

FALL 2018

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Community

THE SPIRIT OF SPINAL CORD INJURY ONTARIO

Our New Look

*Celebrating our
Community*

Win Win –
A Tax Smart Gift

*House Hunting for
a Visitable Home*

Raising Our Voice

SAULT
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COVER STORY: Sault Ste. Marie has set itself up as a model for excellence when it comes to accessibility and they are working diligently to achieve their goals. They are going beyond legislation to foster an accessible environment in a very creative and mindful manner, and are building a broad-based model of accessibility to which other municipalities can aspire.

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Subscription to **Community** is a benefit of joining the Spinal Cord Injury Ontario community. To join, please visit our weblink at www.sciontario.org/join or email communications@sciontario.org.

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For more information, visit us online: www.SCIOntario.org



By Stuart Howe

Our New Look

We've enjoyed many important and entertaining magazine articles under the name Outspoken! over the last 14 years and, as you'll see by this issue's cover, we've taken the plunge and updated our publication's name.

It's a decision that, like any we make, was arrived at with much respect for our history and vision for all we aim to accomplish as a community. Changing something comfortable and familiar, as our community knows more than most, can be difficult. Though it may not be a welcome change for some, updating the name and design of our premier communications tool complements some of the other initiatives we've undertaken to support our three strategic priorities: expand our impact across Ontario; amplify our community's voice and share knowledge. We've refined our branding style, created a new tag line (Peer to peer. Strength to strength.) and improved and integrated our materials, such as our new website, email communications and printed information pieces. We've supported our important advocacy efforts with tools to engage a wider audience, such as our *Your move, Ontario* and the upcoming #peeforfree social media campaigns. And we've streamlined and centralized our processes for smoother delivery of client services. This is all in aid of raising our profile and expanding our reach and network so that our goals to serve, support and advocate for and with people with SCI can be met more effectively for years to come.

Now to the choice of our magazine name: since I came to Spinal Cord Injury Ontario three years ago, I've been struck time and time again by the strength and vibrancy of this community. Though we're spread out across the province and are always trying to do more with less, there is an intense feeling of community at the heart of this organization. It's what clients feel as they get to know us, what makes donors want to share what they can for our programs, what inspires volunteers to give their time and what confirms for corporate, program and government partners that we are a viable and formidable collaborator. When we looked at possible names,

Community was an obvious and unanimous choice. We feel it captures the essence of our magazine's purpose: to inform, inspire and showcase members of our community and the work we do within our community.

And speaking of community, we've just come off two Community Celebration events in Toronto and Barrie, which brought together the people and organizations that work so hard to support clients and their families in these locations. We presented awards and shared stories of how much our work means to those who contribute to it in so many ways. Take a look on page 42 for more on these evenings and stay tuned for more celebrations across the province in the coming months.

I hope you enjoy this first issue of *Community*, and I thank you for making our community as positive and powerful as it is.

Dr. Stuart Howe
CEO, Spinal Cord Injury
Ontario



Addressing the high cost of catheters

If you use an intermittent catheter on a daily basis, as many people with spinal cord injury do, you could be spending between \$4,000 and \$15,000 a year on this vital medical supply. This is a tremendous financial burden and we believe there should be a province-wide comprehensive medical supply coverage program for those with permanent needs. As part of the provincial Intermittent Catheter (IC) Working

Group and together with the Ontario SCI Alliance, we are working to advocate for appropriate, evidence-based access to ICs for Ontarians. And we are set to launch our public #peeforfree campaign to raise awareness on this important issue. See sciontario.org/peefree for more.

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BELIEVE THIS
HAPPENED
TO ME.
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WALK AGAIN?**

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By Joanne Smith

Sicilian Salubrious

On a recent trip to the beautiful island of Sicily, I learned that Sicilians have an increased life expectancy compared to their Italian mainland counterparts.

Moreover, this population has an exceptionally high number of centenarians. Studies demonstrate that several key factors determine longevity, such as genetics and environment. The latter of these two includes nutrition. It has been well established that the Mediterranean diet (high in healthy fats, fish, legumes and vegetables and low in red meat and refined carbohydrates) is one of the healthiest in the world – and one of the best for individuals with SCI. But what is it about the Sicilian diet that is seemingly even more beneficial for us?

Their long life expectancy may have something to do with their long, complex history. Sicily has been conquered by a multitude of nations including the Romans, Greeks, Spanish, Moors, Normans and Phoenicians among others. While Sicilian cuisine falls under the Mediterranean Diet, the turnstile of these ruling cultures over the centuries has heavily influenced their diet making it exceptionally unique. For example, raisins, eggplant, nutmeg, clove and saffron are common ingredients used in Sicilian dishes, but are not found in typical Mediterranean recipes.

Caponata is a delicious example of Sicily's distinct cuisine

and this eggplant based dish has a vast array of health benefits for people with SCI. For instance, eggplant is high in fibre, which not only helps to maintain regular bowel routines, but also helps stabilize blood sugar levels, which is important for weight loss. Vinegar supports digestion, which is vital for those of us with compromised digestive function, and it supports bone health by enhancing calcium absorption. Lastly, the eggplant, tomatoes, garlic, raisins and olive oil make up an army of antioxidants to help protect us from one of our biggest enemies, cardiovascular disease.



Serve Cantata cold or warm as an appetizer, side dish or snack!

CAPONATA

- 5 tablespoons olive oil
- 1x 1½ pound eggplant, unpeeled, cut into ½ inch cubes
- 1 medium onion, cubed
- 4 large garlic cloves, chopped
- 1x 14½ ounce can diced tomatoes in juice
- 3 tablespoons red wine vinegar
- 2 tablespoons drained capers
- 2 tablespoons raisins
- ⅓ cup chopped fresh basil
- Toasted pine nuts

1. Heat oil in heavy large pot over medium heat. Add eggplant, onion and garlic cloves. Sauté until eggplant is soft and brown, about 15 minutes.
2. Add diced tomatoes with juice, raisins, then red wine vinegar and drained capers. Cover and simmer until eggplant and onion are very tender, stirring occasionally, about 12 minutes.
3. Season caponata to taste with sea salt and pepper. Mix in fresh basil.
4. Transfer caponata to serving bowl. Sprinkle with toasted pine nuts. Serve warm at room temperature, or cold. (Caponata can be made two days ahead. Cover and chill.)

fruitful elements

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2018 PEER CONNECTIONS OTTAWA

Vehicle Modification Fair

By Wendy Hough, Development Officer

Once again, the weather was smiling on the Ottawa Spinal Cord Injury Ontario team, offering up September sunshine!



The annual Ottawa Peer Connections Vehicle Modification Fair was held at The Ottawa Hospital Rehabilitation Centre September 27. More than 70 people were in attendance to see the latest and greatest in modified vehicles.

We were pleased to welcome as our co-sponsors for the evening teams from Burn, Tucker and Lachaine LLP and Modern OT. Thank you for coming out to join us for the evening and for your generous support!

Guests were able to check out vehicles and speak with vendors from Silver Cross, Savaria, Conval-Aid and Liftability. Some friends of Spinal Cord Injury Ontario brought out their special rides for people to see as well! Fun music, great food and prizes rounded out a fabulous and informative evening for all. ●



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Access Visual Art



AccessVisualArt.ca

You'll get information on if, and how, art venues you want to visit are barrier-free:

+ Access designations



accessible



partially accessible



not accessible

+ Photos & dimensions of entrances, doorways, interior spaces

+ Washrooms

+ Automatic door openers

+ Parking

+ Program description

+ Maps

Your Guide to Barrier-Free Art Spaces.

Access Visual Art (AVA) is an online information resource dedicated to providing physical accessibility information about Ontario's art venues. This resource includes image-rich and detailed reports gathered from surveys and site audits, presenting up-to-date profiles on the accessibility features of venues such as museums, galleries, studios, theatres and other facilities used by the visual arts sector.

As people with physical disabilities, we often do not have access to enough information and support to know which venues we can go to or how we might engage with art spaces. AVA is a response to this existing gap, building a portal to accessibility in the visual art sector because no such resource database yet existed. While many existing platforms use a crowdsourcing model that is limited to a few categories without precise explanations, AVA uses research methods based on surveys and audits that results in accurate and reliable data.

The barrier is not that people have disabilities, but that our built environments can be disabling!

Partners

AVA is a network of art and disability individuals and organizations based in Ontario. Our two main partners are AccessTO, an online resource that publishes information on barrier-free venues, and Akimbo, a digital resource that promotes visual art in Canada.

Get More Information

accessvisualart.ca
info@accessvisualart.ca
[@accessvisualart](https://www.instagram.com/accessvisualart)



Get Involved + Get Listed

Art venues can fill out the survey at: akimbo.ca/ava



SCIO's Diane Morrell (left) and Peer Support Volunteer Denise Ellibtt



By Beverley Jenkins

SAULT STE. MARIE Leads the Way

Known as a traditional North American gathering place for millennia, Sault Ste. Marie grew from its indigenous roots with the development of steel, power and paper industries. It is surrounded by an exquisite wilderness environment for outdoor sports and artists like the Group of Seven, and famous Sault natives including astronaut Dr. Roberta Bondar. Sault Ste. Marie is now a bustling city and continues to be an important destination for business, trade and travel.

The city council is determined that the city be a leader in being accessible and barrier free. Guided by the four core principles of dignity, independence, integration and equality of opportunity, they are committed to providing quality goods, services and facilities that are accessible to everyone in a manner that respects the dignity and independence of people with disabilities. The City's Accessibility Advisory Committee advises Council and city agencies, boards and commissions, in promoting and facilitating a barrier-free Sault

Ste. Marie for citizens of all abilities. They are doing this to meet the requirements of the Accessibility for Ontarians with Disabilities Act and the Human Rights Code, but in speaking with them, they are going beyond the legislation to foster an accessible environment in a very creative and mindful manner, and are building a broad-based model of accessibility to which other municipalities can aspire.

I spoke with Don McConnell, Director of Planning and Enterprise Services who provided insight into what the city has already done and what they are planning to do. He has worked as a professional planner in northern Ontario for 38 years, and has been involved with all aspects of municipal planning. He said, "The current city of Sault Ste. Marie Multi-Year Accessibility Plan is a five-year plan starting in 2016 and ending in 2020, and

we are well underway to achieving our goals.

Diane Morrell, Spinal Cord Injury Ontario's Regional Services Co-ordinator in the Sault has a close working relationship with the city. Her office is located in the community centre next to Nancie Scott, Accessibility Co-ordinator for the city of Sault Ste. Marie. Diane said, "We have a wonderful complementary partnership, and we make recommendations to the city regarding accessibility needs, and offer ideas on how to make things better. We are fully immersed!" Diane is an active member of the Accessibility Advisory Committee and the chair of the site plan sub-committee.

There are nine major initiatives being undertaken by the city to ensure accessibility for everyone. Don said, "We are doing this to create a barrier free environment for people with physical disabilities, including our aging population. By allowing greater accessibility to accommodations, businesses, and recreational venues, everyone will benefit."

Ernest Hemingway, world renowned author, was quoted in the Toronto Star on August 28, 1920 saying, "At the present time, the best rainbow trout fishing in the world is in the Rapids at the Canadian Soo."

units required under the Ontario Building Code (15% of all new residential units) will be eligible for a partial tax grant of up to three years. Don said, "We look at each proposal on a project by project basis. If a new building

exceeds the 15% requirement, then the city may allow an additional tax rebate year. This is intended to get ahead of our baby boomer aging population."

2. Downtown Community Improvement Plan Grant Programs

Inclusive environments enhance the quality of life for all and promote acceptance. Pursuing exterior or interior building enhancements can provide opportunities to incorporate designs that create accessible spaces to the general public. Applicants can receive direct grants or a tax increment equivalent grant/rebate, depending on the project. Barrier free considerations include accessible door handles, wide



THE CITY'S KEY ACCESSIBILITY PROJECTS ARE AS FOLLOWS:

1. Rental Housing Community Improvement Plan (CIP)

This plan has been undertaken for a number of years, with the intention to increase the city's inventory of affordable rental accommodation. This will benefit both local residents and support the current initiatives to attract newcomers to the community. Specifically, the CIP permits the use of property tax assistance, including grants, as an incentive to encourage new investment in rental housing. A grant may be provided as a direct payment or as a tax credit. This includes all vacant and occupied properties zoned to permit apartment buildings of four or more units.

