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SPINAL CORD INJURY BC

SPRING 2018

NAVIGATING AGING ISSUES

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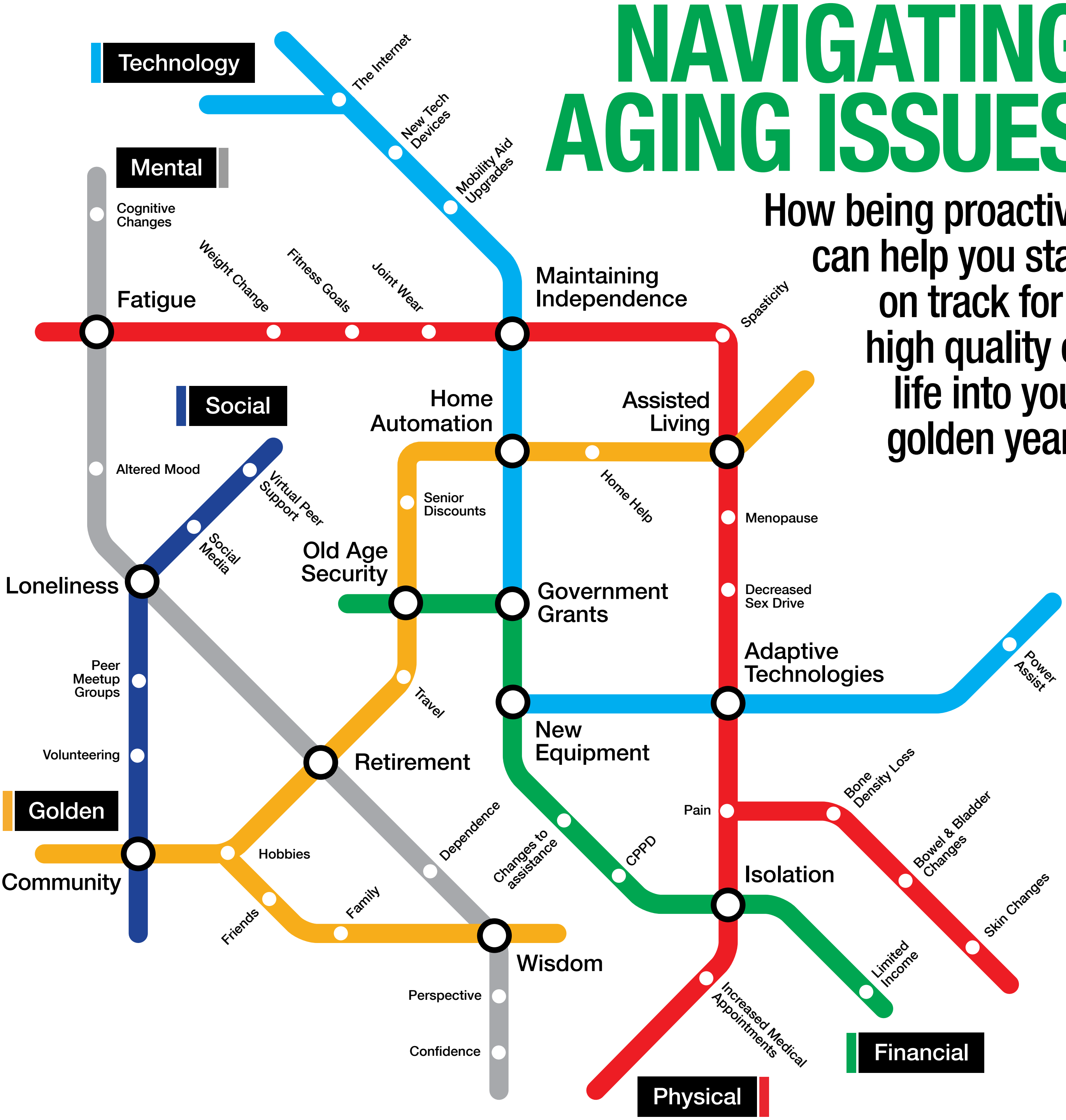

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editor's message

Are TNCs coming to BC?

In February, the provincial government's Select Standing Committee on Crown Corporations released its report on transportation network companies, or TNCs. If you're not familiar with the term TNC, here's how the government defines it: "A company that provides pre-arranged transportation in a privately-owned vehicle for financial compensation paid to the driver and the TNC. The TNC engages exclusively in app-based ride-hailing services."

Uber and Lyft are examples of TNCs. After a lot of due diligence, SCI BC sees the potential for these companies to benefit British Columbians with disabilities. But are we closer to seeing ride-sharing companies setting up in BC? Maybe.

The committee invited 67 expert witnesses to provide input on the potential impacts of TNCs on communities and how they should be regulated. SCI BC was pleased to provide one of the 13 written submissions to the committee. Our submission was based on the input we received from participants in the two accessible transportation workshops we co-hosted with Uber, and the knowledge, wisdom and experience of our frontline staff.

The Committee's report underscores the complexity of introducing TNCs into BC's transportation mix. You can read the report, along with SCI BC's submission, on the provincial government's website (https://www.leg.bc.ca/parliamentary-business/committees/41stparliament-3rdsession-cc/).

I was pleased to see SCI BC's perspectives, ideas, and concerns reflected in the report. For example, in the area of accessibility, the Committee took our advice and made a number of recommendations in an effort to ensure that TNCs deliver equitable and timely service to all British Columbians. Requiring wait-time standards or service guarantees and incentivizing drivers of wheelchair accessible vehicles with a trip bonus are examples of ways to achieve this. The committee also recommended that TNCs' online applications meet or exceed established mobile accessibility standards, and provide inclusion training for drivers.

The committee made several other important recommendations. For one, it favours a provincial approach to regulating TNCs, which would allow for TNCs to operate in all parts of the province, potentially opening up accessible transportation options in areas where they are most needed. In other words, everywhere!

For example, if people with disabilities' accessible vehicles could be used for ride-sharing, the number of accessible vehicles available could increase dramatically. In smaller and remote centres, this might provide the only accessible transportation option, especially with the impending loss of Greyhound service in the north. With the addition of incentives for drivers to take accessible rides, the number of times people with disabilities are passed over should decrease.

There may also be opportunities for people with disabilities to generate income by being drivers or offering their accessible vehicles for use in TNC fleets.

As for regulation, it's vital that it ensures equal access to TNCs and that the same service standards are applied for all customers, including cost and wait times. Safety and security measures relevant to people with disabilities must also be applied, including accessibility-related TNC driver training that is developed and delivered by people with disabilities. Complaint mechanisms must be accessible, safe, open, and responsive.

It seems inevitable that TNCs will enter the BC market. When is unclear, but it is encouraging that the government has listened to the diverse input it received and is preparing accordingly. It's also encouraging that TNCs like Uber have been proactive in developing accessible products for the BC market so that when they are approved, they will be ready to serve British Columbians with disabilities.

CBM

– Chris McBride, PhD, Executive Director, SCI BC

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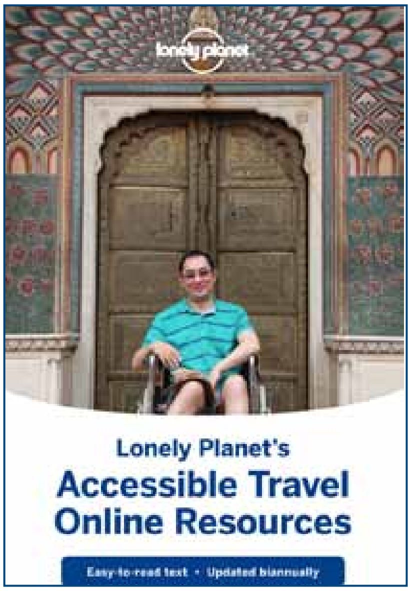
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NEOMANO

We've seen many prototype robotic gloves for decades, but none have become commercially viable. South Korean company Neofect hopes to change that with the NeoMano—a robotic glove that's worn on the thumb and the first two fingers. The mechanism is straightforward, with titanium wires running down the inner length of each finger. When the grip function is triggered from the rubber pad remote, the wires are reeled in, allowing users to grasp and lift objects as heavy as a kilogram. The remote can be operated with an elbow or arm, and the company is also working on voice and head-movement controls. A battery on the back of the glove provides power. Neofect has applied for FDA approval and hopes to be selling a refined version of NeoMano by year's end, at a price of about $1,200 Cdn. More details at www.neofect.com.

GILLETTE TREO

The Gillette TREO is designed specifically to allow a caregiver to safely and effectively provide a shave to anyone who can't use a razor independently. It features a wide, easy-to-grip handle that allows the razor to be used like a paintbrush in the caregiver's hand. The handle also has a unique "divot" that caregivers place their fingers on for a steadier shave, as well as a built-in reservoir of shaving gel, allowing caregivers to lather and shave in one motion. A clog-free head is another feature. Since October, Gillette has been testing the TREO in a pilot program which saw 50,000 units provided free to people in the US and the UK who requested them. The data gathered in this pilot will help determine the final design.

WHEELAIR

The wheelAIR seat back is intended to provide a modern solution to the often serious problem of temperature regulation for people with SCI, along with others who use wheelchairs. The wheelAIR uses a built-in, battery-powered fan to gently blow air onto a user's back, reducing core temperature by taking away excess heat and moisture. The cushion itself is constructed of quality foam and fabric to provide ergonomic support. Staels Design, the Scottish company behind the wheelAIR, just received a major boost in January when it made a deal with investors on the UK version of the TV series Dragons' Den. Visit www.wheelair.co.uk for more details and video.

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Join our South Fraser Active Living Group, sign up for Cooking & Nutrition workshops in Surrey, pop in on the new Women's Group in the Okanagan, connect with WAGS (Wives & Girlfriends) of SCI in Vancouver and around BC, or drop in to any of our ongoing coffee groups throughout BC. You can also check out SCI BC's Virtual Peer groups from the comfort of home. Visit sci-bc.ca/events or email babbott@sci-bc.ca for details!

Ramp up your career.

You have the skill, potential and drive, but finding your career path after an SCI can be tough work. This year's SCI Forum is all about employment, helping you to discover new opportunities, identify workplace rights and supports, grow in a current role, or forge your own path. The 2018 Forum takes place Saturday, April 14 at the Blusson Spinal Cord Centre. For more info and to RSVP visit sci-bc.ca/sci-forum-2018.

Have a ball.

Going through Paralympic withdrawal? All of the fast-paced action of the Canadian Wheelchair Basketball League (CWBL) will be on display in Vancouver from April 6 to 8, when the top female club teams from across Canada compete in the 2018 CWBL Women's National Championship. Visit bcwbs.ca/news/events for more info, then come out to the Richmond Olympic Oval to cheer on your favourites.

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Women of… SCI

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A few days ahead of International Women's Day, more than 50 women with SCI and related disabilities gathered in an airy, sunlit hall at Vancouver's VanDusen Botanical Garden for a day of hands-on workshops, empowering discussions, and mutual understanding.

Formerly the Women's Tea, this year's Women of SCI (Strength – Confidence – Independence) event saw the diverse group of women channel their inner yogis, bust out some hip-hop moves, improve at improv, and learn to throat jab an attacker. Lunch was served, along with poignant lessons on confidence, and an all-star panel of women living with SCI rounded out the afternoon.

