

# NeuroMatters

Connecting YOU to the Research

## Acquired Pressure Ulcers

***What causes sitting acquired pressure ulcers in people with spinal cord injuries?***

***International inquiry begins its work.***

The questions have eluded scientists, health practitioners and individuals with SCI for years, "Why do some persons – after being pressure ulcer free for years – suddenly find themselves with a pressure ulcer," and "Is there any way we can pre-determine risk factors so we can step in to take preventative action sooner?"

Sitting-acquired pressure ulcers (SAPU) are one of the most common, unpleasant and expensive secondary health consequences of sitting in a wheelchair. They also can have a significant impact on an individual's daily life. SAPU can occur during acute care immediately following a spinal cord injury (SCI), or arise many years later just when you don't expect it.

"The risk is always there," explains Dr. Keith Hayes, Principal Investigator for the Canadian arm of the AusCAN Pressure Ulcer Risk Assessment Study, the largest, most comprehensive study of its kind on SAPU.

"For some, a SAPU can suddenly become a problem after 10-15 years," says Hayes, "And we don't really know why, because no research before this has looked at the multiple pre-disposing factors,

including the individual's genetic make-up."

AusCAN is an international partnership between clinician-investigators in Australia and Canada led by Dr. Michael Stacey and Jillian Swaine. The project is funded by the Ontario Neurotrauma Foundation (ONF) and the Rick Hansen Institute in Canada, and the National Health and Medical Research Council in Australia. In keeping with the project's international reach, wound care experts from around the world are consulting on the project. This multi-million dollar collaboration is designed to identify those clinical, demographic, psycho-social and genetic factors that predispose some individuals more than others to the risk of sitting acquired pressure ulcers following a spinal cord injury.

Hayes, Chair of the SCI Quality of Life Committee at ONF, expects that once the study is complete, researchers and clinicians will

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finally have a risk assessment tool specifically suited for assessing risk of SAPU in individuals with SCI.

"We now also have a best practices framework to implement the findings", he adds.

**Significant impact on daily life**

The study recently started collecting data and interviewing its first participants. Project Coordinator, Dr. Karen Campbell RN, spent the past few months setting up sites and training research personnel to do participant interviews. As an expert in wound care and researcher at Parkwood Hospital rehabilitation program in London, Ontario, Campbell knows the effect SAPU can have on an individual's daily life.

"The human impact is most significant", she explains, "For an individual sitting in a wheelchair, the chair represents freedom. If sitting has to be limited because of a SAPU, that person may have to stop working, give up being active, decrease their participation in recreational and social activities. It also puts them at risk of an infection, which can become fatal."

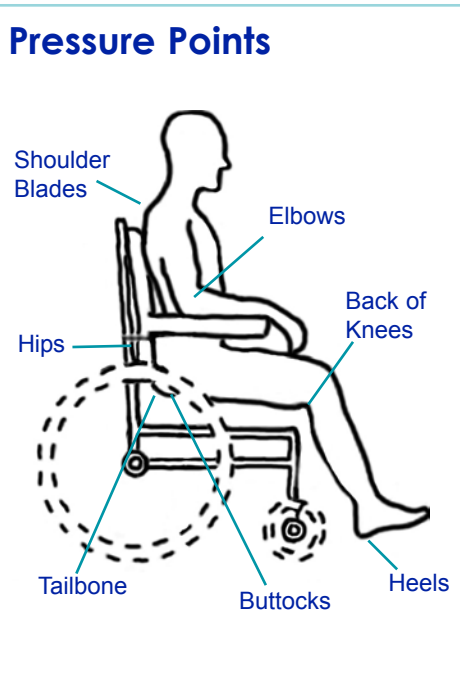
**A comprehensive look**

In Canada, over 28% of individuals with SCI sustain a SAPU at some point. Although there have been a number of studies that have looked at SAPU development,

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none have evaluated multiple risk factors, and no study had focused on ulcers acquired from sitting, a condition specifically experienced by persons with SCI.

Another unique aspect of the AusCAN study is its focus on genetics to see if some people are predisposed to developing pressure ulcers, or having pressure ulcers that do not heal properly.



**Identifying the risks**

One of the aims of the study is to develop a risk assessment tool for SAPU that occupational therapists and other clinical staff could apply when assessing for wheelchair seating and pressure relief care. Current risk assessment tools weren't created for individuals with SCI and simply aren't good enough for assessing all factors that affect someone who is sitting all day.

