

# NeuroMatters Winter 2017



Welcome to the Winter 2017 edition of the Ontario Neurotrauma Foundation NeuroMatters newsletter.

Last November ONF laid the groundwork to support positive change for people with spinal cord injury who were seeking primary care and pain management options as well as effective treatments for neurogenic bladder. These important and persistent health issues were discussed and debated at three one-day summit sessions held in Toronto. Leading clinicians, researchers, people living with SCI and their advocates as well as policy makers participated. You can read more about all three summits. And a summary video presentation will soon be available through the SCI Ontario [website](#) that includes an introduction from Premier Kathleen Wynne.

Also in November at the National Conference on Ageing, former ONF CEO Sue Lantz served as conference chair and ONF staff facilitated and led sessions as well. The topic of aging well and safely gets some attention in this edition. Will clinicians be getting out their prescription pads to order exercise? Research is pointing to the importance of physical activity as a significant factor to help reduce falls and other injuries in older adults. With another successful Fall Prevention Month completed, the message is getting out there.

Congratulations are due to a team of researchers from Ontario and Quebec, the latest recipient of the ONF/REPAR acquired brain injury research grant. This work will explore the use and effectiveness of technology for those living with traumatic brain injury.

I hope you find the information in this issue of NeuroMatters good reading.

Kent Bassett-Spiers

CEO, Ontario Neurotrauma Foundation

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## **Technology platforms to support those with TBI and their caregivers subject of new ONF/REPAR research commitment**

### *Second phase of research to better understand and meet long-term needs*

A team of researchers from Ontario and Quebec has had their work into the long-term health effects on those aging with traumatic brain injury (TBI) funded for a further two-year period. This research will help increase the understanding of how technology may help these individuals and their caregivers. This team builds on the outcomes from the first phase of research that increased knowledge of the health needs for those who are living with TBI and are aging.

The research is jointly supported by a partnership between the Ontario Neurotrauma Foundation (ONF) and the Quebec Rehabilitation Research Network/Réseau Provincial de Recherche en Adaptation-Réadaptation (REPAR)

Declines in function for people with TBI can extend beyond the acute period of recovery. This challenges the once-held assumption that TBI was an acute episode characterized by a period of recovery, and a stable functional trajectory thereafter. Findings from other recent research into this area included evidence to indicate those who experienced a TBI earlier in life may show more than expected decline in functions of key sections of the brain.

Caregivers may experience a heavy burden of care over several years – even decades – depending upon the severity of impairments or challenges experienced by a loved one with TBI. Aging adds another level of complexity for everyone.

Phase One research pointed to technology as a potential solution to better support those with TBI and their caregivers. The newly-funded research will test this hypothesis and identify specific

technology such as mobile applications, telehealth and others using several methods that will engage a variety of stakeholders.

“Our overarching goal over the next two years is to develop, evaluate, and implement social and technological interventions that will support family caregivers of individuals with TBI, in providing long-term care to individuals with TBI in the home and community, and maintaining their own wellbeing as they, too, are aging,” according to the approved grant proposal.

“This was a thorough and well thought-out application,” says Corinne Kagan, Senior Director, Acquired Brain Injury at ONF. “This work is impressive because it will link quality of life to use of technology in a practical and meaningful way.” Technology could include various platforms that address care and diagnostics as well deficits in comprehension, mobility and communication. Social interventions could include care networks and community and in-home support systems.

The partnership between ONF and REPAR was established in 2007 as an initiative to help leading neurotrauma researchers collaborate across Ontario and Quebec to attract funding, build research capacity and increase the impact of their work. More than 100 researchers have been engaged in joint projects that to-date have been able to leverage almost \$20-million in research funding.

The Spinal Cord Injury team and their work will be featured in the next issue of NeuroMatters.

## **Three tough SCI health issues tackled at November summit series**

### ***Specialists, researchers, people with SCI, policy makers collaborate to identify paths to potential solutions***

People living with spinal cord injury face complex health issues with day-to-day functions that others take for granted. Identifying current barriers, recommendations for potential solutions and approaches to address three of these issues – access to primary care, urological and pain management – have emerged as a result of three Ontario Neurotrauma Foundation summit sessions held in November.

