

THE ARTS ISSUE: MUSIC, THEATRE, SCULPTURE AND MORE

the spin

SPINAL CORD INJURY BC

SUMMER 2015

RollPlay

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contents

SUMMER 2015

features

11 Love Online

SCI BC Peer Johanna Johnson reflects on her life-changing success with online dating.

14 Cover Story

Vancouver's Realwheels Theatre company is putting actors with disabilities on centre stage.

19 Privilege to Pee

Homegrown artist Kyla Harris shines a spotlight on the monetary, ecological, and psychological impact of our daily bodily functions.

22 Harmony & Healing

Music provided a great deal of the motivation and inspiration Simon Paradis and his wife Kara Stanley needed to deal with Simon's SCI and traumatic brain injury.

27 Finger-tapping Music Therapy

The MusicGlove promises a fun, new and harmonious way for people with quadriplegia to regain vital hand function.

30 Instant Diagnosis

A new diagnostic device developed at ICORD provides immediate confirmation of urinary tract infections.

32 Breathing Easier

A recent breakthrough could someday allow ventilator-dependent quadriplegics to breathe without assistance.

departments

4 editor's message

Why you should consider participating in research.

6 gear & gadgets

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

8 events

Important dates for your calendar.

8 ask the SPIN DOCTOR

New resources for would-be mothers with SCI.

29 Participate in Research

ICORD research that could benefit from your participation.

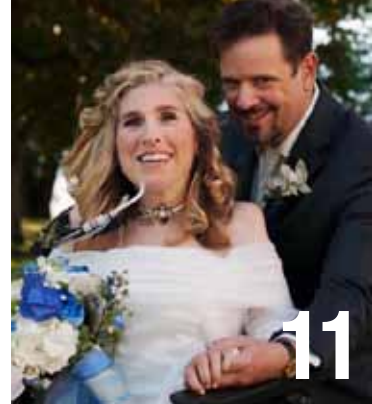
34 last word

Stemming the media hype over stem cell therapies.

Cover Photo: Dave Symington stars in the Realwheels production Re-calculating. Photo Credit: Kevin Statham



6



11



27



19



22



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You can't win the game if you're not on the team.

You've probably seen recent media coverage of a deluded Italian surgeon's plans for a head transplant procedure, and stem cell companies' dubious clinical trial "progress" updates. But I'm going to resist commenting on these stories and instead focus on why your participation in SCI research is important.

I recently returned from two international SCI research conferences where I was impressed by how much quality research is being done in the field of SCI. Most of this is not what we would call "cure research." Instead, it's focused on maximizing people's potential by advancing rehabilitation strategies to improve functional recovery; reducing secondary complications; increasing independence, accessibility and inclusion through assistive technologies and government policies; and fostering social and emotional wellbeing.

Within this vast spectrum of research is an essential, common element: people with SCI. Without participation by people with SCI, researchers would be unable to conduct their research, let alone know what they should focus on.

Researchers face many challenges, including finding funding. But one of the biggest stumbling blocks they encounter is finding enough people to participate in their research. Whether it's responding to a survey, getting hooked up in a Lokomat, or having recordings taken during various activities, people with SCI are critical to SCI research.

Yes, it's true that many of the studies require a commitment of valuable time. It's also true that getting to labs can be inconvenient. And it's true that participants are often left unsatisfied with their involvement because there isn't any follow up about how the study turned out and what the results of the research mean. But on the flip side, there's usually some form of compensation, small as it may be, for participating in research. Depending on the study, you may directly benefit from improved health or social engagement. When made aware of the results, there's also the personal satisfaction of knowing that you've contributed to scientific advances that will benefit not only you, but many others.

The current reality is that the field of SCI research is built on studies using a small number of motivated people who can't possibly reflect the true diversity of people with SCI. So how can we get more people involved?

SCI BC has always been a supporter of research that will lead to benefits for people with SCI, and we're fortunate to enjoy a very close and supportive relationship with ICORD, the world's largest and most broadly-based SCI research centre. We do a lot together, like supporting ICORD's accessible fitness centre (PARC), hosting cooking and nutrition classes and many other Peer events at the Blusson Spinal Cord Centre, and translating research knowledge through webinars, Café Scientifiques, and SCI BC TV.

So I'm pleased to announce a new partnership with ICORD that will help move SCI research forward at a faster pace. Through an agreement that helps support our Peer services, SCI BC will raise awareness of and participation in select research studies. With ICORD's outstanding researchers, we're going to let you know about how you can get involved, and share information with you about the study's progress and findings.

This is a big shift for SCI BC but we think it's an important one for people with SCI and researchers alike. Through our partnership with ICORD, we really hope you will gain a better appreciation of the research being done in this province and that you will consider participating in research studies. After all, it can't happen without you!



- Chris McBride, Executive Director, SCI BC



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Executive Editor..... Chris McBride
Managing Editor..... Cliff Bridges
Assistant Editor..... Maya Pankalla
Design..... Cliff Bridges
Contributors.....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

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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
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Spinal Cord Injury BC, 780 SW Marine Drive
Vancouver, British Columbia V6P 5Y7 T: 604.324.3611

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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

Chilliwack: Pete Froese, Peer Program Coordinator
E: pfroese@sci-bc.ca

Fort St. John: Lori Slater, Peer Program Coordinator
T: 250.787.1912 E: peervolunteerstj@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

Vancouver: Brad Jacobsen, Peer Program Coordinator
T: 604.714.4185 E: bjacobsen@sci-bc.ca
Richard Peter, Peer Program Coordinator
T: 604.714.4185 E: rpeter@sci-bc.ca

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

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

Williams Lake: Sandra Stuart, Peer Program Coordinator
peervolunteerwl@sci-bc.ca

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Go behind the scenes

MAVI JEANS

Since their creation in 1991, Turkey's Mavi Jeans have become a global fashion name. They're primarily sold online, but the company does have two brick-and-mortar stores in Canada, both of them in Vancouver. One reason for success might be customer service—for example, the company was quick to respond to requests from expecting mothers for maternity versions of their jeans. In Vancouver, the maternity fit is offered as a bespoke option for any of the company's jeans—for just an extra \$20, Mavi will take the band off any jean you purchase, replace it with one of three styles of elastic waistband, and sew the fly together. All the bands are adjustable to accommodate a growing baby. Several of our staff and peers have noticed that these maternity versions are also ideal for wheelchair users. Not only are they easier to put on and take off (there's no button to close them), they combat quad belly and sit more comfortably around the hips, waist, and thigh area than conventional jeans. They look better, fit better, and feel better, and tops hang and fit without bulging over the jeans. Find out more at ca.mavi.com.



COLOPLAST EVE CATHETER

The new SpeediCath Compact Eve women's catheter combines function with a modern aesthetic design inspired by female cosmetic products such as lipstick or mascara. The company says its goal with the Eve was to make the catheter not just non-medical, but stylish and intuitive to use. It opens with a single twist, and it's re-closable for discreet and hygienic disposal. The triangular shape ensures easy handling, a better ergonomic grip and stable placement. About the size of a tube of mascara, the Eve fits easily into the smallest of handbags. SpeediCath Compact Eve also has a unique hydrophilic coating making it instantly ready to use, and there is also the option to connect a urine bag. Visit www.coloplast.ca to find out more.



Innovations

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

LOOPWHEELS

Jelly Products Ltd. is a British company that appears to have re-invented the wheel. The company's flagship

product are Loopwheels—wheels with integrated suspension. Instead of spokes, Loopwheels have three composite springs which work together as a self-correcting system. Specially-designed connectors attach the springs to the hub and rim. Originally, Loopwheels were designed to be used on commuter bikes, but following a successful Kickstarter campaign, the company will soon be launching Loopwheels for wheelchairs in 24 and 25 inch diameters. The company says that, in addition to providing a quieter ride with less vibration, Loopwheels will help you push over uneven streets, rough tracks, and grass and gravel paths with less effort. And by taking advantage of the stored energy in the springs, you'll have extra power to get up or down curbs. They're extremely strong and durable, needing very little maintenance. With quick-release axles, Loopwheels fit most active wheelchairs. Visit www.loopswheels.com for more information.

ONIT ABILITY BOARD

The Onit Ability Board provides a safe paddleboarding experience for wheelchair users. The system consists of an all-terrain surf chair, a secure locking mechanism, the board itself, outriggers, and a ramp that allows most paddlers to wheel independently aboard from the shore. Once on the water, the board gives you the freedom to manoeuvre and glide, accessing all that nature has to offer. For those needing extra assistance, a paddling instructor, volunteer or friend can stand behind the chair and lend a helping hand. Benefits promised include improved balance, increased strength, cardiovascular exercise and stress reduction. Visit www.onitabilityboards.org for more information.



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PG Centennial BBQ.

This year's Prince George Peer Summer BBQ is going to be bigger and better than ever. Why? Because SCI BC is celebrating PG's 100th anniversary—and how far the city has come in terms of accessibility and universal design. The BBQ will happen on July 12 at the Kinsmen Hall. It's free, fun and open to everyone. Email Brandy at bstiles@sci-bc.ca for details or visit www.sci-bc.ca/event-detail/summer-bbq.



Our own Amazing Race.

The Bus Stop Hop is Vancouver's only wheelchair accessible scavenger hunt! Teams of four (two people using wheelchairs or other mobility devices and two able-bodied people) will use Translink's accessible buses, trains and boats to race across the city while growing comfortable using public transit. This year's race is on Sunday, July 19. For details, email Alfiya at abattalova@sci-bc.ca or visit us online.



2015 Parapan Am Games.

You don't need to travel to Toronto to enjoy the athletic spectacle that is the 2015 Parapan Am Games, expected to be the largest yet. From August 7 to 15, you can take in the action and cheer on BC's and Canada's Parapan Am athletes on CBC television and the CBC website. Follow the lead up to the games and look for the TV and online broadcast schedule at www.cbc.ca/sports/parapanam.

ask the SPIN DOCTOR

Ann from Kelowna writes, "My husband and I are anxious to start a family—but I'm also anxious about the challenges of giving birth as a mother with SCI. Any advice?"

This issue's question couldn't be more timely. In the past few months, we've been working with a number of health professionals and partner organizations to produce a much-needed information resource for would-be mothers with SCI.

