

Community

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COVER STORY: Nancy declined her first offer to visit Yellowstone National Park, thinking it was too difficult a journey. When she finally toured the park with her family, she was pleasantly surprised to discover that it was one of the most accessible places she has ever visited.

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EDITOR, ADVERTISING, SALES

Bev Jenkins

bevjenkins@sciontario.org

CONTRIBUTIONS

Mary Dufton, Laura Fielding, Stuart Howe, Nicole Jacobs, Jeffrey Kerr, Iris Kulbatski, Paul Livingston, Wayne MacDonald, Wendy Murphy, Wendy Hough, Linda Rapson, Joanne Smith, Sumner & Lang, Nancy Xia

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G. Bruce Chapman

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By Stuart Howe

Community Connected

Welcome to another edition of Community. We're excited to increase access to our quarterly magazine by providing an online as well as a print version (check out sciontario.org/community). This means it will be easier for everyone to read, watch and share the content we put together for you, and that we can add to it between issues.

It also means when people search online for topics we've written about, our stories will come up, raising awareness of our work and opening doors for more people to engage with us or tap into our services.

This kind of growth and access characterizes the Spinal Cord Injury Ontario community. No matter where we are in the province, our community members are working to improve things for people with spinal cord injury and other disabilities. On both a personal and systemic level, we are on alert for discrimination and inequality. We keep an eye on language, perceptions, portrayals; seizing every opportunity to help people become aware of what they think they know about disability and those who live with one. Keeping the conversation going, initiating or contributing to open, respectful dialogue on the importance and the right to include everyone is where real change occurs.

The notion of full accessibility is a symbol of that change. How easy does your local business make it for you to shop there? How much does your city or township invest in accessible sidewalks and public places? What are the supports made available by your government to create an equal playing field for us all, no matter our circumstances? How many people understand that what's good for one is good for all? That every venture should start with the idea of making it work for everyone? Accessibility shouldn't be an add-on or after-thought or an unwelcome, legislated order; it needs to be the new, the only, way. It'll take time, for sure, but it will never happen without the shared vision that it simply *must* happen.

Our government relations and advocacy efforts are on fire, which means, of course, that there's great need for increased equality and inclusion, and also that we are in a strong posi-

tion to effect change. We have grown powerful relationships with people in all levels of the government, in business, in the charitable sector like our friends at the March of Dimes, with whom we just shared a Queen's Park Day, in health care, with community groups and with individuals who are passionate about moving the needle on accessibility and equity.

We're proud to launch our #peeeforfree campaign this month and excited about our next Queen's Park Day in March, where we'll talk with MPPs about the high cost of catheters and how the provincial government might help. And we're pleased to keep working to improve things at Spinal Cord Injury Ontario so that we're in an increasingly stronger position to achieve our vision of people with SCI living the life they choose in a fully inclusive Ontario. I invite you to enjoy the diverse collection of articles in this issue of *Community*, and to connect with me at any time to discuss our work.

Dr. Stuart Howe
CEO, Spinal Cord Injury Ontario

Can we talk about the high cost of peeing?

#peeeforfree

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BELIEVE THIS
HAPPENED
TO ME.
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WALK AGAIN?**

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SUPPORT MYSELF?**

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By Joanne Smith

Skip the Detox

Every year between New Year's Eve and Easter, people tell me about the latest 'detox' they're doing either as part of their New Year's resolution or spring-time cleanse. While these all sound like quick, healthy ways to purify the body, increase energy and/or lose weight, most of these intense, short-term concoctions are actually detrimental to liver function, making you feel worse.

The liver has more than 500 functions. For example, it regulates glucose, produces and secretes bile, stores vitamins, converts thyroid hormones, purifies and clears harmful substances such as bacteria, as well as breaks down and detoxifies medications. This last function is particularly important after a SCI because many of us are suddenly consuming medications that we weren't prior to injury such as ibuprofen, acetaminophen, antibiotics and steroids. Consuming these medications on a long-term basis, while necessary to control infection, pain and inflammation,

can place an extra burden on the liver. Therefore, it is essential that we consume the proper nutrients the liver needs to help ensure these medications are being properly detoxified and cleared from our system, and to help reduce the burden on the liver and ensure it is able to fulfill all of its other important functions.

The trick to supporting liver function is to do it throughout the entire year with the foods you eat every single day – not through a seven-day liquid gimmick. These kinds of so called 'cleanses' are often too harsh for your liver, creating free radicals which, in excess, can damage cells (including liver cells) and leave you feeling

tired, irritable and headachy.

This year, I ask and highly recommend that you skip the packaged detox and instead consume at least one of the following foods every day!

LIVER LOVING FOODS/DRINKS

- Broccoli
- Cabbage
- Cauliflower
- Brussel sprouts
- Asparagus
- Mushrooms
- Legumes/lentils
- Jerusalem artichokes
- Citrus fruits/fresh lemon water ●



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Kingston:

COMMUNITY DINNER CELEBRATION

Kingston was the focus for our Community Celebration Dinner on November 28.

Erika Schmutz, power engineer and former Paralympian was the MC for the evening alongside keynote speaker, Drew Cumpson, founder of H&D Consulting. Bryce Donald, Spinal Cord Injury Ontario's Regional Service Co-ordinator in Kingston, was on hand to present awards to these valued community members:

- Peer Support Volunteer Award: **David Baldwin**
- Health Care Professional of the Year Award: **Dr. Sussan Askari**
- Community Family Volunteer Award: **Tamara Van Grunsven**
- Community Volunteer Award: **Rachel Holthof**
- Award of Appreciation: **Bergeron Clifford LLP**

Special thanks go out to Bergeron and Clifford LLP for their continued support of the Kingston Peer Support program and turning it into a model for Ontario, one which we would like to emulate in other regions. ●

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1. Back row L-R: Chris Clifford (Peer Support Program Sponsor), Sussan Askari (Kingston Health Care Professional Award), Tamara Van Grunsven (Kingston Family Volunteer of the Year), Rachel Holthof (Kingston Community Volunteer Award), Sheila Casemore (SCIO), Bryce Donald (SCIO). Front Row L-R: David Baldwin (Kingston Peer Volunteer Award), Peter Athanasopoulos (SCIO), Erika Schmutz (Master of Ceremonies), Drew Cumpson (Keynote Speaker).

2. L-R: Bryce Donald (SCIO), Chris Clifford (Peer Support Program Sponsor), Ari Wahl (SCIO).



JOIN OUR COMMUNITY

"I like what you're doing."

This simple thought built our community these past 73 years. And it's the thought that continues to strengthen our work - and resolve - to expand our reach and impact. We invite you to join our inspired group of change-makers - all it takes is a word from you that you want to stay in touch on our initiatives to **support, serve and advocate** for and with people with spinal cord injury. It's the thought that counts for vital change.

STRENGTH IN NUMBERS

If you are aligned with our mission and vision, you are a welcome member of our community. There's no membership fee to pay or application to complete - just let us know you're interested and we'll connect with you about our work, while we honour your privacy and communication preferences.

If you want to expand your involvement with Spinal Cord Injury Ontario, there are lots of ways to do that - volunteer, donate, become an advocate - and if you want to lend your support simply by **becoming a member of our e-community** or

Chris Rice, Peer Support Volunteer, and his sister Felicia.

engaging with us on **Twitter, Facebook or Instagram** - that's meaningful too. It's all about expanding the number of people who believe in what we do, which demonstrates and deepens the impact we have on those living with spinal cord injury.

We are proud to count among **our powerful community** all those who give flight to our work:

- people with spinal cord injury and other physical disabilities
- families and friends of people with SCI and other disabilities



- health care professionals (including MDs, RNs, NPs, PSWs, SWs, OTs, PTs and RTs)
- government staff whose work supports our advocacy efforts
- businesses that want to engage their staff in a dynamic charity or want to partner with us as sponsors or employers
- interested members of the public looking for awareness, education and a sense of community
- our vendors - people and businesses that help us deliver our programs
- our staff and volunteers
- our donors

For more on how you can join our community, please visit www.sciontario.org ●

In Our Nation's Capital

It was great to get together in Ottawa recently with Spinal Cord Injury Ontario staff members (l-r): Federico Boccheciampe, Chris Bourne, Angela Clair, Peter Athanasopoulos, Stacey Moore, Wendy Hough (Missing: Paul Livingston) Looking to connect for services and support? Call 613-723-1033 or visit ottawa@sciontario.org.



Making the Magic Happen!

ADVOCACY IN ACTION

By Peter Athanasopoulos,
Senior Manager, Government Relations and Public Policy



Going to the bathroom shouldn't mean going broke.
[#peeeforfree](#)

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Catheters can cost one person thousands per year.
[#peeeforfree](#)

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Can we talk about the high cost of peeing?
[#peeeforfree](#)

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sciontario.org/peeeforfree

The advocacy department of Spinal Cord Injury Ontario is committed to **amplifying our community's voice**. To achieve this effectively, we are actively pursuing three strategic directions.

1. **Enhance our capacity** for people with SCI to engage decision makers.
2. **Building coalitions** that unify influential stakeholders and organizations that share a common voice for optimal health and well-being for people with SCI.
3. **Fair and equitable services across Ontario** that impact the quality of life of people with SCI.

ENHANCE OUR CAPACITY

Our greatest strength is our community of people with SCI sharing their lived experience. Learning from people who live with SCI in Ontario generates understanding of how programs, services, research and policies should function. Only those relying on our government systems and supports

can provide the greatest knowledge and perspective to make them work best.

To harness this knowledge and perspective of the community, we have actively engaged people with SCI and are asking them to develop a relationship with Members of Provincial Parliament (MPPs) across Ontario. We describe them as Peer Activists and presently have 83 in the 127 ridings across Ontario. If you wish to participate in Peer Activist work, email us at advocacy@sciontario.org

If Peer Activism is not your thing but you want to contribute, you still can.... Simply, join the movement and become a **campaigner** at www.yourmoveon-tario.ca and sign up to receive regular communications. You will have the opportunity to participate in our calls for action and get play-by-play information on how we are tackling fair and equitable services for people with SCI in Ontario. Get involved today!

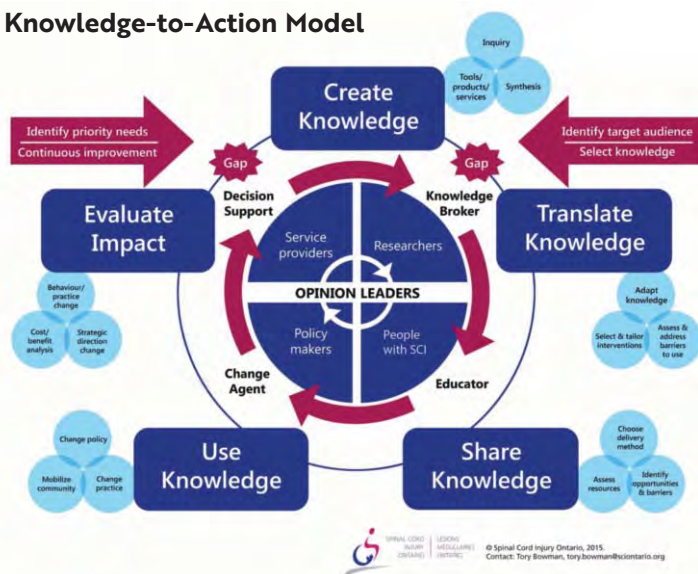
Building Coalitions

Our coalitions build on our credibility. With 100+ organizations and corporate partners by our side, we become a stronger force. We have representation across the entire continuum of care, including; researchers, hospitals, clinicians, service providers, community organizations and corporate affiliates. Our established coalitions have the skills and expertise to facilitate qualitative and quantitative research, informatics, business cases, economic analysis and corporate resources. Collectively harnessing the economy of SCl with those with lived experience, we can address and resolve systemic barriers that impact the quality of life of people with SCl most efficiently. To view the progress of our advocacy partnerships, visit www.sciontario.org/ontarioscialliance.