"Once we know the risk factors," says Campbell, "We'll know what clinicians need to focus on. A risk assessment tool will be invaluable for letting those with SCI know what to watch for, what their individual risks are."

Pressure ulcers are localized breakdown in skin and/or underlying tissues. Sitting-acquired pressure ulcers (SAPU) occur over bony places in the pelvis that support weight in a sitting position, the most common places being the two bones on the bottom of the pelvis and the area at the top of the hip bone. Those with restricted mobility and diminished sensation are more likely to acquire a SAPU and although they can start out as superficial early stage ulcers, they can quickly become deep ulcers with serious outcomes.

**Stay tuned for further information**

The AusCAN Study takes place over the next 3 years, with subjects participating at five clinical centres in Australia as well as the Hamilton, London, Toronto and Quebec City sites in Canada. Study participants will be followed for 3 years.

The project's aims are to:

- Identify factors associated with SAPU following SCI and to develop a risk assessment tool
- Determine costs for treating a SAPU
- Determine impact of a SAPU on the individual's quality of life and participation

For more information about this study, please contact Karen Campbell: karen.campbell@sjhc.london.on.ca Telephone: 519-661-2111 ext 82287

# ONF-REPAR Team Funding Program

In 2007, the Ontario Neurotrauma Foundation and REPAR (Réseau provincial de recherche en adaptation réadaptation) initiated a program to advance Ontario and Quebec rehabilitation research collaborations in neurotrauma. Grants were awarded to six Ontario-Quebec rehabilitation research teams. Each team had an Ontario and a Quebec co-lead; three teams focused on key areas of acquired brain injury (ABI), three on spinal cord injury (SCI).

The cornerstone of the ONF-REPAR Partnership is the Team Development and Research Program. The funds support programs that move research into practice, foster team development, and build capacity of younger researchers by working with senior researchers. Although the grants were modest, by combining the expertise and experience of researchers across two provinces, the ONF-REPAR teams have produced high quality, cross-provincial research in the area of SCI and ABI. The membership of the teams represents some of the leading researchers and clinicians in Canada.

Following the completion of their first 3 years of research, each team's funding was renewed for another 3 years. Each is now in a renewal phase where they are progressing even further. The 6 teams accomplishments are highlighted on the next few pages. The work of 2 teams is reviewed in detail.



## Spinal Cord Injury Mobility Team (SCIMob)

### *Enhancing Mobility and Postural Control*

Immediately following an SCI, it is very difficult to accurately predict clinical outcome. Secondary complications continue to be a concern during acute care and rehabilitation, and later on in life. What appears to make a difference over the long term is increasing mobility and postural control at all stages of care.

SCIMob designed a clinically-orientated mobility research agenda for persons with SCI (including sitting, wheeling, standing, and walking) in order to maximize functional restoration, enhance mobility, improve health status and quality of life. Eventually, the findings can be translated into clinical best practices.

The research team is focusing on three themes:

- 1) Understanding trunk control after SCI and its role in walking, standing and wheeling.
- 2) Role of wheeling mobility in preventing musculoskeletal injury, pressure sores and de-conditioning in wheelchair users.
- 3) Computer and animal modeling to provide a theoretical framework for the proposed experiments/projects.

#### **The team**

Led by Milos Popovic and Molly Verrier (ON), and Rachid Aissaoui and Laurent Bouyer (QC), the team includes 18 researchers and their students from 6 academic health science centres and 4 rehabilitation centres in Quebec City, Montreal, Toronto, St. Catharines and Hamilton.

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## Cognitive Sensory Motor Team (COSMO)

### Understanding and measuring integrated functioning following traumatic brain injury (TBI)

Individuals who sustain a traumatic brain injury (TBI) often lose their ability to multitask, that is, perform simultaneous tasks at the same time as well as focus on the task at hand. This can make their return to prior activities challenging. The objective of this study is to promote an effective return to activities in the community (home, workplace, school) following a TBI by looking at how well children and adults are able to multi-task. This means looking at the degree of recovery from a functional,

rather than medical perspective.

Tests currently used by clinicians to assess how well someone with a mild to severe TBI will function in the community aren't always a good indication that an individual is ready to return to daily activities. Results from this work are expected to provide clinicians with more information in their diagnoses, and help them make better decisions about clinical management, including when it is appropriate and safe for a patient to return to prior activities, particularly high-risk

ones (e.g., driving and fast-paced sports such as hockey).