Later that evening, panelist Tara Llanes, a professional mountain biker and all-around athlete, took to Instagram: "What an incredible group of women that shared some nuggets of wisdom on #selflove."

We couldn't agree more!

Want to join us next year? Keep your eye on sci-bc.ca/events

Iconic.

Erin Clark, a Canadian who now lives in Spain, has taken the highly competitive world of pole sport by storm. Based on pole dancing, pole sport incorporates acrobatics with artistic moves on a vertical metal pole, all choreographed to music. Rules and competitions are governed by the International Pole Sports Federation (IPSF), which is working hard to have the increasingly popular sport become part of the Olympics.

Clark was born with sacral agenesis, which resulted in paralysis in her legs. Originally from Ontario, Clark started her career as an improv and circus artist in New York. Several years ago, she moved to the Spanish town of Vila-seca, where she began training with a studio of circus artists. They recognized that her strong, petite frame and performing background made her a great candidate for pole sport.

She gave it a try—and just months later, she was crowned the winner of Spain's first para-pole sport division at the 2017 Spanish Pole Sport Nationals. She went on to compete at the World Pole Sport Championships that year, where she came second to a competitor with functional legs and hips in a category still graded on able-bodied judging criteria. The ensuing dispute led to the creation of proper functional categories in para-pole sport. These will be introduced during the 2018 World Championships, in which Clark will no doubt be considered a favourite to win.

But for Clark, excellence in pole sport is only one of many life pursuits. Unapologetically creative, sexual and worldly, she uses her physical attributes, along with her writing skills and social media, to challenge stereotypical views of people with disabilities—particularly in the context of sexuality.

"For me, being a competitive pole dancer is not my primary goal," says Clark. "It's the most visible thing I'm doing, but I'm using it as a way to talk about the things I was already talking about and presenting. Now it's just another element of my lifestyle, but isn't any bigger than any other thing that I'm doing."

Learn more at www.howtobeasexicon.com, and check out her viral video on YouTube—search for "My Wheelchair Won't Stop Me Being a Pole Dancer." ■

PHOTOS BY ELI MORA PHOTOGRAPHY

Risky Business

When the widely-respected Cochrane Collaboration published its review suggesting there was no benefit to single-use catheters, UBC's Dr. Andrei Krassioukov had doubts. So he and his team committed themselves to setting the record straight.

Reduce, Reuse, Recycle. While it's a great mantra for a beleaguered planet in this 21st century, it just isn't applicable when it comes to urinary catheters, according to an international group of researchers led by Vancouver's Dr. Andrei Krassioukov.

In 2014, the Cochrane Collaboration published results of its systematic review of 31 clinical trials that compared single-use to multiple-use catheters and their effect on urinary tract infections, or UTIs. The bottom line, concluded Cochrane reviewers, was that there was no convincing evidence that the incidence of UTIs was increased by reusing catheters.

Cochrane is a unique, well-established organization that collects data from many studies around the world and subsequently provides evidence to guide best practices in medicine. Its credibility stems from the fact that it's a global, independent network of researchers, clinicians, and others interested in health—one that prides itself on being free from commercial sponsorship and other conflicts of interest. So when Cochrane speaks, people listen. And if you're going to challenge its findings, you'd better have your facts straight.

When Krassioukov read the Cochrane catheterization review shortly after it was published, he immediately had a gut feeling that it might be one of those rare times when Cochrane didn't get it quite right.

Two years prior, Krassioukov, who is a physiatrist, professor of medicine at UBC and an ICORD investigator, had spent a great deal of time working with athletes prior to and during the 2012 Paralympic Games in London. He had spoken at length with many of these athletes specifically about UTIs and catheterization.

"Wheelchair athletes from wealthier countries would only use each catheter once, while athletes from developing countries would clean and reuse their catheters again and again," says Krassioukov. "The athletes who used catheters only once experienced three to four times fewer urinary tract infections than athletes who reused catheters."

Based on these observations, and his own previous research that concluded single-use catheters resulted in fewer UTIs, Krassioukov assembled a team to re-examine the evidence. It included UBC medical student Kate Christison, who, under Krassioukov's guidance, assumed the role of project co-lead, along with Dr. Matthias Walter, a UBC and ICORD postdoctoral research fellow.

"The 2014 Cochrane review skewed neither in favour of re-using catheters nor against single-use catheters," explains Christison. "The authors questioned whether healthcare providers should cover the cost of pricier single use catheters based on their conclusion that there is no difference between multiple-use and single-use catheters. Our findings challenged this conclusion. After our team independently reviewed data from each study included in the Cochrane review and completed an independent analysis, we found there was a trend to support single-use catheters over re-use."

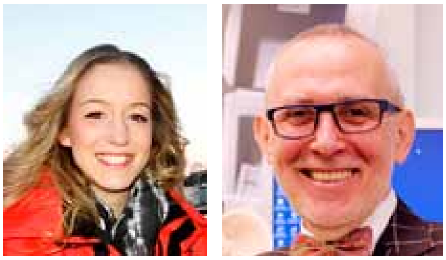
The team then sent its findings to acting editor-in-chief at Cochrane, which had only recently published a 2017 follow-up analysis that had reaffirmed the findings of the original 2014 review.

"No organization is perfect or above scrutiny," says Christison. "As it should, the Cochrane Collaboration explicitly welcomes feedback and, from our experience, responds to such feedback appropriately. (They) swiftly withdrew the publication in question after receiving our comments, and cited our team publicly as the reason for doing so."

Meanwhile, Krassioukov's team published its own results late last year in the *Journal of Neurotrauma*. The essence of those findings was that the 31 studies reviewed in the original Cochrane review do, in fact, tend to favour single-use catheters.

Christison says it's a relief to have the record set straight. But she also concedes that the original Cochrane re-

Kate Christison and Dr. Andrei Krassioukov



view probably did some damage prior to that, in terms of skewing the policies and practices of healthcare providers towards catheter reuse, with a possible consequence being unnecessary UTIs for people with SCI.

"Off the top of my head, there is no other Cochrane review that had such a huge influence and was withdrawn for a reason similar to this one," she says. "It's unfortunate that, only after our team identified discrepancies in the 2014 Cochrane review, this publication's strong impact on healthcare providers and agencies to recommend reuse of catheters in individuals relying on intermittent catheterization has finally been challenged. Our experience provides a reminder that the critical appraisal of research always requires a keen eye, regardless of its source."

In the interim, what should you, as someone with an SCI, do?

"At this point, we do recommend single-use catheters for intermittent catheterization," says Christison. "There is no standardized method to clean re-usable catheters, and certainly no research to support that they are as effective as single use catheters for reducing the risk of urinary tract infection."

Christison and the rest of Krassioukov's team are now conducting a new systematic review to determine if it can, in fact, make strong recommendations in favour of single-use catheters.

Around the world, and even from province to province in Canada, there are large differences in the coverage of costs for catheters. In some countries, such as France, it's actually illegal to reuse catheters. Other countries claim they can't afford to cover the costs of single-use catheters.

Here at SCI BC, we think it's obvious that this is a short-sighted approach, as one person's yearly cost for single-use catheters is insignificant compared to the treatment and lost productivity costs of a single UTI.

Christison agrees.

"While we do recommend that readers strive for single-use catheterization, we know this is likely cost prohibitive for many individuals," she says. "We wish to encourage healthcare providers to advocate for the health of their patients and to cover the cost of single-use catheters. To spin this further, no one would consider re-using syringes and needles anymore, so why would someone think that re-using catheters will have no implications?" ■

ask the SPIN DOCTOR

Cody from the Okanagan writes, "I've been taking Cipro for a nasty UTI. Haven't I read that antibiotics like Cipro can be dangerous?" Answering our question this issue is Dr. Rhonda Willms, Medical Manager of the Spinal Cord Injury Program at GF Strong Rehabilitation Centre.

Among the many great reasons to prevent UTIs is to avoid the need to be prescribed fluoroquinolone antibiotics, such as Cipro and Levaquin.

If you've recently been prescribed one of these, you may have noticed that they now carry a black box warning on the packaging. That's because these types of antibiotics have been determined to have some potentially serious side effects, including tendinitis and/or tendon rupture, muscle pain or weakness, joint pain or joint swelling, peripheral neuropathy (a type of nerve damage), and central nervous system effects—psychosis, anxiety, depression and suicidal thoughts.

These side effects can occur hours after exposure to fluoroquinolones, but they also might not show up until weeks later. Some patients report these side effects lasting a year or longer.

The incidence of these side effects is very low. But, specific to the side effect of tendon damage, there are factors that can increase the risk: corticosteroid use, kidney disease, high physical activity levels, diabetes and rheumatic disease all may raise the risk of tendon rupture.

As the evidence against fluoroquinolone antibiotics has mounted, various public health authorities around the world have been prompted to issue warnings about them. For example, in 2016, the US Food and Drug Administration (FDA) released a warning that, for many conditions, the risks of using fluoroquinolones outweighs the benefits.

"Because the risk of these serious side effects generally outweighs the benefits for patients with acute bacterial sinusitis, acute exacerbation of chronic bronchitis and uncomplicated urinary tract infections, the FDA has determined that fluoroquinolones should be reserved for use in patients with these conditions who have no alternative treatment options," wrote the FDA in a press release announcing its warning.

In January of 2017, Health Canada followed suit, issuing its own warning about fluoroquinolone side effects and introducing the requirement that manufacturers include warnings on any packaging.

So where does that leave people with SCI, given that many of the UTIs they experience are complex, and fluoroquinolones are viewed as one of the few effective antibiotics for treating these UTIs?

The answer is not straightforward. If your UTI is uncomplicated, your physician may have some other antibiotic options. But if your UTI is complex, fluoroquinolones may still be the preferred option.

What is clear is that avoiding UTIs in the first place is the best strategy of all.

Aging & SCI

Research shows that people with SCI are living longer than ever before. Yes, there are a host of potential health problems that accompany aging for people with SCI. But some planning and forethought during your younger years can help keep your quality of life on the right track well into your golden years.

"Aging happy and well, instead of sad and sick, is at least under some personal control," once wrote the brilliant Harvard psychiatrist and author, George E. Vaillant. "We have considerable control over our weight, our exercise, our education, and our abuse of cigarettes and alcohol. With hard work and/or therapy, our relationships with our spouses and our coping styles can be changed for the better. A successful old age may lie not so much in our stars and genes as in ourselves."

In recent decades, variations of Vaillant's view of aging have become more common in the world of medicine, in both research and everyday practice. A singular focus on simply preventing or postponing death has given way to an emphasis on increasing quality of life in our later years—and an understanding that the way we live our younger lives is the key to making this happen.

For readers of *The Spin*, the need to plan for our older years may be even more vital, since SCI brings with it a host of secondary complications, a tendency to overuse certain body parts in order to remain mobile and independent, and a predisposition to a range of cardiovascular and pulmonary disorders.

With all this in mind, we set out to examine health and aging in people with SCI—how SCI affects aging, the most common physical and mental health problems people with SCI are likely to experience, and the ways that planning and prevention can help mitigate the threat and improve quality of life in our later years. Lending a hand are two recognized experts in SCI and aging: Denver's Dr. Susan Charlifue, and Dr. Sander Hitzig from Toronto.

