20 YEARS OF CHANGING LIVES

The Ontario Neurotrauma Foundation held its Annual General Meeting in June. As AGMs go it was pretty standard except for one thing, the Foundation has something special to celebrate this year – our 20th Anniversary. While we recognize this milestone we also pause to reflect on who matters most to us in our work – those living with acquired brain injury and spinal cord injury. Over the past two decades ONF implementation-focused research along with care guidelines and standards are helping to improve the lives of tens of thousands of Ontarians. This is what we do and why we do it.

You can read a bit more about some of our achievements over the years [here](link to AP page) and the ONF Annual Financial report is available here and the ONF Annual Financial report is available here (link to AP page).

The work of ONF is accomplished through a strong and growing network of partners. Our long-standing partnership with the Rick Hansen Institute includes joint research activities as well as collaborative presence at conferences and activities focused on the research, care and treatment for those living with SCI. We are proud of our ongoing work with Spinal Cord Injury –Ontario in engaging the SCI community in our work. Our most recently expanded partnership with the Ontario Brain Injury Association is opening new doors to strengthen the voice of the ABI community in this province. The network of partners focused on neurotrauma prevention continues to expand and be strengthened, particularly through the collaboration around fall prevention initiatives including the annual Fall Prevention Month.

And this has all emerged in the past 20 years. It is a considerable achievement and we – and those who are the focus of our efforts – are grateful for the continuing support for ONF by the provincial government. While AGMs celebrate the past and this one was special we think the next 20 years hold great promise for ONF to continue to make a difference in the lives of Ontarians living with a neurotrauma injury.

Kent Bassett-Spiers

CEO Ontario Neurotrauma Foundation

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Happy 20th Birthday Ontario Neurotrauma Foundation

$100-million investment in research, care, treatment and prevention initiatives
In 1998 a group of individuals concerned about the lack of focus on research needed to ensure better care for those who experience neurotrauma took the bold step that led to the creation of the Ontario Neurotrauma Foundation. The Ontario government, recognizing the potential of the initiative, stepped up to fund the work and since that time has invested more than $100-million to improve the lives and health of those living with spinal cord and acquired brain injury.

That investment has helped create one of the strongest provincial networks of individuals, researchers, community organizations in the country all of which are brought together through the work undertaken by ONF.

Marking the 20th anniversary of an organization that has achieved such a broad range of successes provides the ideal opportunity to recognize those individuals who have made this possible. Beginning with this issue of NeuroMatters, we will be highlighting a selection of our achievements and the people who made them possible.

One of those people is Corinne Kagan, Senior Program Director of the ONF ABI program. She was the first ONF employee hired in 1998. Her 20th Anniversary with the Foundation was celebrated at the Annual General Meeting in June.

New evidence, guidance offered to healthcare providers/patients in revised ONF concussion guideline

Hope and help to manage long-term concussion symptoms

Patients often say they can’t find easily understood information when their concussion symptoms are prolonged. The Ontario Neurotrauma Foundation (ONF) has addressed this issue in the new edition
Once thought to be a brain injury that would resolve itself quickly, evidence now shows that there can be long-term consequences of concussion that are significant and management requirements are more complex than was understood even 20 years ago.

“We believe this guideline will give people strategies to help them better cope when a concussion does not heal according to their expectations,” says Dr Shawn Marshall, an Ottawa-based physician and researcher associated with The Ottawa Hospital Research Institute, and the Chair of the ONF Concussion Guidelines project team. “The team had feedback that patients would benefit from access to understandable and reliable information.”

As with past guidelines and standards developed by ONF, the third edition of the concussion guidelines for healthcare providers is grounded in recent research and the knowledge of healthcare providers from physicians and nurse practitioners to neuropsychologists, physiotherapists and organizations representing patients.

Dr. Marshall has heard from patients and colleagues that patients often showed up in their doctors’ office with a copy of the healthcare provider guidelines in hand, hoping they would provide helpful information during their discussion. “Frankly we know patients, family and general practice physicians have to work as a team using dependable and evidence-based quality information.”

The new patient guidelines were reviewed by patients themselves. One patient who participated in the review process says, “With the knowledge comes power, in terms of referrals. So, had I had the
knowledge…I would've gone forward to request other referrals sooner, and that may have made a
difference, not only to access supports and services, but to rehabilitation in a faster form."