#### The team

Led by Michelle Keightley (ON) and Isabelle Gagnon (QC), this team of 13 researchers and their students come from 9 universities and rehabilitation centres across Quebec and Ontario. They are renowned experts in the fields of mTBI (concussion), multi-tasking and tool development, and represent pediatric and adult expertise.

## Community Reintegration Research Action Team (CRReATe):

### Transforming community integration for adult ABI survivors and their families

One of the most effective ways to help individuals with a TBI find greater meaning in their lives is through programs and activities that lead to better integration back into the community. To address this vast area of study, the CRReATe team chose to support a series of pilot projects, some of which have led to funding being obtained from agencies such as the Canadian Institutes of Health Research and the Fonds de recherche du Québec-Santé.

The focus of the CRReATe program is to support community

reintegration of individuals who've sustained a TBI. Through several projects, the team has developed sustainable interventions and evaluation methods that can be used to measure the impact of cognitive challenges on everyday activities.

Programs include:

- Personalized Community Integration
- Communication through the Arts
- Social Communication Program
- Leisure Education Program
- Managing Dysexecutive

Syndrome (Cognitive Orientation to Daily Occupational Performance)

#### The team

Led by Deirdre Dawson (ON) and Carolina Bottari (QC), the team includes 8 researchers and their students from University of Toronto, Université de Montréal, Université du Québec à Trois Rivières, Community Head Injury Resource Services, Toronto, Toronto Rehabilitation Institute and Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal.

## IMPACT Team

### SCI-IMPACT secondary health complications following spinal cord injury

Secondary health complications following SCI can have a significant effect on the lives of individuals. The SCI-IMPACT study aims to describe, characterize and improve the health, economic and quality of life impacts of secondary health complications for individuals with SCI, their families, healthcare providers, and the healthcare

system. This large team has divided up their work into subgroups of secondary complications.

Highlights include:

- **The pressure ulcer working group** produced a publication assessing the cost-effectiveness in an SCI population of electrical stimulation plus standard wound

care as compared with standard wound care only.

- **The bone health working group** is translating knee and hip bone density scanning techniques to various Canadian SCI care facilities to assess risk of fracture.

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- **The sexual function working group** is investigating the relationship between sexual function and autonomic dysreflexia.
- **The neurogenic bowel working group** is summarizing data from a series of interviews with individuals with SCI and care providers about living with neurogenic bowel in order to identify priority areas of bowel management.
- **The pressure sore working group** is writing up their findings

regarding costing of different types of pressure ulcer treatments.

- **The quality of life working group** is maintaining a website which informs researchers of the usage of various instruments for measuring quality of life and participation.
- **The physical activity working group** is conducting a literature review on the usage of video game technologies in the field of rehabilitation and assessing whether patients find using the

Wii motivating and acceptable in a therapeutic setting.

- **The pain management working group** is newly formed and currently setting its priorities.

#### The team

Led by Catherine Craven (ON) and Désirée Maltais (QC), there are almost 30 researchers and their students involved in the team from 14 institutions in Quebec and Ontario.

## Who Goes Where, and Why?

### HIPE Study concludes its time for a set standard of care

Two people in the same city, each sustain a head injury. Both are treated initially at the local hospital. One is then discharged to a rehabilitation centre where she receives physical, speech and occupational therapy every day for 8 weeks. The other remains in the hospital then is eventually sent home. Both were ideal candidates for immediate rehabilitation. Why one went one place, and the other remained at the hospital, is not clear.

The above hypothetical example is not uncommon, according to the results of a study that's been looking at the questions of head injury admissions across Ontario and Quebec. The availability and accessibility of rehabilitation services for persons with an acquired brain injury or traumatic brain injury (ABI/TBI) seemed to vary across regions, as well as admission and discharge criteria and the length of time rehabilitation services are

provided. "All across the board we found that there was no set standard of care," says Bonnie Swaine, Researcher and Scientific Director of CRIR in Montreal, "There seemed to be no way to determine who should get rehab, and who should not."

#### Complex study for a complex issue

Four years ago, Swaine, from Quebec joined up with Dr. Nora Cullen from Ontario, as

Co-Principal Investigators for the **Head Injury Partnership Endeavour (HIPE)** to learn more about the referral, admission and discharge of persons with ABI/TBI.

