

Community

THE SPIRIT OF SPINAL CORD INJURY ONTARIO



Nancy Xia
shows us
how it's
done on
CortreeTV

pg 22

**AGM: A
Community
Affair**

pg 6

**Technology:
Anything is
possible**

pg 14

**#PeeForFree
gets serious**

pg 18

**A move to
accessible
housing**

pg 27



SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO

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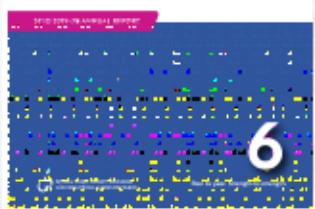


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10



20



24



22

COVER STORY: Our community is made up of people who know their stuff. Part of our job at SCIO is to tap into that and share the insights and information that come from experience. CortreeTV is a dynamic new initiative from SCIO's Cortree Disability Education Centre that showcases fun and functional videos made by community members on every topic under the sun. Our cover shows Nancy Xia sharing her mat workout with viewers.

opening notes

4 Rolling Through Barriers as a Community

SCIO in action

6 All around Ontario
6 AGM: A celebration of community
8 Scotiabank Toronto Waterfront Marathon
8 SAVE THE DATE! Bowl with SCIO!
9 Thanks to you, more people are Safe@Home
10 Rolling Through Barriers
10 Champions in our midst
13 Virtual Peer Connections Take Off
22 Tune in to CortreeTV
30 Research Corner

wellness

12 Silver Lining
16 In Pursuit of Freedom and Dignity

voices

20 The new workplace: Accommodating everyone at home
24 A Day in the Life... Shruthi Dhananjaya

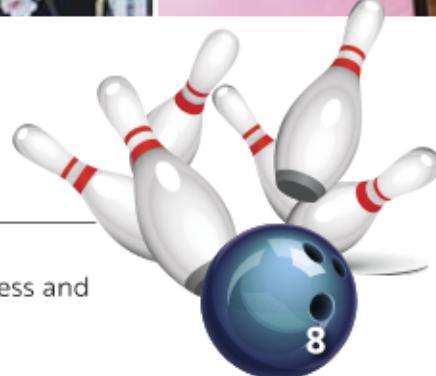
progress

14 Re-imagine what's possible
18 Peeforfree inspires action of access and affordability of medical supplies

home & away

26 Home Smart Home
27 Barrier-Free Real Estate

30 GUIDE TO ADVERTISERS



SAFE@HOME
Connecting in a Crisis

9

"I know I'm not the only one who feels this renewed commitment to finding the resolve, resources and ingenuity to address these barriers, once and for all."

Stuart Howe, SCIO CEO



14



26



SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO

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By Stuart Howe

Rolling Through Barriers as a Community

In the middle of a cold, raw March in Ontario, we began to realize the very real danger the coronavirus could have on every aspect of our lives. Amid the growing loss and pain in our communities, and around the world, it became a time to reflect and rethink how we work, shop and socialize. And in the wake of worldwide protests against racial oppression, we've become acutely aware of the deep and destructive systemic barriers that go beyond those related to disability.

It's been an emotional and complex 2020 and, from my vantage point as CEO for this strong and proud charity, I feel in the wake of such challenges, a new clarity has emerged. I see a more direct route to achieving the organizational goals we've set before us. I see the many barriers facing our community members with SCI and their families, and I see our role in helping dismantle them – through advocacy, policy change, services, education and collaboration in the creation of lasting solutions. This is what we've done for the last 75 years, but somehow the intention and route to do so has become more potent and visible. Is it that when the chaos of a global pandemic starts to lessen, the simplicity of our work, our values and our sources of joy reveal themselves?

I haven't figured out exactly why this clarity is here, and perhaps I won't bother to try. I just know that my discussions with colleagues, Board members, clients, family members, volunteers, donors and partners from the medical, government and business sectors have been exhilarating as much as they've been productive. I know I'm not the only one who feels this renewed commitment to finding the resolve, resources and ingenuity to address these barriers, once and for all.

HERE ARE SOME OF THE WAYS WE ARE WORKING WITH OUR COMMUNITY TO DO THAT:

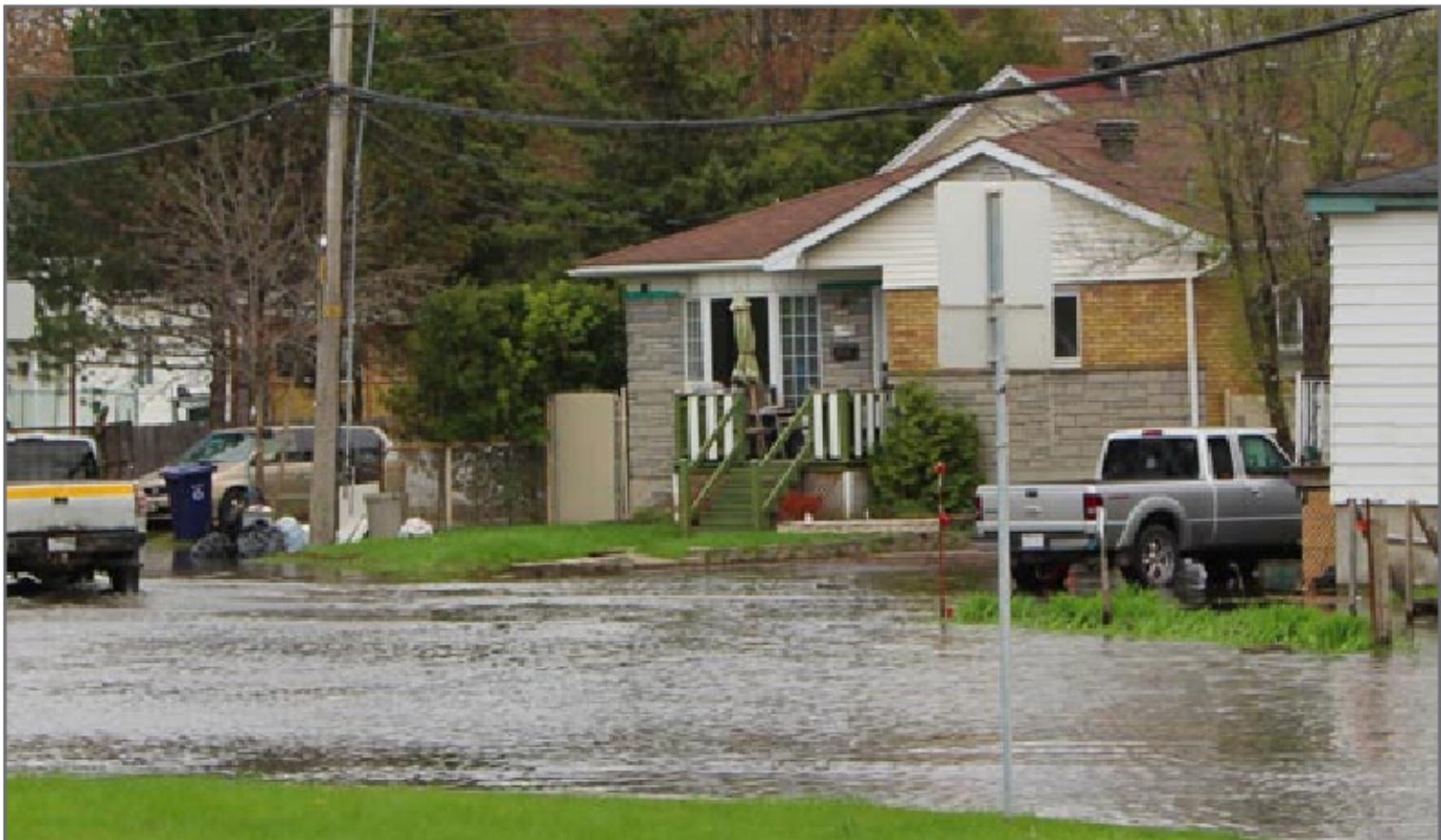
- Our #peeforfree campaign is being refreshed and reworked – with a powerful new committee that is setting out to produce a Business Case for the government to change and improve access to medical supplies. (Read more about this from Project Manager John Gregory on page 18.)
- We are engaging our community in new ways to solicit their participation and engagement at every level; our June 24 Annual General Meeting and Town Hall was a great example of that. (see page 6)