Charlifue is Co-Principal Investigator of the SCI Model System at Craig Hospital, and she has managed and completed seven major investigations of aging with SCI in the USA and the UK. Hitzig is a scientist at St. John's Rehab Research Program at Sunnybrook Research Institute, an assistant professor at the University of Toronto, and an affiliate scientist at the Toronto Rehabilitation Institute. His research focus is examining the consequences of aging with an SCI and other disabilities, and identifying factors that promote health and wellbeing.

Let's start with a caveat.

When it comes to SCI and aging, there's a lot we know. But both of our experts, Charlifue and Hitzig, made it abundantly clear: there's a lot we don't know. Aging and geriatrics research in the general public is a growing field—not surprising, given our greying population. But people with SCI form a very small subset of the general public, one that's had arguably more pressing issues that have demanded attention. So aging in people with SCI really hasn't been the subject of a great deal of quality research.

> "We do know that people with SCI are at risk from premature aging in some of the body systems—most notably in the cardiovascular, endocrine and musculoskeletal systems."

Add to this the fact that every individual ages differently. There are many factors involved—where you live, your financial means, your support network, your ethnicity, your ancestry, and, specific to SCI, your level and completeness of injury. So some observations and recommendations we make here may be relevant to your individual situation, and some may not.

So...how long will you live?

The short answer is, no one knows. We are all different and for any individual, life expectancy can't be predicted.

What we do know is that, in general, SCI can impact life expectancy, but less so than was the case in decades past. The general consensus is that the average life expectancy for people with SCI hovers just below the average for the general population.

The bad news is that level and completeness of injury can make a difference in terms of life expectancy.

Here's what our friends down the road at the University of Washington's Northwest Regional Spinal Cord Injury System say about longevity on their website: "By 1998, persons with SCI had an estimated life expectancy that showed greater resemblance to that of the general population: for those with complete tetraplegia (quadriplegia), life expectancy was 70 percent of the life expectancy of the general population; for those with complete paraplegia, it was 86 percent; and for anyone with significant motor preservation (incompleteness), it was about 92 percent."

Given that this data is 20 years old, we can probably assume there have been modest further improvements in these estimates. The bottom line is that anyone who is paralyzed from an SCI has the potential of living a long and fulfilling life. But that doesn't mean it's a given.

Physical Health: Triple Jeopardy

It turns out that aging can present a triple threat for people with SCI.

First, you may have to deal with the same age-related risks that everyone else is at risk of. No one, disabled or not, gets a pass when it comes to the aging process. Disease, fading strength and mobility, a growing waistline—these are potential realities for every human being, including people with SCI.

Second, while there are large gaps in knowledge, it's clear that, with age and over time, SCI contributes to and amplifies decline in various body systems. The result is an elevation of risk in key areas, which we've listed in the sidebar below. Denver SCI peer counsellor and researcher Richard Holicky, who has been writing about SCI issues since his own injury in 1989, summed it up nicely in a 2014 feature in *New Mobility* magazine: “In addition to the normal wheeler problems—skin breakdown, shoulder problems, pain and plumbing malfunctions—we’re also more likely to face high blood pressure, cholesterol disorders, diabetes, and being overweight or obese. Nor are we immune to more mainstream diseases such as coronary artery disease and cancer.”

Third, SCI often triggers some declines in some body systems prematurely.

“There is a body of evidence that suggests that, in some body structures, people with SCI may see changes earlier than their non-disabled peers,” says Charlifue. “For example, upper extremity musculoskeletal changes due to pushing wheelchairs will be evident, as will some other osteoarthritic changes.”

Hitzig agrees. “We do know that people with SCI are at risk from premature aging in some of the body systems—most notably in the cardiovascular, endocrine and musculoskeletal systems,” he says. “This means that people with SCI, especially those who rely primarily on wheelchairs for mobility, are at higher risk for earlier onset of cardiovascular disease and diabetes. As well, there is a higher risk for osteoporosis, even in young adults, and there are high rates of shoulder pain.”

Physical Health Implications of SCI & Aging

People with SCI are at risk from many of the same health problems as the general population. But your SCI can increase the risk of some of these threats, and in some cases, trigger their early onset. Not only that, you’re also susceptible to a variety of other conditions specific to your SCI. But don’t despair—as you’ll read on the following pages, taking steps while you’re younger can help alleviate many of the risks.

Nervous System: Decreases in strength, walking ability, reaction time and fine motor skills are all possibilities. Although rare, you could also experience worsening of neuropathic pain. And overuse of upper extremities can lead to nerve entrapment in the shoulders and arms—up to half of people with SCI deal with some kind of pain in their upper extremities.

Musculoskeletal System: Common problems are osteoporosis (loss of bone mineral density) and resulting risk of fractures, and once again, overuse of the shoulders, resulting in nerve entrapment and rotator cuff injuries—many of which can be irreversible. Other potential problems are arthritis, joint stiffness, and overall diminishing of strength.

Cardiovascular System: Cardiovascular disease (CVD) is the leading cause of death for people with SCI. People with SCI are three times more likely than non-disabled people to have heart disease, and four times more likely to suffer a stroke. Many CVD risk factors—blood pressure disorders, inflammation, abnormal cholesterol, and abnormal blood sugar—can be amplified by SCI.

Respiratory System: SCI compromises our breathing ability, and aging can amplify this effect. This contributes to fatigue and a loss of vitality, and an increased susceptibility to pneumonia and sleep apnea. All of these conditions can, in turn, elevate the risk of CVD.

Gastrointestinal System: Increased constipation, incontinence, gallstones, acid reflux, and weight gain are all commonly reported as people with SCI age, and may necessitate changes in programs, diet and personal assistance.

Urinary System: Age also commonly brings with it decreased bladder capacity and kidney function, increased risk of UTIs and kidney stones, and increased risk of bladder cancer.

Immune & Endocrine Systems: For people with SCI, age can further limit the body’s already compromised ability to produce key hormones—human growth hormone, testosterone, and estrogen. As well, insulin production can decrease, leading to higher risk of diabetes. And the overall immune response is often compromised with age.

Integumentary System: SCI brings many risks to skin health no matter your age, but aging compounds the problems. Decreases in collagen production, skin elasticity and thickness are all common. This, along with a loss of “padding”, makes aging skin more susceptible to burns, tears, bruises, and pressure ulcers.

Others: Increased sexual dysfunction and spasticity are also potential problem areas.

Both Charlifue and Hitzig say that it’s not clear if these premature declines are a byproduct of age itself, or the number of years since injury.

“Duration of injury is a factor in some cases, but isn’t always the determinant,” says Charlifue.

“In terms of the cardiovascular and endocrine systems, it’s difficult to tease apart what’s occurring due to chronological age and what’s due to years post-injury,” adds Hitzig. “But some of the studies suggest that inactivity and sedentary lifestyles are the contributing factors in these cases (thus, years since injury is likely involved). In terms of the musculoskeletal system, years post-injury plays a prominent role. Interestingly, in some adults who sustain their injury when older, they don’t lose as much bone mass compared to younger adults, because they may have already experienced typical age-related losses in bone mass, and they have ‘less to lose’ so to speak.”

At this point, you’re probably wondering, “What chance do I have, given this aging triple threat?” But it’s not all bleak.

Planning: The Key to Aging Well

As we’ve already outlined, aging with SCI can be challenging. Not only do you have to worry about all the standard age-related health problems that everyone is at risk of, but you have to deal with the fact that SCI amplifies the threat of some of these scenarios—and that in certain areas, it triggers early onset as well.

The good news is that you can lessen the severity of some of these threats, and even eliminate them.

“Fortunately, some of these issues can be addressed through lifestyle changes—eating better, not smoking or drinking, and exercising regularly,” says Hitzig. “Although it can be more difficult for people with SCI due to paralysis and impact of other secondary health conditions like pain, living a more healthy lifestyle will help to circumvent or mitigate the onset of cardiovascular disease and diabetes. Eating healthier may also have benefits for the digestive system,

(continued on page 19)

exPEERience. Meet some of your SCI BC Peers who are dealing with the challenges of aging.

Sherri Newcomen, 74
T5-6 | Kelowna

Many readers will recognize Sherri Newcomen, as she was an SCI BC Peer Counsellor in the Okanagan for many years.

Newcomen was injured in a motorcycle accident in 1982, when she was 38.

"Now, at the age of 74, I am feeling blessed to be living in an era where society has become more familiar and accepting of people in wheelchairs," she says. "Life hasn't always been so easy. I found it challenging to maintain my independence. Thanks to supportive family, friends, health care professionals and many others too numerous to mention, I have maintained my independence. But aging with a disability does have its challenges!"

As with so many people with SCI, one of the most severe challenges Newcomen has had to stare down is losing mobility after a lifetime of relying heavily on her shoulders.

"A few years ago, I switched from driving a two-door car, which I pulled my folding wheelchair in and out of several times a day, to a lift-equipped van with a six-way power seat—and a rigid frame wheelchair," she says. "My shoulders were wearing out from overuse, and it hurt to go anywhere. Arthritis had set into joints; stiffness and back pain was getting me down. After a short time using the van, my body ailments almost disappeared, so I'm now getting out more and enjoying life."

She adds that pressure sores, along with bowel and bladder function, are ongoing concerns as she ages. "Proper care and treatment is necessary, so don't delay in getting the help you need to deal with it to maintain a healthy lifestyle," she advises. "For anyone, and especially those with new injuries, I suggest keeping up with current information on SCI research, talking to others, joining a support group, getting out and enjoying yourself, and always maintaining a positive attitude!"

Bruce MacLeod, 75 | T11-12 | Horsefly

Bruce MacLeod was injured in a car accident in Parksville in 1981. In 2001, 20 years of wear and tear on his shoulders finally caught up with him. He and his wife sold their general store, and MacLeod retired at the age of 59.

"I finally got an old used electric wheelchair in 2003," he says. "Today, my shoulders have recovered to the point where they only hurt when I laugh."

In 2005, MacLeod and his wife moved back to his home community of Horsefly in the BC Cariboo. He began to face some challenges in his 70s. In 2012, while transferring, he scraped his butt. This quickly developed into a serious infection. He's battled it ever since, and has been told it will never completely heal due to a number of factors including his age.

"I have also had pneumonia twice since we moved to the Cariboo, which is a new experience," says MacLeod. "But other than my butt I am healthier than many of my AB friends."

On a personal level, he had to deal with the death of his wife in 2016, and his own health flagged during this time. But despite that, he remains optimistic—and determined to remain as independent as possible in his own home. "I'm very fortunate to have a very upbeat attitude; I accepted my disability right away and worked hard to be in shape when I got out of GF Strong," he says. "I have smoked pot ever since my accident, so I feel that it has kept me on an even keel." He credits much of his resolve to a life-time dedication to volunteering.

MacLeod has plenty of advice for younger Peers. "Avoid relying too heavily on their shoulders—and to pay careful attention to avoid damage to aging skin. Learn proper bladder care, this is paramount; bowel management the same. Watch your diet; most of us eat the same after our accident as we did before and become overweight, and it's much easier to put it on than take it off. Strive for high-fibre diets, lots of protein, less carbs; it's all out there for you to research. And exercise moderation with alcohol."

Jim Derby, 77 | C4-5 | Chemainus

Jim Derby was injured relatively recently. In 2012, at the age of 71, he fell some 12 feet while working on his boat.

