



Brain Injury Association of Canada
Association canadienne des lésés cérébraux

THE BRAIN TRAIN

Get on board with BIAC

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YOU GOTTA WALK, BEFORE THEY MAKE YOU RUN...

— by **Madeleine Welton**

'Walking' is the act of putting one foot in front of the other to propel oneself in a forward direction. "You don't know how hard it is until you can't do it" says Madeleine.

For many brain injury survivors, the ability to walk is a new found and exciting freedom. Recently I received a request to participate in a brain injury association 'walkathon'. It made me think back to the time when I had to re-learn how to walk; it was the most important thing in my life. This led me to ask our editor, Barb Butler, if I could write an article about walking. In spite of the many proposals she receives, Barb agreed to include my story in the newsletter. I'm in!

Nine months after sustaining an acquired brain injury, I was determined to start walking again in order to become self sufficient. In spite of being paralyzed on the left side, I was determined to get out of the wheelchair and get going.

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Immediately after my release from the hospital's rehabilitation centre, the insurance company's case manager enrolled me in a provincially funded "out-patient head injury clinic". Their idea of 'physiotherapy' involved taking patients to *(continued on page 2)*



Madeleine at the 2007 national brain injury conference in Montreal

Word from the President

It is my privilege to address you as the newly-elected President of the Brain Injury Association of Canada (BIAC). As a person whose life has been changed forever by the effects of having several family members with acquired brain injury I know that there is a tremendous amount of work for us to do to educate people about abi, to reduce injuries through prevention and to improve the lives of all Canadians affected by this silent epidemic. I also know that, by working together, we can make a significant difference.

We are already well on our way to having a film released on helmet safety and proper use. We continue to work with CSA towards standards for all recreational helmets sold in Canada. We are grateful to have the support of Dr. Hedy Fry, M.P. from Vancouver, in this endeavour.

I have met people from coast to coast through our Hawaiian Oyster Odysseys, the Pacific Coast Brain Injury Conference and our Annual Conference who are affected by acquired brain injury or who are committed to supporting those who are. These people continue to affirm my commitment to doing my best in working towards ensuring that brain injury receives the attention it deserves.

In closing, I must thank our Past President, Mireille Provost, for the tremendous amount of work she had done over the past several years. Also I would like to express my gratitude to the Board of Directors who have committed to moving the visions of BIAC forward. Together we can make a difference.

Shirley Johnson
President

You gotta walk, before they make you run... *(continued from page 1)*

the basement of the building in groups of 10 and making them walk laps in the corridors. Although I wanted to improve my walking, I knew that this was not the answer to any of my physical woes.

The most positive change towards my recovery happened with the hiring of a physiotherapist assistant. This came about when I met my physiotherapist who said: "You went to the gym alone?" and "You went swimming alone?" Shortly after that, I was provided with a physiotherapist assistant. My physiotherapist assistant was exactly like a personal trainer who also understood the effects of living with acquired brain injuries.

In the warm weather we would walk outside. Walking is considered a viable cardiovascular work-out. It is the easiest, most enjoyable and beneficial cardiovascular exercise available. All it takes are good shoes, comfortable clothing and a desire to walk.

In terms of fitness training there are several benefits to walking. If you walk fast enough, you'll achieve cardiovascular benefits. Walkers sustain fewer injuries compared to runners, cyclists etc. Stretching one's calves and loosening the ankles is recommended before going on a walk.

Walking is often recommended as a good way to lose weight. According to an article I read, you need to burn 3,500 calories to lose a pound. Also, if you walk 30 minutes a day all year, you can be 10 pounds slimmer with no other changes in your life.

Another piece of trivia I came across is that 'walking' stimulates the right side of your brain. It is suggested that after a day of work, which involves mostly the left side of the brain, going for a half hour walk is refreshing. Normally, I walk first thing in the morning so I can be as refreshed as possible all day long.

Walking helps me to improve. If you consider that I progressed from a wheelchair to being able to run three 10 km races and a couple of triathlons, I think I'm quite satisfied with my accomplishments for now.

By the way, it took me seven years to be in a position where I could move from walking to running again. At first, it was slow and agonizing and often I felt no progress was being achieved. When my body was finally ready; I practiced running three times a week for three months.

But that is another story.....

Brain injury sufferers find hope with group

— by David Hutton, The Star Phoenix

Monday, August 27, 2007 — If they were a political party, they'd call themselves the Brain Dead Party. They'd travel the province, they say, making promises that couldn't be kept because they wouldn't be able to remember they made them.