Healthcare providers, researchers, those living with SCI and policy makers focused on building a common understanding of the current state and looked towards what might be needed and possible to move to more consistent evidence-based care.

#### **Need for a cohesive approach to pain management**

Dr. Eldon Loh, lead researcher of the team at the Lawson Health Research Institute in London, Ontario, chaired the first of the one-day summits. His team launched [Clinical Practice Guidelines for Managing Neuropathic Pain with Patients who have Experienced a Spinal Cord Injury](#) last summer. Summit participants focused on what might be possible from basic science to implementation projects.

“Our discussion ranged from a national pain strategy for those living with SCI to better coordination of all research efforts to connecting with organizations like the Multiple Sclerosis Society or the Canadian Pain Coalition to find common ground and share our learning,” says Dr. Loh. “There is a consistent lack of strategy and access to services to help anyone adequately



manage neuropathic pain. There would be a great benefit in establishing a cohesive approach.”

Interest in research and best practices into non-pharmacological treatments is a growing area says Dr. Loh. He believes that ONF has a role to identify and advocate for increase funding for research in the area of neuropathic pain management. “ONF has played an important role in bringing people to the table, we need them to continue this,” he says.

Each of the three meetings had its own unique agenda and atmosphere, says facilitator Jerry Mings. He was the common connection for the sessions. “In all meetings the focus was listening to the voice and the needs of those with SCI and the complex health care issues they faced. There is a genuine desire to find solutions,” he says.

(Photo: Neuropathic Pain Summit organizing team)

### **Neurogenic Bladder Surveillance and Treatment Guidelines hold promise**

At the Urohealth Summit meeting, four challenging bladder management issues were identified and discussed and preliminary solutions were identified:

- Limited resources, skills and access,
- Standardization of care and practice in Canada,
- Diagnosis and treatment of urinary tract infection,
- Expertise in complex surgical procedures.

“One of the emerging action items, Canadian Neurogenic Bladder Surveillance and Treatment Guidelines, holds a lot of promise to address these four health areas,” says Urohealth Summit Chair Dr. Blayne Welk who is affiliated with the Lawson Health Research Institute.

“While several societies have published guidelines, it was generally recognized that none of these were ideal or practical. A rigid evidence-based approach will not be possible. The group determined any guidelines must use expert opinion and consensus, and be informed by the best available evidence,” he added.

More than 20 specialists in urological care from across Canada participated in the summit.

“Each Chair worked hard to ensure the day was well-spent by participants,” says Jerry. “They realized their discussions were taking place in the middle of what is a time of change for the Ontario health system and their efforts could influence that change. They incorporated presentations, panels and working sessions, and the voice of those with SCI was imbedded throughout.”

### **Better understanding of the primary care challenges and opportunities**

The final summit explored the issue of access to primary care and supporting healthcare providers in their work with people with SCI. Dr. Joseph Lee and colleague Dr. Jamie Milligan (both from the Centre for Family Medicine in Waterloo, Ontario) and more than 60 participants heard the kick-off talk from Deputy Minister Dr. Robert Bell, Ministry of Health and Long Term Care (MOHLTC). Dr. Bell emphasized the importance of primary care health providers in the delivery of the province’s “Patients First” agenda in his keynote address.

Dr. Lee noted that the summit participants found the perspectives offered by patients and family physicians to be very powerful in identifying the current gaps and opening the door to opportunities to improve primary care for this group of patients.

“Many of the barriers and challenges we have identified were re-affirmed including knowledge gaps, physical, systemic and most particularly attitudinal barriers,” says Dr. Lee. “The group discussions were exceptional and helped increase the understanding of both the challenges and opportunities.”

While there is much work to be done there was a general consensus that best practice templates and guidelines – imbedded in an interdisciplinary model based on collaborative and consistent communications processes – would support family physicians to become more knowledgeable and confident in caring for those with SCI. And those with SCI would be able to access consistent care in their communities.