“This patient-focused guideline has been developed by the Ontario Neurotrauma Foundation (ONF)
in consultation with patients, their families and a broad team of healthcare professionals and
researchers with knowledge of the most up-to-date information,” says Corinne Kagan, Senior
Program Director, Acquired Brain Injury (ABI). “We heard through our healthcare provider networks
and directly from patients that there was a gap in the kind of practical, evidence-informed information
available in simple, clear language. The patient version addresses this gap.”

The Ontario Neurotrauma Foundation Guidelines for Concussion/Mild Traumatic Brain Injury (mTBI)
and Persistent Symptoms are available here. The patient guidelines can be found here.

ONF ABI program research project
focuses on new thinking about brain injury recovery

Thinking outside the box may lead to a new route to improve memory function for those who
experience moderate to severe traumatic brain injury (TBI). Dr. Robin Green, Senior Scientist at the
Toronto Rehabilitation Institute and Canada Research Chair (tier II) in traumatic brain injury, has
received a grant through the Ontario Neurotrauma Foundation (ONF) Acquired Brain Injury (ABI)
program to further test and expand a unique behavioural intervention that may improve not just
compensate for memory loss.

“We know it is hard to achieve improvements in memory with those who are in the chronic stage of
brain injury. Traditional approaches address compensation options of memory functions,” says Dr.
Green. “We are aiming to actually restore brain structure and function as well as to mitigate further
decreases. In this way we can help to promote healthier brain aging, and improve day-to-day memory
functioning in a very flexible way. We are trying to promote greater participation in every day life.”

Dr. Green’s lab has previously shown that people with even quite severe brain injury months and
years post-injury can carry out such brain exercises in their own home with very minimal supervision.

Those participating in a pilot research project for the study were engaged in the intervention and
experienced good outcomes individually without additional rewards or encouragement required to
ensure their compliance. This new grant will explore the outcomes with additional rewards and offers
encouragement to family members to help them support participants.
Another key outcome of the work to be completed through the grant (which is entitled “Addressing a gap in evidence and care: Development of a remotely delivered learning and memory intervention and province-wide delivery infrastructure”) is to evaluate the benefit of expanding this relatively easy-to-apply and low-cost treatment protocol provincially.

Access to treatment remotely could break down some of the barriers to treatment for those who do not live in major Ontario centres. Dr. Green is already communicating with partners across Ontario and in other provinces. If successful, the study could lead to significant improvements in the lives of people across the province.

“There are always complexities when applying new treatments and we hope to increase the understanding of what works for individuals and why,” says Dr. Green, who leads one of the largest and best-established ABI clinical programs in the province. “We are trying to build an approach based on hard science that also takes into consideration that each person participating in the study is an individual with unique needs. During and after the study, participants and family members will be asked questions about what facilitated and what impeded participation in the treatment.”

“Dr. Green’s research is intrinsically aligned to our goal of moving evidence to practice,” says Corinne Kagan, Senior Program Director ABI Program, ONF. “The simplicity but power of this approach gives us new hope that those who have been debilitated by TBI will see improvements in their daily lives and their ability to meaningfully participate in their communities.”

**Researcher Profile**

*Dr. Cathy Craven,*

*University Health Network, Toronto*
Dr. Cathy Craven focuses on research that improves the care for individuals living with spinal cord injury. She recently received funding from the Ontario Neurotrauma Foundation and partner
What prompted your interest and obvious commitment to research in the area of spinal cord injury and rehabilitation?

Prior to medical school, I completed a degree in kinesiology my mentor at the time recommended I use my knuckle dragging skills to referee wheelchair basketball in my lunch hour. It was an amazing experience to work with people who had spinal cord injury, watching how motivated and determined they were to live life to the fullest inspired me to choose rehab medicine in medical school. Understanding the range of needs of these patients, I became determined to develop a broad toolbox of rehabilitation solutions.

You have received several grants from ONF, and REPAR (and others) over the past several years. What do you consider to be the most important “break through” in your work to-date?

I think I’ve been good at pulling people together to work towards a common goal. Many of the grant applications were developed by diverse groups of people who bring unique perspectives. Most of my work has been looking at the medical and health consequences of various health conditions following SCI.