The set, titled *Pregnancy and Spinal Cord Injury: An information guide for women with SCI*, includes an introductory brochure and a full-length booklet, both of which are available online at no charge. The guide provides women with SCI with information that will help them plan for their pregnancy and start key conversations with their health care providers about their care plan. The topics covered in the guide address the most common pregnancy-related concerns and challenges faced by women with SCI, including:

- medications and their impact on pregnancy and mothering
- the impact of bladder and bowel function during pregnancy
- secondary health complications such as autonomic dysreflexia, deep vein thrombosis, and spasticity as they relate to pregnancy
- choosing equipment during and after pregnancy
- selecting a health care team to meet your needs

- what to do when your baby arrives, and how to maintain your post-pregnancy physical and mental health

- breastfeeding as a mother with SCI.

Both documents emphasize the need for any would-be mother with SCI to work closely with members of her health care team before and during pregnancy—and to reach out to other women with SCI who have given birth.

"We believe this is an important resource for women with SCI who are contemplating motherhood," says Dr. Chris McBride, SCI BC executive director and one of the guide's authors. "We created this resource because trusted SCI-specific information on pregnancy is hard to find. We're

grateful to those who contributed their expertise to the writing of these resources, and also to the partner organizations who helped support their production: the Rick Hansen Institute, Vancouver Coastal Health, and BC Women's Hospital & Health Centre."

Visit www.sexualhealth.sci-bc.ca to view or download this important new resource.

Email your questions for the Spin Doctor to Brad Jacobsen, SCI BC Peer Program Coordinator, at bjacobsen@sci-bc.ca. Any advice given is general in nature and is not intended to replace advice specific to your personal situation provided by your family physician or SCI specialist.



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love online

■ relationships



When I read the story about online dating in the Spring issue of *The Spin*, I was intrigued—particularly because I’m one of those who found the love of my life online.

— by Johanna Johnson

As readers learned in the last issue of *The Spin*, some people with SCI succeed with online dating—and others not so much. I’m in the former group, and believe it can work for other Peers. So I thought I would share my story in the hope that it might inspire other readers who are seeking love and companionship to at least consider trying this phenomenon of modern life.

Rewind to about seven years ago. I had tried many dating websites—some that don’t even exist today. Nothing had worked. “Why do I need a man to validate my existence?” I found myself asking. All the dates I’d had up to this point had been no-shows or bizarre. I stopped checking the sites I had previously visited regularly. But from time to time, when I was on Facebook, I’d check out the *Are You Interested?* app. It was always good for a laugh. Then one day I saw a smiling face with sparkly eyes—and he had clicked “yes” on me.

“He doesn’t look like a total freak,” I thought. “What the hay!” So I clicked on the “yes” button. And my life changed forever.

Almost immediately, I had doubts. “What am I doing?” I thought to myself. “This will simply be another disappoint-

ment.” I felt like I’d been in contact with every reject out there: the guy with the cripple fetish, the guy with the wife, the guy who would communicate endlessly on email and phone but never showed up for in-person meetings, and, of course, the one that knew I was in a chair and had seen many pictures of me but walked right past me at a very small Starbucks. That one hurt.

So I assumed that I would probably never hear from this sparkly-eyed cutie that had clicked “yes” on me.

But the next day I had a message. It was funny, intelligent and hopeful. I responded. Soon we were sending messages back and forth, and as we did, I got to know Greg. We had a lot in common and, while he was a few years older than me, we had basically grown up in the same area of Vancouver.

The next step was to meet for coffee. I was always very careful; the first few meetings had to be in a public place during the day. Greg and I decided to meet at a Starbucks at UBC. It was perfect. I knew the area, and it was close to his work (he really did have a job, yippee!). What did I have to lose?

In confirming the details, he sent me a message saying: “How will I know which person is you?” My first thought

upon reading that was, “Is he stupid? I’ll be the one in the wheelchair. Duh!” I thought about it for a while, and realized that maybe he didn’t know I was in a chair. Greg had access to my page on Facebook but maybe he hadn’t looked closely at the photos (I suppose it was a bit vain of me to think he had). So I sent him a message saying, “You can’t miss me—I’m the one in the wheelchair.”

I wasn’t sure what to expect in response. Greg seemed nice enough to meet for coffee, but who knew? The chair had definitely been a deal breaker with other guys.

“Okay, will you be coming by HandyDART?,” Greg replied. “I can meet you at the drop off.” I didn’t know what to think, so I told him not to worry: I had my own van and my assistant would drop me off. But I did ask him how he knew about HandyDART. He messaged back that his mother was in a wheelchair and she often used the shared ride service.

Wow! What does this mean? Is Greg sensitive and caring? Is he just a cool down-to-earth guy? Is he looking for a young version of his mother to fulfill an Oedipus complex? I forced myself to stop analyzing everything and just focus on meeting the guy!

We met face-to-face on July 31, 2008. It was a grey, rainy day (which was really irritating because I wanted to wear a semi-tarty top) and, as with all of my “first dates”, I felt sick to my stomach. I had it all planned out: I would get there fifteen minutes before our planned meeting time so that I could compose myself, find a good place to sit (not with my back to the door), have my coffee already bought and in my cup holder, re-apply my lipstick, and scrunch my wet frizzy hair.

As I was rolling toward the Starbucks, I saw a guy standing in the rain with a large umbrella in his hand looking up and down the street. Immediately, I said to my assistant Irene, “Oh no! (Actually, this is a somewhat sanitized version of what I actually uttered.) That’s him!”

He was 20 minutes early and clearly there to assist me into the building. Irene thought it was so sweet, but I was baffled. My carefully thought out “staging” plans were destroyed.

We met, went inside and found a table. He insisted on buying my coffee. “Damn,” I thought. “Now I’m beholden to him.” Irene set me up with the cup and then went off to kill time for a bit before we met at our pre-planned location.

(While I’m on the topic of Irene, I have to say she was my biggest cheerleader.

While others would look at me blankly when I talked about how tough it was to find a decent guy, Irene would always be encouraging, reminding me of my wonderful qualities and beauty. I couldn’t have hung in there without that support. So, thank you, Irene.)

Greg and I proceeded to sip our coffees and chat. He was kind, interesting and funny, and I did my best to come off the same way. Of course, we were both a bit awkward and nervous—who wouldn’t be?

But at the end of our conversation, we agreed to meet for coffee again.

Greg walked with me to where I was parked and we said goodbye. My emotions were mixed. Did he like me? Did I like him? Would this go anywhere? I didn’t feel an instant spark, but I thought that was a good sign. The instant spark thing had never worked for me in the past. Again, I asked myself, “What have I got to lose? If he wants to meet again, let’s do it!”

Needless to say, the spark eventually ignited and burned brighter every day. Our courtship lasted for quite some time. After we had been dating for a couple of years, we started to talk about marriage. Naturally, I was scared. Was I worthy? Am I enough for him? I had all those insecurities that are often attached to a disability. The one thing I didn’t doubt was Greg’s devotion. And, near the second anniversary of our first meeting, Greg told me a story that sealed the deal.

“I saw a vision, the most spectacular sight I’d ever seen, coming toward me,” he said. “Her friend was holding an umbrella over both of them. I thought, ‘I’ll never have a chance with this gorgeous woman!’”

I asked, “Are you talking about the first time you saw *me*?”

Greg said, “Of course.”

This sealed the deal for me. His version of when we first met reinforced the fact that he always saw the person first. Not my chair; not my limitations. He saw me.

Precisely four years after the day we first met in person, we were married. It was the best chance I’ve ever taken. ■

Experimental Cancer Drugs Show Promise in SCI

A group of drugs being tested for cancer could also hold promise for use in SCI, according to researchers at The Imperial College London.

The researchers treated spinal cord injured mice with drugs called nutlins. The mice were subsequently able to regrow nerves across the injury site. About 75% of the mice regained the ability to walk on a ladder.

The study results were published in the journal *Brain*. The drugs involved, which have been found to be safe in early cancer trials, have been shown to suppress tumours. In the SCI study, the drugs stopped a particular series of proteins from interacting to restrict nerve growth.

“Unlike in the limbs, nerves in the spinal cord don’t regenerate after an injury,” says Dr. Simone di Giovanni, the Imperial College London scientist who led the study. “We’re only just beginning to understand the fundamental reasons for this striking difference. We have identified a mechanism that controls nerve regeneration, and there are already experimental drugs that target this pathway, suggesting an opportunity to translate these findings into the clinic.”

Giovanni says the results were “very encouraging,” but he cautioned that they now have to be replicated in rats, whose spinal cords more closely resemble those of humans.

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Vancouver's Realwheels Theatre company is working hard to nurture talent in the disability community and put ability centre stage.

It's mesmerizing theatre: two 30-something brothers drop in from the ceiling, spinning, looping, hurtling towards the stage floor, their skydive gone horribly wrong. Frozen in time, with one of their two chutes failing to deploy, the two revisit their lives together. Before the end of the play, one man emerges in a wheelchair. To the audience's surprise, he stays in that chair for the curtain call.

That man, James Sanders, is a professionally-trained theatre actor who lives with quadriplegia. The 2007 award-winning play *Skydive*, which he co-created and starred in, reached more than 30,000 people in seven Canadian cities, breaking ground in both the disability and theatre communities.

Prior to this success, Sanders had been having trouble getting cast in roles that weren't written for a wheelchair user. His newly-formed Realwheels Theatre company was the antidote, and it could not have produced a more impactful inaugural show. For once, the focus wasn't on

Sanders' chair. The theme of *Skydive* wasn't disability. Instead, as long as the characters were weightlessly suspended, so were the audience's preconceptions; the focus was on the characters themselves.

Three professional plays and a series of community projects later, Realwheels Theatre continues to fill a valuable and necessary niche in the theatre community. The small not-for-profit arts company, which shares office space with Spinal Cord Injury BC in Vancouver, produces performances that deepen audiences' understanding of the disability experience. Though Realwheels often includes performers of all physical (and theatrical) abilities, its award-winning shows are not explicitly about disability. Instead, disability forms the landscape against which universal issues are debated and explored, normalizing the unknown and inspiring audiences to embrace inclusion of disability onstage and, more importantly, offstage.

"Over 13% of Canadians self-identify as a person with a disability," says Rena Cohen, the Managing Director of

Realwheels. “Among our colleague theatre companies, we’re just starting to see some casting decisions made from the perspective of, ‘There’s two teachers and a judge in this script—well, why can’t one of them be in a wheelchair?’”

Realwheels advocates for inclusion in the industry. Cohen and her colleagues ask artistic directors of other theatre companies to consider casting actors with disabilities. And they also reach out to post-secondary institutions to encourage students with disabilities to consider professional theatre training—not just in acting, but in the range of disciplines that bring theatre to life.