"What we were trying to find out," explains Swaine, "Is the clinical reason for deciding that someone is ready to go to rehab." Although there are tools that can be used, research has uncovered varying and inconsistent methods



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and reasoning for deciding “this person is ready”.

The comprehensive study was conducted with 433 professionals from 13 hospitals and 16 rehab centres that provided acute care and rehab services to persons with ABI/TBI across Quebec and Ontario. Those surveyed included physiotherapists, occupational therapists, social workers, doctors, nurses and other clinicians.

### Results so far

The most striking observation we've made to date”, reports Cullen, “is the discrepancy across the organizations in terms of the kind care provided and the criteria whereby patients are admitted. ...there are a lot of people not getting access to the same level of care.”

In her role as a physiatrist and researcher, Cullen knows too well the importance of providing rehabilitation as soon as possible. “The earlier the better, and the more directed the better,” says Cullen.

Key findings include:

- Not all hospitals or rehab programs in Ontario have official discharge policies or guidelines.
- Numerous different outcome measures are used to help in referral decisions to hospitals and to rehab centres.
- Over 1/3 of all hospital participants in both provinces are not sure/don't know whether their hospital program routinely uses standardized tools to assist in ABI/TBI referral decisions.

### Study Recommendations and what's next

- Create “standard of care” guidelines
- Identify common outcome measures for determining ‘who should go where and why’.
- Design standardized, best-practices procedures.

Swaine and Cullen hope that new national standards of care or best practice guidelines can then be used by accreditation bodies to apply to rehab centres in both provinces that offer rehab for those with brain injuries. Long term, those who are able to benefit from rehabilitation will have equal access to resources, and there will be better application of such resources.

## Back to the Community after Rehabilitation

### Now how to move on?

What happens when a person with a spinal cord injury (SCI) completes rehabilitation? Ideally, that person returns to his or her own community and continues with daily life and work. But so many factors have now changed that could affect quality of life and the ability to participate fully in the community, including the workplace.

An Ontario and Quebec inter-provincial project, **“Towards Interventions Focusing on Community Living and Quality of Life for Individuals with Spinal Cord Injury”**, is about the importance of two ultimate outcomes of rehabilitation after a spinal cord injury – community living (COM) and quality of life (QOL).

“The purpose of our research,”

says Kathy Boschen, Ontario lead for the project, “is to look at life lived back in the community again post rehabilitation.”

“We’re looking at some very tangible goals, as well as some less tangible ones like improvement in overall quality of life,” she explains. “The focus of our COM-QOL work is on living in the community – coping, adjusting, and adapting

once someone is back home after rehabilitation.” For example, how can you get to see your doctor if the office isn't accessible? What new wheelchair skills do you need in order to access this common but now challenging community-based service? If you're in a wheelchair, you may now need to learn how to bump up a curb, wheel up a ramp,

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knowledge  innovation  implementation



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or maneuver into an elevator.

Boschen, a rehab researcher at Bridgepoint Health and the University of Toronto, is one of the eight researchers in COM-QOL who brings specific rehab research expertise to the project. The group has divided their work into six areas, one being a study and training program in wheelchair skills. Run by the Quebec lead for the project, François Routhier, it looks at how an individual with SCI can build up a new skill set of wheeling for daily living, good health, recreation, and athletic participation.

The other five areas of the research program are:

#### **Exercise and Physical Activity:**

This program is studying, evaluating, and promoting the importance of physical activity and health, including healthy eating habits.

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example, embrace the changes in your life rather than ignore them – that's the cognitive therapy part."

Felteau is no stranger to the impact of a TBI. Nineteen years ago she sustained a brain injury but through mindful meditation learned to heal at a deeper level. Although the approach may not be suitable to everyone, for those willing to give it a try and stick to it, the skills imparted can lead to positive changes that continue to produce benefits.

"The idea", says Bédard, "is to learn how not to push feelings under the carpet but to re-name them, learn to live the rest of your life with the new reality."

#### **Ground breaking research for a complex issue**

MBCT was initially developed to prevent relapse of depression but until this study had never been applied to the treatment of depression for those with a TBI. Part of the problem is that the psycho-

**Social Support:** This area is looking at how best to provide support to families of those who return to the community following an SCI. A brochure is being published and offered free of charge that provides resources to family members for informational, emotional, and practical support.

