FALL 2020
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Community

THE SPIRIT OF SPINAL CORD INJURY ONTARIO

& BEYOND »

SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO

We serve, support and advocate for and with people with spinal cord injury and other disabilities.

COVER STORY: *We celebrate 75 years since our founders established the Canadian Paraplegic Association, which led to revolutionary change for people living with spinal cord injury and to the vibrant organization Spinal Cord Injury Ontario is today. We honour all the work and change that has occurred since 1945 and look beyond to the future, where we continue to realize our vision of people with SCI living the life they choose in a fully inclusive Ontario.*

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> *It is planned in the future to have all people with paraplegia in Canada to become members if they so desire and in this way, we will be able to help one another become self reliant and productive members in Canada's future.*
>
> **John Counsell**

SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO

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We thank our writers, photographers and advertisers!

A Vision of Independence

By Stuart Howe

I'm thinking a lot about our founders who gathered back in 1945, struggling with the newness of spinal cord injuries after the hardship of war, driven by a singular vision: *independence*. They could plainly see what was missing from the landscape all those years ago: the best in SCI medicine; services to enable community living; reliable mobility devices; an accessible environment; funding to expand programs; and government engagement.

As SCIO celebrates 75 years of consistently moving closer to that vision of independence for Ontarians with SCI, I am struck by how closely SCIO's current goals match those of our founders. Not to say there hasn't been huge advancements in all aspects of SCI these last 75 years, because there has: quality medical care; supports for independent living; increased levels of accessibility; legislation mandating equity; societal attitudes; and impressive technology in mobility devices and other equipment. Despite the improved landscape, we are still tasked with advancing the most basic aspects of living with SCI and other disabilities, 75 years on.

It's because of our determined and skilled community that we can both celebrate how far we've come, with gratitude and empathy for those who've struggled to get us here, while we resolve to get where we need to be, today and for the next generation. When young Danielle Kane was shot on the Danforth in Toronto two years ago, she received excellent medical care, and had all the support she needed to recover and start her new independent life. But there was no place for her to go. "Despite all the assistance I received," said Danielle, "They did not prepare me for the world outside the rehab centre, where there is a never-ending set of challenges for someone like me." She could not return to her basement apartment and she found there was not a single wheelchair-accessible apartment available in Toronto. Only through media attention and Go Fund Me donations was she able to buy and renovate a home in Oshawa. "But not all folks living with a disability are so fortunate as to be a headline," says Danielle.

So how can our founders' vision of independence be realized if there's no accessible housing? If catheters cost way too much? If the best wheelchairs are out of our range, and repair times render us immobile? If there are places we can't visit? If we can't find a physician closeby who understands SCI? If disability funding doesn't cover our basic expenses? If employment opportunities are dismal? If we're seen to be 'less than' because of mobility issues?

The answer is us. Not only SCIO staff or volunteers or clients or donors or family members or government partners or scientists. But all of us. Collectively, this powerful SCI community, who knows what it's like to move through immense challenges, will continue to do what our founders did - envision and build an equitable world in Ontario and across the country. It's because of the founding of the Canadian Paraplegic Association 75 years ago that Canada has a federation of SCI organizations, including SCIO. We're here to listen to our communities and realize that vision, finally. So we can get on with living the life we choose.

I hope you enjoy this issue of *Community* magazine, where we take a look back at our rich heritage and beyond to our strong future.

Dr. Stuart Howe
CEO, Spinal Cord Injury Ontario

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& BEYOND»

I think the thing that impressed me most about them was the general integrity and interest of not only the staff but the patients themselves in getting the job done and helping other people any way they could. It was very much a self help group.

Ken Langford

OUR HERITAGE…

We are a community because, at one time not too long ago, there was almost no support for people with spinal cord injury in this country. When our founders returned to Ontario from the Second World War, having sustained spinal cord injuries, they came together to build a community to improve medical care, rehabilitation and opportunities to live independently. In 1945, they formed the Canadian Paraplegic Association, out of which grew Spinal Cord Injury Ontario (SCIO) and a network of autonomous SCI organizations across the country.

Headed by founders **John Counsell**, who fought and was injured at Dieppe, and **Al Jousse**, we partnered with medical leaders in SCI and the newly established Department of Veteran Affairs to establish **Lyndhurst Lodge**, a community-based rehab centre located on Lyndhurst Avenue in Toronto. Counsell then brought the first folding, self-propelled wheelchair to Canada, causing a revolution in mobility. (In fact, he ordered 150 chairs from California-based Everest & Jennings and, thanks to Board member **Conn Smythe**, stored them in Maple Leaf Gardens in Toronto.)

Other founders who worked with John Counsell, Al Jousse and Conn Smythe were **Ken Langford**, **Andy Clark** and **LM Wood**. Over the next few decades, equipment innovations, strong advocacy and improvements in rehabilitation advanced the rights and living conditions of people with SCI. In 1974, Lyndhurst Lodge was left behind and **Lyndhurst Centre** opened on Sutherland Drive, the first and only hospital in Canada for the rehabilitation of patients with spinal cord injury. It was regarded as a model for the nation and the world. Today, the site is part of the University Health Network's Toronto Rehabilitation Institute and

> *"Without the support of awe-inspiring SCIO I would still be suffering with tremendous depression. I now see that life with a disability can again be rewarding, fulfilling, exciting and precious."*
>
> **Client**

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JOANNE SMITH PUTS IN A 60 HOUR WEEK, HOSTS A TV SHOW, DOES VOLUNTEER WORK, MODELS AND IN HER SPARE TIME SKIS, SAILS, TRAVELS AND PLAYS TENNIS.

AND TO THINK THEY SAID SHE WAS DISABLED.

Your support makes a difference !

CANADIAN PARAPLEGIC ASSOCIATION ONTARIO

520 Sutherland Drive Toronto ON M4G 3V9 Tel: (416) 422-5644

home to SCIO's provincial offices.

The 1980s and 90s saw advances in employment, housing access and attendant services in the Toronto Region, with SCIO actively engaged in all initiatives and offering its own programming at the Lyndhurst Centre, one of five Toronto Rehab sites. **Rick Hansen** launched the "Man in Motion Tour" in 1985 with our support, drawing much needed attention to spinal cord injury. And in 1996, the first pilot Wheelchair Relay Challenge was organized in Ottawa. Wheelchair Relay Challenges were SCIO's signature fundraising events for many years.

We've grown to have a powerful presence across the province with staff in 13 locations, supporting people with SCI and their families with regional service co-ordination, peer mentorship, health care partnerships, access to information and resources, SCI research and advocacy to improve the landscape in all areas relating to accessibility and disability.

Along with our extended community of volunteers, clients, family members, donors and partners in government, business and health care, we are honoured to carry forth our founders' tradition of innovation and action every day in Ontario, as we work for and with people with SCI to live the life they choose. Thank you for your part in that vision. ●

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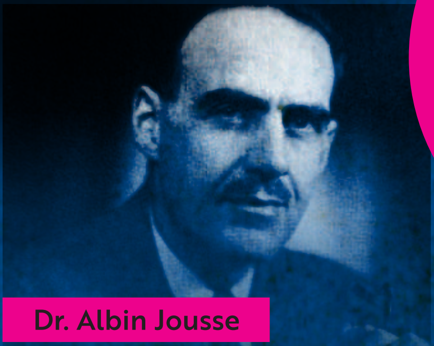
1945 to 2020

THE FUTURE IS ACCESSIBLE

You've made so much possible! Here's a snapshot of the work you have fueled and funded over the last 75 years.

Prior to 1945 only between 1% and 10% of people who sustained a spinal cord injury survived longer than a year.

1945



Dr. Albin Jousse

In 1945, Lyndhurst Lodge is created to become the world's first spinal cord injury rehabilitation centre, initially for the benefit of injured veterans. Dr. Albin Jousse becomes the first Medical Director.