And yet, despite their efforts, finding a professional actor with a disability in Vancouver remains a challenge.

“There’s long been a gap in training opportunities in the performing arts for people with disabilities,” says Cohen, noting that some of the mainstream training institutions in Canada have started to ad-

dress this. “At Realwheels, we’ve started providing mentorships and other forms of training, while advocating for accessibility and inclusion on several fronts.”

The scarcity of professionally-trained actors with disabilities became distressingly clear when Realwheels was forced to find a replacement for Sanders. Following two successful performances, *Skydive* and *Spine*, the actor started to experience health challenges and was forced to back out of a third: *Whose Life Is It Anyway?* Realwheels began the process of locating a fitting replacement—an appropriately-aged actor with a disability who could hold his own with the show’s A-list cast. The company looked across Canada, but wasn’t able to identify a suitable stand-in. The role went to award-winning Vancouver actor and Sanders’ long-time friend, Bob Frazer, thus rounding out an entirely able-bodied cast.

“You always want to cast the best actor for the role—that’s your obligation

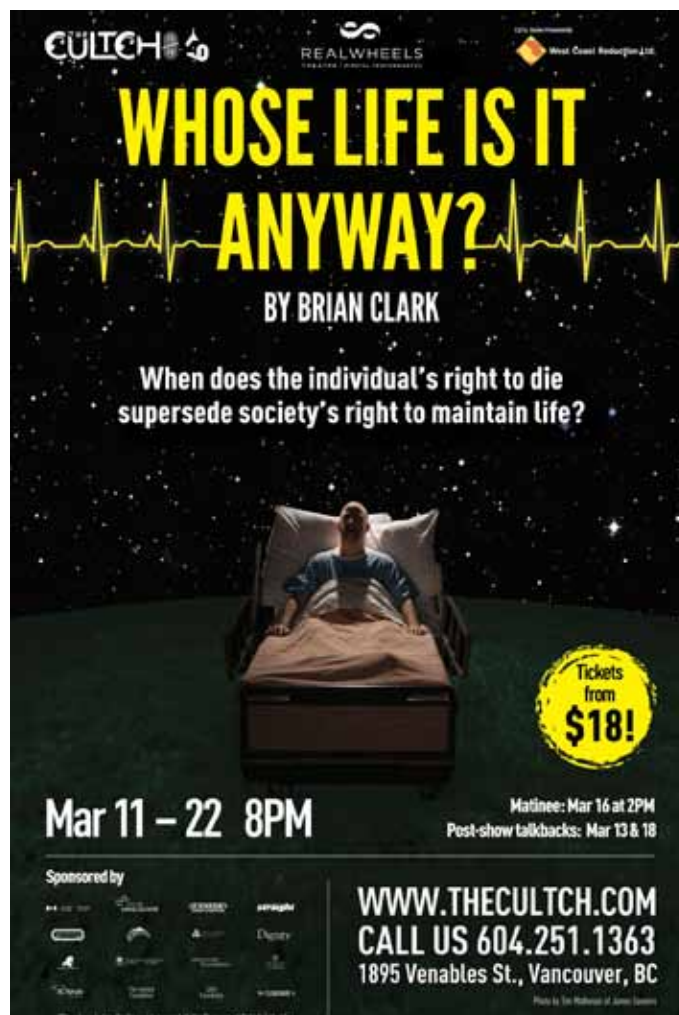
as an artist, as an arts company,” says Cohen. “But the other side of that is always, how do we shift things so that what we’re seeing on stage, what we’re seeing on movie screens, is reflective of the real world and all of its people.”

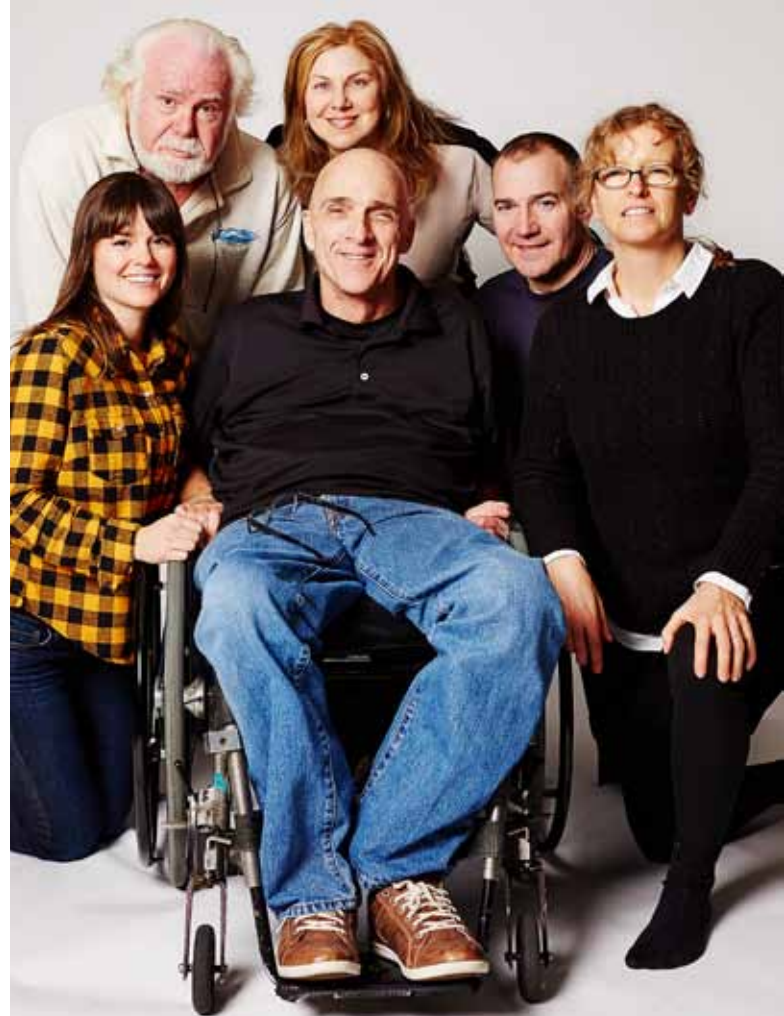
Earlier this year, Realwheels staged *Re-calculating* and cast an amateur actor—local drummer Dave Symington, who has lived with quadriplegia for four decades—in the lead (and only) role. Throughout the play, Symington’s live drumming was interwoven with memories and emotions. It was a rare and candid glimpse into the lived experience of disability, and the universal questions of attitude and identity. For the show’s star, whose initial reaction to the project was a combination of trepidation and nausea, it proved the perfect opportunity to re-evaluate and process his own identity after the recent death of his mother.

“I agreed to do it because as much as I knew it scared the hell out of me, there



LEFT: Realwheels followed up the inaugural success of *Skydive* with the 2010 production *Spine*, which once again starred James Sanders. RIGHT: The official poster for the 2014 production *Whose Life Is It Anyway?*





ABOVE: Realwheels' latest production is *Re-calculating* starring musician-turned-actor Dave Symington, who has lived with quadriplegia for four decades. Throughout the play, Symington's live drumming is interwoven with memories and emotions. RIGHT: Symington with the Realwheels crew (left to right): Communications Director Lindsey Adams, Co-writer Lucas Foss, Producer Rena Cohen, Director Jeffrey Renn and Co-writer Liesl Lafferty. (Photos by Kevin Statham)

was this part of me that really wanted to say 'yes' and take that risk, to push my boundaries a little bit," says Symington, who, at the age of 59, came to the show without any formal theatre training. "I think I learned a paragraph, and I was amazed that I could even memorize a paragraph. I read the lines for [the show's producers] and I just remember they said something like, "Yeah, I think there's something there."

For the play's director, Jeffrey Renn, working with Symington proved to be a fascinating learning experience.

"There's no difference for me between directing someone with an ability or a disability," says Renn, himself a seasoned actor and director. "The most important thing when I direct something is to make the space as you would for a child—to take away everything that in any way could impede or get in the way of their creative process, and make the person as comfortable as possible with the permission to be and do anything."

But while working on *Re-calculating*,

Renn did find a slight inconsistency. Although Symington had no trouble remembering his lines, he was having difficulty repeating the moves and positions the duo had practiced. Eventually, Renn approached his actor about it. "We realized that as a quadriplegic, he had no muscle memory," recalls Renn. "So there was no part of his body that remembered the move from the time before. We had to then find a way around that, and we created a kind of memory map."

That map—an actual diagram—allowed Symington to imprint the moves in his head and remember them sequentially. *Re-calculating* opened in January to rave reviews.

Onstage, Realwheels brings the same professionalism and production values to its community projects. The Wheel Voices series—including *Wheel Voices to the Max!*, *Wheel Voices Live!* and, most recently this June, *Super Voices*—unites the disability community with professional artists for a series of workshops, culminating in an annual live performance. The

free workshops are open to anyone who self-identifies as a person with a disability, and explore stories through theatre, music, visual arts and dance to develop emerging talent in the community.

"The concept behind Wheel Voices is that there are a lot of opportunities for people with disabilities to engage in sports—you've got wheelchair basketball, adaptive sports and so on—but there aren't a lot of opportunities to engage in the arts, and very little in terms of performing arts," says Cohen. "So that's where we've stepped in: we're providing experiences in the performing arts to help fill the gap in both exposure to performing arts and training opportunities for people who are serious about developing themselves as artists."

A hallmark of Realwheels is its audacious vision for production. It doesn't distinguish between professional or community productions, and seek to achieve exceptional mise-en-scène—or production values—in either case. "We provide the community with as near a

professional experience as we can muster,” says Cohen. The theatre company also believes in creating opportunities for the performing arts to become an integral part of healthy community life.

These days, Realwheels relies on a small team—Cohen, Interim Artistic Director Renn, and Communications Director Lindsey Adams—to help move the collaborative community projects from the idea phase to professionally-staged productions. “We don’t want audiences to have the experience that somehow watching our community projects is in any way a compromise,” says Cohen.

For *Super Voices*, the company worked with award-winning projections designer Jamie Nesbitt, integrating stunning visual projections with live theatre. Honing in on the superpowers that people with disabilities possess, from patience and compassion to alternate modes of communication, *Super Voices* moved “beyond the typifying of people with disabilities as objects of pity or mere sources of inspiration.” The show deconstructed clichés with confidence, creativity and a bit of comedy, too.