**Participation and Quality of Life, "PAR-QOL":** This is a web-based tool kit ([www.parqol.com](http://www.parqol.com)) now available for professionals, family members, and individuals with SCI.

**Pain Management:** A new focus is neuropathic SCI-related pain. A pain self-management program originally developed in Ontario and piloted in Toronto – with "promising results" – will be translated into French, then pilot-tested in Quebec. Ontario members of the research group are assisting in its development

and launch.

#### **Transfer and Use of New**

**Knowledge:** Embedded throughout this research program agenda is the expectation that everything learned from each area will be shared with other researchers, clinicians, and consumers to improve community integration, social participation, and quality of life.

The COM-QOL team continues to be keenly aware of the need to move their research results into practice to better assist individuals with SCI and their family members to successfully make the transition post-injury back into the community.

"Our team believes in partnership and collaboration," adds Boschen. "We're creating more knowledge and building new capacity collaboratively from both provinces to do our work."



logical and emotional effects of a TBI are difficult to see and assess, and therefore, difficult to analyze. Bédard praises the Ontario Neurotrauma Foundation for supporting such a complex study. "It's a real testament that the Foundation got behind it," he adds.

The Mindfulness Study was originally piloted in a few sites in Ontario. More recently, this larger randomized, controlled trial was conducted at three sites, St. Joseph's Care Group in Thunder Bay, Ottawa Hospital Rehabilitation Centre and Toronto Rehab.

Approximately 120 TBI participants were involved during the ten-week intervention. Organizations around the world have expressed interest in the study, including the U.S. Department of Veteran Affairs and the International Brain Injury Association, where the report was presented this spring.

A final report is being prepared in addition to a standardized manual for facilitators/trainers using MCBT for TBI.

*For further information, Melissa Felteau, Clinical Educator: [melissafelteau@shaw.ca](mailto:melissafelteau@shaw.ca)*



# A Mindfulness Approach to Treating Depression

*Spells hopeful news for those with a TBI*



When it comes to reducing depression for those who've sustained a brain injury, a combination of eastern-based strategies and western therapies may be the answer. It's called "mindfulness-based cognitive therapy" (MBCT) or mindful awareness. The approach was tested during a recently completed research trial for treating the emotional and psychological symptoms that arise after a traumatic brain injury (TBI).

"We've seen positive results," says Melissa Felteau, Clinical Educator with the coordinating research team in Thunder Bay, one of three sites where the study was conducted with individuals with a TBI. "We saw participants calm down, be less reactive to experiences, as well as have less physical experience of pain."

The most exciting result for Felteau was seeing how participants lessened their isolation and started to feel whole again. "Individuals finally let go of their judgment," she explains, "They became more compassionate toward others, toward themselves, and more accepting of their own

injury. They're finally able to say, 'I love myself now even though I am living with the effects of a brain injury.' It is then that they can feel part of the community."

Principal Investigator for the study and Scientific Director at St. Joseph's Care Group of Thunder Bay, Dr. Michel Bédard, is also optimistic about the study, stating, "By the end of the 12 week trial, there was greater reduction in depression symptoms in the treatment group than in the control group."

## The debilitating effects of depression

Over 1/3 of people with brain injuries will experience depression,

according to current studies. Such depression continues well after the injury and can be equally debilitating as physical challenges.

"A TBI changes your circuitry -- which has emotional, psychological as well as physical implications," explains Bédard, "It reaches far beyond the injury itself."

For example, an individual following a TBI may no longer be able to return to their previous workplace, or if they're a student, may have to quit or alter their studies. Some simply cannot do their job as well as before, or are overwhelmed by the changes brought about by the injury, including big changes in personal relationships. All these factors affect a person's self image and quality of life, which in turn triggers changes in emotions and behaviour.

These issues, however, often go untreated because the physical, behavioural and cognitive concerns are seen as the primary focus. Many turn to drug therapies to fight depression. But drug therapies don't work for many, or for others, are not an option.

## Learning to reframe and accept

MBCT uses a very different approach. By applying the skills of meditation and mindfulness to intentionally pay attention to the present moment, participants learn how to put aside their tendency to judge, to compare or wish for things to be different. This helps them view their changed lives with more equanimity, see more possibilities for problem solving, and regain a sense of wholeness.

"Meditation allows us to slow down, and catch our thoughts," describes Felteau. "It is then that we can choose how we relate, for

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