

BIST BEACON

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BIST First Annual 5 km

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Greetings from the Board

The BIST Board of Directors wishes all BIST members and potential members a healthy and happy Spring. Beautiful weather should be just around the corner.

2011 has gotten off to an exciting start for BIST. The interest in and feedback from our Family/Caregiver Support Workshops has been terrific. We want to thank Social Work Consulting Group for their significant efforts with this initiative.

Also, our signature annual awareness event at Nathan Phillips Square is approaching very quickly. We look forward to seeing everyone on Thursday, June 16th at Nathan Phillips Square from 12:00 pm to 2:00 pm. This year's event promises to be biggest and most exciting yet. From the creative entertainment, to the VIP survivor tent, to the artists' displays and more, this event is so important for both our own members and the general public who lack awareness of all aspects of Acquired Brain Injury. Please email us at info@bist.ca if you wish to volunteer at the event.

We are excited to announce the first ever BIST 5km Run/Walk 2011, which will take place on Saturday, September 24, 2011. Details will be posted on our website, so stay tuned for more information about fundraising opportunities for this event.

The Board of Directors encourages all BIST members to attend our monthly community meetings. Our next community meeting has a special emphasis on volunteer appreciation. If it were not for our volunteers, BIST would not be where it is today. Our next community meeting is Monday, April 25, 2011, at 6pm at Northern District Library (40 Orchard View Blvd – Room 200 (2nd Floor). The turnout at our community meetings has been increasing every month, and we look forward to this trend continuing throughout the remainder of 2011 and into the future.

Finally, we encourage all BIST members and potential BIST members to visit our website, www.bist.ca. The website is user friendly and the content is continually being updated. The "Upcoming BIST Events" section keeps members updated on important dates and BIST activities. The BIST Board is looking forward to an exciting Spring and Summer, and we thank our dedicated members for their support, energy and enthusiasm.

Jonathan M. Burton,

Chair of BIST Board

BELIEVE IN YOURSELF!!!

By Margaret E. Green

I remember reading a children's book to my two children, who are now adults, and parents themselves. Many of you must know the book, The Little Engine That Could, by Watty Piper. Although the story is actually a children's story, the message is for us all.

You may remember the small train stopped at the foot of a mountain, and could not move at all, and was carrying a load of toys. Up ahead were animals, and all were counting on the engine to pull their train. The engine hitched herself to the train - - and as it began to move, she repeated: "I think I can. I think I can. I think I can.", and reached the top of the mountain.

YES!! Having a belief in what you CAN do is all-important. Each one of us is good at something, and if we focus on what we CAN do, then other positive things will come into our lives. Too many people say negative things, as "You cannot . . ." do this; or "You cannot . . ." do that. But the belief that we ourselves have that really makes a difference.

Negative thinking is just that. It is negative, and pulls us down. Reach for the top of that mountain - - whatever you goal might be.

If you try your hardest, and do your best - - then - - no matter what anyone says TO you, YOU KNOW YOU DID YOUR BEST!!

March Community Meeting

By Ian Bowles

The community meeting on March 28th was an excellent event, and not just for the opportunity to grab some snacks and hang out with friends. There was a "volunteer orientation" at 5:30, where a number of individuals new to the group were introduced to BIST and what we do. That merged in to the general meeting, which was very well attended. Michele Meehan returned and gave a talk about how to develop a "unified" approach to our selves, recognizing that we each are composed of body, emotions, mind and spirit. There was a lot of interaction as members of the audience asked questions and Michele helped us to work through the concepts. I think everyone got something out of the discussion, as we all recognized times when we let our emotions run away with us.









Upcoming Community Meetings

Date: Monday May 9th, 6:00 pm - 8:00 pm

Focus: Volunteer Appreciation

Location: Northern District Library- 40 Orchard View Blvd, Room 200 (2nd Floor)

Date: Monday May 30th, 6:00 pm - 8:00 pm Focus: Tribulation to Triumph "A Survivors Story"

Guest Speaker: Greg Noack

Location: Northern District Library- 40 Orchard View Blvd, Room 200 (2nd Floor)

Date: Monday June 27th, 6:00 pm - 8:00 pm

Focus: Public Speaking

Guest Speaker: Toastmasters

Location: Northern District Library- 40 Orchard View Blvd, Room 200 (2nd Floor)

Date: Monday July 25th, 6:00 pm - 8:00 pm

Focus: Summer Picnic

Location: High Park (more details to come closer to the date)

Call for Volunteers

BIST has a lot of exciting things planned and we need your help. We are looking for dedicated volunteers to help BIST develop and launch new programs, plan and host exciting new events, and enhance our awareness campaigns.

