

the spin

SPINAL CORD INJURY BC

WINTER 2018

Calorie Crunch

New research explores the link between SCI and obesity — and suggests you might need to eat a lot less than you think



Your mobility freedom is our top priority.



Sidewinder Conversions is committed to enhancing your mobility freedom, independence and quality of life. Since 1999, we've been providing safe and reliable accessible transportation solutions and service in a caring, professional manner.

Our selection of side and rear-entry accessible conversions are available on most full-size vans and minivans, and feature industry-leading technology, ease of use and functional aesthetics. With power and manual options, along with a range of driving controls, mobility aids and stowage lifts, our conversions provide the optimal blend of performance, safety and style.

Whether you're an independent driver, an assisted passenger or a caregiver, our team of qualified experts can help you choose the right solution to meet your mobility and lifestyle needs.

SIDEWINDER 
Conversions & Mobility Ltd.

44658 Yale Rd. W.
Chilliwack, BC V2R 0G5
PHONE: 1-604-792-2082
TOLL FREE: 1-888-266-2299



sidewinderconversions.com

Follow us on:



 **PROUDLY CANADIAN** 



Transport Canada approved and certified CMVSS, FMVSS or CSA compliant
Licensed motor dealer registered with the VSA (Vehicle Sales Authority of BC) www.mvsabc.com

contents

WINTER 2018

features

10 Walt's Time

Peer counsellor extraordinaire Walt Lawrence celebrated the 50th anniversary of his SCI in grand style.

14 Cover Story

University of Manitoba researcher Dr. Kristine Cowley is trying to determine just how much she and other people with quadriplegia should—or should not—be eating.

17 Assistive Technology for Good

The Neil Squire Society teams up with TELUS to unlock the world of smartphones for people with quadriplegia.

18 Bacteria Beater

A new antibacterial indwelling catheter being developed in the UK may offer a much-needed improvement.

22 It's All Downhill From Here

SCI BC Peer Cole Hoodicoff gets an unforgettable introduction to the world of adaptive mountain biking.

26 Moving Matters

For SCI BC Peers, especially those with quadriplegia, moving can be a particularly stressful undertaking.

29 Stealing the Spotlight

Neuromodulation appears to have huge potential to restore bladder, hand and other important functions. But is the media focus on walking obscuring this?

departments

4 editor's message

Introducing LivingwithSCI.ca—an online resource for people with SCI that's based on truth and trust.

6 gear & gadgets

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

7 room for debate

Should wheelchair and scooter users be in the bike lane?

8 events

Important dates for your calendar.

9 peer shoutouts

Giving credit where credit's due.

20 ask the SPIN DOCTOR

Eliminating blockage-causing sediment in your urine.

33 participate in research

ICORD research projects that need your participation.

34 last word

A new app will make filling your gas tank a lot easier.



Now online: LivingwithSCI.ca

Everything you need to know about SCI. From the people who've been there

START HERE ABOUT US

Understanding SCI Pain Sexual Health Bladder Management Bowel Management Mobility and Accessibility

Nothing but the truth...except trust.

The truth is under attack. From fringe and even some mainstream media outlets forwarding their own agenda, to bogus claims of health benefits by unscrupulous companies pushing a staggering variety of snake oil, and autocratic (and wannabe autocratic) world leaders seeking absolute power, the attack on truth is coming on many different fronts. The damage from these attacks isn't limited to truth; they take a toll on truth's close ally, trust.

Truth and trust are foundations of civil society and democracy. They are foundations of constructive public discourse, public and private partnerships, and, more fundamentally, healthy relationships. When truth and trust are undermined, as we are witnessing on a global scale today, the pillars of our civil and progressive society are steadily eroded.

In the chaotic midst of such attacks, how do we know what the truth is? The short answer is that you need to turn to those you can trust.

At this point, I could take this editorial in many directions, but I'm going to veer to the positive and highlight a small example of resistance, where truth and trust have fortified a partnership resulting in a credible, validated, and invaluable resource for people with SCI, their families, and clinicians alike: the new LivingwithSCI.ca website.

LivingwithSCI.ca represents a partnership between SCI BC, GF Strong Rehab Centre, and peers like you. All have a long history of working together in trusting relationships, and we are all inspired to present factual, validated, and truthful information about how your body works after SCI, the rehab processes one goes through after injury, and the shared wisdom and experience of Peers who have gone through the challenges others are currently facing.

The project got its start when GF Strong identified a need to revamp its patient information resource binder. SCI BC and our Peers confirmed the need to update the binder and provide it in a more modern, user-friendly way. We all wanted to develop a resource that would be useful for people with SCI, their families, and health professionals anywhere in the province—and beyond. We all agreed that a new, web-based resource was the way to go.

Together, we developed the website, with SCI BC taking on the design and hosting roles, GF Strong clinicians reviewing and validating the information resources, and SCI BC Peers providing the stories and context upon which the site was built around.

In truth, the project took much longer to complete than any of us anticipated, but trust and a common motivation to provide credible information from trusted sources allowed us to work through the challenges we faced along the way. The end result is what we believe to be an invaluable new resource for anyone with lived SCI experience and health professionals alike.

The website is and always will be a living entity that will be updated as new information is made available and new stories and experiences are added. Although I hope you trust me, I strongly encourage you to check out the site for yourself and to provide us with your honest feedback, truthful stories, and constructive suggestions for how we can improve the site.

When truth and trust win, we all win. Best of the season,

- Chris McBride, PhD, Executive Director, SCI BC



The Spin is the quarterly magazine of Spinal Cord Injury BC. An online edition of *The Spin* is available on the SCI BC website www.sci-bc.ca.

Executive Editor Chris McBride
Managing Editor Cliff Bridges
Assistant Editor Alison Brierley
Design Cliff Bridges
Administration Maureen Brownlee

SUBSCRIPTIONS

Free subscriptions are available for BC residents and health professionals:
T: 604.324.3611 TF: 1.877.324.3611 E: thespin@sci-bc.ca

ADVERTISING

Advertising rates and a publishing calendar for *The Spin* are available online at www.sci-bc.ca. You can also contact Terry Chen at tchen@sci-bc.ca or 604.326.1212.

SUBMISSIONS

Submissions, suggestions and comments are greatly appreciated—please email these to thespin@sci-bc.ca or send by regular mail to:

Assistant Editor, *The Spin*
Spinal Cord Injury BC, 780 SW Marine Drive
Vancouver, British Columbia V6P 5Y7

COPYRIGHT

You are welcome to reproduce material from *The Spin* after gaining permission from the Executive Editor. All reproduced material must be appropriately acknowledged.

The opinions expressed in *The Spin* are not necessarily those of SCI BC. Also, SCI BC does not endorse nor is responsible for the products or services advertised within *The Spin*. The information contained within *The Spin* is presented for the purpose of educating people about spinal cord injury. Nothing contained in *The Spin* is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider.

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

Return undeliverable Canadian addresses to:
Spinal Cord Injury BC, 780 SW Marine Drive
Vancouver, British Columbia V6P 5Y7 T: 604.324.3611

To update/change delivery address, email thespin@sci-bc.ca or call 604.324.3611.

SCI BC HEAD OFFICE

780 SW Marine Drive, Vancouver, British Columbia V6P 5Y7
T: 604.324.3611 TF: 1.877.324.3611 F: 604.326.1229
E: info@sci-bc.ca

REGIONAL PEER CONTACTS

Fort St. John: Lori Slater, Peer Program Coordinator
T: 250.787.1912 E: peervolunteers@sci-bc.ca

Kelowna: Scott James, Peer Program Coordinator
T: 250.308.1997 E: sjames@sci-bc.ca

Nanaimo: Bert Abbott, Peer Program Coordinator
T: 250.616.1186 E: babbott@sci-bc.ca

Prince George: Brandy Stiles, Peer Program Coordinator
T: 250.563.6942 E: bstiles@sci-bc.ca

Quesnel: Alison Duddy, Peer Program Coordinator
E: peervolunteerq@sci-bc.ca

Metro Vancouver: Teri Thorson, Peer Program Coordinator
T: 604.714.4185 E: tthorson@sci-bc.ca

Metro Vancouver: Ryan Clarkson, Peer Program Coordinator
T: 604.714.4185 E: rclarkson@sci-bc.ca

Metro Vancouver: Randeep Sharma, Peer Support Specialist
T: 778.707.5058 E: rsharma@sci-bc.ca

Vernon: Sonja Gaudet, Peer Program Coordinator (Okanagan)
E: sgaudet@sci-bc.ca

Kamloops/Kootenays: Joshua Dueck, Peer Program Coordinator
T: 250.306.7061 E: jdueck@sci-bc.ca

Victoria: Scott Heron, Peer Support Specialist
T: 250.812.0773 E: sheron@sci-bc.ca

SCI BC acknowledges the financial support of the BC Gaming Commission, the Rick Hansen Institute, and the BC Paraplegic Foundation.



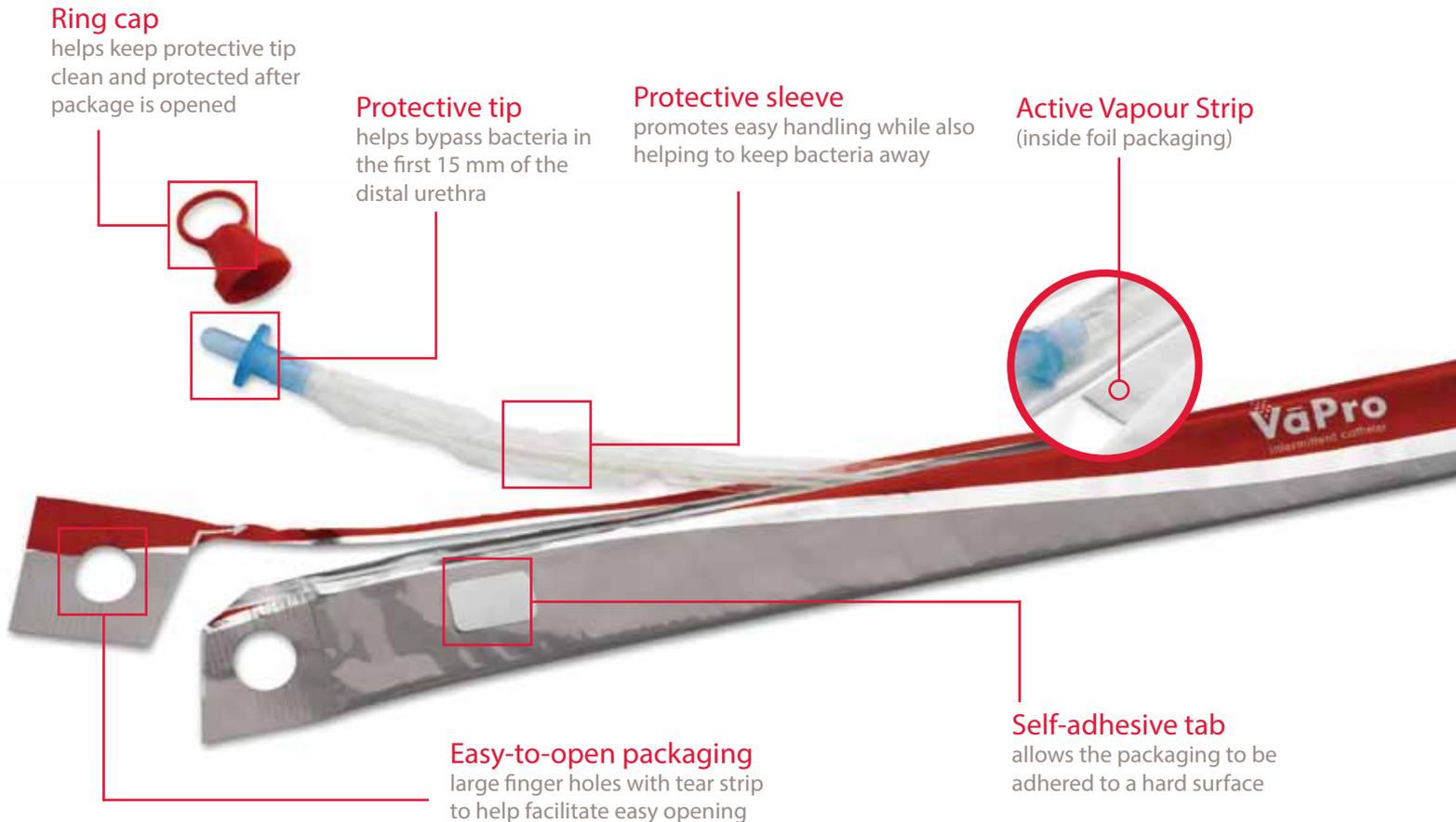
NEW!
Hollister
Tip and Sleeve
Catheters



VaPro

Touch Free Intermittent Catheter

Simple. Clean. Independence.