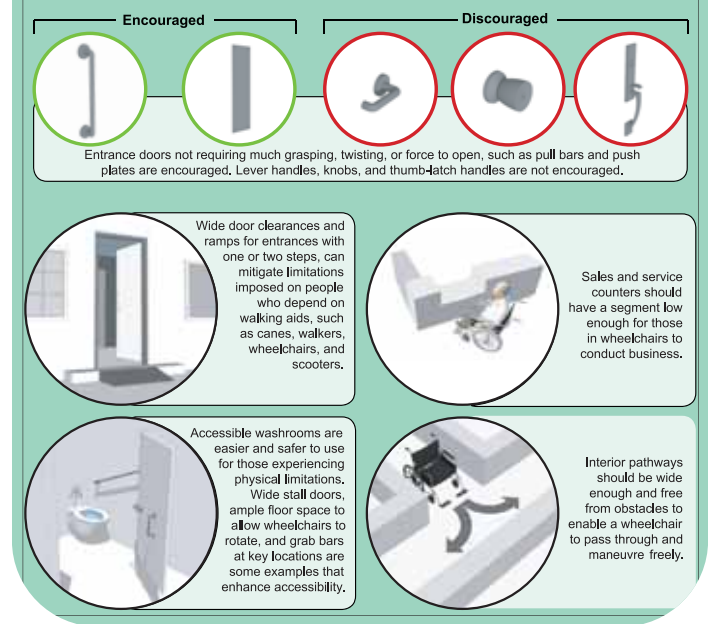
One of the main objectives of the plan is to encourage the construction of additional barrier free accommodation. Projects which meet the minimum number of barrier free



door clearances and ramps for entrances, accessible washrooms, wider interior pathways that are free from obstacles, and sales and service counters that have a lowered segment for people who use wheelchairs.

The façade improvement grant encourages commercial building owners to invest in façade renovations and storefront improvements. This downtown improvement grant now includes a section on funding for accessibility. Previously it was only available for façade improvements. The grant, up to \$25,000, incentivizes businesses to improve accessibility of older buildings and make the downtown more beautiful.

"The city will be implementing a Universal Design Policy in the city's Official Plan," said Don. "It is a subtle but important inclusion for us to put accessibility at the forefront. It's an encouragement for other municipalities to do something about barrier free environments and we want them to replicate our plan as much as possible."



3. Power Wheelchair Charging Stations

The city is in the process of having designated power wheelchair charging stations in all municipal buildings, all city owned facilities, some outdoor facilities and in partnership with many frequently used places like shopping malls. The city has their own electricians who will install the stations and the city is extending this offering to the rest of the business community. The stations will be identified with a blue plug and a sign that can be placed in a store window. When in place, the city will provide the charging locations on a map on their website.

4. Accessible Sidewalks

The city is moving towards the development of more wheel friendly sidewalk surfaces. Rather than using trowels for expansion joints between concrete slabs on the sidewalk, they are moving towards using saw cuts which are very thin with less spacing between the concrete slabs. This will mean a smoother ride for anyone using a mobility device. They are also changing walkways so that paving stones will no longer be used as pedestrian surfaces, but will only be used as visual accents and edging for pathways, creating a smoother path for travel.

5. StopGap Program

This program was not created in Sault Ste. Marie, but adopted by the city as a beneficial to improving accessibility. It is innovative in that it uses the Ontario Works Job Development Program to help introduce people to carpentry where they learn to build ramps. StopGap gets made to order ramps for local businesses, and this is supported by the local Downtown Association.

6. Public Restroom Map

The city has posted a map of accessible restrooms on their website.

7. Vulnerable Person Registry

This important program was developed in Sault Ste. Marie more than ten years ago and it is growing. People can self-identify as vulnerable (any disability) in certain situations, whether it be a fire at their address, or larger scale, say a gas leak in a whole neighbourhood. We use geographic information systems mapping when 911 is initiated and addresses are given. A vulnerable person will be given a red flag regarding vulnerability in the emergency so first responders can meet their unique needs in the most appropriate way.

Currently, between 1,200 and 1,500 people are registered for the program in Sault Ste. Marie. The program is now being offered by other cities including the city of Vaughan.

8. Downtown Public Furniture

The city is in the process of upgrading street and park furniture in the downtown area by installing barrier free tables and new benches with arm and back rests, which as we all age, will be appreciated.

9. Multi Use Path

Sault Ste. Marie has a very popular highly used trail that is ten feet wide, and 24k long. This multi-use path is divided for cyclists and pedestrians in the downtown area. There are plans to extend the path 3k in the downtown next year as part of a public works program. The path is built to a high standard out of asphalt. It holds up well in the weather, with parts of it being plowed in the winter months.

Sault Ste. Marie has set itself up as a model for excellence when it comes to accessibility and they are working diligently to achieve their goals.

For more information on topics discussed in this article, please visit www.saultstemarie.ca. ●



3rd Annual OT Consult Ergo Golf Invitational – Ottawa

By Wendy Hough, Development Officer

Many mulligans and lots of best balls have once again meant fun and fundraising for Spinal Cord Injury Ontario. The 3rd Annual OT Consult Ergo Golf Invitational hosted by the wonderfully energetic Mario Le Bouthillier, Occupational Therapist and Owner of OT Consult Ergo, raised an incredible \$6,425 to support the work we do to serve, support and advocate for and with people with spinal cord injury. This year's event was held September 12, at the Pine View Golf Course in Ottawa and the weather was smiling on us!

We were so excited this year to welcome the Ottawa accident and injury law firm of Auger Hollingsworth as one of our event sponsors. We would like to make a great shout-out to Richard Auger and Brenda Hollingsworth who not only sponsored the event but joined us for the day bringing their entire team of fun-seeking golfers with them.

Power Plus Mobility was once again our event meal sponsor. Your continued support of our work and the OT Consult Ergo Golf Invitational is greatly appreciated as was the fabulous meal.

From hole sponsors to companies providing prizes and auction items, the tournament was very well supported by the Ottawa community. None of this could have happened without the participation of all of the golfers for the day. Thank you so much for joining us to make the day such an overwhelming success. We had an exciting finish this year with two teams tying for top honours and the much-coveted OT Consult Ergo Golf Invitational trophy. Congratulations to our returning champs from ProMotion Orthotics and the Quantum Rehab/VitaCare team. Well played!

Thank you again to everyone who contributed to this fantastic event! We hope to see you again next year for the

4th Annual OT Consult Ergo Golf Invitational.

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Dinner Sponsor:

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- Pine View Golf Course
- ProMotion Orthotics
- Régimbal Awards and Promotions

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- Permobil
- Rideau Carleton Raceway and Slots
- Rockport Cruises 1000 Islands
- White Sands Golf Course

Bronze Level Sponsors:

- Absolute Comedy Club
- Caravella Restaurant
- Courtyard Restaurant
- Golf Works Canada
- Mama Grazzi
- Plasmart
- Shoppers Home Health Care, Orleans
- Woodway Holistic Esthetics ●



1. Chris Bourn, Brenda Hollingsworth (Auger Hollingsworth) Richard Auger (Auger Hollingsworth); Stuart Howe
2. Team OT Consult Ergo
3. Charlie's Angels
4. Winners (L to R) Team ProMotion Orthotics; Mario Le Bouthillier; Team Quantum Rehab/VitaCare

Win Win A TAX SMART GIFT

By Paul Livingston, Senior Development Officer

At 116 months we are experiencing the longest bull market in stock market history. It is three months older than the tech bull market that ended in 2000, and its duration is more than twice as long the average bull market length of 57 months. These facts combined with the time of year mean it is an excellent time to think about portfolio rebalancing and tax smart planning.

Win

When you donate securities directly to Spinal Cord Injury Ontario you will pay no capital gains tax on the appreciated value of your securities and you will receive a tax receipt for their market value. Your gift will result in a tax credit that will reduce your income taxes in the year of your gift – or you can carry it forward for up to five years.

Tax advantages of gifts of securities.

Suppose you sold a stock that you bought for \$4,000 and it is now worth \$10,000. You would have to pay tax on your capital gain. If your marginal tax rate is 43.41% you would owe \$1,302 in taxes.

Suppose instead that you donate the stock directly to Spinal Cord Injury Ontario. You would have to pay \$0 tax on your capital gains. You would receive a tax receipt for the entire

\$10,000. At a 43.41% marginal tax rate you would receive a tax credit of \$4,341 that can be applied anytime within five years. If you were to add the tax saved by not having to pay the capital gains tax (\$1,302) your total tax savings would be \$5,643. In this example a generous donation of \$10,000 is made for a cost of \$4,357.

Donating securities is easy.

Once you have consulted your professional advisors for an approach that ensures your donation maximizes your tax advantage then all you need to do is:

1. Let us know about your gift at 1-877-422-1112, ext. 214 and we will send you a Securities Transfer Form.
2. Fill in the form - it's a simple one page document.
3. Send the form to your professional advisor, bank or investment firm and they will send the securities to Spinal Cord Injury Ontario's account.



How is the market value of my gift determined?

The market valuation for the tax receipt will be the greater of the unit closing price, or the average of the high and low market price, on the donation date. The tax receipt donation date will be the day the security arrives in Spinal

Gift of Securities

	Gift of securities transferred directly to SCIO	Sell securities and donate cash
Current Fair Market Value	\$10,000	10,000
Amount Paid (Cost Base)	\$4,000	\$4,000
Capital Gain	\$6,000	\$6,000
Taxable Capital Gain at 50%	\$0	\$3,000
Tax on Capital Gain at Marginal Rate*	\$0	\$1,302
Tax Credit on Donation at Marginal Rate*	\$4,341	\$4,341
Net tax savings	\$4,341	\$3,039
Total Tax Savings	\$5,643	\$3,039
	Tax credit of \$4,341 plus \$1,302 in tax on gain not paid.	Tax credit of \$4,341 less \$1,302 in tax paid on gain

*example uses a marginal tax rate 43.41%

Cord Injury Ontario's brokerage account. It is important to consider that the process is usually quite quick, but for some securities like mutual funds it can take a little longer so it is important to undertake the process in advance of year end. Please consider sending the Securities Transfer Form document by email or fax. Sending by post mail will



delay the start of the transfer process and may affect the receipt value.

Are there limits on the donation?

There is no limit on the size of your donation, however the maximum amount of all donations an individual can claim on their tax return each year is 75 per cent of net income.

Which securities can I donate?

Gifts eligible for this preferred tax treatment include any of the following securities: Stocks, Bonds, Mutual Fund Units, Warrants, Bills and Futures that are listed on the stock exchanges prescribed by Canada Revenue Agency.

In general the best strategy is making a gift of securities with large capital gains from non-registered accounts (not held in an RRSP, RRIF, or TFSA). Your professional advisor can help you make the best choices that consider your unique circumstances with respect to portfolio rebalancing and optimal tax planning.

Win (The other Win?)

Your support will help fill gaps in service and funding from the provincial government and play an essential role in the empowerment of people living with a spinal cord injury. Your generosity will provide lived experience knowledge, support and services based on 73 years of expertise. ●

CALENDAR OF EVENTS

PEER CONNECTIONS: SOCIAL COMMUNICATION – LONDON

Please join us, along with Connie Ferri and Stephanie Muir-Derbyshire, Speech-Language Pathologists from Parkwood Institute, to talk about navigating social communication after an injury and how to answer tough questions. Light lunch will be included.

Date: Monday, November 19

Time: 11:45 am – 12:45 pm

Location: Parkwood Institute,
550 Wellington Rd, Room 4AE-186, London, ON

For more information contact:

Julie Watson, Peer Support Co-ordinator
(T) 519-433-2331, Ext. 102
(E) julie.watson@sciontario.org

FOOT CARE – BARRIE

Please join us as Kathy Shannon discusses all things foot care! From toenail care and swelling to correct fitting shoes, we will cover everything from heel to toe!