For audiences of Wheel Voices projects, the result is vital insight into the lived experience of disability, making it less alien and alienating. And for performers, Wheel Voices is exactly that—a real voice and an unabashed authenticity in a safe, encouraging environment. “It’s about overcoming fears and insecurities,” says Cohen. “To perform in front of an audience, especially if the performance is based on your own story—that’s a huge confidence booster and deeply empowering.”

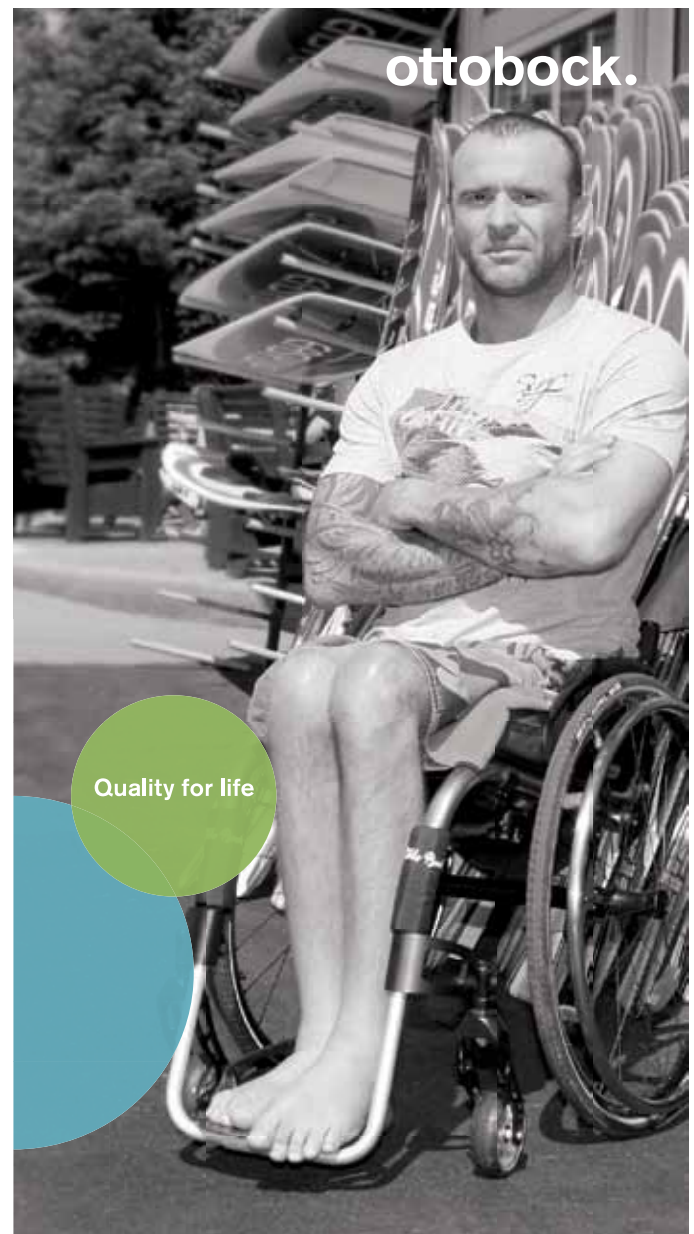
Although James Sanders is currently on medical leave from the company—focusing on his health and enjoying being a husband to Barbara and Dad to four-year-old Max—he remains closely connected to Realwheels. His wisdom, insight into disability, and original vision for the theatre company continue to influence artistic decisions and advocacy initiatives.

Next year’s Realwheels stories are already lined up: *Creeps*, a play exploring the plight of people with cerebral palsy trapped in a sweatshop (written by the late David Freeman, a playwright with CP) will celebrate its 45th anniversary on the Realwheels stage. Wheel Voices is set to light up the Fox Cabaret with *Sexy Voices*, a burlesque-format study of sexuality, identity and the true fullness of the disability experience. (What better venue to bare all than a former adult cinema?) And Wheel Voices participants will be celebrating a variety of their own successes, from book launches, to stand-up comedy gigs and video projects.

Clearly, the talent pool is growing. The curtain is lifting on a scene that reflects an unapologetically diverse society. And our applause for Realwheels cannot be contained. ■

Get involved in Wheel Voices! Head to www.realwheels.ca for more info about upcoming workshops.

Do you think characters with disabilities should be played solely by actors with disabilities? Voice your opinion by taking our poll at www.sci-bc.ca/poll.



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Are you having difficulty passing an intermittent catheter?



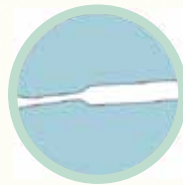
Bulges

in the urethra prevent an easy passage of the catheter and increase the risk of injury.



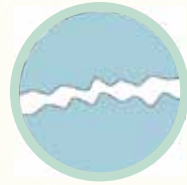
An enlarged prostate

or a spastic sphincter make passing the catheter into the bladder even more difficult.



Strictures

(urethral contractions) may make the usage of a traditional catheter impossible.



Scarring

after micro traumas result in a more difficult passage for the catheter.

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Privilege to Pee

Homegrown artist Kyla Harris shines a spotlight on the monetary, ecological, and psychological impact of our daily bodily functions.

The first time Kyla Harris, 30, opened her box of art supplies in front of a classmate at London's Chelsea College of Art and Design, she was embarrassed.

"It was almost like the equivalent of opening a pencil case and taking out a pen, in terms of art material," says Harris.

Almost, but not quite. Instead of heading to the local art store, Harris had looked within for inspiration—and supplies. And so *Privilege to Pee*, a five-foot chandelier assembled from more than 3,000 of Harris' own used, sterilized and hand-painted catheters, was born.

At once beautifully opulent and disturbingly raw, the hanging "Lumen" illuminates the tensions within Harris' own disability experience: between comfort and discomfort, dependence and independence, right and privilege. Every time she had used a catheter in Canada—essentially, whenever she needed to pee—she had been required to pay for it out of her own funds. "It felt like I was literally throwing money in the bin because these things were designed for one use," says Harris, who spent most of her life

in BC before relocating to England five years ago. "I felt really lucky and extremely privileged to be able to afford that, but at the same time felt that it was a dehumanizing experience to have to pay for a bodily function."

In London, under the National Health Service (NHS), she found that catheters were covered. "They were so precious to me by that point, and yet I wondered how much waste I was creating as well," says Harris. She began to collect them, first sterilizing each one in a barber's jar. Over four years, she built up her stock and contemplated how best to use them in a way that would exemplify "privilege" in its physical form.

Because of Harris' disability—she sustained a C5/6 break in a diving accident in Squamish, BC, at the age of 15—much of her sculpture and installation art is collaborative. She works with personal assistants to test out her vision and help bring it to life. "I was relying on them to sense how the material worked and flexed and changed," says Harris. "So there's almost a performative aspect in my work that's pushing the boundaries of intimacy and understanding between the two of us."

That performative thread, and an emphasis on the viewer's own experience, weaves through her other pieces. Harris' *Blocks* series sees her classmates propping up cumbersome, abstract shapes in unexpected places—on the stairs to the Tate Gallery, in a red telephone booth, in a passerby's vehicle, in a tight bathroom stall. Oddly, Harris never intended the piece as a commentary on accessibility. "It's about how influential space can be, about how your environment emotionally affects you—the idea of claustrophobia, too many things in your environment. It was a really crude way of doing that."

Probe, a chair cushioned with protruding rubber gloves and imagined for a room made completely out of medical supplies, explores the ways in which something is rendered useless. "A chair is meant to be sat on and used, and when you can't do that for fear of breaking or disrupting it, it gives this kind of tension," explains Harris. "You could have experience with a dentist or a pregnancy and know what a rubber glove is, so I think I try and make my work relevant to people that don't have experiences with disabilities as well."

At one art fair, Harris' chandelier caught the eye of a man who'd had a kidney operation several years prior and had used a catheter himself. "He got incredibly emotional and started crying," recalls Harris. "And he was very moved by my story and how in a sense ours related through this object. There are those people that look at it and find something familiar about it. It's a trigger for people's memories; it's a trigger for associations."

These days, Harris has her eye on more than catheters. She's looking forward to professional representation—a gallery in Soho (London) has its eye on her—as well as a foray into yet another domestic art: cabinetry. No details yet, but she assures us she'll continue to challenge the boundaries and explore her own lived experience.

"I think all art is a statement, even if it's not trying to be a statement...I think I only have my perspective to give." ■

To see more of Kyla Harris' work, head to www.kylaharris.net.



4. *Articulated Jaw Ashtray* in bronze.

5. The *Blocks* installations are a series of cumbersome, abstract shapes placed in unexpected locations.

6. Harris relies on assistance from her personal assistants and classmates for setting up her installation art.

"People have their own associations and their own experiences with these materials. I think all art is a statement even if it's not trying to be a statement." — Kyla Harris



1. *Privilege to Pee* is a chandelier assembled from more than 3,000 of Harris' own used, sterilized catheters.
2. Harris' work on display at London's Working Men's College.
3. *Probe* is a chair cushioned with protruding rubber gloves.

"I use this word quite often: ABJECT. There's this abject sense of being drawn to and repelled from something, and I think that's what I really like to do in my work." – Kyla Harris





Harmony & Healing

Is there a link between health and music?

Sir Elton John is among the many who believes there is. “Music has healing power,” he once said. “It has the ability to take people out of themselves for a few hours.” Fellow piano man Billy Joel uttered similar words. “I think music in itself is healing. It’s an explosive expression of humanity. It’s something we are all touched by.”

And there’s a surprising amount of recent scientific research that confirms music’s ability to lower blood pressure, lower heart and respiratory rates, beef up the immune response, and improve our capacity to learn. But we’ve actually recognized the power of music for thousands of years. In ancient Greece, Aristotle, Plato, Pythagoras and Hippocrates wrote of music’s healing influence. Music was also used as therapy by the ancient civilizations of India, Africa, Europe and Asia, and among North American Aboriginal people.

Here at home, Simon Paradis and Kara Stanley, a husband and wife team who live on the Sunshine Coast, don’t need to be convinced.

In 2008, Paradis fell from scaffolding on the jobsite. The injuries he sustained were devastating: a T12/L1 SCI, and a serious brain injury. After being airlifted to hospital, he was put into an induced coma to reduce the swelling in his brain. His situation was grave.

Paradis not only survived, he made an amazing recovery. And while he and Stanley both credit excellent medical care and support from friends and family, they can’t emphasize enough how important music has been in the last seven years.