"I have constant pins and needles on both sides," says Derby. "I've had physio twice a week since I was injured, trying to maintain my mobility. I am able to walk with forearm crutches for a short distance, but I have continuing pain, managed with a little pain medication. I have also had a number of UTIs that cause setbacks when they occur."

Generally, he says his physical health continues to be quite good, but he concedes that trying to maintain a positive mental attitude is something he has to constantly work at. For this, he mainly relies on his personal network of family and friends.

"I have an exceptional, caring, loving wife," he says. "We have three married sons and five granddaughters, all giving love and support. I have a large group of friends and a wheelchair group that keep me busy socially. We are also quite avid gardeners with always something to do around our property."

His advice to younger readers? "Try to stay positive and keep engaged with family, friends and pets."

Carol McLelland, 74
C4 | Fort St. John

Carol McLelland is another senior who acquired her SCI relatively recently—in 2011, as the result of an auto accident. She's clearly a glass-half-full type. She balances the reality that she can't walk with the fact that she hasn't been able to feel pain in her knees since her injury. "And I sure don't wear shoes out like I used to," she adds.

She says that she has a joyful life.

"I have been blessed with good health and work at staying that way. I feel my life is full and happy and I am aging gracefully."

She concedes that she's recently had increasing problems with secondary health complications. "I do have more UTIs," she says. "I do have bad spasms some days, but they are either from catheters or seating problems."

She says she's also in a good place mentally.

"Like most people, I have down days, but they don't last long. I have a very strong support group around me—my husband of four years, my two sons, my caregivers, as well as the birds, squirrels, deer, coyotes and other furry people outside to keep me sane. I also go to coffee and tea groups to keep in touch with other Peers, who are so amazing."

Staying active is also important for McLelland, who says she still likes to "flirt with boys and give free hugs to anyone who wants one."

"I own a couple of small businesses that keep my mind active," she continues. "I read a lot and paint; these keep my mind active. Mentally, I'm still a kid at heart...I enjoy and love the people and things I have around me."

She offers some sage wisdom to younger readers. "Aging is mostly in your mind. Don't sit around moping about what can't do; get out and do what you can. You can be your own best friend or worst enemy. There's no sense thinking about what could have been; instead, think about what you have and what lays ahead."

Tom Parker, 75 | C6-7 | Richmond

Tom Parker was injured at the age of 19 while skiing on Grouse Mountain. That didn't deter him from enjoying a lengthy career in several positions across Canada, including a spell as a counsellor with SCI BC. But in 2006, when it came time to choose a location for their retirement home, Parker and his wife Patricia decided on Richmond's city centre.

"As I age, this allows me to maintain my social interaction without having to drive everywhere," he says. "In addition, we live in a housing co-op, so we're actively involved with both young families and other retirees."

Staying socially active is vital to Parker, and continuing his life-long involvement in sports and recreation deep into retirement has been an important way for him to achieve this. While he's not an active competitor much anymore, he remains involved through volunteering.

"I relish the opportunities to be involved and share my knowledge in areas where I was active in my working years," he says.

He concedes that aging has brought several health challenges. "Over the years, my active life style resulted in many fractured bones—which, since retirement, have become much more serious. I have been using a power wheelchair since suffering a major fracture I got while on a cruise in 2012, which resulted in an extended period of no exercise—even transfers were out of the question. The resulting transfer difficulty has greatly reduced my ability to travel. This is the hardest part of this limitation." His limited transfer ability has also led to skin breakdown in sweaty seating areas, which necessitates reliance on home support workers most mornings to reduce the care load on his wife.

"Another change due to aging is in bowel routine," he says. "Over the years since injury, my diet seemed to have little effect on bowel routine; now I am actively researching diet issues as they relate to SCI to try to bring back regularity." He's also experienced more bouts with AD and low blood pressure as he's aged.

"Being aware of changes to health—and being willing to talk to peers and medical professionals about alternate ways of coping—has been very important in dealing with the aging process," he concludes.

Karin Watson, 75 | C5-6 | Courtenay

Karin Watson retained a high level of mobility after being injured in a 1982 car accident in the UK. But she admits that her abilities, along with her physical health, have declined since she turned 70.

"I have really only in the last five years experienced loss of function as a result of conditions showing up," says Watson. "For example, temporal arteritis (inflammation of the walls of arteries), which necessitated me taking prednisone for three years. Which, in turn, did a number on my muscles and eyes." She explains that cataracts are a well-known potential side effect of prednisone.

She then endured a bout of cellulitis in her leg, and she's never enjoyed the same mobility since. She's also been experiencing more kidney stones and UTIs. "So I'm aware," she says, "of losing function after interventions, which didn't happen when I was younger."

Mentally, she says she always struggled with a sense of isolation after her injury.

"But in some ways, this is lessening as my choices lessen," she says. "I am becoming more at home with myself. Even now, I am still learning to take up as much space as I need—when I'm parking, swimming, in a meeting—to be comfortable. There is more peace as I age."

Watson offers this advice for younger Peers. "Enjoy what you have while you have it. Physical activity of whatever kind supports both body and mental health. I find contact with other disabled people very useful for support and mentorship; I probably would have learned more from others in my position if I had looked for them earlier."

and having a good diet can help skin integrity and bone health. Trying to adopt a healthier lifestyle—for instance, adhering to a Mediterranean diet or getting regular exercise—will benefit the whole body, and should be a priority, for people with SCI and anyone else."

Charlifue points out some other good habits that can pay off. "I think the advice I would offer is probably the same as we would offer to anyone who is aging in general—get immunizations; don't smoke; use alcohol sensibly if you use it at all; develop a strong social network of family, friends, and faith community if that's important to you; and make sure you have a good network of health care providers who listen to you."

In other words, cleaning up your act can help. But here's where it gets a little tricky: adopting a healthy lifestyle when you're already in the midst of your later years—or already dealing with one of the age-related health threats we've discussed—can only help so much.

What's required is a proactive approach. If you want to increase your chances of living well into your later years, you need to take action now. Make a plan while you're younger and healthy, and act on it. And if you think you've got oodles of time, think again.

"It's always important to plan ahead, and this is probably the best advice we can give," says Charlifue. "If something you're doing causes pain, look for alternative ways of doing things to minimize that pain. If you have weight issues and your diet could use some adjusting, try to make small but meaningful changes now to help control obesity—which also has a negative impact on weight shifts, transfers, etc. If you have consistent bowel or bladder troubles, seek other ways to manage bowel and bladder evacuation. If you have pressure sores, greater attention early on will help minimize repeated pressure injuries."

Hitzig is equally adamant that the time to take action is right now, no matter how young you are.

"Unfortunately, people with SCI don't have the luxury of putting off beneficial lifestyle changes, because of the number of challenges to their health," he says. "An able-bodied person who is in their 20s might be able to eat whatever they want, not exercise, drink and party, smoke—and then might be able to get their act together when they're a bit older and reverse some of the effects of the negative lifestyle choices. People with SCI don't have this luxury. Given the changes to a person's body post-injury, especially with relation to losing bone mass in the lower limbs and physiological changes that happen to the cardiovascular and endocrine systems, there is a need to be proactive in making health a number one priority."

> "Unfortunately, people with SCI don't have the luxury of putting off beneficial lifestyle changes, because of the number of challenges to their health."

Hitzig admits that he often feels a bit guilty giving this advice, since everyone, regardless of ability, struggles with always eating right, getting enough exercise and sleep, and managing stress.

"People need to enjoy life, which means sometimes eating those things that we shouldn't but do anyway," he says, admitting that he has his own weakness for chocolate chip cookies. "Likewise, trying to exercise despite having to work full-time is tough. Regardless, as people age, they need to re-assess what their level of function is and try to plan accordingly in ways that may not always be our ideal but would let us still continue to enjoy our lives. For people with SCI, this might be the realization that switching to a power chair would be better for their shoulders if pain becomes an issue, or accepting the need for a support worker if your strength starts to wane with older age, making doing transfers or other care activities more challenging."

Lack of space prevents us from getting too deep into individual health pitfalls and how to avoid them, but we will stress that the shoulders issue is critical because, by the time you're feeling chronic pain as the result of overuse, the damage may be irreversible, and the result could be a catastrophic loss of your independence.

"The old saying of 'use it or lose it' really doesn't apply anymore," says Charlifue. "We're more likely to recommend 'conserve it to preserve it.'" The bottom line? Heed the warning signs, overcome your pride, and switch from a manual to power chair or a car to a van as required, and make changes in your daily activities (for example, transferring) to remove stress from your shoulders before it's too late."

If you're willing to take Charlifue's and Hitzig's advice to heart, but don't know where to start, there are several excellent online resources to help you make a plan. A great starting point is the 100,000 KM checklist (eprimarycare.onf.org/rsc_files/Cravens_Checklist.pdf), prepared by Dr. Cathy Craven, a physiatrist at the Toronto Rehabilitation Institute who specializes in the prevention and treatment of secondary medical complications of SCI. And some excellent planning guides that are specific to various injury levels have been developed by the Spinal Injuries Association (SIA), the UK's equivalent of Spinal Cord Injury BC. You have to register with SIA to gain access to these guides, but there is no charge to do this—visit www.spinal.co.uk to learn more and get started.

What about mental health?

Of course, there's more to good health than preventing physical ailments. That brings up the question: are people with SCI at greater risk for depression and anxiety as they age?

On the surface, there's a lot to deal with as you grow older with an SCI. In addition to all the physical health concerns noted previously, there's the realities of shrinking independence and greater reliance on assistance—at the same time as the people around you are also losing their own vitality. There's the potential for social isolation, anxiety and uncertainty about what the future will bring, and perhaps angst over shrinking bank accounts.

"Issues of mental health are extremely important to address in people with SCI, as there is evidence that rates of depression and anxiety are about 30 percent higher in people with SCI than in the general population," says Hitzig.

"Studies in SCI suggest that depression is common and more severe for older individuals and those injured longer," adds Charlifue.

But both of our experts concede that there's a flip side to this. "Some studies in SCI have shown that life satisfaction is not necessarily negatively impacted by aging, so this is really a mixed bag and probably has a lot to do with one's world view in general, overall health, social support, expectations, etc.," says Charlifue. "In terms of perspective on life, one thing that happens in people who acquire a disability is something called a 'response shift', which means that what people see as important to their lives changes after going through an injury," says Hitzig. "For instance, people may start to feel connections with friends and family as being much more important than other life domains such as employment because their capabilities or perspectives on life have changed. As a result, several studies have shown that ratings of quality of life in people with SCI tend to be comparable to ratings of the able-bodied population."

For example, one major study of aging with SCI published in 2005 observed that mental health actually improved over time for some people. The possible reasons for this, according to the researchers who conducted the study, were that older adults in general develop and make better use of certain coping strategies for managing pain and disability than younger people do, and that their acceptance of disability is much higher.

While we wait for more definitive studies of mental health and aging in SCI to be completed, Charlifue and Hitzig say there are plenty of strategies for staying emotionally well that people with SCI can employ as they age. These include closely monitoring medications and educating yourself on their side effects and possible negative interactions, having some financial savings in place for use in older age, and staying socially connected, even though a shrinking peer network can make this challenging. Staying physically active is also important, as are staying engaged in activities that give you pleasure and getting out into the community as much as possible.