- We have established a comprehensive Continuous Quality Improvement (CQI) program that all staff will participate in this year.
- Information sharing at SCIO has risen to a whole new level, with community members with SCI and others taking to video to share their expertise in fun and fundamental ways through CorteoTV. (see page 22)
- Though our face-to-face events have been cancelled due to COVID-19, that hasn't stopped us from connecting with each other through portals such as VIP4SCI and our new virtual Peer Connections events. (see page 13)

Through all this, our supporters have come to understand their philanthropic contributions, at any level, are critical in breaking down barriers that have too long kept people with spinal cord injury from living the life they choose in a fully inclusive Ontario. Our Safe@Home campaign reached its fundraising goals, thanks to generous donors and a match from our Board of Directors. And July's Rolling Through Barriers Month was a fabulous expression of support, where a diverse group – from mayors to law firms to radio personalities to schoolchildren to Members of Parliament – spoke out publicly about the need for accessibility for all, and 'demolition crews' raised funds and shared creative videos of rolling through personal barriers.

Thanks to our community for being strong in the face of barriers of all kinds, and for being an active part of the movement to break them down with solution-focused clarity.

Dr. Stuart Howe
CEO, Spinal Cord Injury Ontario



Weather the storm, be prepared

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ALL AROUND ONTARIO

Thanks for getting involved with SCIO in new and interesting ways! Even with the cancellation of face-to-face events, we've connected with people from across the province via Zoom, VIP4SCI, social media and video. We've supported each other, shared information, raised funds and even had a bit of fun. We look forward to when we can see you in person again!

AGM: A celebration of community

Our Annual General Meeting (AGM) of June 24, 2020, was a completely virtual affair for the first time in 75 years and a powerful celebration of community.

After CEO **Stuart Howe** welcomed guests to the Zoom meeting, he introduced **John Shepherd**, a Ph.D. student of Rehab Science at UofT, fierce advocate for his community and recipient of the 2018-19 Patti Dawson Activist of the Year award. John spoke about the inherent strength of the SCI community with moving examples of how powerfully people have come together to advocate for improved equity in this province.

Stuart and our Chair of the Board of Directors, **Bob Nigol**, then presented their joint report, highlighting the diverse activities from our 2019-20 year, many of which are included in our 2019-20 Annual Report (available online at sciontario.org).

After a comprehensive and engaging Treasurer's Report from Treasurer **Mark Abrahams**, Board member and Chair of our Governance and Nominations Committee **Craig Brown** presented the slate of 2019-20 Board members, but not before sharing appreciation and praise for the extraordinary contribution of two outgoing Board members: **Cindy Scott** and **Anita Kaiser**.

We heard from SCIO's Regional Services Co-ordinator in Sault Ste. Marie. **Diane Morrel** spoke passionately about her city, whose motto is "Naturally Gifted", and the challenges brought about by COVID-19. Staying together during this time was critical in the Sault as well as across the province and Diane thanked SCIO and the Board of Directors for providing the long-distance support felt so strongly by her community.

Board member **Dana Francoz** lost her internet access during the meeting unfortunately so didn't get a chance to talk as expected about volunteerism and her long history with SCIO through her mother, **Marjorie Francoz**. "My mom has taught me the power of volunteering my time," she says. "I am thrilled to serve on the Board of SCIO – the organization that helped my mom, and that my mom herself supported through her work as a Peer Supporter for as long as she was able. I am honoured to pick up her torch."

WE HEARD BRIEFLY FROM OUR 2019-20 CORE AWARD RECIPIENTS:

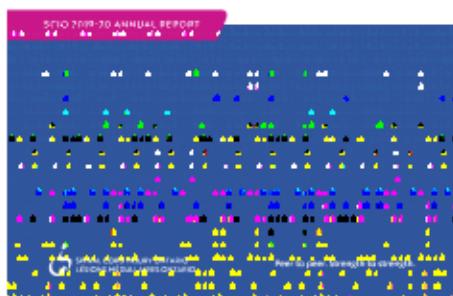
This year's **Patti Dawson Activist of the Year** is **Chris Stigas**, a man who describes himself as "keenly focused on advocating for people with disabilities for inclusion, while pushing decision makers for equitable and meaningful access to goods and services." Chris is a very active and valuable member of our community who is changing things for the better.

This year's **Employer of the Year** worked with SCIO's Employment Service team to hire 25 job seekers in a variety of roles, including disability consultant, customer service and support positions associated with CNE's rides. **Canadian National Exhibition** was represented at the meeting by **Jean-marc Valmont**, **Olivia Barreyre** and **Kirsten Argue**.

This year's **Vigmond Philanthropy Award** was presented to two men who have made a deep and positive difference in our Kingston Region community for many years. They have represented spinal cord injury clients as personal injury lawyers since 1999 and have received several distinctions for their work with clients, in and out of court. **Ted Bergeron** and **Chris Clifford** of Bergeron Clifford Injury Lawyers was represented at the meeting by Chris Clifford.

Thanks to all who could join us for this special meeting and for contributing to a memorable year at SCIO. We love our community and this 90 minutes together demonstrated so many reasons why.

STRENGTH IN NUMBERS



CELEBRATE
STRENGTH



Spinal Cord Injury Ontario is thrilled to invite you to
The Diamond Ball – a spectacular evening of food and
music in honour of our 75th Anniversary celebration.

Over the last 75 years, you've helped advance
transformative and groundbreaking programs and
services for people living with spinal cord injury.
Please join us on Thursday, November 5, 2020 as
we honour this incredible history of innovation,
advocacy and philanthropy!

THE DIAMOND BALL
NOVEMBER 5, 2020

SCIONTARIO.ORG/DIAMONDBALL

75
& BEYOND »



SPINAL CORD INJURY ONTARIO
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Scotiabank Toronto Waterfront Marathon

Every year, thousands of Canadians participate in the Scotiabank Toronto Waterfront Marathon to raise vital funds for their favourite charity.

We have shared so many wonderful memories with you at this event. Unfortunately, the event has been cancelled this year and while not a surprise it is still a disappointment. We hope that you will join us next year when we plan to come together again as a community to Walk, Run & Roll to the finish line. Together, we'll travel the road towards a fully inclusive future for people living with spinal cord injury.

Questions? Please email us at: events@sciontario.org

Roll It.
Walk It.
Run It.

Cheer.
Donate.
Celebrate.



Come out and build
a team, rebuild a life!



MCKENZIE LAKE
LAWYERS



SAVE THE DATE! Bowl with SCIO!