One of the big breakthrough moments from my perspective, was publication of “Spinal Cord Injury: A Manifesto for Change” in 2014. The Manifesto offers a specific call to action to healthcare providers, patients and stakeholders to focus on reducing the health consequences and mortality related to heart disease, fractures and pressure sores. In Ontario, we have the expertise in heart disease, osteoporosis and wound care but not specific to persons living with SCI. The Manifesto provided details and statistics on the morbidity and mortality rates for SCI patients who experience these health conditions. Much of what I have initiated in terms of developing new research teams and driving health system transformation in the last few years was in direct response to this “call to action”.

You established the SCI Rehabilitation Translational Continuum Team or ReCon Team earlier this year. What skills and knowledge do you look for when you recruit members to research teams such as ReCon?

I love to work with new people with novel ideas, so for this team I invited individuals who bring considerable expertise from a broad range of fields such as cellular modelling, animal models and basic science. They are all passionate but many are new to SCI, some are experienced in SCI but not with the specific health conditions we are exploring. Some are early in their careers, others bring a depth of experience but few have worked together in past. I’m really trying to follow a novel path to bring novel results.

I have observed that at the big scientific and medical meetings when people come together we may not talk the same language. Through the ReCon team we are hoping to develop a common language Once we can talk the same language, we can work collaboratively to facilitate development of novel rehabilitation solutions For instance, in SCI research, most human subjects
are male, but most animal models are female. How do we know that what we learn from animals is transferable to humans? So, one of the approaches we will be exploring is reverse translation – looking at the end and trying to back into the solution.

ReCon has been the most fun thing I’ve done in my career in a long time!

_How could the outcome of your current research project improve the lives of those living with SCI?_

I think it will help us know what works and what doesn’t in terms of care options. Can we stop doing the things that don’t work? Can we demonstrate that funding therapies with potential to work in humans and animals, should lead to better products at the end of the day? By operating beyond the silos I believe it is possible to establish a better connection between everyone along the SCI care continuum. That kind of imbedded connection will improve care.

_Based on your knowledge and understanding of SCI, do you have a message for those who establish policy with respect to the care and treatment of those living with SCI?_

Having a spinal cord injury and adapting to it is one challenge. But the ongoing health conditions are very hard on those living with SCI and their caregivers. If we could reduce the incidence of spinal cord injury that would be great; however, for the thousands of people in this province living with SCI and complex chronic health conditions because of their injury, reducing the incidence and severity of these conditions would lead to significant improvements in overall health. The cumulative burden of these conditions wears people down and robs them of their quality of life. It also needs to be easier for people to navigate the health care system when they are ill as it is much more difficult to navigate diagnostic testing from a wheelchair.

I’m very passionate about this field. What I love about individuals living with SCI is they are well-educated and motivated to get better, despite trying circumstances. I am specifically interested in understanding how muscle, bones, and the nervous system interact.

I have a vision and I keep driving towards in my work. Our next big win will be to understand the physiological drivers’ specific to spinal cord injury that will lead to healthcare system reform. .

**ONF, SCIO continue planning for Care Pathways**

A $6-million commitment in the 2018 Ontario budget that would improve care for persons with sustained brain or spinal cord injuries resulting from a motor vehicle collision continues to be in the planning stages with the Ontario Ministry of Health and Long-term care.
The funds were allocated to the Ontario Neurotrauma Foundation (ONF) and Spinal Cord Injury Ontario (SCI Ontario) to develop care pathways to better the health services and systems of care for those who experience spinal cord or traumatic brain injury following a collision.

"This funding is a significant and important step that will improve the lives of those who experience catastrophic injuries in vehicle collisions," says ONF Chief Executive Officer, Kent Bassett-Spiers. “We look forward to working with the spinal and brain injury communities to develop and implement new care pathways."

The 2017 government report on automobile insurance “Fair Benefits, Fairly Delivered” included recommendations to change the way in which evidence-based care is provided and funded for those who experience neurotrauma as a result of a motor vehicle collision.

The funding would be distributed over a three-year span to support new and existing programs implemented to harmonize private and public care for those living with neurotrauma as a result of a vehicle collision.