Fair and Equitable Services Across Ontario

Combining coalitions and Peer Activists across Ontario is powerful. By harnessing this power, we can be an effective resource to all levels of government that make decisions affecting people with SCl. Through comprehensive consultations with opinion leaders (people with SCl, researchers, service providers, policy makers) and using our knowledge to action framework, three priority areas have been identified.

Knowledge-to-Action Model



Priority # 1 – Province Wide Medical Supply Coverage Program

Spinal Cord Injury Ontario and key Alliance members have come together as a coalition of clinicians, organizations, people with physical disabilities and policymakers to examine and address issues related to intermittent catheters use in Ontario. The role of the **Intermittent Catheter Issue Working Group** is to:

- Compare international best practice with existing practice in Ontario (and Canada) while assessing the current evidence base in order to inform provincial health policy.
- Release a position paper based on the Working Group's overall findings that will guide policy development. Our submission to Health Quality Ontario can be found on our website.

- Advocate to provincial policymakers to ensure that Ontario provides adequate access and the best available evidence for individuals who need access to intermittent catheters.

What we learned is that people are spending a great deal for catheters with limited supports. To discuss this issue with the Ontario Government, join us on **March 18** if you're in Toronto as we share solutions with MPPs across Ontario at our Queen's Park Day. It's here, where we will officially launch our **#peeforfree campaign** to raise awareness of this important issue across the province.

Priority # 2 – Access to Mobility Devices

Spinal Cord Injury Ontario and key Alliance members have come together to examine and address issues related to access to mobility devices in Ontario. In 2018, the Task Force partnered with the University of Toronto's Public Good Initiative to conduct an independent review of the Mobility Device Sector in Ontario. Recommendations can be found at www.sciontario.org/ontarioscialliance.

Presently we are working with PC Caucus Services and the Ministry of Health and Long-Term Care (MOHLTC) to ensure our recommendations are implemented. To be involved in this initiative, support your community by engaging your MPP.

Priority # 3 – Accessible Health Care for All

During the Ontario SCI Alliance Retreat on April 13, 2018, we gathered numerous engagement strategies to address key challenges and systemic barriers in key topic areas. Our intention is for the Alliance to be an enabler and community mobilizer for primary care providers and people with SCl. The community plan aims to organize and mobilize primary care and interdisciplinary supports for people with spinal cord injury in the community. Our goal is to leverage the evidence and support of key topic areas (**neuropathic pain, bladder management, and prevention and treatment of pressure injuries**) and transfer this valuable knowledge and education to family physicians and people with SCl across Ontario. To execute this priority, we are creating knowledge exchange initiatives with our partners and hosting meetings with primary care providers through Ontario's Telemedicine Network (OTN). To access our professional learning platform, visit sciontario.org/cortree.

To complement this knowledge exchange, we are also building a **physician engagement network**. If you know family physicians serving people with SCl in your community, please let us know. The larger the network, the more health and well-being support there will be for people with SCl.

To further support this priority, we are building a Virtual Information Platform for people with SCl (VIP4SCI). This technology aims to connect people with SCl with their circle of supports virtually. You can join the research study through our Research web page.

As we increase enhanced interest from family physicians and inter-professional teams in the community to join our family physician engagement network, we will encourage and provide resources and advocacy to develop **Accessible Mobility Clinics everywhere in Ontario**. ●

Introducing Young Professionals Board Members

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.

In this issue of *Community* magazine, we introduce you to Darrell Booker, Emily McIntyre and our newest member, Chris Stigas.

Darrell Booker

I am one of the owners with In-Trend Home Solutions. My career originally began in construction. After five years working for a builder in the Niagara Region, I decided to continue my



education and graduated from Griffith University in 2009. Upon return to Canada from Australia I started to work in business development. I worked as an Insurance Broker for three years before deciding to become an entrepreneur with a close friend from university. Working with people who have sustained a disability is something very close to me as my father sustained a severe injury when I was 18 when he was struck by a motor vehicle. Seeing this firsthand really changes your perspective and I think I can relate to those in this situation to provide assistance where needed.

Being involved with Spinal Cord Injury Ontario means a lot to me as we continue to create awareness and advocate for people with disabilities. I joined Spinal Cord Injury Ontario in 2017, and last year I was able to MC our annual comedy night. It has been a great experience so far as I have had the opportunity to meet some really amazing people at the organization and on the Young Professionals Board. I look forward to continue working alongside them in the future.



Emily McIntyre

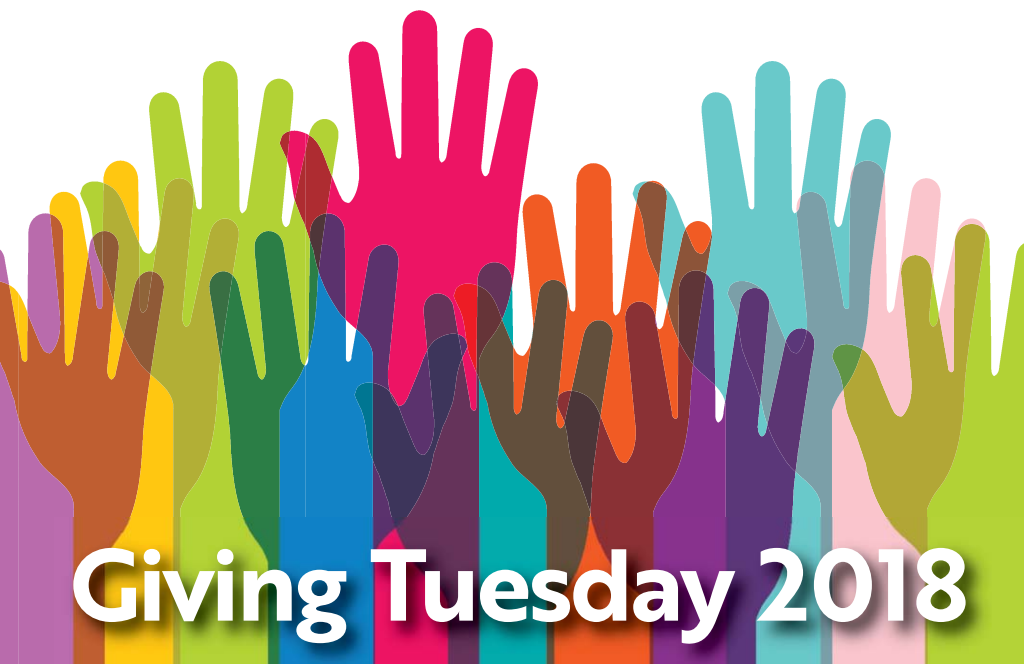
I worked as a researcher during an internship with Spinal Cord Injury Ontario, as a partnership with York University where I was offered the Knowledge Mobilization award to help complete our study. Through this research, we were able to better understand gaps in health and community services for individuals in Ontario and provide a detailed report and presentation to Spinal Cord Injury Ontario.

I have completed a Master's in Critical Disability studies from the School of Health Policy and Management at York University. My major research paper deconstructs disabling spaces in Nepal's tourism industry and dismantles stereotypes about what type of body should be in the workplace and participating in risky activities. I am currently an employee at York University working as a Research Co-ordinator on four SSHRC and CIHR funded projects related to health policy and I also manage the students.

I am passionate to help ameliorate the negative effects of health inequalities and disparities through research that offers recommendations at the policy, program and system level. I am dedicated to tackling systemic barriers that impact individuals with disabilities. I have lived experience of breaking my neck and have a brain injury and as such, I have felt the lived effects of systemic barriers of access to care. I am committed to providing a critical disability lens to policy and care.

Outside of research, I directed an inclusive adventure race, Wildcat

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Giving Tuesday 2018

By Paul Livingston, Senior Development Officer

Did you know that when someone in Ontario needs a wheelchair, hospital bed or other equipment, these necessities are not fully funded by the government?

In fact, unless someone has additional insurance, they can expect to pay at least 25% of the cost, and in some cases, the full amount. When an item costs thousands of dollars, 25% can be impossible, especially when one's financial well-being has likely been impacted by a spinal cord injury.

In the last six months, more than 50 people got the equipment and mobility aid they needed with the support of Spinal Cord Injury Ontario's Enhancing Independence Program.

Thanks to our generous community, Giving Tuesday 2018 was a great success and \$17,414 was raised in support of the Enhancing Independence Program, which provides essential equipment and mobility aids to people who need them but cannot afford them.

The success of the day was made possible with the support of individual donors and greatly assisted by PIA Law who generously matched the first \$5,000 in a donation. 100% of funds raised go to the provision of



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equipment and mobility aids and Spinal Cord Injury Ontario pays for the costs of running the program.

"The law firms of PIA Law (McLeish Orlando, Oatley Vigmond and Thomson Rogers) were honoured to support Spinal Cord Injury Ontario's Giving Tuesday initiative, in support of its Enhancing Independence Program, again this year," said Patrick Brown, Managing Lawyer, PIA Law. "We are extremely grateful to all those who so generously donated to this incredibly important initiative."

Thank you to all of the generous donors who contributed to our campaign. It's great to see our community come together to support one another.

Giving Tuesday takes place every year on December 3, which coincides with the International Day of Disabled Persons. When you see an email or social post on this important day of giving please remember all those whose lives you can help change for the better. ●

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ACCESSIBLE YELLOWSTONE NATIONAL PARK

By Nancy Xia, Community Resource & Education Assistant

Two years ago, when my friends asked me to go with them to Yellowstone National Park, I pictured a very high mountain and a rocky path leading to the summit where my friends would have to carry me up... fearing of becoming their heavy burden I declined their kind offer.

But this past September, I was almost forced to go under pressure from my family. The trip was on my Mom's bucket list. In preparation, I dropped 10 lbs. to hopefully lighten their load. Surprisingly, it turned out Yellowstone National Park is one of the most accessible places that I have ever visited.

We spent five days exploring Yellowstone and Teton National Park (connected to each other). We saw all types of geographic wonders: geysers,

canyons, waterfalls, hot springs, lakes, snowy mountains and of course, mega volcanos lurking beneath us. We also saw bison, deer, goats, giant crows, and best of all "Yogi and Boo Boo." We were told that if we were to get in before 7:00 a.m., we could see thousands of animals coming out for breakfast.

There are information and visitor centres near all five gates as well as inside the park. You can get an Accessibility Guide mapping out every

accessible trail and bathroom. All of the iconic attractions have wheelchair ramps and accessible paths paved around them. I was left behind twice when I couldn't physically make it, but was told between the heavy exhalations of other people that it was not worth it. A few places were not paved, but they were relatively smooth.

Strangers were eager to help when I really needed it. I would say that people who use power wheelchairs might have a more quality experience compared to those who use manual wheelchairs. It did require a lot of energy and endurance to push. Thankfully I had a big wheel in front to elevate my casters. If you are like me and use a manual wheelchair, be sure to bring all of your assistive devices, a

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Anita Kaiser

PATTI DAWSON ACTIVIST OF THE YEAR AWARD

By Sumner & Lang

Anita Kaiser is passionate about research. With a background in applied chemistry and biology and a Master's in Rehabilitation Science from the University of Toronto, it makes a lot of sense that Anita is highly interested in research studies that impact people in the spinal cord injury community.

Once studies are completed, she gets the information out so people are informed about how to best take care of their health. She also encourages others to get involved in research right from the beginning, at the design stage of a study, to ensure that any outcomes are of particular relevance to people with an SCI. "Too often, studies with a lot of potential end up having little use to this community because there were flaws or omissions in the design stage," she says. "I hate to see wasted opportunity as a result of a poor study design. We need good research as step one. Step two is putting it to use. So those are areas where I invest some of my time."

Anita is a big believer in following personal interest when getting involved in volunteering or contributing to organizations like Spinal Cord Injury Ontario and others in the SCI sector.