Simple insertion and removal

- Ready to use with pure catheter hydration technology
- Designed to be evenly lubricated for easier insertion
- Helps provide ease of insertion and withdrawal with smooth eyelets

Touch Free

- The catheter can be gripped anywhere along the protective sleeve
- The protective tip helps shield the sterile catheter, during insertion and removal, from bacteria located within the first 15 mm of the distal urethra



ATTRACMOUNT

The Attracmount is a fresh take on a cell phone holder. It's a two-part solution that consists of a strong, industrial-grade magnet that can be securely strapped around any tube on a wheelchair, and a cell phone case with a similar magnet on the back. The magnets are powerful enough to keep your phone securely in place, but it's still easy for even those with limited hand strength to remove the phone easily. Attracmount is also ideal for keys. See it in action at www.handizap.com.

KÜSCHALL SUPERSTAR

Swiss manufacturer Kuschall has borrowed heavily from Formula One racing technology to design and develop what it claims to be the world's lightest wheelchair. The Swiss company's new Superstar manual wheelchair frame weighs in at 1.5 kilograms, thanks to extensive use of graphene, the semi-metal which is known to be the strongest material known to man—it's more than 200 times stronger than steel and 10 times tougher than diamond, but still incredibly flexible and ultra-lightweight. The wheelchair features an X-shaped geometry with road dampening properties, a customized backrest, and a tailor-made seat with an integrated seat cushion. This allows the wheels and pushrims to be moved closer to the user's body, which the company says minimizes the risk of sustaining repetitive strain injuries. Visit www.kuschallsuperstar.com for more details and video.



XL-SEAT

The XL-SEAT, made by Canadian company Adapt Solutions, gives wheelchair users easy, powered lift access into the existing driver or front passenger seats of most minivans, pickups, and SUVs. It's installed using the seat's original floor bolts with little or no modifications, and is powered by your vehicle's battery. To use, fold the XL-SEAT down, transfer aboard, and then activate the device until it lifts you to the level of the seat. All existing seat functions remain operational. The cushioned transfer board is covered with vinyl for easy transfers. It's available in black, tan or grey, and has a 125 kg capacity. Visit www.adaptsolutions.ca to learn more.

PARAFRICTA

Parafriкта is a UK-based company that has developed a proprietary, ultra-low friction fabric that helps prevent skin damage. The fabric is made from special fibres that are woven in such a way as to create exceptionally low coefficients of static and dynamic friction when it comes into contact with other fabrics, wound dressings and human skin. It's strong, breathable, and silk-like, and because it doesn't rely on coatings for its slipperiness, it can be washed repeatedly at high temperatures. Parafriкта currently makes three lines of products from its fabric: bedclothes, bootees, and undergarments. Some of the sheets in the bedclothes line are designed to make self-repositioning, along with moving and handling by carers, an easier, safer task. You can learn more at www.parafriкта.com.



Innovations

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



Room for Debate



Should wheelchair and scooter users be allowed to use bike lanes?

Standalone bike lanes are gaining a foothold in many BC cities. Some advocates have suggested that the steadily growing ranks of wheelchair and scooter users should be able to use bike lanes. Currently, in BC, wheelchair and scooter users are designated as pedestrians by the Motor Vehicle Act, and must stay on sidewalks unless there are none present. But around the world, wheelchair users legally use bike lanes (the photo is from Seville, Spain). We asked our Facebook community what they thought. Here's a sampling of responses, the majority of which were in favour of using bike lanes (note that some have been edited for clarity and brevity).

- 

If there is a bike lane available, I use it. It's safer compared to having to manoeuvre over inaccessible sidewalks. In winter, the sidewalks are usually not clear but the bike lanes are. I think the question should be, "Do you use the bike lanes, and why?" The answer is safety for us. —*Robyn Artemis*
- 

I use them all the time, unless I'm walking with a friend or in a situation that feels unsafe. I can go much faster in the bike lanes and they're always smoother than the sidewalks. Depending on how fast you travel in your wheelchair, it can be dangerous to pedestrians if you use the sidewalks. —*Dave Symington*
- 

Bad idea. Cyclists ride much faster than any wheelchair, whereas pedestrians can more easily adjust to wheelchairs. —*Jennifer Strong*
- 

They should definitely be allowed because of safety issues. There is a danger of scooters and wheelchairs being toppled over when riding on sidewalks if the riders (usually elderly) go over the curbs, which are four to five inches high. Many sidewalks are quite uneven due to settlements. —*Louis Yong*
- 

When in Prince George, I used the bike lane everywhere I could. The sidewalks are so bad I'm surprised the bolts didn't fly out of my chair. —*Wes Belland*
- 

While cyclists have manoeuvrability, they cannot stop on a dime, and when a scooter or chair stops dead in front of them, there will be accidents. The person in the chair/scooter is not required to wear headgear and they will suffer head injuries when they are knocked over by cyclists. The damage to the cyclists will most likely be similar to (running into a car door), as the height of the person in the chair or scooter is about the same. —*Linda Watters*
- 

I like the idea, but I think cyclists would mow us down. I've almost been run over by bikes on the sidewalk. —*Star Trickey*
- 

The bike lanes are absolutely for wheelchairs too, of course...I don't wait for an official go-ahead, I just use them—I'm a tax payer and I helped pay for those lanes. —*Mark Stockbrocks*
- 

No. They go at a different speed (closer to pedestrian speed) and should stay on the sidewalk for safety. —*Sonia Furstrand*
- 

I use the bike lanes with my mobility scooter and power wheelchair when the lanes are separated from the cars, etc. It's less stressful and easier than bumpy, crowded sidewalks. —*Janice Laurence*
- 

I use the bike lanes with no problem with my wheelchair, and sometimes I use a handcycle too. Anything with wheels should be able to use the bike lanes; no need for a separate lane for wheelchairs. It's about inclusion and community, not segregation. —*Clyde Lee*
- 

For their safety, I believe that persons in wheelchairs and scooters should be on the sidewalks because many bike lanes do not have protection from the street (vehicles). Scooters and wheelchairs simply do not have the quick manoeuvrability that a bicycle has, and are often lower than a bicycle (rider's) line of sight. —*Sonja Prince Heaton*
- 

If the person using a wheelchair or scooter feels better/safer/more comfortable using a bike lane, they should be able to do so. Just remain aware that vehicle drivers have been known to "challenge" those using bike lanes. —*Kipawa Harder*
- 

Bikes, wheelchairs and scooters go at very different speeds. This means a lot more passing in bike lanes that are narrow because they're designed for the width of a bike, not a wheelchair or scooter. The wheelchairs and scooters that I encounter do not seem to come equipped with much of the safety gear that bikes have and do not follow cycling rules. For example, I've almost never seen them with rear view mirrors...Also, most of the wheelchairs and scooters I pass aren't equipped with lights at night. As well, I've never seen a wheelchair or scooter user use hand signals to indicate turning (or indicate turning in any other way). So I'll often be biking and have the person in front of me stop to turn without any forewarning, or I will be in the middle of passing someone when they start turning into my bike, causing me to have to swerve out of their way, which is dangerous for both of us. I feel like if we're going to share the same space, then we need to be following the same rules and using the same safety equipment. —*Rachel Link*
- 

I use them to avoid the discomfort of curb cuts and sidewalk cracks that kill my neck and back. I don't know if it's a problem, I make way for bikes although going uphill I pass bikes every time! —*Patty Clarke*

Visit facebook.com/SpinalCordInjuryBC to join in on this and other conversations.



See world class skiing.

Prince George’s Caledonia Nordic Ski Club is proud to host the 2019 World Para Nordic Skiing Championships. It’s your opportunity to witness 140 elite athletes from 20 countries compete in four cross country skiing and four biathlon medal events. Come out and cheer on Team Canada’s six athletes, including BC’s Natalie Wilkie and Emily Young. The event takes place from February 15 to 24. Visit www.2019worldparanordic.ca to learn more.



Find events at a glance.

A new year is upon us—and with it comes an exciting slate of events for SCI BC Peers. Seminars, virtual Peer sessions, local coffee get-togethers, and numerous sports and recreation opportunities are just some of the events coming up in 2019. The easiest way to stay informed about all events being held in every corner of our province is to bookmark the events calendar at the SCI BC website (www.sci-bc.ca/events), and check it often for the most up-to-date info.



Women: explore your health.

Join other women with SCI, along with researchers and clinicians, for a Café Scientifique event titled *Women’s Health After SCI: Motherhood to Menopause*. It’s your opportunity to learn more about the latest advances in research and clinical practice for women’s health following SCI. The free event, which will be held at the Blusson Spinal Cord Centre on February 13 from 5 to 8 PM, includes a wine and hors d’oeuvres reception. Email Amanda Lee (alee@icord.org) for details.



victoria
250.661.2131
 vancouver
1.877.215.7609

- driver adaptation & transfer seating
- accessible vehicles
- experienced, professional staff
- extensive inventory



Silver Cross
 AUTOMOTIVE
silvercrossauto.com

Peer Shoutouts

1 Congrats to **JOSH DUECK**, SCI BC's Kootenays Peer Coordinator, for his recent appointment to the position of Executive Director at Freestyle BC. It's the first time that someone with a disability has held the position. Freestyle BC is our province's arm of the Canadian Freestyle Ski Association, which supports promising athletes in their quest to compete and medal at the Olympics, World Championships, World Cups and X Games. Josh, who was injured during a ski jump, has a long history of winning in the sport—he's an X-Games and Paralympic gold medallist, a recent BC Sports Hall of Fame inductee, and the first person to ever perform a back-flip on a sit-ski. Note that we're not saying goodbye to Josh—his new position is part-time, allowing him to continue the excellent work he's doing to strengthen the SCI BC Peer community in the Kootenays and Okanagan.

Are you an SCI BC Peer who has something to shout about? Or do you know a Peer who has recently accomplished something noteworthy? Send the details to info@thespin.ca.



1

2 He might be retired from SCI BC, but **PAT HARRIS** isn't just sitting around. Recently, Pat and his wife Nancy were inducted as 2018 Citizens of the Year by the Prince George Community Foundation. The award is given annually "to those who have gone above and beyond in community volunteerism and philanthropy." Pat and Nancy were singled out for tirelessly promoting fair and equal treatment for the city's citizens with disabilities. In particular, the Prince George Community Foundation acknowledged the couple for championing accessibility improvements at many of the city's public facilities including the Prince George Airport, along with many of the area's most popular outdoor recreation areas, such as the Ancient Forest. They're also recognized for challenging the building industry and the public at large to embrace accessibility.

3 It's been a big year for **THOMAS VENOS**. The 18-year-old from Anmore, BC was recently announced as the recipient of the James H.G. Roche Memorial Scholarship, held in trust at the Vancouver Foundation. The \$7,500 scholarship has helped Thomas attend the kinesiology program at the University of Alabama. In addition to allowing Thomas to pursue his academic dreams, the scholarship is giving him a better chance to achieve his dream of representing Canada in the 2020 Paralympics. The University of Alabama's varsity wheelchair tennis team had been actively recruiting Thomas, who has already represented Canada as a junior player. Playing and practicing daily with his Crimson Tide teammates promises to help him break the top 50 of the world rankings—something he needs to do in order to gain a Paralympic birth on Team Canada.



2



3

Walt's Time

Walt Lawrence has lived a remarkably long and healthy life for someone with C2-C3 quadriplegia who is dependent on a ventilator. That's given him the opportunity to make a remarkably generous contribution to BC's SCI community—and he's far from finished.