**NeuroMatters News**

*Making fall prevention a health systems focus*

A group of individuals representing a broad range of stakeholders from across Ontario’s healthcare system have been working quietly to lay the groundwork for a system-wide focus on prevention of falls for adults and older adults. For years, the statistics regarding injuries that result from falls have indicated that by decreasing the number of falls, costs to the healthcare system would be significantly reduced. Reducing falls would also decrease the physical, emotional and social consequences for those who experience an injury as a result of a fall.

“ONF has co-ordinated this collaborative effort for the past year and we have a group of dedicated and knowledgeable people around the table,” says Hélène Gagné, Program Director, Injury Prevention. "We have our sights set on a Think Tank gathering of leaders in the field later this year to help bring practical options to the table that will improve system delivery of services and programs in a seamless and timely manner to older adults."

*Loop survey results*

This September marks the third year since the Loop launch. A platform created to provide a variety of services to the Fall Prevention Community of Practice (CoP); Loop has been an instrumental resource for practitioners, program planners, researchers, policy planners and others who have an interest and work in the area of fall prevention.

To better understand the member base and usage of the platform, the annual survey has been conducted which will provide informed data to the development of the services offered. The 2018 Loop Report is scheduled for release in September, coinciding with the Loop anniversary.

*ONF/RHI funding opportunities*
A call for Letters of Intent (LOI) went out to meet the needs of funding opportunities in the area of Spinal Cord Injury (SCI) research focused on the recommendations from summits on: urohealth, neuropathic pain and pressure ulcers. The deadline for all LOI was July 1 – the next phase in the timeline will be the Invitation to Submit Full Proposals which are to be expected August 15.

ONF and OBIA break new ground to give people living with ABI a greater voice in the conversation about their care

Talk about partnership...

Over the years the Ontario Neurotrauma Foundation (ONF) and the Ontario Brain Injury Association (OBIA) have partnered on initiatives that have improved the care of those living with acquired brain injury. In late 2017, ONF and OBIA realized that a new kind of joint effort would be needed to strengthen the voice of the ABI community. Today, ONF and OBIA share a staff member, Chad Debison-Larabie, who is focused on building new communications channels and programming.

Ruth Wilcock, Executive Director of OBIA, and Corinne Kagan, Senior Director, ONF Acquired Brain Injury Program, reflect on what prompted this new level of partnership and what changes are possible given this new focus and effort.

ONF and OBIA have worked together on many projects and activities over the years. What makes this approach to partnership different that work done in the past? What gap are you attempting to fill or opportunity are you seeking to take advantage of?

Ruth We are sharing “human resources” in order to bring into fruition a common goal. ONF and OBIA have always shared the goal of bringing the needs of those living with brain injury to the attention of decision-makers and influencers in government. The gap? Brain injury needs a stronger voice and presence in order to influence policy on care, treatment and support for those living with brain injury. This is an “invisible” disability which seems to make it “invisible” to policy-makers. We want to change that.

Corinne ONF has funded several projects in the past that were more research or project orientated. In the early 2000’s ONF provided support to OBIA in their work with the 21 Community Brain Injury Associations across the province. This new collaboration is different because we both want the ABI community to be able to speak with one voice. It doesn’t mean that there is only one key issue that will come to our attention, but as a community we need to strengthen the networks to be able to gather the opinions and understand the needs, issues and priorities of the full community.

Cultivating this ABI stakeholder network will be helpful to the work of ONF and OBIA by advancing priority issues, helping us learn more about research priorities and needs of people
with ABI. We also expect to galvanize various stakeholders to provide advice and push information into the broader community. Overall, we hope to improve OBIA’s ability to speak provincially about what people with ABI need.

**Sharing staff is perhaps the most powerful way to demonstrate to stakeholders that organizations are committed to make a difference. Have you received feedback and questions from others about this approach?**

**Ruth** The feedback that I have received is that having a strong stakeholder network is essential to bringing about systemic change and, most importantly, that ONF and OBIA are the organization to do this. OBIA has always “been the voice” of those living with brain injury and understands at a very grassroots level what the needs of those living with brain injury are. ONF’s goal is moving research to evidence-based practices with the ultimate outcome of improving the lives of those living with brain injury. Both organizations are committed to making a difference but come at it from different angles and bring complementary experience to the table. Hence, all the feedback I have received is that this is a perfect fit for this type of partnership.

**Corinne** I’m hearing that it’s an excellent idea and that people look forward to getting involved and seeing this new network grow.