"There really is something for everyone," she says. "What are you good at? What do you love to do? Whatever it is, there's a role to play in overturning barriers to inclusion in our society. Your passion and your impact can be one and the same. Anyone can get into advocacy in whatever area matters to them the most."

In addition to her work as a Research Assistant at Toronto Rehab's Lyndhurst Centre and activism in the research realm, Anita is a member of Spinal Cord Injury Ontario's Board of Directors, is leading its Quality Improvement Committee, and has been a Peer Support Volunteer since 2000. She is also an advocate in public policy and has been active in three of our organization's campaigns: Primary Care, Alliance Retreat Community Mobilization, and Provincial Election.

Anita feels honoured to be the recipient of the Patti Dawson Award – and also personally touched.

"I knew Patti," she says. "She was a remarkable person. I first



Anita Kaiser (right) receives the Patti Dawson Activist of the Year Award from Patti Dawson's sister Pam Russel at Spinal Cord Injury Ontario's Toronto Community Celebration, September 2018.

saw her was when I was a patient at Lyndhurst, just after my injury in 1996. She was volunteering at the hospital, helping patients with mobility issues. I thought, 'Now that's amazing, a person in a chair helping a person in a chair.' I hadn't seen that before. I thought it was so cool. She was an inspiration to me and set the stage for my future role as a volunteer."


Anita and Patti eventually shared an office at Lyndhurst and worked side by side.

"Patti was a trailblazer – with a bulldozer! She created a massive path and was a force to be reckoned with. She would stand for no injustices. And she believed in the role of good research in policy change. She showed me how to be an advocate, not just for myself but for others. She had the power to change lives, which is why I have ended up here today."

Pam Russel agrees with Anita's characterization of her feisty twin sister.

"Patti was passionate about accessibility and fairness," she explains. "She was very outgoing and opinionated. At the same time, she was also understanding and compassionate. She spent a lot of time visiting people in their homes, working with them on their housing and transportation needs. And if Patti ever caught someone unlawfully using an accessibility parking spot... Look out! She had a lot of time for righting wrongs."

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

Ignore the distractions.
Focus on the drive.
Get home safe.

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THE UK LEADS THE WAY

By Jeffrey Kerr

At the end of November, I attended the Home Modification Conference in Vaughan, Ontario. This is an annual event that brings together individuals and businesses that are connected with or involved in modifying homes for accessibility.



Wet Room in the UK. Picture supplied by Paul Smith, Foundations.

One of the biggest challenges to making home modifications a reality in Canada is funding. The March of Dimes Canada did a study that showed the average cost to modify a home is \$8/day. Yes, you're reading that correctly! This is the average home modification cost amortized over the lifetime of the renovation.

Sadly, despite the March of Dime's findings, there is very limited funding available in Canada to modify homes.

The United Kingdom (UK) has addressed the funding question, and I think it's a model that Canada should look at closely. One of the presenters at the Home Modification Conference was Paul Smith. He is the Director of an organization called Foundations in the United Kingdom. His presentation focused on home adaptations (modifications) in England.

Foundations is a government organization that has been set up to oversee a national network of home improvement agencies (HIAs) across England. Foundations uses a collaborative approach to make connections between the public, private and academic sectors with the goal to effect change. The fact that Paul travelled 'across the pond' to share his expertise and experiences working in the UK with the pioneers of the home modification industry in Canada speaks volumes about his dedication to this field.

In the UK, people with disabilities can apply to their local HIA for a grant called 'Disabled Facilities Grants' or DFGs, to pay for home modifications. HIAs are located throughout the UK and have a mandate to ensure people are able to stay safe, secure and warm, and remain independent in their own home. To achieve their mandate, they provide grant money to people with a permanent physical disability, learning disability, sensory impairment or mental illness.

In the UK, home owners and tenants have a statutory (legal) right to grant money to adapt their homes. Paul told me that the UK Government invests £500 million per year (approx. \$854 million CDN) in the program and it's based on a simple business case: "If you have a disability, you're much more likely to remain in your own home if it's properly adapted. The alternative of moving into care is something no one wants and this costs far more for the individual and the state."

continued on page 41



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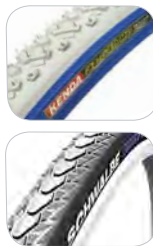
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Still Working Towards Accessible Parking



Wendy Murphy

The availability of accessible parking is a long-standing issue impacting many people with disabilities across Ontario. Effective and efficient solutions are needed to ensure a streamlined, consistent parking permit system in Ontario. A 2017 document issued by the Minister of Government & Consumer Services states that there are over 729,000 Accessible Parking Permits (APPs) in circulation in Ontario.

The program is administered by Service Ontario, and Service Ontario is responsible for the policy that governs the program and for issuing the permits. While the program is administered by Service Ontario, municipalities are responsible for determining the rights an APP holder may have in their jurisdiction. Law enforcement agencies in each municipality are responsible for applying fines and enforcing the municipal rules of APP use.

Wendy Murphy, who has been working with Spinal Cord Injury Ontario said, "I was elated when the Accessible Parking Permit program was implemented in the late 80s. I felt it a move toward better access as a whole. It proved we all as people with physical disabilities had a voice that would better facilitate our needs. That right has been dreadfully impeded the last two-to-five years with the number of permits now in circulation. I also see a problem with the permit being easily transferable; being passed on or borrowed by friends and family members. Today, I'm often forced to sit in my car and wait for a spot to become vacant by an individual who eventually walks out to their car. It is a very frustrating reality."



Here are some facts on the Accessible Parking Permit program:

- The permits were initiated in the late '80s early '90s
- There are well over 729,000 active APPs in circulation across Ontario
- In 2016, law enforcement agencies seized over 1,300 APPs due to abuse
- APP holders do not require a driver's license or need to own a car and can be of any age
- Regulated health practitioners, not Service Ontario, are responsible for establishing whether someone meets health eligibility criteria
- APPs can be used in any municipality in Ontario and also outside Ontario's borders
- Ontario has the highest fines in Canada for abuse and misuse of the APP

Wendy said, "While I noticed problems with the permit system after 2010, I became a more active advocate on this topic in 2015 working with both March of Dimes, Canada and Spinal Cord Injury Ontario in the hope of seeing change. I have since brought both organizations together in the hope of seeing more significant progress; the power in numbers theory. APP aside, we are hopeful to seeing a Private Members Bill passed that will devise a plan to better regulate the permit.

And on October 25, 2018, Parliamentary Assistant to the Minister of Labour, Gila Martow (MPP for Thornhill) announced the reintroduction of her Private Member's Bill 39, Accessible Parking

and Towing Industry Review Committee Act, 2018. The Bill aims to assist motorists in their time of need by streamlining a patchwork of local regulations currently governing both the towing industry and the use of accessible parking permits throughout the Province.

The Bill calls for the creation of a taskforce of municipalities, non-profit and non-government agencies, health care organizations, and other partners to develop a streamlined, fair and innovative approach to existing regulations and modernize technology systems currently in use.

"Thousands of Ontarians struggle with mobility issues. They don't need the extra burden of complex accessible parking rules that vary between municipalities," said Martow. "Ontarians who require accessible parking shouldn't face the added trouble of having their spots taken up by users of fraudulent permits."

Spinal Cord Injury Ontario welcomed the news with CEO Dr. Stuart Howe commenting: "For people with disabilities, accessible parking spaces are an integral part of an independent lifestyle. Spinal Cord Injury Ontario welcomes Bill 39 because we know how vital it is to have a streamlined, consistent parking permit system across the province. We hope this Bill, if implemented, can mark the end of the inappropriate use of parking permits and ensure that permits are available only to those who need them. As a charity, we are working toward our vision of a fully inclusive Ontario and this Bill would be an encouraging move in the right direction."

Martow added that improvements are needed to protect consumers. "Many people don't know what their rights are if they find themselves needing a tow or roadside assistance. Bill 39 will strengthen protection for drivers across the Province by making sure they're treated fairly," said Martow.

Bill 39 – Accessible Parking and Towing Industry Review Committee Act, 2018's current status: *Ordered referred to the Standing Committee on Social Policy.*

The full Bill is available at:
https://www.ola.org/sites/default/files/node-files/bill/document/pdf/2018/2018-10/b039_e.pdf.

In brief, the issues needed to be addressed are:

1. Ontario needs a standard practice across all municipalities on the use, equality and procedures of parking permits for people with disabilities.
2. End inappropriate distribution and use of parking permits.
3. Ontario needs a plan to ensure parking permits are available to those who need them, particularly in response to demographic trends such as population aging.

Join our Community!

Sign up to stay engaged with Spinal Cord Injury Ontario's programs, services and events and learn more about what we are doing about this and many more issues. Receive our monthly enewsletter – FYlonSCI – and other communications that match your interests. Visit www.support.sciontario.org to sign up. ●



By Dr. Lara Fielding,
Behavioral
Psychologist

Four Steps to Clicking the Internal "Refresh" Button

HOW TO BE MENTALLY AND EMOTIONALLY PREPARED FOR THE NEW YEAR

By the end of a long, and particularly trying 2018, it's normal to feel worn out and not exactly pumped for taking on new tasks. The motivation tank is dry and the pull to shut down and avoid is stronger than ever! We can all use some tools for clicking the internal refresh button. Here's how!

STEP I: FIND MOTIVATION IN YOUR VALUES

Values are different from goals. Values are your internal GPS, and help you connect to your why. They are chosen by you, and only you, and provide you with stamina to endure discomfort in the service of the kind of life you want to design.

Values are the direction you want your life to take, and the kind of person you want to be! And.... It takes some serious intentionality to get connected to them.

Let's Practice: Complete the following sentence for the areas of your life where you're feeling burnt out.

I'd like to be the kind of person
that others see as

And I'd like to show these
qualities in my behaviour by

Next, keep this vision of
the you you'd like to be in
2019 in mind as you go
through the following
steps.

STEP II: VALIDATE THE DISCOMFORT

Our default reaction when we feel internal discomfort such as awkwardness, uncertainty, anxiety, or frustration, is to do something to get rid of the feelings. This is natural of course. Who wants to feel uncomfortable?

But when you're feeling burnt out, and you've been pushing through the whole year, it's time for another approach.

Rather than smothering your feelings, ignoring your emotions, and pretending you're 'fine', practice getting curious and open to your experience. The validation skill is the simple act of non-judgmentally acknowledging that the experience is present. Just like getting validated in the parking lot simply says, "you were in the building."

Let's Practice: The easiest small step you can take towards validating your emotions is to label them. Finding the right emotion word for your emotions actually activates parts of the brain that dampens over reactivity and motivates effective behaviour. Gently allow yourself to have and hold that emotion. As you do so, notice how you feel in your body.

STEP III: KEEP YOUR THOUGHTS IN CHECK

Just like our actions, our thoughts can fall into habitual patterns when we're stressed out. These patterns can pull us into low mood and motivation. But actually, seeing your thoughts as just thoughts, rather than facts takes some practice.

What happened in Step I when asked to visualize your ideal self in 2019? Did your mind offer up 'reasons' you cannot do those things? Or did you skip through the exercise entirely?

continued on page 41



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Save the Date – Tuesday, March 5, 2019

Registration begins at 5:30 pm

Games begin at 6:00 pm

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Kitchener Waterloo Roll and Bowl

Save the Date – Tuesday, March 26, 2019

Registration begins at 5:30 pm

Games begin at 6:00 pm

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Please contact: bowlevents@sciontario.org
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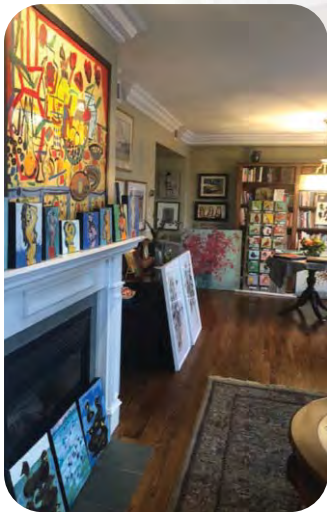
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the Slopes!**

*Thanks to all who joined us
at our 19th annual Ski and
Snowboard Day at
Craigleith Ski Club on
Thursday, February 14, 2019.
Over the 19 years we've
hosted Ski Day, our
generous community has
helped raise \$1.3 million!
Stay tuned for an update
on this day in our next
issue of Community.*

Ottawa's Art & Soul

By Wendy Hough, Development Officer, Eastern Ontario

A great big shout out to Cindy Scott and Roger Bryanton for opening their home and hosting the 5th Annual November Art Show. It was an incredible evening full of colour and splendour.