John Counsell

Canadian Paraplegic Association (CPA) is founded by John Counsell, Arthur Hay, Joseph Wrangham, Jack Higman, Douglas Quirt, Edward Higginbottom and Andrew Clarke, a group of WWII veterans with spinal cord injuries. The first offices of this organization were located in Maple Leaf Gardens thanks to Conn Smythe. John Counsell advocated for the newly developed Department of Veteran Affairs to supply each returning WWII soldier with a spinal cord injury an Everest and Jennings wheelchair.

1947

Our first quarterly newsletter, Caliper is created. Through the decades we have been providing information to our community through our periodicals from Caliper, to Outspoken to Community.

1950

The key to Lyndhurst Lodge is handed to John Counsell by representatives of the Department of Veterans' Affairs. Lyndhurst Lodge is transferred to Canadian Paraplegic Association for one dollar.

1951

An in-house school classroom is established at Lyndhurst Lodge to further the goal of ensuring that people could further their education and training to find jobs after rehabilitation.

Ken Langford

1967

Ken Langford becomes the Managing Director of the Canadian Paraplegic Association for the next 33 years.

The Canadian Wheelchair Sports Association is formed to create opportunities for people with spinal cord injuries and other physical disabilities to achieve full community participation.

1974

Lyndhurst Hospital is officially opened as the first and only hospital in Canada for the rehabilitation of patients with spinal cord injuries and becomes a model for the world.

1981

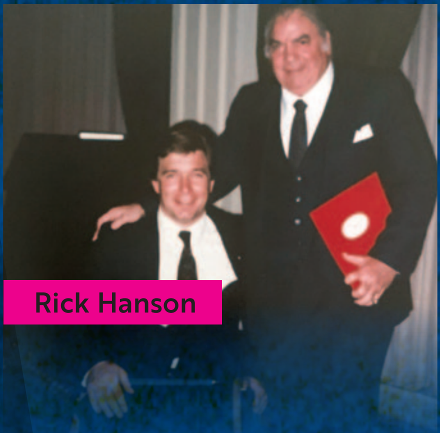
Our first regional office outside of Toronto opened in London. Over the next few decades, we continue to open more service locations. Our reach in 2020 is province wide with locations in Barrie, Sudbury, Sault Ste. Marie, Thunder Bay, Hamilton, Kingston, Peterborough, Ottawa, Waterloo, York, Peel and Halton Regions.

1983

The Nucleus Housing Project was launched to establish the first community-level, attendant services facility for people who have high level quadriplegia.

1996

The Wheelchair Relay Challenge is created quickly becoming a popular event and raising over $4 million during its lifetime.


Rick Hanson

1987

With the help of the CPA Ontario, Darrel Murphy secured funding from the Ministry of Health to provide outreach attendant services to clients living in their own homes.

1997

The Employment Resource Centre opens and is dedicated exclusively to helping people with a disability re-enter the workforce.

Canadian Paraplegic Association begins years of international development in many countries including Jamaica, Senegal and Guyana.

1986

CPA supported Rick Hansen on his Man in Motion tour raising awareness about the potential of people with disabilities, creating accessible and inclusive communities, and finding a cure.

1990

Golf tournaments become one of our organizations signature events. These include the Barbara Turnbull Golf Tournament, The Oviinbyrd Golf Tournament, Rolling Thunder Tournament and Rebuilding Lives, to name a few. The events have raised over $2.5 million over the last 30 years with the help of so many volunteer committee members.

1998

Ontario Neurotrauma Foundation is created through the collective efforts of the CPA Ontario, the Canadian Spinal Research Organization, the Ontario Brain Injury Association, and the Rick Hansen Foundation.

2000

A dedicated group of volunteers create the annual Ski Day now in its 20th year and having raised $1.5 million since inception. One of our favourite days of the year and a great opportunity for our community members to try a new sport or experience it again through adaptive skiing.

2001

Peer Support is expanded across the province. From the beginning, the value of lived experience has been at the heart of who we are.

ALLIANCE
ONTARIO SPINAL CORD INJURY ALLIANCE
ONTARIO ALLIANCE EN LESIONS MEDULLAIRES

2006

SCI Alliance is created bringing together key stakeholders and strategic partners of researchers, service providers, policy makers, funders and people with spinal cord injury to address and resolve systemic barriers in Ontario.

2003

A Postdoctoral Fellowship is established on spinal cord research at Toronto Rehabilitation Institute and University of Toronto. Through the leadership of Toronto Rehabilitation Institute, CPA Ontario supported the first National SCI Conference.

2012

Spinal Cord Injury Ontario rebrands. Survival beyond one year has increased to between 85% and 90%.

2019

Canada's first federal accessibility legislation, the Accessible Canada Act, receives Royal Assent. SCIO Cortree Disability Education Centre and Family Peer Program launches.

2020

SCIO celebrates 75 years of community!

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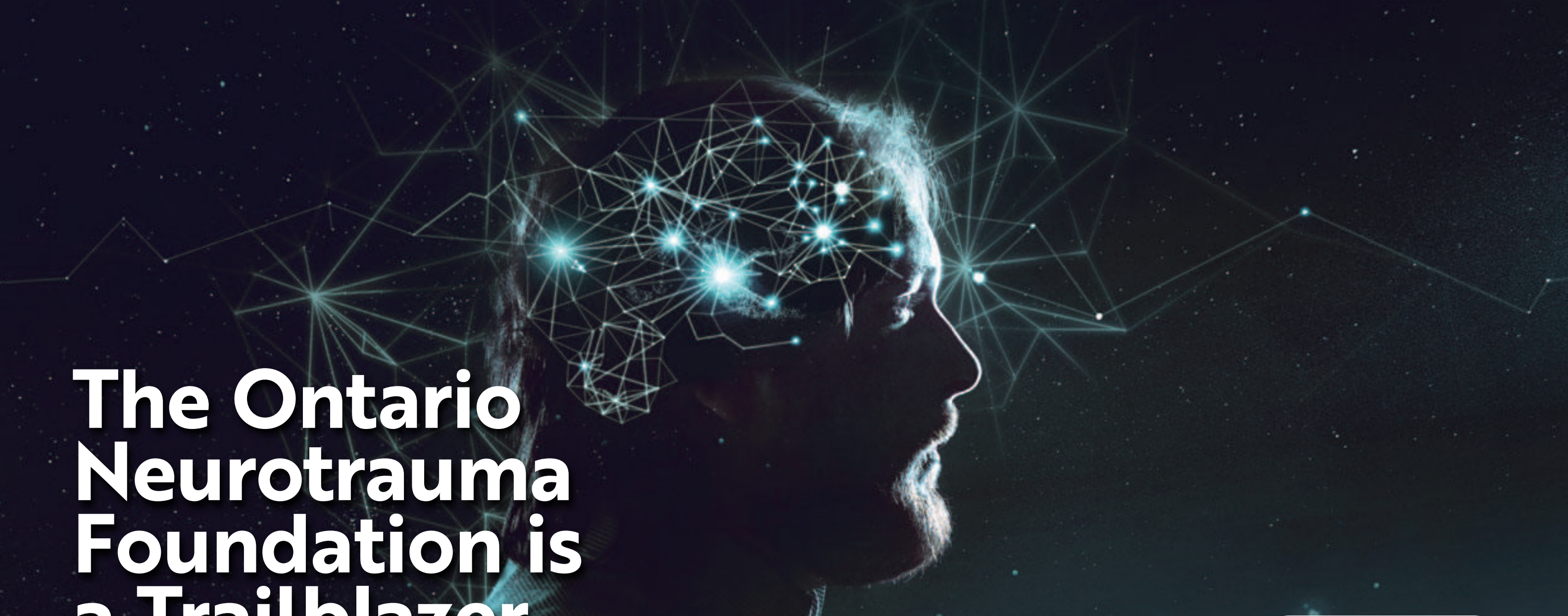
& BEYOND»



The Ontario Neurotrauma Foundation is a Trailblazer in its Field

ONF has radically changed the landscape in SCI research, knowledge sharing and evidence-informed practice.

