

NeuroMatters

Connecting YOU to the Research

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Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

I Want to Thrive, Not Just Survive

Using expressive arts to integrate teenagers with acquired brain injury

It's hard being a teen. Your body's changing, you live in a fast-paced world, and your relationships with friends and family are often awkward as you work through your emotions and talk about your feelings. And as you might expect, these challenges become only harder when you have a brain injury. So if you're a teen with an acquired brain injury (ABI), you might find that participating in "expressive arts" is a great way to share your feelings, get involved in the community, and meet some fun people!

Social Impacts of ABI

As a teen with an ABI, you might have a hard time communicating with others. You might find it difficult to read people's expressions, understand abstract ideas, or get along with some people. Finding the right words, controlling your feelings, and dealing with things that go wrong - they can be frustrating, confusing and sometimes just simply not fun. You may ask yourself: "How do other kids do it?"

Rehab professionals believe that if you're a teenager with ABI you should get involved in your community, and work on developing your social and emotional skills. By doing so, you meet people, you share what you have to offer the world, and you feel good about yourself. The difficulty, however, seems to be in finding a way to become involved.

Because there is so little research about community-based activities in which teens with ABI feel like successful participants, the Ontario Neurotrauma Foundation (ONF) funded a pilot study to look



into whether expressive arts can enable social and community integration. Led by Dr. Michelle Keightley at the University of Toronto, the research team conducted a two-stage pilot training programme involving theatre arts.

The Effectiveness of Expressive Arts Therapy

The use of arts and artistic media ("expressive arts") to explore life situations is a great way to get out and meet people. Here's what is already known:

- The expressive arts cover a wide range of activities (e.g. drawing, group writing, expressive movement, vocal exercises) that empowers youth to explore and develop social communication strategies through creative methods
- The creative process often requires teens to get along and work with each other, and to think about how they feel about themselves and others in the group
- Working in a group setting makes teens aware of what they are feeling
- For those youth with an ABI who have a hard time developing social skills, working together in a group enhances social and com-

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munication skills because others in the group talk through problems together. They can find out how other kids handle social situations!

- The expressive arts offer useful rehabilitation strategies because they allow the teens in a group to develop in a safe and appropriate environment

Stage 1: The Youth Camp Experience

In the first stage of the study, two teenagers with an ABI - recruited from Bloorview Kids Rehab - attended a camp facilitated by theatre artists and occupational therapists. The camp programme included mask work, drumming and story-telling. At the end of camp, the teens gave presentations about the group's progress.

Measuring and Identifying the Effects

The research team collected information from the teens in order to evaluate the theatre arts training programme. Before the start of the camp programme, the researchers had asked the teens how they felt they handled social situations. At the end of the camp experience (i.e. six months later), they asked the teens whether they felt they could better handle social situations. The youth discussed any issues they were experiencing with social or recreational activities, and what areas they wanted to develop. In addition, the team conducted focus groups with the youth, the caregivers and the therapists so that they could get feedback to make future camp sessions fun, useful - and most of all socially effective.

Numerous Benefits

The research team found that the teens who completed the programme:

- picked up on facial expressions with more accuracy and with increased speed
- improved at leisure activities -

and enjoyed them more, too

- talked more easily in public and at home

The programme's facilitator concluded: "On [the] final day of camp both participants demonstrated self confidence in the improvisational work: spoke loudly and clearly, maintained posture, listened to others. Both participants appeared to be really proud of

their new abilities." A caregiver of one of the participants said that this was because "they had time to react, to interact, and to be social on a different time line. At school, or other social environments, everyone else speaks so quickly, acts so quickly, she wouldn't have time to keep up."

Stage 2: More Participants, More Time, Different Measures...

ONF funded a second stage of the pilot study, which was again led by Dr. Keightley and her research team. The length of the programme was extended to a full month, and four teens took part in the programme. Some changes were made including, analyzing the teens' social communication skills by a speech-language pathologist before and after the programme. Working with an occupational therapist, the teens were encouraged to be specific and to describe how they felt they could benefit from the programme - and to then set their own goals.