We're already planning for next year thanks to
our generous sponsors.

11th Annual London Roll & Bowl
TUESDAY, MARCH 2, 2021 – 6-8 PM

Palasad South, 141 Pine Valley Blvd in London

Unfortunately, we had to take a gutter ball for our 5th Kitchener Waterloo Roll and Bowl due to the pandemic but we hope to knock down the pins with your help next year.

6th Annual Kitchener Waterloo Roll & Bowl
TUESDAY, MARCH 23, 2021 6-8 PM
Bingemans, 425 Bingemans Centre Drive Kitchener

Thanks to you, more people are Safe@Home

SAFE@HOME
Connecting in a Crisis

Over the last few months, you have come together as a community to find innovative solutions to the isolation and risks presented by COVID-19.

Our deepest appreciation goes to you – the people and organizations who rallied together in a time of need to become part of the solution.

Thank you for supporting **Safe@Home**. Because of you, and your incredible generosity, \$45,244 was raised to connect newly injured people with their families and their SCIO support network in a secure online environment. This total grows to \$90,488 thanks to our volunteer Board of Directors who spearheaded this fundraising campaign and matched donations to double the impact of all Safe@Home donations.

Thank you to our organizational and corporate champions for their wonderful support in helping to exceed our fundraising goal in support of people with spinal cord injury:

- **Auger Hollingsworth Injury Lawyers**
- **B & J Contracting**
- **Caltrio Company Limited**
- **Hamilton Community Foundation**
- **Insurance Bureau of Canada**
- **McFarlan Rowlands Insurance Brokers**
- **Ottawa Community Foundation**
- **Top Lawyers**

AND THANK YOU TO THE FOLLOWING WHO, IN SUPPORT OF PEOPLE WITH SPINAL CORD INJURY CHALLENGED BY COVID-19, HAVE SHARED THEIR ENERGY, EXPERTISE, AND SUPPORT:

• Our Safe@Home campaign partners: Insurance Bureau of Canada (IBC), Hollister Canada and Hillcrest Consulting

Thank you for sponsoring our Safe@Home campaign to launch VIP4SCI to all our clients during COVID-19

• Our Government Partner: Ontario Government

Thank you for picking up the phone and acting when our clients were in danger.

• Our Medical Supply Manufacturing Partners: Coloplast, Bard and Hollister

Thank you for ensuring our clients maintain a healthy supply of catheters and other bladder supplies during COVID-19. Thanks to you, no client went without supplies and no one was forced to reuse catheters.

• Our Mobility Device Partners: Motion

Thank you for going above and beyond to ensure our clients had access to mobility device repairs and maintenance.

• Our Dedicated SCI Rehab Centre Partners: UHN Lyndhurst Centre, Hamilton Health Sciences, Parkwood Rehab, Ottawa Hospital Rehab Centre, Providence Care SCI Clinic

Thank you for working with SCIO through the SCI Implementation, Evaluation & Quality Care Consortium to convince the Assistive Devices Program (ADP) to expedite mobility device approvals in rehab centers during COVID-19.

• Our Community Partner: Ontario Community Support Association

Thank you for working with us and the Ontario Government to develop the Ontario Community Support Program, a program where volunteers can send groceries and other essential products to our clients' homes.

• Our Active Living Partner: Get in Motion

Thank you for re-launching your virtual exercise coaching service to keep our clients active at home during COVID-19

• Our Research Partners: Ontario Neurotrauma Foundation and Praxis SCI Institute

Thank you for repurposing resources and creating flexibility within existing research grants to study the impact of COVID-19 on our clients

• Our Primary Care Partner: The Center of Family Medicine Mobility Clinic

Thank you for being a provincial primary care resource to all our clients in need of medical supports with SCI complications during COVID-19

• Our National Federation Partner: SCI Canada

Thank you for representing our clients' needs to the federal government and sitting on the COVID-19 Disability Advisory Committee on our behalf

• Our North American Partners: North American SCI Consortium

Thank you for leading a series of weekly virtual webinars to educate our clients about COVID-19

• Black's Distillery, Peterborough

Cheers to Robert and the Black's Distillery family for the donation of sanitizer to our clients in Peterborough. Your spirits and generosity are helping keep communities safe. Thank you so much.

• Dixon's Distillery, Guelph

Thank you for the vats of hand sanitizer that we bottled and distributed to our clients. Your generosity helped protect our community!

• Conquer COVID-19 Team

Thank you for contributing 200 masks and hand sanitizer for our staff and clients. Such important and much-needed PPE.

• The Como Foundation

Thank you for contributing masks for our staff and clients. We appreciate your generosity and want you to know they were put to excellent use. ●

Rolling Through Barriers

For 75 years, through the help of supporters like you, Spinal Cord Injury Ontario has been breaking down barriers for people living with spinal cord injury. In honour of this incredible legacy, we went on a virtual mission to recruit 75 barrier-busting champions across the province.

The response was overwhelming! All month long, we heard from our communities about the challenges they've overcome, the barriers that still exist for them and the importance of accessibility by using the hashtag #rollingthroughbarriers. The stories and words of solidarity were powerful reminders about the importance of sustained advocacy. From staff and clients, donors and volunteers and politicians and media personalities – thank you to everyone who raised their voices and participated!

The inaugural #rollingthroughbarriers would not have been possible without our lead volunteers, **Jake Aitcheson** from Lerners and **John Shamoona** from Stride Rehabilitation. Thank you for your vision and dedication! We are also grateful to our incredible lead sponsors Wright Rehab and Lerners for their generosity and impactful contributions. The support of our sponsors will ensure our clients and their families continue to receive free life changing services that enhance independence.

To cap off the month, we held a variety show on July 30th hosted by Jake and John. The show featured a moving testimonial from Nancy Xia, the top five videos and special performances by comedians **Derrick Tenant** and **Graham Chittenden**, and SCIO's own musician **Vijay Jegathees** and his band Arian Musical Academy. If you missed all the fun, you can watch the videos by searching #rollingthroughbarriers on social media or visit sciontario.org. ●

Thank you to all our sponsors.

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Champions in our midst

Just before Covid-19 changed everything, Dan and Wanita Andress, owner operators of Andress' Your Independent Grocer, ran a 'give a toonie campaign' for SCIO at their store.

The event raised \$633 and Dan and Wanita kindly matched those donations. At Dan's request, these funds were added to funds raised by the Homan Hogan Charity Spiel (which you might have read about in the Spring issue of *Community*) increasing the Spiel total to nearly \$50,000 in support of SCIO programs.

We are grateful to Dan and Wanita for their generosity and for embracing the vision of a fully accessible Ontario for people with spinal cord injury. Thank you to Dan, Wanita and the people of Smiths Falls for being local champions. And a special thank you to the store's caring cashiers, essential workers during this challenging time. It isn't easy to say Spinal Cord Injury Ontario all day, but we appreciate that you did, while inspiring others to care.



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LAWYERS



By Joanne Smith

Silver Lining

Our lockdown eating habits have actually improved.



Our world has drastically changed over the past five months. And so too have our eating habits. A study by the International Food Information Council reports that during the pandemic up to 85% of us have changed where we buy our food, what we purchase and how we store and prepare it. And while studies also indicate that the increased time

spent at home, change of routines, boredom, low mood and constant access to the kitchen has led to eating more during the pandemic, it doesn't mean we're eating poorly.