Readers are the readers of this magazine who don't know Walt Lawrence, the peer counsellor who has plied his trade so incredibly well at GF Strong for the past three decades.

This summer, Lawrence celebrated the half century anniversary of his own SCI. As a high level quadriplegic who still relies partially on a ventilator, Lawrence has defied the odds and avoided the many serious and even deadly health challenges that go hand-in-hand with high level injuries such as his. Along the way, he has worked tirelessly to help other people with SCI regain hope and independence—something he has no plans of stopping despite the fact that, at the age of 67, he's past the age when most able-bodied people have retired.

Lawrence's life with SCI began in the summer of 1968. At the time, he was an aspiring and talented 17-year-old hockey player and pilot who had grown up in Dawson Creek. En route to hockey practice with his Junior A team in Kelowna, he stopped for a swim in Okanagan Lake. An innocent dive into shallow water at Okanagan Lake changed everything in a split second.

He spent the next six months in the intensive care unit at Kelowna General Hospital before being transferred to BC's rehab hospital of the day, the George Pearson Hospital for the Physically Handicapped in Vancouver. In those days, institutionalization was the norm for people with injuries as extreme as his, and Lawrence spent the next 16 years living at Pearson.

A pivotal point in Lawrence's life came in 1985, when he joined several

fellow quadriplegics and moved into semi-independent living at the newly-constructed Creekside development—an innovative housing cooperative championed by SCI BC's Doug Mowat. Creekside was the world's first integrated, self-managed housing project with shared support services for residents, and it would help usher in a new era of independence for people with high level quadriplegia.

Lawrence flourished in his new surroundings. He got engaged to his future wife Wendy while residing there, and also enrolled in a two year course in counselling that would eventually lead him to his position of Vancouver Coast Health peer counsellor.

He lived at Creekside until he and Wendy married and moved into their own home. Shortly after, the couple adopted two baby daughters.

While much has changed since then, one thing that hasn't is Lawrence's steady presence at GF Strong, where he uses his unique combination of life experience and counselling expertise to help others adjust to life after SCI.

The fact that Lawrence has been an incredibly powerful force for good in so many SCI BC Peers' lives over the years was made abundantly clear by the outpouring of love he received during the

50th anniversary of his SCI. Tributes to him appeared in the *Vancouver Sun* and other local newspapers, and on September 23rd, some 300 well-wishers joined him and his family for a "Half Century of Thanks" reception in the Tsawwassen Springs ballroom.

Lawrence threw the party as a way of showing his gratitude to the people who have helped him along his life journey. But it was his countless relatives, friends, and colleagues (many of whom had travelled from far and wide) who used the occasion to heap praise on him for his compassion and commitment as a counsellor, mentor and friend.

Recently, we got together with Lawrence and asked him a few questions about the event, and his amazing life and career.

Walt, were you surprised at the turnout for your 50th anniversary celebration?

I was overwhelmed. I am so blessed. People came from far and wide—from California, from back East, from up North. At the last minute, ten friends came down from Dawson Creek—friends I forgot to invite. My only regret is that, with so many people and so little time, I didn't have an opportunity to thank each and everyone one individually.

What do you credit for your longevity and health?

I'd have to say family and friends. They bring meaning to life when you feel that you've lost it. So I think I was fortunate in the early years after my injury, when I thought I'd lost everything, my family was just there for me. They included me in everything, and so did my friends.

Also, I think it's that we have an inherent desire to contribute, and when you find a way a to do that, I think it brings health; it brings meaning. If we don't have meaning in life, then we physically and mentally go downhill.

You've made an impact in the lives of so many SCI BC Peers. What's the most important thing you think you've been able to do for these Peers during the time you had to spend with them?

I mean, what do I bring to counselling? I have my counselling papers. But what is it that I really bring? It's my injury. I lived it. It's the thing that I hated most—my injury. Now I see it as my biggest gift. When you realize that you have that platform, people listen.

After you get injured, it's pretty shitty. It's an upside-down world. And it does feel like a deep, dark pit. All the things that cause the highest anxiety—they hit





Here's a sampling of the tributes that poured in for Walt Lawrence when we posted news of his 50th "quadversonary" on our Facebook page (www.facebook.com/SpinalCordInjuryBC).

you all at once. Following my own injury, I thought, "What do I have to contribute? I'm a pilot...but can't fly. I'm a hockey player...but I can't play hockey." My body meant everything to me when I was 18, and I found myself pretty low on my body image. I'd lost everything that equated to value to me in those early days. So it was all about revaluing.

And I want to walk with other people through that. In my counselling, I never want to downplay the darkness that they're going through; I want to walk through that with them. I always have the underlying belief that there's a rich life ahead for them. It's all about helping people revalue their sense of worth.

How does it make you feel to see and hear the expressions of gratitude that have been coming from many of the people you've helped?

It's very touching. Very touching. Because I think the most important goal we can have in life is to assist other people. It's to be lending some meaning, giving people a hand, caring for them when they don't feel cared for, walking with them when nobody's walking with them.

As a counsellor, you never really know how you're doing. If you're cutting grass, you can look back and clearly see what you've done. With counselling, you don't always see that. So it's incredible to hear and see these words. What an opportunity I've had. When I first got injured, I would have given anything to be someone else. Now I wouldn't. I'd be a hypocrite if I said I didn't still want to walk, but I wouldn't trade my life for anything.

How long will you keep working? Does the job still give you the same satisfaction and joy?

Absolutely! I'm so fortunate to have been blessed to have this job for 30 years and still love what I do; I still love going to work. I think that I can impart hope and life. I think I can mentor people, if even for a short time. My whole goal is to let people know that they're still of infinite value, instead of feeling like they're a throwaway piece of the puzzle.

I think about this young guy I met back in 1968, Lester Watson. He was 21 years old, and had polio when he was four years old. But he wasn't about his disability at all. He was all about life, having fun, playing crib, and getting out there. He was a huge mentor to me. Over the years, I asked him, "Les, do you realize the impact you had in my life?" And he would say, "Nope." And that's the way I think it is in life—people don't realize that they have an effect on others, every day. It can be positive, or it can be negative. It can take away or add to someone's life. It can build, or it can tear down. And that extends to everyone.

Why would I think about retiring? I think my best years are ahead of me. Again, we have an inherent need to contribute. And that's the way I know how to contribute. I don't how else I could contribute. I could make money, but this feels very fulfilling. It's so fulfilling to help people move forward and through their dark time.

Along with other pioneers like our founding Executive Director, Doug Mowat, you helped lead the movement for deinstitutionalization and independent living. How important was that, looking back?

Originally, when we talked about moving out of the institution, I was skeptical. I credit Norm Haw and Doug Mowat for their perseverance and leading the charge.

When I think back on this, this was such a pivotal point in my life—going from the institution to the community. I wouldn't be married; none of the guys would have been married. In the institution, it feels like you're taking, taking, taking. And you don't have that opportunity to contribute. When you get out in the community, you can start to make your life's contribution.

I think I've read that you believe that the number of people who have helped you over the years could fill BC Place. I know it's difficult, but of all the people you're grateful to, could you single out just a few, and tell me why?

That's an unfair question! But put on the spot, I would say my mom, my dad. My brothers, my sister. Les Watson, the young man with polio who was with me at Pearson. My wife and my kids. Mentors like Doug Mowat and Gary McPherson. And of course, Dr. Paddy Ducklow.

I met Paddy through our faith community; he was our pastor. But he's also a psychologist and a counsellor. He said, "I think

you should become a counsellor." I said, "Oh, Paddy, I don't think I could do that." He said, "You are. You are a counsellor." He told me about a two year course in counselling he was organizing, and said, "I think you should take it." I said, "Are you kidding, Paddy?" And then two months later, he said, "I've enrolled you." So he had faith in me when I didn't have faith in myself.

Anything else you'd care to add, keeping in mind the majority of our readers are your peers, and some of them might be reading this while in rehab?

This comes from my underlying faith: you're of infinite value, even though you sometimes don't feel like it. You're not a throwaway. You can contribute. At first you might feel like you're dependent on everyone around you. And you are. But in that puzzle, they're dependent on you, too. Never forget that. Never forget that you're of value even though you can't see it at the time. Life is a big adventure.

Also, I'll repeat some great thoughts from a good friend, Terry Forster, who has since passed away. He told me, "I think the biggest thing during preparing someone for discharge is not teaching them where they can get their chair fixed. It's not where you get your supplies. It's not where you live. Instead, it's make sure you don't hide yourself behind the computer and the TV and avoid your community." So the message is to get out there. Otherwise, you'll wither away. ■

More than just numbers.



- CSIL bookkeeping services
- Fully computerized bookkeeping and payroll services for small to medium-sized businesses
- Personal and corporate tax preparation
- Provincial and federal fuel tax rebate
- Customized service to meet your needs
- Pick-up and delivery available

I'm Walter Gagen. Call me – I'm able!

(604) 597-5100 Toll Free (866) 277-2745 Email wgagen@telus.net Website www.gagen.ca

Calorie Crunch

University of Manitoba researcher Dr. Kristine Cowley is trying to determine just how much she and other people with quadriplegia should—or should not—be eating.



Here's a universal truth for every person on this planet: the energy we consume in food or beverages must not exceed the our energy we expend through activity and exercise, or we'll end up storing it as fat.

Achieving this balance is difficult for many people. But it can be particularly problematic for people with SCI, and especially people with quadriplegia, according to Dr. Kristine Cowley, Assistant Professor in the University of Manitoba's department of Physiology & Pathophysiology.

"For most people living with SCI, excess weight gain is a huge problem," says Cowley, who is herself a C8 quadriplegic. "Initially, when each person goes through rehab, there are way too many things going on to focus on exercise and maintaining health in their life after injury. At the same time, every person paralyzed loses a great deal of muscle mass in their legs. For those with quadriplegia, the problems are even more drastic, because in addition to losing the ability to move their legs or trunk, they also lose the ability to support exercise with their sympathetic nervous system. People with tetraplegia cannot increase their heart rate, sweat in response to heat, or activate the neural systems that support prolonged movement."

Because of this, says Cowley, many people with quadriplegia are overweight and even obese. In turn, this puts people at much increased risk of diabetes and heart disease, in addition to experiencing greater and greater difficulty in moving around, transferring and dressing.

Logically, the easiest way to address this problem is to lower the amount of calories people with quadriplegia put into their bodies until it balances with their energy expenditures. But as Cowley discovered, it's difficult to determine this, because there's been so little research done to determine the energy expended in a day by the average person with quadriplegia.

"Everyone knows they need to eat less than before injury, but how much less?" she asks. "No one can give them a good idea of how much energy they would use just sitting around, and how much they can increase their energy use by with exercise. I had been thinking about this for a long time, and seeing so many people with tetraplegia who were overweight, and hearing them talk about how little they eat, I decided we should try to address this in a research study."

For Cowley, there was also personal motivation to learn more. As a former Paralympian (in Barcelona, she won double gold in wheelchair racing), she had little problem keeping her weight down in the first few years after her injury.

"After I quit racing, I still exercised, just not as much," she says. "I then started to put on weight, although it got a bit better when I became pregnant because I was eating so healthily. But after my kids were born, I got back on the gradual weight gain train. I've been able to stay close to a relatively healthy weight, since my body fat is classified as just 'overweight', but it's been a constant struggle, and it's getting worse as I get older. I exercise a lot and I have spent countless hours trying



"Following my own injury, I knew I used less energy than when I was walking, but I didn't know how much less." — Dr. Kristine Cowley

to figure out what I can eat—and what I cannot—so that I don't continue to expand."

With funding and approvals in place, Cowley and her colleagues got down to the business of conducting the study.

They recruited 25 people with quadriplegia, ranging in injury level from C4/5 to C8, and from complete to incomplete. Over the course of the study, participants were tested to determine their body composition, their energy expenditure while at rest, and their energy expenditure while performing a "steady state" exercise—an activity they could do for a relatively long period of time. The three choices were arm ergometry, wheeling a manual chair indoors on a flat cement surface, and handcycling.