With a preliminary pathway identified the next steps will include a white paper that will define and further explore priorities and follow up with the MOHLTC on links to a potential regional model or link to the Local Health Integration Networks (LHINs).

“There was lot of enthusiasm for moving an agenda forward,” says Dr. Lee. “We are looking to ONF to keep an eye on the bigger picture, and ensure there are strong links, including information-sharing between all three groups: primary care, urohealth and pain.”

A webinar of presentation from the Primary Care summit, with an introduction from Premier Kathleen Wynne, was hosted by SCI Ontario January 26. The presentation materials are available on the SCI Ontario [website](#).

## Prescription for exercise could be the key to preventing falls

*Clinicians can play a key role in helping older adults stay active, healthy and socially engaged*

It may be that the best prescription a health care provider can write to their older adult patients won't include a trip to the pharmacy but take people to the sidewalk, gym or yoga studio.

“We know from the research that exercise appropriate to the age and ability of the individual does more to reduce the incidence of injuries, including falls, in older adults than any prescription can,” says Dr. Jane Thornton MD, PhD, Resident Physician and former Olympic rower. “While it is clear that the old adage ‘use it or lose it’ is true, it’s also never too late to start. Any one of us can increase muscle size and function with regular, appropriate exercise and at the same time improve our balance and agility.”

She shared her experiences and research findings as a panellist at Ryerson University’s National Institute on Ageing Conference (NIA) held in Toronto last November. (More information on the NIA can be found [here](#).) ONF staff facilitated and led sessions at the conference.

The research strongly indicates that preventing falls helps maintain functional independence by reducing the incidence of traumatic brain injury and broken bones, either of which increase the risk of mortality in older adults.

Sue Lantz, NIA Conference Chair and former ONF CEO agrees there is a significant role for clinicians to support and even prescribe more physical exercise and active living options for older adults based on the health and risks and conditions of each individual. “This approach directly addresses two of the four pillars within the [National Seniors Strategy](#) for healthy aging. The first two pillars are Independent, Productive and Engaged Citizens, and Healthy and Active Lives,” says Sue. “Advancing the other two pillars, Care Closer to Home, and Support for Caregivers, can be significantly enhanced – or even determined – by how well the first two pillars are achieved.”

Dr. Thornton gained a deeper understanding of the connections between physical activity, injury prevention, health and independent living while studying preventative medicine in Europe for a

year. There she found that physicians achieved excellent results with older adult patients by asking questions and directing them to resources that included exercise and engaging them socially.

“I found European health care organizations were more likely to have databases and information that specifically targeted the needs of older adults on everything from chronic conditions such as diabetes and heart disease to independent living and physical activity,” she says. “People were encouraged to find a tai chi or yoga group close to their home or a community support group for those who were determined to continue living independently.”

Canada and Ontario are a long way from the prescription for exercise route but the Canadian Medical Association has identified the importance of physical exercise in maintaining health through the “[Demand a Plan](#)” program. Dr. Thornton has shared her perspectives on [Demand a Plan and Healthy Debate](#) blogs .

“Falls and other injuries in older adults can happen due to a lack of balance, trying to do things more quickly than necessary or as a result of too much, too little or a reaction to medication,” she says.

Most older adults visit a clinician – usually a family physician – at least once a year. “This is a great opportunity for clinicians to begin a conversation about physical activity and encourage their patients to find an approach they can enjoy,” says Dr. Thornton. “I like the strategy of asking someone how they might want to keep active – what sort of thing would they enjoy doing that could also help them stay out of hospital and live independently longer. In my experience they usually feel strongly about maintaining their independence as long as possible. Why should a preventable fall take that away from them?”

*Related resources: Loop is an online platform that brings together practitioners, caregivers, researchers, older adult groups and policy planners working for the health and care of older adults. Visit [www.fallsloop.com](http://www.fallsloop.com) to find information or join the conversation to improve the implementation of evidence-informed fall prevention practices. More information on exercise and falls prevention can also be found [here](#).*

## **Concussion clinic guidance to focus on the right care, at the right time by the right provider**

### ***Inconsistencies targeted, application of concussion guidelines supported***

It should be straightforward. Someone who experiences a concussion regardless of the cause should have confidence that they will be able to access appropriate care by choosing or

being referred to a clinic that says it specializes in “concussion care”. Unfortunately this is not the case.