Covid-19 has in fact created a positive shift in attitudes towards the health benefits of food and a greater awareness around food safety, farming and production practices, as well as long-term impacts on our environment.

Purchasing local produce, doing online grocery shopping (which has a lower carbon footprint than in-store shopping) and cultivating home gardens are just some of the trends that have taken root during the lock-down. I was also pleased to discover that a recent Angus Reid Poll indicated that the recent recognition of the economic, therapeutic and health benefits associ-

ated with these pandemic food trends may make them part of our 'new normal'.

So in celebration of this silver lining, my cool summer recipe this year, while nutritious, is more decadent than usual. Go ahead and indulge. We all deserve it!

Raspberry Avocado Ice Cream

- 1 avocado
- $\frac{1}{2}$ frozen banana
- 1 cup frozen raspberries
- 3 tbsp full fat coconut milk
- 1 tbsp maple syrup

1. Add all ingredients to a food processor/blender and blend until smooth and creamy. ■

fruitful elements

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SCIO in action

Virtual Peer Connections Take Off

With COVID-19, our Peer Connections information sessions – usually held in locations across the province every month – moved completely online, allowing us to continue sharing information and insights, and building relationships in a virtual setting.

Feedback from guests of these virtual events has been largely positive. **Sarah Mueller**, SCIO's Barrie Regional Client Services Assistant, says that some community members like the virtual events even more than the in-person meetings. She says, "It's a great way for members who live outside my immediate geographic area to join in." They are also helpful from the presenter's perspective as it gives them the opportunity to reach more people in one session and learn using new technology such as Zoom video conferences.

SCIO Peer Program Co-ordinator **Charlie Warriner** also appreciates that the virtual events reach more people. He sees them helping clients who may feel disconnected or isolated due to the lockdown or live further away from where we've traditionally hosted in-person events. Connecting online, they are now able to see others they used to regularly meet with, helping to maintain important relationships. It can feel safer joining a virtual meeting from the comfort of home. One client shared that their level of injury makes it difficult to venture out and travel to physical meetings, so the online experience is welcome.

We look forward to hosting more virtual Peer Connections events across the province as we continue to hear our community's input on topics and format. We hope you can join us for the next one! ●

CHECK UPCOMING EVENTS AT SCIONTARIO.ORG/EVENTS

Re-imagine what's possible

A beach chair that allows you to wheel through the sand to join your family at a seaside picnic. A drinking system that lets you keep hydrated independently. A crib with a front that swings open so a parent using a wheelchair can reach to comfort their child.

These are just a few examples of the hundreds of assistive devices and technologies that The Tetra Society of North America has created for people with disabilities over the past 33 years. Tetra is a group of over 200 volunteers all throughout Canada who come together from different backgrounds to help find solutions to environmental barriers that people with disabilities face daily.

Computer, mechanical and structural engineers, carpenters, welders, sewers and others donate their time and talent to create devices and modifications that will help people lead a more inclusive and independent life. While some of these devices may already be out in the market, they are usually cost prohibitive and offer a one size fits all approach. With Tetra, there is no catalogue to choose from in the hopes an item works. Their solutions are made with clients' specific needs, abilities and circumstances in mind. The costs are nominal, and the Society will look for funding to offset some of the larger costs.

A pilot project they are presently working on is netClé, an accessible computing interface that allows the user to navigate a cursor with touch or movement from a single finger, limb or even their head. This device, customizable to the client's needs, allows individuals with mobility limitations to operate a computer independently. With the pandemic, netClé



One of The Tetra Society's ingenious, customized designs: an accessible crib.

has been a welcome solution. It has helped people access information, communicate with others and reduce isolation.

Tetra was founded in Vancouver, BC, by Sam Sullivan, who sought a more inclusive life after an accident at 19 had him facing life with tetraplegia. A caring volunteer, Paul Cermak, devised some simple modifications to make Sam's apartment more accessible. This revolutionized Sam's life and gave him a sense of empowerment. He wanted to share this with others who needed assistance and that became the basis of the Tetra Society.

Sylvia Baliko, Tetra's Regional Coordinator for Central Canada, joined SCIO's recent virtual Peer Connections to explain how the non-profit organization works. The process is simple: you complete a request for assistance form on the tetrasociety.org website and head office forwards to a chapter coordinator near you who matches you with local volunteers to create the solution. In Ontario, there are chapters in Windsor, London, Guelph, Hamilton, Peel, York, Toronto, Kingston and Ottawa. However, Tetra's reach is broad with chapters all throughout Canada that can ship and connect with you anywhere in the country. Their goal, Sylvia says, is to "have people with disabilities dream". ●



Meet Charlie

Charlie Warriner (C5,C6) sustained a spinal cord injury when he tripped and fell into the boards during a hockey game. He loves watching sports, playing board games and helping others find their way after a spinal cord injury. **He's here to help.**

Though our offices are closed, we're here to support you by phone, email or video conferencing.

Charlie is one of a team of Peer Program Co-ordinators across Ontario. Connect with us at peerconnections@sciontario.org.

Learn about our Peer Program at sciontario.org/peer



SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO



Randy Meisner (above) and Ari Wahl (centre right) pictured at the recent Hamilton Community Celebration.



In Pursuit of Freedom and Dignity

How BD Canada and SCIO partner together to improve lives.



What makes a great partnership?

Across fields as diverse as business, athletics and even the arts, there are some consistent answers to this question. Whether it's Lennon and McCartney or Ben and Jerry, a handful of fundamental principles persist; shared values, complementary skills and overlapping ambitions top the list.

The partnership between BD Canada (formerly Bard Canada) and Spinal Cord Injury Ontario illustrates the power of connection and collaboration. Together, BD and SCIO help those living with a spinal cord injury achieve greater health, independence and quality of life. Each partner focuses on their unique abilities, which makes the teamwork stronger and benefits everyone impacted by an SCI.

"The expertise SCIO offers its community is outstanding, and their passion and commitment to their mission is just plain inspiring. That makes it easy for BD to join in their efforts, learn from them, and respond to the feedback we gather from their members. The best solutions are found through collaboration."

Values in Action

SCIO is defined by that bold spirit first exemplified by the WW2 veterans who founded this pioneering organization. In its mission to advance the world of health care, BD Canada is similarly committed to providing innovative solutions that improve lives. In its partnership with SCIO, those solutions lie specifically in bladder care devices and infection prevention.

"The design of our products goes hand in hand with education," says **Randy Meisner**, Account Manager within the international business division of BD Canada. "We help educate institutions and individuals on safety best practices to reduce the possibility of urinary tract infections. That is one part of our commitment to advancing health. Another is continually improving medical technologies to meet the needs of our users."

Ari Wahl, Director of Resource Development at SCIO, appreciates the value BD places on both education and product development. Following a spinal cord injury, there is only so much time for education in a hospital setting and, generally, only a narrow range of products are on hand. Plus, even years after injury, changes in life circumstances may demand a new approach to bladder care.

"Randy has spent time educating SCIO staff and clients about additional options to consider that support independence and quality of life," says Ari. "We want our clients to understand the wide range of choices available to them. Randy's work and BD's sponsorship of our bladder and bowel web

page has made it easier to learn about and sample products so our clients can make informed choices."

Combining Skillsets

As with all great teams, BD Canada and SCIO bring complementary strengths to this partnership. On the one hand can be found the research and development behind innovative technologies, such as catheters that offer ease of use and reduce the risk of UTIs. On the other lies the evidence-based studies, personal experience and professional outreach that helps thousands of individuals navigate the challenging journey of life with a spinal cord injury.