... More Benefits!

The research team, again, found that at the end of the programme the teens' communication skills had improved. They talked more, were clearer in what they had to say, and had improved social style. They either met or exceeded many of the goals they had set for them-

selves in the areas of socialization, communication and leisure activities. One participant explained: "I made friends, and I got to know everyone... so I wasn't scared."

The View From Outside

Interestingly, many comments received from the youth and caregivers at the focus groups were about working together as peers -

I made friends,
and I got to know everyone...
so I wasn't scared

and specifically about the special group design for youth with ABI. One caregiver commented: "I think the most positive talk we had around the camp from him was around what happened that day... the dynamics of the other kids and the personalities." Another caregiver stated: "He goes into his school system, he is dealing with kids; they all have their issues, but it's not 20 kids in his class with [a] brain injury, so I think it was very valuable for him."

Moving Forward - the Need to Expand

With these two pilot studies, ONF has entered into an important area of research that will help youth with ABI regain not only social and emotional skills, but also a sense of belonging and an ability to be part of their community. This research shows that a successful expressive arts programme for teens living with an ABI helps to improve their social and community integration. However, these pilot studies only scratch the surface. Further research is required with a larger number of youth and controlled conditions. The research team and ONF would like to do more research, to understand and evaluate the effectiveness of creative arts therapy, in order to assist teens with ABI in participating in their community and in having a rich quality of life.

Peace of Mind

How Attention Deficit Hyperactivity Disorder interacts with traumatic brain injury in children

ONF takes a particular interest in children and youth with traumatic brain injury (TBI). Some kids with a brain injury also have other disabilities, so ONF funds research to find out how those other disabilities can affect a child's brain injury. One example of interest would be Attention Deficit Hyperactivity Disorder (ADHD) and TBI.

Kids with ADHD have a hard time paying attention, and can be more likely to engage in risk-taking behaviour, which may put them at greater risk of sustaining a brain injury. As well, kids who have had a TBI sometimes develop ADHD after their injury. So, within the population of kids with TBI, a relatively high number of kids are also affected by ADHD.

ADHD is a condition that regularly affects 3 - 5% of school age children. It is more common in boys and it occurs in all ethnic groups in every country where it has been studied. It shows up in kids before age 7 with the following traits:

- extreme inattention (a hard time focusing on one thing)
- hyperactivity (a hard time sitting still)
- impulsiveness (a hard time showing self-control)

Sadly, without the right supports, kids with ADHD can face issues such as substance abuse, antisocial behaviour and failure in school. So it is important to understand ADHD in order to help kids affected by it.

ONF has just funded a new project led by Dr. James Hutchison at the Hospital for Sick Children in Toronto. Kids in the study are placed in one of three groups:

- kids who developed ADHD after their injury, known as secondary ADHD
- kids who had ADHD before their brain injury, also known as primary ADHD, and still had ADHD after their injury (secondary ADHD)

- kids with a brain injury who do not have ADHD

These kids will be compared to a group of kids with ADHD and no brain injury.

The researchers already know from earlier tests that brain scans of kids who have primary ADHD look different from those with secondary ADHD and different, again, from those with no ADHD. They know that kids with both primary and secondary ADHD have little self-control. (They often grab things or blurt out answers at inappropriate times.) However, unlike kids with primary ADHD, kids with secondary ADHD gain back their self-control over time. The research team wants to know why and how these two groups differ. They want to better understand the brain so they can help kids with TBI and ADHD.

This exciting study, which will take place over the next two years, will follow each child for 12 months. The researchers want to see whether those children with both primary and secondary ADHD will have a harder time with attention. At 12 months following the injury they will perform electrical monitoring to see how different brain regions synchronize with each other during the performance of a task that requires attention. These tests, along with magnetic resonance imaging (MRI) - detailed images of the brain - will help determine how injuries in certain regions (eg. front of the brain) affect attention. This may help to tailor therapies to improve recovery of attention in children with specific brain injuries.

The results will hopefully have a big impact on the understanding of the brain, so that people working with kids with TBI and ADHD can better help them to manage their challenges - bringing everyone a little bit of peace of mind.

