

# NeuroMatters

## Connecting YOU to the Research

### Community of Practice

*Joining together to help people with ABI and substance abuse*

There is a large and increasing number of people with substance abuse issues who also have an acquired brain injury (ABI). In some ways, this trend is not so surprising: 25% to 30% of people who sustain an injury were intoxicated when the injury occurred, suggesting that there may have been substance abuse before the injury.

Additionally, learning to adjust to life with an ABI can be difficult for some people, resulting in the use of alcohol and drugs in order to deal with anxiety and depression. Sometimes, the use of these substances leads to overuse and dependency on them.

Moreover, the mixture of a number of prescribed medications can have the same effect as being drunk or high. More than half of the people admitted to ABI rehabilitation programmes have a history of substance abuse. Generally speaking, one-third to one-half of people with an ABI have or will develop substance

abuse issues. And yet, until quite recently, service professionals working with people with ABI have had few resources on addiction.

There are many reasons why it has been difficult to address substance abuse and ABI, and to help clients. ABI service professionals do not necessarily know the expectations of addiction rehabilitation programmes, and these programmes may have hidden barriers for people with ABI. Here are some examples of barriers faced by people with ABI:

- The initial assessment to get into a treatment programme may not go well because a brain injury can interfere with a person's ability to give an accurate record of the events that make treatment necessary. Even when a support worker, family member or friend offers to go to the assessment to provide details, addiction professionals may refuse the offer due to concerns about client privacy. This can prevent people with ABI from

accurately representing themselves and from getting the help they need.

- Sometimes a person with an ABI has difficulty reading social cues and paying attention for long periods of time. During an assessment, an assessor might interpret this behaviour as lack of motivation or lack of commitment - which can lead to a person not being accepted into the programme.
- If a person with an ABI gets past the assessment phase and is accepted into the programme, the specific rules or expectations - for example, showing up on time, and not missing appointments - may be unrealistic for those people with ABI who lack strong organizational skills or tire easily. This can lead to people leaving the programme.

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- Sometimes people with ABI do not do well in a group setting, making it harder for them to stay in an addiction rehabilitation programme.

In 2004, a group of professionals in the ABI and addictions fields met to find and develop resources for those who serve people with ABI. Led by Dr. Carolyn Lemsky from Community Head Injury Resource Services (CHIRS), the group consisted of representatives from the Centre for Addiction and Mental Health (CAMH), and the Toronto Acquired Brain Injury Network. The collaboration became known as the Substance Use/Brain Injury (SUBI) Bridging Project. Using pilot funding provided by the Ministry of Health and Long-Term Care, the SUBI project led to the development of the following new resources, all of which were well-received:

- an educational pamphlet
- recommendations for in-patient ABI rehabilitation settings
- a service provider manual
- a client workbook
- a robust website that holds the developed resources
- workshops
- presentations

After the Ministry's pilot funding ended, the Ontario Neurotrauma Foundation (ONF) wanted this work to continue and decided to fund the working group of the SUBI project. (ONF was already familiar with SUBI because it had funded an earlier piece of work that had laid the foundation for SUBI.) In 2008, ONF asked Dr. Lemsky and the CAMH group to start a "Community of Practice" built around SUBI that included a network of key stakeholders in ABI and addiction who could work together to serve their clients.

In order to determine the future

direction of the Community of Practice, the leadership team's first activity was to survey Canadian service providers who had used the SUBI materials. Of the 60 respondents who completed the survey, 72% were ABI providers, 15% were



addiction service providers, and 12% were mental health providers.

In general, the materials were considered useful. The addiction professionals indicated that the materials enabled them to better support people with ABI and to better understand the effect of a brain injury. The ABI professionals found that the provider manual gave insight into the policies and expectations of addiction services. Many of the respondents who had attended a one or two day workshop (versus a one-hour session) reported that they had made greater use of the materials; more changes in their practice, and had more confidence in serving people with ABI and addiction.

Survey respondents also identified that other resources, such as a family guide and an information book for patients, would be useful.