1. Artist Leanne Cusack with her partner Joel Haslam and happy art buyers Miles Underwood and Natalie MacLean.
2. Artist Nicole Allen surrounded by her beautiful work.
3. Local real estate agent Judy Faulkner shakes hands with business lawyer Debbie Weinstein — artist Christopher Griffen in the background.
4. Artists Nicole Allen, Christopher Griffin and Leanne Cusack.

The show and sale of the works of three local Ottawa artists, Christopher Griffin, Nicole Allen and Leanne Cusack, took place on November 15, and raised \$3,125. In addition to the three returning artists from last year, Amelia Carney, an emerging Ottawa-based artist who is presently studying at the Hampstead School of Art in London, had several pieces included in the show.

The proceeds from the show have been donated to support the work of Spinal Cord Injury Ontario in the Ottawa region. Ottawa's Great Canadian Theatre Company also benefitted from this fantastic event.

We would like to thank all of the artists for sharing their talents and lending them to our cause, as well as the generous guests who contributed to make the event such a success. Spinal Cord Injury Ontario is very grateful for the ongoing support of our patrons like Cindy and Roger. We are pleased that Cindy is serving as the Vice-Chair of the Board of Spinal Cord Injury Ontario for 2018-2019. ●

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MY TIME IN THE PEN

By Wayne MacDonald



Whenever I have told people I have spent time in Kingston Penitentiary (KP), they laughed and said I would not last a second amongst the most hardened criminals in Canada. The truth is I did when it was an active prison.

It was in 1995, and my cousin was a professional truck driver with Maritime Ontario. He had his own rig and boy was it a beauty. I had gone on runs with him to Quebec for Canada Post a few times throughout the years. It was always fun riding in the big rig and hearing the chatter over the CB radio while travelling on the open road.

One day he asked me if I wanted to go to Kingston with him. He never told me why he was going and I never asked. We headed out from the Maritime Ontario compound on that early morning towards Kingston and exited off on Sir John A. MacDonald Parkway. As we headed south towards the St. Lawrence, it never dawned on me that Kingston Penitentiary lay at the base of the parkway. As we reached the intersection there were only three options, a right turn, left turn or straight through into the penitentiary parking lot.

As we sat at the red light, the massive structure was ominous and foreboding. I assumed Roy would have to manoeuvre a very tight turn either way because going straight through did not seem like a remote option. When the light turned green, much to my surprise, he proceeded straight through into the parking lot of Canada's most famous prison. He smiled and said, "I forgot to tell you we are going into the prison today." My heart was beating a little faster as we rounded the rear of the prison that backed onto the St. Lawrence.

The walls were high and each corner had a turret where officers were stationed to oversee the guts of the prison. We came up to a set of massive doors that began to swing open upon our arrival. As we passed through the mouth of the beast and the doors closed in behind us, I could only imagine the reaction of new arrivals as they watched their freedom truly slip away at that very moment. We were now in the sally port which was a fenced in cage that held a tractor trailer like ours with room to spare.

We were greeted by guards with guns and search mirrors in the company of some pretty impressive dogs. I was to stay in the office enclosed in the sally port while my cousin was escorted to the area where he would switch out the empty trailer we brought with the full trailer of post office boxes you see at the corners of the roads made by the inmates for Canada Post. The

prison was in lockdown and there was no margin for error.

As I watched the rear of the trailer disappear around a corner surrounded by the heavily armed guards I took in my surroundings. I could hardly believe where I was standing with prison guards chatting away like it was just another day at the office. I was also curious because it was the year that Paul Bernardo was convicted of his heinous crimes, along with his wife, and was sentenced as a dangerous offender to this very prison. He would be following the path I took just a half hour earlier and the guards made it clear to me he would not be welcomed with open arms. A sentiment I was more than okay with.

As the nose of Roy's rig appeared in the company of our welcoming committee, I was still marveling at the enormity of this place. As I climbed into the cab and said farewell to my keepers, I felt a sense of relief that our stay was only momentary and the beauty of the St. Lawrence appeared as the massive doors spit us out to freedom. I could not wait to tell all my friends of my adventure and I was an inmate of sorts.

It was sometime around 2016, I had heard that the prison was being opened for walking tours. I was driving out to Prescott for a couple of days of diving in the summer of 2017, and saw the sign on the 401 advertising the Kingston Penitentiary tour and museum. I made a call to confirm it was open to the public and decided to stop on my way back and revisit my old friend.

That day, I sat at the same intersection that I did in 1995, and I recalled the same emotions seeing the prison. It was a hot day but as soon as you went through the public entrance the thick limestone walls insulated you from the heat. I paid my entrance fee and signed release papers while waiting to start the tour. I found out all the areas we would see and history told would be from retired guards previously employed by the prison.

As I waited, I read some very interesting history. Canada's most notorious prison closed on September 30, 2013, and was one of the oldest prisons in continuous use in the world at the time of its closure. It opened on June 1, 1835, and was among nine prisons in the Kingston area, functioning prior to Canada's confederation on July 1, 1867. The prison cells measured 73.7 cm. (26 inches) wide by 244 cm. (8 feet) deep and 200.7 cm. (6

feet, 7 inches) high and the prison was surrounded by a 12 ft. high wooden picket fence that housed both male and segregated female prisoners. In 1845, the towers, stock walls and the north gate house were completed. In 1859 – 1861, a dome was added connecting four cellblocks. The women's prison opened across the road on January 24, 1934.

Our tour guide arrived and took a small group of us to the visitor's area. It was here that we were told that conversations were recorded at the guard's discretion, and every table was clear Plexiglas so nothing could be passed from visitor to prisoner. We were also told that the guards would never disclose any information about the inmates who called this place home. We all have known infamous names such as Paul Bernardo, Clifford Olson and Russell Williams who were sentenced to this prison but did you know that the patriarch of the "Black Donnelly's", James Donnelly spent seven years at Kingston Penitentiary for killing a man in a drunken brawl in 1857? He was facing being hung, but his wife pleaded for mercy on behalf of her husband. Canada's most notorious bank robbers Norman (Red) Ryan and Edwin Alonzo Boyd had been inmates. It was Ryan who orchestrated an escape with four other inmates over the wall with a ladder in 1923. He was recaptured three months later. There was an eight year old child, Antoine Beauche who was given a three-year sentence at KP in 1845. The wrongly convicted such as Steven Truscott and Guy Paul Morin spent time here.

There were many highlights with a grim undercurrent while visiting the different areas of the prison. In the early days, guards had to live within earshot of a siren to respond to any issues that may arise.

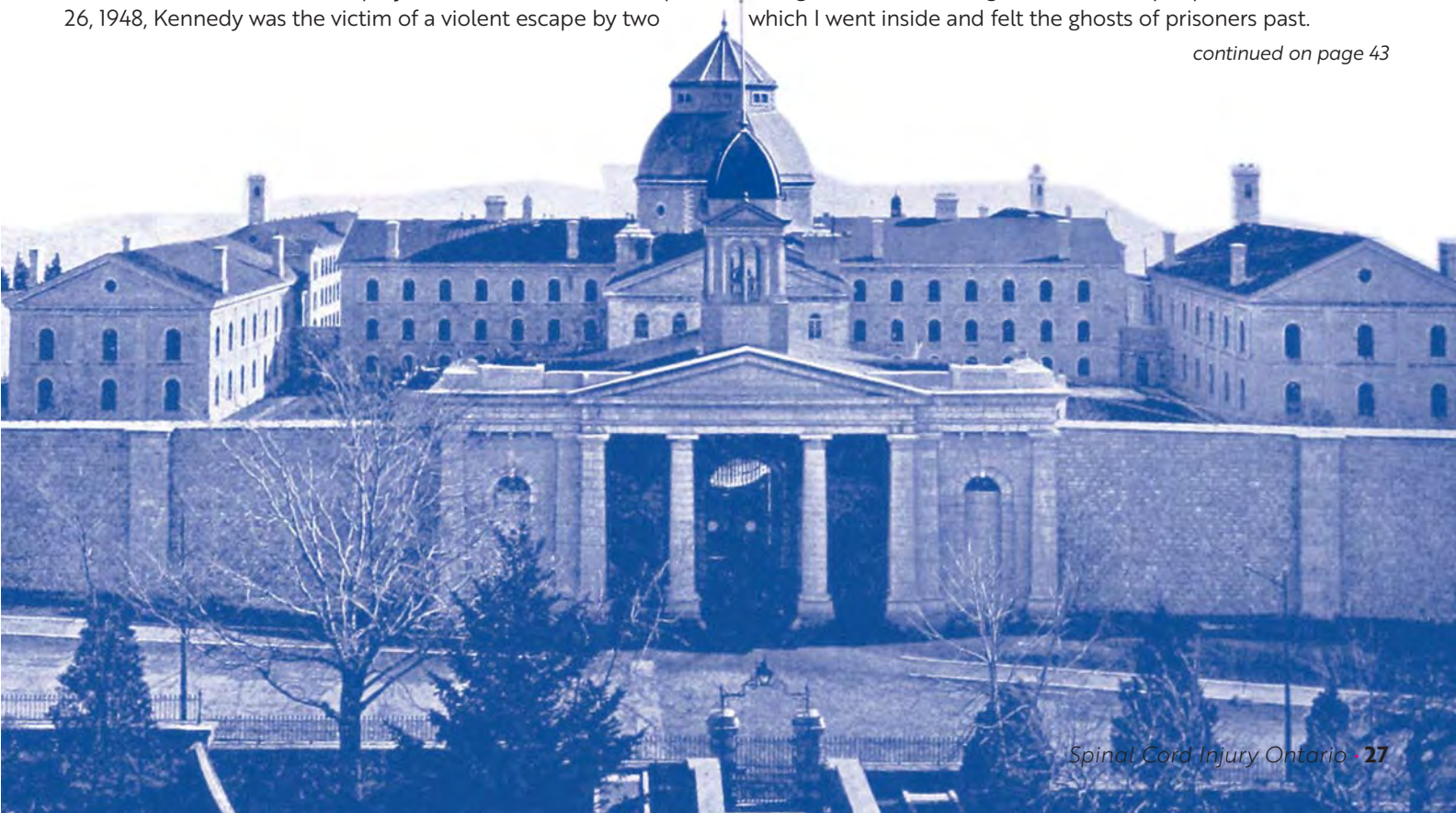
Some guards lived in the prison and raised families there. There was a story told to us of guard and messenger John D. Kennedy. The Kennedy family had a long association with KP over a number of generations. He was born in KP, raised, educated and became an employee of the institution. On April 26, 1948, Kennedy was the victim of a violent escape by two

prisoners: Austin Craft and Howard Urquhart. That morning Kennedy was driving across the penitentiary compound to the North Gate in order to exit the facility. On the way he saw inmate Austin Craft who was also on his way to the gate in order to carry out his job of disposing of garbage there. Knowing Craft, he offered him a ride to the gate. Unknown to the officer, hidden in the trunk of the car was another prisoner, named Urquhart. Once inside the gatehouse, Craft held Kennedy at gunpoint and demanded the keys to leave the penitentiary. Kennedy refused and was shot and killed. Craft then stole the keys, unlocked the main gate and left the institution in the car. This resulted in a large-scale search of the area as police across Ontario were notified of the escape. However, the search was quickly over as later that day both Craft and Urquhart were recaptured a short distance outside of Kingston in the village of Sydenham. Craft was sentenced to death in 1949. His hanging was the last execution to occur in Kingston.