"The expertise SCIO offers its community is outstanding," says Randy. "And their passion and commitment to their mission is just plain inspiring. That makes it easy for BD to join in their efforts, learn from them, and respond to the feedback we gather from their members. The best solutions are found through collaboration."

Advocacy work also benefits from collaboration. Among other events, Randy has attended Queen's Park Day, which raises awareness on important issues related to living with an SCI. Two of those issues are accessibility and financial support for the cost of medical devices.

"We're grateful for BD Canada's commitment toward our community's safety and security," says **Peter Athanasopoulos**, Director of Public Policy at SCIO. "Their willingness to explore solutions for access and affordability of medical supplies is an impressive part of that commitment."

Shared Ambitions

Where else do the ambitions of SCIO and BD Canada overlap? In the space between good corporate citizenship and the need to fill funding gaps. With government providing about 80% of its funding, SCIO relies heavily on corporate support, special events and individual donations to make up the remaining 20%.

"We're a really small organization compared to a lot of other charities," says Ari. "We serve a very small, specialized client base that requires specialized and expensive solutions to support independence. We're reliant on partnerships to fulfil our mission."

On its side, BD's mission to advance the world of health is partly fulfilled by its philanthropic and charitable efforts. The company is committed to improving access to health care, and urology devices play no small part in individual and community health.

"We need greater access and affordability for everyone who relies on these kinds of products," says Randy. "This is ultimately an issue of human freedom and human dignity. That's why BD so strongly supports the work of SCIO. This is a leading nonprofit organization that requires investment in its programs and initiatives so that people living with an SCI can enjoy the active, independent lives they deserve."

Here's a final measure of great partnerships: reward on all sides. When financial generosity meets excellence in service, support and advocacy for people with an SCI, everyone wins. ●

PeeforFree inspires action to improve access and affordability of medical supplies

This may seem an odd time to drive a campaign about peeforfree when we are more than ever staying at home, but it's more important than ever.



by John Gregory
peeforfree Project
Manager

A graphic with a pink and blue background. It features a large, stylized yellow dollar sign (\$) with an upward-pointing arrow at the top. Below the graphic, text reads: "Can we talk about the high cost of peeing? #peeforfree".

SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO

sciontario.org/peeforfree

The SCI community has inspired SCIO's dynamic #peeforfree campaign. In asking what priorities around public policy are critical, access to medical supplies has come to the forefront. Officially launched in 2018, the campaign was paused to generate greater community involvement in advocating for accessible and affordable medical supplies. Here, we explore the progress made and three simple actions you can take from home. Your contribution will add an important personal voice to what we share with the Ontario government.

As intermittent catheters are critical bladder management aids for people with spinal cord injuries, our community is the best place to start to work with the government to improve funding models for better access and affordability of intermittent catheters.



"I believe comprehensive catheter coverage for Ontarians is an issue of equity and respect. Based upon best evidence, we should not expect patients to reuse single-use medical products, like intermittent catheters," explains Dr. Dean Elterman. "Our catheter coverage lags behind the rest of the industrialized world, and our patients deserve better."

7 DOMAINS

This work has engaged a Steering Committee, stakeholder briefing, online portal and two dedicated Town Hall sessions. The seven domains investigated are: user experience; user education; medical supply access; medical supply affordability; other medical supplies; Indigenous & rural communities and health economics.

Government relations consultant Nancy Abbey explains, "This project is vital as it will provide the Ontario government with the necessary compelling evidence for intermittent catheters to be appropriately funded to prevent patients from having to reuse catheters for financial reasons. Individuals should have access to a full complement of catheter options and be able to continue to use the catheter that best works for them as they transition through the healthcare system."

A MYRIAD OF FUNDING PROGRAMS

You may be one of the 38,000 people with a spinal cord injury in Ontario who uses intermittent catheters every day. Unless you are part of specialist programs covering access to single-use ICs, the supply cost can be up to \$2,500 a month.

What is very noticeable is that there are myriad reimbursement programs, yet they have not been looked at as a whole in this province. Different entities are layering upon other programs and often pitting against each other on who should pay. The red tape associated is exhausting for users in accessing funding. The SAIL program in Saskatchewan provides a benchmark model worthy of further investigation. Saskatchewan Aids to Independent Living (SAIL) provides

assistance to people with physical disabilities to live a more active and independent lifestyle. It also helps people in the management of certain chronic health conditions. This umbrella program also includes the PARA program for people living with SCI and they cover 100% of all supplies, including all types of catheters, diapers, gloves, Condom catheters, leg and night bags, suppositories, underpads, wheelchairs, etc. We will explore these in more depth through the small working group.

"While we're trying to support the future, we need to protect the people we serve every day as well, on a day to day basis," reassures Peter Athanasopoulos.

It is motivating to see the energy behind special consideration for Indigenous and rural communities. What happens in Toronto is vastly different than what happens in other parts of Ontario.

YOUR MOVE ONTARIO

We're gathering information through our working groups towards the policy report to redefine how funding for medical supplies functions in this province. SCIO's government relations team will support communities interested in engaging decision-makers around submission to the Government of Ontario. We invite you to go to YourMoveOntario.ca.

The #peeforfree campaign complements the **Rolling Through Barriers** campaign with leaders telling us why they care about accessibility. User testimonials are a powerful voice with which to catch the attention of the government.

3 SIMPLE ACTIONS

We ask for your participation from the safety and comfort of your home.

- 1. Visit the YourMoveOntario.ca webpage** – learn more about peeforfree and summaries of the new reports
- 2. Write to your MPP today** – type in your postal code to send a personalized letter to your MPP. You can edit or send as is.
- 3. Use Your Smartphone to Share Your Voice** – follow the directions for recording a one-minute video using your smartphone. You have everything you need to help create one-minute videos. We have created three questions and simple instructions. ●