Four respondents indicated

that they had started new programmes using the SUBI materials. And over 80% of the respondents expressed an interest in participating in a SUBI Community of Practice.

The Community of Practice

leadership team decided to organize a meeting of professionals in order to discuss challenges, share ideas, resources, and best practices, and also create more service linkages. This group would help to define the gaps in service, find solutions, and develop a framework for the Community of Practice. The goal was to have a representative from both the ABI and addiction fields in each Local Health Integrated Network (LHIN) region in Ontario. 24 people attended the first meeting, at which all but two LHIN regions were represented; the group identified working principles, goals and future plans.

Through discussions being held across the province, the Community of Practice is finding that innovative work is being done in the area of addiction and ABI. And now professionals are connecting to that work.

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ABI and addiction professionals are creating partnerships in the towns and cities where the workshops will be held. In some cases, neither the addiction professionals nor the ABI professionals had ever met to share their insights about their respective fields - and this was the first opportunity to do so.

The SUBI website ([www.subi.ca](http://www.subi.ca)) is becoming a clearing house for all of the information being found and developed in the area of ABI and addiction. As well, training is being planned so that the accumulated knowledge can be shared with others.

The goals of the Community of Practice are as follows:

- To start **new programmes** that support people with ABI and addiction. *Right now, there are four groups, including the leadership team, that are attempting to get funding for SUBI programming from their respective LHINS.*
- To provide **training opportunities**. *The number of opportunities provided, and the number of service providers who attend, will be an indicator of success. As well, participants will be asked to evaluate the training.*
- To increase the **involvement of service providers** in the Community of Practice activities. *Attendance at web/tele-conferences, meetings and presentations will be monitored and so will the distribution of materials. Service providers will be asked to evaluate the project and the materials.*
- To have website visitors access the **online information**. *To do so, a site visitor needs to register and the visitor can then be monitored to see what materials are used.*

The project leadership wants the Community of Practice to

reach far and wide, so it continues to make presentations to ABI and addiction professionals about available materials, project findings, the importance of the Community of Practice, and future developments. As word about the Community of Practice spreads, and more people become involved, the well-being of people with ABI and addiction is bound to improve.

To find out more about the Community of Practice, check out: [www.subi.ca](http://www.subi.ca).

## Conference Notes

by Corinne Kagan

In August, I was fortunate to attend a conference in Vancouver on Mild Traumatic Brain Injury (MTBI). There must have been 500 people in attendance from all over the world, with expertise in neuropsychology, neurology, occupational therapy, family medicine, military affairs, sports, the legal profession, and science, to name a few. The conference focused on understanding the nature of MTBI, its consequences, and approaches to treatment.

Since MTBI is an injury that can be sustained in different 'life arenas' and can affect many aspects of a person's life, it is important to hear about it from different angles. Dr. Gregory O'Shanick opened the conference by providing a superb overview of MTBI, how MTBI is assessed, the mechanism of injury, and outcomes (including recovery patterns and problems experienced by those who don't recover well). From then, there was a steady stream of excellent presentations and information.

Several workshops focused on treatment, including cognitive and

physical rehabilitation, mood disorders and ADHD, sleep problems and dizziness. The presentations by the sports experts (such as Drs. Paul McCrory, Grant Iverson and Ruben Echemendia) and the military were highlights of the conference.

I was particularly thrilled to hear Dr. Erin Bigler speak, as he is a leading expert on MTBI; deftly linking the science to the clinical picture. Many presenters indicated that amazing new technologies are being developed and used in neuroimaging, and that these technologies are improving the ability to see what is happening to the brain after MTBI and to better understand the complications that people can experience.

Also in attendance were two members of one of ONF's key projects in the area of MTBI. Dr. Scott McCullagh and Lindsay Berrigan had a poster of the ONF project "Guidelines for the Care of MTBI and Persisting Symptoms". The guidelines are in the final stages of development, and ONF hopes to publish them in late fall, and then pilot test them in a few healthcare settings.

I came away with a better understanding of sports-related MTBI, and learned more about the broad range of MTBI. I learned about the different approaches being taken by the Canadian, US and British military forces in regards to screening, diagnosis and treatment. There is a lot to be learned from the military, due to the sad fact that MTBI is 'the signature injury' of current wars.