Music was always a part of Paradis’ life. Born in Quebec, he moved with his family to Ontario as a teenager. By then, he was an accomplished musician.

“My father played guitar, as did my uncle Jacques, so they both influenced me quite a bit,” he explains. “There were lots of singing and playing moments with extended family. I really enjoyed a wide range of stuff—I enjoyed playing



Photo: Greystone Publishing

blues-based rock music as a teen; lots of Cream and Rolling Stones. When I went to music school, I started to listen to more jazz, and had a band of fellow students that played everything from Little Feat to No Means No. I always seemed to enjoy a wide spectrum of styles.”

By that time, after several years of friendship that started in high school, Paradis and Stanley had become a couple—and soon after, parents when son Eli was born. In 1996, the young family decided that their fortunes lay in the west, and they packed up and moved from Montreal to the Sunshine Coast.

“Moving out West forced me to spend more time playing country and roots music,” says Paradis. “Just before my accident I was working as a finishing carpenter, but I had just finished a CD with a band I was in, The Precious Littles. Plus I was doing quite a bit of studio work on sessions and was hoping to move more into music production and away from construction a bit.”

Five days before the CD was scheduled to be released, Paradis fell.

For the next 19 days, he lay in a coma at Vancouver General Hospital, with his wife, son and parents maintaining a constant bedside vigil.

“My family was desperate to try and connect with me as I was emerging out of my coma,” he says. “Music was the natural language to do this. One approach was playing Bach on a CD player in my room. The other was my father playing our family catalogue—songs we sang at gatherings—as a way to bring my brain back online. At first there were discreet right hand movements along with the beat of the music. Then one day, during my father’s rendition of Gram Parsons’ *Hickory Wind*, I mouthed the lyrics of the third verse along with him. The next day I started writing down words in a log book, and two days later I spoke my first words.”

Paradis’ family rejoiced. But the initial euphoria over his awakening soon faded. The implications of SCI and all it entails were tough enough, but even more devastating was the brain injury. He had lost control of his left arm, his left eye wouldn’t map properly, he was completely deaf in his right ear, and he had cognitive loss. He spent the next three months in GF Strong, trying to come to terms with the uncertainty of not knowing what, if any, of his lost abilities would return.

One day, a friend showed up at Paradis’ room with a guitar.

“I started thinking about music and trying to play as soon as there was any response in my left hand,” says Paradis. “Things looked pretty bleak at that point. I had never made my principle income playing music but had always approached music with a very high level of professionalism. Having to relearn the most basic things left me doubting there would ever be a return to it—or at least to my previous abilities. At first it was hard to play for more than 10 minutes at a time because it sounded so rough.”

By increments, his situation improved. He began to wrap his head around his new life, and he began to play more with better results. It’s around this time that neuroplasticity—the nervous system’s ability to rewire itself after injury—kicked in. Neuroplasticity is triggered and enhanced by repetitive exercise, so

increasing playing resulted in a positive feedback loop. As his left hand became more responsive, he played more. And the more he played, the more his brain was stimulated to rewire.

He credits his physiotherapist in rehab with motivating him to play to an audience for the first time since his fall. “He convinced me to bring my guitar down to the rehab room and get in a standing frame and play for all of the patients there at that time. I had a few chords down, and played some Elvis and Buddy Holly and such.”

Once out of rehab and back home on the Sunshine Coast, Paradis had to face a new set of challenges. Foremost among these was finding accessible housing. Little was available, so the couple ended up purchasing a house, which was renovated with WorksafeBC funding.

Meanwhile, with steady encouragement from his wife and friends, he continued to relearn his instrument.

During this time, a regular visitor was

friend, fellow musician and bandmate Joe Stanton. “I met Joe on the Sunshine Coast in the late 90s—I was singing a Gram Parsons song at a Canada Day show at a local restaurant,” says Paradis. “We then started hosting a local jam together; Joe already had a pretty established solo career as a singer-songwriter and we became his local band that could support him at gigs and play some of his originals. It was that band that became The Precious Littles. So he and I have been playing together for a long time.”

Paradis credits Stanton, along with his wife, with providing the motivation he needed to keep relearning the instrument—no easy task, as it turned out.

“Although music has always been a source of joy, many of my ‘dark’ moments came when I reached for the guitar. I found myself evaluating my slow progress and wondering, ‘Why am I subjecting myself to this?’ Despair can often be caused by unrealistic expectations, so it taught me to rephrase the

questions that I was asking of myself on many levels, forcing me to be aware that I was a new canvas and I needed to take time with the next painting. So although I was—and still am to a certain extent—frustrated at my progress with relearning the guitar, it served as a reminder that things take time.”

The first real breakthrough happened in 2010. Paradis, Stanton and bass player Gerry Miller were asked to make an appearance at Sechelt’s Olympic Torch Relay concert. They played just one song—but it was a milestone.

“That gig came in the wake of a pretty serious infection that I was still in the midst of curing, so I was pretty exhausted, almost too tired to even have any nerves for it. They had bussed in all of the school kids to the event, and got them wired on Coke drinks. It was really rowdy; I was happy when it was over. Just as a measure of perspective, I had to practice that one song for about three months to be able to play it live.”

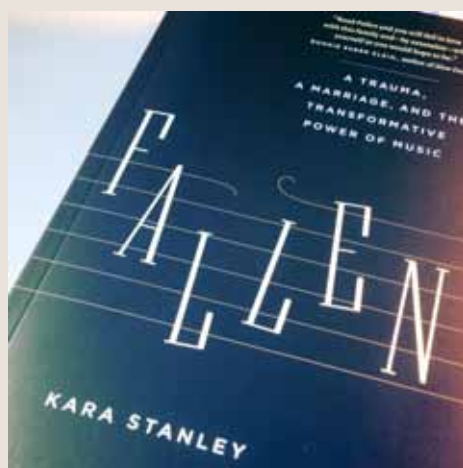
Fallen: A Trauma, a Marriage, and the Transformative Power of Music

As the title suggests, Kara Stanley’s new book is a moving account of how she and her husband, Simon Paradis, relied on each other—and music—to meet the challenges they faced after his devastating injuries.

Stanley, a gifted writer who holds a Master of Fine Arts in Creative Writing from UBC, says there were several reasons she felt compelled to write such a personal and painfully honest chronicle of the couple’s journey back from tragedy.

“Writing, in the form of notes, journal entries, and ongoing research, was an integral part of my processing of Simon’s accident,” she explains. “It was these notes, along with my growing file folder of medical reports and resources that formed the foundation for the book—long before it even conceived of itself as a book. Second, I was inspired in a very real and true way. I am, of course, outrageously biased, but during Simon’s recovery I felt very strongly that I was witnessing something very special. Third, as Simon and I returned home after rehab, we both felt the absence of a community of people to discuss some of the ongoing issues concerning SCI and traumatic brain injury. We were both interested in portrayals in literature and pop culture of real people navigating real problems

with directness and honesty. That was the book I wanted to read, and it was the book I wanted to write.”



She concedes that, during the writing process, it was often hard to relive many of the painful moments and days that followed the accident. But at the same time, she says completing the book has been remarkably therapeutic.

“What I found cathartic about the writing of the book was being able to imaginatively return to those difficult times and, through research, fill in the huge gaps of my knowledge that were present when I initially lived through it. That was empowering. Also, having gone through the long process of writing,

rewriting and editing the book, there was a moment when it felt like we had truly moved on. With the completion of the book, and Simon’s new CD, I think we’ve moved out of feeling persistently traumatized. There are still complications, but we’re tackling them from a very different and more grounded place.”

You can ask for *Fallen: A Trauma, a Marriage, and the Transformative Power of Music* at your local bookstore, or visit www.amazon.ca to purchase it online.



LEFT: Paradis credits duo partner Joe Stanton with providing the motivation he needed to relearn his instrument—and get back on the stage—after his life-altering injury. ABOVE: Paradis on stage during the Pender Harbour Blues Festival.

That experience, as difficult as it was, seemed to reopen the musical flood gates for Paradis. Three months later, he had returned to playing a full evenings set list of about 30 songs with his old band mates.

More opportunities began to appear, and Paradis started chalking up a series of musical successes. He and Stanton began collaborating more, and formed the duo Stanton Paradis. In addition to playing gigs and festivals around the Sunshine Coast and Lower Mainland, they recorded a CD together (*Good Road Home*). Paradis then produced another CD by a local artist. Around the same time, he signed on for a year as a distance learning student at Boston's renowned Berklee College of Music, emerging "as a songwriter, not just a guitar player."

By the beginning of 2015, Paradis and Stanley had both shifted into creative overdrive. Paradis was well into the process of recording his first solo CD, which will be released early this summer.

"The new record has given me the chance to work with both old musical friends who are 'pre-accident' and new musicians who are 'post-accident'. Many of the songs are co-writes with my wife; two of them are covers. It will be more of a compendium of song styles—some rock and roll, some second line sounding stuff, a little country thrown in for good measure, and a few acoustic numbers."

Meanwhile, Stanley was putting the final touches on a book that chronicled the highs and lows of the journey she and Paradis had been on for the past seven years. Not surprisingly, the main theme of the book is how music has helped the couple overcome their challenges (see sidebar) and regain their quality of life.

Looking forward, Paradis is finally able to set some goals—and clearly see the path to achieving them.

"Given the nature and extent of my injuries, I'm now really just trying to get back to as close to my old self on the instrument as possible," he says. "My main

focus is on family, health and then artistic ventures as my stamina allows. I'm mostly interested in writing songs and getting them out there with some live performances thrown in for good measure. I'm not playing music just as a therapy but as an attempt to return to my old self. When I fell, I was a musician who used carpentry to pay the bills. Now, seven years after the fall, I have probably as fulltime a music schedule as I'm comfortable with, with a weekly roster of guitar students and gigs."

In stark contrast to the bleak days that followed his accident, Paradis now says he feels blessed, and is grateful to those who have helped him along the way. Foremost among those is Stanley, who has been there for every step of the journey.

"I was very lucky to meet Kara and have her be such a principle part of my life. We learned how to parent together; how to maintain aspirations as artists while holding down full-time jobs. Now we're songwriting together and growing

old together. It's a real blessing having such a dear friend as my life partner. I don't think I could've ever gotten back to playing music were it not for her courage and patience."

And, of course, there's the music itself—another steadfast lifelong companion.