Kent Bassett-Spiers

Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

TThe numbers are sobering. Neurotrauma injuries affect more than 500,000 Ontarians and their families, at a healthcare cost of about $3 billion annually. When it comes to spinal cord injury, about 85,500 Canadians can be counted, with that number estimated to rise to 120,000 in 2030. In addition, an SCI is one of the most medically complex, high cost and dramatically lifechanging events any person can face.

But as our community well knows, those facts don't tell the full story of living with an SCI or answer the most important questions. How can we achieve the greatest quality of life? Overcome barriers to pursue our goals and dreams? Become the best parent, partner, leader, colleague and person possible?

Every person's journey is different, but there is one vital need: meaningful research that directly informs and improves healthcare practices across the province.

That's where the Ontario Neurotrauma Foundation (ONF) comes in. Established in 1998 through the collective efforts of the Canadian Paraplegic Association (now SCIO), the Canadian Spinal Research Organization, the Ontario Brain Injury Association, and the Rick Hansen Foundation, ONF is a non-profit organization funded by the Ontario government. Its mission is to enhance the quality of life for those living with an acquired brain injury (ABI) or spinal cord injury (SCI) and a focus on injury prevention.

Nancy Lawson is one of many passionate individuals who helped found ONF over two decades ago. A consultant and MBA with professional experience in the not-for-profit sector and personal experience with an SCI, Nancy drafted the proposal that led to the Ontario government promising $25 million in funding over ONF's first five years, with renewal periods thereafter.

"The SCI space in Ontario was pretty disjointed at that time," says Nancy. "On the one hand, an injury has an enormous impact on individuals and families—physically, emotionally and economically—and consumes significant health care and social resources over a lifetime. On the other hand, knowledge of SCI wasn't great. Best practices in care and rehabilitation weren't consistently available. And research wasn't well coordinated. ONF was formed to help lead in all those areas."

ONF's CEO Kent Bassett-Spiers agrees with Nancy's assessment and summarizes the spinal cord injury landscape 20 years ago in one simple phrase.

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& BEYOND»

In my job as a Development Officer I have the honour of helping others see the true value of their philanthropy – of letting them know that any gift is meaningful and changes lives. Our donors and our sponsors are committed to the work we do as an organization and I want them all to feel really great about their choice to support SCIO.

Wendy Hough

"A lot of gaps," he says. "Gaps in the body of research itself, in standard health care practices, in the communication between researchers and practitioners, and in implementation. Ontario lacked a central resource to help guide relevant studies, share knowledge and ground health services in the best possible evidence. More than twenty years later, there are still gaps. But they're narrowing. And we'll keep narrowing them until they vanish and we'll continue to support the communities by connecting practitioners with the latest research to implement standardized best-practices."

To reach and change the lives of as many people as possible, ONF funds research studies that meet the priorities identified by the SCI community.

"We're more prescriptive than we used to be," says Kent. "Where are we going to see tangible improvements in people's lives? What are the most pressing concerns? What is the community asking for? Answers include preventing secondary complications, bladder care, chronic pain, improved hand function, the highest standards of rehabilitation, and a more efficient and responsive health care system. The needs of people living with neurotrauma should drive the research agenda."

With those research priorities set through community consultation as well as strategic partnerships with groups like SCIO, ONF supports studies and clinical interventions that minimize further damage, advance care, and accelerate functional improvements.

For example, it has supported the Riluzole Trial, a drug that has neuroprotective properties and may result in functional recovery. It has also recently funded studies in reactive balance training, electrical stimulation therapy, and the viability of nerve and cell transfers, to name just a few. Each of these areas has the potential to improve clinical practice and quality of life.

Melissa Felteau has firsthand experience with ONF-funded research that has transformed the lives of people living with an acquired brain injury. After her own injury in 1993, Melissa found it difficult to access services to help with her recovery, including ongoing rehabilitation. So she began researching and developing ways to help herself. She applied to ONF to fund a pilot study, was awarded, and has received additional funding over the years.

With that support, Melissa developed and tested Mindfulness-Based Cognitive Therapy (MBCT) for traumatic brain injury.

"In our pilot study, 58% of people suffering from depression after a brain injury recovered from that depression," she says. "And a year later, they remained that way. That was the beginning of a series of studies on MBCT that culminated in the gold standard of research: a multi-site randomized trial. That trial proved its efficacy, and MBCT became the first recognized program for helping to relieve depression and anxiety in people with brain injuries."

The impact of Melissa's pioneering program illustrates the importance of funding studies that have a direct impact on quality of life.

"The research and implementation activities that ONF funds are constantly evolving," says Melissa. "They make sure that we have the most reliable, relevant and up-to-date information possible about ABI and SCI. That translates to people achieving the fullest recovery and the highest quality of life possible. Which puts people in the community, contributing to the economy, and out of the healthcare system as much as is possible. That is an efficient use of healthcare dollars."

Back in the 1990s, Barry Munro was making the same case to the Ontario government: funding this new foundation would significantly reduce hospital stays—both during acute care and for secondary complications—throughout the lifetime of those living with a TBI or SCI.

Barry is Chief Development Officer of ONF and chair of the Canadian Spinal Research Organization. Retired from his work as a personal injury lawyer, Barry now dedicates all of his time finding a cure for paralysis. Twenty-five years ago, he played a key role in securing the funding that ONF needed to launch and operate.

"ONF has played a massive role in establishing province-wide standards for primary care and rehabilitation," says Barry. "Even more, it has earned a national and international reputation as a leader in TBI and SCI research, knowledge sharing, and evidence-informed practices. Before it existed, these were neglected conditions and practitioners operated in siloes. Now, with the collaborations and partnerships it has built, the ONF brand has become a star."

ONF and its many partners work toward the same end: improving quality of life from the moment of injury onward.

"The better health and the greater independence people living with SCI achieve, the less attendant care and health care costs they generate," says Barry. "That means that the more money the government puts into organizations like ONF, the more money it saves. I would even say that the savings are exponential."

Barry briefly ponders a world without ONF and all it achieves through its extensive and impressive collaborations and partnerships.

"It doesn't really bear thinking on," he concludes. "We would move backward to the fractured and siloed system we used to have. This Foundation works with the best researchers, experts and practitioners in the world. Not only that, it's the glue that holds them all together. There's nothing else like it. It's a trailblazer in this field and a provincial gemstone."

SCIO has a great team and strong community. I value being part of the movement for more accessibility and inclusion in Ontario. I love the challenge of growing our audience, expanding our impact, and generating revenue to support our mission.

Tory Bowman

75 & BEYOND»


Rehab Support Worker +
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Vehicle Modification +
Case Management +
Chiropractor +
Massage Therapy +
Personal Support Worker +
Prescription eyewear +
Mobility Devices +
Life skills training +
Physiotherapy +
Vocational or academic training +
Workplace modifications +
Communication aids +
PULL UP

By Joanne Smith

Time to Celebrate

In this special 75th Anniversary Celebration edition, I'd like to congratulate the past and present SCIO staff, volunteers and board members who have dedicated themselves to providing vital services and essential support to people with spinal cord injuries.

Your vision, work and compassion have offered countless individuals a place of belonging and hope, created endless opportunities, helped build a more inclusive society and, most importantly, assisted people in regaining their independence.

So I'd like to ask you all to join me in raising a glass to this caring, enthusiastic and devoted team on 75 years of extraordinary work! Of course, this is a nutrition column, hence I carefully chose this specific celebratory cocktail not only for its fitting name, but researched health benefits.

- Champagne and gin are low calorie alcoholic beverages.
- Champagne contains anti-oxidants that can protect against heart disease.
- Champagne helps prevent memory loss (a study at the University of Reading determined that drinking one to three glasses of champagne each week can boost brain health).
- Gin is made from the juniper berry which is packed with infection-fighting flavonoids.

Cheers SCI Ontario!

French "75"

- 1 oz gin
- 2 oz champagne (or other favorite sparkling wine)
- ½ oz fresh lemon juice
- pinch sugar (optional)

1. Combine gin, lemon juice and sugar in champagne flute
2. Top with champagne ●

> *"Life does not have to end after a spinal cord injury, it just has to be reinvented."*
>
> **Therese Anne Sidler**

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No water,
No mess

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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!