More than anything, I came away with a better understanding of how complicated a supposedly mild injury can be, and a realization that improving diagnosis, assessment and treatment is going to continue to require the effort of many disciplines working together.

## Seeking Answers

*Provincial and National  
spinal cord injury research networks  
pull together to find solutions*



From the moment that a person sustains a spinal cord injury (SCI), in that acute stage, someone else is making choices and decisions that can have a life-altering impact on that person. If a lifeguard moves a person without proper stabilization... if urgent surgical intervention happens or does not happen... if a family member enters or does not enter a clinical trial on behalf of the person who is injured... - all of these decisions are made during acute care. Access to an expert opinion is important at such moments. And that is exactly what the Ontario Spinal Cord Injury Research Network is setting out to provide through its Acute Care Network.

Funded by the Ontario Neurotrauma Foundation, the Ontario Spinal Cord Injury Network - of which there are three components: acute, rehabilitation and community - is a group of SCI clinicians and researchers working with colleagues across the country. Together, they work towards a better quality of life for people with SCI. Says Dr. Michael Fehlings, the Acute Care Network leader: "We are trying to determine the best treatments and practices in acute care, and then use them to develop a standard across the country."

Acute care includes the following points of care:

- recognition of the SCI and initiation of medical attention
- contact with the hospital and pre-hospital care
- transport to the hospital care
- arrival at the intensive care unit of the hospital
- recovery in the spinal unit
- liaison with the rehabilitation unit
- post-discharge follow-up

Each of these points of care has different procedures to deal with the patient. Although service providers do what they can, not all of them have access to up-to-date best practices. There could be a profound improvement in the quality of care and in the outcomes for people with SCI if there were systematic change in the delivery of service through uniform implementation of recommended best treatments and practices. Members of the provincial and national research networks have been assigned different topics; they have been asked to review the pre-existing

**"...we are trying to determine the best treatments and practices in acute care"**

research evidence and to give an expert opinion in their area of expertise. From this pooled information, the team will develop a list of recommendations that will help people with SCI. The team is addressing the following topics:

- neurological and functional assessment
- timing of surgical decompression of the spinal cord
- spinal imaging
- predictors of outcome
- acute critical care
- pre-hospital care
- pediatrics
- centres of excellence
- clinical trials

The challenge for the Network is to determine which treatments and practices in acute care are the best, and to then convince acute care and emergency service providers in Canada to adopt these recommendations. Fehlings compares acute care services to a business and suggests that they should be run like a business, i.e., in the most efficient and most successful way possible. If these recommendations are accepted, they will standardize SCI care in Canada. The services will be the best no matter where in the country a person is injured.

The final recommendations of the Acute Care Spinal Cord Injury Research Network will be presented to hospital policy makers and government decision makers - people who can make change happen. The research review is nearing completion and the recommendations and a series of systematic reviews will be published in the near future.

# What's Happening Right Now...

*In current, state-of-the-art management research*

The Ontario Spinal Cord Injury Research Network started in 2007 as an infrastructure support to carry out research and clinical trials. It is part of a National network and the investigators are involved in some exciting, innovative acute care projects. Here is a look at a few of them. (In the next issue of *NeuroMatters* we will focus on what projects are happening in the area of rehabilitation.)

## Global Blueprint for Stem Cell Transplant for SCI

Researchers study stem cells to understand how they can repair or replace damaged tissue. Stem cells have an amazing ability to develop into different types of cells, such as skin, heart and lungs. Their ability to reproduce and repair the body make them of great interest to researchers studying ways to heal the body - including a damaged spinal cord. Internationally, there are studies going on right now on humans using stem cell therapy. Further, due to a recent announcement by the US Food and Drug Administration, Geron Corporation now has permission to proceed with human studies in stem cell research - a first in North America.