"Music is art, and I think that good art is informed by transparent, considerate insight into the human experience: transforming the personal into the universal. People who suffer any kind of trauma and move through it take with them a unique perspective on quality of life and emotional resilience. So I think that anyone who suffers an SCI should consider any kind of art therapy, as art created in the wake of these experiences serves to inform our culture and enrich its sense of self by raising awareness. Extreme hardships and the unique set of triumphs associated with them—these things resonate, and provide a wealth of perspective." ■

To learn more about Paradis' new CD or where you can see him play this summer, visit www.stantonparadis.com.

Pursue Your Musical Aspirations with VAMS

Simon Paradis is a big fan of the Vancouver Adapted Music Society—VAMS for short.

"For my new solo CD, VAMS was generous enough to lend me their in house engineer, Graeme Wyman, who turned my house into a full studio for a week," he says. "If, like me, music is your preferred form of artistic expression, I would highly recommend VAMS, which does a fantastic job of making music an accessible art form no matter what the severity of your injury may be. So don't let the limitations of the injury define what your scope of artistic expression can be. Music heals and gets us all through hard times. Everyone should have a chance to experience that. I'm still healing, still learning as a musician. I may not be as clever a guitar player as I once was but I'm just as musical as I was prior to my accident, I'm just using a new skill set. VAMS can help complement that skill set."

VAMS was co-founded in 1988 by two Vancouver musicians with quadriplegia—drummer Dave Symington and keyboard player Sam Sullivan. It operates under the umbrella of The Disability Foundation created by Sullivan, who is a former mayor of Vancouver and currently an MLA. Almost three decades after it was created, VAMS continues to encourage and support musicians with disabilities, and has introduced hundreds of people with disabilities to the world of music.

VAMS programs offer musicians with disabilities the opportunity to participate in a community choir, play during gigs and performances, take part in regular jam sessions at GF Strong, get involved in the production of professional music videos, record at a state-of-the-art studio, and more.

Visit VAMS online at www.vams.org for more information and to learn about the many talented BC artists affiliated with the program.



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Finger-tapping Music Therapy

The MusicGlove promises a fun, new and harmonious way for people with quadriplegia to regain vital hand function.

When it comes to restoration of hand function after paralysis, repetition is king.

Repetitive exercises of the fingers and hand have been clinically shown to help restore priceless hand function to many people with high level SCI, along with those who are recovering from other paralyzing conditions such as stroke.

The underlying mechanism involves neuroplasticity—the capacity of the central nervous system to “rewire” itself after it’s been damaged by injury or disease. In other words, neuroplasticity is the ability of the brain and spinal cord to reorganize its structure, function and connections in order to achieve some level of restoration of function.

Research has shown that neuroplasticity is not only real, but can be extremely beneficial if harnessed and encouraged correctly. For example, it’s neuroplasticity that’s at the heart of treadmill training to maximize walking function for people with incomplete SCI.

One of the most effective ways of triggering neuroplasticity in anyone with partial paralysis of the hands is to have them practice specific, repetitive exercises involving the fingers and hand. And when we say repetitive, we do mean repetitive. Recent research suggests that hundreds, if not thousands, of repetitions of challenging tasks are required to trigger the nervous system to rewire itself, with the result being the desired restoration of function.

The problem is that, for many people, repetitive exercises are mind-numbingly boring—and all too easy to abandon before any real benefit has resulted. That’s why California-based Flint Rehabilitation Devices recently brought to market a new rehabilitation device known as MusicGlove.

“The idea for MusicGlove came out of research in Dr. David Reinkensmeyer and Dr. Mark Bachman’s research labs at the University of California in Irvine,” says Dr. Dan Zondervan, who has a PhD in mechanical engineering,

and is vice-president of Flint Rehabilitation Devices. “My co-founder, Dr. Nizan Friedman, was the lead inventor. The basic concept was to come up with a way to sense important gripping movements. Dr. Friedman, Dr. Bachman, and I are all musicians, so adding music was a natural thought as a way of increasing motivation to exercise with the device. The first time we saw someone use the device for hand therapy, we saw their face light up, and we knew we had come upon something special.”

The MusicGlove is a sensorized glove that a user slips on and then chooses a song to play on an included tablet or computer. When the song starts, the screen begins to display a rapidly-changing musical fretboard similar to that used by the popular game Guitar Hero. As the song (and game) progresses, the user presses different fingers to their thumb to mimic the screen. In the process, the sensors on each finger complete a circuit as they come into contact with the thumb sensor—if the appropriate finger comes into contact with the thumb, a “correct” response results.

Because the game is so much fun to play, users find themselves making hundreds and even thousands of finger exercises during the space of one session.

“The core concept behind MusicGlove is not to reinvent what hand therapy is, but rather to use modern technology to increase patient motivation to participate, and give therapists more quantifiable data on patient progress,” says Zondervan. “Recent research has shown that the most important factors in rehabilitation are the dose of exercise an individual receives, the difficulty of that exercise, and the level of motivation the patient has to continue. With MusicGlove, users make thousands of movements in a single 30 minute session. We believe it is this dramatic increase in the number of practice movements performed that has caused MusicGlove to outperform conventional therapy in several randomized controlled trials.”

The completed trials Zondervan is referring to have tested the device with

people who have sustained paralysis of the hand as a result of stroke. “However,” says Zondervan, “a group at UCLA has been using MusicGlove for over a year now as an exercise tool as well as an outcome measure in a clinical trial of novel therapies for individuals with SCI. And we just began our own study of the device with individuals with SCI through a partnership with University of California, Irvine. Due to the nature of the intervention MusicGlove provides, we expect positive results, though the study won’t be completed until next year.”

Flint Rehabilitation Devices announced in May that it has been awarded a \$1 million grant from the National Institutes of Health (NIH) to conduct this new trial, as well as a new trial with stroke. This follows on the heels of another positive show of support from NIH—the company was granted an initial \$500,000 in 2014 to commercialize the product.

Which brings us to the fact that, yes, you can actually buy the MusicGlove system right now, as it was recently approved for over-the-counter use by the US FDA and Health Canada. A home version costs \$1,099 USD, while a clinical version sells for \$4,199. The home version contains only one user profile and one glove, while the clinical version allows unlimited user profiles and six gloves—small, medium and large ones for each hand. Unfortunately, there’s no insurance coverage at this point, but we think the price is

actually pretty reasonable. Granted, the home version only has one glove—Zondervan explains this is because the primary target population is people who have sustained a stroke, which typically results in paralysis only on one side of the body. (We feel it’s important to point out that it hasn’t yet been proven to be effective for SCI—but hopefully soon will be.) But he says the company will sell systems with two gloves for a reasonable up-charge. You can buy the home version at the company’s website, but Zondervan adds that he is currently in talks with a Canadian distributor who will eventually sell the product direct to consumers in our country.

As for supervision by an OT or PT, it’s not necessary, although Zondervan suggests that professional assistance could help a user maximize their experience with MusicGlove.

One final thought: we realize that MusicGlove is a rehabilitation device and not an instrument, but we were curious if anyone who’s been a musician prior to paralysis might benefit from the technology as a way to play again.

“Yep!” says Zondervan. “We’ve had several customers who used to be musicians who were inspired to use MusicGlove out of their desire to return to their instrument.”

Check out www.flintrehab.com for more information and a demonstration video. ■



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, much more. In other words, it's about maximizing recovery, independence, health, and quality of life today. And it doesn't happen without you. That's why SCI BC and ICORD are partnering to help raise awareness and increase participation in SCI research. Working together, we can make SCI research more meaningful and move it along at a faster pace. Starting this June, SCI BC and ICORD will work together to highlight some of ICORD's world-leading research and invite you to be a part of it. Please read about these studies below.

CHOICES: Cardiovascular Health/Outcomes: Improvements Created by Exercise and Education for SCI

ICORD researcher Dr. Andrei Krassioukov is leading a multi-centre study on the effects of exercise interventions on cardiovascular health of individuals 18 to 60 years old with chronic, motor complete traumatic SCI at the C4 to T6 level. Location: Blusson Spinal Cord Centre. Compensation for participation: yes. Website: www.choicesproject.ca. Contact: Cameron Gee (email: cgee@icord.org or choices@icord.org; phone: 604.675.8856).



MRI Study on SCI Neuropathic Pain

Researchers at ICORD's Brain and Spinal Cord Imaging Laboratory (Drs. Kramer, Laule, Kollind and MacMillan) are conducting a study to assess damage in the spinal cord after injury and how this might influence whether or not you experience neuropathic pain (e.g., burning in the legs). The researchers are seeking participants with SCI (paraplegia or tetraplegia) between the ages of 19 and 65 years of age who live with and without neuropathic pain. Location: UBC MRI Research Centre. Compensation for participation: no. Contact: Dr. John Kramer (email: kramer@icord.org; phone: 604.675.8876).



How Do People Use Their Wheelchairs? Exploring Mobility Patterns Among Canadians

ICORD principal investigator Dr. Bonnie Sawatzky is conducting this study to better understand how individuals in the Lower Mainland use their wheelchairs and what factors are related to increased mobility and community participation. Participants must be over 12 years of age, and use a manual wheelchair for the majority of their mobility. Location: Blusson Spinal Cord Centre. Compensation for participation: no. Website: www.icord.org/research/participate-in-a-study. Contacts: Franco Chan (email: fchan@icord.org), Mehdi Eshraghi (email: mehdi.eshraghi@alumni.ubc.ca), or Bonnie Sawatzky (email: bonitas@mail.ubc.ca).



Lactation Support for Women with Spinal Cord Injury Survey

The Perinatal Interest Group is seeking women with SCI who have had a baby post injury to learn about their experiences with breastfeeding. This is a collaborative project between VCH, BC Women's Hospital and SCI BC. The goal of the study is to identify key gaps in knowledge and care in lactation support for women with SCI. The results of this study will be used to inform future research agendas and make policy recommendations. Location: online. Compensation for participation: no. Website: www.survey.ubc.ca/surveys/scilactation/scilactation. The principal investigator of this study is Melanie Basso of BC Women's Hospital. ICORD researcher Dr. Stacy Elliott is a co-investigator. Contact: Melanie Basso (email: mbasso@cw.bc.ca; phone: 604.875.3799).



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

Instant Diagnosis

A new diagnostic device developed by ICORD researcher Dr. Babak Shadgan provides immediate confirmation of urinary tract infections.

We may not have warp drives or transporters yet, but Dr. “Bones” McCoy’s medical tricorder from the universe of *Star Trek* is slowly but surely moving from the realm of fiction to the real world—and that’s good news for people with SCI.