Date: Wednesday, November 28

Time: 2:00 – 4:00 pm

Location: Ed Gilbert Room, 345-80 Bradford Street, Barrie ON (enter through Door #5)

RSVP: Sarah Mueller, Peer Support Coordinator,
(T) 705-726-4546, Ext. 221
(E) sarah.mueller@sciontario.org

PEER CONNECTIONS: LOVE, SEX & RELATIONSHIPS – TORONTO

Please join us as we explore the world of love, sex and relationships with an SCI. We will touch on topics like the importance of an intimate relationship and reproductive health. Bring your questions and share your experiences!

Date: Thursday, November 29

Time: 6:00 – 7:30 pm

Location: Lyndhurst Centre, 520 Sutherland Dr., Toronto, ON,
Patient Cafeteria

For more information contact:

Nouma Hammash, Peer Support Coordinator
(T) 416-422-5644, Ext. 222
(E) nouma.hammash@sciontario.org

MARK YOUR CALENDAR

Join us for the 19th annual Ski and Snowboard Day at Craighleith Ski Club on **Thursday, February 14, 2019**.
Learn more at sciontario.org/skiday

Below: Team Rolling Thunder.
Right: Spinal Cord Injury Ontario
staff members at the start line.



2018 Scotiabank Toronto Waterfront Marathon Success!

It might have been freezing and there were rumours of snowfall, but that didn't stop a brave group of Spinal Cord Injury Ontario supporters from hitting the streets of Toronto on Sunday, October 21, to take part in the Scotiabank Toronto Waterfront Marathon races.

More than 40 people chose to represent Spinal Cord Injury Ontario in either the 5k, half or full marathon and in doing so they raised thousands of dollars and a great deal of awareness for the work that we do.

After the races, our athletes joined us at **Black & Sutherland LLP's** offices for a well-deserved post-race party. A delicious brunch of bagels, muffins, fruit and lots of juice and caffeine was served up by our kind sponsors and attendees were enchanted by the magic courtesy of illusionist **Aaron Paterson** and the soulful sounds of **Dan Walsh** and **Mark Wilson**. It was also great to see so many young faces at our craft corner! We were thrilled to have had many members of our community come out to support us.

A huge congratulations to our racers, runners, and rollers including but not limited to: roller Chris Stigas and his network who raised a whopping \$5,858; Team Rolling Thunder from Burlington – roller Brian Campbell and wife Claire, their

family and supporters who raised \$1,895; roller Beverley Davis, her sister Valarie and her family who raised \$1,410; and the Black & Sutherland LLP team who raised \$1,160.

Thanks also to all of the Spinal Cord Injury Ontario staff members who walked and rolled with us again this year.

We had prizes for participants and fundraisers so congratulations to our raffle winners...

- The three \$25 Cineplex gift cards door prizes for those who attended the After Party go to: Claire Campbell, Alice Yuan, Marco Petrovic.
- The raffle prize for our fundraiser who well extended the \$150 mark to receive a \$75 VISA gift card was: Valerie Davis.

We want to extend a special thank you to racer Lynn Turnbull and Black Sutherland LLP for graciously hosting our inaugural Scotiabank Toronto Waterfront Marathon After Party. ●



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MORE ABOUT THE SCOTIABANK TORONTO WATERFRONT MARATHON

"We are thrilled with the turnout at this year's Scotiabank Toronto Waterfront Marathon and thank all the runners for joining us," said Clinton Braganza, Senior Vice President Marketing at Scotiabank. "On top of the amazing athletic accomplishment of finishing a marathon, runners have also raised funds for a variety of important charities, through the Scotiabank Charity Challenge, including organizations committed to helping young people in the community reach their infinite potential, a key priority for Scotiabank."

An IAAF Gold Label race, the Scotiabank Toronto Waterfront Marathon is Canada's premier, big-city running event, the Athletics Canada National Marathon Championships, the World Masters Athletics Marathon Championships and the Grand Finale of the 8-race Canada Running Series. This year the race attracted 25,000 participants from 70 countries and raised \$3.5 million for nearly 200 charities through the Scotiabank Charity Challenge.

The Scotiabank Charity Challenge is a turnkey fundraising program that provides a simple and effective way to support local causes that make a big difference in people's lives. Participating charities keep 100 per cent of the proceeds raised, as Scotiabank pays for all transaction and credit card fees. Participants who raised \$2,500 as part of the Scotiabank Charity Challenge will receive 1000 SCENE® Points. ●

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**SPINAL CORD
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By Jeffrey Kerr

HOUSE HUNTING FOR A VISITABLE HOME

Whose house for the holidays? This is a question I like to ask to illustrate the importance of a visitable home.

For many people, particularly for readers of *Community* magazine, family gatherings happen at a location that is accessible to all guests. This was certainly the case for many years at my family get-togethers as we always included my Aunt Jeane in our celebrations. Because she had MS she used a wheelchair for mobility and that meant we needed to gather at a home that had an accessible entrance and accessible main floor bathroom.



A visitable home is exactly what my clients Lauren and Alex are house hunting for. Lauren's brother Paul was recently in an accident that resulted in quadriplegia and Paul needs to use a power wheelchair for mobility. Lauren and Alex currently live in a multi-level townhouse with stairs to the front entrance. It's not accessible for Paul, who prior to his accident spent a lot of time at their home, especially during the Blue Jays season.

Lauren and Alex want to continue to host family gatherings that include Paul and his partner Aimee. They've made the decision to purchase a home that is already wheelchair accessible or can be renovated.

In my Spring 2015 article I introduced the concept of visitable homes. To recap, there are three basic elements to consider:

1. An entrance way at the front, side or back of the home that is free of steps.
2. Wider doorways – at least 36 inches – and clear passage from room to room on the main floor.
3. A powder room or main bathroom that can be accessed by visitors who use mobility devices.

A mechanical lift is often the only option when houses are close together and lot sizes are small. Landscaping can be utilized when there is enough outdoor space around a home. (For more info on entrance solutions please see my article "Roll On In" published in *Outspoken!* Winter 2016.)

In condominium buildings, an entrance solution can be achieved with proper landscaping and automatic door operators. (Please see my article "Opening Doors" in *Outspoken!* Spring 2018 for more info on door operators.)

Once inside, a visitable home needs a main floor bathroom. However, finding a home with one can be a challenge. And if there is a main floor bathroom, they are often very small and tucked away, and rarely large enough for a person using a wheelchair to access. In Paul's case there also has to be enough room for the person assisting him. This is when some creative solutions may be necessary.

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Left: Lubna and her husband Samir with their newborn daughter Zara and son Zayed
Above: The happy family now all grown up.

Dream Delivered

By Nancy Xia, Community Resource & Education Assistant

Lubna Aslam works for Spinal Cord Injury Ontario as an Employment Counsellor. Her kindness and warmth is always appreciated by her colleagues and clients. She is a great cook and her dish is always a great hit during each pot-luck luncheon. She often talks about how her children help her in the kitchen and enjoy making all kinds of food with her. When she shared her story with me about being a mother, I thought it was so powerful that I just had to share it with you.



Lubna always had a strong maternal instinct. Ever since she was little, she'd ponder with joy about having her own family and being a mother one day. When she was 18, her mother found out that she was pregnant. When her brother was born, he invoked strong maternal feelings in her and she enjoyed caring for him, and giving him all the attention she could. When he was a bit older, he was diagnosed with autism. This familiarized her with the perceptions of parenting challenges and the power of unconditional love.

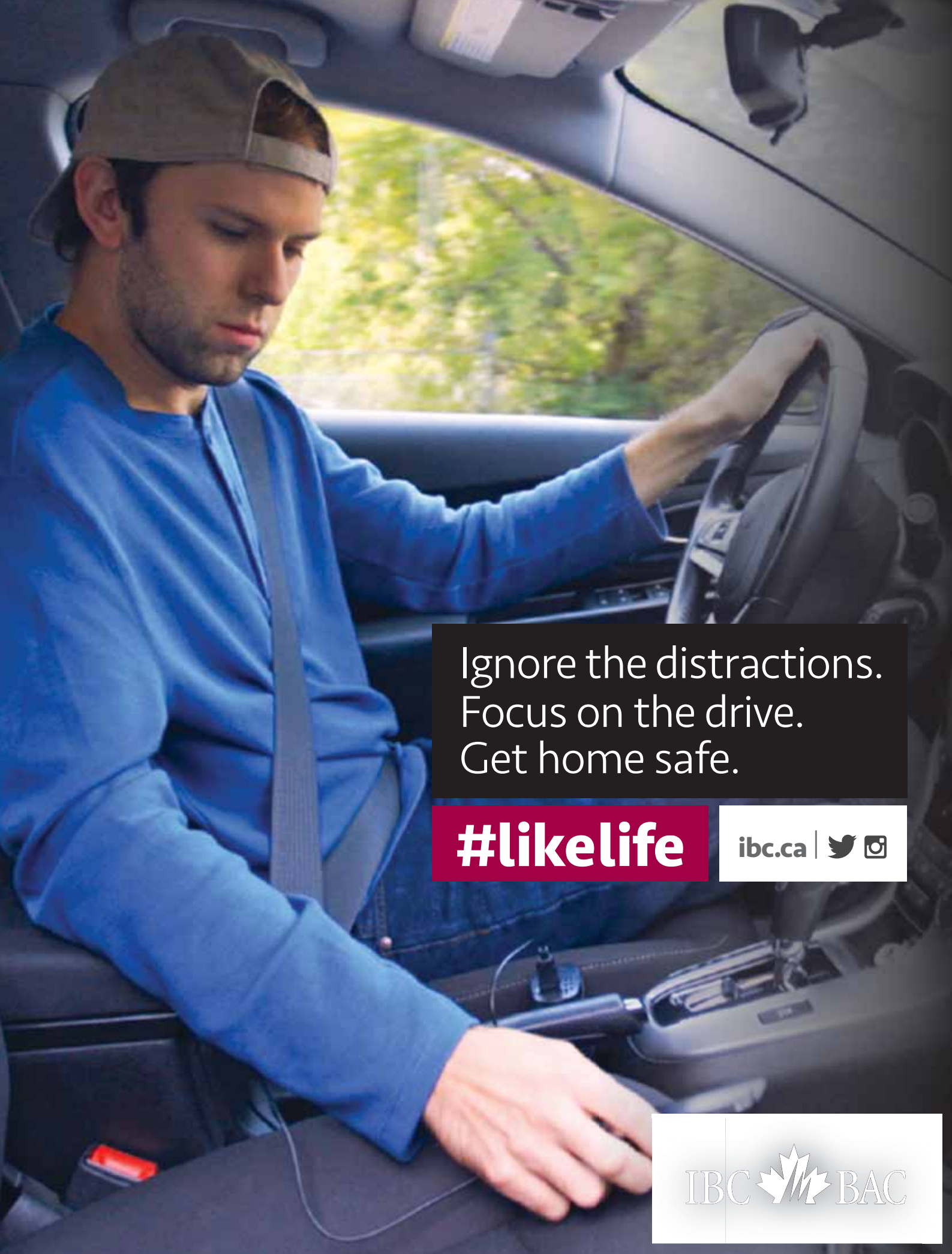
Fast forward to age 22, Lubna married Samir Umer. They went to the same high school together in Kuwait and had been best friends since they were 15 years old. Her dream of being a mother was about to become reality when she was pregnant with their first child at the age of 25.

However, when the fetus was only six-weeks old, she was in a severe car accident where her SUV rolled over and she sustained a spinal cord injury at the level of T10. She had a miscarriage at the same time. It was absolutely devastating.

The months following the collision were the darkest time in their lives. She had three unsuccessful spine surgeries in Saudi Arabia. It wasn't until September 2002, that her condition was finally stabilized after receiving a fourth surgery in the Mayo Clinic in United States. During rehab, besides grieving over the

loss of her baby, Lubna was struggling with the loss of her bodily functions and issues with her self-image. She went from feeling desirable to feeling disposable. Her lack of experience in bladder management intimidated her when she thought about being intimate with her husband again. Meanwhile, Samir was coming to terms with the realities of Lubna's disability and the uncertainty of their future. While Lubna had some levels of peer support, her husband was all alone fighting his own battle. Gradually, they were separated by an invisible barrier.