"Our main goal," explains Cowley, "was to use this information so we could estimate how much energy a person with quadriplegia would use over the course of a day, and then to compare this to the values to what you would get if you were to enter your age, gender, height and weight into a reputable online energy-expense calculator, which are, of course, only designed for able-bodied people (for example, www.healthcalc.com/diet/energy-expenditure-advanced). This way, we will have a better idea of how much we should reduce our daily calorie intake in order to balance our energy use with our food intake to reduce weight gain."

The eye-opening results were published in the September 19th issue of the journal *Frontiers of Physiology* (see the complete study at <https://tinyurl.com/y98xrx4b>). Essentially, there were three important findings.

First, most participants had sufficient body fat to be classified as obese—in fact, only two were not.

Second, the energy they expended while resting was significantly lower than that of able-bodied people with the same physical characteristics—age, gender, weight, and height. Basically, an inactive male with complete quadriplegia would expend only 74 percent of the energy a sedentary, able-bodied person of similar age, height, and weight would expend.

Third, the participants also used much less energy during steady-state exercise than able-bodied people with similar physical characteristics. Those able to do moderate intensity exercise for about an hour would expend about 79 percent of that of an able-bodied person. For those able to do high intensity exercise, plus be active in a manual wheelchair during the day, their energy expenditure would still only be about 88 percent of a comparable able-bodied person.

So what does all this mean?

“Basically, if they can’t exercise or choose not to, most people with quadriplegia will need to reduce their daily food calorie intake to less than 74 percent of the amount suggested by online calculators for an able-bodied person of the same age, height, weight and gender,” says Cowley. “And some people with very low levels of energy use while resting will have to reduce food calories even more, to possibly less than 60 percent of an able-bodied person with similar characteristics.”

Moving forward, Cowley and her colleagues are trying to determine how people with quadriplegia can either increase the duration of time they can spend exercising, or increase the intensity of exercise they can maintain, but in such a way that the risk of dreaded overuse injuries is minimized. High intensity interval training (HITT) or functional electrical stimulation (FES) exercise are two options being considered.

“We also think that some consideration should be given to developing quadriplegic-specific dietary guidelines,” she says. “Such guidelines may also be useful for people with paraplegia-level injury with very sedentary levels of activity. You can imagine that, if a person is trying to lose weight, and only requires about 1,100 calories per day, then providing a calorie deficit of say 200 calories per day means they should only consume 900 calories per day. Some people may need to consume even less food energy. Therefore, quadriplegic-specific food guidelines should target food choices

that provide a sufficient range of foods to meet the minimum daily recommendations of vitamins, minerals and essential amino acids, while providing sufficient fibre, etc. Definitely, at these low levels of food intake, taking a vitamin/mineral supplement would likely be needed.”

If you have thoughts on the value of such guidelines, or would like to relate your own experiences with weight management, Cowley invites you to email her at Kristine.Cowley@umanitoba.ca.

She says the research was satisfying, both professionally and personally.

“Following my own injury, I knew I used less energy than when I was walking, but I didn’t know how much less,” she says. “I also didn’t know why I was so impaired when it came to exercise, and why I fatigued so easily. I had very little idea of how much energy I used over the course of a day, and I had no idea how many calories I burned by exercising. Fast-forward about 25 years, and a research-based PhD later, and I finally found myself in a position to answer these questions.” ■



Alliance Mobility Solutions

info@amsvans.ca

www.amsvans.ca



 **BraunAbility**
Life is a Moving Experience



 **vmi** imagine possibilities

Wheelchair Vans & Adaptations • Braun & VMI Vans • Vehicle Lifts • Driving Aids

Richmond Office: #110 – 12211 Vulcan Way | 604-370-7004

NEW! Kelowna Office: 1075 McCurdy Rd | 236-420-1400

assistive technology for good



Want to streamline your life with a smartphone, but don't have the finger function to use one right out of the box? The Neil Squire Society has teamed up with TELUS to get you up to speed.

As an ICORD researcher, and as Executive Director of the Neil Squire Society, Dr. Gary Birch immediately saw the potential for smartphones for people with disabilities when they emerged in the 2000s. But he also concluded that, for him and anyone else who is quadriplegic, they could pose some challenges to use, given that they rely on finger touch and typing.

So he decided that the Neil Squire Society, with its mandate of empowering Canadians with disabilities, was in a perfect position to influence policy and promote assistive technology aimed at making smartphones an option for anyone with limited hand function.

"We participated in the accessibility hearings that the CRTC conducted in 2008," says Birch, an electrical engineer who is recognized globally for his work in brain/computer interfaces. "Since that time, the Society and TELUS have collaborated in various ways to improve the accessibility of telecommunications and, in particular, the accessibility of mobile devices. In 2016, we proposed an accessibility initiative to TELUS. One of the key elements was to co-develop and deliver a program that would help people with disabilities learn about and employ assistive technology to use smartphones."

TELUS was eager to get onboard, and agreed to fund the Society and work collaboratively to create the Assistive Tech for Good program. It was recently unveiled and will operate as a pilot for about two and a half years, after which time its sustainability will be evaluated. At this point, it's available in the Lower Mainland, but it will be expanded throughout BC early in 2019.

Through Assistive Tech for Good, TELUS customers who have a disability that prevents them from easily accessing or using their smartphone or tablet will receive personalized assistance from Neil Squire Society accessibility and assistive technology specialists.

"The program will provide technologies and expertise," says Birch. "It can span the full spectrum from helping a customer to selecting and configuring a phone that best meets their needs, to working with a customer to select an assistive technology such as a LipSync interface device, or even providing assistance with mounting the assistive technologies or training on how to use the assistive technology or related assistive software. In some circumstances, where we think it would be useful for the TELUS customer, we will also recommend and facilitate a connection to The Tetra Society of North America, which is a partner with the Neil Squire Society on this service."

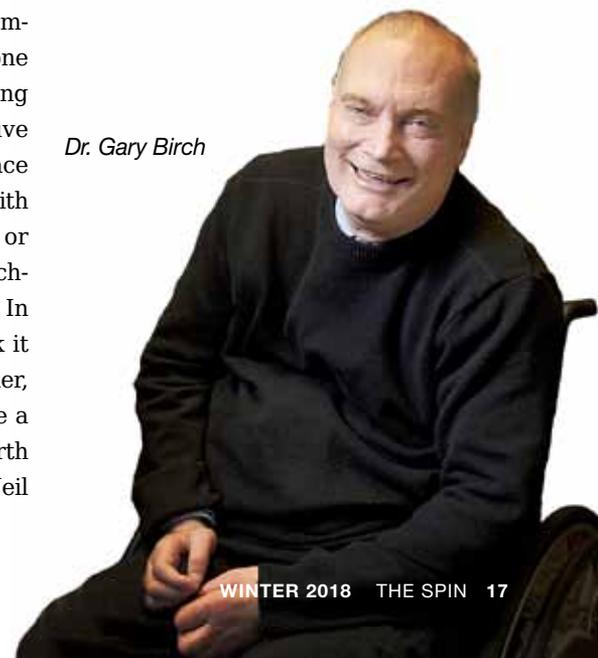
There's also the possibility of receiving financial support. Birch points out that this is not for the smartphone itself; it's intended for the assistive technology that may be required by a given customer.

"The criteria will be based on demonstrated financial need, keeping that definition somewhat open-ended," explains Birch.

He adds that, for customers outside the Lower Mainland, the Neil Squire Society will primarily use the same distance technology delivery used in its Distance Computer Comfort program.

If you're keen to learn more, and are a TELUS customer or want to become one, phone TELUS customer support at 1.866.558.2273. ■

Dr. Gary Birch



Bacteria Beater

Many people with SCI rely on indwelling catheters. Unfortunately, repeated infections and blockages often go hand-in-hand with indwelling catheter use, sometimes with dire consequences. A new antibacterial indwelling catheter being developed in the UK may offer a much-needed improvement.

Clean intermittent catheterization is the bladder management technique of choice. But not everyone has the hand strength and dexterity to cath themselves four to six times a day, which is why many readers rely on indwelling or Foley catheters.

The problem, as we know all too well, is that there's an increased risk of UTIs and blockages with indwelling catheters, regardless of whether they're urethral or suprapubic. In turn, UTIs are the underlying cause of many other health problems, including autonomic dysreflexia, and, over the long term, re-

petitive UTIs have even been linked to bladder cancer.

A new antibacterial indwelling catheter developed by researchers at the UK's University of Nottingham promises to reduce the risk of developing UTIs, as well as dangerous blockages.

There have been a few attempts to create an antibacterial catheter in the past—one approach was antibiotic coatings, and another employed silver, a known anti-bacterial agent. Neither was effective, according to Dr. Katie Belfield, a research assistant at the University of Nottingham's School of Medicine.

"In 2012, a nationwide trial in the UK showed that available silver and

antibiotic-coated urinary catheters did not actually prevent infections, even for short-term catheter users," says Belfield. "So that really left no anti-infection technology available to urinary catheter users."

Belfield then began working on a different approach with Professor Roger Bayston, a University of Nottingham researcher who invented Bactiseal anti-bacterial neurosurgical devices.

"These devices are sold worldwide, and a recent (2018) nationwide trial in the UK demonstrated that Bactiseal hydrocephalus shunts significantly reduced brain infections, whereas silver-coated catheters did not," she says. "Seeing the enormous clinical need for something similar in urinary catheters, we repurposed the technology."

What makes the new catheter stand out from previous efforts is that, like Bactiseal devices, it relies on antimicrobials that are impregnated into the catheter material, instead of coating only the exterior.

"This means that, as urine rinses away some of the antimicrobials on the catheter surface, the molecules inside the silicone catheter material can continuously migrate to the surface," explains Belfield. "This keeps the level of antimicrobial drugs at the surface high so they can protect against bacteria over a long period."

She adds that the new catheter uses three distinct types of antimicrobials, a term which includes both antibiotics and antiseptics.

"The antimicrobials we impregnate into the catheter have all been used clinically, and their safety is well-known. The three different antimicrobials work in different ways. Firstly, rifampicin is an antibiotic that is used commonly to treat tuberculosis, but it also kills staphylococci—the bacteria that cause staph infections and that can cause MRSA (methicillin-resistant staphylococcus aureus) catheter infections. It prevents bacterial cells from making proteins, which they need to survive. The second is sparfloxacin, also an

antibiotic, which works by preventing bacteria from making DNA, which they need to replicate. The third is triclosan, an antimicrobial, which disrupts the bacterial cell membrane, causing the death of the bacteria.”

Belfield says that there are two reasons for using this combination.

“The first is that, by using three, we can cover the spectrum of bacteria that are responsible for UTIs. Secondly, we have chosen these three so that at least two of the antimicrobials will kill each bacterial species. If you have two antimicrobials working against one bacterium, it is much less likely that the bacteria can become resistant. The bacteria are unable to develop resistance to two antimicrobials at one time. This is called the Dual Drug Principle.”

Additionally, the catheter design further prevents antibiotic resistance by restricting the bacteria-killing activity to the catheter surface; the antimicrobial drugs are not spread throughout the body like they are when taking antibiotic tablets orally.

“This prevents bacteria in the gut or skin from being exposed to the antibiotics and becoming resistant,” says Belfield. “In addition, fewer infections means fewer courses of antibiotics, so less resistance.”

She points out that, in addition to preventing UTIs, the new catheter also reduces blockages.

“One of the most common causes of catheter blockage is infection by the bacterium *P. mirabilis*. This bacterium is capable of changing the pH of urine from acidic to alkaline by producing ammonia. At an alkaline pH, minerals such as calcium, magnesium, and phosphate normally found in the urine can attach onto the catheter and form crystals. The crystals can block the catheter and also provide more surfaces for more bacteria to attach to. The antimicrobial urinary catheter kills *P. mirabilis* and our laboratory studies show that this prevents catheter blockage.”

Belfield says the catheter’s effectiveness has been demonstrated in the lab,

and there’s also good supporting evidence from Bactiseal products such as the brain shunt described above.

“It’s been used in over 90 countries, so we know that it is safe and also that it prevents brain infections,” she says.