We Asked For It

ONF recently surveyed readers on what they thought of *NeuroMatters*. Here's what the 46 respondents had to say:

Would you recommend NeuroMatters to a friend?

Yes: 100% No: 0%

Do you find the writing easy to read?

Yes 97.8% No 2.2%

Is the content useful?

Yes: 100% No: 0%

Have you ever forwarded NeuroMatters to a friend/family member/co-worker?

Yes: 56.8% No: 43.2%

When you come across a topic you want to learn more about, do you follow up on ONF's website?

Yes: 64.4% No: 35.5%

Thanks for taking the time to help us help you!

**TELL
a
FRIEND**

**each issue
is free**

* E-mail subscribers get special updates!

research news, book reviews, upcoming events, consumer items for people with a spinal cord injury and an acquired brain injury as well as family and caregivers

Sign up online for your copy of the *NeuroMatters* e-zine at: www.onf.org or if you are a consumer living in Ontario, contact ONF at: (416) 422-2228 to receive your copy by mail.

ONF and REPAR

A cross-provincial research partnership

In 2006, the Ontario Neurotrauma Foundation (ONF) and the Réseau provincial de recherche en adaptation-réadaptation (REPAR- Quebec Rehabilitation Research Network) created a partnership to promote collaboration between Ontario and Quebec researchers working in the field of rehabilitation for people with acquired brain injury (ABI) and people with spinal cord injury (SCI).

The aim of the partnership is to build on the expertise in rehabilitation research in Ontario and Quebec by:

- promoting the sharing of ideas and knowledge in rehabilitation research
- providing researchers with access to more participants and data for their projects
- promoting research in different locations
- reducing national competition for funding by promoting joint applications to national funding bodies
- ultimately, improving the quality of life for people with neurotrauma

The two organizations created a Team Development and Research Programme, which is funding six key rehabilitation research projects, each one jointly led by a Quebec and Ontario researcher. Here's an overview of each team and project.

Understanding and Measuring Cognitive, Motor, Sensory and Psychosocial Functioning, to Improve Diagnosis, Prognosis and Treatment Following TBI

Brad McFadyen (University of Laval) and Robin Green (Toronto Rehabilitation Institute) are leading a team of 14 researchers in a project to better understand and measure the abilities of people with TBI. There is lack of knowledge about (a) the relationship among thinking, motor, sensory and social abilities (which are often disrupted after a traumatic brain injury), and (b) how the severity of the injury and the length of time after the

injury, affect the measurement of these abilities.

To conduct this research, the team will:

- interview and hold focus groups with consumers and other stakeholders to get information and understanding about the differences in people's functioning
- coordinate pilot studies - in various locations - that study different combinations of abilities
- create accurate, advanced and standardized measures of disability for different levels of TBI
- develop more awareness of thinking, sensory, motor and social functions in people with and without TBI

Head Injury Partnership Endeavour (HIPE)

Quebec and Ontario have rehabilitation programmes from acute care to community support for people with head injuries, however, there are differences in practice from one facility to another. It is also not clear which model of care best helps people with head injuries.

Bonnie Swaine (University of Montreal) and Nora Cullen (Toronto Rehabilitation Institute) are leading a seven-member team of Quebec and Ontario researchers who are addressing these issues. Their project seeks to:

- identify the different approaches to acute care and rehabilitation for people with brain injuries in Ontario and Quebec
- determine what differences facilities have and what the two

provinces' approaches are to care and rehabilitation

- make recommendations regarding consistency of approaches and access to care
- build a larger team to research whether the different approaches affect people's care and rehabilitation

Using a questionnaire and various tests, the team plans to measure people's views about the quality of rehabilitation services they received. They also plan to develop an inventory of existing databases on service delivery. This information will be used to evaluate rehabilitation services.

Transforming Community Integration for people with ABI

People who have sustained a traumatic brain injury (TBI), their families and their caregivers sometimes experience difficulties such as isolation, lack of engagement in meaningful activity, distress, and addiction. Years after a TBI, some people have a hard time completing daily activities, making and carrying out plans, participating in leisure activities, and maintaining relationships.