Above all, get help if you need it.

"Accepting help is not a sign of failure," says Charlifue. "If a person becomes less independent as they age—well, that's pretty normal!"

"Know when and whom to ask for help," adds Hitzig. "This can be a very difficult thing for people to do in general, but it's important to figure out who can give you emotional support, who can give you tangible support, and how you can ask in a way that makes you still feel empowered."

And, says Hitzig, just as with your physical health, every person with an SCI needs to be proactive about their mental health in their younger years.

"It's important to address coping skills and mental wellbeing early post-injury because there are some studies showing that how you cope early post-injury will predict how you cope in the long-term. For instance, one study found that people who were coping poorly at 10 weeks post-injury were also coping poorly 10 years later, while those who did cope well continued to do so at the 10-year mark."

Putting it all together...

By now, the main point we're trying to make should be clear to you: when it comes to your physical and mental health, what you do long before you're older is a major predictor of how you'll fair during the aging process. Just like a retirement fund, the investment you make today has the potential to pay significant dividends later in life, increasing the likelihood that your golden years will be just that: golden.

Yes, we're all different, and aging well depends on a number of factors including genetics. Regardless, taking the time now to contemplate and plan for what may lie ahead will put you in a better position to prevent problems, or make them easier to deal with when they arise.

"Although this is a bit of cliché, there is wisdom that comes with age, and for people with SCI, it's important that we become very adept at knowing our own bodies and what is important in life," says Hitzig. "Being mindful of what is needed to optimize health and wellbeing today will help people avoid difficult situations or at least be able to cope better when there is sudden change in health which can sideline your daily life."

"Aging is a natural process and can be very fulfilling," says Charlifue. "People who age successfully tend to be healthier—remember, SCI is not an illness and people with SCI can be very healthy—and happier, and have more control over their lives." ■

More Information on Aging with SCI

- scireproject.com/community/topics/
- spinal.co.uk/
- spinal.co.uk/learn/understanding-sci/ageing-sci/
- sci.washington.edu/info/forums/reports/aging_6.09.asp
- www.unitedspinal.org/resource-center/askus
- craighospital.org/resources/aging-and-spinal-cord-injury

UBC Researcher Investigates Aging & Participation

Emily Giroux is second year Master's student working under the supervision of Dr. Heather Gainforth at UBC Okanagan. The primary focus of her research is to further understand how participation can be enhanced among people aging with an SCI.

"Participation is recognized by the UN as a basic human right," says Giroux. "Examples of participation include the maintenance of strong relationships and the ability to fulfill daily roles and responsibilities. To conduct my research, I am using reviews of the SCI literature and interviews with people aging with SCI to understand their participation needs and concerns. Ultimately, my research aims to support SCI organizations to develop tools, resources or programs that support people aging with SCI to fully participate in society."

Giroux got interested in this type of research in 2014 when, she volunteered at MacWheelers, a community-based and accessible gym at McMaster University.

"It was such a positive experience for me," she says. "I was fortunate to build long-lasting friendships with members of Hamilton's SCI community, and it inspired me to do research that supports a community that did so much for me."

All of Giroux's research is conducted in partnership with the SCI community, including SCI BC. In fact, that's how her current project came to life.

"Our community partners told us that they needed more information to support people aging with SCI," she says. "I have always had an interest in older populations and I further explored this interest by completing a minor in gerontology during my undergraduate studies. I am extremely excited that my research combines my interests and will support our SCI community partners to further understand the needs of people aging with SCI."

Giroux expects to complete her research late this summer, at which point she'll share her findings with us here at The Spin. Meanwhile, she invites any readers who want to learn more about her research to send her an email at emily.giroux@ubc.ca.

Tetra: Necessity Is the Mother of Invention

Aging often brings with it changing needs—and a heavier reliance on technology and aids to daily living. Most of the time, there's a readily-available commercial solution that meets people's changing needs—from basic independence enhancers such as grab bars and transfer boards, to home automation and power mobility products. But every once in a while, somebody needs something unique; something that just can't be bought off the shelf. And for the past 30 years, the Tetra Society of North America has been there to help in these situations.

Tetra recruits technically-skilled and compassionate volunteers who work one-on-one with people with SCI and other disabilities who need custom engineering solutions to achieve greater independence and quality of life. Recipients pay only the cost of any needed supplies.

Not surprisingly, recipients of Tetra's innovations are often seniors. The photos illustrate some examples of the types of engineering solutions that Tetra volunteers have created for older clients.

Tetra is the brainchild of Sam Sullivan, MLA for Vancouver-False Creek and former mayor of Vancouver. When he became a quadriplegic at the age of 19, Sullivan worked with an engineer to devise solutions to augment his own independence. The result was so successful that he created the Tetra Society, which today operates under the umbrella of Sullivan's Disability Foundation.

Last December, the society celebrated a major milestone—its 30th anniversary.

"Tetra is an amazing story," says Chris McBride, SCI BC Executive Director. "From humble beginnings, it has franchised its operations to 45 locations in Canada and the USA. It has created countless independence-enhancing solutions for our Peers and many others. Congratulations to Sam and all Tetra Society staff and volunteers for three life-changing decades."

For details on Tetra's 30th anniversary, visit the TetraNation campaign at www.tetranation.org—it showcases the great work of Tetra volunteers with short videos of their devices in action. It's a great way to get involved, share, and vote on favourite videos. For more details on Tetra, visit www.tetrasociety.org.

Rare Air

Acute intermittent hypoxia, or AIH, has emerged as a promising treatment to strengthen the respiratory ability of people with high level incomplete quadriplegia. AIH therapy, which involves breathing air containing lower-than-normal levels of oxygen, also has potential to improve walking and grasping for people with any level of incomplete SCI. One of the pioneers of this research is the University of Florida's Dr. Gordon Mitchell, who agreed to share what we think is a remarkable detective story of how basic, incremental science resulted in such a promising treatment.

Hypoxia. It's a word that many readers know well—and dread. After all, hypoxia is one of the most serious consequences of sleep apnea. And sleep apnea is a big problem for a lot of people with SCI—particularly those with quadriplegia.

Hypoxia occurs when body tissues are deprived of adequate oxygen. In extreme cases, death is the ultimate outcome. Even mild to moderate cases of sleep apnea, which limits the amount of oxygen entering the bloodstream, results in hypoxia that can, over time, lead to serious health problems.

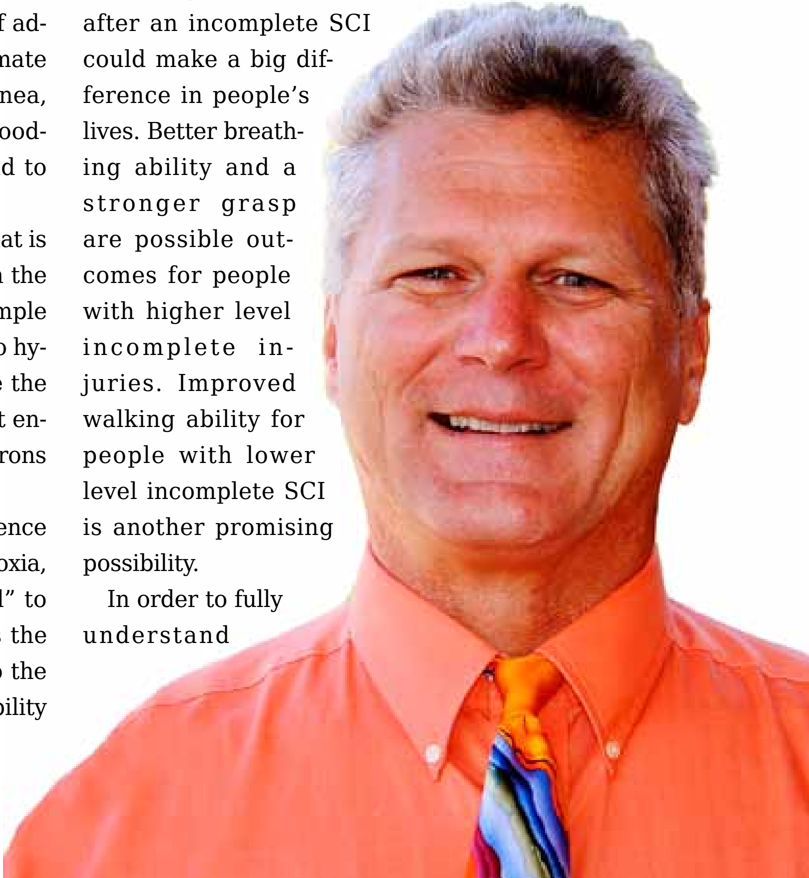
But it turns out that hypoxia has an upside—one that is so significant that it may become a game changer in the search for ways to restore function after SCI. In simple terms, the central nervous system, when subjected to hypoxia, attempts to "fight back" in order to minimize the impact. It does this by producing growth factors that encourage neuroplasticity—the incredible ability of neurons to change, rewire, and regrow.

The best example of this to date is that, in the presence of carefully-prescribed, intermittent, low doses of hypoxia, the nerves that control breathing are "encouraged" to grow and make better connections. This increases the strength of the breathing signal that's being sent to the muscles that control the lungs, and therefore the ability of the lungs to take in more oxygen.

Evidence also suggests that this same benefit of AIH can be used to strengthen the connections of other motor neurons, such as those involved in leg and hand function.

Obviously, any treatment that is able to strengthen the remaining nerve connections after an incomplete SCI could make a big difference in people's lives. Better breathing ability and a stronger grasp are possible outcomes for people with higher level incomplete injuries. Improved walking ability for people with lower level incomplete SCI is another promising possibility.

In order to fully understand



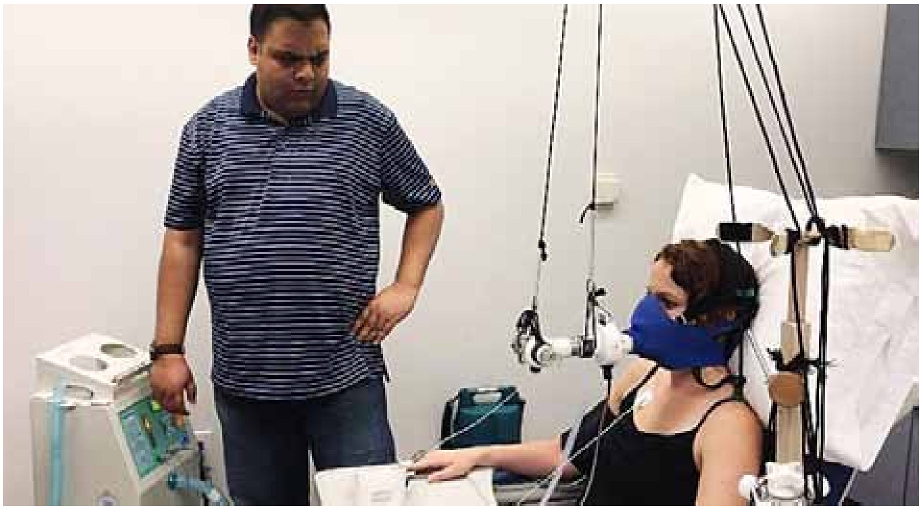
AIH and its possible implications for people with incomplete SCI, let's flip the calendar back a few decades to the 1970s, as Dr. Gordon Mitchell was just beginning his career as a neuroscientist.