Other notable areas we visited were the main rotunda. A monolith rising four tiers high with an impressive dome ceiling and an iron clad guard dome in the middle. Ranges were the spokes of the hub we stood in. Among the three major riots, it was the riot in 1971, where the first order of business was destroying the bell that was rung at every interval of an inmate's day. It was there where inmates housed in protection called "the hounds and undesirables" were brought out in the rotunda and tried by a "kangaroo court" of inmates over the four-day siege. Two of the inmates were killed and 11 injured by the time troops of the Canadian Armed forces took back control.

We would visit a range where clothes and other incidentals were left behind in the cells by inmates who were released. It was there we were told of a group of inmate's unknown to the guards who would facilitate agreements between inmates that owed "vig" to each other, or gangs to prevent beatings and more sinister retribution among the population. Another astonishing fact was each range had a cell for people with disabilities which I went inside and felt the ghosts of prisoners past.

continued on page 43



Chris Clifford has a Balanced Vision

Bergeron Clifford LLP fights for the compensation and recovery resources its clients deserve



"We get involved to ensure fair and reasonable representation on both sides. We do what we can to access the best health care and financial resources on behalf of our clients. It's only fair and right."

Before founding the injury law practice Bergeron Clifford LLP with partner Edward Bergeron, Chris Clifford worked on the defence side of the equation.

"Injury cases need good representation on both sides," Chris explains. "The system should be balanced. But it isn't. Edward and I decided we wanted to correct an imbalance when we started this firm. Which is another way of saying that we wanted to look after people."

Injury law is complicated work, but not only because both the law itself and insurance regulations are constantly changing. It's the unique nature of each case and the difficulty of accessing the best possible care and resources that requires so much experience, expertise and stamina.

"The personal connection with people is the most rewarding part of each day," Chris says. "Working on their behalf within an imperfect system can be frustrating for everyone, however. It's not just dealing with a claim against an at-fault party and

an insurance company. It's accessing benefits and every resource available to maximise recovery. In the meantime, people's lives have been turned upside down. It's a difficult time for them and a complex situation with a lot of moving parts. Our role is to move people along the journey to better health, only one part of which is the actual legal claim."

Chris is committed to improving access to financial and health resources for those with a spinal cord and other injuries. The firm lobbies for change through its involvement in the Ontario Trial Lawyers Association. It answers questions and provides advice for groups engaged in advocacy projects who need a legal opinion. It hosts fundraising events and sponsors teams like sledge hockey. And it partners with organizations like Spinal Cord Injury Ontario.

Recently, Chris accepted the 2018 Award of Appreciation from Spinal Cord Injury Ontario on behalf of Bergeron Clifford for sponsoring events in the Kingston community throughout the year. Asked about the firm's philanthropic side, Chris offered a simple response: "If there's a need and we have the resources, we get involved."

There is a need. Which is why the firm's reach extends well beyond its clients to individuals in the community and to community organizations that rely on partnerships.

"We're paddling in the same direction as Spinal Cord Injury Ontario," he says. "We share the same goals – to help people with a spinal cord injury live full lives and have access to the best services and supports. Spinal Cord Injury Ontario is a tremendous resource for our clients and for so many others. They're great people doing great things. We're huge fans."

Chris estimates that his firm represents about half a dozen clients with a spinal cord injury in any given year. In each case, as in all the others they take on, the emphasis remains on looking after people.

"We get involved to ensure fair and reasonable representation on both sides," says Chris. "We do what we can to access the best health care and financial resources on behalf of our clients. It's only fair and right." ●

ava

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

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Get Involved + Get Listed

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





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

Laura Beard's Journey: Acupuncture can make a difference and so can character

She was just 25 when I met her in 1981. A spunky, larger-than-life goldsmith with a wicked sense of humour, Big Hair and a loud, cheery voice, Laura Beard had the world by the tail.

All was great, except for a pain in her neck and arms that was aggravated by her work making and repairing antique jewellery. X-rays showed an anomaly in her neck bones that accounted for her pain. I treated her with acupuncture and got a great result, first treatment, with her lying down. She was very responsive to acupuncture. In fact, when I treated her sitting in a chair on her second visit, she promptly fainted.

It wasn't that she was afraid of needles. Laura is just really sensitive to acupuncture's effects, including usually-beneficial impacts on the autonomic nervous system, which can lower blood pressure.¹ In fact, during the first 25 years I treated her with acupuncture, she averaged fewer than four treatments a year. The treatments had long-lasting effects that allowed her to continue the work she loved, but there is also a lot of grit and determination in her character. Luckily, Laura is a strong and determined woman, because 11 years ago her world turned upside down.

A message from Laura's mom in January 2007, informed us that Laura had broken her neck in a fall while away on holiday and she was in the Critical Care Unit at Sunnybrook. Luckily, she had purchased comprehensive travel insurance that paid to airlift her to a good hospital in Jamaica and then flew her to Florida for excellent surgical care. It also paid for her husband, David Hustler, to fly from Toronto to be with her. David was an exceptional man, a perfect partner to support and care for her.

Laura and David lived on Algonquin Island, one of Toronto's islands that is accessible only by watercraft, usually the ferry that plows back and forth, weather permitting. David, an "Island Boy", had grown up there and thrived in the quirky island community renowned for its mutual support of their own. He was

known for his dry sense of humour, his artistic creativity and his undying love for Laura. They met at George Brown College in 1978, where they both were studying jewellery arts and were married in 1983.

For most of her first decade using a wheelchair, Laura was fortunate to have a wonderful nurse, Olga Marunga, with her a lot of the time, since David's work insurance covered her care. She became one of the family over time, appreciated by all for her knowledge, her intelligence, her warm and sunny personality and her wisdom.

Olga and other caregivers were there to attend to Laura during the daytime but it was David who turned her at night and took care of her personal care until his own health issues made it impossible. David had a kidney transplant at the young age of 21 that kept him well and functional for most of 40 years. Tragically, he passed away in July of 2017, of cancer related to his anti-rejection treatment. This was a huge loss to Laura and to everyone who knew him.

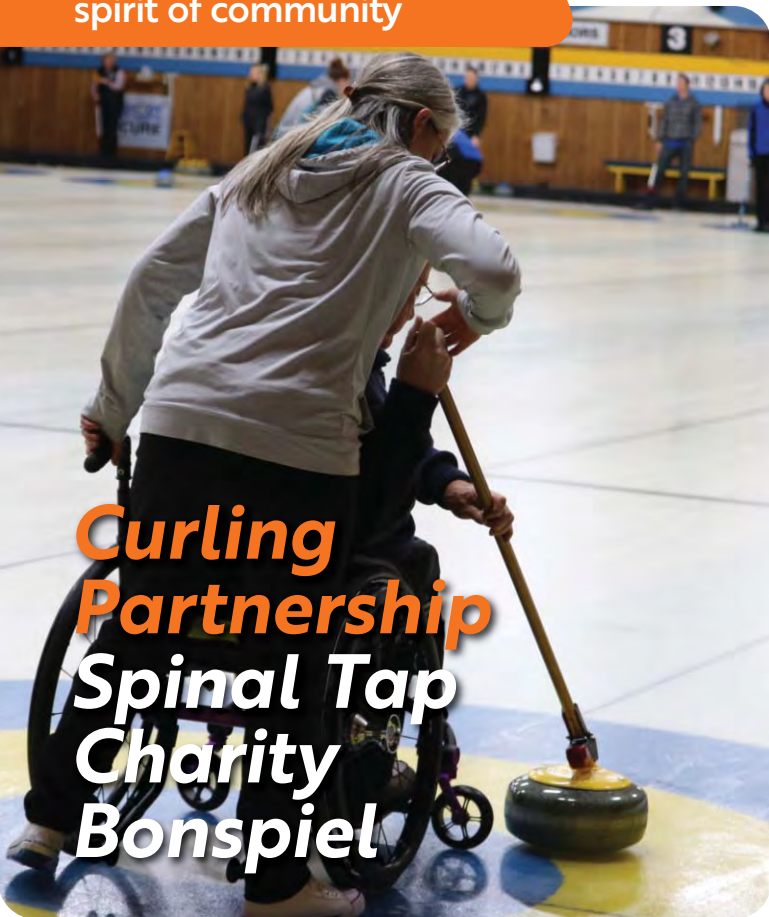
Since David's death, Laura has been cared for by a team of wonderful Island Women who take turns "putting her to bed" and she has several other caregivers who come to her and make it possible for her to stay on the Island for now. Regrettably, it is getting harder all the time to find personal support people who are willing to travel to this jewel of a place.

Since 2007, I have continued to treat Laura with acupuncture and nutritional advice that is important for her comfort and well-being. She takes the ferry on her own to the mainland, speeds along to Sherbourne Street in her chair and boards a TTC bus to my clinic once every few weeks. We catch up while I treat her with acupuncture to reduce pain, lift her mood, and even help with her hemorrhoids (yes, an acupuncture point on the top of your head can actually help with that!).

As spunky, optimistic, strong, likeable people go, Laura Beard is a star. She is an inspiration to many of us who have been privileged to know her, in my case for 37 years. ●



¹ Li Q-Q, Shi G-X, et al. *Acupuncture Effect and Central Autonomic Regulation. Evidence-Based Complementary and Alternative Medicine* Volume 2013, Article ID 2 267959, 6 pages. <https://www.hindawi.com/journals/ecam/2013/267959/>



Curling Partnership Spinal Tap Charity Bonspiel

For the first time on Saturday March 30, 2019, Spinal Cord Injury Ontario will be partnering with the Canadian Spinal Research Organization (CSRO) for their 28th Annual Spinal Tap Charity Bonspiel at the Thornhill Country Club. To date, the CSRO has raised more than \$665,000 to support spinal cord injury research and wheelchair curling programs. The majority of the funds were raised by ongoing supporters, by collecting donations from family, friends and co-workers. This year, the event is in support of Spinal Cord Injury Ontario and all of our services in addition to the CSRO.

For more information, visit www.csro.com/spinaltap2019.

EVENT DETAILS:

March 30, 2019, All Day Event

Thornhill Country Club

\$480 per team (\$120 per person)

REGISTRATION INCLUDES:

- Two 6-end games
- Hollywood Red Carpet themed Dinner & Dance Raffle & Silent Auction
- Entry to the Wheelchair Button Challenge

Correction: In the Fall 2018 issue of Community we featured Michelle Earle: On gratitude; adapting to change and the importance of asking for help. Please note that Michelle's correct blog address is wheeladventures.wordpress.com.

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TEAM ONTARIO

By Wayne MacDonald

1. Team Rees and the Edmonton team
2. Team Rees and the Korean team
3. Team Rees
4. Fantastic scenery on our road trip from Vancouver to Squamish, BC

When I began my curling journey back in 2015, I could have never predicted the experiences that would follow over the four seasons thus far.

The journey began with learning the nuances of the game and developing as a player. The competitive play at a very high level further developed my skills and desire to always strive to improve. I struggled with not finding the right mix of teammates the first two seasons but all of that changed when I received a call from Shauna Petrie and was invited onto Team Rees in 2017. I played many games against them and marvelled at the skill level of the team along with their skip Chris Rees. Chris would make shots that were worthy for able body competition. What was even more compelling was the fact that Chris has quadriplegia with seven nationals under his belt. I would see him preparing before competitions using a special glove with Velcro straps at the fingertips. He would use those along with duct tape to create the shape of the letter "O", so the end of the delivery stick would fit in his hand. The result was an individual with an impressive ability. As much as I admired them, it turned out I was equally admired for my persistence, dedication and hunger to compete.