Fortunately, Psychologist Dan Rohe at the Mayo Clinic came to their aid. He played

A young man with a beard, wearing a blue long-sleeved shirt and a grey baseball cap, is driving a car. He is looking down at a smartphone in his left hand, which is resting on the center console. His right hand is on the steering wheel. The background shows a blurred green landscape, indicating the car is in motion.

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a key role in helping Lubna understand that she was not a compromised version of her previous self. A book called *Enabling Romance* by Ken Kroll and Erica Klein was tremendously helpful in giving her knowledge and guidelines on how to restore her sexuality. About three to four months post-injury, the couple finally had their “first time” post injury. Lubna says she felt like a virgin, insecure and nervous. She was preoccupied by the possibility of incontinence. Samir was also tense and scared of hurting her. However, it was the first step towards rebuilding their relationship and rediscovering each other emotionally and physically.

During the first-year post injury, Lubna was working really hard at regaining her independence. She learned to do all her self-care, she was proficient in the kitchen, she got her driver’s license, and she was socially active. Lubna was also helping her sister-in-law take care of her two-year-old niece while her sister-in-law was studying. This gave her a lot of confidence in believing that she would be able to care for her own children one day.

Thankfully, most spinal cord injuries do not affect a woman’s chance of conceiving and giving birth and in October 2003, a neuro surgeon gave her the green light to conceive again. Before long, they were ecstatic to find out that she was pregnant. Challenges quickly followed as her weight gain was rapid; her doctor needed to frequently monitor her blood pressure and sugar level. Since a lot of the doctor’s examination beds were not accessible, Samir had to pick her up all the time. Transferring became increasingly taxing as she became more and more pregnant. She lost her independence to some level, but fortunately she had a good support network among all of her family and friends.

On September 30, 2004, she entered the delivery room. She was given an epidural to avoid Autonomic Dysreflexia. Though she didn’t feel pain, she could feel all the pressure during her contractions. Fourteen hours of intensive labour later, she gave birth naturally to her son. They named him Zayed. Holding the newborn in her arms, she finally felt like her life was made whole. Months following Zayed’s birth were typically stressful like it is for any new parent. He was not a good sleeper and Lubna had issues with breast feeding. Once again, her family and especially her mother-in-law stepped in and helped with laundry, cooking and other household chores. This gave her and baby Zayed time and opportunity leading to successful nursing and connecting.

In August 2005, she was pregnant again. Though the pregnancy was much harder because she was taking care of a jumpy toddler at the same time, Lubna was rewarded when her daughter Zara arrived as a textbook example of a “good baby,” being a much better sleeper and efficient feeder. Lubna’s wheelchair quickly turned to a stroller. Her son loved to climb onto her lap while she was holding her daughter with the other arm.

From very early on, Lubna could tell that they were very

protective of her. In one incident, they were attending a wedding. When another little boy was crawling toward Lubna and attempting to hold onto her wheel, Zayed rushed to her side and “kindly removed” the boy. He then roared with passion, “THAT’S MY MOMMY’S WHEELCHAIR!”

In 2009, Lubna and Samir immigrated to Canada. The kids were two and four at the time. When they first came to Lyndhurst, Zayed said, “Look Mom, there are so many people using wheelchairs just like you.” It was hard to tell from his tone if it was a positive observation for him. Prior to that point, she had never had a conversation with her children about her disability. It was bittersweet knowing that her son had become aware of her being different from people who do not use mobility devices.

Like most immigrants, there was a lot of adjustment in the beginning. Every time they moved to a new neighbourhood, the children became very conscious of people staring or making inappropriate comments about Lubna’s disability. They didn’t appreciate when strangers would often come up to her and ask what happened to her. At times, they would become visibly upset and Lubna had to calm them down. When Zara was nine, someone in her school said to her, “I am sorry that your Mom is in a wheelchair,” to which she had replied, “Why? My Mom is always happy.” Although quick at the comeback Zara was very troubled by the remark. Just when Lubna was struggling to find words to comfort her, her brother jumped in, “you cannot let other people’s ignorance affect your emotions, Zara!” From that point on, they were very keen on educating their classmates about people with disabilities. They would even introduce Lubna to their friends and let her answer all their questions about living with a disability.

Now that the kids are 12 and 13, they have become two very capable youngsters. Lubna trains them on all life skills like cooking, washing dishes, doing laundry, and other chores around the house. They hold on to her push handles when they cross the road together. They still sit on her lap when sharing a secret. Compared to kids of a similar age, they are more sensitive and empathic to the needs of others, especially people with disabilities. They don’t judge people by their abilities or appearance and they stand up for injustice and inequality. They are also accessibility experts. Zayed would always go ahead to look for ramp or elevator to get into a building. Zara would always check out the washroom to make sure it’s accessible. They are not afraid to speak up to the staff or a venue’s manager about what needs to be done to meet the Accessibility for Ontarians with Disabilities Act (AODA) standards. They are truly Lubna’s pride.

Having a disability did not deter Lubna from enjoying motherhood to its greatest level. Though it was difficult in the beginning, the intense labour did not last long, and the fruitful rewards seem to be everlasting. She hopes that her experience will help newly injured women believe that their disability does not compromise their desirability and their body. They can still be the wife and the mother they may have dreamed of being. ●

Lubna was rewarded when her daughter Zara arrived as a textbook example of a “good baby,” being a much better sleeper and efficient feeder. Lubna’s wheelchair quickly turned to a stroller. Her son loved to climb onto her lap while she was holding her daughter with the other arm.



Michelle Earle:

On gratitude; adapting to change and the importance of asking for help

By Mary Dufton

Following her story in the 2016 spring issue of Outspoken! magazine, Moving Forward Day at a Time, I spoke with Michelle Earle to find out how she was doing.



Michelle continues to learn new ways to adjust to her disability and this spring, she was the keynote speaker at the Ottawa Hospital Rehabilitation Centre's Spring into Motion annual fundraiser where she shared her story of life after a spinal cord injury. We talked about her life, her work, her injury and what she does to stay healthy not only physically, but emotionally, too. It has been more than three years since she sustained a spinal cord injury at the T12 level after she lost her balance while walking down a steep incline in the dark and falling about nine feet.

Although like anyone who has sustained a spinal cord injury, there's a lot to adjust to, but day by day, life is less difficult than it was at first. Michelle finds support from her husband Michael, with whom she can talk about anything, her three children, Jasmine, Joshua and Jordan, and her large network of friends. She knows the importance of maintaining her mental health and sees a counsellor when she needs to.

She maintains her sense of independence by doing the family grocery shopping on Sunday morning, through her career as a mental health coordinator at the Ottawa Youth Services Bureau, and by teaching spinning classes at GoodLife Fitness in Orleans from her hand cycle. Fitness has always been important to Michelle so she is always looking for opportunities to try new sports like adaptive rowing and waterskiing. So

far, she has done alpine skiing from a sit ski which she liked. It gave her a sense of control; she felt part of a community event and a sense of belonging.

"Year one for me was about acceptance. I had to accept that there are things I could not do anymore. I was in mourning and experiencing a sense of loss. No more half marathons. But the question for me became — if I can't do that, then what can I do? I also felt guilty for my injury and that I was imposing on my family. I realized though that these feelings were mine and it wasn't about them but about me."

Last year, Michelle fractured her femur from doing
continued on page 45

1. Michelle and her husband on holiday in Mexico on the beach.
2. Michelle and her husband Michael with their son Joshua at his highschool graduation.
3. At daughter Jasmine's graduation from university with her son Jordan and her husband, Michael.
4. Michelle with the members of her spinning class.

SPINAL CORD INJURY ONTARIO'S Young Professionals Board

Our Young Professionals Board provides an opportunity for young professionals to support the mission and vision of Spinal Cord Injury Ontario, by acting as ambassadors, developing leadership skills and sharing technical knowledge and by engaging other community members in becoming the next generation of Directors.

The purpose of creating the Board was to reach a young population of community leaders to engage them in the Board development process, build future leaders and support fundraising efforts of Spinal Cord Injury Ontario. Although the Young Professionals Board might be distinctly separate from the full Board of the organization, it is fully accountable for representing the nonprofit with integrity and respect.

Members of the Board are dedicated and are working hard to further our mission. In this and future issues of our magazine we will feature their stories so you will get to better know them and the great work they are doing. Here are profiles on two of our Young Professionals Board members.



Omar Ha-Redeye

I'm a lawyer and health advocate who is pleased to be on the Young Professionals Board.

I started out my career in clinical health care as a nuclear medicine technologist. I had a sports injury in 2004 which gave me significant mobility problems, which first raised my attention to accessibility issues. I embarked on further studies in physiotherapy, but ultimately opted to complete a law degree. I currently have a very small legal practice, where part of my focus is on health law, disabilities and discrimination in the workplace.

In addition to participating in Spinal Cord Injury Ontario events, I also sit on our advocacy committee. In this role, we look at laws and regulations and broader governmental actions, to ensure that people with spinal cord injuries receive appropriate care and supports in the community.

My involvement with Spinal Cord Injury Ontario is one of the most important ways I ensure that we continue to have a vibrant society that is inclusive to all, and provides me an outlet to push for further change.



Leigh Armstrong

I previously worked at Travelers Canada (formerly Dominion of Canada General Insurance). In my role as Marketing Manager I worked on many Spinal Cord Injury Ontario events as the organization was Travelers' charity of choice.

I was responsible for the annual Travelers Curling Club Championship fundraiser event. Over my time at Travelers I led a team to raise \$1.3 million dollars for SCI research, programs and services. Through these events and others, I gained a clear understanding of the organization. For the Young Professionals Board, I bring the skill-set of marketing, communications and events experience.

I have a Degree in Marketing and studied at Fanshawe College and Western University. I am also a nationally competitive curler throwing lead rocks for Team Sherry Middaugh (Oakville) on the World Curling Tour. In 2013, I received the Jim & Sharon Vigmond Philanthropy Award from Spinal Cord Injury Ontario. ●



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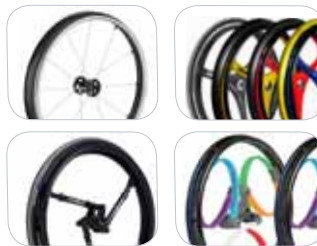
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How Could Acupuncture Help Spinal Cord Injury?

By Linda M. Rapson, MD, CAFCI, Assistant Professor, DFCM, University of Toronto, Affiliate Scientist, Toronto Rehabilitation Institute, Medical Director, Rapson Pain and Acupuncture Clinic

An interesting review paper on this topic was recently published in the peer-reviewed *Journal of Acupuncture and Meridian Studies*. The title is "Spinal Cord Injury: How Could Acupuncture Help?" It is freely available online at <https://www.jams-kpi.com>.¹

When acupuncture was introduced to Toronto's Lyndhurst Hospital in 1992, the Medical Advisory Committee wisely restricted our treatment to the management of pain. Obviously, if we were to try to cure paralysis with our needles, everyone would want treatment. We had no such intentions and our outcomes treating pain were good from the start. We reported results for our first 61 patients to the ASIA meeting in 1995, reporting that 75% had good to excellent results with zero complications. In 2003, we published a case series reporting that 24 of 36 individuals with below-level central neuropathic burning pain responded to an acupuncture protocol of four points on the midline of the head stimulated electrically.² We have done a randomized trial using this treatment and are writing up the results.

Since the 1970s, when I started learning acupuncture, basic research into what happens when thin, solid, stainless steel needles are inserted into particular points on the body has revealed many intriguing scientific facts that may explain and support clinical claims. For instance, animal research showing that electroacupuncture (EA) can improve motor neurons in various ways offers scientific explanations for why improvement of function in SCI might be possible.³ However, to be clear, that does not mean that acupuncture can cure paralysis.

Over the past decade or so, the scientific literature includes clinical trials that suggest that acupuncture has

potential to manage various post-SCI complications and improve outcomes. A "more rigorous systematic review and bias-adjusted meta-analysis of clinical studies," published in 2015, in the *Journal of Neurotrauma* reported that, "Pooled analyses showed that acupuncture may have a beneficial effect on neurological recovery."⁴ However, the authors also state, "The studies were generally of poor quality and publication bias favouring positive studies was evident."