Today, Mitchell is Preeminence Professor of Neuroscience and Professor of Physical Therapy at the University of Florida, and Director of the university's Center for Respiratory Research and Rehabilitation and McKnight Brain Institute. But back in the 70s, he was a grad student who became fascinated with the concept of neuroplasticity—the idea that neurons might have the ability to regrow and rewire themselves in the brain and nervous system.

"My interest in the beginning wasn't focused on SCI at all; I barely thought about that," says Mitchell. "The truth is that I was simply interested in the idea that plasticity is an important feature of the respiratory control system. At the time, there was a very strong sense among respiratory physiologists and neuroscientists that neuroplasticity was not an important feature of motor neurons, nor that it was relevant to the neural system controlling breathing. When I would ask questions about it, most thought the issue had already been solved. Consequently, I focused on other topics for the next ten years of my career."

Then, in the mid-1980s, as Mitchell and his colleagues were studying breathing during exercise, they accidentally observed responses that, in Mitchell's mind, could only be explained by the presence of plasticity in the neural system controlling breathing. Intrigued by the idea that the central nervous system was not just static wiring (think of a house's copper wiring) and the possible implications of this, he made the decision to focus the next phase of his research career on identifying forms of neuroplasticity in respiratory motor control.

Fast forward to the late 1990s. Mitchell, who had completed his PhD at the University of California Irvine, had been a professor since 1992 at the University of Wisconsin's Department of Comparative Biosciences. By this point, research had confirmed that, in animal models, intermittent periods of low oxygen consumption could indeed trigger plasticity in the phrenic nerve, the conduit by which signals to breathe are sent from the brain through the spinal cord to the respiratory muscles. And it was also becoming clear that serotonin, an important growth factor or neurochemical, was involved in the process—the hypoxia triggered release of serotonin near spinal motor neurons, initiating plasticity.



Graduate student Shakeel Ahmed supervises an AIH treatment in Dr. Mitchell's laboratory at the University of Florida.

But what no one had recognized was that all of this could be highly relevant in the SCI world.

"That realization first emerged when Tracy Baker (a graduate student at the time) and I discovered that the actions of serotonin were in the spinal cord, and not in the brainstem as originally thought," says Mitchell. "This finding was made in the late 1990s, but wasn't published until 2002 in the *Journal of Neuroscience*."

The implications were enormous. Since the plasticity was occurring in the spinal cord, it immediately raised the question: could AIH-induced plasticity be harnessed to strengthen spared neural pathways at the site of an incomplete SCI—and restore function in the process?

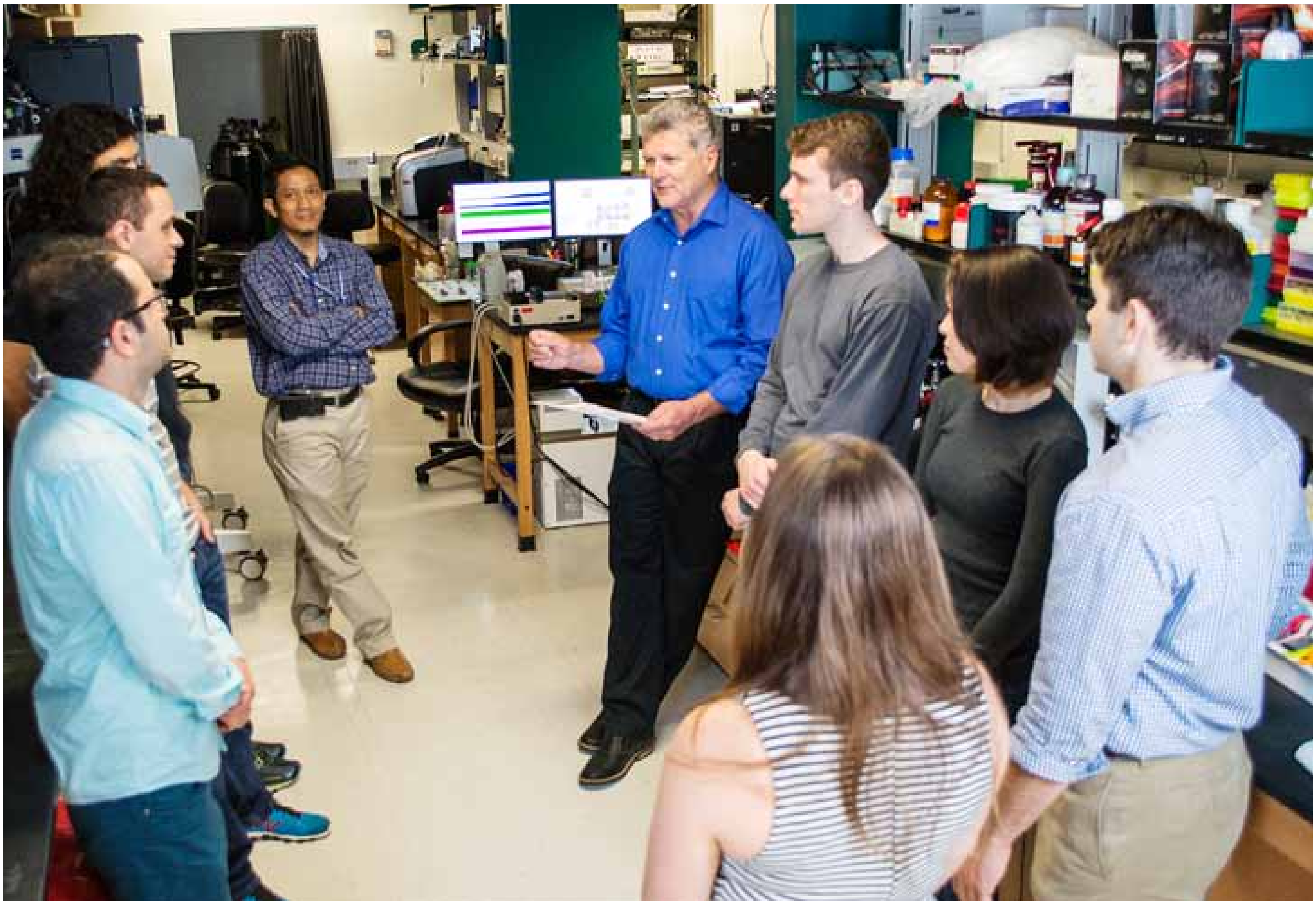
"Some thought it was a naïve idea, but we had to try, using a rat SCI model," says Mitchell.

The resulting study, led by postdoc student David Fuller (now a professor at the University of Florida) saw the rats receive six five-minute episodes of low oxygen per hour for 12 hours each night—the time of the day when rats are most active. The result was a breakthrough: after one week, these daily exposures greatly increased the ability of the rats to generate phrenic nerve activity (and presumably breathing) below the injury. This study was published in the *Journal of Neuroscience* in 2003.

"In the end, we look back and realize that we were lucky in our initial study," says Mitchell. "The key to this treatment is the dose, and it turns out that a low dose is better. High doses of intermittent hypoxia trigger brain and spinal inflammation, leading to pathology and undermining the ability of AIH to trigger beneficial plasticity. With 20/20 hindsight, if we had used a frequency of hypoxic episodes of 10 or greater, we would have been disappointed, and we likely would have moved on to other things."

Over the next decade, Mitchell and other scientists incrementally added to their knowledge and the body of evidence that suggested that AIH had significant potential as a therapy to restore function.

First came the discovery that the release of serotonin after AIH therapy in turn stimulated the production of Brain Derived Neurotrophic Factor or BDNF, and confirmed that it's BDNF that is ultimately responsible for triggering the plasticity in the phrenic nerve.



Dr. Gordon Mitchell leads a discussion about AIH with his laboratory team at the University of Florida.

"This paper gave substance to our mechanistic understanding and led to a 15-year series of papers giving us a fairly comprehensive understanding of just how this works," explains Mitchell. "Understanding mechanisms is really important, since it reassures us that we are studying something real, and improves our ability to refine the best treatment strategies to restore function after SCI."

Meanwhile, complementary work demonstrated that the AIH not only worked in restoring phrenic nerve capacity in breathing, but also in walking ability in incomplete SCI—first in animals, and then in humans.

But Mitchell says the real leap came in 2014, when the Trumbower laboratory (then at Emory University) and the Rymer laboratory in Chicago completed a randomized, double-blind cross-over design study of walking ability in humans with chronic incomplete SCI.

"In this study, AIH was applied for five successive days, either alone, or followed by 30 minutes of walking practice," says Mitchell. "With combined training, the improvement in walking ability was substantial—greater than 35 percent—even days after the training had ended. I think this study raised awareness among a broader community of rehabilitation scientists."

Today, there are six published studies confirming the efficacy of AIH in humans with chronic SCI, including studies of walking ability, breathing ability and hand function. Buoyed by the results, Mitchell and other scientists working in the field now have many additional studies underway, and were recently inspired to create the Therapeutic Intermittent Hypoxia Consortium to share information and stimulate further progress.

Members of the newly-formed consortium, which is led by Mitchell, have their work cut out for them.

"My personal priority is to continue basic research into mechanisms, and to push new knowledge into consideration for clinical application as soon as is practical," says Mitchell, who moved from the University of Wisconsin to his current positions in Florida in 2014. "We have a great team focused on this approach, and we need to test it adequately before we lose that momentum."

Mitchell and his team are seeking answers to several specific questions. For example, are the mechanisms behind improvements in breathing ability the same as those responsible for AIH's ability to improve function in other motor neurons, such as those controlling the legs and hands? Does gender and age make any difference in outcomes in humans, as has shown to be the case in animal studies? Can a combination of AIH and various compounds enhance outcomes, as has been demonstrated with caffeine?

He also wants to know if the therapy has applications beyond SCI.

“Another gratifying outcome would be translation to other clinical disorders that compromise movement,” he says. “If this is a generalizable strategy to restore movement, will it work in those suffering from ALS? MS? Stroke? Peripheral neuropathies? Post-polio syndrome? There are so many other clinical disorders that may benefit from this approach.”

Meanwhile, priorities that other consortium members will work on include development of a standardized device, with safety monitoring and the ability to log data, to deliver the doses of low-oxygen. Identification of biomarkers to help pinpoint which individuals are likely to benefit most from the therapy is another area of research being undertaken by consortium members.

Finally, there’s the burning question of whether or not AIH treatment results in permanent or temporary results.

“What we know is that a single presentation of AIH will trigger plasticity for a day,” he says. “If we expose rats or humans to five to seven days, then the plasticity and functional benefits last nearly a week or more. We don’t yet know if daily use for months will have longer or even permanent effects. That is one of our knowledge gaps.”

If effects don’t prove to be permanent, what are the implications?

“Will a treatment that can help function for a week be useful?” asks Mitchell. “In many respects, AIH is a bit like exercise, but without the need to move. However, it’s clear that traditional rehabilitation in combination is beneficial. Meanwhile, the therapy on its own is easy to administer. It’s not stressful. Would it be worth 45 minutes of time taking therapy, while surfing the web or reading a book or listening to music, in order to enhance walking or hand function for the day? If it’s not possible to elicit permanent effects, it would be really helpful to receive community input on whether or not limited duration benefits will be useful.”