> *Being able to devote time, and listening to individuals with a new spinal cord injury is crucial to helping them cope.*
>
> **Bryce Donald**

75 & BEYOND»

SPINAL CORD INJURY ONTARIO PRESENTS

SKI & SNOWBOARD DAY

SAVE THE DATE!

On Thursday, February 11, 2021, Spinal Cord Injury Ontario invites you to our annual Ski and Snowboard Day at the beautiful Craigleith Ski Club in Collingwood.

Ski Day will look a bit different this year because of important safety protocols but it still promises to be another spectacular day on the slopes in support of people living with an SCI.

Please save the date and join us for our 21st anniversary event as we enjoy private access to the gorgeous hill! Tickets will go live in November.

OATLEY VIGMOND PRESENTS

THE DIAMOND BALL

To ensure the health and safety of our communities, we have postponed our November event until Spring 2021...when it is safer for us to come together and celebrate. A new date will be announced shortly.

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

Hosted at the beautiful and fully accessible Bram and Bluma Appel Salon inside the Toronto Reference Library, The Diamond Ball is our way of celebrating the enormous strides made across Ontario in breaking down barriers for people living with disabilities.

The evening promises to be a fabulous night featuring a cocktail reception, an awards ceremony and a special performance by an award-winning Canadian artist. Your support will raise vital funds for our barrier-busting programs and services that transform the lives of people living with spinal cord injury.

Thanks to our presenting sponsor Oatley Vigmond for helping us bring this special anniversary to life.

Want to help catapult us into the next 75 years? Get involved as a sponsor. Contact us directly by phone or e-mail.

Lali Mohamed
Manager, Special Events and Partnerships
Tel: 416-422-5644 x. 221
E: lali.mohamed@sciontario.org

Roll&Bowl

TIME TO ROLL AND BOWL INTO 2021!

11th Annual London Roll & Bowl

Tuesday, March 2, 2021 – 6-8pm
Palasad South, 141 Pine Valley Blvd, London, ON

5th Annual Kitchener Roll & Bowl

Tuesday, March 23, 2021 – 6-8pm
Kingpin Bowlounge, 425 Bingemans Centre Dr, Kitchener, ON
Online registration will open in Nov. 2020!

For more details and sponsorship opportunities contact:
Sheila Daniel, Development Officer, Southwestern Region
1-877-422-1112 x810 or sheila.daniel@sciontario.org

> *Helping clients see that there is life after an SCI is so rewarding because they usually have many fears when we first meet them.*
>
> **Nouma Hammash**

75 & BEYOND»

> *I'm an Employment Counsellor assisting clients with meeting their employment (and pre-employment) goals. I love working for SCIO and am proud to be able to work with such wonderful people.*
>
> **Marianne Kozinets**

75 & BEYOND»

> *"It is an important cause. I give because I wanted to ensure that help is available for the people who need it."*
>
> **Robert Jackson** *33 years of consecutive giving*

75 & BEYOND»

> *As part of the Employment Services Team my purpose is to help new visitors to our services feel comfortable and motivated towards securing paid employment. I truly believe there is a job out there for everyone regardless of skills & challenges. One of my favourite quotes is 'You have two hands. One is for helping yourself, the other is for helping others.'*
>
> **Jenny Gilker**

75 & BEYOND»

Persistence and Giving Back: Bob's Story

Above: Lali SCIO's Corporate Partnerships and Events Manager (left), Bob (centre), with wife Nancy Kastner (right), daughter Megan (back row), John Izard (back left) and Bob Kaye at the Annual Comedy Night 2020.
Right: Bob sit-skiing.

Bob Pesant was just 16 years old when his high school wrestling career was cut short and his life was changed forever. He had recently started competing for his school at matches against other schools in the province.

In 1973, during a competition, Bob sustained a spinal cord injury to his C4, C5 and C6. Reflecting back, Bob says, "Your mid-teens are such an important time in your life. I was in the midst of making key friendships and just embarking upon my first relationships and, all of a sudden, that stopped."

"I was in hospital for a full year after my initial injury. My parents took turns to come and see me every day. It was an incredibly difficult time. I was so dependent on others and needed to be fed and receive sponge baths."

> *As a Peer Support Coordinator, I feel we act as a GPS for our clients in the spinal cord community.*
>
> **Ron Rattie**
>
> 75 & BEYOND»

Bob initially spent four months in the Toronto General Hospital and eight months in rehabilitation.

His rehabilitation started at the original Lyndhurst Lodge on Lyndhurst Avenue. "It looked like a typical hospital in an old movie; women were upstairs and men couldn't go up there, it had a library like a Sherlock Homes movie, and men had to go through the kitchen to get to the hall that led to their rooms."

"There was an extremely steep ramp into the basement where physio was held. An orderly had to stop you from rolling down too quickly and push you up after physio was over. There was a therapy pool that only two people could use at one time."

On Canada Day weekend 1974, all the patients went home and on Tuesday took the journey to the new Lyndhurst Rehabilitation Hospital on Sutherland Drive.

"I stayed in Unit 1A on the first floor, the second floor wasn't open yet; different areas were still under construction. The gym was completely empty and there was no pool yet. There was a pool table but no one to play with – there weren't enough staff or patients around and no organized recreation classes. But, hey, at least there was free parking!"

"It doesn't matter who you are, I think everyone involved would say it was exciting to move to the new facilities and that both

"I really noticed my new energy streak at the Spinal Cord Injury Ontario Ski Day. I'm relatively new to sit-skiing but I know that core strength is everything. I could feel the difference from all the hard work I'd been doing in the gym as I slalomed down Blue Mountain with my guides."

patients and staff looked forward to future opportunities. We were all involved in creating a whole new work environment."

Bob left Lyndhurst 365 days after he entered the Toronto General Hospital on December 20th, 1974. In the years that followed, Bob continued to build his strength and independence.

Much later he started to develop secondary issues as a result of his injury. In 2015, he spent 116 days in hospital due to wheelchair-induced pressure sores and diabetes.

"I was acutely aware that my level of fitness needed to be improved, so I hired a personal trainer. By attending regular training sessions for two years I gradually improved my strength, flexibility and most importantly, my attitude. I'm now able to get out of bed without assistance, climb stairs and step up onto a platform with four risers."

"I really noticed my new energy streak at the Spinal Cord Injury Ontario Ski Day. I'm relatively new to sit-skiing but I know that core strength is everything. I could feel the difference from all the hard work I'd been doing in the gym as I slalomed down Blue Mountain with my guides. This year was the fourth time that I've attended Ski Day and I absolutely loved it! I'd recommend it to anyone who wants to be active and get out there."

In addition to skiing, Bob's new healthy lifestyle includes aquafit and tai-chi among other activities. Bob was recently recognized for his incredible energy, persistence and huge gains in the gym by GoodLife Fitness as he was shortlisted for their Transformation Challenge.

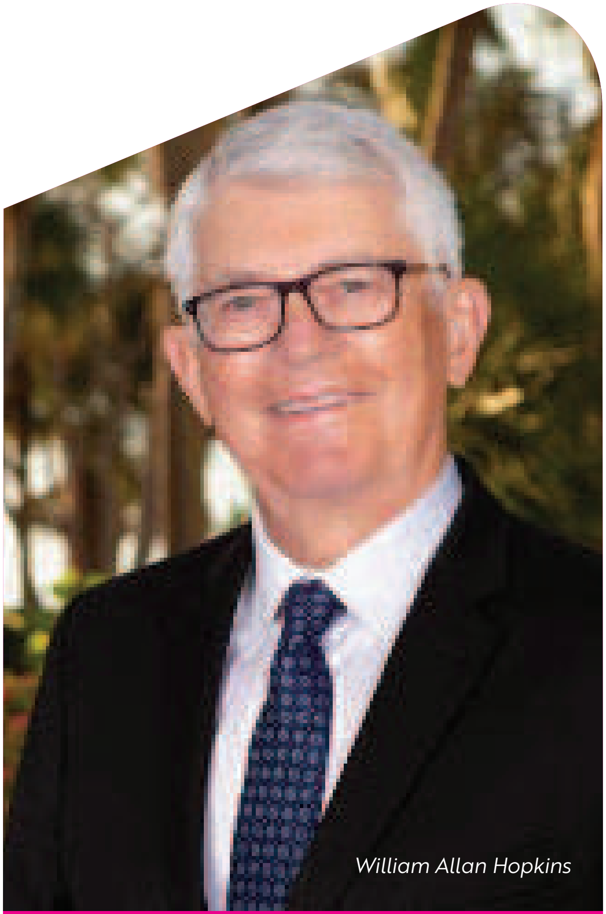
Not only does Bob have persistence in his approach to healthy living and staying active, he also has determination to giving back to SCIO. Bob served on the Board from 1984 to 1991, volunteering as a Director and overseeing the governance of the organization. Even more amazingly, Bob has been a donor to SCIO for 36 years! Almost half of SCIO's lifetime. The giving spirit is strong in the Pesant family with Bob's daughter Megan generously giving her time as a member of our Young Professionals Board which hosts our highly successful Annual Comedy Night.