One of the most impressive and promising portable and non-invasive diagnostic devices we’ve seen has recently been developed right here in BC—a wireless, credit card-sized optical device that can sense the presence of lower urinary tract infections (UTIs).

UTIs are one of the most persistent, damaging and even deadly secondary health complications of SCI. Left untreated, they can lead to kidney damage, sepsis, renal failure, autonomic dysreflexia and a host of other complications. Up to this point, the standard method of diagnosis has involved collecting urine and testing it for the presence of bacteria—an impractical, costly and time-consuming procedure that can take up to 72 hours for definitive results. Needless to say, a UTI can spiral out of control if left untreated for three full days. Meanwhile, precautionary treatment with antibiotics given to patients while they wait for their test results has its own pitfalls, as excessive use of antibiotics is gradually leading to more drug-resistant strains of bacteria.

Another problem with UTIs for people with SCI is that they may not even be able to feel the hallmark sign of a UTI, which is painful urination.

“Early and rapid diagnosis of UTI, in particular in people with SCI and other neurogenic conditions such as MS that are associated with loss of normal bladder function, is critical for rapid treatment and prevention of other serious urinary and general complications that are secondary to untreated acute UTIs,” says Dr. Babak Shadgan, a physician and ICORD researcher who developed the new diagnostic device. “This can save time, reduce the financial burden on patients and healthcare systems, prevent unnecessary referrals to clinics and hospitals, make treatment easier, and promote quality of life for people affected by SCI.”



Shadgan says he arrived at the idea for the device as he studied bladder function using NIRS (near infrared spectroscopy). When he observed higher amounts of oxygen levels in the bladder tissue in some subjects, he was curious to know why.

“When I reviewed those cases, I realized that they were recently affected by a UTI,” he explains. “I conceptualized that UTI-induced inflammation of the bladder wall might result in an increase in bladder wall tissue oxygen saturation, which can then be detected by NIRS.”

Near infrared light has been known about for more than one hundred years, and NIRS systems have been used in many medical applications for decades. But according to Shadgan, they’ve never been used for an application like this.

So how does it work?

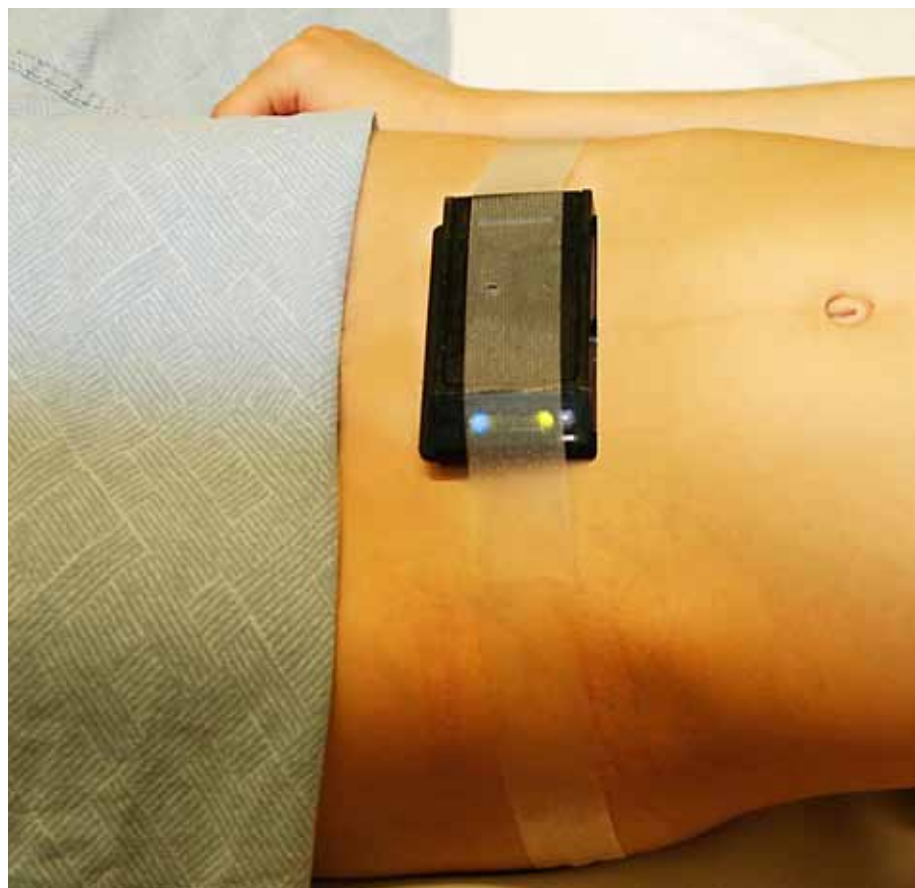
“NIRS is a non-invasive transcutaneous optical technique that uses light in the near-infrared spectrum to monitor changes in the tissue oxygenation and local perfusion level by mathematical calculation of the amount of absorption and diffusion of the light photons emitted into the tissue of interest,” explains Shadgan.

In simpler terms, it works like this: the light, which is completely harmless, is directed from outside the skin into an area of interest on the body. A sensor records how much light returns to the device. When an infection is present, more oxygen (and more blood flow) is present, and this diffuses the light so that less returns to the sensor when compared to a scan of healthy tissue.

In this adaptation of NIRS, the bladder is scanned, and so is a location on the patient’s thigh as a control site.

“When the measurement over the bladder is significantly higher than the measurement on the control site, it may indicate the bladder is inflamed,” explains Shadgan.

The device is about the size of a credit card and is entirely non-invasive. Using it, Shadgan and his colleagues were able to diagnose UTI in 12 pediatric patients. Those impressive results



THE FUTURE OF DIAGNOSTICS: Dr. Shadgan’s device for diagnosing UTIs is about the size of a credit card, and promises to provide immediate confirmation of a bladder infection. The existing method of diagnosing UTIs is urinalysis to test for the presence of bacteria.

were recently published in the *Journal of Pediatric Urology*.

“We have examined feasibility and proof of principle of this method,” says Shadgan. “We are now conducting a larger, multidisciplinary clinical research project, funded by Rick Hansen Institute, to look at the accuracy of our method in diagnosis of UTI in people with SCI.”

That study, being led by urologist Dr. Mark Nigro, is taking place at the Brenda and David McLean Integrated Spine Clinic at the Blusson Spinal Cord Centre in Vancouver. The goal is to study 100 patients.

While Shadgan cautions that results won’t be known for some time, he is optimistic. “From collected data so far, it looks that we’re working on a promising method for early diagnosis of UTI,” he says. He envisions a reasonably-priced device that will not only be available to medical specialists and family doctors, but also to anyone susceptible to UTIs

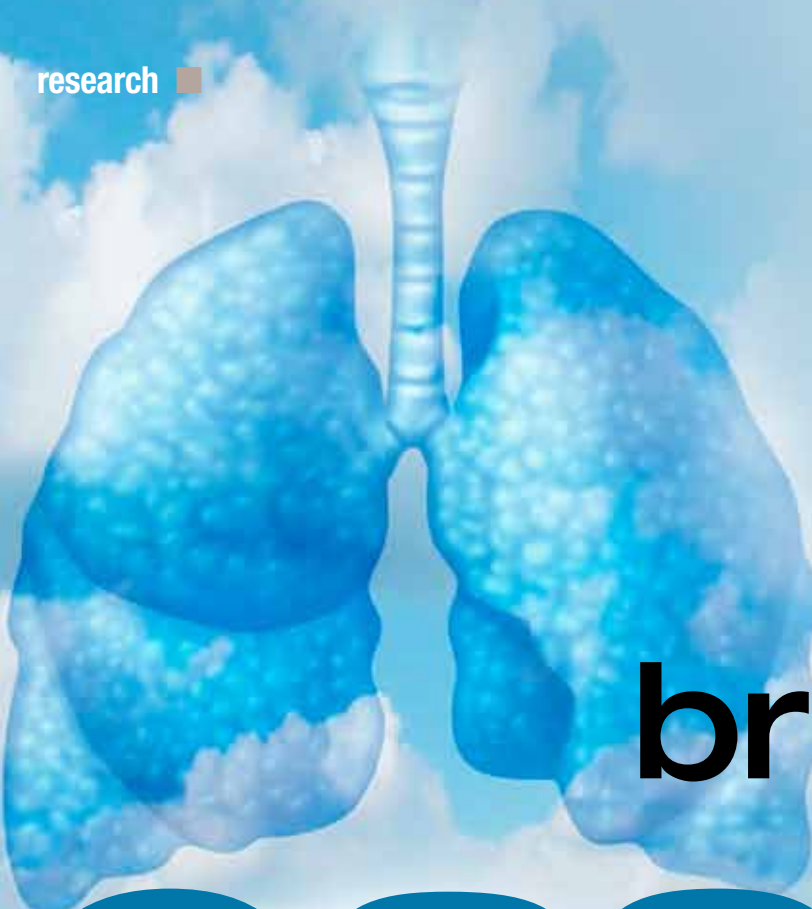
who could use the device wherever and whenever they want for daily self-screening.

“That’s right, our ultimate goal is to design a handheld, user-friendly and simple-to-use device for screening and early diagnosis of UTI at clinics—and for daily monitoring of high-risk individuals at home,” he says.

Shadgan’s work was funded in part by the Rick Hansen Institute, the UBC Urology Foundation, and the Michael Smith Foundation for Health Research, and supported by ICORD. Look for more news on this promising technology in future issues of *The Spin*. ■

Instant Pressure Ulcer Diagnosis?

In the next issue of *The Spin*, we’ll bring you a report on progress being made by two research groups on devices that promise to diagnose the presence and extent of pressure ulcers under the surface of the skin. Beam me up, Scottie!



A recent laboratory breakthrough could some day allow ventilator-dependent quadriplegics to breathe without assistance.

breathing easier

Most of us take breathing for granted—including the vast majority of people with SCI.

But for a small yet significant number of people with the highest levels of SCI, paralysis extends to the muscles of their diaphragm. For these people, every breath they take needs to be provided by a mechanical ventilator—devices that, in addition to being intrusive and cumbersome, make it impossible to smell or taste.

One relatively recent solution has been the NeuRx Diaphragm Pacing System (DPS) which, as the name suggests, stimulates the paralyzed diaphragm muscles much the same way as a heart pacemaker works. In 2013, Health Canada provided full approval for the system, and some of our readers are now using it. Not surprisingly, many who have received the system say they have gained significant quality of life improvements. But the DPS isn't without its drawbacks—the implant requires complex invasive surgery, and it does require ongoing fine-tuning and maintenance.