Current Opportunities:

- 1. Join the Communications Committee to assist with the compilation of the BIST Beacon, potential blog updates, web site management and overall communication strategies. Ideally this committee is looking for someone with a public relations, communications and/or marketing background.
- 2. Plan and support the delivery of the monthly community meetings. You will work with the Facilitator of the community meetings to plan upcoming themes, arrange appropriate speakers, set up the room and arrange for the refreshments. You will be required to work with other volunteers to ensure

- this all gets done in a timely fashion. This opportunity requires that you are able to attend the monthly meetings.
- 3. Join the Program and Services Committee to assist with developing, planning, implementing, overseeing the programs & services that BIST offers to its members.
- 4. Join the Fund Raising Committee in researching new fund raising opportunities and identifying best practices to guide its on-going work. You will need to have experience with fund development and be able to work with the team to build on the successful initiatives already underway and seek new opportunities to support BIST's continued growth.
- 5. Develop and Facilitate Personal Development Workshops as part of a session of 9 workshops on topics such as returning to work, managing relationships, etc. You will be responsible to develop and deliver a 2-2.5 hour workshop for adults with an acquired brain injury. You will need to have experience facilitating workshops, working with individuals with special needs, and have knowledge of programs and services available in the community for participants to access to gain further assistance or information.
- 6. Join the membership committee which includes attending and helping organize the membership table at BIST community meetings, organize the membership database and work with the committee to develop and implement a yearly membership drive.
- 7. Join the Program and Services Committee to assist with developing, planning, implementing, overseeing the programs & services that BIST offers to its members.
- 8. Support BIST at the Brain Injury Awareness Month event on June 16th. Volunteers are needed in the following capacities: support the artists; act as BIST and ABI ambassadors by greeting visitors, passing out materials and helping spread awareness about ABI and BIST; help with event set-up (chairs and tables); and man the membership table.

We expect you will find this a rewarding and meaningful experience and hope that you will gain as much from volunteering with BIST as we will from your involvement and support.

How to Volunteer with BIST

If you want more information about volunteering with BIST, please plan to attend one of the following community meetings where a volunteer coordinator will be happy to answer your questions.

May 30, 2011 August 22, 2011

Or you may contact us at info@bist.ca or call 416-830-1485 for more information.

Upcoming Events

Peer Support Mentor Program Mentor Training

Date: Saturday May 7th, 9:00am - 4:00pm. (Spots still available for new mentors).

Bowling Event

Date: May 10th, 2011 - 1:00 - 3:00pm

Location: Thorncliffe Bowlerama, East York Town Centre, 45 Overlea Blvd.

Meet and Learn Series BIST & Sunnybrook Health Sciences Centre

Date: Five once a week evening (6:30 – 8:00) meetings.

*Start Date: Wed. June 15th, 2011. - *End Date: Wed. July 13th, 2011.

Have you sustained a 'mild' brain injury? Are you interested in learning more about mild brain injury? Would you like to meet others with similar experiences? * Specific topic each evening, including:

- General information about 'Mild' TBI (Traumatic Brain Injury),
- Executive Functions, Impact on families, Getting back to the social scene, Return to work concerns,
- "How I see myself now"

Bowling Event

Date: July 12th, 2011 - 1:00 - 3:00pm

Location: Thorncliffe Bowlerama, East York Town Centre, 45 Overlea Blvd.

For more information about the programs and events listed above please visit the BIST website at www.bist.ca and/or contact Kat Powell at connections@bist.ca or 647-990-1485.

BIAM Event

June is Brain Injury Awareness Month! BIST will be holding its 11th annual BIAM event on Thursday June 16th from 12:00pm – 2:00 pm in Nathan Philips Square. Save the date and bring your friends, family and co-workers.

Volunteers are needed for the event so please forward any inquiries to info@bist.ca or 416-830-1485.

BIST 5 km Run/Walk

Lace up your running shoes and come support BIST in the First Annual 5 km Run/Walk on Saturday September 24th, 2011 at. See the flyer at the end of this newsletter and visit www.bist.ca/run to register.

Darren's Gift

By Danielle Berehowsky, BIST Board Member

It had been a perfect day at the cottage. I would never have anticipated as I lay down to sleep that evening, I would be awoken to news that would forever change the life of my brother Darren as well as the lives of our entire family.



