

NeuroMatters, Winter 2018 Edition

The beginning of a new calendar year provides individuals and organizations the opportunity to pause, take stock and plan for the year ahead. At the Ontario Neurotrauma Foundation we are doing just that as we complete our strategic planning process in the next month or so, just in time for the beginning of our new fiscal year April 1. The commencement of our new three-year funding cycle in 2017 has given us the opportunity to consider what success for ONF should look like in the years ahead.

Through the strategic plan process we will examine and refine our role in supporting the greater community of those living with the effects of neurotrauma, including acquired brain injury and spinal cord injury. Over the past couple of years ONF has made significant process in using implementation science to move research into practice in the care and treatment of those with ABI and SCI. We will be redoubling our already significant efforts, to engage the ABI and SCI communities, looking for significant ways to give them a greater voice in our work.

The recent establishment of the North American Spinal Cord Injury Consortium (NASCI) is a case in point. The Secretariat for the Consortium will be overseen by the Canadian Spinal Research Organization (CSRO) which operates out of the ONF office. You can read more about NASCI in this issue of NeuroMatters but the key focus for the Consortium is to work with and give a collective voice to those living with SCI and their care providers. These perspectives will inform the research focus and work of ONF and other organizations tackling issues related to the care and treatment of SCI.

On the other hand, the ABI community is more diverse and that is why our partnership with the Ontario Brain Injury Association is so important. The strength of OBIA is its knowledge and understanding of the ABI community in order to effectively advocate and raise awareness of the effects of brain injury. We are proud to support the work of OBIA.

And those professionals who work to prevent falls in older adults must be recognized for the difference they are making within this population group by way of Loop, the Fall Prevention Community of Practice (CoP) supported by ONF. Building on joint activities focused on information sharing such as Fall Prevention Month each November the CoP is now working to establish a provincial Fall Prevention Collaborative.

Never let it be said that ONF rests on the laurels gathered over the past 20 years.

Kent Bassett-Spiers

CEO Ontario Neurotrauma Foundation

[In this issue of NeuroMatters...](#)

[Fall Prevention Month picks up speed in 2017](#)

[NASCIC: Community voices have roles in new Consortium](#)

[Provincial Fall Prevention Working Group continues to build interest and commitment](#)

[ONF/RHI team grants focus on improving care and treatment for those with SCI](#)

[Researcher Profile: Dr. Roger Zemek](#)

[Partner Profile: Ontario Brain Injury Association](#)

[Welcome to Mariel Ang](#)

[NeuroMatters News](#)

Fall Prevention Month picks up speed in 2017: more information sharing and engagement

The annual November focus on fall prevention is making significant inroads to engage organizations working with older Ontarians to share the campaign messages. November may have been designated as Fall Prevention Month (FPM) but the information to support fall prevention practitioners is shared by participating partners throughout the year.



More than 75 clinics, organizations that work with older adults officially registered their participation in 2017 by submitting their fall prevention initiatives, a significant increase from 2016, 56 of these confirmed they had implemented FPM initiatives. Fall Prevention Month traffic on Twitter and the Fall Prevention website also increased by more than 200 percent. For instance, page views to the end of November clocked in at 83,000 compared to 38,000 in 2016.

Fall Prevention Month was established in 2015 as an initiative of 13 partners with support from the Ontario Neurotrauma Foundation. FPM offers participating organizations a variety of resources to use for education and knowledge-sharing purposes, encourages participants to hold events targeting staff and older adults and caregivers, and uses online and community media sources to share the fall prevention message.

“Each year we learn a little more about what works for the participating organizations,” says H el ene Gagn e, Program Director Prevention at ONF. “The toolkit continues to be a focus for most of the participating organizations as it offers very good information in a simple format and it specifically highlights the types of activities that can be undertaken to promote fall prevention in November. If we can help reduce the number of injury-causing falls significantly year over year we will collectively improve the mental and physical health of older adults in this province and reduce a significant burden on the health system.”



NASCIC: Community voices have role in new Consortium

A group of agencies, network and organizations from across North America that share the same goal for research, care and spinal research policy have come together to form the North American Spinal Cord Injury Consortium (NASCIC). The Consortium secretariat is overseen by the Canadian Spinal Research Organization (CSRO) at its Toronto office.

“NASCIC will allow for a better alignment of resources and effort towards the cure research continuum,” says Barry Munro, Chair CSRO and Chief Development Officer of the Ontario Neurotrauma Foundation (ONF). “NASCIC is an organization that reflects the community it represents – people living with spinal cord injury and those who care for them.”

