemia (high amounts of cholesterol and fat in the blood), and obesity,” says Cragg. “In addition, there may be other risk factors, including cardiac and vascular dysfunction, and other autonomic disturbances relating to regulation of blood pressure—for example, orthostatic hypotension and autonomic dysreflexia. However, understanding the contributors to risk and the relationships between these contributors is something we are currently examining.”

In other words, like most good science, the study raises many more questions than it answers. The essence of this was captured nicely in a Neurology editorial written about the study. “Despite the accumulating evidence on the associations between CVD and SCI, there is a lack of evidence-based research to guide clinicians in managing CVD risk factors in patients with SCI...It is not surprising that few currently available guidelines address the management of CVD risk factors in patients with SCI and practically all of them are based on expert opinion or results from studies carried out in able-bodied individuals,” wrote Dr. Elena Kuklina and Dr. Ellen Merete Hagen. “Although the results of the study by Cragg et al. take us one step closer to understanding the unique profile of CVD risk in patients with SCI, they are also a timely call for more research to address CVD in this population.”

What Can You Do to Lower the Risk?

What should people with SCI take away from this study? What are steps they can take today to lower their risk?

In terms of the traditional or conventional risk factors, lead author Jacquelyn Cragg says there’s plenty people can do.

“Although we still know only about the tip of the iceberg on the association between the conventional risk factors and CVD after SCI, it’s generally recommended that each individual with SCI should do his or her best to prevent development of CVD,” says Cragg. “Follow guidelines for exercise after SCI, maintain a healthy diet, quit smoking, follow up with your MD on a regular basis, and if needed, stick to any medications your MD deems necessary to maintain good cardiovascular health.”

You can find SCI Action Canada’s Physical Guidelines for Adults with SCI at www.sciactioncanada.ca/guidelines.

As for the non-traditional risk factors which are emerging, such as the role of autonomic dysreflexia (AD), Cragg says that working with your health care professionals to achieve the best possible autonomic function is a worthy goal. And so is taking all possible precautions to avoid AD episodes.

Finally, she says that cardiovascular health is something you should be discussing with your healthcare providers regularly throughout your post-injury life. “We absolutely agree that CV health should be assessed regularly,” she says. “We hope that this study does put cardiovascular health on the radar for general practitioners and physiatrists.”

Here at SCI BC, we also believe that people with SCI—particularly those living in rural BC—need to advocate for themselves and ensure their physicians are aware of the results of this study.
Breathe Easier

After years of testing, the NeuRx Diaphragm Pacing System has finally received Health Canada approval for coverage

Here’s some good news for ventilator-dependent quadriplegics who have been hoping for a life-changing opportunity to use the NeuRx Diaphragm Pacing System (DPS). In December, Health Canada provided full approval for the system, which is built by USA-based Synapse Biomedical and carries a price tag of about $35,000.

The approval means that Canadians with quadriplegia, whose level of injury prevents them from breathing unassisted, can access at no cost a high-tech alternative to the cumbersome ventilator. Previously, the DPS was only available to clinical trial participants or through an arduous procedure to get special permission through Health Canada’s Medical Devices Special Access Program.

The approval is the outcome of years of research that began in 2007 when the Rick Hansen Foundation funded the DPS procedure for a young Vancouver man. That surgery was performed in Cleveland, with Vancouver thoracic surgeon Dr. John Yee in attendance to learn the procedure. Yee and Dr. Jeremy Road, a respirologist who also works at Vancouver Coastal Health, then launched a Canadian site for the clinical trial, and performed several DPS procedures in Vancouver over the next few years. With help from SCI BC, the Rick Hansen Foundation provided funds to enable individuals from across Canada to take part in the trial.

In 2010, Yee and Road, in collaboration with Synapse Biomedical, submitted their clinical data to Health Canada, and requested the procedure be approved.

Fast forward to 2013. Health Canada had not yet approved the DPS procedure, but Lise Belanger, a clinician and spine nurse in Vancouver, was determined to gain access to the system for a young patient on the acute spine unit at Vancouver General Hospital. Belanger got in touch with Dr. Colleen O’Connell, a New Brunswick physiatrist who had recently gone through the process of applying for the DPS for her own patient through the Medical Devices Special Access Program. With O’Connell’s assistance, Belanger completed the lengthy application process.

In her application, Belanger re-emphasized the many benefits of DPS use—greatly reduced or eliminated ventilator dependence, the ability to taste and smell again, and minimized risk of pneumonia. She personally followed up to ensure that Health Canada heard her patient’s story, emphasizing how this device could dramatically improve his quality of life.

Belanger’s hard work paid off late last year, when Health Canada not only approved the device for her patient, but for all Canadians across Canada with SCI who are ventilator-dependent and lack voluntary control of their diaphragms.

With this approval, hospitals can now stock the device, which means that there is no cost to the patient.

“I was delighted,” says Road, who, along with Yee, pioneered the technique in Canada. “We had a lot of experience with the system, and the Health Canada application had been in for some time. There isn’t a large need for this, but for the people who do fit the criteria, it certainly is a bonus to them.”

Road has seen the impact the system can have firsthand. “I think it gives people a lot more mobility. The taste of food is improved. The humidification of the air is improved by taking air in through the nose. I also think people have a better feeling about themselves, not being on the ventilator; and feeling more free and breathing more normally. I think overall it’s been very successful.”

If you think you might be a candidate to receive the NeuRx DPS, the first step is to speak with your physiatrist or respirologist.

About NeuRx DPS

NeuRx DPS is implanted through minimally invasive laparoscopic surgery and provides electrical stimulation of the muscles of the diaphragm. A patient’s diaphragm is first tested to ensure it can respond to stimulation.

A surgeon then opens small holes in the abdomen and inserts a laparoscope so the diaphragm muscle can be seen. The surgeon then places small electrodes in the diaphragm. The electrodes are then attached to a small external battery-powered pulse generator, which stimulates the diaphragm, causing a contraction of muscle.

This allows air to fill the upper and lower parts of the lungs rather than forcing air in with a mechanical ventilator. The stimulation is then used to condition the diaphragm, enabling the patient to breathe longer without the need of a ventilator.

The device is controlled through a four-channel, battery-powered external pulse generator and eliminates the need for a source of electricity and concern for power outages.

In the US clinical trial, more than 50% of the eligible participants were able to completely eliminate their need for mechanical ventilation. The device was approved by the FDA in June 2008. For more information on the NeuRx DPS, visit the Synapse website at www.synapsebiomedical.com.
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