"Between all of us, we amount to at least one brain," jokes Wes Mierau, much to the delight of the 10 brain injury victims gathered around the table at a coffee shop just beyond Saskatoon's downtown.

There's Warren Dittmer, a 64-year-old veteran of the group, a football fan dressed in Saskatchewan Roughrider green. His head is shaved bald, revealing the scars from the brain surgery he underwent. He fell off a ladder and cracked his skull.

Then there's David Kalyniuk, a 64-year-old man who was injured falling from a semi truck's sleeper.

Kalyniuk is the brains of the operation, or at the very least his black leather notebook is. His brain foggy after the accident, and his short-term memory unable to process like it once did, he turned to writing everything down.

"It's my life line, my computer," he says.

He has contact information for every person who's ever spent a morning with the group – around 30 in all, he says, counting the names one by one. *(continued on page 5)*



Brain Injury Association of Canada sees broadest ever representation at conference in Montreal

Annual conference attracts delegates from every province and one territory

— by Anna Mather

From coast to coast to coast, the contributions of the all provincial delegations, as well as the Nunavut representation was much in evidence at the fourth annual Brain Injury Association of Canada (BIAC) Conference this month near Montreal. On the weekend of July 13th to July 15th, the picturesque Pierrefonds, Quebec played host to delegates from across Canada. The theme of the conference was Skills for Surviving Everyday Life and participation included representatives from every province and one territory.

BIAC was formed in 2003 after a working group met in Pierrefonds, Quebec during a National Brain Injury Conference. The 19 member Board of Directors is composed of provincial and territorial representatives and nationally elected members.



The BIAC Annual General Meeting (AGM) saw the election of long-time Victoria activist Shirley Johnson as the new president of BIAC. As past vice-president and as a woman with several multi-generational family members with acquired brain injury (ABI), Shirley brings a 20 year journey of experience from which to draw wisdom. Looking to the future, Shirley anticipates working “in greater collaboration with all provinces and territories to ensure all Canadians affected by ABI have the resources they need to live their own lives and to educate others”.

In addition to being elected as president for the next three years, Shirley joins newly elected vice-presidents of BIAC including Brain Injury Association of Alberta president and Conference chair Meloni Lyon (RN) as well as Keri McGrath, director of the Newfoundland and Labrador Brain Injury Association. Barb Butler of Regina, President of the Saskatchewan Brain Injury Association was elected as secretary while Howard Stevenson from Mississauga, Ontario was elected Treasurer.

Mireille Provost of Gatineau, Quebec and a former president of the Gatineau Brain Injury Association stepped down as BIAC president to many accolades after three very busy and successful years.

Keynote speaker, The Honourable Hedy Fry (MP Vancouver Centre) emphasized the importance of having champions of a cause inside the system as well as on the outside. She also highlighted the significance of strategic alliances needed to get a cause placed on the public and political agenda. With reference to her own efforts in building strategic alliances within government, Dr. Fry noted “a good idea crosses party boundaries.” She is currently seeking support from the health critics for all parties in an attempt to pass her private member’s bill, Bill C-412 which addresses the issue of helmet standards.



Mireille Provost and Richard Kinar

Following Dr. Fry’s address, Richard Kinar was presented with the National Volunteer of the Year Award in recognition of his outstanding contribution to the brain injury community. Recently, Richard was featured in a full page spread in the Vancouver Sun for his work on helmet safety issues.

Also Recognized with a National Volunteer Leadership Award was delegate and recreational therapist Derrick Moran of Toronto and formerly of Edmonton for his work on building sponsorship relations across Canada.

From the other side of the country, the Maritime delegation also made their presence felt. First time conference participant and mother of survivor Randy White, Marine White of St. John’s, Newfoundland joins Grant Harrison from Fredericton, New Brunswick and Eric Creamer from PEI as well as Jane Warren from Nova Scotia as provincial representatives on the BIAC Board of Directors. See complete Board list elsewhere in the publication. *(continued on page 4)*



BIAC representation at conference in Montreal *(continued from page 3)*

Nunavut delegate, Rannva Erlingsdottir Simonsen, was the first national BIAC conference participant from a territory. Rannva is looking to establish a network of support in Nunavut for people affected by brain injury. Working with many women who have acquired brain injury through domestic violence, Rannva says she is "more than happy to try to get some support networks up and running. There isn't really anything of that nature that exists now, but it is desperately needed". Rannva also cited the wisdom, hope, compassion and humanness of conference delegates as most memorable and adds that these qualities are, "something that we need more of as a society".