NASCIC founders have begun to connect with the many dozens of grassroots SCI community organizations. Many of these organizations, often peer-support groups, are active on social media platforms such as Facebook. “They are sharing their collective knowledge daily,” says Barry. “NASCIC will help to bring their voices together, create goals and take action to pursue projects that will empower the SCI community.”

The NASCIC office is co-located with ONF in Toronto.

Provincial Fall Prevention Working Group continues to build interest and commitment

A February 2017 webinar that explored the interest and opportunities for inter-LHIN collaboration on Fall Prevention in older adults met with overwhelming support from fall prevention practitioners. Two key themes emerged – knowledge sharing, and provincial collaboration and oversight. Looking for ways to work together to eliminate duplication, and to increase capacity for practitioners across the province, a Working Group has continued to explore collaborative possibilities over the past several months.

The Working Group identified that [Loop](#) (the Fall Prevention Community of Practice communication platform) could be used more effectively to share knowledge and that webinars could also be a useful tool to engage practitioners on an ongoing basis. The Working Group also suggests that the work done on the 2011 Provincial Integrated Fall Prevention Framework and Toolkit is a great starting point to revisit collaborative strategies and initiatives.

This small group has met three times, and is well on the way to having a proposed structure for a high-level Ontario Fall Prevention Collaborative. Membership would come from leaders in LHIN, Public Health, government and other key stakeholder groups across sectors. This Collaborative would work to develop a systems-based approach with consistent components for fall prevention planning and implementation in Ontario.

Communication with webinar participants, Loop members and fall prevention stakeholders is ongoing with more news about next steps towards formalizing the Collaborative to be available through Loop.

ONF/RHI team grants focus on improving care and treatment for those with SCI

The Ontario Neurotrauma Foundation in partnership with Rick Hansen Institute has funded [two new team grants](#). These two-year grants provide researchers with \$20,000 for each of the two years. Developed by the Ontario Spinal Cord Injury Network (OSCIRN) this grant initiative

facilitates building teams focused spinal cord injury research and implementation projects in Ontario.

The grant opportunity was announced at the May 2017 OSCIRN meeting as the next step to build collaborative research activity in spinal cord injury along the continuum of care. The OSCIRN team-building grant aims to integrate Ontario researchers, clinicians, students and community in partnership with other provincial, national and international research teams or members of research community.

Improving the successful translation of promising animal therapies to humans through the use of viable adult human spinal cord tissue

Principal Investigator: Dr. Tuan Bui, University of Ottawa

Comment from Dr. Bui: A number of exciting approaches have been developed for improving the quality of life for those with spinal cord injury based upon animal models of spinal cord injury. However, an obstacle to validating these approaches for actual application to the treatment of those with spinal cord injury is a lack of platforms to test these approaches on human spinal cord tissue. Our group is one of the first to have developed techniques to generate viable cell cultures derived from human spinal cord tissue. With the funding from ONF/RHI, we will be able to use these cell cultures derived from human spinal cord tissue in order to properly test and validate a number of exciting new approaches discovered by our group using animal models of spinal cord injury. This is an important next step towards getting closer to providing individuals with spinal cord injury treatments that will lead to functional recovery.

Development of the Spinal Cord Injury Rehabilitation Translational Continuum Team

Principal Investigator: Dr Cathy Craven, University Health Network, Toronto

Comment from Dr. Craven: Although there is much excitement for bringing researchers and clinicians together to encourage knowledge translation, very few initiatives succeed. The spinal cord injury (SCI) Rehabilitation Translational Continuum Team (ReCon Team) was formed in January 2018 to address major gaps between knowledge produced in a laboratory setting and its clinical application. Having consensus on study methods and study outcomes is vital to advancing the field of SCI rehabilitation. The aim of the ReCon Team is to bring patients, scientists, clinicians, and students, from cellular, animal and human research programs together to work on common goals. We are committed to understanding how muscle, bone and the nervous system interact to influence the type and outcomes of rehabilitation for individuals with SCI over the course of their lifetime.