With the generous support of donors and sponsors, events like our Comedy Night bring our community together. When we can get together again we're sure to see Bob there and, with his focus on healthy living, we should be seeing him for years to come. ●

Working at SCIO gives me the privilege of connecting with newly injured people and other members in the spinal cord injury community. Living with a spinal cord injury myself, my role is to help my clients adapt to their new life after a spinal cord injury by providing them with information and resources.Our goal is to help our clients live the full lives with or without disability.

Nancy Xia

75 & BEYOND»



William Allan Hopkins

Allan Hopkins in Memoriam

SCIO lost a dear friend and true champion in August. Allan Hopkins was a husband to Claire, a father to Jillian and Sarah, a LEGO building partner and Papa to three amazing grandsons, Will, Campbell and Thomas. He was an avid traveler, a frustrated golfer, a mentor and a true business leader.

To SCIO Al Hopkins was instrumental in advocating for a barrier-free Ontario. Al spearheaded the Wheelchair Relay in Toronto since the beginning of this major SCIO community fundraising event in the 1990s. Along with his wife, Claire, and daughter, Jill, he assembled the support of family, friends and corporate partners to create the lead fundraising team for many years. He was an ardent supporter of full employment for people living with spinal cord injuries and other disabilities and often supported SCIO's Employment Services. Al's big heart made a big difference to the SCIO community. Al's family honoured SCIO by choosing us as one of their charities of choice for in memoriam donations. We appreciate his and his family's enthusiastic contributions over the years and express our deepest sympathies at the loss of this cherished member of our community.

Leading With Empathy

Meet Eugene Wai, SCIO's newest Board member

Dr. Eugene Wai

Well before training as a surgeon with a specialty in spinal trauma and reconstruction, Eugene Wai knew he wanted to combine his love of science with his desire to help others. As a young man, he was influenced by Hawkeye Pierce on the television series M*A*S*H, a talented doctor known for his humanity and compassion under wartime conditions. Like Hawkeye, Eugene knows that making a difference in the lives of people takes more than finely-honed surgical skills.

"The reality is that a spine surgeon can only help a small number of people who are seeking relief or improvement of their condition," says Eugene. "So first, I can help by listening to patients more, being empathetic, and connecting on a personal level. And second, I can look for ways beyond my technical skillset as a surgeon to reach more people and have a greater impact on the spinal cord injury community. That's been more of a focus in the past few years."

Outside of the lab and the operating room, Eugene has two passions: improve the flow of patients with back pain through the healthcare system—getting to the right resources and specialists in a timely manner—and provide more community-wide supports to build better overall health.

"Spinal surgery is like rescuing people down river who are drowning," he says. "That's important. That's needed. But I would also like to move upstream, to help prevent an emergency as much as possible. That means focusing on lifestyle: exercise, nutrition, sleep and stress management. It's better to rely less on medical technologies, when possible. There are interventions that help ward off injury and also treat pain. But there isn't a coordinated way to harness and deliver them."

Eugene wants to work more at the regional and provincial level to help people access appropriate care and support. Joining the Board of Directors at SCIO is one way to do that. Another is to help develop a technological platform that improves the coordination of health services for people with spinal cord injuries. The ideal would be a centralized, interactive online resource that integrates artificial intelligence and analytics with a full range of health providers.

"We can improve the virtual care model in general, so those with mobility challenges can be served better without having to travel to a health centre," he says. "A virtual resource can also improve overall community health, which would help to prevent injury."

In the meantime, before bringing these future ambitions to life, Eugene has one overarching priority.

"As a member of the SCIO Board, I have a lot to learn and a lot to do," he says. "And it all begins with listening to people. Logic, analysis and technical skills have always played a large part in my work as a researcher and surgeon. But empathy is just as important. So I'm here to listen first." ●

Dr. Eugene Wai is the Head of the University of Ottawa Combined Adult Spinal Surgery Program, a Clinical Investigator at the Ottawa Hospital Research Institute, and recently led the implementation of evidence-based national standards and practices into the hospital's Acute Spinal Cord Injury Program.

> *Even on the days we feel we haven't accomplished much, we benefit our clients and community as a whole just by being present and by leading by example. We show others what can and should be the norm post injury.*
> **Matt M.**

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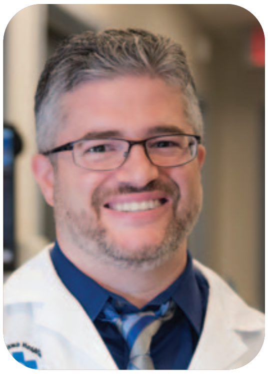
Research Studies at The Ottawa Hospital Offer Promise and Hope

Dr. Tsai



Dr. Sachs

The Ottawa Hospital photo credit

Dr. Eve Tsai and Dr. Adam Sachs work in very different ways to improve the lives of people with SCI.

What's new in medical research related to spinal cord injury? If you ask Dr. Eve Tsai that question, be prepared for a lengthy and excited reply about the potential of stem cells to repair damaged spinal cords. Her passion for the topic spills out with every explanation and anecdote.

Dr. Tsai is the Suruchi Bhargava Chair in Spinal Cord and Brain Regeneration Research and Associate Professor of Surgery in the Division of Neurosurgery at The Ottawa Hospital and the University of Ottawa. Her research interests include spinal cord repair strategies, nerve regeneration, MRI imaging of spinal cord tracts, and clinical outcomes after spine surgery. In addition to her medical degree and training at the University of Toronto, Dr. Tsai has also completed a PhD in spinal cord repair and has won numerous clinical, research, teaching and humanitarian awards.

But she doesn't want to talk about any of that. She has too much to say about expanding spinal cord research at The Ottawa Hospital and translating that research into effective therapies that make people's lives better.

"A lot of research in any area is conducted on animals," she says. "And there is a very high failure rate when those studies are translated to people. For example, rat stem cells act and respond differently than human stem cells. It's always best to work with live human tissue, but that's been difficult when it comes to the spinal cord. It hasn't been available as an option."

But that is changing in Ottawa. Because Dr. Tsai is a practising neurosurgeon, she has the skill to remove the spinal cord from bodies donated to science for organ transplantation and research. This makes it possible to gather stem cells from human spinal cords for use in studies. Stem cells are unique because they can replicate and have the potential to repair damaged cells, like the nerve cells in an injured spinal cord.

> *I am grateful for the opportunity to work with amazing co-workers, making a positive contribution to society and working towards our shared purpose as an organization.*
>
> **Lubna Aslam**

Dr. Tsai has a future ideal in mind: to use a person's own stem cells to repair their spinal cord. In order to get there, she needs to work with donated human tissue.

"Maybe we'll be able to take some of a person's stem cells, grow more outside their body, and then return them to the spine to do some repair," she says. "Or maybe we can use some biomedical devices to directly apply growth factors to a person's stem cells in their body. Or create a scaffold for the nerves to be regenerated. There are lots of investigative possibilities."