Ontario was also well represented with eight members of the Brain Injury Society of Toronto (BIST) and two members of the London Brain Injury Association.



Conference speakers also included Dr. Donna Ouchterlony, Director of the St. Michael's Hospital Head Injury Clinic in Toronto. One of the most striking elements of Dr. Ouchterlony's presentation was a series of slides depicting ABI-related statistics showing over 80,000 head related injuries in Ontario alone.



Pictured left to right Craig Dunn (Nfld.), Ian Young (AB), Sarah Briggs (ON) and the youngster of the group Steve Harrison (NB).

Cited by many as the highlight of the weekend was the survivors forum. This forum was held just prior to the AGM and was facilitated by George Kapetanakis, executive director of Networks Activity Centre Society of Alberta, Edmonton. The panel included presentations by ABI survivors from across the country.

Sarah Briggs of Mississauga, Ontario

A competitive skier, Sarah experienced significant physical trauma in a downhill ski race in Quebec in 1994. In the fall of 2001, while attending Queen's University for Teacher's College, the first mention of brain injury as a possible consequence of her crash was brought to Sarah's attention. Since then Sarah has attended courses through the Ontario Brain Injury Association, as well as participated in conferences and meetings to learn as much as possible about the subject. Currently Sarah is participating in her first rehabilitation program at

George Brown College in September 2007 for a program called Autism & Behavioral Science.

Craig Dunn of Gander, Newfoundland

At the time of his injury, Craig was diagnosed a three on the Glasgow coma scale. Since Craig's diagnosis in 1992, he has gone on to excel competitively in badminton and golf winning tournaments and championship titles in both sports. He now works as a coach at the newly formed Gander Community Tennis Club.

Steve Harrison of Fredericton, New Brunswick

"I shake so much I could be a high school cheerleader," said Steve, who was injured at the age of 19 and was told he would never walk or talk again. Now 23, Steve does both. His talent for public speaking is so impressive that Steve was recently invited by the Premier of New Brunswick to speak at the provincial legislature. Steve currently lives at home with his father, takes courses at the local community college with the help of a care worker and he is working towards the goal of living independently.

Ian Young of Edmonton, Alberta

Ian spoke of the important role of humour in his rehabilitation process as well as the strength he gains from the support of fellow survivors. He currently lives independently, does Tai Chi and works as a medical correspondent volunteer for CJSR FM 88.5 at University of Alberta. He has been offered his own segment on the news hour program which he may appropriately title "The Open Mind with Ian Young".

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Brain injury sufferers find hope with group

(continued from page 2)

"This group has given me hope," says Kalyniuk. "I wouldn't miss these meetings for the world . . . unless I forgot."

The group meets at the coffee shop, or in a hospital cafeteria, every second Tuesday. They have been for more than seven years now. They're all brain injury survivors. People who have suffered debilitating strokes, brain aneurysms, been in severe car accidents fallen off trucks, ladders and buildings. They are shades of their former selves, still coping with a range of symptoms. Their files are closed by the health-care system, which now offers primarily pharmaceutical help, so they turn to each other for support.

Every year in Saskatchewan, about 2,200 people sustain an acquired brain injury. Many of those go untreated and most of the residential care is directed toward those with greater needs, leaving few resources for those who have recovered substantially, like the members of the support group.

The group was formed in 2000 by ABI, the Acquired Brain Injury outreach program, based out of City Hospital. When many of their patients finished treatment, program staff weren't sure what else they could do to help. There were few support groups in country, let alone the province.

"There's a limited amount of support out there with people with brain injuries," said Rob Jameson, a co-ordinator with ABI who recommends patients to the group. "People heal from the outside so their friends assume they're OK. They'll ask them questions like, 'Why aren't you back at work?' It's an invisible disability. It's frustrating to explain, but in a group like this they don't have to worry about explaining."

The biggest struggle for many of the group members has been coming to terms with their new selves after the accident. Their bodies want to return to their old ways, but their minds won't follow.

In his prime, Mierau, one of the four men who started in the group, could knock off complex crossword puzzles, build houses and manage hundreds of numbers in his head at the same time. He had a significant vocabulary, a photographic memory and possessed a rare mathematical acumen. His construction company's finances existed on paper but, Mierau says, they were also stored in his head, alongside timelines and budgets for each of the six or seven projects he contracted at any given time.