Darren had been enjoying a late night at a friend's cottage. From the account of his friends that were there, Darren had tripped backwards over a planter box and could not regain his balance, falling off the deck that was 17 feet high.

When we arrived at the local hospital in the early morning, we were ushered into a private room to wait for the Doctor to tell us the extent of Darren's injury. I had lived my entire life, not knowing a room like that existed. We understood already that Darren's accident was very serious but my mother, brother Drake and I waited in silence, each of us living in our mind's hell, none of us anticipating what was to come that day or in the years that followed.

When we finally were able to speak to the doctor, we were told that Darren had sustained an epidural hematoma. They told us that the bleed in the brain was small but he needed to get surgery quickly to minimize the damage that was being done to his brain.

I have never been so attuned to the clock and time passing. While my brother and mother left for Toronto to meet the Air Ambulance at St. Mike's hospital, I sat with the very still body of my brother and waited. For the 45 minutes that it took the ambulance to arrive (15 minutes later than what I was told, which nearly sent me over the edge), I talked to Darren, hoping that on some subconscious level, he would hear and know how much he meant to our family. I told him he needed to dance with Dylan (my 4 year old niece) at her wedding. He was needed to be the voice of reason to our nephews Duke and Daniel. Drake needed his best friend and I needed the shelves in my basement installed. I promised him all kinds of things and begged him to fight.

After Darren left in the Air Ambulance, a nurse said that she would pray for a miracle. Hearing her kind words made me almost hysterical. Up until that point, I didn't think the possibility existed for Darren to lose his life. I knew the injury was very serious but I thought it was fixable in the same way you would repair a broken leg.

When I arrived at St. Mike's, Drake met me outside the hospital. The Doctors said that Darren might not make it through the surgery. I remember my whole body going numb with the news. I also remember minutes later, an overwhelming resolve and emotion that refused to believe what I was being told.

From that moment on, hope and faith became our battle cry and this has carried us and sustained us since that Sunday morning when the surgeon told us that the operation was a success.

And it has been a battle. From early on, it was frustrating to hear that the future for Darren was so uncertain. Brain injury is so personal and recovery is so varied. We had to learn patience. Though it is a cliché, we had to learn to take things one day at a time. It was such a victory when Darren was first able to give the ICU nurses a thumbs up after days of trying. I remember 'willing' him to do it day after day instead of trusting in the process of time. Waiting to hear Darren put a sentence together, watching him learn to drive again, making sure he was ok to live on his own, were unpredictable accomplishments.

But the most challenging part was coming to terms with the fact that Darren was no longer the same person. As he was able to handle the more functional aspects of life, we saw the emergence of someone who had a different outlook on life from the most simple things to more complex ones. His personality had also changed.

He was no longer the fun loving, go with the flow guy he was before. He took the world way more seriously than he ever did. We had to deal with huge anger and inflexibility issues. We also had to accept that though he hid it well (which was part of the problem), his executive level functioning was impaired and we had to be more understanding when his judgment and reasoning seemed flawed.

Probably the saddest part of Darren's injury has been the broken relationship with Drake. They don't seem to have found the way back to the bond they once shared. It is hard to watch and accept.

Darren's accident, though, has also been a backhanded blessing in some ways. In the immediate moments following his accident, there was crystal clarity of what is important in life. The family unit was never stronger as we came together to help in Darren's recovery. It was amazingly powerful to see the unconditional love my mother had for her child. Time and time again, the beauty of watching her interact with a son who was so wounded was incredibly powerful and I will cherish this knowledge in my own heart.

As well, I think the benefit of time has provided me with a new insight into my own life. For the longest time, I wanted things to be the same, to go back to normal. When I was finally able to take a step back and really look inward, I saw that there was no going back. I am different now. I am still not sure whether it was a 3 year journey of change for me as well, or whether the change happened in the instant I knew that I had no control over Darren's recovery. My faith has intensified. My gratitude for all that I have, has never been greater and I have a deep belief that no matter what happens in my life, I have the fortitude to handle it and come out better for the experience. As I approach middle age, I know that I want to make a difference. I want to leave the world a better place for the survivors and their families of brain injury. I have learned to love deeper and to accept the kindness of people.