This is not to suggest that acupuncture has been proven to improve function in SCI. However, there is basic scientific research that shows complex effects using acupuncture as a treatment tool in spinal cord injury.

Clinical trials of various qualities indicate that acupuncture has a role to play in the management of several complications of SCI, including neurogenic bladder and bowel, in addition to pain. These common problems are the focus of this article.

Neurogenic bladder affects 69-92% of patients with SCI and neurogenic bowel affects 50%. Since the advent of the Magic Bullet, bowel treatments may have become less onerous, but the cost of intermittent catheterization (IC) equipment and bowel meds are still issues for both consumers and insurance companies.

A recently published study by the China Academy of Chinese Medical Sciences in Beijing involved 16 individuals with acute or subacute SCI due to transverse myelitis (TM).⁵ TM is an inflammatory disorder of the spinal cord that produces symptoms and signs of SCI and can lead to complete paralysis. They all had stable bladder dysfunction caused by the TM and received electroacupuncture treatment bilaterally to three acupuncture points over their sacrum. The treatments were done five times a week for four weeks, three times a week for the next four weeks and participants were followed up for six months.

Results were carefully monitored using a variety of measures. Pre-treatment, all participants had abnormal voiding that required assisted measures to empty their bladders including abdominal pressure or intermittent catheterization (IC) >50% of the time.

¹ Fan et al. *Spinal Cord Injury: How Could Acupuncture Help?*. *J of Acupuncture and Meridian Studies* 2018;11(4):124-132.

² Rapson LM, Wells N, Pepper J, et al. *Acupuncture as a promising treatment for below-level central neuropathic pain: a retrospective study*. *J Spinal Cord Med*. 2003 Spring;26(1):21-6.

³ Fan et al. pp 125, 128-129.

⁴ Ma R et al. *The impact of acupuncture on neurological recovery in spinal cord injury: a systematic review and meta-analysis*. *J Neurotrauma* 2015;32(24):1943-57.

⁵ Wu J et al. *Effects of electroacupuncture on bladder and bowel function in patients with transverse myelitis: a prospective observational study*. *Acupunct Med* 2018;36:261-266.

⁶ Wong AM et al. *Clinical trial of acupuncture for patients with spinal cord injuries*. *Am J Phys Med Rehabil* 2003 Jan;82(1):21-7.

⁷ Liu Z et al. *Electroacupuncture improves bladder and bowel function in patients with traumatic spinal cord injury: results from a prospective observational study*. *Evid Based Complement Alternat Med* 2013; 543174.

After the eight week series of acupuncture treatments, 5 of 16 patients resumed normal voiding, 6 of 16 were able to void with pressure on the bladder instead of IC and 5 had no change. Those who used pressure on the bladder were tested for reflux by voiding cystourethrography and none was found. Nine patients had provided post-void residual urine volume (RUV) data at baseline that ranged from 33-600 ml. Three had normal RUVs at the start (33-80 ml) and 6 had abnormal levels (150-600 ml). Post treatment all were normal (12-20 ml and 25-100 ml).

Neurogenic bowel, a condition that affects more than 50% of patients with SCI, is a problem for many individuals. A 2003 paper from Taiwan reported a randomized clinical trial involving 100 acute traumatic ASIA "A" or "B" SCI patients who got either acupuncture and regular rehab therapy or rehab alone.⁶ The acupuncture was initiated in the ER or soon after admission. It consisted of a combination of four surface electrodes (TENS) on acupuncture points on the hands and ankles and needle treatment of four acupuncture points related to the spinal cord in the outer ears. Assessments at admission, discharge and one year post-injury showed significant improvements in the acupuncture group overall, with a higher percentage of patients in the acupuncture treatment group recovering to a higher ASIA impairment level than they had at the beginning. There was also a statistically significant improvement in "bowel functional independence measures" one year after SCI, compared with the no acupuncture group.

An observational study of 14 chronic patients with SCI showed that after two months of acupuncture with electrical stimulation, 4 of 14 patients resumed normal bowel movements ($P=0.025\%$), 5 reduced dependence on "supplementary defecation methods" and 5 had no changes.⁷ As with all of the studies, there were no complications from the acupuncture treatments.

Back in the '90s, at my clinic, we treated a man with a complete SCI, using a neurogenic bladder acupuncture protocol developed by Dr. Sona Tahan, the Director of Education for the Acupuncture Foundation of Canada and Dr. Richard Cheng, a urologist who was studying acupuncture with AFC. Our patient had a baseline urodynamic study at Lyndhurst's Robson Clinic prior to treatment. After a few acupuncture treatments, the patient noted significant changes and his next scheduled urodynamic test showed improvement in several parameters.

The Tahan bladder protocol uses points that stimulate the sacral nerves to the bladder and some traditional acupuncture points. It has been used clinically with success in Canada and abroad for more than two decades, mostly with non-SCI bladder dysfunction.

In fact, one of the traditional acupoints, just above the ankle, is now used by urologists for irritable bladder and is referred to as the "posterior tibial nerve stimulation point" rather than "Spleen 6" or its Chinese name, "San Yin Jiao".



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MS Ride 2018

FOR THOSE I LOVE AND RESPECT

It was 1979. I was 14 years old and my sister was 11. Our family was turned upside down when I would watch my Dad carry my Mom up and down the stairs and throughout our house. One day her legs ceased to move and we could not understand why.

My Mom was only 34 at the time and seemed to be in great health. It would take more than four months for her to regain function in her legs again. Doctor's appointments lead to a diagnosis of Primary Progressive MS after a spinal tap. I remember how distraught my parents were after consulting with an MS specialist who basically said, "you have MS, so deal with it and you will possibly be using a wheelchair for the rest of your life."

It would take close to two years before my Mom could return to work, and the threat of the diagnosis seemed at bay. This terrible disease would return again in her hands. She had to be fed, showered and dressed. My Dad never wavered throughout and would show me what "for better or worse" meant, and we worked together as a family. Once the function returned to her hands, my Mom was back at work and life seemed to fall back into place with her unwavering determination.

Some 20 years later at the age of 34, I too would be stuck a blow that would completely change my life forever. I would be fighting for my life with major head trauma and spinal cord injury in 1999 after falling off a roof. Now I was embarking on a journey where my legs ceased to move.

As I was battling back to my new normal, my Mom was dealing with the ongoing effects of her progressive diagnosis. In 2009, she underwent a hip replacement followed by a knee replacement in 2010. The irony was she was learning from me and me from her. From the day I entered rehab to the day I left and beyond, I challenged myself just like I knew she challenged herself. Through all the pain and agony, we both strived to be the best we could be against all odds. Just as there is no magic pill for regeneration from a spinal cord injury there were no medications or support for MS patients like there are now. We were both left with the only thing we had, being our iron will never to fail.

When I moved to London in 2015, I would become friends with two more people dealing with the effects of MS. Sandy is an amazing woman with a smile and attitude like no other. I met her after being invited to a music circle she hosts every second Sunday in her home. Her MS was so progressive that she has lost all function from her neck down, yet she is a funny, outgoing and takes it all in stride. Sharon lives in the same building and uses a power wheelchair. She too is a bubbly outgoing person who does not let her MS deter her as much as possible.

Over the years I have participated in many endeavours that required stamina and believing in my abilities. As fate would have it I was at a restaurant in Alton, Ontario, celebrating Thanksgiving with my family at Rays 3rd Generation Bistro. There was a duo playing and I was asked if I would like to play a few songs on their break. I did and afterwards spoke to a woman who really enjoyed my songs. Little did I know that friendship would blossom. She is very athletic and is a long-time horse enthusiast with three horses of her own. We stayed in contact and as time went on Sue and I decided to participate in the MS ride from Grand Bend to London and back. Her enthusiasm was contagious and before I knew it I had clocked more than 800 training kilometres with her along with over \$2,000 in donations! I was doing this for my Mom, Sandy and Sharon, along with all those dealing with the most prevalent disease in Canada. More people are diagnosed with MS here than in any other part of the world.

As the July 28 race day start was approaching we were keeping a close eye on the weather forecast. This summer had been very hot, humid and unstable but the weather gods seemed to be smiling on us, and a more favourable weekend was predicted. We left London very early on the 28th and arrived at the Grand Bend Motorplex to a cool, brisk wind along with a buzz of activity from 1,466 fellow riders and volunteers.

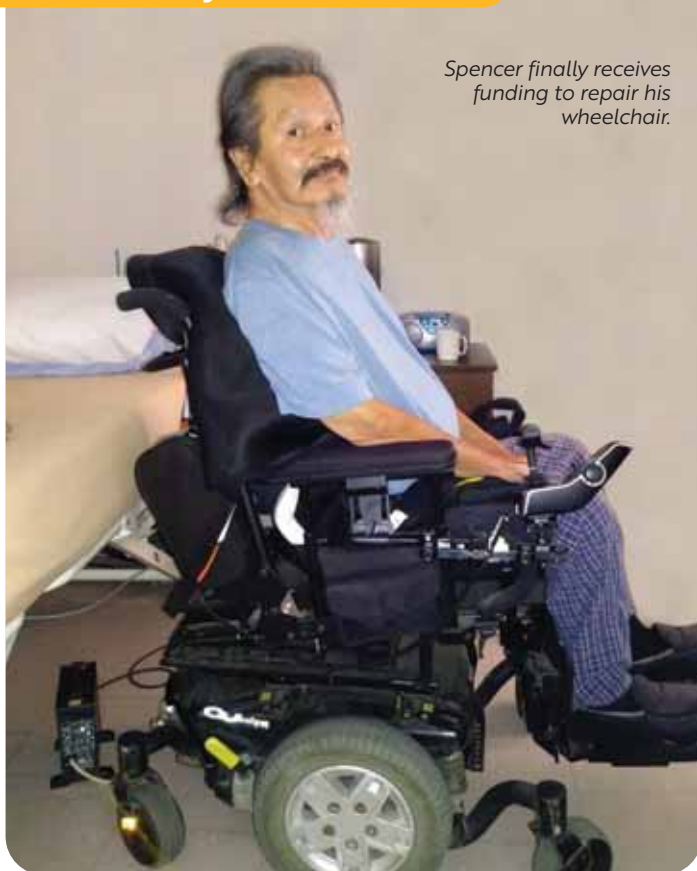
Sue and I had pre-registered, so we could arrive at a more leisurely pace. Team Cowbell was the largest team and would be first to begin the event leaving at 7:30 a.m. I was immediately struck by how well the event was organized. Our luggage was tagged and would be awaiting us at Western University in London. Food and beverages were readily available. No detail was overlooked as we prepared ourselves to begin our journey. We both felt good and the enthusiasm of our fellow riders was contagious. We moved to the start line and after being given some basic ground rules our group departed.

As we left the Motorplex parking lot and onto the road, I could feel the adrenaline working through my arms and torso. We paced ourselves at a good attainable speed and enjoyed the

continued on page 44



As I was battling back to my new normal, and my Mom was dealing with the ongoing effects of her progressive diagnosis. In 2009, she underwent a hip replacement followed by a knee replacement in 2010. The irony was she was learning from me and me from her.



Spencer finally receives funding to repair his wheelchair.

Dreamcatcher Charitable Foundation

By Robert Murphy, Regional Services Co-ordinator

In a previous issue of our magazine, I shared with our readers the many requests for support I receive as a Regional Services Co-ordinator. The nature of these requests varies but a consistent theme remains: clients require financial support in order to obtain much needed assistive devices and equipment.

In the area I serve, the Hamilton Niagara Haldimand Brant region (HNHB), we are fortunate to have access to some unique funding sources; however, given very strict eligibility criteria, many clients we support are financially ineligible for these programs. For some, their income is too high and for others they may have transitioned from one system of support, namely Ontario Disability Supports Program (ODSP), and are now receiving Canada Pension Plan (CPP) and Old Age Security (OAS). While a case can be made for income support for equipment costs even when an individual transitions from ODSP to CPP/OAS, the likelihood is they will no longer have access to the coverage and benefits offered through ODSP. For Spencer Waboose, this is exactly what happened.