With funding from the UK’s National Institute for Health Research, Belfield and Bayston recently completed a small clinical trial of the new catheter, with 30 participants testing it for safety.

“The majority of participants said the antimicrobial urinary catheter was as good as or better than their usual catheter and that many had less pain with it,” says Belfield. “The full details have been recently published in the scientific journal *Neurourology and Urodynamics*.”

With the small trial establishing safety, the researchers are now in the process of securing funding for a larger, longer term trial to determine the effectiveness of the catheter. They expect to start that trial by January, 2020.

That means people won’t be able to use the new catheter anytime soon. But if benefits are confirmed in a larger-scale trial, it may not take long to roll it out to the public, given the same technology has already been declared safe and effective in other applications.

“The technology is protected by a patent,” says Belfield. “We’re working with a commercial partner, but it’s confidential at this stage. They will be manufacturing the catheters for the upcoming trial as

a practice run, if you will, for distribution to participating healthcare systems. We hope that the antimicrobial urinary catheter will be attractive to healthcare systems if we can demonstrate that it is cost-effective; I think that will really determine its uptake.

“We don’t expect the catheter to be significantly more expensive, but there would be a slight price increase to pay for the antimicrobials. The cost of UTIs is enormous, and in the UK, recent estimates say each episode of CAUTI costs about \$3,000 CDN. If our catheter is a few more pounds or dollars more expensive but prevents UTIs, it seems cost-effective. However, to show this, we are going to calculate this with the help of health economists during the next trial.”

She adds that work to date suggests the catheter would be effective for up to 12 weeks. “For those that experience recurrent infections or blockages, increasing the catheter life past a few weeks is a good start!”

The upcoming trial will only include people in the United Kingdom, but there’s a way for SCI BC Peers to contribute to the study.

“The input of catheter users into the trial design and study is invaluable,” says Belfield. “If you’d like to help shape the research and be willing to answer some questions from me every once in a while, please get in touch with me at Katherine.belfield@nottingham.ac.uk.” ■



Professor Roger Bayston



Dr. Katie Belfield

ask the SPIN DOCTOR

Angie writes, “I’ve tried many things to reduce sediment in my bladder, including cranberry tablets, anti-bacterial catheters, frequent irrigation, uva ursi, lemon juice, etc. I even switched to a supra-pubic drainage system. Nothing has worked. I drink as much water as humanly possible but sediment still builds in my bladder very quickly and threatens to block my catheter. I feel it’s the hardest aspect of my disability to manage. What can I do? Will the new Duette catheter help?” To answer this issue’s question, we reached out to Dr. Lynn Stothers, ICORD Principal Investigator ICORD and Professor of Urology at University of British Columbia.



Angie, thanks for taking the time to write about a common and difficult situation—that is, sediment in the urine that seems to persist despite people’s best efforts to find a solution. The list as to “why” sediment happens is actually a long one. Getting an answer requires a physical exam, along with other common tests of the urine and blood, and sometimes imaging studies. For this reason, it’s difficult to speak to your individual situation without seeing the results of these types of investigations. The bottom line is that there are many conditions that can cause sediment in your urine, so an evaluation needs to be completed to find underlying causes and determine how they can be treated appropriately. Health care providers can provide insight through their investigations and examinations and create a personalized solution that fits your medical history and your personal needs.

Generally speaking, in the context of SCI, the most common cause of an abnormal amount of sediment is acute cystitis, more commonly referred to as a urinary tract infection or UTI. Unfortunately, there is a clear link between UTIs and indwelling catheter usage.

For most people with SCI, the standard treatment for UTIs is antibiotics. Have you ever had a serious UTI that required antibiotics? If so, think back to the time immediately following treatment—was sediment less of a problem for a period of time afterwards? If so, this could be a clue that your ongoing, chronic sediment problems are the result of a low level UTI that, without antibiotics, is persistent within your bladder.

If your catheter is the culprit, there are essentially two potential problems: improper hygiene during catheterization, and irritation resulting from the catheter being in constant contact with the tissue within your bladder.

I realize that you may be practising the best possible hygiene in your daily routines, but I can’t understate the need for this. Extreme care must be taken to ensure your catheter is clean and sterile, that this isn’t somehow compromised during insertion, that your drainage bag is emptied properly, and that you’re making your best efforts ensure your bladder is fully drained.

Another consideration for those who use intermittent catheters to empty the bladder is to check the technique

with ultrasound to ensure that the bladder is emptying with catheterization. Sometimes poor catheter technique—such as not leaving the catheter in long enough to empty the bladder—can result in residual urine. If this is repeated over time, it can lead to sediment. Of specific importance to women is the condition of prolapse—where the bladder can be in a low position. Pelvic organ prolapse or POP can cause extra challenges with catheterization.

Let’s touch on the idea of diet. The foods we eat result in different components entering the urine. In some people, certain components can lead to the formation of sediment in the urinary tract. Stones can form from this sediment, so health care providers may examine patients for the presence or absence of stones. Generally speaking, avoiding caffeine and alcohol, which dehydrate and irritate the bladder, is important to maintaining bladder health for some people.

You’ve indicated that you’ve tried multiple non-traditional treatments. There’s little scientific evidence to definitively conclude that any of these treatments are effective. Nevertheless, many people do anecdotally report that they’ve had success with D-Mannose, cranberry extract and others. One in particular that you haven’t mentioned is cream of tartar, or potassium bitartrate, which is a dry, powdery, acidic byproduct of wine production. On various online communities for people with SCI, such as the CareCure Community hosted by Rutgers University (www.carecure.org), many people with SCI report being able to reduce their sediment from drinking a teaspoon of cream of tartar dissolved in a glass of water twice a day. Again, there’s no scientific proof to support the use of cream of tartar. A key concern is that all intake of both medicines and supplements may have risks and benefits and can be dangerous if not taken in appropriate doses and under medical supervision. Before using any supplements or medications, check with your doctor and get personalized instructions for you.

In conclusion, I will repeat that there could be other factors also at play—for example, excessive sediment can be a byproduct of diabetes and bladder stones, common conditions for many people with SCI. This again underscores the importance of having a thorough assessment, which should lead to a diagnosis and effective personalized treatment plan for you.

SCI BC's 24/7
Resource Centre
has you covered!

SCI RESOURCES

sci-bc.ca/resource-centre

Newly Injured?

Learn about life after spinal cord injury, get involved in our community, find a lawyer, get support, and ask questions



sci-bc.ca/newinjury

ACCESSIBLE



Housing

Find accessible housing in BC

Employment

Look for new career paths and job opportunities



Travel

Go exploring with tips, videos, airport advice, and virtual tours of BC parks

SCI Information DATABASE



Browse our online encyclopedia with more than 800 informative and current resources



QUESTIONS? CALL OUR INFOLINE!
1-800-689-2477 info@sci-bc.ca
TOLL-FREE 9AM - 5PM Monday - Friday

New and exciting!

SCI SEXUAL HEALTH RESOURCE

Visit us online
scisexualhealth.ca



Connect with Peers who've been there too!
Join in online or with any phone or tablet.

VIRTUAL PEER GROUPS

SWAP SHOP



Buy or sell SCI items online!

sci-bc.ca/swapshop

Wheelchairs and vehicles, adaptive equipment, and so much more



Spinal Cord Injury BC

Safe & Happy Holidays...



...From the staff of Access Driver Rehab Specialists!

Our Driver Rehabilitation Specialists provide the highest quality driver evaluation and rehab services—when you want, and where you want. We are the only program in BC that offers a mobile service throughout the province, as well as Alberta and the Pacific Northwest. We offer assessments, training, and driver rehabilitation in either a sedan or high tech (electronic controls) van.

Access Driver Rehab Specialists—your key to independence.



ACCESS DRIVER REHAB SPECIALISTS

Phone: 604-263-5218

email: AccessDriverRehab@gmail.com

www.accessdriverrehab.com



It's all downhill from



After his injury, Cole Hoodicoff never expected to be able to rip down a rugged mountain trail. That all changed when SCI BC Kootenays Peer Coordinator Josh Dueck invited the Castlegar teenager to a mountain bike camp.



that what he was about to try would be something much tamer.

"I'd heard of adaptive mountain biking, and thought maybe I'd be looking at taking the bike for a spin on the road or something," recalls Hoodicoff.

After he'd swapped out his wheelchair for a state-of-the-art Explorer III Off-Road Handcycle, he found the courage to drop into the muddy dirt trail.

Later, he confessed that the experience "completely and utterly" blew his expectations out of the water.

"There's berms and banked corners like crazy, and you're flying down from the top of a mountain, down a little windy trail with trees, and over these huge drops," he says. "I almost went down on the first corner, but as soon as I saw what I was actually doing, it blew my mind. Because I never would have expected that I, not being able to walk, would be able to go down a trail like that."

The entire epic adventure was organized by Josh Dueck, SCI BC's Kootenays Peer Coordinator. Dueck took care of the logistics, secured the adaptive gear, and applied the gentle peer pressure that would eventually see Hoodicoff reach his empowering "aha" moment at the bottom of the run.

A Paralympic ski champion and multi-medallist in Paralympic, X Games, and World Cup events, Dueck knows better than most about the power of a healing dose of adrenaline in the great outdoors.

"I really love the idea of getting to learn more about yourself through adventure and activity," says Dueck. "Nature's a great teacher, whether it's biking, paddling, or surfing. Whether it's moments of solitude, or whether it's collective conversations and shared experiences, there's something about self-realization in these environments that helps us transcend the limitations of our physical bodies and give in to something that's a bit bigger than ourselves."

While Dueck made his mark as a skier, he's fallen in love with the relatively young sport of adaptive mountain biking and has worked hard to fit it into his Peer events.

The world's first adaptive mountain bike trail is the Jetton Park Trail Loop, completed in 2007 in North Carolina. Since then, facilities have been springing up around the world. The first purpose-built aMTB trail in Canada was constructed, somewhat ironically, on the prairies, just outside of Regina.

Here in BC, the Spine Trail opened in 2017. Located just north of the old mining town of New Denver, the 2.7 kilometre adrenaline rush winds through sub-alpine meadows and canopies of juvenile spruce. The views are spectacular—to the west, the imposing Valhalla Range gives way to a blue strip of Slokan Lake below; to the east, the snow-capped Kokanee mountains are just as breath-taking.

Like other purpose-built aMTB trails, the Spine trail is somewhat different than traditional mountain biking trails. It has been carefully constructed with greater widths and turning radii, along with less severe inclines on the uphill stretches. This makes it ideal for even first-time adaptive mountain bikers such as Hoodicoff, regardless of whether they're using kneeling or recumbent bikes.

Hoodicoff was enjoying a summer off from his engineering classes at Selkirk college 100 kilometres south in Castlegar when he learned that a group of local Peers with SCI were planning on hitting the new trail—and that he was welcome to come along.

The invitation came from Rosland resident and fellow Peer Kim Joines,

here!

Cole Hoodicoff had been down some hills in his 18 years. Down the Red Mountain ski hill that left him a T2 paraplegic at 11 years old. Down the rocky road of adjusting to teenage life with an SCI in small town BC.

Hoodicoff wasn't thinking about any of that on a rainy day this past July, when he edged his way over the lip of the Spine, BC's first purpose-built adaptive mountain-bike (aMTB) trail.

He had been invited to try adaptive mountain biking with a small group of SCI BC Peers. While he'd seen plenty of regular mountain biking videos of riders ripping down trails on two wheels with precision and style, he imagined



who had been helping Dueck to create outdoor Peer opportunities since SCI BC hired him as the Kootenays Peer Coordinator in 2016.

“The idea,” says Dueck, “was pretty simple—to provide an opportunity for local Peers with SCI to experience mountain biking, paddleboarding, and just getting together—the whole idea of peer mentorship.”

When he learned that Dueck was behind the invitation, Hoodicoff was even more intrigued. The two had met years before at Sunnyhill Health Centre, when Dueck popped into the newly-injured boy’s room.

“When I met Josh, he seemed so happy,” recalls Hoodicoff. “And that kind of surprised me, honestly, because he was in a wheelchair. So was I, but I wasn’t too happy about it, although I was trying my damndest to deal with it.”