Deirdre Dawson (Baycrest Centre) and Hélène Lefévre (Institut de réadaptation de Montreal) are leading an 11-member team of researchers in a project to determine the best practices for community inclusion for people with moderate to severe TBI.

The team will begin its work by sharing information, undertaking focus groups with stakeholders, and coordinating pilot studies to look at different approaches to community integration.

The project will use elements of the Habilis Programme (which helps people with TBI, as well as their families and caregivers, to develop life skills and social roles) and the

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Cognitive Orientation to Occupational Performance approach (which teaches people to identify and achieve worthwhile individual and community goals).

SCImob: Enhancing Mobility for People with SCI

Ontario and Quebec already have established internationally recognized research programmes in SCI rehabilitation. This project brings researchers together who will, for the first time, influence clinical practice. A 22-member research team led by Dr. Sylvie Nadeau (University of Montreal) and Prof. Molly Verrier (University of Toronto) is focusing on mobility and people with SCI while they are sitting, wheeling, standing, and walking. The areas of focus are:

- bringing back and improving movement
- improving health status and quality of life

The project will look into how the level and completeness of a spinal cord injury affects trunk muscles and the ability to sit and walk. The project seeks to outline a step-by-step strategy on how to improve movement for persons with SCI. Once the researchers finish developing their strategy, each step will then be shared with rehabilitation professionals across both provinces as best practices. Initially the project will focus on people who have acute injuries, but eventually it will extend to people with chronic SCI.

Towards Interventions Focusing on Community Living and Quality of Life for Individuals with SCI

A seven-member team of Quebec and Ontario researchers led by Dr. Kathy Boschen (University of Toronto) and Dr. Luc Noreau (Laval University) is studying the importance of community living and quality of life for people with SCI. The ultimate goal of rehabilitation is for people to be living in their community and for them to be satisfied with their quality of life, but researchers would like to know

what tangible steps can be taken by rehabilitation professionals to make these outcomes possible. What exactly makes people content?

- During the first phase of this project researchers will gather information from stakeholders through questionnaires and tests about the terms "community living" and "quality of life" to better understand what these terms mean and how they can be measured
- The team will then study how effective various intervention strategies (like pain management, meditation, and other coping techniques) are in regards to enabling a person to live in the community and have a satisfying quality of life
- Following that, the project will look at the impact of social policies on community living and quality of life for people with SCI. The researchers hope to look specifically at housing and employment issues and public planning for people with SCI in these areas.

SCI Impact Team

A team of 21 researchers and clinicians - with backgrounds in health economics, psychology, social work, nursing, physiotherapy, occupational therapy, kinesiology, medicine, psychiatry, and surgery - will be working together and researching the prevention, treatment and measurement of secondary health issues (sexual health, bowel care, bone mass loss, pressure sores) facing people with SCI. Led by Dr. Cathy Craven (Toronto Rehabilitation Institute) and Frédérique Courtois (University of Quebec), the team is undertaking four pilot projects that will:

- examine whether participation in an exercise programme can reduce or prevent autonomic dysreflexia (very high blood pressure developing quickly) brought on by ejaculation
- record people's experiences with bowel care, to develop a better way to measure results in bowel care management

- share knowledge about how to measure bone mass density in the knees of people with SCI, in order to improve care for people with osteoporosis and reduce broken bones
- develop a way to measure the social and financial cost of pressure sores, and assess the savings associated with using electrical stimulation therapy

The ABI and SCI research expertise in Quebec and Ontario is very strong, and these two provinces represent over 60% of Canada's population. It is expected that the six projects will be completed within the next two years and will lead to even larger scale projects. Through the leadership of the research teams, ONF and REPAR hope that the projects they are supporting eventually result in changes that make a difference in the lives of people with ABI and people with SCI.

In the Next Issue of *NeuroMatters*...

As a research organization, one of the hardest questions ONF has been faced with is: "How many people sustain an ABI every year?" ONF has funded an ABI Dataset Project that has managed to come much closer to the answers to this question and many others about the incidence of ABI and the health care that people are receiving. Some of the key results will be highlighted in the next issue of *NeuroMatters*, as well as a description of another important project collecting information about people with ABI.