We began as a team with the 2017 Kathy Kerr international bonspiel in Ottawa. It was my first international competition in Canada, and our team would end up playing Switzerland in the finals and win the competition. We all continued to practice and prepare for the ultimate competition competing in the Provincial championships which were held at the home club in Toronto at the Toronto Cricket and Curling Club. I spent a lot of hours on the ice in Ilderton to prepare for this competition because I felt I was the weakest link and strived to be at my best.

Team Rees would go on to be undefeated in round robin and win the finals to represent Ontario at the National Championships in Leduc, Alberta at the end of March. It was back on the ice to practice, practice and practice. I was amazed at my good fortune being part of such a powerful team.

The other aspect of being part of the competitive circuit is funding. Since Curling Canada covered a percentage of the costs for us to go to Leduc, we had to come up with some funds. One of our teammates, Shauna Petrie, was fortunate to have a club coach whose son owned a company called Hairy Tarantula and she was able to secure a very nice sponsorship from them. We also held a very successful St. Patrick's Day fundraiser at my home club in Ilderton, complete with silent auction and live music provided by yours truly. The club members were amazing with their generosity and support, and the club manager Bruce left no stone unturned to help our team. I was later featured on Rogers TV regarding our journey to Nationals. We would come in fifth place in Leduc, but the experience was second to none and I was also proud of representing our province in my third year of curling!

The summer passed and it was back on the ice to begin the new season. Now that we had secured funds that were enough to allow us to enter local bonspiels along with a major event held in Richmond, BC, from November 14-18, 2017. We arrived

in Richmond on November 14, for the 12th Annual Canadian Open. There were teams from all across Canada along with three Korean teams. From the opening ceremonies, I was pumped to be part of something I had only heard about.

Shauna did an awesome job getting us there and having a hotel within wheeling distance of the venue. We would not fare well that week and decided to shuffle the line-up for the last day. I was now shooting lead rocks, Jim was second, Shauna being vice and Chris, skip. We seemed to be stronger that day but it was too late. For the final day Jim, his wife and I were treated to a road trip through Vancouver all the way out to Squamish. The scenery was spectacular and our tour guide was fantastic, although a little crazy on the winding road towards Whistler. We would take the red eye back to London that evening. The following weekend our team competed in the Kathy Kerr in Ottawa. With the new positions, we finished in fifth place. We competed next in Peterborough where we would be in the final game to place second. It seemed that our performance was in an upward trajectory which pleased us all. We were also looking for a new coach and Shauna was very interested in Marv Schmitt who owns Western Ontario

Curling Resource and Training Centre Ltd. He had many years of coaching experience and we were all delighted when he agreed to come on board.

The Provincial competition was held January 3, this year, at City View Curling Club in Ottawa. It was much earlier than last year's competition, so we all had to be ready to go right after the Christmas break. We arrived the evening before the event and with our new coach we planned our strategy for the next couple of days. We all wanted to make it to the finals and keep our title.

Through the round robin play we would have a one and two record. With our draw to the button we would be playing Team Bax in the semifinal. The game began at 10:00 a.m. and by the fourth end we were down 7-0. During the fourth end break our coach told us we were strong and could come back. In the next four ends we would steal two points per end to tie the game. An extra end would decide the winner. Our coach was thrilled with the turn of events, as were we. My first two rocks were in the house and their lead missed both of his take outs. The momentum seemed to clearly be continuing in our favour. Guards were placed and we would win the right to play Team Armstrong in the final. We had not fared well in the round robin against them but they had seen our comeback against Bax, so I know they were feeling the pressure. Our final game began at 2:00 pm with a tie game to the fifth end. In the end, we would lose but the fact we had been in the finals two years running was not lost on me. I drove home feeling pretty good about our future.

Now that we have an experienced coach with strong players, I see Team Rees being the team to beat for years to come. ●

We arrived in Richmond on November 14, for the 12th Annual Canadian Open. There were teams from all across Canada along with three Korean teams. From the opening ceremonies, I was pumped to be part of something I had only heard about.



Para DanceSport Continues to Break Ground in Canada

By Iris Kulbatski, PhD

On October 20, 2018, dance enthusiasts of all ages and abilities gathered at the Thornhill Community Centre to commemorate the excitement and beauty of ballroom and Latin dance sportsmanship, artistry and entertainment. In collaboration with Canada and Ontario DanceSport's Ontario Open Championships, WHEEL DANCE held its Third Annual Canadian Para DanceSport Competition and Showcase.

The Ontario Open Championships are a full day and evening of amateur DanceSport competitions. WHEEL DANCE's Para DanceSport events included competitive Para DanceSport as well as showcase performances. Unique to Canada and North America, this competition has attracted Para DanceSport athletes from Canada, U.S.A. and Mexico over the past three years. This year, the event celebrated the culmination of dance training by WHEEL DANCE members, the ongoing recognition of WHEEL DANCE as an Associate Member of Canada DanceSport, and the receipt of a generous Collaborative Grow Grant from the Ontario Trillium Foundation (OTF) in support of the growth and development of Para DanceSport in Ontario and Canada.

Since 2014, WHEEL DANCE has received generous funding from the OTF. The new Grow Grant, awarded to WHEEL DANCE, Canada DanceSport and Ontario DanceSport, is a testament to the power of collaboration. Over the next three years, the grant will be used to develop an internationally recognized Para DanceSport program, to eliminate barriers

continued on page 44





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Morgan Austin's job is to help clients live their best lives possible after a spinal cord injury. It's also his calling and his passion.

Avast region. Remote locations. Fly-in communities. Close ties to the land.

There isn't one phrase to describe the Thunder Bay and surrounding area that Spinal Cord Injury Ontario's Regional Services Co-ordinator Morgan Austin oversees. It is an immense territory marked by diversity, complexity and, sometimes, extremes. City dwellers and isolated populations. Varied cultural backgrounds, including indigenous communities. Places where roads end but settled areas continue on. Logistical challenges in accessing goods and services. Extreme weather for months on end. Breathtaking beauty year-round.

"There are a lot of differences in people, cultures and regions out here," says Morgan. "My role is to help each person who needs our services to navigate the health care and support system – from the first moment of injury to wherever they want to go in life. A big part of what I do is help people identify their own barriers – to returning home, education, work, achieving life goals. I see myself as a translator of a large system and a problem solver."

To succeed in his role, Morgan holds one principle in mind above all others when working with clients from the moment of injury onward: listen and learn.

"My work is based on relationships," he says. "And relating to people in the north means sharing stories. Every person moves through their journey after a spinal cord injury in their own way. Some of those differences are rooted in culture and some are individual. I need to learn before I can help. Especially when it comes to working with indigenous communities. There is a history of colonialism in the health care system, just as everywhere else in this country. It's a very complicated situation. Approaching people in a respectful manner means being aware of past histories. It means listening first."

Morgan's goal isn't just to provide access to services but to help clients develop the skillset they need to succeed at their own goals. Given the vastness of the region, that path varies greatly from person to person and place to place. Some clients plan to return to their office job in the city; others want to continue to hunt, fish and trap on the land year-round. Some can be picked up at the hospital and driven home to begin the next stage of their recovery; others fly back to a remote community and receive ongoing support there.

"Space and distance provide their challenges," says Morgan.



The Honourable Raymond Cho, Minister of Seniors and Accessibility with Morgan Austin.

"Travelling to receive services can be hard – long distances and difficult weather at times. And passing along goods can be hard. We had one client living in a remote area who needed a ramp for his home. It was designed at our end, so we could send the right lumber and build instructions. Then we fundraised for the cost of the wood and the cost of flying it in. We also had to consider, who is going to build it – is there a family member, a friend? Communication can be slow, as lots of people in this region don't have computers or internet access. It took months to get this ramp designed, paid for, sent and installed. If you live in Toronto, you don't face these logistical complexities."

The hospitals and health centres in the Thunder Bay region also do not have the support networks that can be found in a city like Toronto. It's a changing health care landscape where even the service providers are struggling with time, distance and funding. Morgan maintains relationships with partner organizations, services and individuals across the region to co-ordinate support. Sometimes he needs to call on a chain of contacts to transport something like a wheelchair from the city to a client. The chair may hitch a ride on several vehicles driven by people who don't know the client personally and aren't part of the health care system but are willing to help along the journey.

Logistical challenges, access to rehab and regular health care, modifications to homes never seen, communication difficulties, variability in client culture and lifestyle – these are the daily challenges Morgan faces. It can be frustrating work at times.

"Things can move slowly," he says. "And there are limited resources. But I consider this work to be a gift. I spend a lot of time getting to know people during a difficult period in their life. Being able to advocate for them is the most enriching part of my work. My role is to see two, three, four roads ahead for systemic navigation of the whole system. My role is also to be led and guided by the client. I'm passionate about those relationships and advocating on their behalf."

Originally from the south, Morgan has been living in the Thunder Bay region and building those relationships for 15 years now.

"I admire the fabric of the people here," Morgan adds. "There is so much resilience and strength in everyone I have met. And a tremendous sense of community. To be successful in this work, you need to have a footprint in the community. Being involved, attending events, playing sports, sharing stories, knowing as many people as possible. That's a big part of what I do. And I consider it a privilege." ●

Peer Support in the North

A conversation with Peer Support Co-ordinator Matt M., who brings practical knowledge and experience to those who need it in the Thunder Bay area.

Q: What do you do as Peer Support Co-ordinator?

Matt: I connect people like me – people living with a spinal cord injury – to anyone newly injured, or even people with an old injury, to help create a better situation for independent living. There are two of us here and we share our real-world experience. Sometimes I call us general factotums of disability from a lived experience point of view. We're happy to help out in any way we can.

Q: What do people need the most help with?

Matt: Given the sheer size of this area, transportation is at the top of the list. It's a very spread out population, and the distances that need to be travelled sometimes are immense. Getting to a medical facility or even just out to an event can be a challenge. Or when getting discharged from the hospital, it's not good if someone is just going to be readmitted because they can't access services or groceries. People also want to participate in the community – socialize and enjoy events.

Q: What are some other unique challenges of working in the Thunder Bay region?

Matt: There are different micro climates based on proximity to Lake Superior, so weather changes a lot. It can be minus 30C one day and plus 1C in the next breath. Also, because of distances, isolation can create difficulties, not just for accessing services but also for mental health. It can be hard, especially early on, to get out and connect with others. That can be tough mentally and emotionally. Transferring safely in and out of aircraft or boats is another challenge that comes to mind. We don't just rely on trucks and vans. In Toronto, you're generally not trying to move a person from a wheelchair into a Cessna. And with weight restrictions, only so much equipment can come along with someone.

Q: How else do you share your lived experience with others?

Matt: By providing a lot of practical details. For example, a lot of people don't have paved roads, so how do you use your wheelchair to get around? I have personal experience with that. Or if someone wants to play sports or get back to hunting, how to do that? Sometimes I work on setting up community events, sometimes I connect people to groups. For example, Wounded Warriors or Paralyzed Veterans of America can help people get back out on the land. That's where who you know and networking can come in.

Q: What can be unexpected about your work?

Matt: Well, you actually expect people to reach out at any time. There aren't really any off-hours. We might get a call at 9:00 pm because someone is out in the rain or snow and

their power chair died on them. Of course, you always answer the phone. And then you call on your network – you know a guy who knows a guy and you go down the chain. And then 20 minutes later, the person who called is in a van and the wheelchair is also loaded in and we're working on getting the battery fixed. Sometimes peer support is also peers of peers, at any time of the day or night.

Q: What do you like best about what you do?

Matt: I like the practical elements of helping. For example, keeping in mind that people who have difficulty accessing medical services also don't have the internet or Google. They need written resources and materials – hard copies. Or helping people achieve mobility outside the home. Basically, the practical side of life that reaches beyond a textbook: daily living, how to use equipment in the real world, how to network for resources. That's where experience is invaluable. ●

Spinal Cord Injury Ontario's Young Professionals Board's 4th Annual Comedy Night

COME OUT AND SHARE SOME GREAT LAUGHS!