There has been a proliferation of such clinics in the province over the past decade due to the increased profile of concussions. The Ontario Neurotrauma Foundation initiated the development of Concussion Clinic Standards at a spring 2016 summit to reduce inconsistent approaches to care, the need to have individualized requirements addressed and to further encourage the use of known and effective therapies. The first version of the standards will be released this spring.

“The goal is to provide guidance to clinicians that will help support them to work within their scope of practice providing the care that is required,” says Corinne Kagan, Senior Director Acquired Brain Injury at ONF. “It’s important that there is a common understanding across the system regarding the processes around concussion care, including timing of treatment and strong connections to primary care clinicians.”

### **Finding care is a maze**

Katelin Sims felt like she was in a maze when looking for a clinic able to address her post-concussion treatment. “I found out that any clinic can call itself a concussion clinic, regardless of the level of expertise in providing care specific to concussions,” says Katelin. “While most provide adequate care, these clinics are not all the same and it took some time to find one that was right for me. Health care professionals there provided the navigation through the healing process and I could focus on getting better, not figuring out if an appropriate treatment plan was in place.”

Neuropsychologist Dr. Diana Velikonja is a member of the ONF Acquired Brain Injury Committee and is helping lead this effort. “Clinics have developed their own approaches to concussion care – some of this based on the available evidence-based guidelines and some is not”, she says.

“There continues to be a need to evaluate the evidence supporting the treatment options and the care pathways providers follow in providing concussion treatment,” she says. “People looking for concussion treatment must have confidence that the clinic they choose will have those standard processes in place.”

In an ideal world each person with a concussion would be properly diagnosed then educated about their symptoms and recover. If symptoms persist they would be followed by an interdisciplinary group of professionals who have specialized training in concussion and work within their scope of practice to provide evidence-based care. Their family physician would be part of the care process.

Ruth Wilcock of the Ontario Brain Injury Association (OBIA) says Katelin’s experience is all too common.

“Many people have knowledge of other types of injuries but concussion isn’t that well understood, so it’s difficult to know if you have found a clinic to provide the best care,” she says.

“We often hear ‘where can I get help and when am I going to get better?’ They desperately try to find treatment in any form so that they can recover as quickly as possible.”

### **Standard approach will help patient, health care providers**

Ruth wants patients to be able to determine if the clinic they are choosing adheres to evidence-based standards. They are then able to make better informed decisions about the care they receive. “The goal of setting these standards is both to help the patient and the clinician,” she says.

“We would like to see private practitioners such as physiotherapists or chiropractors feel they can work effectively with physicians and other health care providers in the interdisciplinary team,” she says. Concussion clinic standards will provide guidance with respect to the various roles in the care process across the health system.

“People should know that this is a journey and that it may take more time than you realize to find the best clinic and health care team,” says Katelin. “By establishing standards for the operation of clinics, over time the public can feel confident that the care practiced at a clinic follows the standard processes and care guidelines that reflect the most current research. This can help them with their recovery.”

“The challenge will be to keep these standards practical and ensure they are easy to implement,” says Corinne. “This should help reduce the overall burden on the system, the clinicians and patients while supporting the right health care provider to deliver the right care at the right time.”

*ONF will release the first version of Standards for Concussion Clinics in the spring of 2017. The third (updated) version of the Adult Concussion Guidelines is also expected to be published in 2017.*

## **Another successful Fall Prevention Month**



For the month of November 2016, ONF and the Fall Prevention Community of Practice promoted Fall Prevention Month alongside a slew of partner organizations across Canada. This was the second annual Fall Prevention Month campaign in Ontario. Fall Prevention Month encourages organizations to coordinate their efforts for a larger impact. Organizations participate by planning activities and sharing evidence-based information on fall prevention.

An evaluation of the efforts and impact is underway, but we are already noticing a positive trend. New this year was a [campaign website](#), featuring an events calendar, information on fall prevention for older adults, and a toolkit of resources for organizations looking to participate.