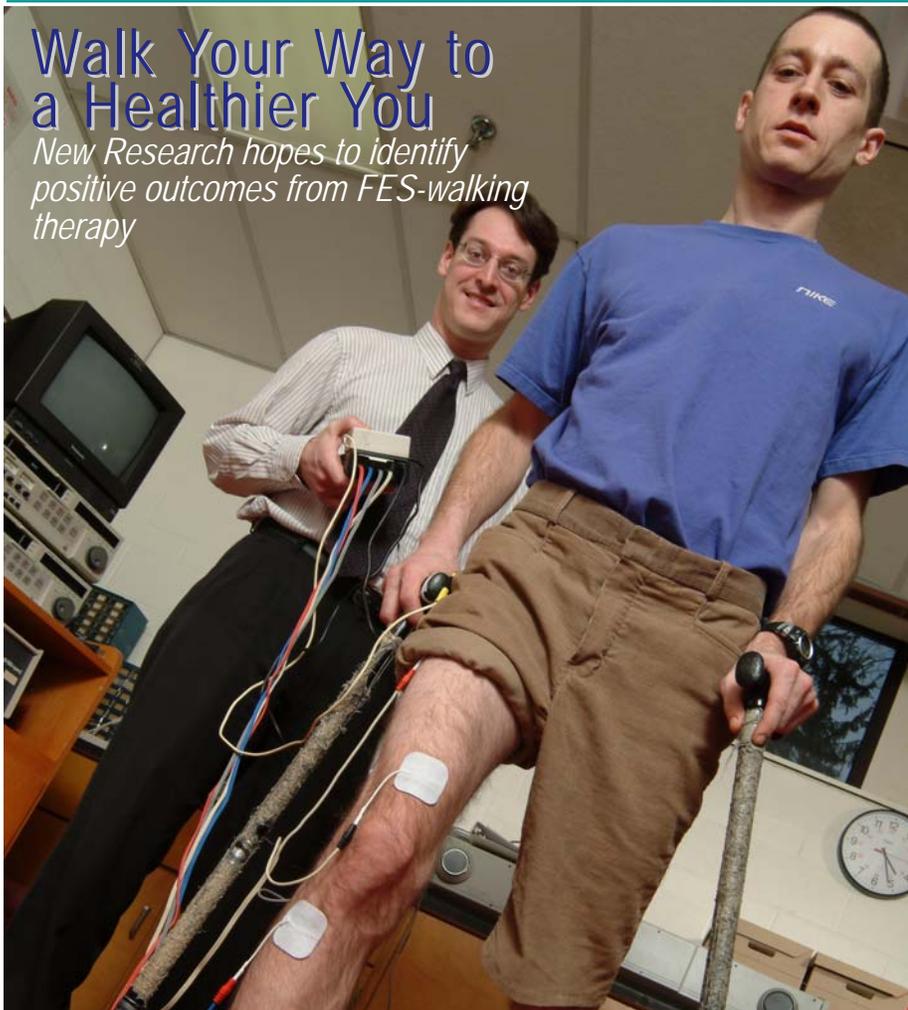


Photo by James Atkinson, MediMedia, courtesy of Toronto Rehab

Walk Your Way to a Healthier You

New Research hopes to identify positive outcomes from FES-walking therapy

As we all know, messages speed through the spinal column along an information highway from the brain to another part of the body telling it to move. When a person has a spinal cord injury (SCI), this "accident on the highway" blocks the flow of information. For many years, researchers have been trying to find ways to repair the highway so that regular traffic can resume. One type of therapy that has had some success is Functional Electrical Stimulation (FES). The purpose of FES therapy is to get the messages between the brain and the rest of the body moving again. This therapy has been around for quite awhile and has sometimes been used as an embedded assistive device, (i.e. put inside a person's body) to help with movement.