On March 6, get ready for a fun night out with friends that is guaranteed to be filled with laughter. Spinal Cord Injury Ontario's Young Professional Board is pleased to present this year's 4th annual Comedy Night at YWCA. Our diverse group of comedians this year is sure to bring out the laughs!



All proceeds benefit Spinal Cord Injury Ontario's service, support and advocacy programs for people with spinal cord injury and their families.

EVENT DETAILS

Date: March 6

Time: 7:00 pm – 8:00 pm cocktails and hors d'oeuvres
8:00 pm – 10:00 pm Comedy Show

Place: 87 Elm Street, Toronto, ON M5G 0A8

Tickets: \$50 per person

To register please visit:

<https://sciontario.org/comedynight>



Help Make Exoskeleton Better: Take the Survey...

By Stefane Guevremont



ExoPlus Solutions, a company based in London, Ontario is working on a new design of Exoskeleton. The founder, Mitchel Brogan, has several other projects and companies to his credit. Among others, Able Bionics which is a nonprofit organization that helps people walk again using exoskeleton therapy. (Able Bionics website: www.ablebionics.com.)



ExoPlus Solutions' current project is a design and build of a new type of exoskeleton which will enable the wearer to walk on all fours, crouch, get up and walk upright. (ExoPlus Solutions website: www.exopl.us.)

Some reasons that lead our company to choose this design were:

- Walking on all fours is the natural progression of the human being towards walking in an upright position;
- Some studies point to the possibility for recovery of a partial spinal cord injury, using quadrupedal exercises;
- An exoskeleton that can move in all these positions provides greater autonomy for the user.

At ExoPlus Solutions, we are seeking honest feedback on the design with professionals and consumers, and to do this, we are asking you to take a five-minute survey. All responses are voluntary and are confidential. Responses will not be identified by individual. All responses will be compiled together and analyzed as a group.

To complete our survey, please visit:

<https://goo.gl/forms/OzXlpHMABenCvAqu2>.

Thank you so much in advance for your contribution, in this endeavour, to create something that changes our world.

Sincerely,

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Introducing Young Professionals Board Members

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Adventure Race, to break down barriers of who can participate together in sport. I also have six years of experience in the tourism industry and have led accessible tours, and I am a technical committee member for the Standards Council of Canada/International Organization for Standardization to help form standards for accessible tourism in Canada and beyond.

I love working on the Young Professionals Board in creative and productive ways and I am very much looking forward to the 2019 Comedy night!

Chris Stigas

In November 2014, I sustained a C5 C6 spinal cord injury. Prior to that I worked as a commercial industrial electrician. Since then my life has done a complete 180° turn. All of the things I thought mattered, really didn't matter. I now had to face a whole new world of actual problems, adaptations, and just simply surviving day to day, literally minute to minute.

My journey has taken me through the full spectrum of the health care system from the 911 call, to emergency decompression surgery, ICU, inpatient, outpatient, rehab, transitional housing, and finally living independently in the community.

As my recovery progressed, I began to look at how I could re-engage myself with life. Advocacy quickly became a natural and easy fit for me. Now four years out I am on the Accessibility for Ontarians with Disabilities Act Council for the United Health Network, I have recently been appointed by the City of Toronto to the Advisory Council on Accessibility to the TTC (ACAT). In between all that I have managed to create my own product called the HandiCup which is a para and tetraplegic friendly cup holder for both manual and power wheelchairs that is available online.

This past October I rolled my first 5k marathon, and was the highest fundraiser for Spinal Cord Injury Ontario. From there I was invited to the Young Professionals Board, and I happily accepted. So far, I have only participated in one general meeting, but I consider myself a very resourceful and positive person. I am graciously excited to bring these qualities to the Young Professionals Board and help move forward the fantastic work they and all their people do for 2019 and years to come any way I can. ●



Anita Kaiser

continued from page 16

We're honoured as a family to keep Patti's memory alive with this award – and pleased that Anita has received it."

Anita holds Patti in mind in all of her activism and advocacy work, and in particular as a Peer Support Volunteer.

"I think of Patti's impact on me when I saw her in Lyndhurst. She opened my mind. Since my injury, I have gone back to school, got married, had a child, and got involved in sports. You can have a spinal cord injury and achieve your dreams. You can also help yourself and others at the same time. I want to have the kind of impact on others that Patti had on me."

Asked about her reaction to receiving an award with Patti's name on it, Anita tears up.

"You don't get into advocacy for accolades. But this is such a personally poignant award for me. It's a reminder of Patti's journey and mentorship. I picture her smiling at me and giving a big thumb's up. That means a lot to me." ●

Sumner & Lang is a writing team in King City, Ontario, that loves working with Spinal Cord Injury Ontario.

Accessible Yellowstone National Park

continued from page 14



nice pair of gloves and maybe be willing to temporarily surrender your pride by asking others to push you.

This vacation turned out to be one of the most affordable as well. The ticket to the park cost us \$35 per week/per vehicle. We spent around \$500+/person on plane tickets during low-season. You can decide how much you want to spend on your accommodation and rental vehicles. You can save by booking your stay via Airbnb, though their location might not be the most ideal.

I really encourage you to go and you will be amazed and humbled by nature's craftsmanship. Don't worry about a possible volcano explosion; any local will tell you that they'd rather stay exactly where they are than have to survive a volcanic winter elsewhere in North America.

The parks are huge and there are many hidden gems. I have a detailed travel plan and many more tips to share. Please get in touch with me for information at nancy.xia@sciontario.org or drop in the Resource Centre at Toronto Rehab – Lyndhurst Centre. ●

The UK Leads the Way

continued from page 18

GRANTS CAN BE USED TO PAY FOR:

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- Through Floor Lifts
- Wider Doors
- Wet Room (bathroom) with Zero Threshold Shower
- Accessible Controls
- Stairlifts
- Ceiling Tracks
- Accessible Toilet
- Accessible Kitchen
- Improved Heating
- Safety Features

I'm impressed with the UK model for organizing and funding home modifications for a number of reasons. First, the UK government has acknowledged the benefit, both economic and socially, to keeping older adults and people with disabilities in their homes and the community in which they feel comfortable for as long as the person chooses.

the modified home for at least five years. Approximately 40% of applicants are tenants, and 60% are homeowners.

I'm impressed with the UK model for organizing and funding home modifications for a number of reasons. First, the UK government has acknowledged the benefit, both economic and socially, to keeping older adults and people with disabilities in their homes and the community in which they feel comfortable for as long as the person chooses.

Second, having an established network of home modification contractors is crucial and third, the involvement of an OT at the start of the process is another important factor.

Here in Canada, the Canadian Home Builders Association (CHBA) is leading the way with the formation of a network of expert home modification contractors across the country. And the CHBA recognizes and embraces the importance of OTs throughout the process. These are two important steps towards creating a viable and sustainable home modification model in Canada.

For more information on home modifications in the United Kingdom, Foundations or Disabled Facilities Grants you can visit these websites: www.AdaptMyHome.org.uk and wwwFOUNDATIONS.uk.com. ●

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Four Steps to Clicking the Internal "Refresh" Button

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Or maybe you noticed judgments about the exercise?

The key is to catch yourself when your mind pulls you away from the things you need to do to take care of yourself – and then redirect to the present moment.

Let's Practice: A simple way to practice stepping back and observing thoughts is to start speaking about your thoughts as thoughts, rather than facts. Take a full minute or two to just sit in silence. Soon your mind will start generating thoughts. Preface each thought with; "I'm noticing I'm having the thought." And then redirect your attention to your 'direct experience': the things you can touch, smell, taste, or hear.

STEP IV: CHANGE YOUR REACTIONS

One of the largest predictors of the effects of stress on our mental and emotional well-being is how we react to triggers in our lives. Our reactions may be larger more obvious discomfort avoidance behaviours, such as using substances, yelling or arguing. Or our reactions might be that insidious way we tighten our shoulders, furrow our brow, or clench our teeth.

Maybe others notice, maybe they don't. But your reaction has a huge impact on your stress levels and mental health.

So, the key here is to control the only thing in your control, which is your actions.

Let's Practice: Right now, as you read these words, practice with me. Sit up as much as possible in an relaxed but attentive position. Place both palms on your knees and up towards the sky as you allow your shoulders to drop down. Open your chest, and soften your belly. Notice how you feel, in this very moment.

This simple practice sends a powerful message from your body and up into your mind. It says, "I am open to my experience. I am safe. There is no danger present." From an evolutionary view, you simply would not take this position if there was a real physical threat.

It can feel very much like we're not safe when we're stressed and burnt out. In truth, you are safe, you've got this. Practice these four simple steps to reconnect to your big picture values, and mindfully master the discomfort that comes up as you pursue what matters. ●

LARA E. FIELDING, PsyD., Ed.M., is a psychologist who specializes in using mindfulness-based therapies to manage stress and strong emotions. She studied the psychophysiology of stress and emotions at the University of California, Los Angeles and Harvard, before getting her doctorate at Pepperdine University graduate school of education and psychology, where she is currently adjunct professor. In her private practice in Beverly Hills, CA, she specializes in treating young adults challenged by the stresses of transitioning roles and responsibilities resulting in difficulties with mood, motivation, and emotion regulation. Her values mission, and aim of her work, is to empower young adults through self-awareness, bridge the gap between research and people, and lowering barriers to availability of science-based mental health interventions.

To learn more, visit mindful-mastery.com.

Connect with Lara Fielding on Facebook, Twitter, Instagram and LinkedIn.

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The great benefits for your company in partnering with Spinal Cord Injury Ontario include exposure to a dynamic community of over 30,000 clients, families and friends from across the province and Canada.

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We will work with you to create a customized corporate engagement plan, which can include sponsorships, cause-related marketing programs, participation in fundraising events, corporate and employee volunteering, and workplace giving.

As a small grass roots non-profit, we guarantee that your corporate participation will have great impact for

people living with a spinal cord injury in your community and across the province, and satisfy your business partnership needs.

PARTNERSHIP OPTIONS

The following partnerships offer many benefits including enhanced brand awareness, community reputation and employee spirit.

Philanthropy

As a registered Canadian charity with over 73 years of history in Ontario, we will provide you with tax benefits, a tax receipt and recognition for your financial support. You also receive peace of mind from knowing your investment in SCIO directly impacts the services, support and advocacy we provide to strengthen our community.

Sponsorship

Here are a few dynamic and engaging sponsorship opportunities to consider:

- Promote a strong presence of your company at popular community events in Toronto and across the province.
- Outline your business offerings on a relevant topic within the Living with an SCI section of our website (give us your logo, ad and a link to your content and we're good to go!)
- Become a go-to company for our community by getting listed. Your brand on our popular online business directory is a smart match.
- Get your workforce up to speed on expert disability awareness training for your HR department and staff. Online or in person, our training is developed and often delivered by those with lived experience.

Cause-related marketing

Harness the brand equity of Spinal Cord Injury Ontario by creating a special promotion that is mutually beneficial, advertises your company's brand and supports a cause close to the hearts of your customers and employees.

Corporate teams

Form a corporate team to participate in fun activities-based events such as golf, curling, snowboarding or lawn bowling. There's always something exciting going on at SCIO.

Gifts in kind

We accept gifts of goods, products, services and used vehicles – items our community is always in need of, and highly appreciative of receiving. Your gift will be evaluated in accordance with our gift acceptance policy.

Employee engagement and volunteering

Getting involved with SCIO is a fantastic team-building and volunteer opportunity that will motivate and unite your employees. On your company employee volunteer day, consider coming to work for us. We can customize an opportunity that helps you to meet your business and social responsibility goals while raising your company's profile in the community.

Event hosting

Raise awareness for your company by organizing a fundraising event or golf tournament on our behalf. Our team will guide you through the process of creating a successful event.

Matching gifts

Maximize and encourage employee giving by matching your staff's charitable contributions or create a corporate matching challenge.