Researcher Profile: Dr. Roger Zemek

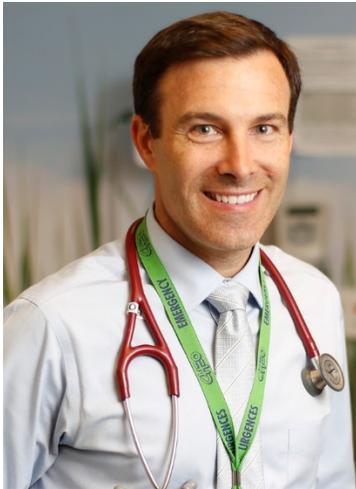
Dr. Roger Zemek

Associate Professor, Dept. of Pediatrics and Emergency Medicine

Clinical Research Chair in Pediatric Concussion, University of Ottawa

Director, Clinical Research Unit, Children's Hospital of Eastern Ontario

Physician, Children's Hospital of Eastern Ontario Emergency Department



What is the most satisfying part of your work as a researcher? I see myself as a clinician-researcher, one role is not independent of the other for me. The questions raised through my clinical work in the Emergency Department at CHEO guide my research. I am very motivated to find answers to the questions asked by families whose children have experienced concussion. So, in my case, the clinician in me who is frustrated by the lack of evidence-based treatments for concussion has helped me focus my research in order to find the best answers for families.

The 5P Study which you led has been an important base for discussion about the recognition, care and treatment of concussions. Building on the evidence you have gathered and analyzed for 5P what do you see as the next step in terms of research on the subject? The 5P study is a starting point and its strength was the massive cohort of patients – more than 3000 children who had been diagnosed with concussions from across Canada. Data from these patients were captured in a similar care setting (the emergency department) in the acute phase of their injury. This has provided an excellent baseline. The next phase of this research will be to identify and analyze the key predictors to better understand which treatments, including return to physical activity, have been effective.

The real future after the 5P study is to examine the potential treatments and gaining a better understanding of the ideal recovery regimen that includes a balance between engaging in activity and cognitive tasks and moves the patient towards recovery as quickly as possible. Evidence is already leading to a new approach that encourages appropriate physical activity and return to the tasks of daily life. Gone are the days when someone is left in a dark room and told to move as little as possible. There has been a lot of attention given to concussions, particularly relating to children and youth in sports and other activities of childhood (playgrounds, etc.). This appears to have panicked some parents who may now be more reluctant to allow their children to experience formal and informal sports and play activities.

What do you believe health care professionals and researchers can do and say to help parents and caregiver take a more “informed but concerned” position when making decisions? As an emergency physician I don't have the opportunity to counsel families and patients in the same way that a family doctor does, but as a pediatrician and researcher I am very engaged in guideline development for pediatric concussion. It is all about finding the best balance for each individual in terms of risks and benefits of physical activity. Sports offer much to kids and with the risks of obesity due to the lack of physical activity becoming a greater concern, we need to find that balance.

Children need to be involved and engaged in the world around them and we need to work on making the games and activities that children participate in as safe as possible without going overboard. If the standards appear too high, no amount of activity will appear to be safe and we don't want that. Living a concussion-free life is not a reasonable or practical goal. As clinicians and researchers we need to ask questions such as: What are the best choices for individual patients? What are the alternatives to some physical activities that can be considered? Can we change rules and policies around sports that could lead to safer play?

Ensuring patients young and old receive the most appropriate and timely diagnosis, care and treatment for a concussion can vary by region. Based on your experience, what changes would you like to see at the systems level to ensure consistency in care and outcomes for all patients? There is currently no effective way to offer a definitive concussion diagnosis for some people who experience a concussion. For instance, loss of consciousness may be criteria – in some cases – to indicate severity of injury and guide the course of treatment. In other cases, no cognitive changes could lead a clinician to believe the injury is not serious only to have cognitive symptoms appear later when there are no physical symptoms. These cases do not mean the diagnosis has been missed but rather there may be another reason such as in the case of post traumatic stress disorder when the physical symptoms are healed but the psychological symptoms related to the injury emerge later.

So how do we tackle this? Treatment guidelines are critical to ensure a consistent approach to assessing and diagnosing concussion. Making sure guidelines have reached and are being used by the target audience is critical especially since guidelines support research by providing a common language for clinicians. Currently there is an element of interpretation or subjectivity in the diagnosis and treatment process. Clinicians should be encouraged and supported to make evidence-based treatment decisions.

And finally, developing a fool-proof bio-marker such as a blood or serum test, EEG monitoring or MRI techniques is the ultimate solution in terms of both diagnosis and understanding when the treatment is complete. Currently there no way to tell why recovery takes longer in some people than others. Biomarkers would also address this – knowing when the brain is better.