Hoodicoff remembers asking Dueck if he could get off the ground and into his wheelchair. “Josh wheeled backwards, got on the ground, and got back into his wheelchair—and that blew me away,” says Hoodicoff. “And then we went out back, and he got into his truck. And my life was transformed.”

In the eight years since he left Sunnyhill, Hoodicoff has transferred countless times from the ground to his chair. Every time, he thinks of “how Josh did it.”

So not surprisingly, Hoodicoff jumped at the opportunity.

Fast forward to a grey, soggy day in July, when the trio of Hoodicoff, Dueck and Joines, along with a small group of fellow adventurers, headed up to the Spine trailhead and unloaded their gear in the mud.

“I saw the bike and I was just amazed,” says Hoodicoff. “I was in awe. The Explore III that Josh brought was just so, so beautiful. Majestic. Big words to use for a bike, but I seriously dream about that bike. Just the way it looks, how much of a personality it has. The minute I saw it; the minute I rode it. It’s such an awesome piece of equipment.”

And it truly is an amazing piece of kit—it features an ergonomic aluminum frame, full independent suspension, hydraulic disc brakes, 22 gears with power assist, and precise chest steering. The model’s nearly \$12,000 CDN price tag, is, however, a little intimidating.

One by one, Hoodicoff’s new friends took turns setting up in their rides with

chest forward and knees tucked, and then dropped into the trail. When it came to Hoodicoff’s turn, the rain eased up, and so too did the young man’s nerves. He leaned into the chest plate, turned the handlebars, and let gravity take over.

“It blew everything that I ever expected I would be capable of even doing out of the water,” he says. “And it really opened my eyes, a lot bigger, to see what is possible for somebody like me, especially because my injury is rather high. I have no core control, no balance.”

While Hoodicoff had no idea about the epiphany that lay in store for him, it was all part of Dueck’s plan for his young protege all along.

“I definitely had to re-frame what outdoor adventure meant to me after my injury,” says Dueck, who found old friends harder to keep up with and familiar environments more challenging to navigate after his own injury in a ski jump accident. “It’s not impossible, but I certainly had to redefine what outdoor exposure and adventure looked like in my new world. It’s about being okay with having to readjust your perspective.”

Today, Dueck is inspired to help his growing gang of Kootenay-based wheelchair users discover—or rediscover—that sense of confidence and adventure. In the process, they all learn through a shared Peer experience—about the power of adventure and sport, but also about overcoming any of the challenges of life with SCI.

“It’s very important to meet Peers who have been through something similar; to meet those other people in wheelchairs and ask the personal questions that you’ve been unable to ask anyone else because nobody else would know,” says Hoodicoff, who had never spent any time with another wheelchair user since his injury. “To talk to and ask, well, ‘How do you overcome this or that challenge?’ If they can overcome those challenges, I should be able to overcome mine.”

Nature had met nurture—and Hoodicoff was hooked. He followed Dueck to an adaptive paddleboarding event near Fernie a day later, and tagged along



on a cross-Kootenay road trip the week after that. In short, he dropped all of his previous summer plans, helping out where he could, and taking peer mentorship cues from Dueck.

“I think I definitely see myself wanting to be in that position,” says Hoodicoff. “I would love to be an inspiration to anyone and everybody who could use it.”

Less than a month later, he found himself face-to-face with the Spine Trail again—this time with a little more experience. Around him, a dozen adaptive mountain bikers, both amateur and expert, prepared to shred the gnar as part of a larger SCI BC Adaptive Mountain Bike weekend, held in partnership with the Rad Society and Kootenay Sufferfest. The youngest adaptive rider, Lucas, was about the same age as Hoodicoff when he first got injured. Needless to say, Hoodicoff was in his newly-discovered element.

Chalk another victory up for Dueck, and all of his SCI BC Peer Coordinator colleagues across the province who also embrace outdoor adventure as a great way to empower Peers in every aspect of their lives.

“We live in a golden era,” says Dueck. “There are so many resources and adaptations that are available to us—from mountain biking to hiking to surfing and skiing and everything else. If we’re able to provide some direction and some resources for folks to adjust their equipment so that they’re able to enter and enjoy these environments, that’s pretty awesome.” ■

Interested in connecting with the Kootenays SCI community, over coffee, on the water, or out on the trails? Contact Josh Dueck at jdueck@sci-bc.ca or 250.306.7061. Plus keep an eye on sci-bc.ca/events for outdoor events, including Learn to Camp weekends and outdoor sports camps, coming up throughout the province in 2019. Want to learn more about adaptive mountain biking and the different types of aMTBs available? Visit www.breaktheboundary.com, an excellent online resource based in Australia.

Congrats to Our 2018 Scholarship Winners

The power of post-secondary education for people with SCI can’t be understated. That’s why SCI BC is proud to partner with the Vancouver Foundation on a new provincial scholarship fund specifically for students with SCI.

The newly-created GRAGOPEAN Scholarship fund was established by a group of donors to assist persons with SCI attending post-secondary schools in BC with their tuition, books, learning aids and, in some cases, supports related to their disability such as housing, transportation, and in-class assistance including note-taking. More than \$250,000 in scholarship awards is available through the GRAGOPEAN Scholarship fund each year, making it one of the largest scholarship funds of its kind.

In this inaugural year, we were pleased to award the following 10 students a combined total of \$77,000 in awards:

- Tomas Bourassa / Mechatronics Systems Engineering, Simon Fraser University
- Daniel Duffy / Associate of Arts Program, Langara College
- Emily De Boer / General Studies, Kwantlen Polytechnic University
- Jessica Kruger / Baking & Pastry Arts, Vancouver Community College
- Fiona Ma / Nursing Sciences, BCIT
- Riley Martin / Law, University of Victoria
- Pierce Pineau / Business and Aviation, University of the Fraser Valley
- Barbara Schober / History, UBC
- Robert Shaw / Interdisciplinary Studies, UBC Okanagan
- Holli Vander Wyk / History, UBC Okanagan

In addition, we’re also pleased to continue our long-standing administrative role with the BC Paraplegic Foundation (BCPF) Bursaries, provided annually to support individuals with an SCI with their post-secondary education. Funds for these bursaries are provided by the foundation itself, as well as individual donors. Here’s a recap of the bursaries provided this year:

- The Scott Stanley Scholarship was created by Mr. Stanley, a lawyer with Murphy Battista LLP. This year’s recipient of this award is Riley Martin, enrolled in the Juris Doctor of Law Program, University of Victoria.
- Held in trust at the Vancouver Foundation, the James H.G. Roche Memorial Scholarship supports one to two individuals per year. The fund was generously established by the partners, family and friends of James Roche, a former director and board chair of SCI BC, who sustained an SCI in a skiing accident. This year’s recipient is Thomas Venos, enrolled in the kinesiology program at the University of Alabama.
- The C.W. Deans Memorial Scholarship is held in trust by UBC and is provided to UBC students with SCI. The Joseph David Hall Memorial Scholarship is also held in trust by UBC and is provided to UBC students with SCI, with a preference for students in engineering. First preference for both awards is given to students recommended by Spinal Cord Injury BC; our selection for both awards this year was Michael Prescott, who is enrolled at UBC in Rehabilitation Studies.
- Finally, the BC Paraplegic Foundation Scholarship Award was given to Kristian Oaken-Shield, enrolled in Acupuncture Studies at the Oshio School of Acupuncture and Herbology, Victoria.

The next round of applications for both the GRAGOPEAN Scholarships and the BC Paraplegic Foundation Bursaries will be in the Spring of 2019. For further information, including eligibility criteria, visit <https://sci-bc.ca/about-us/scholarships-bursaries>, or email scholarships@sci-bc.ca.



Moving Matters

(or Peek Before You Pack)

Moving is a challenge for everyone. But for SCI BC Peers, especially those who rely on government services, moving to a new location in our province can be a particularly stressful undertaking.

For some, it's about living in a location with a milder winter or being closer to family members. For others, it's about being closer to specialized medical care. And sometimes, it's all about relocating for a new job, or simply needing a change of scenery. Whatever their reasons, some SCI BC Peers, like other British Columbians, choose to move to a different town or city within our province.

Moving is universally acknowledged to be one of life's most stressful events, regardless of ability. Factor in an SCI, and

the degree of difficulty is compounded. And if that SCI is high level, the stress is increased exponentially.

The most obvious problem for anyone with an SCI is the challenge of finding affordable, accessible housing. It's really, really tough. In fact, according to Heather Lamb, one of SCI BC's information resource specialists, housing is the number one issue that Peers contact her about. The shortage of accessible housing is a long-term, chronic problem in our province, and we could write volumes about that alone.

But there's an additional layer of complexity that's specific to people who rely on caregivers to maintain their independence.

Consider the experiences of Ken Legros, C4 quadriplegic and SCI BC Peer, who recently moved from Prince George into his new apartment in central Kelowna—a process that took almost four years to complete.

Legros is originally from Victoria, but had made his home in BC's north since 1989, where he lived in Terrace and Prince George.

"I decided to make the move after going through a rough stretch finding care aids, and after enduring long, cold winters for 28 years," says Legros.

His first step, once he'd made up his mind to move, was a staggeringly long and drawn out search for a fully accessible apartment that he could afford. He contacted the Canada Mortgage and Housing Corporation (CMHC), which provided him a list of subsidized housing in three different locations in the Interior region.

"Once I had the list, I looked at all the possibilities and evaluated them by accessibility and location," says Legros. "I came to the conclusion that I wanted to settle in Kelowna, as I have several friends here. With that decided, I contacted the Society of Hope (the largest steward of accessible, subsidized housing in the Okanagan) and requested a housing application. After sending in the application and meeting all requirements, it was all about playing the waiting game."

And wait he did. Finally, after three and a half years, a suitable unit became available. And that's when Legros' work really began.

He had to deal with all the usual exhausting aspects of moving—finding a mover, packing, cleaning, forwarding mail, changing addresses and doing all the time-consuming chores that anyone would have to do. But by far, the biggest challenge turned out to be transitioning his caregiving needs.

Legros has been a client of BC Health's Choice in Supports for Independent Living (CSIL) program since 1998. CSIL clients receive funds directly from their local health authority to hire, train and manage their own caregiving staff.

Suddenly, he had to deal with giving notice to his caregivers in Prince George, while simultaneously trying to find and hire qualified workers in his new community—he would need support from the moment he arrived. "I had to make sure I had care aids lined up by putting ads online, and then taking applications and doing over-the-phone interviews while still in Prince George," he says.

But the most jarring aspect of his CSIL transition was yet to come.

"I'd first talked with CSIL staff in the Northern Health Authority months before the move," he says. "According to them, it would be an easy move—my file would be transferred to the Interior Health Authority, and when I arrived in Kelowna, they would come over do a meet and greet, go over my file and assessment, and it would be done."

Well, that wasn't the case.

"After the interview and assessment was done here in Kelowna, I was told by my new case worker that I had to reapply for CSIL—even though I have been on it since 1998 and had 20 years of history," Legros explains. "So what I thought would be an easy cut-and-dry transfer became a stressful start to the settling into Kelowna."

CSIL's lack of portability for those moving within BC isn't widely-publicized—we had to really dig to confirm this fact when we wrote this story. But

you would at least expect that the program's staff and administrators across the province, including the Northern Health Authority personnel who advised Legros, would be knowledgeable about this aspect of the problem.

Fortunately, Legros was told that CSIL would maintain his level of funding support at his previous, Prince George level while his application would be processed and his needs reassessed.

But when we interviewed him at the beginning of November for this story, he was still uncertain about his status going forward with CSIL. "It's taken me a month to figure out all this," he says. "I'm not moving to a different province, so this should be easy—why would my needs change from Prince George to Kelowna? I'm still in the 'waiting for approval' stage which is adding more stress, not knowing the outcome. But all I hear from my case worker is, 'It will be okay, but it still needs to go to a supervisor for approval on hours allowed.' I won't know until



For Ken Legros, moving from Prince George to Kelowna was a three and a half year ordeal, made all the more stressful by his 11th hour discovery that he had to reapply for CSIL.

closer to the end of November. I think that once you're approved for CSIL, and if you're moving within BC, you should be able to continue your daily lifestyle, because the criteria and guidelines are the same in all regions. They should not make someone's life so stressful, and make it so hard to move, for anyone simply trying to better their quality of life."