As an undergraduate and then throughout medical school, Dr. Tsai was always interested in spinal cord and brain regeneration.

"I'm drawn to the idea of hope," she says. "I've always been struck by how one brief moment, like a sudden accident, can change a person's life dramatically and forever. So, I'm inspired by the patients I work with to make this research relevant for them. It's all about translating lab results into benefits for people. I'm hopeful that I can make a difference."

Like Dr. Tsai, Dr. Adam Sachs also works within the Neuroscience Program at The Ottawa Hospital's Research Institute. And similarly, his goal is to restore movement for those with a spinal cord injury. But his research focus is entirely different.

Dr. Sachs is Head of Integrated Spine Surgery, Director of Neuromodulation and Functional Neurosurgery at The Ottawa Hospital, and Associate Professor of Surgery at The University of Ottawa. Prior to medical school, he completed a Bachelor of Science in physiology and math and then a master of science in applied mathematics. Today, he investigates how brain-computer interface (BCI) technology makes it possible to control objects outside the body using only the brain.

A brain-computer interface makes it possible to understand how our brain signals interact with our physical movement, like lifting an arm or pointing a finger.

"We can place electrodes in different areas of the cerebral cortex," explains Dr. Sachs. "This is the outside layer of the brain that allows us to process information through our senses, like vision and touch, and to control our physical movement. We use those electrodes to gather data about neural activity so that we can potentially develop computer algorithms to

continued on page 26

Want to help advance science and help others with SCI?

If you are interested in joining the research study "NeuroCognitive Controller: Implanted device for assistive communication for persons with tetraplegia Safety Study" run by Dr. Sachs at The Ottawa Hospital or if you are interested in learning more about stem cells for spinal cord and brain repair or contributing to the research, please contact Nella Bianconi at 613-761-5073 or nbianconi@ohri.ca.

As an RSC I have the privilege of working with clients who have sustained an SCI and are facing challenges that require the understanding and expertise that SCIO can provide. Having the opportunity to make a positive impact and help clients get through critical circumstances is extremely fulfilling. Working with SCIO allows me to draw on my personal background and professional skills to make an important difference in the lives of my clients.

Chris Bourne

I love working for SCIO. Being able to give back to the SCI community is so rewarding. Watching a person go from , 'I don't think I want to live' to 'Wow, I had no idea I would be able to do this' explains it all.

Diane Morrell

Research is the way forward

Caring for a loved one who has a spinal cord injury can be a stressful and sometimes physically painful situation. Interest and awareness of the needs of family members who care for people with an SCI is increasing. Researchers are looking at issues related to caregiver distress and life satisfaction. However, no survey exists to look at the physical aspects of providing assistance to someone with an SCI (e.g. shoulder/back pain), as well as the emotional impact (e.g. depression), the presence or absence of social support (e.g. having a personal support worker), and being in control of caregiving tasks. Researchers at Toronto Rehab Institute/UHN are testing a new survey designed to measure distress and benefit. They are asking family members to complete a survey with questions about your experience with providing care to someone with an SCI. Giving them 10-15 minutes of your time can assist in building new tools to support other caregivers. If you would like to participate or would like to know more about the study, visit our Participate in Research section of our website or contact:

Gaya Jeyathevan, PhD
Post-Doctoral Fellow/Project Coordinator
Tel: (905) 903-8019
Gayathiri.Jeyathevan@uhn.ca

decode that activity into actions."

What kinds of actions? Today, the movement of a robotic arm. In the future, possibly a person's own arm. The idea is to decode simple thoughts about intended movements and then bypass the spinal cord injury to communicate directly with technological devices. The overall goal is to improve quality of life through greater mobility and independence.

In fact, Dr. Sachs is currently recruiting participants willing to have electrodes implanted in their brain to move toward exactly that goal. For a phase one safety trial underway, he is looking for people in the Ottawa area with a C5 level or higher injury, a fair amount of upper body disability, and otherwise good health.

Aside from the health criteria and willingness to have surgery, Dr. Sachs shares some insights about who might enjoy helping to develop this cutting-edge technology.

"Ideal study participants might be interested in science and engineering, in the idea of advancing knowledge, or just in helping others with SCI. There is a time commitment, of course. But ultimately, we would love to hear from people who enjoy learning about new technologies and therapies. That's a great fit for this kind of study."

Will they get to take home a robotic arm as a parting gift for participating?

"I'm afraid not," laughs Dr. Sachs. "All I can offer is a sense of purpose and accomplishment. Studies like this will make a difference in people's lives in the future." ●

75
& BEYOND»

I believe our volunteers make us stronger! Whether they are Board or Committee members, peer or advocacy volunteers or local event volunteers, we ultimately could not be successful in our mission without them! Their compassion, unselfish caring, patience, and just plain love for their community is the heart of our organization.

Sheila Daniel

75
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We address and resolve systemic barriers that impact the quality of life of people with an SCI.

Peter Athanasopoulos

"We can place electrodes in different areas of the cerebral cortex," explains Dr. Sachs. "This is the outside layer of the brain that allows us to process information through our senses, like vision and touch, and to control our physical movement. We use those electrodes to gather data about neural activity so that we can potentially develop computer algorithms to decode that activity into actions."

> *After my accident the CPA helped me find the strength to build new dreams. Together we made them realities and for the record I'd just like to say Thanks!*
>
> **Rick Hansen, 1988**

> *The most important fact in the development of a successful plan of re-establishment is and will continue to be, the leadership available from the casualties themselves.*
>
> **Albin Jouse**

> *SCIO brings the community together. The peer groups get individuals to come together as one, allowing us to be social and safe.*
>
> **Holly McCausland**

Plan a legacy that will have a lasting impact for generations to come.

Lynn Turnbull

"When we write our Last Will and Testament, we consider people and things we love. We leave gifts to benefit others, so that a little piece of us can live on. Spinal Cord Injury Ontario has been part of my family for a long time. My sister Barbara was a client, a fundraiser, a donor, and a much-loved community member of the organization. Through Barbara, I've seen first-hand the powerful impact Spinal Cord Injury Ontario's services can have on a person's life. For this reason, I too fundraise, donate and have made the decision to leave a gift in my Will so that Spinal Cord Injury Ontario can continue their life-changing work even when I'm gone."
Lynn Turnbull

Looking after those you love and the causes you care for.

"I have been a donor of Spinal Cord Injury Ontario for 34 years. I have no connection with anyone with an SCI but I believe that the work that SCIO does to support people with an SCI is quite invaluable. That is why I continue to support their good work."

34 years of giving, St. Chatharines' donor

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You care about looking after those you love. You want to know that your legacy includes making certain they will have enough to thrive. You also care that the good work you have supported in your life continues to get done. It can seem that these two things are in competition. They don't have to be.

Those you love and the causes you care about are all part of your legacy. Look after your loved ones first, make certain they are taken care of. Then, determine a percentage of your estate, as large or as small as fits your life, that you will give in service of the cause that is part of who you are.

What then? Add one sentence in your Will.

By simply adding one sentence to your Will, you engage the same easy mechanism the majority of generous Canadians who have made a planned gift have used to add to their lasting legacy. You just add a sentence to your existing Will (called a codicil) or new Will and you have added to your legacy of caring for your community. That's it.

It is important to mention that planned giving offers many ways to increase your impact and even lower your taxes, like making a charity a beneficiary of your insurance, RRIF or RRSP. These are worth reviewing in the context of your goals and financial life, but an uncomplicated gift in your Will is the most likely starting point for making certain the causes that are part of your life's work can continue to do the work you care about and continue your legacy.

Your Legacy

We are happy to help however you prefer.
To chat, get more info, or just get sample language for your Will call Paul at 1-877-422-1112 ext. 801
or email giving@sciontario.org
or visit: sciontario.org/mylegacy. ●

Mike Rathwell and Nancy Hayes from Motion with Ruth Whiting and Bryce Donald in the foreground.

It Takes a Village to Save a Life

With no government funding available for the assistive devices he needs, Hilton Simzer has had to rely on generous donations of time and equipment to safeguard his health.