By late-June 1994, all that was gone. Mierau was in a severe car accident. Stubborn with the hospital staff and convinced he was OK, he was discharged from the hospital the afternoon of the accident. But he began feeling symptoms the next morning and, at the urging of his wife, visited the doctor. The night he returned to the hospital he suffered a stroke causing injuries to the brain stem.

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In A Nutshell

— by Barb Butler, Editor

You have before you the latest edition of The "Brain Train". Of particular interest to you may be the article about the conference that was held in July at Pierrefonds QC. It is not too early to start planning to attend in 2008. It gets better and better with each passing year. Also as a proud Saskatchewanite I encourage you to read the article which was first printed in the Saskatoon Star Phoenix about a group of male survivors. It is a great read. I would invite you to share any comments with me at barbbutler@biac-aclc.ca. Enjoy the fall weather in your part of the country. We do indeed live in a beautiful country.

BIAC representation at conference in Montreal *(continued from page 4)*

Delegates and corporate sponsors were treated to a Hawaiian Oyster Odyssey (HOO). The Hawaiian themed welcome party, which was also held in seven other cities so far this year, included an exciting lineup of food, drink and entertainment before corporate recognition awards were presented to National Diamond sponsors, TD Bank Financial Group, Diageo and The Insurance Bureau of Canada. BIAC also announced the winner of the 2007 HOO National Grand Prize, a trip for two on Air Canada to Hawaii. This year's winner, Anna Greenblatt, is a registered occupational therapist as well as a partner and director in Inter-Action Rehabilitation Inc.

Both the scope and contribution of all delegates and sponsors to the fourth Annual National BIAC Conference was inspiring, however much collaborative work remains to be done in order to further the educational, social and political goals of the Canadian brain injured community.



Erin Creamer (PEI) and Howard Stevenson (Ontario) - renewing old friendships, BIAC is like a huge family.

For more information on BIAC, please visit: www.biac-aclc.ca

The writer of this article, Anna Mather, recently completed her MSc in Politics and Communication at the London School of Economics and Political Science and has a longstanding interest in ABI and related issues.

Brain injury sufferers find hope with group *(continued from page 5)*

"They didn't think I was going to live," he says.

Mierau's mind, once a wide and clear thoroughfare, had careened into a brain-addled fog. His symptoms aped the last throes of Alzheimer's disease: increased irritability, chronic confusion and moods that lurched from a bland, fatuous cheerfulness to depression and then back again. Outgoing and gregarious by nature, he was now wary of strangers. He spent most of that first summer lying on the couch.

Time, therapy, rehabilitation and the support of his wife brought about incremental improvements, he said. Finally, when the fog began to lift, he started with the group.

"The old Wes was gone and was never coming back and I had to accept that," he says. "These guys, who were going through the same thing, helped me accept that."

Now, Mierau is more talkative than ever, the bullheaded leader of the group, focused on helping people who are going through what he once did. Shades of his old self peek through, he says, but his life, he feels, has improved; he's learned to relax. He's had no choice, he says.

"I've learned that I can only work on one project at a time and focus on one thing at a time now," he says. "If I'm laying down laminate floor, the house could be burning around me and I wouldn't know."

The group grew slowly from the initial four members. ABI sent over facilitators and speakers for the first while, but couldn't afford the resources after the second year. But the people kept coming, multiplying to more than 20 by the fourth year. The older members of the group took on the role of elders, encouraging the new members to share their experiences, making fun of their own nuanced problems so newcomers felt comfortable. Some, especially younger men who were convinced their injury wasn't that bad, wouldn't return to the group. But most have stayed.

Two years ago, at the encouragement of his wife, Duncan Elliott, a 40-year-old father of two, showed up for coffee with the group. His biggest struggle, like many in the group, was with his family. He suffered a stroke after medical complications from appendix surgery. His two young children couldn't understand why their dad would drive across the city and forget they were in the back seat when he was supposed to drop them at school.

"My wife didn't marry this guy," he says. "She married someone else . . . it's been hard for her and for us. She sees the problems and gets frustrated more than I do. I'm just along for the ride, she has to watch it from the sidelines."

The men's wives, at the encouragement of ABI, have recently formed their own coffee group, for their own respite and leisure, and to help cope.

"There's a lot more guys out there like us," says Mierau. "And they're not getting help, not talking about it, not laughing about it. It does us the world of good. . . . We've all become lifelong friends."

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