Since June 2005, ONF has been funding several new and exciting research studies into FES therapy at Toronto Rehabilitation Institute (Toronto Rehab). In the past, it was believed that FES therapy just increased muscle size and the range of motion in people with SCI.

Recently, researchers have found that FES therapy can do more.

Led by Dr. Milos Popovic, researchers at Toronto Rehab - Lyndhurst Centre have been studying whether intensive and repetitive FES treatments can help people with acute and chronic SCI

recover movement in their arms, hands, legs and feet. The researchers wanted to get muscles working well enough again, so that participants would not have to be as dependent on wheelchairs, braces, canes, and other assistive devices.

FES therapy works like this:

- Self-adhesive electrodes are placed on various muscles of a participant's body
- The electrodes are connected to a control box
- The participant (or a clinician) flips a switch on the control box
- An electrical zap from the control box makes the muscle contract
- The zap acts like a traditional message from the brain to the muscle
- The contraction of the muscle makes the body part move

Prior to the study, some participants' muscles could move a bit, others not at all. After 12+ weeks of FES therapy, some of the muscles that had previously not been able to move were able to contract, and muscles that had previously been weak were stronger. With more zapping, the muscle contractions became even stronger, and participants were able to better control them voluntarily. The research results were promising!

In another study, five participants exercised on a treadmill three times a week, over 16 weeks. (Those who could not walk or support body weight on their own were supported by a harness and a counterweight.) By the end of the study, all participants had improved their mobility - and their overall sense of well-being - because they were less dependent on assistive devices for mobility. One participant did not improve her walking speed, but at the end of the therapy she did choose to walk without a brace. Many participants were so pleased with their results that they wanted to continue; they felt that the therapy was improving their health. Improving their health? That's right!

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The participants reported benefits beyond improved mobility. There were fewer secondary medical complications such as urinary tract infections and pressure sores, and reduced muscle atrophy and spasticity. One interesting and unexpected finding was that two of the participants discovered that they had increased bone mineral density when they went for their regular bone density check-up. Could it be that this form of therapy would prove useful in treating or preventing secondary complications that ultimately affect quality of life after SCI?

Now, another study is looking at whether FES therapy can restore or improve walking ability in people with chronic, incomplete SCI, and whether it has other health-related benefits. The researchers will look specifically at short and long term effects on spasticity, muscle atrophy and bone loss. In this study, 32 participants will exercise three times a week for 16 weeks. Some of them will take part in the FES-assisted walking therapy, the rest in resistance and aerobic exercises. The researchers will compare the results between the two groups to determine whether FES-assisted walking therapy is more beneficial than resistance and aerobic exercises.

The research into FES therapy is exciting and promising. The studies to date have shown that this form of therapy can, indeed, improve a person's functional abilities. It is still to be determined how effective FES walking therapy is on secondary health issues such as bone loss, spasticity, and muscle atrophy. The research is in its final phase and will be completed by early 2010.

For people with spinal cord injury (SCI), the journey to reach the point of optimal health and reintegration into the community in the aftermath of the injury is a continuous process that can pose significant challenges and barriers for them. These challenges and barriers can result in medical complications and delayed independence at a time when they are trying to put their lives back together.

WAVE Hello to Good Vibrations

Passive Standing and Whole Body Vibration come together in a promising new study

Russian scientists thought that vibrating an astronaut's entire body might create the amount of resistance needed to reduce or stop the bone loss and muscle atrophy. However, scientists found that vibrations at low frequencies caused motion sickness, and that the rapid and forceful muscle contraction that accompanied high frequency vibrations caused muscle injury. Recently, scientists discovered that intermittent vibration at moderate frequencies increases muscle and bone mass.

Thereafter, researchers began studying the impact of Whole Body Vibration (WBV) therapy on elite athletes, postmenopausal women, seniors, people with cerebral palsy, people with Parkinson's disease and stroke survivors. WBV therapy has shown improved muscle strength, balance, mobility, gross motor skills, gait, and flexibility in these various groups. Moreover, WBV therapy had few reported negative effects.