Although stem cell research has great potential for people with SCI, many researchers are concerned about how study findings will be shared around the world and how to ensure that international studies will be safe and ethical. The research networks, along with ONF, the McLaughlin-Rotman Centre for Global Health (an organization that "harnesses the advances of innovative technology for global health equity") and the Stem Cell Network (an organization that "supports cutting-edge projects that translate research discoveries into new and better treatments for millions of patients in Canada and around the world") plan to hold a conference to bring key international stakeholders together to discuss these issues and come to an agreement on the best practices in stem cell research. The

international meeting is to be held in May 2010 at MaRS, an innovation centre in Toronto's Discovery District.

## Benefit From Early Spinal Cord Decompression

Participants in this clinical trial had spinal cord compression at the time of their injury and were operated on for decompression either within 24 hours (group A) or after 24 hours (group B). Joining a North American study on the Surgical Treatment of Acute Spinal Cord Injury, researchers seek to determine the best time to operate after a SCI. There are over 370 participants so far, and there have been some interesting results. 24% of people who had surgery within 24 hours improved in their function by two levels on the American Spinal Injury Association (ASIA) impairment scale. In contrast, only 9% of those who had surgery after 24 hours improved the same amount. This study will provide data to determine whether early decompression, within the first 24 hours, facilitates functional recovery and if so, whether the data can be used to support its implementation at various Trauma 1 centres in Ontario.

## Evaluation of Riluzole

In association with the Christopher Reeve Foundation, and as part of another multi-centred North American clinical trial, this first-time human study will evaluate how safe and effective the drug Riluzole is as a treatment for SCI.

Riluzole has been shown to prevent nerve cell death. Spinal

cord injury occurs in two phases. The first phase consists of the initial injury, which kills and damages many cells in the spinal cord. The second phase consists of a progressive zone of deterioration, spreading out from the initial injury. The secondary phase is actually much more harmful - both in size and in cell death - than the initial injury. During this secondary phase, there is an increase in the amount of sodium inside cells in the nervous system, due to disruptions in the electrical charge in these cells. This causes the activation of channels that pump calcium into the cell. The increase in calcium leads to an increase in a chemical called glutamate, which is toxic in large amounts. By blocking the sodium channels, one can protect the cells from dying from glutamate toxicity. Riluzole is a sodium channel blocker, and can therefore protect neurons and supporting cells from death during the secondary phase of spinal cord injury.

To ensure standardization of outcomes in this trial, all of the participating clinicians have been trained to classify and measure their results similarly. Ethics approval has been obtained at all the centres. Participant recruitment will be starting within the next few weeks. The goal is to move towards a larger randomized controlled trial if the findings are promising.

## We Can Work It Out

Have you ever noticed how some people define themselves by the work they do whether it is paid or volunteer? It's "I'm Dr. Sally Brown" or, "Hi, I'm John and I'm a soccer coach". We identify who we are by what we do. And we judge others by what it is they do. For example, we tend to respect firefighters for their brave work. We believe that a construction worker is strong, and that a caregiver is tender and kind. Because there is such a powerful relationship between people and the work they do, not having a job can be hard. Unfortunately, unemployment is a reality for many people with an acquired brain injury (ABI).

The physical, emotional, cognitive and behavioural challenges that people can experience after an ABI can make returning to work difficult, and there may be a need for assistance from those at the workplace and from professionals who provide support. However, there is surprisingly little information about the best way to determine whether a person who has sustained an ABI is actually ready to return to work.

The Ontario Neurotrauma Foundation has therefore awarded a doctoral fellowship to Ms. Mary Stergiou-Kita to research ways to assist people with ABI in returning to work. Combining her background as an occupational therapist and her experience with people with ABI, Ms. Stergiou-Kita will be creating guidelines for clients, family members and interested stakeholders to

determine whether a person is prepared to go back to work.

In an initial study, Ms. Stergiou-Kita interviewed experienced occupational therapists to find out what considerations and actions were important to them when focusing on a client's back-to-work readiness. As one occupational therapist who participated in the study said, "The evaluation gets very tricky. As much as I would love to say, 'I'm going to do the person's assessment and I'm going to look at the demands of the work and try to put them together'... I wish it was that nice and clean. It's not." As Ms. Stergiou-Kita explains, "For a client to be work ready there needs to be a fit between the client's abilities, the work demands, the workplace culture, and the potential for workplace accommodation."