The new workplace: Accommodating everyone at home

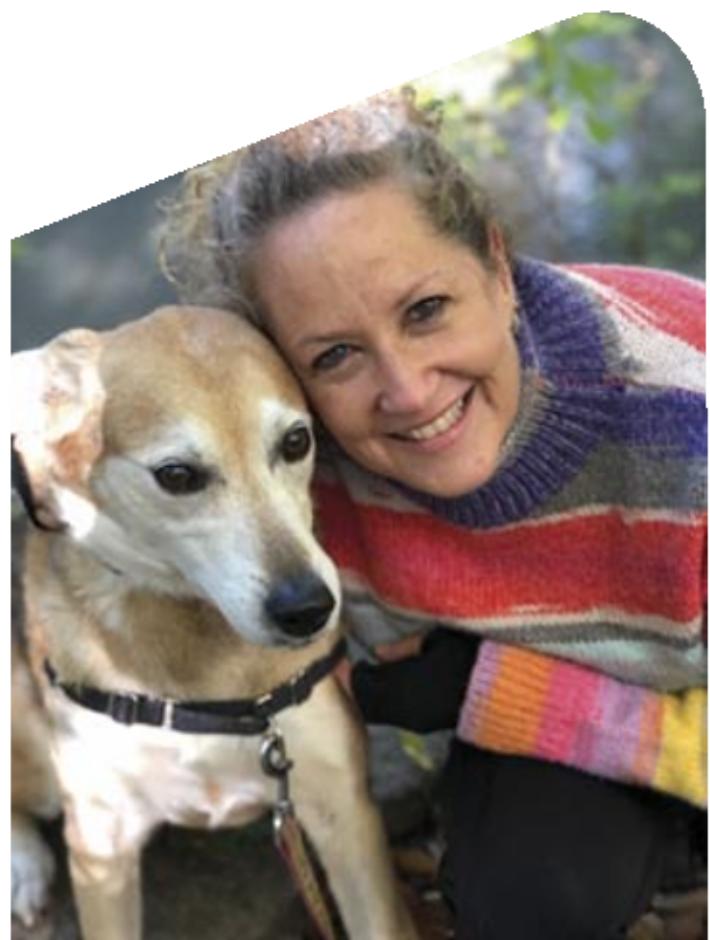
By Marianne Kozinets

As an Employment Counsellor with Spinal Cord Injury Ontario, I am familiar with the idea of accommodations. Workplace accommodations make it possible for people with disabilities to efficiently and successfully do the job. We at Employment Services have supported people with a variety of accommodation needs including assisting clients with low vision to purchase appropriate screen reading software, ASL and Intervenor interpretation on worksites, assisting with flexible work hours/breaks schedule, job modification and accessible workstations. Typically, the average workplace accommodation for a person with a disability costs the employer less than \$500. and our team has worked with businesses of all kinds to help make people transitioning into jobs as seamless as possible.

For myself, I have never considered the idea of an accommodation. Probably the only situation close to that was when I lived in Chicago with three young children at three different schools/daycares and needed to leave my office by a certain time to avoid the \$1 a minute (US dollars!) late fees, which can add up quickly. This wasn't considered an accommodation at the time, just a request, which most days was completely doable but due to the nature of my job, there were a few days where back-up plans needed to be in place. I remember the panic of trying to organize these things when there was an emergency at work. The idea of not being able to effectively do my job was difficult and upsetting. But that was a long time ago.

At the beginning of March 2020, I was living with my 17-year-old daughter who was finishing her last year of high school. She spent 95% of her time in her room and I pretty much had the house to myself. We had an abundance of space and were ignorantly blissful in our mundane lives. Within a few short weeks, the world changed for everyone. For us it meant the return of my two older sons. The house soon became chaotic, crowded and small. And no one was leaving to go anywhere. It was all us, all the time. Fun at first, then a little less fun....

Our new-found offices and work arrangements didn't come without challenges. Having one of my adult kids ask me, "What's for dinner?" while I'm clearly on a Zoom meeting was especially irritating.



Marianne and her canine coworker.

The day came where we were told we would not be working from the SCIO office and it was time to set ourselves up at home. My first thought was, "Yay, sleep in!!" But I quickly came to my senses and thought about the nature of my job and how I value face-to-face contact and being with someone rather than using a phone or video call. There is depth that gets missed when people can't look into each other's eyes, read body language, posture etc. I was concerned about how to maintain a connection with my clients. The ability to learn and consult with my colleagues on a day-to-day basis is something that I also value and knew it would be missed.

I set myself up on the dining room table, where it seems my three kids had already staked out a place for themselves. One had recently launched his own start-up business, another was finishing his last year of university and the other was finishing her last year of high school. It

became obvious that we all had work to do around the dining room table. No one was too interested in hosting Zoom meetings from their bedrooms or bathrooms, and I guess being around the dining room table made sense.

Day 1 of work from home got started. Our laptops were all
continued on page 29



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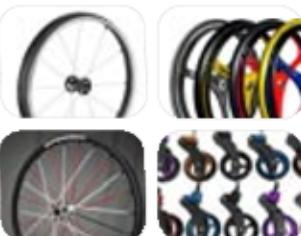
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Tune in to CortreeTV

Information is everywhere: opinions on products; insights on investments; specs on systems. All you need to do is Google an item and you've got millions of hits on why you should buy it or how you should do it or why you shouldn't. But who's behind the wall? Who stands to benefit from your decision to purchase or act?

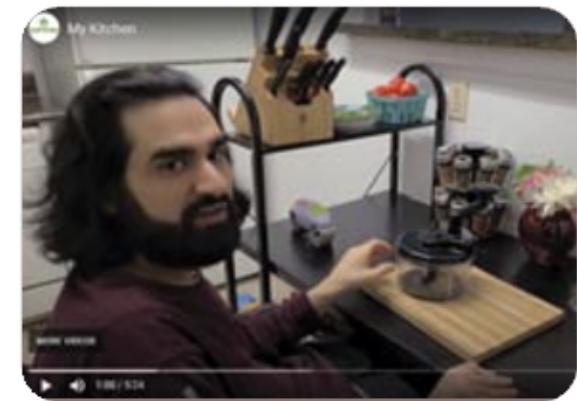
One reason retailers feature consumer reviews on their websites is because we all know there's great value in the opinion of those with direct and personal experience. We tend to trust someone who's been there, and is willing to share what they've learned.

Which brings us to CortreeTV, a very new, very exciting social learning feature of SCIO's Cortree Disability Education Centre.

CortreeTV is all about the personal experience: *How I did it. What I learned. What's the easiest way to do it. What's the safest way. Where I got it. Why it's better. How you can do it, too.*

CortreeTV takes a community-based approach to enhancing the learning experience, giving Cortree users the chance to view, interact with, and even create and share your

**CortreeTV is all about the personal experience:
How I did it. What I learned.
What's the easiest way to do it.
What's the safest way. Where I got it.
Why it's better. How you can do it, too.**



own video-based learning content.

While the CortreeTV team are publishing self-produced disability-related video content on a weekly basis, we're looking forward to seeing all Cortree users view, ask questions and comment about these videos – and we're even more excited to see all Cortree users produce and share their own videos.

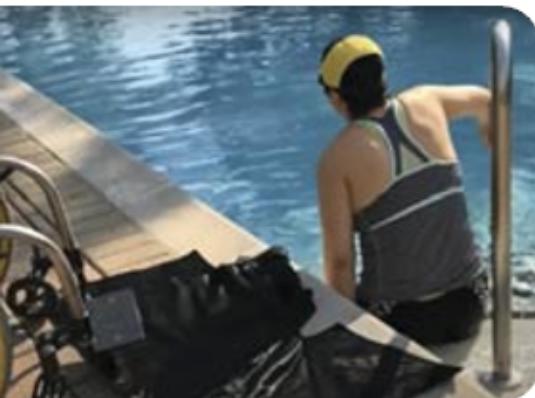
These videos don't need to be Hollywood productions. Members of the Cortree learning community are simply keen to learn your tips, lessons, routines and approaches to living a healthy, happy life. Cellphone. Webcam. No special effects needed. Only you and the value of your own experience and tips.

So sign in. Select the left menu. Head to the CortreeTV. Check out the short, informative and entertaining videos already shared. And, when you're ready, take a look at our video on how to shoot your own video, start filming and share what you know!

Visit sciontario.org/cortree to sign in or register to Cortree.



Clockwise from top right: Oda shows us around his accessible kitchen; Nancy does the splits while she keeps us in stitches; Oda demonstrates home wheelchair weight training; Nancy shows us how she transfers into her condo's outdoor pool.



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A Day in the Life... Shruthi Dhananjaya

Shruthi Dhananjaya is the Communications Co-ordinator in the Marketing and Communications Department at SCIO, working on digital communications strategies and co-ordinating the promotion of SCIO's events, campaigns and initiatives. A fan of the outdoors, she enjoys hiking, biking and spending time in nature. She is also an avid reader and can be found curled up with a good book and a strong chai latte. We caught up with Shruthi to find out what inspired her to work at SCIO and to learn more about a day in her life...