Hilton Simzer

I felt lost. Thankfully, Chris from Spinal Cord Injury Ontario provided me with valuable information and the comfort of knowing that there was a community of people offering support and guidance to me, including Sally, the peer mentor he connected me with.

Megan, client

75 & BEYOND»

“This is my lifeline to staying healthy and living longer,” says Hilton Simzer, who experienced a spinal cord injury almost 40 years ago. “I couldn’t even measure the difference it makes in my quality of life.”

Hilton is referring to an adjustable electric bed with a pressure relief surface recently received from SCIO after a long, complicated and collective effort involving his Physiatrist, Community Occupational Therapist, and SCIO Regional Services Coordinator, along with manufacturer Permobil Canada and accessibility solutions provider Motion.

Because the Ontario Government’s Assistive Devices Program (ADP) does not support specialized beds and support surfaces, Hilton found himself at a loss as to how to overcome his recurring pressure injuries caused by the use of a standard bed and mattress. He not only requires frequent repositioning, but also a low air loss mattress to prevent tissue damage.

Having been in and out of hospital to address his pressure injuries, Hilton and his professional care team know how effective the therapeutic bed and mattress are for maintaining his health. They also know how prohibitive their cost is as non-funded items.

“It’s frustrating that people like Hilton can’t get the funding they need—and therefore the therapeutic devices they need—to keep them healthy and out of the hospital system,” says Dr. Karen Smith, a physician at Providence Care Hospital in Kingston, Ontario and professor at Queen’s University School of Medicine.

“We recently had Hilton in our rehabilitation centre for a month to treat his injuries,” she says. “He received the same support and care he currently has at home, with one notable exception: an electric, adjustable bed with a pressure distribution surface. His injuries began to heal phenomenally. We discharged him home and, within four weeks, his injuries were back, same as before. He

I am privileged to do my job. I work hard, try to be fair and I care.

Angela Clair

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Knowledge is power.

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Permobil donated its electric, adjustable Tröst bed to Hilton, along with side rails. The bed is compatible with the therapeutic support surface also manufactured by Permobil, called SelectAir, that Motion donated. Between the two companies, and with some help from the Rotary Club of Kingston, Hilton received about $11,000 worth of essential equipment.

doesn't have the equipment he needs to maintain his health."

Dr. Smith explains that working with patients with spinal cord injuries often requires taking on an advocacy role. Given the cost of essential equipment and supplies not covered by ADP—from lifting devices and ramps to commode chairs, catheters, hospital beds and mattresses—there are always concerns with discharging patients who can't afford the cost of their supplies and equipment.

"The catastrophe here is that it would be far cheaper for the Ontario government to supply Hilton with the equipment he needs than to pay for his hospital stays," says Dr. Smith. "It's more than reasonable to assume that he would need rehabilitation care and also acute care, should his injuries worsen resulting in sepsis. Never mind maximizing patient independence and quality of life. Those are also compromised by living with chronic tissue damage."

Occupational Therapist, Ruth Whiting, who has worked with Hilton over the past few years, says that many clients with a spinal cord injury need an electric bed and pressure relief systems to avoid and heal injuries. Like Dr. Smith, she finds herself engaged in funding searches to help her clients. Ruth and SCIO have previously helped Hilton secure funding for his wheelchair, wheelchair repairs, seating cushions and batteries.

"When it comes to ADP-approved equipment, Hilton needs help paying for the 25% not covered by the program," says Ruth. "There are charities that support these co-payments but might not be able to fund the remaining amount. With a bed and mattress, there are hardly any options for funding, government or otherwise."

Ruth explains that when clients with an SCI are discharged from hospital—whether after their injury or after secondary complications—the Local Health Integration Network (LHIN) can provide only two months maximum of rental equipment to help pressure injuries heal. In addition, the LHIN's limited pressure relief mattress options are not sufficient for higher needs clients.

In the end, gaps in the system place additional workloads on people like Ruth. Many community therapists are contracted services and are not compensated for time spent on funding searches, applications, and coordination between different groups and agencies. They do it out of professional responsibility and because they care about their clients. Without charities stepping in to work with occupational therapists in partnership, the funding gaps would be even greater.

My team connects people who want to change the world with those who can. We transform donor and volunteer contributions into positive impacts for our clients. Big and small changes to improve quality of life for our clients and their families. We aren't a huge charity but we have huge impact on the people we serve.

Ari Wahl

75
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Spinal Cord Injury Ontario also helps clients with funding shortfalls. Regional Services Coordinator Bryce Donald met Hilton when he asked for help acquiring more cost-effective continence supplies.

Spinal Cord Injury Ontario also helps clients with funding shortfalls. Regional Services Coordinator, Bryce Donald met Hilton when he asked for help acquiring more cost-effective continence supplies. Bryce tried to get him enrolled in the Ontario Disability Support Program (ODSP), but Hilton's income is just above the cut off. Yet, he cannot afford the cost of needed supplies.

"More than 80 percent of clients I see lack full funding when it comes to equipment and supplies," says Bryce. "I would say I have helped about a dozen clients acquire a specialized bed or pressure relief mattress. If we can't locate funding, they stay in the hospital or they're discharged and then the clock starts ticking. Clients can rotate in and out of hospital care to help manage secondary complications."

In addition to the funding gap so many clients face, Bryce describes a knowledge gap between what health teams know their patients need to stay out of the hospital and what the Ontario government is willing to subsidize for their care.

"What's interesting about Hilton is

that he's a very independent, strong willed, do-it-yourself kind of guy," says Bryce. "He has only recently reached out to SCIO, because his supply costs have started to outpace his income. He now needs additional care for his pressure injuries. He wouldn't ask for anything if he didn't need it. And neither would Dr. Smith, who contacted me about the bed that will prevent re-injury and recurring hospital stays."

With no way to fund the equipment deemed necessary for Hilton, Bryce was forced to escalate this situation to SCIO's senior leadership, who in turn solicited support from its corporate donors. Two new members then joined "Team Hilton" to help him regain his health and live independently: Mike Piccin, National Clinical Education Manager for Permobil Canada, and Jeff Preston, Director of Product and Marketing at Motion.

As a provider of mobility and accessibility solutions, Jeff is well aware of the funding shortfalls many people with disabilities face. He has helped Motion clients to access funding for essential devices, either to make up for what's not covered by ADP or to cover the full cost of non-funded equipment.

"It's abundantly clear that Hilton needs a low air loss mattress and an electric bed to help him with positioning," says Jeff, who is also involved in advocacy work to build awareness about assistive devices and to impact government policy. "It's in everyone's best interest for Hilton and others like him to live safely and independently at home. Assistive devices play a huge role in that, but the funding model has not evolved to meet clients' needs holistically."

Jeff believes in Motion's mission of "Make Life Accessible" when it comes to getting quality, life-enhancing devices to those who need them.

"This is a human rights issue," says Jeff. "The gaps in our system strip people of the quality and dignity of life they deserve. Hilton is not looking for some kind of special treatment. He's looking to get up every day and go about his life without continual re-injury. How is that asking too much of our society?"

With a commitment to providing Hilton with the therapeutic surface he requires, Jeff contacted Permobil to see if they could help with the bed. Permobil is guided by its founding philosophy that every person with a disability has the right to compensate as far as possible with high-quality technologies.

"We would never say that electric wheelchairs are essential devices while electric beds are not," says Mike Piccin of Permobil. "But the Ontario government makes that distinction. So people like Hilton face an extremely poor quality of life without the equipment they need to remain healthy. He can access funding for his daytime hours but not for his nights. That imbalance prevents him from participating fully in life."

Permobil donated its electric, adjustable Tröst bed to Hilton, along with side rails. The bed is compatible with the therapeutic support surface also manufactured by Permobil, called SelectAir, that Motion donated. Between the two companies, and with some help from the Rotary Club of Kingston, Hilton received about $11,000 worth of essential equipment.

"Hilton can't heal without the right products," says Mike. "And many people just can't afford them. But in the end, those products cost just a fraction of years of hospital care. And they dramatically change people's lives."