Here at SCI BC, we agree—we believe BC Health should have removed this lack of portability from this vital program a long time ago. We're hoping we'll have an opportunity to discuss this problem with BC Health.

Caregiving wasn't the only area where a surprise lay in waiting for Legros. He'd also assumed that, since he wouldn't be ditching his wheelchair anytime soon, his BC Transit subsidies would also be transferable to Kelowna. But again, that wasn't the case.

"After 33 years as a quadriplegic, I suddenly had to reapply to BC Transit to get reassessed," he says. "Despite being registered in Prince George, I needed to prove that I still needed taxi savers and specialized transit. So...let's add more stress to the move."

However, he adds that, at the time of writing, BC Transit was in its final stages of approval, and he was expecting to get a letter of acceptance within a couple of weeks.

For the most part, life's back on track for Legros now that the bulk of the hard work has been, and he's settled in his new home.

"Things now are going better. I've been trying not to stress, and am just taking the little steps to complete the process for getting the approval for everything. I'm very happy on my decision to move to Kelowna. I've wanted to do this for years; start a new chapter in my life. And my new place is great—like a penthouse suite!"

We asked Legros if he had any advice for other Peers contemplating a similar move. Not surprisingly, he says the top priority should be your caregiving and CSIL, if that's what you rely on.

"Please contact both health author-

Moving: A Priority Checklist

Heather Lamb, SCI BC Information Specialist

- **HOUSING:** This is obviously the most important factor. Without housing in place ahead of time, I would advise people to be very cautious about even thinking of moving.
- **CSIL:** Talk to your local (current) case manager, and the Home and Community Care office in destination community, to confirm details of interim CSIL support and the reapplication process required. Also contact the Individualized Funding Resource Centre (IFRC) Society, as they are more familiar with CSIL across the province. (www.ifrcsociety.org)
- **CAREGIVERS:** Talk to Peers in the destination community to see if they know of any caregivers looking for work, and for their recommendations about the best ways to recruit caregivers in your new community.
- **MEDICAL:** Ask your current GP for a referral, or talk to family members or peers in your destination community to find a suitable doctor who is accepting patients. Find out whether the doctor will prescribe necessary medications—especially pain management meds. Know the locations and hours of walk-in clinics in the new area. Fill prescriptions before the move to ensure an adequate supply. Have a current list of medications on hand. And know where the closest pharmacy is.
- **MEDICAL SUPPLIES:** Make a list of medical equipment stores in your new community and ensure they can meet your equipment maintenance and medical supply needs. Have an adequate supply of catheters and other needs on hand before the move.
- **PACKING & UNPACKING:** Arrange for family and friends to assist with the tedious chore of packing and unpacking. Ensure that necessary items such as a hospital bed or commode can be packed last and unpacked first to ensure they're available when needed. You might also want to consider rental equipment for a few days during the move.
- **TRANSPORTATION:** Familiarize yourself with your new specialized and regular transit services, along with accessible parking options and rules. Find out which gas stations offer full serve.
- **SUPPORTS:** Have a support system in place in your new community—for example, SCI BC Peer connections, family support, and friends who can help out with information and assistance.
- **EVERYTHING ELSE:** Make a checklist of all the usual businesses and facilities people need to find when moving, such as location of grocery stores, schools, recreation centres, restaurants, and more. Find out which grocery stores or restaurants have delivery—especially for the first days after the move.

Have more questions? Contact the SCI BC InfoLine toll-free from 9:00 am to 5:00 pm, Monday to Friday, at 1.800.689.2477. You can also reach us via email at info@sci-bc.ca.

ities for clarifications on the process of file transfer before deciding to move, because when you find out the news as I did, it's pretty stressful—it leaves you in the dark with more work to do than need be. It's not like you have enough to

deal with just with address changes and the cost of moving to begin with. Above all, good luck in your endeavour and do your homework first. And when it works, it will be rewarding because you're in a place you want to be." ■



Stealing the Spotlight

Neuromodulation, also called neurostimulation, is increasingly being recognized for its potential to restore function for people with SCI. In recent issues of *The Spin*, we've told you about several studies that have successfully employed the technique to achieve improvements in bladder and hand function. But it's a different story in the mainstream media, where the neuromodulation buzz is all about walking.

Neuromodulation is an exciting avenue of research when it comes to restoring function after SCI. No other research area—stem cells included—has yielded such intriguing, encouraging, real world results as neuromodulation, which essentially involves electrically stimulating key areas of the injured spinal cord to “wake up” damaged lines of communication between the brain, the cord itself, and the areas of the body targeted for movement or function.

Here at SCI BC, we've been particularly excited about the prospects for

neuromodulation to make improvements in areas identified by people with SCI as high priority. For example, as we've reported in previous issues of *The Spin*, there's a growing body of evidence that it can be safely and effectively used to restore bladder function for people with all levels of injury, and, combined with physical therapy, improve hand function for people with quadriplegia. Additionally, other neuromodulation research suggests it could also be used to improve bowel and sexual function—other high priority areas for people who live with SCI.

Meanwhile, in the mainstream media,

there's also a buzz about neuromodulation. But the difference is that it's mainly about the possibility of it restoring the ability to walk. Even highly-credible journals and magazines are feasting on the hype. You've probably seen some of the headlines. “New spinal cord therapy helps paralyzed patients walk again,” declared the October 31st issue of *National Geographic*. A similar headline appeared in the scientific journal *Nature* on the same date: “Three people with spinal-cord injuries regain control of their leg muscles.” There are many more examples.

Granted, some of this walking-focused research is credible (even if the walking being described is not really walking in the functional sense), and the results are certainly worthy of acknowledging. The problem we see is that this media coverage is too optimistic and unrealistic. This area of research is still in its infancy, and only a handful of people have been studied. So the degree to which the findings hold up, or are relevant and applicable to all people with SCI, just isn't known. Given a finite pool of research funding, we think that this “walking” or “cure” focus will eclipse what we think is other equally or even more important stuff—being able to grab a cup of coffee independently, or take a pee when you want without risk of accidents or UTIs.

We know that, when it comes to SCI, nothing grabs the public's attention more than the word “walking”. The media knows this and responds predictably. Funders, both private and public, also seem to get caught up in the hype and direct the bulk of their resources to these types of research efforts.

Not surprisingly, many researchers follow the money. This was evident dur-

ing a recent SCI symposium held in Richmond, BC, which several SCI BC staff members and Peers attended. The symposium, titled Working 2 Walk, is hosted annually by Unite 2 Fight Paralysis, a US-based non-profit organization focused on advancing SCI research. This year's version marked the first time the event had been held outside of the USA. Not surprisingly, given the buzz over recent results, neuromodulation was a central theme during the symposium.

The proceedings kicked off with a surprising but welcome acknowledgement of Dr. Kim Anderson-Erisman and her groundbreaking research to pinpoint the priorities of people with SCI themselves—research that made it abundantly clear that improvements in hand, bowel, bladder, and sexual function were their highest priorities, with walking farther down on the wish list.

Despite this acknowledgement of Anderson-Erisman and her findings, the focus of the researchers present seemed to drift, within the first few presentations, to the potential of neuromodulation as a means to restore walking. Only questions and comments from the audience periodically brought the conversation back to neuromodulation's potential to improve bladder and hand function. (Note that this is not intended to be a criticism of the symposium or its organizers—it was highly informative and really well-organized.)

Several of those questions came from Anderson-Erisman herself, who was in the audience. Formerly of the Miami Project to Cure Paralysis, she's now a professor in the Department of

Physical Medicine and Rehabilitation at MetroHealth Medical Center and Case Western Reserve University School of Medicine in Cleveland. She's also been quadriplegic since 1988.

Her 2004 study, published in the *Journal of Neurotrauma* and titled *Targeting recovery: Priorities of the spinal cord injured population*, is considered to be the most comprehensive and conclusive of its type. In fact, almost 15 years later, it's the third most cited paper in the *Journal of Neurotrauma*.

"I do believe the priorities are still the same today," says Anderson-Erisman. "They've been confirmed by other groups over the years, plus no new treatments have become widely available to improve arm, hand, sex, bladder, and bowel function, so they still have a significant impact on people on a daily basis."

So not surprisingly, while it's not her area of expertise, she is among those who would like to see neuromodulation fully explored as a way of restoring critical functions like bladder and hand strength.

"I am supportive of neuromodulation," she says. "I believe we have to explore and develop multiple intervention options for SCI because they won't all be applicable to every person. There are many types of neuromodulation—epidural, transcutaneous, peripheral nerve, brain. I think we need to acknowledge and support the promise of all neuromodulation."

At present, the majority of neuromodulation research in the media spotlight uses either epidural stimulation or transcutaneous stimulation. These are strikingly different, and each has advantages and disadvantages.

The epidural approach, being used primarily by researchers focused on restoration of walking, is invasive—it involves surgically implanting a stimulator device in the body, along with up to 16 electrodes on the surface of the spinal cord. In contrast, the transcutaneous approach, used by most researchers involved in restoration of hand and bladder function, is non-invasive: an external stimulator worn on the body is connected to up to six electrodes attached to the skin above the spinal cord.

"Epidural is receiving extra press—almost too much press right now—because of some extreme examples on walking," says Anderson-Erisman. "I think mainstream media is glamorizing it, and misleading the public and people with SCI on the applicability to the community at large and access to it."

Her concern is with the most publicized study, completed in France, that has tested the epidural approach to restore walking—but only for people with incomplete injuries.

Our impression here at SCI BC is that media coverage seems to be pumping up the hype without much acknowledgement of this—and without fully recognizing that it requires a complex, highly invasive surgery, along with repeated surgeries to replace a relatively short-lived battery for the stimulator itself. Other realities not being openly discussed epidural neuromodulation are a suspected lack of durability of the system in the body, the extreme expense that may preclude practical and widespread application, and the fact that this technology, while promising on many levels, is years—and perhaps even



Dr. Kim Anderson-Erisman

decades—away from being confirmed as a viable approach.

Compare this to neuromodulation research using a transcutaneous approach. It requires no surgery; the stimulator is worn by the user, and the electrodes are attached securely to the skin above the target area of the spinal cord. The most popular technology used with this approach has been developed and is being commercialized by California-based NeuroRecovery Technologies. We should note that the company is currently lacking funding needed to achieve FDA approval.

In the past two issues of *The Spin*, we've reported on two studies using this approach. These studies, both completed at UCLA by Dr. Parag Gad, demonstrated successful results—one in restoration of bladder function (including the ability to urinate on command), the other in restoring hand strength and dexterity for people with quadriplegia.

What's intrigued us about these studies is that, unlike using epidural stimulation to help people with incomplete injury walk, they suggest that the technology involved could be commercially viable and available to make a difference in the lives of our readers in as little as two or three years, if funding can be found to confirm benefits and safety through larger scale studies.

"Yes, the transcutaneous approach is much lower-hanging fruit than invasive approaches and could be a good way at obtaining data about applicability in a larger number of people," agrees Anderson-Erisman. "Studying hand, bladder, bowel, sexual function is inherently safer than walking because you don't have to worry about people falling."

However, she also believes research to explore the invasive approaches in hand, bladder, bowel, and sexual function should continue. We agree. In fact, we think the entire field of neuromodulation, in all its forms and for all types of potential benefits, warrants more research, including the moon-shot work being done to use it to restore walking. That would require a balanced approach—by the media, by funding agencies, and by the research community.

But once again, our fear is that this balance is lacking—it seems like the epidural approach, particularly in the context of restoring walking, seems to be increasingly stealing the spotlight from research in transcutaneous neuromodulation as a way of improving bladder, hand and other functions deemed to be far less exciting than walking. One possible consequence of this is a delay in developing, in a realistic time-frame, practical ways of greatly improving the quality of life of our Peers, in areas that they have themselves identified as their priorities.