Q *How would you describe your role as communications co-ordinator at SCIO?*

A My role is to co-ordinate the development and distribution of SCIO's community communications (including this magazine!) and support the organization's marketing and communications initiatives. Specifically, I plan and co-ordinate content for SCIO's social media channels and monitor community engagement. I also work with staff on storytelling on the work being done at SCIO.

Q *When did you apply for this role and what made you apply?*

A I applied for the role in March of 2020 and began the next month, in April 2020. I applied because I was looking for a role that would be communications and marketing focused, challenging and rewarding, and also could put my government communications experience to good use. It was an interesting experience as the whole hiring and onboarding process was done completely virtually. The experience really made me appreciate the technology we have available these days!



The best part of my job is knowing that my work is directly impacting the SCIO community and making a difference in people's lives.

Q *What do you love most about your career at SCIO?*

A While I love the communications projects that I get to work on, it's the people here at SCIO that makes a big difference for me. I am happy to work with a great team of colleagues and mentors, both in the Marketing and Communication Department and within the organization as a whole. The best part of my job is knowing that my work is directly impacting the SCIO community and making a difference in people's lives. I love learning more about the services and work that SCIO provides, and then finding creative ways to share SCIO's achievements with our community on social media.

Q *What does a day at work look like for you?*

A My days have looked very different lately as a result of the pandemic. Since we are in lockdown, I am working from home and only go outside the house for grocery shopping and to grab essentials. I am actually enjoying working from home as I have a great home office set up and there are lots of meetings and opportunities to work with colleagues virtually.

Q *When you're not at work, what do you like to do?*

A I enjoy spending time in the outdoors, whether it's going on hiking trails or just relaxing in the park.

Q *Do you have any hobbies?*

A I love to read both fiction and non-fiction books. Fun fact: I wrote my Master's research paper on Jane Austen's *Pride and Prejudice*.



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By Jeffrey Kerr

HOME SMART HOME

Technology is constantly evolving and improving to adapt to our changing needs. A good example of this is the use of smart home technology to provide greater independence at home for people with disabilities.



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I was introduced to a smart home device called emitto by my client Paul (pictured above). The condo he rented had a fully accessible bathroom, a power door opener that was activated by pushing a button or key FOB, and window coverings that could be raised or lowered by remote control. However, Paul does not have functional movement below his shoulders so pressing buttons would be a challenge. His solution included using emitto.

Emitto is a device that enables you to use your voice or a wheelchair mounted switch to wirelessly control everyday things within your home environment. Michael Cullen, one of the Co-Founders of Novalte, the company that developed emitto, is a person who understands the need for smart home technology. Michael has used his background in engineering and years of experience working with occupational therapists and patients at West Park Healthcare Centre and Holland Bloorview Kids Rehabilitation Hospital to develop technology to help PWD communicate, drive their wheelchairs and control their homes independently.

"Emitto was created out of a need that I had as a Biomedical Engineer to tailor technology to make it work for individuals with mobility challenges. Before emitto, I

would use a mix of other devices but in the end I would always have to hack something to make it work the way our clients needed to. The thing is, not all technologies are created with limited mobility in mind; the end functionality is there but the method that a client needs to access it is different."

In addition to helping Paul, Michael has worked with over 400 clients with varying levels of mobility and kept seeing the same issues over and over again:

"Our clients want to be able to utilize smart technology in a way that works for them and not worry about the complexities of the technology." Emitto works like a central hub that connects to all of your devices and then you communicate with emitto. For individuals that have difficulty with their speech, the system is set up with an accessible switch. There is a screen that scrolls through all of the different devices that are connected to the system and the client simply hits the switch when the device appears on the screen. The system can also be operated by eye gaze and sip and puff technology too.

For clients like Paul who can speak clearly, the system is easily controlled by voice commands using Google Home voice recognition software. With some additional Novalte hardware added to the existing power door operator Paul simply says "Hey, Google, open door," and the door to his condo opens. He can also use this technology to open the door for visitors or his housekeeper when he's not at home. And the window blinds that were originally operated by remote control can now be controlled by voice commands.

Paul also has Novalte hardware connected to his adjustable bed, which allows him to raise and lower the bed by voice commands. Emitto can be connected to smart plugs (small wifi adaptors plugged into regular outlets) so lights and

other items can be controlled. "Hey Google, turn on the spider lamp," is all Paul needs to say to light up his home office.

Paul's system is part of the first generation of emitto. The technology has evolved and so have the support services available. Smart screens for video chatting can now be incorporated into the emitto system. This makes communication much easier and helps minimize the social isolation that Michael says is a big concern with his clients.

Installation and tech support can now be done remotely. If a client gets a new TV, wants to make changes to how the system works, or if there is a glitch, it can all be fixed remotely. Michael says that new users often need a fair bit of

training to efficiently use the system and having the ability to do this remotely is very helpful, plus it reduces the amount of face-to-face contact that is required.

An internet connection is required for the system to be voice controlled and for remote support. However, if an accessible switch is used as a controller, most of the core

features can work without the internet.

The upfront cost of the emitto system starts around \$2,000, depending on what is included. Installation costs start at \$200. The monthly maintenance and tech support package ranges from \$70 to \$150 / month. A system similar to Paul's would cost approx. \$5,000 with a monthly fee of \$70.

It's not surprising to hear that this technology is gaining in popularity all across Canada. Paul is very happy with his emitto system and it affords him a lot of independence. Check out his video at www.Novalte.ca ●

*Jeffrey Kerr, Barrier Free Real Estate Specialist
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Barrier-Free Real Estate

Ihis forward to **Jeffrey Kerr's** new book, *Barrier-Free Real Estate, Achieving Freedom At Home*, Hon. **David C. Onley**, CM, OOnt, says, "In a world with precious little information on accessible housing, I find *Achieving Freedom At Home* an invaluable resource for buyer and seller alike and thank Jeffrey for his major contribution to improving the lives of persons with disabilities."

We talked with the author about his book and long career in barrier-free real estate.

Q *What inspired your focus on accessible housing?*

A Three people inspired my decision to focus on accessible housing: my mother, my aunt and Kevin Rogers.

My mom was an OT and physiotherapist and my aunt had MS and was a teacher. They both worked at Lyndhurst Centre in Toronto with patients with SCI and they taught me a lot about accessibility at a young age.

Early on in my real estate career I met with Kevin Rogers, the Information Officer at the Canadian Paraplegic Association (now SCI Ontario) to ask for his advice on selling my aunt's wheelchair accessible condo. Kevin encouraged me to use my experience in home construction and real estate to focus on accessible homes. I'm very happy that I followed through with Kevin's advice. Focusing on accessible housing has been very gratifying.

continued on next page

Q What inspired you to write a book about accessible housing?

A Over my 21 years in the real estate business I've worked with many individuals who have SCI and other mobility challenges, families with children who are disabled, and older adults. I've learned a great deal from working with these clients and I want to share my knowledge to help others and also create a resource for people that need an accessible home now or in the future.

Q Will the information in the book be relevant to readers across the province?

A Absolutely! The information in this book is relevant to readers across Ontario and Canada. I cover a very wide variety of topics that are relevant to all homes. For example, I have chapters on aging in place, entrance solutions, bathroom solutions, kitchens, elevators, visitable homes and smart home technology.