Spencer came into financial need after his powerchair would no longer hold a charge. His chair required new batteries and as an adult over the age of 65 with low income, he did not have the financial resources to pay for batteries. It is also important to note that had Spencer been living in the "community" rather than long-term care (LTC), he would have been eligible for funding through a uniquely City of Hamilton program. The City of Hamilton's Special Supports Program provides a wide range of health-related benefits to City residents living independently in the community to improve their quality of life, health, wellness, safety and self-sufficiency. As a resident in LTC, Spencer would not be eligible for coverage and he would have to look elsewhere for funding.

After an exhaustive search, leaving no stone unturned, we reached an impasse: there simply were no sources of funding to repair his wheelchair. That was until Spencer mentioned Dreamcatcher. While I was aware of what was colloquially referred to as the Dreamcatcher Fund, it did not occur to me to apply on his behalf as I understood their mandate focused on Aboriginal Youth. What I would learn is the Dreamcatcher Charitable Foundation provides life-changing opportunities to Aboriginal People through the provision of financial grants.

Furthermore, the Foundation addresses situations that are unique to the First Nations community and provides financial assistance to eligible applicants in the areas of: Arts and Culture, Education Support, Health Support and Sports and Recreation. As Spencer identifies as Pic Mobert First Nation, we were able to quickly complete the application which is available online. In two weeks, he received a letter notifying him that his application had been approved!

Since delivery and installation of the batteries, Spencer has been able to resume activities of daily living. He is very thankful for the financial support and wants everyone to know about the good work that is being done at Dreamcatcher. As a RSC, it was refreshing to work with an organization that's responsive and helpful at the application stage. The process was seamless and the turnaround time for a response was quick. ●

For more information on Dreamcatcher Charitable Foundation:

Telephone: 905-768-8962 • Toll Free: 1-866-508-6795
Fax: 905-768-8963 • (E) info@dcfund.ca
(W): <http://www.dcfund.ca>

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Learning to Mono-ski after his SCI..

The #ResilientONES

By Sebastian Leal Buffington

"I was in full survival mode, and I knew that in order to survive I had to stay positive."

I am 26 years old and I live in Mexico City. Roughly two years ago I was in a skydiving accident that left me with paralysis from the chest down. It took me several months to really understand the seriousness of my injury. I was always expecting to recover motor movement as time went by and that never really happened.

Naturally, we compare ourselves to others, and seeing the rest of my peers at the rehabilitation centre advance and get motor movement back, while I did not, was difficult emotionally to say the least. However, just as we compare ourselves to those who are more fortunate, we should never forget about those who are less fortunate than ourselves. Despite my limitations, I always tried to remember and focus my mind on everything that I still had, everything that I still would be able to do even if I would be using a wheelchair for the rest of my life.

I realized that I could not be angry at the person who collided with me and caused my injury. If I went down that path of sorrow and depression I could go so deep that I might not be able to come back from it and recover my sanity and mental health. And I realized how important a role sanity and mental health would play in my recovery.

I needed to let go of the past and focus all my thoughts and energy on the present, and stay positive. Thinking back, I think that having a smile on my face and staying positive was what helped me get through the toughest moments. What helped me stay positive, despite my prognosis that it was 96% likely that I would never walk again, was being thankful for my family, for my life, and hope for a better future. I was in full survival mode, and I knew that in order to survive I had to stay positive.

It was the worst time of my life, but also one that would force me to adapt, grow, and become a better, stronger person. I had the wonderful opportunity to spread positivity and light amidst the darkness that surrounded us all at the time and that was something else that kept me going. Something that I was gifted with after my injury was being able to change other people's lives by setting an example in terms of confidence,

positivity, resilience and never giving up. It's been more than two years since my injury and I still do some type of therapy almost every day to keep my body healthy and ready for when the time comes that SCI can be cured. It's so exciting for me to think of the future. We live in an age of technological advancement where everything is possible. Someone once told me, believe your diagnosis but not your prognosis. The world we will live in ten years from now, 20 years from now will be so unfathomably different with technology that it makes me excited and hopeful.



First time standing using braces.

Advice for those who are in a difficult moment in their lives, is to stay positive at all costs, and never lose hope. You might not see the light today, but you will if you maintain a positive mindset. Thanks for listening.

To stay connected with Sebastian and see more of what he is up to visit his Instagram page @sebasleal.

See more about #Resilient Ones on page 45



WHEN A PERSON IS INJURED, THE COST OF QUALITY CARE ADDS UP.

Your clients cannot afford to compromise on their recovery, even when insurance limits are capped. We fight to ensure that your clients get funding for the care and treatment that they need.



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During my years of diving in different parts of the world, I have had many adventures with Hubert Chretien of Freedom at Depth on different wrecks in the St. Lawrence River. Our main departure points would be from Prescott or Brockville.

St. Lawrence Adventures 2018

By Wayne MacDonald

These dives were typically low visibility with a high current and varying degrees of hazards. That aside, it was the history of what we descended to that was always intriguing. Most of the wrecks sunk in the 1800s and onwards. I also liked the fact that this was more of technical diving which helped increase my skill level and sensibility under harsher conditions.

This summer we would have a set of dives leaving from Brockville and a set from Rockport. While waiting for Hubert and other divers one day, I wheeled through the Canada's first railway tunnel in Brockville. The tunnel was built between 1854 and 1860 to allow the fledgling Brockville and Ottawa Railway to connect the Brockville industrial waterfront area to the outlying areas lying between the St. Lawrence and Ottawa rivers. The way they have transformed this tunnel is an experience in itself. While music is playing, a varying array of colour changes take place from one end to the other. It's a photographer's paradise and the squeal of kids echoes through this impressive piece of history.

Once everyone arrived, we left the dock to see the wreck of the Dalriada. This would be one of my most challenging dives to date. My dive partner Kat and I would descend from the surface down 20 feet to a rock ledge. From there we would use a line that went from the rock ledge to the wreck

below at approximately 70 feet. The factors in this dive included an extremely high current and low visibility due to an overcast sky above. When the wreck came into view at the stern, its props were massive. We would make our way into the wreck with the current remaining strong. We soon realized that my arms were not strong enough to continue penetrating the wreck, so we converted to a drift dive. Upon ascent to the surface we were greeted by a torrential down-pour. It's never easy on the St. Lawrence.

I would do a second set of dives departing from Rockport on September 6 and 7. Rockport is located off the 1000 Island parkway east of Gananoque. It has been a port since the late 1700s. For decades boats were built in Rockport; from small wooden St. Lawrence skiffs to large tour boats used on the St. Lawrence River, in Canada's capital city Ottawa on the Rideau and Ottawa Rivers, and as far away as Banff National Park in Alberta. The area is still famous for boat building, as the industry is producing ice boats that make winter travel to local island homes possible. It now hosts tour busses full of travellers that will take one of the many available tour boats.

I arrived on Thursday the 6th to a bright sky and the river looked calm. The interesting part of the dives I would be part of over the next couple of days would be that they were in the U.S. waters of the St. Lawrence River. That would mean clearing American customs at Boldt Castle located on Heart Island before going to our wreck site. The other sad factor was that a boat had capsized in the area and OPP boats, divers and helicopters were scouring the area for a missing 11-year-old boy. When we departed the OPP dive boats had moved upriver. I privately paid my respects as we made our way to the castle. During that ride, we would pass the shortest bridge between Canada and the United States joining two islands. I would also be seeing Boldt Castle from a different perspective this time.

During the previous summer of diving I had treated myself to a helicopter flight over the 1000 Islands which included seeing the castle from the air. George Boldt managed the Waldorf Astoria in New York City as well as the Bellevue Stratford in Philadelphia. The family spent many summers on the island and the quaint cottage expanded over the years. In 1900, George began a project to build one of the largest private homes in the U.S. He hired the architectural firm G. W. & W. D. Hewitt and hundreds of workers to build a six-story 'castle' as a present to his wife. There are also four other masonry structures on the island. The construction of Boldt Castle ceased abruptly in early 1904 after the death of Boldt's wife, Louise Kehrler Boldt. George Boldt never returned to Heart Island, leaving this structure for 73 years as a monument of his love.

The 1000 Islands Bridge Authority acquired Heart Island and the nearby yacht house in 1977 for one dollar. Under the agreement all revenues obtained from the castle operation would be applied towards its restoration. This would allow for the preservation of the island and for the enjoyment of future generations. In the two decades after acquiring the property, the 1000 Islands Bridge Authority spent some \$15 million for restoration and improvements and work continues annually. As we got closer to the mammoth struc-

ture it was clear this gift was something to behold.

After clearing customs, we would make our way to the SS Keystorm, a steel freighter that sank in 1912 after hitting Scotch Island shoal. The captain and first mate were found guilty of negligence after the sinking. It is one of Hubert's and many divers favourite wrecks and is one of Ontario's premier wreck sites. Her stern rests 112 feet below the surface and her bow is about 20 feet from the surface. The other interesting feature was the air bubble located about 25 feet from the surface that has been intact since she sank in 1912.

After a relaxing boat ride and gearing up we arrived and tied off to the mooring line. Not far from us was Singer Castle on Dark Island. It had been known as the Dark Island Castle for a number of years. It was built from 1903-05 around the same time as Boldt Castle for Frederick Gilbert Bourne, president of the Singer Manufacturing Company. It is now used for private functions and has many old Singer sewing machines on display.

As I closed up my dry suit the nagging question remained, would my legs be dry after my dive. I had ankle valves installed to prevent inversion while diving. It can occur if air gets trapped in the feet of the dry suit. You could invert with feet pointing to the surface and be in an uncontrollable ascent, which is very dangerous. Hubert had a friend skilled in gear repair look at it. He determined that the valves were incorrectly installed and he reinstalled them following the manufacturer's guidelines.

Once down on the deck of the Helen C with gear checked and my dive partner Hubert in the water we descended to the Keystorm. We would spend time exploring the inner sanctums of this freighter and visit her air pocket. The current was not strong so navigation was easier. Once back on board the moment of truth would be revealed, would my legs be dry? As I peeled off the dry suit I let out a holler because my legs were dry! Hubert and I would wait for the other divers, including a diver who was blind, to descend on the America and I would phone Norm, my new hero with the good news of his repair.

On the way back to Rockport, Rhiannon Rollings who was one of Hubert's assistants explained the fascinating history about the area. Hay Island is an island where hay was grown for horses used in the American Civil War and as a landing strip for pilots training during the World War eras. Thwartway Island housed WWI soldiers suffering from PTSD and effects of mustard gas in a rehab centre that was built there. Death Dealer Island was a stronghold for the smuggling trade. Today the presence of Canadian and U.S. customs police boats is a prominent sight on these waters due to the smuggling trade. Then there is the 1000 Islands Park of which approximately 100 islands are kept as no access environmental stewardship sites. This region, the Frontenac Axis, connects the Canadian Shield from Algonquin Park in Ontario to the Adirondack Mountains in New York. Smuggling of booze, butter and horses would start at the base of Horse Thief Bay road in Rockport. Everything was shuttled over a series of islands to the U.S. mainland.

When we arrived back in Rockport our captain Vince would be the only person allowed to leave the boat. There was a phone that was connected to U.S. customs on Heart

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UTI Prevention for People with Spinal Cord Injuries

By Derek Oh, Co-founder, Szio+

Urinary Tract Infections (UTIs) are one of the most common visits to a doctor and people with SCI have an even higher risk of infection.

When bacteria enter the urethra and travel into the bladder and kidney, this causes a urinary tract infection or bacteriuria (bacteria in the urine but no symptoms). Three common reasons why people with SCI are at risk include:

1. Intermittent catheterization – constant change increases likelihood of introducing bacteria.
2. Indwelling (Foley) catheters – direct pathway enables bacteria to always be present.
3. Neurogenic bladder – lacking bladder control due to a brain, spinal cord or nerve problem.



SELF-CARE TIPS FOR PREVENTION

- Catheterize more frequently;
- Intake enough fluid for urine to be clear or lightly yellow;
- Proper hygiene by constantly washing.

TREATMENT FOR UTI

First-line treatment are antibiotics to eradicate infections. Sometimes various antibiotics may be required due to increased resistance.

PREVENTION OPTIONS FOR UTI

Doctors may prescribe low dose daily antibiotics but it's understood that antibiotics usage can lead to side effects and resistance.