Since launching the bilingual website in the late summer, there have been over 38 000 pageviews by approximately 4300 unique users! Thousands of toolkit resources were downloaded by organizations participating in Fall Prevention Month. Most visitors were from the city of Toronto, but also Kitchener, Ottawa, London, Belleville and Winnipeg.

The most popular resources were:

- [Six Warning Signs of Falls](#)
- [Infographic of Ontario Fall Statistics](#)
- [How to Lower your Fall Risk](#)
- [Activity Guide: Guerilla Marketing](#)
- [Fact Sheet with 3 Key Messages](#)

Each week of the campaign, a different partner organization “took over” the [Twitter](#) account and tweeted out fall prevention messaging. By the end of the campaign, we posted 171 tweets and garnered 188 followers. Many groups participating in Fall Prevention Month retweeted us and used our #PreventFalls2016 hashtag on their own tweets.

We would like to thank everyone who participated in Fall Prevention Month 2016 and contributed to its success! We have started planning for 2017 and are strategizing how to grow the campaign. For information about fall prevention year-round, please visit [Loop](#), the online communication platform for fall prevention. content

## Talking cure, taking action: a partnership perspective from CSRO

For more than a decade the discussion about a potential cure, or cures, for spinal cord injury has inspired and deflated hopes, created advocates and dissenters. No longer considered an “unachievable endeavour or hope” a cure is in sight today although efforts are still not supported collectively and lack consistent leadership. But there’s a strong movement in the SCI community to change that attitude and landscape while securing funding for cure-focused research.

“We must get back to basics, addressing the perspectives of those living with SCI. That means identifying what a cure for spinal cord injury really means,” says Barry Munro, Chief Development Officer for ONF and the Chair of the [Canadian Spinal Research Organization](#). “We need to educate people about the research underway and the potential it offers to restore the vital functions that are impaired by SCI.”

One such flagship movement for education and advocacy is led by [Unite2Fight](#) Paralysis an organization of and for those with SCI that has been around since 2005. Calling itself the “voice of the cure” Unite2Fight is making the case for a cure loud and clear.

Among its many programs and activities the US-based organization addresses SCI issues head-on at its annual meetings at the [Work2Walk Conference](#). Conference participants include leading researchers, clinicians and those living with SCI. In its initial years this conference emphasized education but in October 2016 the spotlight was on grassroots advocacy and every attendee, Barry included, was challenged to identify and commit to be involved.

Talking about a cure for SCI is definitely out of the closet as far as CSRO and Munro are concerned. And now is the time for action to make the possible a reality. “We will be taking a more direct approach in our efforts to raise the profile and speak to the achievements of cure research initiatives in the context of restoring critical functions,” he says.

“We want CRSO to be the go-to Canadian organization supporting and encouraging cure advocates in Canada,” he says. CSRO will launch a webinar series of short videos this spring each focusing on a cure-related research direction, project or possibility. Building momentum for the investment in cure research has also changed the research funding model. “There is a shift to Letters of Intent and a peer review awards process and follow-up much like the models used by government and pharmaceutical companies to fund research projects.”

And there are many others contributing to the conversation and providing support for advocacy efforts, says Barry. He points to the frank book “Don’t Call it a Miracle” by author Kate Willette. She says the SCI cure isn’t a miracle but represents effort and commitment to advocacy – a movement – by those with SCI and anyone who cares for and about them. Willette uses the example of the AIDS cure campaign that turned a killer virus into a chronic illness. (*Don’t Call It a Miracle* can be downloaded free of charge [here](#).)

“Willette’s book is a reminder to all of us about the progress that has been made towards a cure and the promise of what is possible in the next few years,” says Barry. content

# Partner Profile: Quebec Rehabilitation Research Network/Réseau Provincial de Recherche en Adaptation-Réadaptation (REPAR)



ONF established its partnership with REPAR in 2007 as an initiative to help leading neurotrauma researchers collaborate across Ontario and Quebec to attract funding, build research capacity and increase the impact of their work.