From these findings, Ms.

Stergiou-Kita developed the Work Readiness Evaluation Model (WREM), which highlights some of the key steps that are important to the evaluation of work readiness. The development of a shared understanding of an individual's needs among people who are helping the individual return to work is also important to the evaluation of work readiness.

She now plans to look at what other research exists in the area of work readiness and ABI, review the findings, and then get feedback from stakeholders (people with ABI, family members, employers, occupational therapists, insurers, and other healthcare professionals) to develop the guidelines. The best feedback and practices will form the basis of the work readiness guidelines.

These guidelines are not intended to show that a person must be

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able to do specific tasks before being able to work. Instead, they will identify factors that professionals, clients and other stakeholders might want to consider - for example:

- personal factors, such as memory, attention, anxiety and energy level
- environmental factors, such as available transportation to the workplace
- support factors, such as financial compensation, accommodation and the opportunity for work trials or other on-the-job assistance

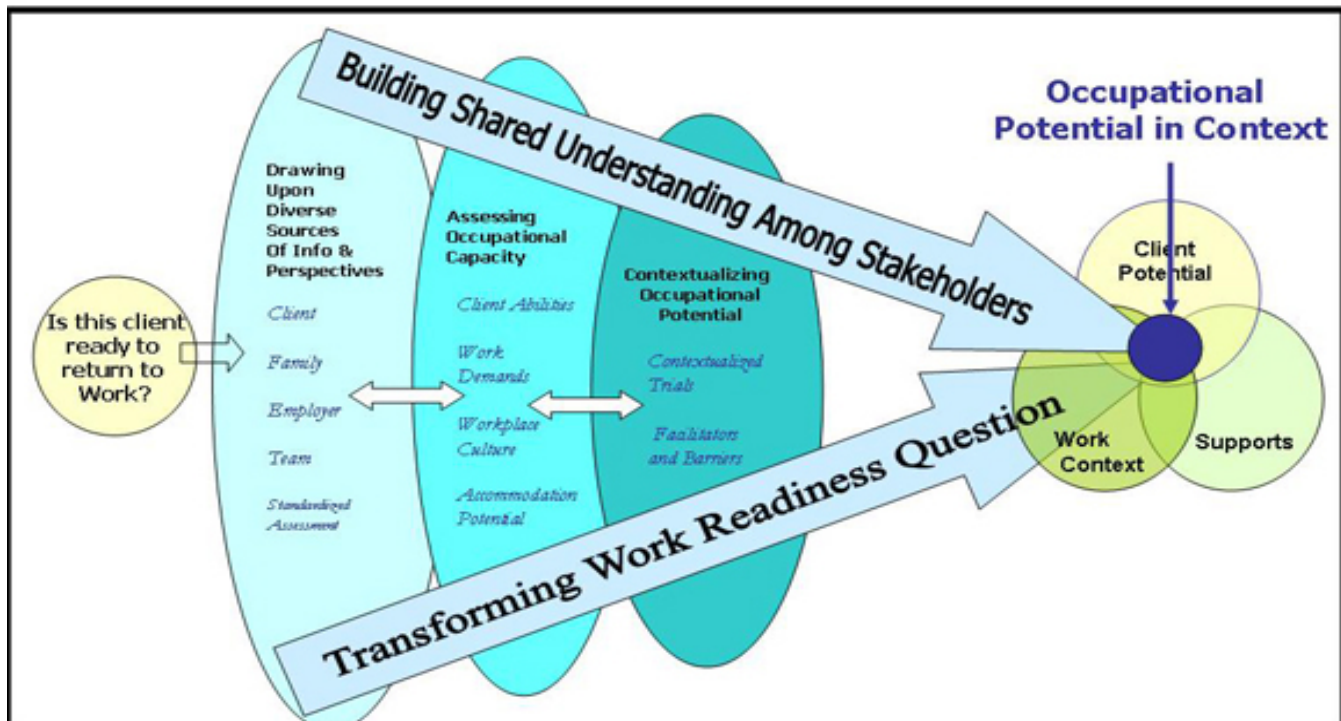
Experts from the Institute for Work and Health, professionals (e.g. therapists, doctors, and