Clearly, while the entire AIH research field is promising, there remains a lot of work to be done. And that’s where the elephant in the room becomes really obvious: who funds this research?

“It is very hard to raise adequate funds for this type of research, as much as we wish to know the answers,” concedes Mitchell. “Efforts are underway to secure adequate funding in each of these areas, but we are far from our goals.”

The reason is clear. How do pharmaceutical companies, who are by far the largest funders of all medical research, make money from low-oxygen air?

Mitchell concedes this is a concern. But based on existing interest, he is optimistic that a medical device manufacturing company may step up to the plate. And he also believes the work is so important that other funding sources that aren’t motivated solely by profit will eventually see the value and come to the table—for example, private foundations and forward-looking government agencies that recognize the work may actually result in cost savings down the road.

Meanwhile, the promise of this research makes it easy for Mitchell to get into his lab every morning and help lead the charge—even after four-plus decades as a scientist working in the field.

“For me, there is a lot of gratification in understanding basic biology—such as the fact that there is plasticity in the neural system controlling breathing, and that we are gaining understanding of how it works. When I was a grad student, we thought of motor neurons as ‘copper wire’ relays between the brain and muscles. Now we know that phrenic motor neurons have exceptional capacity for plasticity. I also find gratification in seeing ideas developed through studies of respiratory physiology translate into an understanding that similar plasticity occurs in other motor systems, including those governing leg, arm, tongue and laryngeal functions.

“And of course, the usual use of the word translation is to see benefits in healthcare. This is an enormously gratifying part of our investigations. After so many years of basic research, we are seeing clear potential that the ideas may impact clinical practice. For me, the ultimate hope is for progress to continue as we explore basic biology, and translate that knowledge to SCI and many other disorders that compromise movement.” ■

Don’t try this at home, kids.

Perhaps you’ve read this and are scheming about ways to try AIH on your own. After all, a form of intermittent hypoxia is already being used by endurance athletes seeking to enhance training by mimicking a high-altitude setting. But Mitchell advises against it—there are just too many unknowns, and exact dosages are critical for safety, in terms of oxygen content of the air and the duration and frequency of treatment.

Meanwhile, you might be wondering who makes a good candidate for AIH. Generally, anyone with an incomplete injury could potentially benefit. But Mitchell points out that, for the moment, some people have to be excluded.

“For example, we currently rule out individuals with a history of seizures in our studies, yet we have no real knowledge that this is a problem,” he says. “It is possible that repetitive acute intermittent hypoxia could even suppress seizures. Experience may eventually tell us that these concerns were unfounded, but a cautious approach is prudent for now. For those with sleep apnea, we also run into a dilemma. Almost 80 percent of individuals with cervical SCI have sleep apnea. Can we rule them out from studies, particularly since daytime intermittent hypoxia is in fact more effective at improving breathing in otherwise healthy people with sleep apnea? These types of dilemmas are the reason we need to keep pressing to obtain real evidence concerning the limits. Clearly, this is a process. I expect that, even if this treatment makes it to clinical practice, we will continue to learn and evolve and refine our therapeutic use—just as with any other treatment.”

Vantastic

Need wheels? Delta Wheelchair Vans, owned and operated by SCI BC Peer Barb Schober, can help—with either a short term rental, or a purchase of a gently-used van.

Last October, SCI BC Peer Mark Stockbrocks parked his wheelchair accessible van on Vancouver's Laurel Street and wheeled into nearby GF Strong Rehabilitation Centre for a routine appointment.

About 25 minutes later, he returned, only to be devastated to find that his van—one of his most important sources of independence—had been stolen.

Ultimately, the van was found by police and returned to Stockbrocks, but not before he discovered the great expense and the sheer impracticality of relying solely on wheelchair accessible taxis, which often took up to two hours to arrive. Fortunately, he was pointed to Delta Wheelchair Vans, owned and operated by fellow SCI BC Peer, Barb Schober. There, Stockbrocks was able to rent a van until his own had been returned.

"Barb runs a professional operation," he says. "It was great! I think Barb has done a great job providing the service."

Schober got into the business quite by accident. She was just four years old when her family immigrated from the former Czechoslovakia. In 1991, when she was 15, Schober was struck by a car at a crosswalk. The result was a C1-C2 complete SCI.

"My level pretty much precludes any physical independence or activity," says Schober. "Given those limitations, I'm more or less a perpetual student. I have a Master's degree from UBC, where I've been doing my PhD part-time, in history—I'm on the final leg, writing my thesis."

She concedes that, from a financial point of view, it probably wasn't the best field to choose, which is how she found herself looking for business opportunities to augment her income early in her academic career.

"Since I was using the internet so

much as just part of daily life, I began to notice how some products were significantly less expensive to buy in the USA—especially wheelchair vans," she says. "I started to import and sell them right about the same time that Walt and Wendy Lawrence, owners of Freedom Vans, decided to leave the rental business, about seven years ago. As I already had extra vans on hand, it seemed like a natural progression to branch out from sales to both sales and rentals. I didn't actually buy Walt's business; it was more like filling the void once they closed."

Today, with hard work and assistance from family members, Schober's business is thriving. She offers a fleet of accessible vans from various manufacturers including Toyota, Honda and Dodge. They feature lowered floor conversions, side-entry ramps, and retractable Q'Straint tie-downs. Most accommodate a passenger in a wheelchair, but she also offers vans with hand controls for renters who can drive.

In addition to rentals, Schober imports and rehabs gently-used vans, which she offers for sale. And if she doesn't have one to meet your needs, she also offers her extensive experience to help you find one that's ideal. She's happy to do business with you no matter where you live in BC or, for that matter, Canada.

"The most enjoyable aspect of my business is being able to provide people with a very much-needed service," she says. "Vancouver is a beautiful city to visit and live in, but it's not easy to navigate for wheelchair users without a vehicle of their own—especially if they wish to venture beyond the city centre. Being able to rent a van is often the deciding factor for a family trying to plan a holiday."

She also enjoys helping her local Peers. "Having access to a rental is vital in order for them to see their doctors or just get out of their care facilities for at least a day. It's always nice to feel useful and to hear that you've helped someone who wouldn't otherwise have any transportation options."

But Schober points out that, despite offering the convenience of working from home, the business can be challenging.

"I deal with all of the bookings and office tasks, while my mom handles all of the cleaning and demonstration duties," she explains. "Maintenance and repairs are constant. Seasonality is also a big challenge—summers are very busy with the influx of tourists and visitors, whereas the rest of the year can be very slow, with the exception of the Christmas holidays, which book up months in advance."

She says it's always tough to predict exactly the right number of rental vans to have on hand at any given time.

"Aside from tourists or locals in need of brief rentals for outings and appointments, we also serve a number of ICBC and WorkSafe clients, which tend to be longer rentals in duration but hard to predict or schedule for. With the overhead costs and insurance being so high, you don't want to have vans sitting idle, but you also don't want to turn people down because no vans are available. Currently we have eight vans for rent. I try to sell the older vans after three to five years of service, during periods of less demand. Even the buyer's market can be unpredictable though, with some vans selling immediately and others taking much longer to find the right buyer. Everyone has particular needs, whether they're renting or buying."

Despite the challenges, Schober says operating the business is a good fit for her—particularly since it offers the flexibility of allowing her to continue her education, and of working at home.

"I do recommend any situation that allows someone with an SCI, especially a high level SCI, to work from home. Between health and caregiver issues, I can't even imagine trying to commute every day to work a conventional nine-to-five job. The trick is to identify a niche that hasn't been filled, whether it's disability-related or not."

If you need wheels, you can get more info about Delta Wheelchair Vans by visiting www.bcwheelchairvans.com. ■

Hidden Assets

Recent research from Case Western Reserve University reveals the spinal cord may have the ability to control breathing all by itself, without a connection to the brain. Perhaps more importantly, the work also illustrates that the emerging field of optogenetics offers great promise in neuroscience research.

In October, you may have seen headlines implying that researchers at Cleveland's Case Western Reserve University (CWRU) had restored breathing in rats with high level, complete SCIs. "Drug therapy 'restores breathing' after spinal injury," proclaimed the October 17 headline on BBC's news website.

That headline is, of course, somewhat misleading. What the researchers had actually done is demonstrate they could initiate a breathing-like movement by triggering a response within the rats' spinal cords, which had been completely severed from the brain. So we want to make it clear: this story is not intended to suggest a new therapy is imminent that would allow high level quadriplegics to ditch their ventilators.

Nevertheless, and despite the fact that all this research has only been carried out in animal models, the work is fascinating for at least two reasons: it further reveals that the spinal cord is capable of controlling some functions in the body without any input from the brain, and it demonstrates the significant potential for the emerging field of optogenetics to be a game changer in SCI research and the entire neuroscience field.

The research was conducted in the lab of Dr. Jerry Silver, Professor of Neurosciences at CWRU and a pioneer in SCI research targeted at restoration of breathing function in high level quadriplegics. Spearheading the research was Jared Cregg, one of Silver's grad students.

"In 2008, Warren Alilain in our lab pioneered the use of optogenetics for restoration of diaphragm function after SCI," explains Cregg. "In this early study, we found that stimulation of a diverse population of spinal cord interneurons and motor neurons could evoke rather bizarre activity from the diaphragm. This activity was difficult to explain because it was very different from respiration and seemed to be generated spontaneously by neurons in the cord. We started to realize that there was circuitry within the cord that was very poorly understood."

It was apparent to the researchers that what they were witnessing in these animal studies was not breathing—a rhythmic activity that is controlled by the brain. Instead, they theorized that the movement in the diaphragm they were seeing was some kind of ancient "startle and gasp" reflex.

"This may be a primitive response that has been kept in the spinal cord for emergencies, like gasping and screaming in response to danger," says Silver.

Cregg says this new work was an effort to better understand this mysterious circuit. "We saw this as a critical first step in understanding how to promote diaphragm function after injury," he says.

What they discovered was that this circuit is normally silent, thanks to a group of neurons that prevent it from activating. Cregg and his colleagues demonstrated this by bathing those inhibiting neurons in an agent that prevented them from issuing the silencing or blocking signals. Sure enough, in the absence of the blocking signals, the "startle and gasp" reflex began to fire.

However, there was little rhythm in the responses, and there were also long intervals between responses. It became clear that the researchers would have to find a way of triggering the response in a more regular and controlled way if they were to elicit activity that might more closely resemble breathing and sustain life.

That's where optogenetics comes in. On a very basic level, optogenetics involves introducing light-sensitive molecules sourced from other forms of life (for example, from the retinas of fruit flies or from certain algae) into a neuron cell body so that, in the presence of light, the molecule converts it into an electrical impulse, triggering the neuron to respond. These photosensitive molecules can be introduced very selectively into only the desired neurons using genetic therapy techniques.

Again, in really basic terms, optogenetics allows researchers to very selectively target a specific kind of neuron within the nervous system and brain, and then turn those neurons on to see their effect on a specific condition or disease. The potential of this is enormous.

Jared Cregg

As an example, think about depression. We know that some types of depression can be alleviated by using electrical signals to stimulate neurons in an area deep in our brain. But this process is not selective. An entire region and all of its different kinds of neurons are electrically activated at once, making it difficult to know exactly what kind of neuron is responsible for what—it's kind of a shotgun approach. With optogenetics, it's theoretically possible to stimulate only one of the thousands of types of neurons in our brains, allowing us to assess the function of each type in a systematic approach. Little wonder that few subjects in the neuroscience world generate as much excitement as optogenetics.