Q Is the availability of accessible housing the same throughout the province?

A Larger urban centres tend to have more options for accessible housing, however more and more opportunities to modify homes are being developed in smaller centres too. An example of this is the Canadian Home Builders Association's (CHBA) Home Modification Council. The CHBA is creating a network of contractors across Canada that specialize in accessible renovations which will make it much easier for people to find experienced contractors.

Q What is one of your favourite gadgets or improvements to homes to make them accessible?

A I love to see houses and condos with a zero threshold, roll in shower that can accommodate a bath chair on wheels. They are the number one requested feature by my clients. A spacious and modern shower can be appreciated by everyone plus they are a great value-added feature when it comes to sell.

Q With people spending more time at home now, what is the most important improvement people can make to their home?

A I think having an accessible home office and a safe place to self-isolate are two important improvements that people should consider.

The COVID-19 pandemic has made the home office a vital part of almost everyone's household. Working from home was already gaining in popularity, but I think now it will become the accepted and expected norm for many jobs going forward.



Jeffrey Ker with Hon. David C. Onley, CM, OOnt

The pandemic has also shown us the importance of having a safe and comfortable place to self-isolate. And with a bit of creativity, a home office can also be the ideal location to self-isolate.

Q More and more people are looking to "Age in Place." What should they consider to make this happen?

A Successfully aging in place may only require simple modifications to their current home. An accessible entrance or a modified bathroom may be all that is needed. It could also mean moving to a home that can accommodate other members of their extended family – I call these multi-generational family homes. In my chapter on aging in place, I've included a detailed list of things to consider and questions to help readers make the decision that is right for them.

Q Do you think Ontario's home building standards will ever change to become more accessible?

A Change is happening thanks to research at the University Health Network's KITE Rehabilitation Institute. Their research has already resulted in an increase in the width of stair treads required by the Ontario Building Code (OBC.) This one change will greatly reduce the number of at home falls. KITE is also researching hand rails along ramps and stairs.

Change in the condominium industry is occurring thanks to the Daniels Corporation. Daniels is going above and beyond the OBC requirements with the Accessibility Designed Program on their pre-construction condos. I've sold several of these suites which include a bathroom with a five-foot turning radius, roll in shower, and roll under vanity, and a roll out balcony.

Q What is the most satisfying aspect of your career?

A Every client that I work with is unique and has their own specific needs. I love the challenge of finding a housing solution that works for each one of them. My job requires me to listen and learn every day, sometimes I need to be an advocate for my clients, and other times I need to be a quarterback for a team of rehabilitation experts that is advising my client.

I'm definitely not a traditional REALTOR® and this makes my job fun and exciting.

Q How can readers access your new book?

My book is available through Amazon in both print and e-book. Visit my website for the link: www.AccessibleHomeFinder.com ●



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The new workplace

continued from page 20

charged up and ready to go. Within minutes I was told to, "Shhhh" while I was on the phone. It seems that is not feedback I appreciate and found myself getting irritable. This is not my first time working in a "group office" but I never had this response before. I had my own issues concentrating as well and would take client calls outside (March was a cold month and difficult to take notes with my mitts on). I would watch my kids work while Snapping, YouTubing, Tik Toking at the same time and felt they needed to know that that wasn't a great work ethic. Apparently, they weren't fond of my feedback either. When I returned to work on Day 2, my son had put a Post-it note on my computer saying, "Aaron's office. Please leave." This was becoming a hostile work environment and clearly it was not going to work.

I set myself up in the kitchen, the kids started doing their Zoom meetings and phone calls in the basement (apparently, I wasn't the only annoying one sitting around the dining room table). I started a Zoom support group to connect with clients, I adjusted to making more phone calls and emails to reach out to both clients and colleagues and set up some rules and boundaries about sharing this public workplace that we called home.

Our new-found offices and work arrangements didn't come without challenges. Having one of my adult kids ask me, "What's for dinner?" while I'm clearly on a Zoom meeting was especially irritating. There was the time the dog decided it was

dinnertime at 3:00 in the afternoon and, after much barking, I literally had to feed her so she would stop hitting me with her paw (not a good look on Zoom). And as much as I try to visibly ignore some of the chaos that is going on around me to keep things professional, I know some clients from my support group will recall when the tree-removal pro at my neighbour's knocked on my glass back door (with his saw!!) which happened to be right where I was sitting. I screamed loudly and literally jumped out of my chair!

To balance things out a bit, I guess my kids did not realize their new household chore is official Geek Squad to my many tech issues. One of the many rules we (I) established is to come running when you hear the words, "Oooh nooo, my Zoom has disappeared!" And I'm pretty sure my son who is working on Pacific Time may not enjoy his mom bellowing from the top of the stairs, "DINNER!!!" while he's on his Zoom meetings.

My point is that concessions, accommodations and adaptions have had to be made by everyone. This is a daily reality for everyone, but during these times, compromise and re-adjustment can be more difficult. We have experienced huge changes and loss at such a rapid pace with COVID-19 and have had to navigate so many unique experiences. I'm hoping in the end we can come out of this with more patience, empathy and an intact sense of humour. The way this situation has progressed has taken away our sense of control, but it's important to remember that we always have control over the way we choose to deal with what comes our way. To quote The Tragically Hip's Gord Downie, "No dress rehearsal. This is our life." ●

Research Corner

Spinal Cord Injury, Urogenital Health and Pregnancy Project (SCI-UP)

Pregnancy in women with an SCI can bring different considerations than just what are covered in the average pregnancy help books. Bladder health care and management are among some things that women considering pregnancy need to discuss with their health care professionals.

Spinal Cord Injury Urogenital Health and Pregnancy (SCI-UP) Registry was created by **Dr. Anne Berndl**, assistant professor at Sunnybrook Health Science Centre and **Dr. Anne Harris**, epidemiologist and Assistant Professor at Ryerson University's School of Occupational and Public Health. With the assistance of a generous grant from the Ontario Neurotrauma Foundation, the research aims to improve understanding surrounding the impact of pregnancy on urogenital health. The goal is to help understand the differences in bladder health for women with SCI who have and have not had a pregnancy. Other important pregnancy and birth outcomes in women with SCI, such as risk factors for preterm birth, triggers of autonomic dysreflexia and incidence of breastfeeding are other areas that will be studied through this registry. Participation is easy and involves a simple online survey. It is completely anonymous and you may skip any questions that you do not feel comfortable answering.

To learn more and participate see the post on our website at <https://sciontario.org/urogenital-health-and-pregnancy/> or click on "Participate in Research" from our main menu.

Contact: claire.mazzia@utoronto.ca ●



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Brian's all in.



Brian Cameron likes to win. Be it in the courtroom, or playing poker in his downtime, this hardworking lawyer knows how to keep his cards close to his chest, which may be one reason why he's at the top of his profession.

As a personal injury litigator, Brian gets satisfaction from the opportunity to make a difference in the quality of his clients' lives, especially when they may not yet be aware of the hand that they've been dealt.

What makes him a good poker player also helps him win cases. "I see myself as a storyteller. I share my client's life story with the jury so they can see how drastically the defendant has changed their life ... and I have a good poker face when I need one."

Brian excels at breaking down legal complexities to their simplest form for his clients. He treats them with a level of dignity and compassion that has contributed to his being recognized as a certified litigation specialist. That kind of passion, commitment and dedication means that Brian's all in when it counts the most.

To learn more about Brian visit
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