**What is the key outcome you want to achieve through this particular partnership arrangement?**

**Ruth** Simply put, to build an expansive stakeholder network enabling OBIA and those living with brain injury to have a strong voice and presence with decision makers, ultimately leading to better outcomes and access to services for those who have sustained brain injuries.

**Corinne** To strengthen the ability OBIA to speak to the priority issues of people living with ABI and the ABI community. To ensure that ONF’s work is grounded in the needs of people with ABI and the systems that provide care and support them.

**How are you measuring the success of this approach?**

**Ruth** For me the initial and also ongoing measurement is the number of people that we are able to engage coupled with the number of champions we are able to recruit and develop to carry the message into the broader community and to policy-makers.

**Corinne** I think there are short-term and long-term measures to consider. In the short-term, indicators of success might focus on building and tracking connections, i.e. the number of members in the network, the number of people engaged in or knowledgeable about ONF and OBIA activities.

Longer term we could measure success in terms of increased engagement in the stakeholder network. For example, people in each Local Health Integration Network (LHIN) being able to speak for the network, be active champions, and have the ability to connect to and inform people around the province on challenges, changes and progress on issues of importance to them.
I would hope the new stakeholder network will help develop initiatives in the ABI community. An example of this would be increasing participation in the Ontario Brain Injury Survey and sharing these results broadly. Ideally in the long-term we would like the network to grow into an ABI Alliance similar to the one that is functioning so well with those who live with spinal cord injury. Like SCI, the ABI network would actively represent people living with ABI, their caregivers, service providers and the greater community.

**KW clinic offers new care model for Ontarians living with spinal cord injury**

*Model improves outcomes*

As we continue to address the need to provide more accessible care for those living with SCI, ONF is constantly seeking new opportunities to partner with organizations to increase the access to primary care. In collaboration with the Centre for Family Medicine in Waterloo, the ONF in partnership with the Rick Hansen Institute (RHI) will support the opening of five new mobility clinics across Ontario.

The $700,000 grant from ONF will be used to develop new clinics that model the existing Waterloo facility. SCI Program Director, Tara Jeji says, “This has been a long-standing partnership and we are proud of the work that has been done – it’s rewarding to see better patient outcomes. We now have the opportunity to take this model to scale by providing equitable access to primary care across the province.”
Fall Prevention Month for all ages

Fall Prevention Month (FPM) is still a few months away; but the ONF Prevention team and collaborators have been busy building toolkits and resources to ensure an impactful campaign for the fourth annual FPM. Throughout the month of November, organizations and individuals are encouraged to join together in coordinating fall prevention initiatives to lower the rate of falls across the lifespan. Through the updated toolkit for older adults and the new toolkit focusing on children's fall prevention, caregivers, health care professionals, and parents can stay informed with evidence-based information and plan fall prevention activities.

Last year's campaign engaged over 9000 international web-based users and this year with new content targeted at falls within a younger demographic, the team behind FPM hopes to see even greater engagement. Securing both provincial and cross-provincial partners, the 2018 FPM campaign aims to remind all members of the fall prevention community that “We all have a role to play!”

Reflections on the feedback from the NeuroMatters Two-minute Survey

In the last issue of NeuroMatters, we asked our readers to take two minutes to let us know how we are doing with the online format and approach. We understand how busy everyone is and we are grateful for the thoughtful ideas and feedback received.

What do you like? Research and general news about what is happening in terms of people, activities, conferences, and symposium reports were the leading choices. We will be continuing to focus on these areas in each issue. On the technical side, you let us know that readability, navigation, and the level of detail provided met your expectations. Two years ago, we moved to an online format and this has been well received. You are also looking for better options to share the content so we are working on that one.
In NeuroMatters we bring the voice of those living with neurotrauma in the context of news from across the spectrum of neurotrauma research, care and treatment. We’ll continue to look for new and fresh ways to bring you this information and always welcome your input.

And by the way, the winner of the $50 Indigo gift card is reader Ruth Morrison. Congratulations Ruth and thanks for taking two minutes with us.

Welcome – Program and Stakeholder Engagement Coordinator, Chad Debison-Larabie

With an interest in strengthening the relationship between ONF and its stakeholders, the Program and Stakeholder Engagement Coordinator position was created to support the ONF ABI program initiatives as well as the Ontario Brain Injury Association (OBIA) strategies and implementation tactics.