Dr. Nick Reed (Toronto) and yourself are leading the project to revise and update the Pediatric Concussion Guidelines for the Ontario Neurotrauma Foundation. What changes or revisions are likely to make the most positive difference in supporting those involved in caring for children and youth with concussions? The most important recommendations will be those that support people to get back to their life as soon as they feel comfortable – no more “bedroom jail” approach. I believe recent evidence focused on physical rehab as early as possible – starting with appropriate activity level – will make a significant change in the lives of the patients. It will be interesting to see how healthcare providers and families will react to them.

Another feature of the revised Pediatric Guidelines will be a focus on using digital communication tools to share them broadly. Keeping pace with the digital world ensures these guidelines get to those who can use them. Reaching the target audience using modern communication methods sends an important and positive message supporting the up-to-date approaches to diagnosis and treatment.

Partner Profile: Ontario Brain Injury Association



OBIA History

The Ontario Brain Injury Association (OBIA) has been supporting people living with the effects of an Acquired Brain Injury (ABI) for more than 30 years. The journey of OBIA began when several determined families whose loved ones lives had been devastated by acquired brain injuries (ABI) came together to form what was a then small grass roots organization. OBIA is now the largest brain injury association in Canada.

Mission

The OBIA mission focuses on education, awareness and support. More than 10,000 professionals have taken OBIA training programs, more than 90,000 calls have been received on the organization's helpline. OBIA has taken the lead on provincial awareness campaigns such as D.O.N.T (Drive Only Never Text) and Concussions Hits Home (domestic violence and brain injury). OBIA also hosts the largest brain injury conference in Canada, providing education opportunities for people across Ontario, Canada and Internationally.

Partnership Details

Since ONF's inception, OBIA and ONF have worked together to enhance the lives of those living with brain injury. Through research and project grants, and collaborating with OBIA to include the voice of people living with ABI in ONF research and resource material, OBIA and ONF have developed a strong partnership.

One such project has been OBIA's ongoing research collecting epidemiological data on brain injury across Ontario. This research has evolved over the last 25 years beginning with a short quality of life survey and evolving into the current format, a questionnaire used to collect a broad range of information on people living with brain injury. It is the only research of its kind in Canada.

ONF has been a supporter of OBIA in this research for many years and as the evolution of this data collection continues, so does the partnership between the two organizations. Presently, OBIA and ONF are looking at how to use this data and build on the current questionnaire to target more specific subjects and areas of interest in the brain injury realm. More targeted data can help to inform public policy work around the needs of individuals living with brain injury.

Brain injury is often misunderstood and can be misdiagnosed leaving individuals with limited access to services and supports that can help them to be successful in their everyday lives. With the help of ONF, OBIA hopes to continue to advocate and raise awareness about brain injury.

Continuous effort to increase awareness and drive systemic change

Through the calls that OBIA receives on its 1-800 helpline often the biggest obstacle that people living with brain injury face is access to services. OBIA's challenge and goal is to increase awareness about brain injury to both the general public and government in order to drive systemic change. With increased awareness and systemic change, OBIA believes that this will provide greater access to services and supports for those living the ABI.

Welcome to Mariel Ang, Project Coordinator, Prevention



Mariel Ang is the newest member of the Ontario Neurotrauma Foundation (ONF) team joining as the Project Coordinator, Prevention. She has a key role to coordinate the Loop platform and Fall Prevention Month planning and activities.

Mariel is familiar with fall prevention as a result of a previous position with the Centre for Studies in Aging and Health in Kingston, Ontario. There she worked on the South East Ontario Regional Integrated Fall Prevention Strategy. Most recently, Mariel worked with the University Health Network and Bone and Joint Canada, a knowledge translation organization specializing in musculoskeletal disorders, to implement a national best practice rehabilitation program for individuals with hip and knee osteoarthritis.

“I hope to lend my skills and experiences in project coordination/management and knowledge translation into this role with ONF,” says Mariel. “I look forward to working with you all in our efforts to reduce falls across the lifespan!”

If you have any questions about Loop or Fall Prevention Month, please don't hesitate to contact Mariel at mariel@onf.org.

NeuroMatters News

Outcome of ONF Summit on Neuropathic Pain featured in The Canadian Journal of Pain article

Outcomes from the November 2016 National Canadian Pain Summit that explored effective neuropathic pain management following a spinal cord injury (SCI) have now been published in the Canadian Journal of Pain. [“Advancing research and clinical care in the management of neuropathic pain after spinal cord injury: Key findings from a Canadian summit”](#).