Now, Toronto Rehabilitation Institute (Toronto Rehab) researchers, led by Dr. Cathy Craven, are studying whether WBV therapy can help people with spinal cord injuries (SCI). This ONF funded study is looking into how passive standing, together with WBV, can impact

bone mass, as well as muscle and fat mass, in men with motor complete paraplegia. This group was chosen because:

- participants needed to be able to safely transfer from their wheelchair to the standing frame
- researchers wanted to restrict participants' body mass index
- researchers were worried about

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Study participant uses the WAVE therapy machine.

Photo by James Atkinson, MediMedia, courtesy of Toronto Rehab

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the risk that vibration therapy could potentially pose to young women.

This study has two phases, with the first phase focusing on finding the best machine and equipment to carry out the WBV therapy, and the second phase focusing on how effective this form of therapy is on this group of study participants.

After a SCI, bone mass of the hips and knees decreases by 3% to 4% a month, for up to 18 months. This decline in bone mass puts people with SCI at greater risk for broken leg bones. Not surprisingly, then, 25% to 46% of people with SCI break their bones during their usual daily activities. There are currently no established treatments to stop the decrease in bone mass, so finding ways to increase bone mass and reduce breaks is a priority for the research team.

During this study, participants will receive intermittent WBV therapy for 45 minutes, three times a week. Since it takes three months to increase bone mass, this nine-month study will give enough WBV exposure to participants to assess the effectiveness of the therapy. All participants will be supported by the EASYStand 5000 passive standing device, which allows participants to be upright on the WBV plate without contraction of the leg muscles.

The research team has chosen the WAVE Manufacturing WBV platform to apply this therapy. The platform gently shakes the participant; the vibration is intended to mimic the mechanical strains on a bone during weight-bearing activity, and stimulate bone formation. The study hopes to:

- determine whether passive

The Consumer Connection

The Ontario Brain Injury Association (OBIA) is providing a limited number of subsidized rates for ABI survivors and their caregivers interested in attending "Harness the Power After Brain Injury", the 2009 ABI Provincial Conference.

Featuring keynote addresses by neuroscientist Dr. Byran Kolb and Dr. Abe Sniderman, the conference will be of interest to not only healthcare professionals, but also consumers. In fact, over one third of the people who have attended past ABI conferences have been consumers and caregivers!

Don't miss the opportunity to attend. Topics will include: plasticity, mindfulness, the art of intervention, and other strategies to harness the power within a person to help with the rehabilitation process.

The conference will be held at the Sheraton on the Falls Hotel, Niagara Falls from October 28 to October 30, 2009. More info: please contact OBIA, 905-641-8877 or 1-800-263-5404 (toll-free) obia@obia.on.ca, www.obia.on.ca.

Last November, ONF sponsored consumers to attend the 3rd National Spinal Cord Injury Conference: *Innovation, Impact and Future Direction*. The conference was attended by hundreds of people interested in issues related to SCI. Here's what some attendees had to say about it:

"I was very intrigued by topics offered that were more directed to the consumers, who are more concerned with viable solutions post injury from a quality of life perspective. The idea of bringing consumers together with this community of doctors, researchers and therapists ... allows for some valuable dialogue to be passed back and forth" - Joel Bancescue

"...what resonated with me, as a person with a SCI, was the concern about the impact of living with this injury and its effect on being able to live to one's potential." - Beverley J. Davis

"I will remember this conference for a long time and do my best to pass the information on to people with SCI in my community." - Elizabeth Winkelaar

standing and WBV can improve bone health - and decrease muscle atrophy - in men with motor complete spinal cord injury

• evaluate secondary outcomes of WBV, such as:

- whether it decreases waist size, and promotes positive changes in lipid profile, blood glucose and insulin regulation - all of which affect the risk of developing coronary artery disease
- whether it helps people lose excess weight

- whether it reduces spasms
- whether WBV therapy is safe for people with SCI
- determine how successful a larger, more involved study might be in the future

WBV therapy seems like it may be a giant leap forward for people with SCI. Hopefully, researchers will find that this form of therapy does, indeed, prevent a decline in bone mass and muscle atrophy. Recruitment of participants is ongoing; the results of this study will be available in March 2010.