“I look forward to bridging the gaps within Ontario’s ABI community,” says Chad. “With past experience in public relations and community outreach, this role is the perfect opportunity to marry
Chad joins the foundation with wealth of experience in program development and management. Having completed a Master’s degree in Health Sciences with a specialization in neuroscience and biomechanics, Chad is passionate about the work being done in the ABI community and the mandate to create stronger links within the community of practice.

For questions related to the ABI community across Ontario, please don’t hesitate to contact Chad.

Upcoming Conferences

Summer may be underway, but we have no intent on slowing down – there is a bustling conference scene in store over the months to come!

The summer/fall line-up includes:

**Global Conference on Ageing** – Toronto, Canada (August 8-10) The International Federation on Ageing (IFA) is hosting the 14th annual Global Conference on Ageing purposed to bring together key players from over 70 countries to strengthen knowledge transfer across the field of ageing. This year the theme of the conference targets moving Towards a Decade of Healthy Ageing: From Evidence to Action. With four sub-themes the conference will also cover: Healthy Ageing, Combatting Ageism, Age-Friendly Environments and Addressing Inequalities. Harnessing a goal to be the global point of connection for networks of experts, the IFA’s body of members help to influence and shape age-related policy. Loop is a proud partner of the IFA and conference.

**Neurotrauma Week** – Toronto, Canada (August 11-16) This year will be the 3rd Joint Symposium of the International and National Neurotrauma Societies and the AANS/CNS Section on Neurotrauma and Critical Care will take place in Toronto. The symposium gives opportunity for knowledge exchange, preclinical and clinical lessons and visions for the future of neurotrauma research and care. Neurotrauma 2018 host and co-hosts, Dr. Michael G. Fehlings, Dr. Anthony E. Kline and Dr. Eve Tsai have developed a program inclusive of informative discovery, translational and clinical sessions and workshops as well as programs for students and early career investigators. ONF is a proud silver sponsor of the symposium with additional contributions including opening remarks by CEO, Kent Bassett-Spiers and program directors, Corinne Kagan and Tara Jeji to share stories of lived experience.

**Spinal Cord Injury Awareness Month** – (September) Managing care and bettering the lives of those who have sustained SCI is a mandate that governs work at ONF, but over the month of September special emphasis is given to raise awareness for the work and research implemented to shift health care solutions to address the needs of those living with SCI.

**ISCoS 2018** – Sydney, Australia (September 13-15) The 57th Annual Scientific Meeting of the International Spinal Cord Society combined with the 25th Meeting of the Australia and New Zealand Spinal Cord Society expects to host over 1000 international delegates. This will be an
occasion to share knowledge that will generate evidence-based best practices and ultimately standardize care in the management of spinal cord injury (SCI). This interdisciplinary meeting will bring together a variety of medical practitioners and care providers with efforts to exchange knowledge and experience as they explore new studies and developments within their scope of work. SCI Program Director, Tara Jeji has joined the ISCoS communications committee in hopes of fostering knowledge exchange as it relates to SCI on an international level.

**End Falls this Fall** – Orillia, Canada (September 27) This fall the 11th annual Fall Prevention Conference will take place with keynote speaker Dr. Al Salmoni addressing the theme It Takes a Village to Prevent a Fall. This conference targeted at health care providers with an interest in fall prevention is hosted by the North Simcoe Muskoka LHIN. The ONF Prevention team is looking forward to the rich knowledge exchange and informative presentations.

**BIST Hero 5K Run, Walk and Roll** – Toronto, Canada (September 30) It’s that time of year again – as summer dawns the acquired brain injury (ABI) community prepares for the annual 5k run that aims to raise money and awareness to better the lives of those living with ABI. This year the ONF-Incredibles plan to leave their mark with exciting costumes, and hopefully some record-breaking times!

**Brain Injury Canada National Conference** – Ottawa, Canada (October 18-19) This year the National Conference program will offer two different key themes on each day in response to the needs of the ABI community. Attendees can attend sessions on Navigating the Trends of Brain Injury and Evidence-Based Treatment for Persistent Concussion/mTBI. The conference will provide opportunity for the ABI community across Ontario to connect and explore trends as they relate to management of care.