For natural prevention, cranberries are accepted as the UTI prevention superfruit but it's important to note that not all cranberry supplements are made equal.

CRANBERRY PROANTHOCYANDINS (PACS)

Research has shown that proanthocyanidins (PACs) are the active component of cranberries preventing bacteria like E Coli from adhering to the urethra and bladder wall which allows them to be flushed out. Through clinical trials, 36mg of PAC (measure by BL-DMAC method) is required to effectively reduce recurrences.



"Natural products, like cranberries, can aide in reducing the number of UTI recurrences. Not all cranberry products are the same and attention should be given to those with the right amount of the active ingredient from the cranberry (Proanthocyanidins). These are still not a cure but are clinically proven to show reduction in UTIs and can help minimize the need for prophylactic antibiotic usage."

Dr. Leslie Carr, Staff Urologist, Sunnybrook Hospital, Toronto

SZIO+ 36PAC UTI PREVENTION SUPPLEMENT

Szio+ is a Canadian company that has produced a cranberry supplement with 15% concentration of PACs resulting in 36mg of PAC in each capsule taken once a day for prevention. Szio+ uses whole fresh cranberries ensuring you get the insoluble fibres (seeds, skins, pulp, flesh, etc.) providing improved bioavailability, absorption and effectiveness.

SZIO UTI TEST STRIPS

These test strips check Leukocyte and Nitrite and are designed for consumer use should they wish to check themselves. This test is simple, convenient and accurate, and similar to the dipstick found in some doctors' offices. Results are in two minutes and have easy instructions to follow. It is still recommended to consult with a physician regardless of the results.

For more information, visit www.szioplus.com or call 1-888-622-3613. ●



YOUR MOVE, ONTARIO

Raising our Voice

The more we work together for positive change in this province the closer we get to living the lives we choose.

The **Your move, Ontario** campaign that we launched in the spring for the provincial election is still going strong, raising awareness and opportunities to take action for change. Some highlights of our advocacy work over the past few months:

Connecting with your MPP

Members of Provincial Parliament (MPPs) are important champions for people with spinal cord injuries in Ontario. As a resident in your community, your elected MPP has the influence to represent you at Queen's Park. They represent your needs for accessibility and health care, as well as fair and equitable services. If you haven't already, check out yourmoveontario.ca to connect with your MPP on the issues that matter most to you.

Access to Medical Supplies

If you use an intermittent catheter on a daily basis, you know it can cost between \$4,000 and \$15,000 a year for this vital medical supply. As you read on page 4, to address this financial burden, Spinal Cord Injury Ontario is part of the provincial **Intermittent Catheter (IC) Working Group**, a forum for interested clinicians, organizations, people with physical disabilities and policymakers to advocate for appropriate, evidence-based access to ICs for Ontarians. We've recently submitted a response to Health Quality Ontario's health technology assessment on ICs and will report back on developments.

Increasing Access to Primary Care

On September 25, we hosted a certified webcast on Improving Primary Care for People with Spinal Cord Injury and Other Physical Disabilities in Ontario in partnership with the Ontario Telemedicine Network (OTN) Professional Learning Series. Our panelists shared critical information about supporting people with SCI in the community, important advocacy to improve accessibility in doctors' examining

rooms, and our direction to develop stronger services for people with SCI across Ontario.

Online with OSOT

Our own Peter Athanasopolous, Senior Manager of Public Policy and Government Relations, presented a webinar for the Ontario Society of Occupational Therapists on October 31 entitled **Amplifying the Community Voice: New Initiatives at Spinal Cord Injury Ontario**. These kinds of community touchpoints strengthen relationships and increase awareness and knowledge of our services and programs. Thanks for having us, OSOT!

Queen's Park Day – December 11, 2018

We have recently secured a Queen's Park Day for our campaign on "Access to Medical Supplies" under the sponsorship support of MPP France Gelinias (Opposition Health Care Critic). Details to come. ●

KNOWLEDGE IS POWER

We are almost set to launch a new e-learning platform – both for our community and a wider audience. The plan is an expanded and professional set of online courses, starting with topics most relevant to our community's needs: **Choosing a Wheelchair; Nutrition; Sexual Health; Vehicle Modification; and Pain Management**. In collaboration with our delivery partner, Embodia, we will launch the series of courses on Sun Life Financial's new health and wellness platform for people with disabilities looking to increase their personal health, well-being and independence. We will communicate instructions on accessing these modules, which will be available without charge to our clients. Watch this space for more updates on this exciting venture! ●



Celebrity fashion designer BECOMES A PIONEER OF ADAPTIVE CLOTHING



In 2009, Izzy Camilleri made a major shift in her business that likely puzzled her peers in the fashion world. But Izzy knew that she was doing something important.

One of Canada's leading innovative and celebrated fashion designers, Izzy has designed award-winning clothing for national and international clients for over 33 years. She has worked with a diverse mix of celebrity clients including David Bowie, Angelina Jolie, Daniel Radcliffe, Meryl Streep and Gord Downie.

But when Izzy met Toronto Star journalist Barbara Turnbull in 2004, she was inspired to serve an entirely different clientele. Barbara, who died in 2015, had a high-level spinal cord injury and used a wheelchair. She was a valued member of the Spinal Cord Injury Ontario community, and an advocate and successful fundraiser for spinal cord research. At the time, Barbara was looking for a designer to create a custom shearling cape and was referred to Izzy because of her experience in working with leather. This design commission unlocked a new world of knowledge and opportunity for Izzy.

Including people with disabilities in the process and the team

"Working with Barbara opened my eyes to the clothing challenges and limited options for people who use wheelchairs," explains Izzy. "I started to address those challenges and find solutions and, as time went on, started kicking the tires around adaptive clothing. The more I got into it, I came to understand the research and knowledge required. Barbara helped by connecting me with a small group of wheelchair users whom I could ask questions and work with as a focus group."

By 2009, Izzy's pioneering line of stylish, well-fitting, comfortable clothes for people living with physical disabilities, IZ Adaptive, was born. Her designs accommodated the day-to-day physical realities of customers, such as jeans cut to prevent bunching and discomfort and coats made with ease-of-dress in mind. From 2009 to 2016, IZ Adaptive gained global customers, sold products online, introduced menswear, and did season after season of collections.

Along the way, Izzy hired a customer care representative through Spinal Cord Injury Ontario's Employment Services. Izzy and her team felt it was essential to have a wheelchair user helping customers and understanding their needs, based on personal experience. She has since hired a finance manager through Spinal Cord Injury Ontario, continuing her commitment to inclusion and to having a diverse group of employees who can learn from and help each other.

Photos courtesy of izadaptive.com



Designer Izzy Camilleri (left) with model/client Joanne Smith.

Growth of a category, more clothing options for people with disabilities

In 2016, IZ Adaptive went on hiatus to restructure, scale and expand, returning in September 2018 with the launch of a new line. Today, a number of well-known brands have followed Izzy's lead with adaptive clothing lines: a positive sign that the importance of this category is now being recognized.

"In the fashion world, there's so much available; I don't need to be yet another person creating more stuff," says Izzy. "With IZ Adaptive, we can help people; improving lives by giving them options. We'll continue to expand our line, get into different categories and keep on growing. It's our mission to provide timeless, adaptive clothing to as many people as possible, so that they can live in comfort, style, dignity and empowerment."

Do you want to learn more about Izzy's adaptive clothing line? Visit the IZ Adaptive website at izadaptive.com.

Are you an employer looking to fill a vacancy or someone with a spinal cord injury or other disability looking for a job? Learn more about our Employment Services and contact us at sciontario.org.

A DAY IN THE LIFE... FEATURING Nicole Jacobs



volunteers and newcomers do as well. I continually connect with our regional offices to make sure we are on track for events and that recognition is received for all of our generous donors and sponsors. I make sure that we engage our community and expand our reach to learn more about the value and importance of our events. I am looking forward to growing our partnerships and increasing outside engagement with Spinal Cord Injury Ontario.

I am grateful for the team I have here at Spinal Cord Injury Ontario and am lucky to be working with such dedicated and hard-working individuals.

What made you want to work at Spinal Cord Injury Ontario?

Many years ago, when I was completing my Master's Degree in Sport Management with a focus on Paralympic Studies, I was introduced to the world of Wheelchair Rugby. This kicked my passion about Disability Rights and Awareness into high gear. Through research, I learned about Spinal Cord Injury Ontario and all of the incredible work that happens here. My career took me on a path of working in disability sport to managing major corporate

accounts at an international not for profit, with many hours spent volunteering with the Parapan Am Games and the Invictus Games. Upon learning about this position with Spinal Cord Injury Ontario, it felt like a piece of my puzzle dropped into place and I couldn't be happier to have joined this wonderful team.

What is your job title?

I am the Manager of Partnerships and Special Events with Spinal Cord Injury Ontario.

How long have you worked at Spinal Cord Injury Ontario?

I started in September 2018 and I am very excited to be a part of this fantastic team.

What does a typical day at work look like for you?

When I get into the office, I am greeted by the friendly faces of my colleagues. My typical day is filled with logistics planning for upcoming events and strategizing on how to make them a success. I ensure that we are always ahead of the planning process to execute with excellence and that not only do our attendees feel honoured but our staff,

What do you do to relax when you're not at work?

Outside of the office you can find me spending the majority of time with my family, friends and most certainly my rescue dog, Tweedy. I love spending time practicing yoga and going out for a run. I am also a bit of a foodie. Whether it is cooking up a new dish, baking something tasty, or trying out a new restaurant, you can always count me in. As well, I love to travel and am always up for a new adventure whether that is travelling across the world, or exploring the great outdoors and going on a camping trip.

What motivates and inspires you every day?

I am truly passionate about making a difference and creating a positive impact in this world. I am a strong believer in opportunity for all and want to empower others to dream big and work hard for what they want. I find strength in those around me who are paving a path for equality and know that one tiny ripple can start a wave. To stay inspired daily, I surround myself with wonderful people who keep me smiling and always make sure that my heart is at the forefront of everything I do. ●

An Art AND A Science

Sound research is critical in shaping the experience and opportunities of people with spinal cord injury. Spinal Cord Injury Ontario funds research in some cases, leads research teams or projects, and participates in diverse research as much as we can.

We believe in collaboration to achieve optimal results, and welcome information about research opportunities for our community.

OPPORTUNITIES FOR RESEARCHERS

Spinal Cord Injury Ontario wants to help researchers share ethics-approved research opportunities and results with our community. If you are a researcher, affiliated with a research organization, consider our research promotion package that gets the word out in a big way and generates the interest and engagement of relevant participants. An investment of \$300 gets lots of promotion for three months.

Our promotion package offers three months of exposure for \$300 and includes:

- A complete description of the opportunity and link to online form on this web page
- A post on our website News feed
- Five posts on Twitter
- Five posts on Facebook
- A link from our e-newsletter FYI on SCI to Research Opportunities
- An intranet post, to reach our staff members across the province, who can share information with their local community

Preference will be given to research that includes people with spinal cord injury from the planning stages of the study, and all projects must meet the following requirements:

- The research must have ethics approval and be associated with a research-oriented organization
- The research must benefit people with spinal cord injury
- Payment/compensation in some form to study participants
- A plan to disseminate research results to the community

INTERESTED IN PROMOTING YOUR RESEARCH PROJECT?

Visit our website at www.sciontario.org to complete our online application form, and we will contact you after receipt to confirm participation and answer any questions.



OPPORTUNITIES FOR RESEARCH PARTICIPANTS

Participating in ethical research studies can be a rewarding experience, not to mention super helpful for moving science forward! Spinal Cord Injury Ontario may not be affiliated with the researcher or the research project and provides this information as a resource to those who may be interested in participating. To learn more about a particular study please contact the person identified with each project.

We encourage you to do your own research before agreeing to participate in any study.