Let's get back to our CWRU researchers, who realized that optogenetics would allow them to turn on those neurons which were responsible for the "startle and gasp" reflex in rats. A suitable photosensitive molecule was introduced into these neurons using gene therapy techniques. Then, via a tiny fibre-optic LED inserted into the spinal cord, regularly-spaced light bursts were introduced. Sure enough, the result was a more regular diaphragm movement similar to breathing.

"Although the spontaneous bursts observed after blockade of inhibition were slow and irregular, we could time them at the same rate as respiration—making them highly rhythmic and very similar to normal respiration," says Cregg.

However, he cautions that what he and his colleagues don't yet know is if these movements would be enough to sustain life.

"Of course, this is a long-term goal of the project," he says. "Initially, we need to further characterize the network we have discovered, hopefully describing it in much greater anatomical and molecular detail. This will help us to tap into this network in a much more sophisticated way."

The potential is huge. Translation into a human therapy would mean that those with the highest of SCIs would not have to rely on mechanical ventilators. But make no mistake—this is a very distant goal. Gene therapies in humans remain off-limits for the most part, and the source of the photosensitive molecules themselves may well mean they will be rejected when introduced into the human body.

"There is a long way to go with these types of potential therapies," Cregg confirms. "Nonetheless, we are seeing rapid technological progress within the field every day. The more we learn about how the spinal cord works, the more we think that there is hope for those living with SCI. Meanwhile, optogenetics is an exciting tool because it allows very precise manipulation of circuit activity. Future research in optogenetics will allow manipulation not only of circuit activity, but also of gene pathways, cell signalling, and even the growth of axons. The possibilities for the use of these technologies in SCI are endless."

The research was published in the October 17, 2017 issue of the journal *Cell Reports*. ■

Participate in Research

SCI research is about much more than test tubes, stem cells, and a far-off cure.

At ICORD (International Collaboration On Repair Discoveries), SCI research is also about improving bladder, bowel, and cardiovascular health; taming pain and autonomic dysreflexia; enhancing sexual health and fertility; new assistive technologies; wheelchair design and ergonomics; and much more. In other words, it's about maximizing recovery, independence, health, and quality of life. But it doesn't happen without you. That's why SCI BC and ICORD are partnering to help raise awareness and increase participation in world-leading research. Working together, we can make SCI research more meaningful and move it along at a faster pace, and we invite you to be a part of it.

Dysport: Treating Urinary Incontinence

Overview: Urologist and ICORD researcher Dr. Lynn Stothers and her team are evaluating if a treatment called Dysport is an effective and safe way to manage urinary incontinence caused by neurogenic detrusor overactivity (NDO). NDO is a condition that may occur following an SCI in which the bladder muscle contracts too often and involuntarily, which may result in urinary incontinence. Dysport is a treatment containing botulinum toxin A, which, when injected into muscle, usually causes the muscle to relax for several months.

What to expect: Two doses of Dysport will be evaluated in this study. In order to evaluate the effectiveness and safety of these doses, it's important to compare them to a placebo. Some participants will receive the placebo during the first study treatment only. For the second and subsequent treatments, all participants will receive Dysport (600 units or 800 units). Participants will be assessed for approximately two years to gather long-term data and allow patients in the study to have multiple treatments if required.

Who can participate: You may be able to participate if you are aged 18 to 80 years old, you have been diagnosed with NDO, you have had urinary incontinence for at least three months as a result of NDO, you have an SCI at the T1 level or below which occurred at least six months ago, you have had an inadequate response to oral medications after at least four weeks, you are routinely performing intermittent catheterization to empty your bladder (every four to six hours during waking hours), and you are able and willing to complete all study requirements including regularly completing the seven-day electronic bladder diary and attending all scheduled visits. If you are a female of childbearing potential, you must have a negative pregnancy test result and be willing to use reliable contraception throughout study participation.

Why participate: Your urinary incontinence may get better from taking part in this study. It's expected, based on past studies, that Dysport treatment may improve urinary incontinence and reduce the pressure in your bladder. High-bladder pressure is associated with a long-term risk for damage to the kidney and urinary tract. Taking part will help care providers learn more about Dysport. This may help others with neurogenic detrusor overactivity in the future.

Location: Vancouver, BC.

For more information or to participate: Please contact the study co-ordinator, Ivy Allard, by email (ivy.allard@vch.ca) or phone (604.875.4111 ext. 69876). Further details are at www.icord.org/studies/2017/06/dysport.

Outdoor Leisure Participation

Overview: Led by ICORD researchers Dr. Ben Mortenson and Dr. Jaimie Borisoff, this exploratory study examines wheelchair users' experiences participating in spontaneous outdoor leisure activities. The goals of the study are 1) to explore the barriers and facilitators experienced by wheelchair users when participating in outdoor leisure activities, and 2) to inform further research and development with creating new opportunities for informal outdoor recreation activities.

What to expect: Data will be collected via a semi-structured interview with each participant. The survey takes 60 to 90 minutes to complete.

Who can participate: You may be eligible to participate in this study if you use a manual wheelchair for four or more hours a day and are fluent in English.

Why participate: You may want to participate in the study to increase the understanding of what activities individuals in wheelchairs participate in, what activities they want to participate in, and what the perceived barriers and facilitators are for these activities. The researchers hope to identify changes that can be made to the built environment and new adaptive devices that might be developed to facilitate spontaneous participation in outdoor leisure activities.

Location: The interview surveys can be completed at the Blusson Spinal Cord Centre, G.F. Strong Rehab Centre, by Skype, or at a location of your choice.

For more information or to participate: please contact the study co-ordinator, Ashley Menzies, by email (ashley.menzies@alumni.ubc.ca) or call 604.714.4109

Learn more about what makes ICORD one of the biggest and best SCI research centres in the world, and the research they are doing, by visiting www.icord.org/research/participate-in-a-study

The Herb That Soothes

New evidence from Spanish researchers helps to confirm that cannabis can help to calm spasticity in SCI

For decades, many of our peers, along with many other people with SCI around the world, have maintained that cannabis is more than just a pain reliever—it's also effective at calming spasticity. But actual scientific evidence of this has been scarce. Little wonder since, until recently, cannabis has largely been off-limits to researchers due to its decades-long prohibition.

Recently, a small but seemingly thorough research effort from Spain provided some proof of the ability of cannabis to reduce spasticity.

The study, conducted by researchers at the Hospital Universitario y Politécnico in Valencia, tested the cannabis derivative Sativex over a six month period in 15 participants with SCI. Their conclusion was that it was beneficial to mitigate spasticity.

Satívex is, of course, somewhat controversial. The controversy stems from the fact that, to the uninitiated, it appears to be a pharmaceutical synthesis of one of the active ingredients in cannabis, much like Marinol. But that's not the case at all. Although the company behind Sativex, UK-based GW Pharmaceuticals, appears to have tried to reinforce that its product is a carefully-formulated pharmaceutical, in fact it's simply strong, concentrated whole-plant cannabis oil to which a small amount of alcohol, peppermint flavour and preservative have been added. The result is a nice little bottle of cannabis liquid—you simply spray it into your mouth. And yes, it will get you high, just like the spliff you roll yourself.

Critics claim that this approach is simply a way to exploit a low-cost, natural medicine and generate profit from it. Its obscenely high price tag (for example, in New Zealand, a year's supply is estimated to run about $16,000 per individual) makes it easy to agree with this. Little wonder that many insurers in the 24 countries that have approved Sativex are reluctant to provide coverage.

However, it should be noted that, on the positive side of the ledger, Sativex is consistent. In other words, each dose is exactly the same as the next. In the world of medicinal herb, unless you're growing yourself or know exactly how and where your supply is grown, it's hard to imagine this type of consistency being possible.

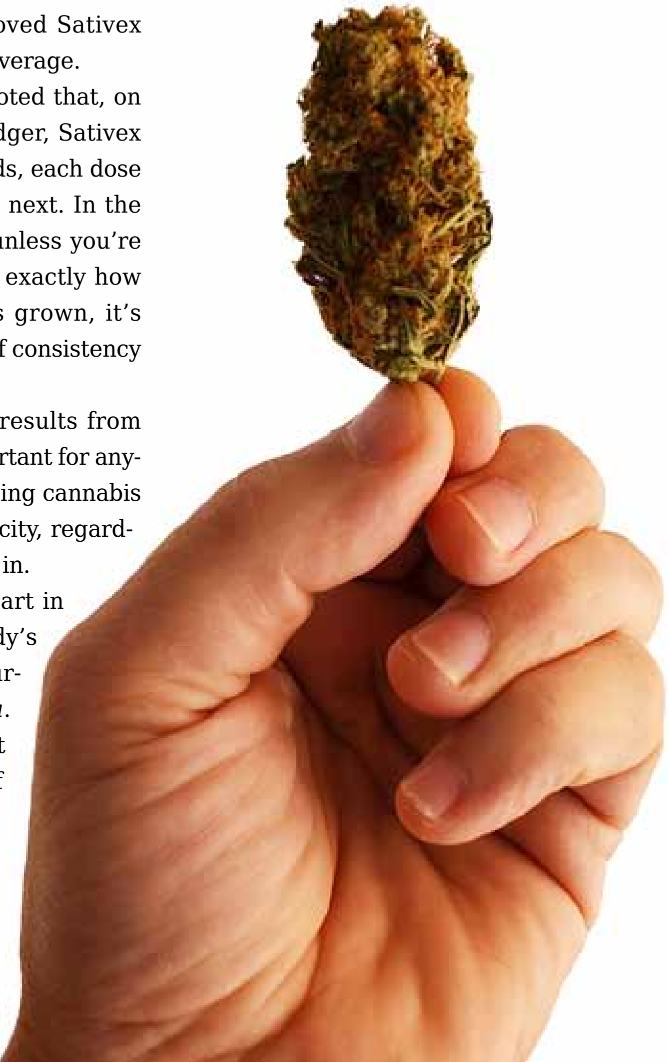
Controversy aside, the results from the Spanish study are important for anyone who is interested in using cannabis as a way of calming spasticity, regardless of the format it comes in.

"Fifteen patients took part in this study," wrote the study's authors in the Spanish journal *Revista De Neurologia*. "A significant improvement was observed on three of the scales recorded…The use of the drug was withdrawn in two patients due to side effects."

While the study concluded Sativex benefits those suffering from spasticity associated with chronic SCI, it also noted that, "Further studies need to be conducted before the use of this drug can be recommended and so as to define a complete profile of its long-term side effects."

That might seem to many as an overly cautious approach, given the thousands of years of cannabis use by mankind, not to mention that Sativex has also been confirmed in much larger studies as an effective treatment for MS-related spasticity.

Regardless, every single one of our readers—even those without Health Canada-approved medical marijuana status—will soon have the opportunity to legally try and evaluate cannabis as an anti-spasticity and neuropathic pain treatment on their own terms. And hopefully, the soon-to-be legal status of cannabis will prompt more researchers to investigate and confirm its benefits for people with SCI. ■




EF-150


EF-275


EF-250