Workplace giving

Start an employee fund drive offering workers the opportunity to make a one-time gift or spread out payroll deductions over the course of a year.

Advertising in Community Magazine

Our quarterly magazine reaches about 12,000 consumers. You can broadcast your corporate logo and unique messaging, and receive recognition from SCIO for your generous support.

Board and committee roles

Do you have a specialized skill set? Or a depth of knowledge about living with an SCI or disability? There are committee and board roles across the province with your name on them.

CAN WE TALK?

We'd love to chat with you on any of these opportunities. Please connect with Ari Wahl, 416-422-5644, ext. 264 or philanthropy@sciontario.org ●

Examining the impact of Virtual Integration Platform for individuals with Spinal Cord Injury (VIP-4-SCI)

During this study you will have access to a web-based platform that will allow you to virtually connect with your network of care (including your SCIO Regional and/or Peer Co-ordinators) using your computer, tablet or mobile phone. You'll have access to the web platform for one year and will be asked to complete a brief survey after each use of the video consultation feature so that the usage of the platform can be evaluated by the research team.

ARE YOU SUITABLE TO PARTICIPATE?

To participate in the study, you:

- live in Ontario
- are a client with Spinal Cord Injury Ontario
- can be male or female

You will not be able to participate in the study if:

- you are not comfortable communicating in English
- you have no access to a mobile phone, computer or tablet with an internet connection

If you have questions regarding this study and your potential participation, you may contact:

Dr. Chip Rowan 416-597-3422, ext. 6217 | chip.rowan@uhn.ca

fora**healthy**me™



INVESTIGATORS ON THIS STUDY INCLUDE:

Principal Investigators: Dr. B Catharine Craven

Co-investigators: Mr. Courtney Cole, Dr. Stuart Howe, Dr. James Milligan

This study is funded by:



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Where Next Happens

Home at Last



By Nancy Xia, Community Resource & Education Assistant



In Dean Wardak's collection of memorabilia, there is one item that weighs quite heavily in his heart. It's a newspaper article that dates back to April 2011. The article is entitled *Teen in Critical Condition*. It talks about a young man who had crashed into a tree driving 100 km/hr in a 40 zone. The driver was badly mangled in the smashed vehicle. It took firefighters 45 minutes to get him out. He was found without vital signs. In the photo, the scene of the crash was like a war zone with small pieces of the wreckage scattered everywhere. That driver was Dean.

He remembered nothing of that night. In his father David's account of the story, Dean was attending his best friend's 18th birthday party that evening. Planning to get drunk, he walked to his friend's house. By the end of the party, Dean was so intoxicated that he stumbled home without any shoes or a jacket. When he reached his house, with a hazy mind, he got into the family's parked

car and drove off without a destination. When David found out that Dean still had not returned and the car was missing in the driveway, he was hectic and went in search of Dean in the middle of the night. When he finally saw a host of bright lights in the distance, he ran towards them knowing that they were the lights of police cruisers, ambulance and fire trucks. David was in total despair when he arrived at the scene and the only way he recognized the vehicle was by its license plate. Worse yet, when Dean was pulled from the wreckage, his son was beyond recognition.

Dean was resuscitated in the ambulance that took him to Credit Valley Hospital in Mississauga. One of the Emergency Room nurses attended the same church as the family. She was not optimistic about his survival and carefully suggested that it might be necessary to call their priest to give Dean his last rites. After a few imaging exams, Dean was found to have sustained a severe brain injury and a spinal cord injury at the C7 level. He was then transferred to St. Michael's Hospital where there was a more advanced trauma unit.

In the next two weeks, Dean was in a deep coma, attached to every type of tube and machine available to keep him alive. During a family meeting, the doctors brought up the option of pulling the plugs on him since they did not think Dean would ever wake up. His family had already lost Dean's mother in 2007.

Refusing to give up, they turned to their church and all their friends for prayers. His family congregated in his room every day to beg for a divine intervention.

Dean's stepmom Ruth is a professional singer and she would sing to Dean every time she was visiting. One night, when she ran out of songs to sing, she started singing *Rock-a-bye-baby*. Little did she know that when Dean was a baby, his parents received a gift of a mobile to hang above his crib, and it played *Rock-a-Bye-Baby*. It was supposed to soothe him, but every time it played, Dean would burst out in a crying fit. This time, when Ruth sang *Rock-a-Bye-Baby*, Dean's eyes opened. (Later on, they would joke that Dean had woken up because he wanted her to "zip it".

The prognosis was not good though. For weeks, Dean was unresponsive to any stimulus. All he did was stare blankly at the ceiling, which the doctors said would be the only thing that he could ever do. Prior to his injury, Dean was very active and sporty. He was the lead singer in a band and often performed in the school's talent shows. He loved baseball, hockey and snowboarding. He played in the Mississauga Hockey League and was a member of his school's curling team. It was devastating to think that he might not ever be able to speak or move again.

During one prayer vigil, when Dean's brother Chris was standing at the end of the bed, he thought that Dean was looking at him, but he wasn't sure. So, he raised his eyebrows at him, and Dean raised his eyebrows to copy him. Chris got everyone's attention. He raised his eyebrows again. Dean followed. That was the very first time he reacted to anything. Everyone cheered and Dean started laughing too. This glimpse of hope dared them to believe in more. Surely a week later, Dean said his first word by calling his stepmom "Mama." And for the next few days, he kept on calling Ruth 'Mama', until one night, when Ruth came to visit and said, "Mama is here." Dean responded, "Hi Ruth." Two months after the collision, Dean's self-awareness came back, but his mentality was like that of a

His powerful testimony of resilience and human strength has touched thousands of people in local schools and churches. Cancer patients have come up to him and told him how much they were inspired to fight their illness with hope and positivity.

two-year-old. He was able to participate in simple conversations, but he could not understand where he was and who he was. David was determined to raise him from scratch all over again and believed that he would grow up faster this time.

David took on the responsibility of being the primary caregiver. With motherly tenderness, he helped Dean with feeding, showering, dressing, getting in and out of bed, and almost every single task of his daily living. He was also his therapist. When Dean's eyes were crossed, David was determined to fix them by placing his index fingers in front of his eyes and asking Dean to look straight at the fingers. Dean also had problems with controlling

his facial muscles. He would make funny expressions every time he moved his legs. David put a mirror in front of him to make him more aware of this habit.

When Dean was severely depressed over his disabilities, David had to become his emotional punching bag, sharing his pain and burden. David rarely got angry when Dean had these moments. The rest of the family was also amazing. His grandmother Rena, brother Chris and sister Chantelle took responsibility in caring for him. They would accompany him to doctor's appointments. When David couldn't be there, they would help him get in and out of bed and make sure that he was well fed. During his darkest period, Dean turned to his friend Emily who works as an elementary school teacher. Being a great listener and life coach, she helped Dean realize that he still had a wicked sense of humour and an adorable personality. She helped Dean embrace his new self and encouraged him to kick-start a new life.

Today, Dean is almost eight years post injury. With the support of all of his family and friends, he has rebuilt his life in every way. Though his hands and arms are still a work in progress, he is able to stand and walk with aids. He graduated from Sheridan College with straight As and is now enrolled in the Professional Writing Program in York University. He is a motivational speaker who informs young people about dangerous driving habits. His powerful testimony of resilience and human strength has touched thousands of people in local schools and churches. Cancer patients have come up to him and told him how much they were inspired to fight their illness with hope and positivity.

Dean still treasures that newspaper article. At the time, it helped him fully comprehend why he was in the hospital. But today, the article shows him how far he has moved forward from that point. Dean is now looking ahead to make more use of his story and his talents. With his loved ones supporting him, he knows that everything is possible for his future.

Visit Dean's website at www.putyourheadingear.com. ●

My time in the Pen *continued from page 27*

The segregation unit held inmates due to mental illness, protection from gangs or because of their crimes like Bernardo's. They would spend 23 hours a day in these cells. The cells were actually bigger with windows than those on the range, and some inmates would try and get into trouble to acquire one of these larger cells with windows.

There was an enclosed children's play area inside the prison for family weekends. Each unit was separated by fencing and there always had to be someone visible to the guards at the window of these tiny units at all times during visits. The workshop was another impressive structure inside the walls. It fell victim to an inferno set using the chemicals available to the inmates during workshop hours. With the thick limestone walls it was still standing despite the fire. We would also see a hospital, a psychiatric hospital, a gymnasium, exercise yard and vocational shop.

One of the last stories we were told was of an investigation called Correct Zero. KP became a "dumping ground for bad guards," with some guards terrorizing fellow staff and inmates, according to a 1989 report commissioned by KP's warden. In 1999, new warden Monty Bourke requested the RCMP begin an investigation code-named Correct Zero that would use inmates as paid informants. Eight guards were fired, although one firing was overturned. Two of the implicated guards killed themselves before the investigation went public. An informant told CBC Radio News in 2001, under instructions from special prison investigators, he bought and sold booze, marijuana, cocaine and heroin through some guards, giving them a cut. One guard agreed to a \$180,000 mortgage from a mob-connected inmate who was one of the police informants.

I would visit a smaller museum later that summer inside the former warden's house across the road from KP. The women's facility was behind it. I spent more than four hours looking at all of the astonishing exhibits and history of the life of an inmate. It was here that a retired guard disclosed his knowledge of Bernardo and Olsen's demented brains. He headed the extraction unit for KP, was a black belt in three martial arts disciplines and his wife was a forensic psychologist for the prison.

I highly recommend a visit to this amazing yet unsettling part of the Canadian story. This building is right at the waterfront and a great way to start your time in Kingston. The architecture and history are fantastic. ●

Para DanceSport

continued from page 34



to participation, and to foster an active lifestyle for people of all ages and abilities. The OTF Grow Grant marks a major milestone for Para DanceSport provincially and nationally, and its impact has already been felt. Within the first six months, the grant has supported the further training and international certification of WHEEL DANCE's Head of Classification, Dr.

Sivakumar Gulasingam. Upon successful completion, he became the first International Paralympic Committee sanctioned Para DanceSport Classifier for both North and South America.

WHEEL DANCE is proud to be training dancers, instructors and classifiers, organizing competitions and workshops, providing performance opportunities, and building the infrastructure and governance of the sport from the ground up. This year's competition and showcase was well attended by WHEEL DANCE's passionate and committed dancers, their friends and families, our skilled and dedicated instructors and Para DanceSport classifiers, our generous volunteers, local community members and the media. Aside from the skill and artistic talent displayed on the dance floor, the truest measure of the day's success was witnessing the joy, camaraderie and support shared on and off the dance floor, as well as the resounding message that every *body* can dance!

For more information:

www.wheeldance.ca • www.facebook.com/wheeldance
www.twitter.com/WHEEL_DANCE • (T) 647-297-3198
(E) wheeldance@outlook.com ●

About WHEEL DANCE

WHEEL DANCE is a federally incorporated Canadian non-profit that provides subsidized social and competitive wheelchair dance classes to wheelchair users and their friends, family, and community members. As an Associate Member of Canada DanceSport, WHEEL DANCE is the National body for Para DanceSport in Canada recognized by Canada DanceSport and the World DanceSport Federation, providing the only pathway for Canadian athletes to compete at future Paralympic-level Para DanceSport events. WHEEL DANCE is also an official Partner of ParaSport® Ontario.

Dr. Iris Kulbatski is Founder and Executive Director of WHEEL DANCE. She holds a PhD in Medical Science, with a specialization in spinal cord regeneration. She is grateful to be a part of the WHEEL DANCE community and for the opportunity to bring awareness to issues of accessibility and inclusivity.

GUIDE TO ADVERTISERS

Spinal Cord Injury Ontario thanks its advertisers who have made it possible for the production of this issue of Community.

For information about advertising in Community, email Bev Jenkins at bev.jenkins@sciontario.org

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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
www.oatleyvigmond.com/rob



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