In November, researchers at Case Western Reserve University in Cleveland announced that they have developed a procedure that restores function to muscles involved in the control of breathing, even when those muscles have been paralyzed for more than a year.

At the Neuroscience 2014 conference held in Washington, DC, principal investigator Dr. Philippa Warren described to attendees how she and her team had successfully tested a two-step approach to repair the nerve damage in spinal cord injured animals—damage that prevented them from breathing on their own.

“We show that respiratory paralysis can be reversed at long intervals after spinal cord injury,” said Warren. “This has the potential to alleviate the long suffering of currently injured patients, improving their quality and, potentially, length of life.”

Warren and her colleagues focused their efforts on a group of nerves that extend from the respiratory control center in the brain stem down to the C3 through C5 ver-

tebral levels of the spinal cord located in the neck. These fibres, or axons, control the diaphragm muscle. Following injury, these fibres die, causing loss of the connections between the brain and diaphragm. At the same time, in an effort to preserve tissue, the body immediately responds to the injury by sending specialized glial cells to the site of the trauma. These glial cells, which normally support neurons, deposit scar tissue which extends several inches up and down the spinal cord. This scar tissue is very dense, contains sugars that inhibit new neuronal growth, and does not reduce in length or intensity over time. This process essentially prevents the formation of any new connections to enable functional recovery.

The researchers developed a technique to treat the injury site with a specially-designed enzyme called chondroitinase. This treatment was combined with respiratory therapy to strengthen the remaining functioning respiratory muscles.

First, they injected chondroitinase at the site of respiratory nerves in the damaged spinal cord. Chondroitinase is a bacterial protein that has some unique properties. Previous research has demonstrated its ability to “digest” the sugars that compose the scar tissue which forms quickly at the lesion site following injury. The action of the enzyme enabled both the formation of new connections and stimulation of dormant pathways in the respiratory motor system. Second, the animals were exposed to brief periods of conditions with low oxygen, making them breathe harder and faster to rehabilitate the respiratory muscles. This treatment is referred to as intermittent hypoxia.

The combination of enzyme injection and intermittent hypoxia treatment boosts levels of serotonin. Commonly known for its ability to help relieve anxiety disorders and its role in sleep, serotonin also acts more broadly as a neurotransmitter to help stimulate nerve cells. By increasing serotonin at nerve connections and at the specific receptors on the fibres themselves, the researchers were able to



Dr. Philippa Warren

help restore diaphragm function back to normal levels in the animals.

This result is a breakthrough—not only because function to the paralyzed diaphragm was completely restored, but also because researchers were able to use the procedure in animals that had been injured for a year and a half.

However, Warren makes it clear that more research is required to perfect the treatment. About one third of the animals in the study failed to respond to the study. And of the animals that did respond, a third experienced erratic breathing.

Investigators found that the animals with erratic breathing were flooded with too much serotonin during their treatment. A simple fix involved administering a serotonin receptor blocker, which restored these animals to normal breathing. Warren and her colleagues are now further studying the serotonin-overload phenomenon in animals to expand their knowledge of the treatment strategy.

So, while the treatment strategy holds

great promise for use in humans, the technique must first be optimized and shown to be effective in larger animals with spinal cords more similar in size to that of humans.

“Treatment increased the strength of nerve connections—not at the site of injury, but where the diaphragm nerves leave the spinal cord,” Warren said. “This may have huge implications for the treatment of (people) with spinal cord injury. Our work offers new hope that it might be possible in the future to repair paralyzed respiratory muscle activity, even at long time periods after severe spinal injury, allowing patients to breathe normally again.”

These results also reinforce previous findings about the potential of chondroitinase to be used in the restoration of other important functions following SCI and other neurotrauma, such as brain injury. Published animal studies from more than a dozen independent laboratories have demonstrated that the application of chondroitinase resulted in improved recovery of function following injuries to various areas of the brain or spinal cord. These functions included walking, forelimb grasping, sensation, binocular vision and bladder control.

Up to this point, there have been no clinical (human) trials involving chondroitinase, as it’s believed that repeated injections of the enzyme may increase the risk of trauma, infection, and a negative response from our immune systems. However, work is underway to engineer a version of chondroitinase that is safe for human testing. ■

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In the market for a ceiling track lift? How about a hospital bed, a beach wheelchair, a wheelchair van, a sip and puff page turner, or even a wheelchair? If so, consider saving money by buying it used at Spinal Cord Injury BC’s always popular online Swap n Shop. As we went to press, there were nearly 70 ads posted for a wide variety of SCI or disability-specific goods for sale by private individuals, including all the items mentioned above. Over the years, hundreds, if not thousands, of our Peers and their families have successfully sold or purchased quality used items at the Swap n Shop section of our website. Check it out at www.sci-bc-swapnshop.ca.

Stemming the Hype

A new University of Alberta study reveals just how unrealistic the media's coverage of stem cell therapies can be.

Most of us already suspect that the media can be over-enthusiastic in its coverage of all things stem cells, creating false hopes and expectations in the process. But a recently-completed study by University of Alberta law researchers quantifies just how unrealistic media coverage of stem cell therapies really is.

The study, co-authored by Timothy Caulfield and Kalina Kamenova, examined 307 reports of stem cell research that were published in major daily newspapers in Canada, the USA and the UK between 2010 and 2013. The duo found that the majority of these news stories lacked balance—they tended to be highly optimistic about the therapies they were describing and the timelines involved in bringing them to the mainstream for public use, while overlooking the challenges and hurdles that need to be overcome in order to do so.

Specifically, the study concluded that 69 percent of all news stories analyzed predicted that the therapies described would be available within five to 10 years—or even sooner. While stem cell therapies hold considerable promise for many conditions including SCI, these timelines are clearly unrealistic—the vast majority of stem cell therapies being tested are at the beginning (evaluated for safety as opposed to effectiveness) of a long and difficult approval process. The authors note that the average time to get any new drug from the lab to market is 12 years—and the majority of new drugs are nowhere near as complex as the process of transplanting any kind of stem cell.

The result is that this rosy perception of stem cell therapies rubs off on an easily-influenced and sometimes vulnerable public, says Caulfield, who is a professor,

lawyer, health policy expert, research director of the U of A's Health Law and Science Policy Group, and author of two books that debunk celebrity culture: *Is Gwyneth Paltrow Wrong about Everything* and *The Cure for Everything! Untangling the Twisted Messages about Health, Fitness and Happiness*.

"Pop-culture representations have an impact on how the public perceives the readiness of stem cell research," says Caulfield, "and that in turn feeds into stem cell tourism, marketing of unproven therapies and even the public's trust in research."

He adds that one of the most alarming aspects of the research was the media's response—or lack of it—when a prominent biotech company discontinued its SCI-specific stem cell trial in 2011. Geron Inc. made headlines when it became the first company to secure FDA approval for its clinical trial of an embryonic stem cell-derived therapy for SCI, and was considered a leader in embryonic stem cell therapies. The company's decision to halt its work on stem cells was considered a significant setback for the field.

"We were surprised that the exaggerated claims of rapid translation (from basic research to clinical use) did not dissipate more after the Geron trial was abandoned," says Caulfield. "It's amazing how consistently overly optimistic the predictions remained."

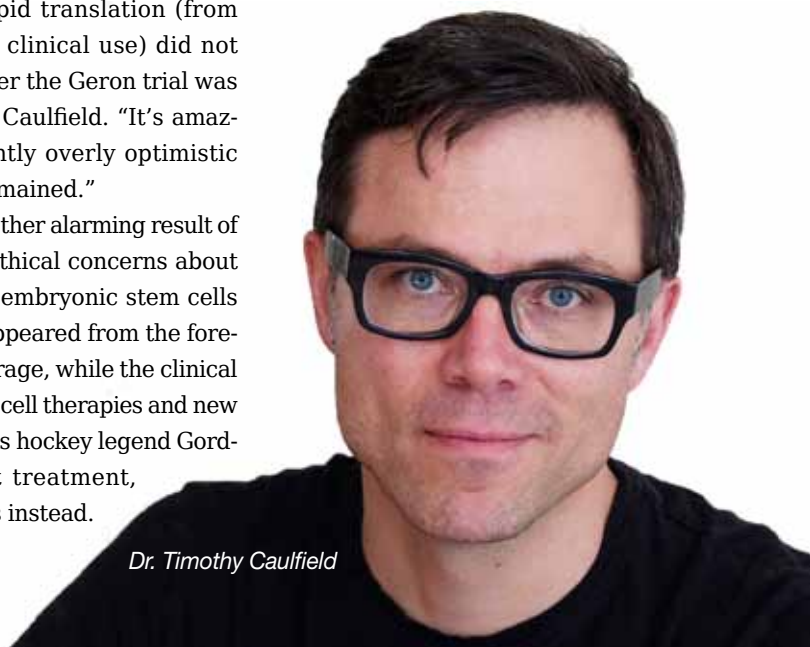
He adds that another alarming result of the study is that ethical concerns about the use of human embryonic stem cells seem to have disappeared from the forefront of news coverage, while the clinical translation of stem cell therapies and new discoveries, such as hockey legend Gordie Howe's recent treatment, grab the headlines instead.

But Caulfield is quick to point out that it's not just the media that can be blamed for creating the unrealistic expectations when it comes to stem cell therapies.

"The pressure to hype is everywhere," he says. "I've called it a hype pipeline. For example, our findings showed that many scientists have often provided, either by implication or direct quotes, authoritative statements regarding unrealistic timelines for stem cell therapies. There is career pressure, institutional pressure, commercialization pressure, patient pressure, public pressure and, of course, media spin. Also, I think the pressure from government to commercialize research is part of the problem. Everything must now be portrayed as if it will be in the clinic tomorrow. It's a complex problem that involves many actors working in concert."

That, says Caulfield, makes it a tough problem to fix. "Everyone—researchers, institutions, and the media—have to dial back the rhetoric. I don't think we need to hype science to make it interesting and exciting. I believe the public understands that it will take time. Creating false expectations isn't going to help. In the short term, some appear to benefit from the hype—for example, more newspapers may get sold, and researchers might secure funding. But in the long term, it hurts everyone, including the science. I also think it hurts public trust in science."

Caulfield's study was published in the March 11, 2015 issue of the journal *Science Translational Medicine*. ■



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