Hilton is now benefitting from that change and is optimistic that his injuries will heal.

"I'm hoping to see a big improvement by the spring," he says. "I've been less and less mobile, more confined in my apartment, and in a lot of pain. With this bed and mattress, I believe I will get my life back. I appreciate how hard everyone has worked on my behalf. My message to all of them is, thank you for helping me to take care of me."

SCIO, with Bryce's leadership, was able to resolve Hilton's life-threatening situation, but Hilton is one of hundreds of people in need of life-changing support.

An effective way to help people get the essential equipment they need is to make a donation to SCIO's equipment program, *Enhancing Independence.* Through negotiation and donations of equipment, SCIO's RSCs can facilitate even more equipment needs. Please consider a donation today sciontario.org/essential

Until the Ontario government modernizes its funding and provides better public coverage for essential equipment and supplies, it will fall on the generosity of caring members of our community to alleviate the suffering of people falling through the funding gap. ●

It shouldn't be called a work/life because cause that sounds precarious; like a juggling act; one too many balls and the act is over. Working for SCI Ontario is not an act – it is a passion. And you should never have to balance your passion.

Robert Murphy

75 & BEYOND »

The only way to do GREAT work is to LOVE what you do.

Jenny Rodriguez

75 & BEYOND »

It's so rewarding to play a small part in helping people see their potential and achieve their goals.

Christine Senick

75 & BEYOND »

For Over 63 Years Lyndhurst Has Been A Part of My Family

By Jeffrey Kerr

I've been helping Lyndhurst clients buy and sell wheelchair accessible homes since 2004, and a contributor to Outspoken! *and* Community *since 2013. So when it was announced that the fall 2020 edition of* Community *would be dedicated to the 75th Anniversary, I thought it would be a great time to talk about my mother's connection to Lyndhurst.*

Mary Lou Kerr - Graduation Picture 1958

It all started in 1957 when my mom, Mary Louise Kerr (Smyth), was chosen for a summer intern position at Lyndhurst, located at 51 Lyndhurst Avenue, near Casa Loma.

The following year she graduated from the University of Toronto with a diploma in occupational therapy and physiotherapy. Back then the OT/PT program was a combined three year course. My mom's class started with 68 students, but only about 42 graduated. They were all women.

She really enjoyed her intern position, so after graduating, at the age of 20 years old, Mary Lou applied for a full-time job. She was hired right away as a staff physiotherapist.

At the time there were no OTs at Lyndhurst but there was a significant job overlap between OT and PT and Mary Lou was glad to have the OT training. She was assigned to 5 or 6 patients at a time and worked with them on a daily basis. One of her memorable accomplishments was starting a writing class for patients with quadriplegia. Using the splints

She really enjoyed her intern position, so after graduating, at the age of 20 years old, Mary Lou applied for a full-time job. She was hired right away as a staff physiotherapist.

designed for eating, Mary Lou attached a pencil to it and was able to teach her patients to write again.

Jack Nutt was one of Mary Lou's favourite patients. They still stay in touch so I reached out to Jack to ask him his story and memories from his time at Lyndhurst. I was amazed at the clarity of his memories from 60 years ago. The stories he told me of his journey, his time at Lyndhurst, of working with my mom and the other staff was like he was talking about yesterday.

On June 21, 1959, 17 year old Jack and his friend Barry Blackman went swimming in a river near St. Mary's outside of London, Ontario. They were with some girls that they'd just met. Jack, trying to impress them, dove into the shallow river and hit the bottom. He sustained a partial lesion of his neck.

Even though it was a long way from their home in St. Mary's, his parents made the decision to send him to Lyndhurst because it had a great reputation for helping patients with spinal cord injuries. Looking back now, he is very grateful they made that choice.

When he arrived at Lyndhurst he was "the first young guy" there. Jack said the other patients at the time were older, some of them lumberjacks and industrial workers who were injured on the job.

Participation was essential at Lyndhurst. There was an unwritten rule that patients had to attend classes or they would be asked to leave. This was fine with Jack. He arrived motivated and ready to work, especially when he found out that the cafeteria was the only place meals were served; in order to eat, Jack needed to figure out how to get there.

Jeffrey Kerr and Mary Lou Kerr at Blue Jays Game May 2019

Jack Nutt and his Mother Maggie in Jack's Boat

After breakfast, Jack's typical morning schedule had him starting with Mary Lou, working on his leg muscles. Then he had matt class with George White. George was a retired army guy that Jack describes as "always yelling, but never angry." After that, it was back to physio with my mom to "work every muscle in my arm and fingers."

Jack told me about chair class which was also with George White. When the weather co-operated the class was held outside on the tennis court. Jack remembers George standing off to the side with his whip (think Indiana Jones) and snapping and cracking it to help motivate his students. One time a neighbour called the police thinking that people were being disciplined but it was all just for show and the matter was settled quickly.

Another of Mary Lou's favourite patients was Gaston Herbert. He was one of the "older lumberjacks" that Jack remembered earlier. Mary Lou also stayed in touch with Gaston and I recall going with her to visit him just after he'd purchased a new full size accessible van. Gaston didn't drive himself so the driver controls were not modified. He relied on others to drive it for him and that included Mary Lou. Gaston was very excited to show off his brand new van and we all got in with Gaston riding shotgun and went for a drive. I'm pretty sure that was the first time my mom had driven a full size van!

Mary Lou worked at the original Lyndhurst location until 1960 when she had an opportunity to go to the Rome Olympics. Although she was an accomplished tennis player, she went to Rome as a spectator, not an athlete.

In 1978, a part time physio position became available at

continued on next page

> *As a RSC, networking with community partners has given me the edge in connecting with resources that have assisted the clients, their families and those working with them, to find resources that will improve or resolve their life situation.*
>
> **Jackie Wright**
>
> **75** & BEYOND»

> ***I asked my mom if there were any differences being a physio in 1958 vs. 1978 and she told me a lot had changed. Physios in 1978 were given a lot more discretion to treat their patients. It was no longer necessary to get her supervisors' approval to change aspects of treatment.***

Lyndhurst, now located at 520 Sutherland Drive, and my mom was excited to come back. I was 6 years old at that time and my sister and brother were 10 and 11 years old, respectively. My Aunt Jeane (I've mentioned her a few times in my earlier articles) was volunteering as a teacher in the Lyndhurst classroom at the time and put a good word in for her.

I asked my mom if there were any differences being a physio in 1958 vs. 1978 and she told me a lot had changed. Physios in 1978 were given a lot more discretion to treat their patients. It was no longer necessary to get her supervisors' approval to change aspects of treatment. Mary Lou worked primarily in the therapy pool until 1982.

My mom made a lot of lifelong friends from her time at Lyndhurst, and positively impacted a lot of people. One of the first things Jack Nutt said to me was "I credit your mom with giving me 60 years of independence." It was a very powerful statement and I can't think of any higher praise for the work that my mother did. ●

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Research Corner

Chronic Conditions Course for People with an SCI

During the pandemic many of us are coping with feelings of stress, isolation and depression. These can be exacerbated by chronic pain issues. We are also spending more time on the internet looking for answers which sometimes don't work for us. Researchers at Lawson Health Research Institute are exploring the effectiveness of a program in reducing psychological distress and improve coping and quality of life among persons with SCI. These courses were designed because so many people never seek treatment, but many have access to the Internet. Because sustaining a spinal cord injury can often be connected with symptoms of depression, anxiety, and pain it was felt to be important to provide information that could be used to manage these symptoms. Participants interested in the courses can apply online by completing the online screen. Once the screen is completed, a telephone interview will be set up with the research staff to discuss your concerns and ensure the courses will be suitable for you. Among the participants found to be suitable, half will begin the Chronic Conditions Course for persons with SCI while the other half will receive the Psychoeducation SCI Rehabilitation Course.

Participants will receive up to $50 in Amazon gift cards.

Participate

If you would like to participate or would like to know more about the study visit our Participate in Research page on our website or contact the Principle Investigator:

Dr. Swati Mehta, PhD
Scientist, Lawson Health Research Institute
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