The [Neuropathic Pain Summit](#), sponsored by the Ontario Neurotrauma Foundation and the Rick Hansen Institute, was chaired by Dr. Eldon Loh of the Lawson Health Research Institute in London, Ontario. Dr. Loh also led the team that analyzed summit findings and wrote the journal article. Summit participants included clinicians, researchers and policy-makers as well as people living with SCI who together addressed an agenda that focused on the current state of the field, creation of a long-term vision and steps to move the vision into action.

The Canadian Journal of Pain is the peer-reviewed publication of the Canadian Pain Society. The CPS is a society of scientists and health professionals who have a vested interest in pain research and management. ONF contributors to the CPS article included Dr. Tara Jeji (Program Director Spinal Cord Injury) and Dr. Keith Hayes (Provincial Lead, Spinal Cord Research).

Implementation moves into the active phase for Clinical ONF/INESSS Practice Guidelines for Moderate to Severe TBI and the ONF Standards for Post-Concussion Care

The implementation phase activities for both the Clinical Practice Guidelines (CPG) for the [Rehabilitation of Adults with Moderate to Severe TBI](#) (ONF and the Institut national d'excellence en santé et en services sociaux INESSS) and the ONF [Standards for Post-Concussion Care](#) are now well underway.

“We have nine active implementation projects for the CPG that are being supported by ONF and three others that are still in the planning stage,” says Judy Gargaro, Clinical and Systems Implementation Associate at the Ontario Neurotrauma Foundation. The reach of the projects ranges from local to regional to provincial to regional. The goal is to increase the degree of sustainable implementation of specific recommendations from the CPG and to build capacity to implement other recommendations.

Patient and Family materials will soon be released to support Post-Concussion Care Standards and clinicians across the province are being surveyed to identify their needs with regards to concussion care education. ONF and its collaborators have been invited to present their implementation work at several conferences and symposiums this year.

New clinical practice guideline published for acute SCI

Clinical practice in the management of those with acute spinal cord injury has evolved significantly over the past several decades and a recently completed literature review has led to the development and publication of [“A Clinical Practice Guideline for the Management of Acute Spinal Cord Injury: Introduction, Rationale, and Scope”](#) in the Global Spine Journal. Dr. Michael Fehlings is the lead author.

The evidence reviewed in the development of the Guideline addresses the lack of consensus on several approaches to acute management of those with SCI. “The ultimate goal of these guidelines is to improve outcomes and reduce morbidity in patients with SCI by promoting

standardization of care and encouraging clinicians to make evidence-informed decisions,” say the authors.

Feedback Sought on potential ECHO Ontario Project Concussion Program

The [Extension for Community Healthcare Outcomes \(ECHO\) Ontario Project](#) is considering the addition of a concussion program and requires input from clinicians. Project ECHO Ontario links expert specialist teams through an academic hub – in this case the University Health Network – with healthcare clinicians in local communities. Should approval for the site be received from the Ministry of Health and Long-Term Care, ONF and several of its partners will be involved in curriculum development and building a network of “experts”.

ECHO, first established in the US, offers a successful, practical case-based learning model available to any primary care or allied healthcare practitioner who has access to the internet. ECHO program content is focused on often difficult-to-treat conditions regularly dealt with by these practitioners such as Chronic Pain and Opioids, Mental Health and Addictions, Care of the Elderly and Epilepsy. The areas of the ECHO curriculum are generated first and foremost by the clinician users of the ECHO and filled in by “experts” using clinical research and case examples.

The first step, conducting a [needs assessment survey](#) for primary care and allied healthcare practitioners is underway. Given that concussion management involves many different healthcare professionals those involved in post-concussion care are encouraged to complete the survey as soon as possible.

BC-based professor recognizes ONF support in early years of SCI research and advocacy

Dr. Kathleen Martin Ginis started her career working with the spinal cord injury community in Ontario. She recently shared with “[Business in Vancouver](#)” (BIV) 2017 Life Sciences" magazine that the Ontario Neurotrauma Foundation, and especially Dr. Keith Hayes (now ONF Lead Spinal Cord Injury Research and Chair, Spinal Cord Injury Committee), positively influenced her career. As a result of a suggestion by Dr. Hayes, she successfully applied for a Social Sciences and Humanities Research Council grant in 2007. As a result, she was able to found SCI Action Canada, a national alliance to advance physical activity participation for those with SCI. “This direction would never have happened for me (if he hadn’t) encouraged me to write the grant that got SCI Canada on the map,” she was quoted as saying in BIV.

Dr. Martin Ginis is now a professor at the University of British Columbia Okanagan in the faculty of Health and Social Development.