QUESTIONS TO CONSIDER BEFORE SIGNING UP

- **Does the study have ethics approval?**
If a research study has ethics approval it has been reviewed by a panel of experts to ensure that the benefits of the study are balanced against risk and that the rights, dignity, confidentiality and safety of the research participants will be protected.
- **What are the risks and/or benefits to being involved?**
Different studies have different types of risk. It is important to understand the risks involved before you agree to participate in research. Not everyone who participates in research will benefit directly. Sometimes the benefits are to society by providing researchers with new information about a disease or condition.
- **What is informed consent?**
Informed consent is a process where you learn about the study, your rights as a participant and risks or benefits to participation. It is up to you to decide if you would like to volunteer. Consent must be freely given and can be withdrawn at any time without penalty of any kind.
- **How will my privacy be protected?**
Information you provide should remain confidential. Results should only be shared as a group and your information should not be identifiable.
- **What happens if I change my mind and no longer wish to participate?**
You should be able to withdraw from research at any time without penalty of any kind.

For more information, please visit Research Opportunities on our website at www.sciontario.org. ●



Celebrating our Community

We appreciate our community every day as you help us move closer to our vision of an inclusive Ontario. These last few weeks, we hosted celebrations in Toronto and Barrie, with more events planned across Ontario in the fall, winter and spring.



1. Toronto event MC Luke Anderson.
2. Toronto event keynote speaker Kevin Rempel.
3. Barrie event MC Drew Rigden and keynote speaker Mike Johnson.

More than 100 people joined us in September in Toronto as MC **Luke Anderson**, Executive Director of StopGap Foundation, and keynote speaker **Kevin Rempel**, 2013 World Champion and 2014 Sochi Paralympic bronze medalist in sledge hockey and founder of The Sledge Hockey Experience, helped us honour key individuals who've made extraordinary contributions to our work:

- **Anita Kaiser:** Patti Dawson Activist of the Year
- **Gloria Kwan:** Health Care Provider of the Year
- **Julie Hayes:** Peer Support Family Volunteer of the Year
- **Apple Canada:** Employer of the Year
- **Tom Scanlon:** Sharon and Jim Vigmond Philanthropy Award
- **John Anacleto:** Peer Support Volunteer of the Year

In October, Barrie was the focus of celebration as MC **Drew Rigden**, Deputy Chief Building Official, City of Barrie, shared the stage with keynote speaker **Mike Johnson**, CEO of SCI Supply Inc. **Heather Hollingshead**, Spinal Cord Injury Ontario Regional Service Co-ordinator for Barrie and area, was on hand to present awards to these valued community members:

- **Kevin McKenzie:** Community Volunteer of the Year
- **Michael Thompson:** Community Family Volunteer of the Year
- **Dennis Burke:** Peer Support Volunteer of the Year
- **Sheena Gow:** Health Care Professional of the Year

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House Hunting for a Visitable Home

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Another option to open up space within an existing bathroom is relocating the bathroom vanity. I'm seeing more and more restaurants with open concept wash stations outside of the toilet stalls. Why not consider that option at home?

Door hinges that swing out, or pocket doors allow more space within the bathroom. And temporary screens and curtains can also be used.

The Canadian Mortgage and Housing Corporation (CMHC) has published a number of fact sheets on visitable homes. Here are four benefits highlighted by CMHC:

1. Convenience: There's easy access for aging parents, young children, parents with strollers, visitors who use a wheelchair; as well as for moving heavy items.
2. Community: It creates an accommodating environment for residents of all ages, especially for the elderly, where everyone feels welcome and engaged.
3. Comfort: A spacious open concept with large doorways and hallways makes moving around easier and provides pleasing esthetics; plus, there's less risk of falls and injury caused by steps.
4. Maintenance: No front steps makes snow shovelling a little easier in the winter.

CMHC is actively involved in studying how to bring visitable homes into the mainstream housing industry. I will post their research on my website.

Lauren, Alex, Paul and Aimee are pictured in front of a house that I showed them. It's a Century Home that's fully accessible near Broadview and Danforth in Toronto. They decided it wasn't quite the right fit for them so it is still a great opportunity for someone else who is in the market for an accessible home.

It was during this viewing that I got inspired to share their story, and they readily agreed! Finding a home that is already visitable - like the one pictured - is rare, so we're focusing on homes that already have a main floor washroom and adequate space to add an entrance solution.

The plan is to be settled in their visitable home in time for the Blue Jays 2019 season opener. And from that point on, when they're asked "Whose house for the holidays?" they will be able to say "Everyone's welcome at Our House!" ●

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MS Ride 2018

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scenery and well wishes of our fellow riders. I would be the only rider using an arm bike in this event and I was admired by all those I encountered. When we reached the first at stop I was chomping at the bit to spend as little time as possible resting. Sue was always the voice of reason and an excellent partner to have at my side.

We carried on through to Ilderton where like the previous stops was organized and inviting. The temperature had started to increase but the wind was 90 per cent in our favour. We spent our longest time at the Ilderton stop to eat, rehydrate and I got a tune up on my bike. We continued on and I could start to feel the effects of the kilometres we had completed. At our last official stop I would have the biggest mental challenge of the whole day. It seemed as if we were on a constant climb into London. I felt like the swimmer who could see the shore but it never seemed to get any closer. At one point I stopped and felt completely depleted but again Sue was my voice of reason and had a calming effect on me. I thought about those who could not do what we were doing and Sue told me later she saw something rise up inside me as we carried on. We crossed the finish line at Western University to cheers and we felt amazing because we were in the middle of the pack. We had finished 86km in 4.5 hours!

We were registered in Ontario Hall overnight and a volunteer took my bike for storage in the music room. I went to get a massage but was told the spots were all booked. As I was leaving a fellow rider asked if I was the guy on the arm bike? When I told him I was, he offered his spot for a massage, saying, "you deserve it more than me." I was very touched by the support and caring of everyone for each other. We made our way to our room in Ontario Hall with a completely accessible washroom and cleaned ourselves up for dinner. The dinner was phenomenal and later we attended the opening ceremonies where everyone was given their own pizza. When I got my cushion off my bike later I found out the volunteer had tried to ride the bike up the hill and was amazed at how hard it was. It was now time for a solid night's sleep even though the adrenaline was still pumping.

The next morning, we had breakfast and would be invited to be part of the Anderson Brewing team in London for 2019. The same volunteer would be helping us prepare for our journey back to Grand Bend. He was so impressed that I was vertical and ready for challenge number two. We left Western and would have an average speed back of 23km per hour even though on the six or seven hills I averaged 6km per hour with the temperature and wind in our favour. We reached the Motorplex in 3.5 hours and completed 156km (109 miles in two days)!

We enjoyed the comradery and atmosphere as the last bike crossed the finish line. As we made our way back to London the skies poured down and we reveled in our accomplishment and good luck. The MS Society reached 108% of their goal, raising \$1,514,199.76 and ran a flawless event. Sue and I felt so good to know that we had a little part in that. ●

St. Lawrence Adventures 2018

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Island and once he announced we had landed on Canadian soil we were allowed to leave the dive boat.

The next day was another stellar day and we would follow the same procedure to the Keystorm. With my new-found confidence of my dry suit I would be diving with Rhiannon. We had another relaxing dive on the Keystorm with dry legs. We would enjoy the passing of a freighter between us and Singer Island during our safety interval before we would descend on the America.

The America was a four-legged barge that was used to dynamite the channel to make navigation safer for the freighters passing Singer (Dark) Island. When it sank in 1932, it flipped upside down after a half ton of dynamite exploded on her deck, so the legs as well as twin props are now the highest points of that wreck. We would moor to a large concrete block located a distance from the shipping channel. Once in the water we would follow a line down to the large anchor chain and follow the chain to the wreck. This procedure would keep us at a depth and out of harm's way if a freighter passed over us. We explored the wreck and followed the chain back to our ascent line. Once on board we did the same procedure to gain access on Canadian soil.

It was a fun two days and I always marvel at the history the river holds. I know in years to come I will be descending in her waters and learning more about this mighty river. ●

The #ResilientONES

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Sebastian's story is the first feature from fourOnes Studio, that launched a Never Give Up #ResilientOnes Campaign in time to observe the American National Spinal Cord Injury Awareness Month this past September. The campaign features monthly stories of individuals from around the world living with a physical disability and why they never gave up despite the challenges they faced. The year-long campaign aims to raise awareness and shed light on LIFE after a spinal cord injury. The Never Give Up #ResilientOnes Campaign is still accepting stories. For more info on the campaign please visit: <https://www.axs.world/nvrgivup-campaign>. ●

NURGIU↑

"It's not about how you act during success, it's about how you act in the face of adversity."

Sebastian L. Buffington

#ResilientONES

NURGIU↑

"Stay positive at all costs, and never lose hope. You might not see the light today, but you will if you maintain a positive mindset."

Sebastian L. Buffington

#ResilientONES

Michelle Earle

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something as innocent as putting her socks on and getting dressed. She was on bed rest for six weeks. She also became depressed from not being able to go out and it was also winter, which brings darker and colder days.

"Not being independent, your mind can go to dark places and I kept apart from my friends, got depressed and lonely."

Her husband, family and friends were a great support and helped her get better. But for Michelle, it really hit home how serious her disability was when she couldn't feel pain.

Michelle strives to promote awareness and sensitivity of the needs of people with disabilities.

"Because I use a wheelchair, I don't always have the freedom of going into places that have stairs or an accessible washroom. Before my injury, I didn't understand the issue of cars parking or idling in a reserved spot for people with disabilities. Now I do. I approach them saying that there are others who are trying to find a spot because you are waiting for someone at the door. But I know I can't fight everyone's battles."

Michelle also feels very strongly about reserving accessible washrooms specifically for those who need them. "If you have four washrooms and one is accessible, if you don't need it don't use it. I can't wait more than two minutes. It upsets me when there are other washrooms that are available for use. I think it's a lack of awareness on their part rather than trying to make things difficult. When you use a wheelchair, you have so few things that are accessible to you and then there are people without disabilities who have no need for them. You feel like you have been wronged — like you don't matter."

Dealing with her feelings is a big part of her recovery. "You are not in a hopeless situation. Keep an open mind and look for ways to do things you used to do but in a different way. It took me a long time to realize that asking for help is a sign of strength. We all need help once in a while. People don't know how you are feeling unless you tell them."

"When I sustained paralysis, people rallied around me and were wonderful, but some moved on. Some are still around. Even though I am still living with this adjustment every day they don't always ask me how I am managing. Unless you share where you are at any certain point, people don't know. In one of my blogs I spoke about when people ask how we are and we always say we are fine. But it opens the door when you ask, "how are you managing?"

This fall, Michelle will be joining the Board of Directors at the Ottawa Hospital Rehabilitation Centre. She was excited to share her story of her life post injury at the *Spring into Motion* event. It brings meaning to her life. Everyone has a difficult story. She is also planning to take a cruise with her family this winter. She had booked one last year, but could not go because she was hospitalized.

Life goes on.

Read Michelle's blog at: <http://www.wheelchairadventures.wordpress.com>. ●



Last, but
not least

On Wednesday, October 3 we hosted the Rebuilding Lives Golf Tournament at Rattle Snake Point Golf Club in Milton.

Summer had well and truly left the building, it was long sleeves and full length pants all round but our golfers were kept warm by the great atmosphere, community spirit and cheer that was available by the bucket load.

For many, this would be the last game of golf for the season and talk about going out in style! More than 100 golfers joined us on the day, teams competed in a four ball better ball format and took on all the challenges that Rattle Snake Point could throw at them.

In total the day raised over \$85,000!

A huge thank you to all of the golfers who came out to play and thank you to our sponsors Bruce Power, Provincial Building & Construction Trades Council of Ontario and Central Ontario Building Trades. ●



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Rob is a seasoned litigator.



As an experienced advocate for seriously injured clients and their families, Rob Durante has successfully represented clients at all levels of court in Ontario. He is also an in-demand speaker and authority on issues concerning personal injury law. To relax at the end of the day, Rob enjoys spending time in the kitchen, cooking and creating traditional Italian dishes passed down from his parents.

Rob understands that in litigation, a recipe for success includes prep work. Like a chef, a lawyer always needs to be in prep mode, getting ready for the next step. Adding creativity to the mix helps Rob blend all the ingredients he needs to build a difficult case into one that wins the day.

Rob gets great satisfaction when he's able to help provide a sense of justice and closure for family members who can then begin the healing process. That level of commitment means that when the pressure is on, Rob can really take the heat.

To learn more about Rob visit
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