“...there needs to be a fit between the client’s abilities, the work demands, the workplace culture, and the potential for workplace accommodation.”

neuro-psychologists), and individuals with ABI who have returned to work, will be asked to meet to develop the guidelines. Once finished, the guidelines will be tested by a group of occupational therapists and their clients for three months. Afterwards, Ms. Stergiou-Kita will evaluate how well the guidelines worked with those who used them from information contained in surveys and in-depth interviews. If the guidelines are a success, they will be tested in larger clinical trials.

At this point, Ms. Stergiou-Kita is completing the literature review. She will be focusing on developing the guidelines in the near future. To find out more about her work, you can contact her at: [mary.kita@utoronto.ca](mailto:mary.kita@utoronto.ca).

## The Work Readiness Evaluation Model (WREM)



Reprinted from Stergiou-Kita et al. (2009). Evaluating work readiness following acquired brain injury: Building a shared understanding. Canadian Journal of Occupational Therapy, 76(4), 276-284, with permission of CAOT Publications ACE

# Get it Right

## *Knowledge Mobilization Seminar Series*

Knowledge mobilization has often been described as “getting the right information to the right people in the right format at the right time.” For the past five years, the Ontario Neurotrauma Foundation (ONF) and law firm Thompson Rogers have funded the Canadian Paraplegic Association (CPA) Ontario to get practical and innovative spinal cord injury (SCI) research findings, best practices and resources into the hands of clinicians and clients with SCI. ONF’s collaboration has paid off.

The Knowledge Mobilization Seminars take the form of “lunch and learn” sessions that provide ONF-funded researchers an opportunity to present and share their research work with SCI consumers in a simple, understandable format. They also provide an informal opportunity for researchers and consumers and their families to talk. Previous seminars have covered topics such as:

- pain management
- SCI Management
- primary health care
- clinical trial opportunities
- health promotion

Videos of these seminars can be found on the CPA Ontario website at: [www.cpaont.org](http://www.cpaont.org).

The next seminar is scheduled for October 21st at Bingeman’s Conference Centre in Kitchener. It will focus on best practices in primary healthcare for people with mobility challenges. This is an important topic for people with SCI for the following reasons:

- It is hard to find a family doctor with an accessible office and accessible equipment (e.g. transfer lifts, examining table).

- It is hard to find a family doctor who understands the effects of, and complications associated with, a spinal cord injury.
- Most people with disabilities need to see a doctor more often because of the very nature of their disability.
- As baby boomers age, there will be greater demand for accessible services.

The seminar will provide an overview of the Williamsburg Mobility Clinic Demonstration Project; a look at current issues and challenges of access to primary care; and tips on how to talk to your family doctor.

The Williamsburg Clinic is a state-of-the-art example of best practice in primary care. It was developed with the assistance of the ONF, the Centre for Family Medicine Family Health Team in Waterloo Region, and the Schlegel-University of Waterloo Research Institute for Aging. The Clinic will not only serve people with disabilities, but also be a primary care teaching clinic that provides education and training opportunities in the areas of family medicine, pharmacy and social

work to students from McMaster University and the University of Waterloo. Through inter-professional teams comprised of physicians, nurses, pharmacists, social workers, dieticians and other health professionals, the Clinic will provide support and service to patients, their primary care providers and their families. It will also provide best practices to other potential primary care clinics.

The Clinic hopes to be able to reach out to more patients with mobility issues as its reputation spreads. The Clinic will continue to develop further clinical, educational and research projects involving patients with mobility issues.

For information about the Knowledge Mobilization Seminars, please contact CPA Ontario’s Elizabeth Cabral at 416-422-5644 ext. 254. An additional seminar is being planned for March, 2010. The topic is still to be determined. Please visit the CPA Ontario website for updates at: [www.cpaont.org](http://www.cpaont.org).