"I believe that the research enterprise needs to rethink what it's doing," concludes Anderson-Erisman. "Upper extremity loss, bladder, bowel, and sexual dysfunctions are all primary results of SCI, they're not just secondary 'oh by the way' problems. People are living with SCI every day and they have an expertise that scientists, clinicians, funders, regulators don't have. It's time for people with lived experience of SCI to be viewed as partners in this whole endeavour, because we can only be better by working together." ■



We can help you explore work and training suited to your individual needs.

Contact your local

WorkBC Employment Services Centre
Centre de services à l'emploi

NORTH SHORE

106 - 980 West 1st Street | North Van
Tel 604.988.3766

VANCOUVER NORTHEAST

312 - 2555 Commercial Drive
Tel 604.708.9300

VANCOUVER MIDTOWN

110 East 3rd Avenue
Tel 604.829.2300

VANCOUVER WESTSIDE

300 - 2150 West Broadway
Tel 604.688.4666

VANCOUVER CITY CENTRE

900 - 1200 Burrard Street
Tel 604.434.0367

VANCOUVER DOWNTOWN EASTSIDE

Suite 200 - 250 West Pender Street
Tel 604.872.0770

VANCOUVER SOUTH

7575 Cambie Street
Tel 604.263.5005

Find your centre at vancouverworkbc.ca

Canada

BRITISH COLUMBIA

The Employment Program of British Columbia is funded by the Government of Canada and the Province of British Columbia.

Supporting your independence.



At Regency Medical Supplies, we're proud to have supported the independence of SCI BC members and people with spinal cord injuries for more than 50 years. Today, we're still your specialist for daily care needs and mobility equipment. If you're in the Lower Mainland, please stop by our 6,000 square foot showroom to learn more about the products we carry. If you're anywhere else in BC, shop online at www.regencymed.com or call us toll-free at 1-800-663-1012 to speak with a customer service representative.

- Coloplast/Mentor Condoms & Catheters
- Tyco/Kendall Catheters & Condoms
- Med-RX Intermittent Catheters
- Bard Urology Products
- Urocare Condoms & Leg Bags
- Rusch Urology Products
- Hollister Condoms & Leg Bags
- Golden Drain Condoms



Regency
MEDICAL SUPPLIES

Putting people first since 1966.

4437 Canada Way, Burnaby BC V5G 1J3
Within BC's Lower Mainland: 604-434-1383
Toll free within Canada: 1-800-663-1012
www.regencymed.com

Advancing Your Mobility

Keeping Your Independence
in Motion

Advanced
MOBILITY PRODUCTS LTD

www.advancedmobility.ca

1.800.665.4442

Burnaby.Nanaimo.Kamloops.Kelowna



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.

SCI Self-Management Mobile App

Overview: This study, led by ICORD researcher Dr. Ben Mortenson, will evaluate the effectiveness of a self-management intervention that features the use of the self-management app to help people with SCI attain self-selected goals and improve personal management of health.

What to expect: You will be asked to complete a series of questionnaires and, where applicable, two interviews over four data collection sessions. The study will involve multiple contacts and ongoing use of the mobile app. Data collection will take between 5.5 to 7.5 hours and additional app usage will take between 10 to 60 hours.

Who can participate: You may be eligible to participate in this study if you are 19 years of age or older; can speak, read, and write in English; were discharged from an inpatient rehabilitation facility following SCI at least one year ago; are living in a community setting; have reliable access to the internet; are capable of providing your own informed consent; and have not previously used a self-management app focused on SCI. Other inclusion and exclusion criteria may apply. Please contact the study coordinator for more information.

Why participate: Most people with SCI develop secondary complications, and mobile applications for self-management have been shown to be effective in patients with other chronic health conditions, but have not been assessed for patients with SCI. A mobile app could be an effective means of improving self-management skills in people with SCI. You will receive \$100 (\$20/each session) to help compensate your time spent in the study.

Location: This study will take place by phone/Skype or in person at a Metro Vancouver location convenient for you.

For more information or to sign up to participate: Please contact the study coordinator, Jodine Perkins, by email (mortenson.lab@ubc.ca), or by phone at 604.737.6491.

CoPILOT: Collaborative Power mobility Innovative Learning Opportunity

Overview: For many people with spinal cord injury, a powered wheelchair can make a difference in mobility. This can be seen both indoors and outdoors. Wheelchair skills training is an important part of learning to use a powered wheelchair safely for taking part in daily activities. Led by ICORD researcher Dr. William Miller, the purpose of the study is to evaluate a powered wheelchair training program that is designed to improve training for new powered wheelchair users.

What to expect: In this study, participants will be randomly assigned to one of two groups. Both groups will be asked to complete data collection on two separate days. Each data collection session will take up to 2 hours. They will also take part in 12 one-hour wheelchair training sessions with an occupational therapist.

Who can participate: To take part in this study, you must have a spinal cord injury; be a new power wheelchair user; be able to communicate and complete study questionnaires in English; and have no visual or hearing impairments which may influence safety or communication.

Why participate: In addition to receiving wheelchair skills training, participants will receive \$25 for each data collection session that they attend.

Location: The study will take place in the Blusson Spinal Cord Centre (818 West 10th Avenue, Vancouver).

For more information or to sign up to participate: Please contact the study coordinator, Erica Digby, by email (erica.digby@ubc.ca) or call 604.714.4108.



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

Get Gassed!

Many people with disabilities find it pretty difficult to gas up at a self-serve gas station, which is why we think Canadian laws should change so that anyone with a disability can get full service at any station. But in the interim, we're pleased to see the rollout of a new app that provides an innovative, alternate solution.

Drivers with SCI and other disabilities have it pretty good in Richmond and Coquitlam. That's because both cities ban self-serve gas stations. But Richmond and Coquitlam are the exception in our province and, for that matter, all of Canada—and that's why the reality for many Canadians with disabilities is a struggle at the pumps.

Here at SCI BC, we'd like to see this inequity addressed through legislation. Full service at the pumps for drivers with disabilities could be mandated by Bill C-81, the Accessible Canada Act, which is currently under Parliamentary review, or by provincial accessibility legislation, which will be developed soon. The Americans with Disabilities Act (ADA) is one example of legislation which provides this type of regulatory relief.

While that may or may not happen, a solution is being offered via a new app developed in the UK.

The app, called FuelService, is the brainchild of Niall El-Assaad, a 42-year-old quadriplegic who lives in Northwest England. El-Assaad, an experienced IT professional, is to be commended for his vision—and for entirely self-funding and self-promoting the app.

Here's how it works. Drivers with disabilities download and use the free app, or its associated website (fuelservice.

org), to locate and send a request for assistance at a nearby service station where staff are available to help drivers with disabilities. The phone rings at the station, where the staff presses 1 if they have someone who can assist the driver, or 2 if they don't. When the driver arrives at the selected station, the app alerts staff of their presence at the pump.

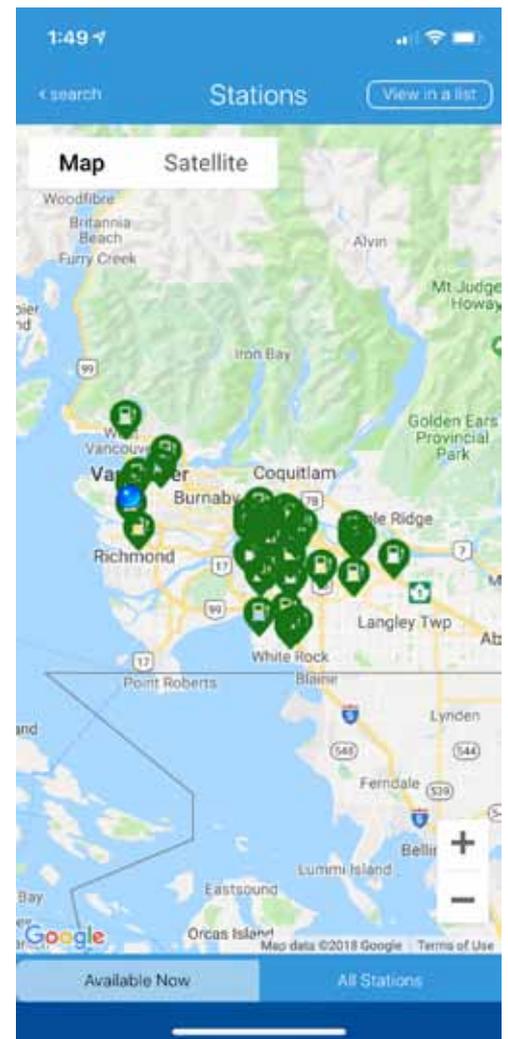
Naturally, the app is available for iOS, Android, and Windows phone.

El-Assaad's tireless work on the app began to pay off last year, when Shell became the first gas station company in the UK to sign up. Today, 822 Shell locations offer the service across the UK.

"It's been running for over 12 months in the UK, and we are helping well over 10,000 disabled drivers to get fuel," says El-Assaad. "It's at about 20 percent of all UK stations, with more on the way."

Meanwhile, interest is also growing internationally, including here in Canada. The good news for SCI BC Peers who drive is that, at the time of writing, the app was not only being pilot tested in many gas stations in the Lower Mainland, but 161 Chevron stations across the province were on the verge of debuting the service. And Shell is also reported to be in the process of rolling out the service at its stations across the entire country.

The app has also been embraced throughout Ireland and the Netherlands.



El-Assaad says the job of convincing gas stations to get onboard is getting easier all the time.

"The disabled community has been banging this drum for years and they're right," he says. "Disabled drivers depend on their cars, so providing good facilities for them will add up to more sales."

Participating gas stations pay a small service fee for each transaction, but El-Assaad is not out to make a profit—he donates all proceeds to SCI research.

"It was a massive problem I had for myself, so when I go and get fuel easily now, I'm so happy," says El-Assaad. "The feedback we get from other users who it's helped is amazing, and to know that it's helping others is a fantastic feeling."

You can learn more and download the app at www.fuelservice.org. One final note: it would be irresponsible of us if we didn't remind you not to use the app while driving! ■

Greater Reach & Better Service



SCI BC is proud of our newest sponsor, Chairstuff, and their dedication to the SCI community.

Chairstuff has your back ...

And your front! We understand bowel and bladder issues from the inside. Over the years, our staff has been made up of people living with different disabilities, and we regularly mesh with the local SCI peer community. Combine this with our legendary efficiency, wide range of products, and competitive prices, and you have a winning team in your corner. Our products include:

Intermittent Catheters

Bowel Products

External Catheters

Foley Catheters

Drainage Bags

Contact us for free product samples or to chat about your specific needs!

A supply company by people with SCI—for people with SCI

“ I have been ordering my colostomy supplies, catheters, and leg bags through Chairstuff since 2001. They’ve been a great company to work with. My stuff is always on time and that’s pretty great considering I live 900 kms away from where they do business.”
— Crystle

“ I switched over to Chairstuff from one of the bigger companies, which was more expensive. I like dealing with Steve because he’s a dude in a chair who’s got his own business. Anytime I need supplies, they’re delivered to my door. If I need them right away, Steve meets me where I need to be met.”
— Kevin



All your bladder and bowel needs – direct to your door.

1-866-363-0025 | 604-876-4133
info@chairstuff.com
chairstuff.com

“We’re here for you 24/7. We mean it.”

STEVE MILUM
Founder & CEO
Chairstuff





WE ARE BESPOKE

NOUS SOMMES SUR MESURE

WHEELCHAIRS | FAUTEUILS ROULANTS



BATEC MOBILITY



BENOIT SYSTEMES



SPINERGY ZX-1



VARILITE CUSHIONS & BACKS



AELITE CRUTCHES



TIRES



WHEELS, SUSPENSION, PUSH RIMS & AXLES



ACCESSORIES



OFFERING A FULL PRODUCT LINE !

...and a host of other products from fine manufacturers around the world.

OFFRANT TOUTE UNE GAMME DE PRODUITS !

...et toute une gamme de produits additionnels de première qualité.



51 Caldari Rd, Units 6-7B
Concord, ON, L4K 4G3



t. (416) 661-4499
e. 49@49bespoke.com

49BESPOKE.COM