## **REPAR Mission:**

Foster clinical research in rehabilitation aiming to reduce or compensate for deficiencies, incapacities and disability stemming from physical impairments by supporting multidisciplinary and multicentre research activities; facilitate knowledge transfer between researchers and clinicians; and train the next generation of researchers. REPAR members include established researchers, emerging researchers, collaborators, students and partner members, who work in the field of rehabilitation in Quebec.

## **Focus of effort**

1. Competitiveness and Innovation
2. Knowledge Exchange and Application
3. Training the Next Generation of Researchers
4. Partnership Activities
5. Research Promotion and Demonstration

## **ONF/REPAR neurotrauma research partnership details**

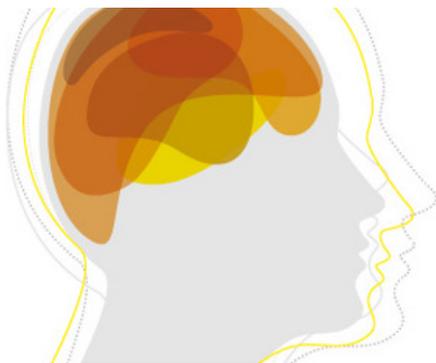
The aim is to promote research collaborations between Quebec and Ontario through the creation of research teams in neurotrauma rehabilitation in order to produce high quality inter-provincial projects in spinal cord and brain injuries. The aim of the current phase of the ONF-REPAR Partnership is to strengthen and further build on what has already been achieved through the work of the teams, while ensuring a connection with national neurotrauma research projects.

More than 100 researchers have been engaged in joint projects that to-date and have been able to leverage almost \$20-million.

NeuroMatters will be featuring one of our partners in each issue.

*ONF is proud to work with a number of [partners](#) to determine the key causes of neurotrauma and support the development of interventions and policies that make a difference.*

## **New guideline for moderate to severe TBI making headway in Ontario and Quebec**



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### **CLINICAL PRACTICE GUIDELINE FOR THE REHABILITATION OF ADULTS WITH MODERATE TO SEVERE TBI**

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The [Clinical Practice Guideline for the Rehabilitation of Adults with Moderate to Severe TBI](#) released in October 2016 is being shared by allied health care professional organizations and more broadly at meetings, conferences, through newsletters and online communications. Coming next? Follow-up with Ontario stakeholders, webinars for health care professionals looking for practical information and an implementation plan to support sites to put selected recommendations into practice.

ONF and the Institut national d'excellence en santé et en services sociaux (INESSS) developed the guideline following three years of consultation and evaluation. The guideline offers 266 recommendations for rehabilitative care of adults with moderate to severe TBI.

“The Project Team is very encouraged by the initial interest in the guideline. The website is being accessed regularly and feedback is positive,” says Judy Gargaro, Clinical and Systems Implementation Associate at ONF. More than two thirds of users return to the website regularly. “Each user will access and need different information. In addition we are continuing gather more insight on tools and indicators to support implementation of the recommendations, though all this will take some time.”

The Team is also exploring options for publication in one or more peer-reviewed journals. In addition upcoming conferences and presentation opportunities are being identified.

While the development and launch was a joint activity and information-sharing will be ongoing, the Ontario and Quebec teams will now concentrate on the implementation needs that are appropriate to their province.

In Ontario 18 organizations completed a survey last summer meant to inform the implementation process. Input was received from twelve rehabilitation sites (8 from specialized rehabilitation and four from general rehab) and from six acute sites. Summary reports that summarize and provide provincial context have been sent to all participating sites. All will be contacted in the coming weeks to review and potentially support implementation efforts.

ONF is also interested in feedback from allied and other health care professionals implementing the recommendations. These learnings will be assessed and used to improve practical implementation strategies for the recommendations.

## Upcoming events, meetings and conferences

**March 8 – 9 [Clinical Trials Ontario Conference](#), Toronto**

**May 13 - 14 The first-ever combined meeting of the Ontario SCI Research Network and the Canadian Spinal Cord Network, Toronto.**

**June 15-16 [Slips, Falls and Trips International Conference](#), Toronto**

**June 19 – 21 [Global Implementation Conference](#), Toronto**