I also have never been so proud of Darren. In the early days, he fought like a warrior to get his life back. And he did so, not realizing the extent of his injury. He trusted us enough to endure the 6 hours of therapy a day; he battled the fatigue; he overcame the stares people gave while he struggled to speak. Three years later, he has embraced his new life. He accepts his daily challenges with grace and has a positive outlook to what the future holds for him. It has been a remarkable journey and I feel privileged to have been a witness to the transformation. I thank all the people who supported our family. They came from unexpected places and gave us hope and prayers. I thank the therapists who are so dedicated and kind. They have a very hard job and they battled for Darren right along side him.

Mostly, however, I thank God. I believe He held us in the palm of His hand and gave us daily blessings to help us cope. Faith can create miracles and Darren's recovery is a miracle.

As you face your changed life because of brain injury, you will have adversity and challenge in ways you never dreamed. Do not let anyone though, place limitations on what is possible. Fight. Challenge the status quo. Be the miracle story. And most importantly, don't forget to look for joy. It's there.

Finally, remember this saying which came my way shortly after Darren's fall.

Just when the caterpillar thought his life was over, he turned into a butterfly

Peer Support Mentoring Program

The Peer Support Mentoring Program for People Living with ABI (the first shared activity of OBIAs' Community Support Network), connects an individual who is a "veteran" of a life experience involving Acquired Brain Injury (the "Mentor") with a "Partner" who is coping with a similar ABI-related situation and is in need of support from a knowledgeable friend. Both Mentors and Partners can be survivors, unpaid caregivers or family members. All Mentors will be trained before being matched with Partners through training materials that have been developed and will be provided for that purpose. The role of the Mentor is to provide support, share information and resources with Partners who are coping with a similar ABI-related situation. These situations may occur at various points post injury. Mentor/Partner matches are based on similar experiences and/or demographics and personal interests. Most of the mentoring will be conducted over the telephone (some by e-mail), making it possible for anyone in Ontario to participate. The Ontario Neurotrauma Foundation has agreed to develop and oversee the program evaluation for this program.

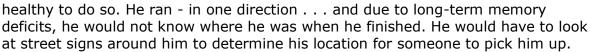
For further information, or if you are interested in becoming a mentor or partner, please contact Kat Powell the Peer Support Coordinator for GTA. connections@bist.ca or 647-990-1485.

Run to Remember

A marathon a day for Brain Injury

David McGuire sustained a traumatic brain injury in 2005. He was told he may never walk again.

However, not long after his injury, he started running . . . first to the barber, then to the doctor who reinforced it was



David continued running, and completed his first marathon in 2006, a year after his injury! This was followed by a triathlon in 2007, Ironman in 2009 and the Disney World Challenge in 2010 (1/2 marathon + full marathon.)

David is very humble and says "I am just a guy with brain injury - but I can run, and I have a story to tell."

A Run to Remember is a cross-Canada run commencing April 2011, with David McGuire running a marathon a day from St. John's Newfoundland to Victoria, BC - a timeframe of 8 months. The event's objective is to raise awareness of the serious issue of brain injury and brain





injury prevention, and inspire people across Canada to think about brain injury prevention, with specific focus on youth.

On April 1st 2011 David starts his journey. Follow him at http://www.runtoremember.com/or check out his blog at r2rdavid.blogspot.com

More details to come as to how BIST members and volunteers can support David when he comes through Toronto at the end of June.

Spring is Here!

The days are getting longer, the weather is warmer and everyone is excited to get back on those bicycles. Safety should always be your first priority no matter what your age and the importance of wearing a helmet can't be emphasized enough.

Did you know...?

- 45.5% of all injuries from bicycling are to the head.
- Wearing a properly fitted helmet has been shown to reduce brain injury by 88% and head injury by 85%.
- Cycling-related injuries are the third leading cause of hospitalizations and the second leading cause of emergency department visits among children injured in falls.



 Boys and young men are 4 times more likely to be injured or killed in a cycling-related crash than girls or young women.

[Sources: OIPRC (2007). *Head Injuries*. Ontario Injury Compass. Vol. 4, Issue 11. OIPRC (2007). *Injuries among children*. Ontario Injury Compass. Vol. 4, Issue 12. Tator, C.H. (2009). *Catastrophic Injuries in Ontario: Causes and Prevention*. U of T Press.]

All persons under the age of 18 are required by law to wear an approved bicycle helmet when travelling on any public road. Parents should set a good example for kids by always wearing their helmet, no matter the distance, near or far.

When purchasing a helmet, look for one that fits comfortably and meets safety standards. Check the inside of the helmet for stickers from one or more of the following organizations:

- Canadian Standards Association (CSA)
- American Society for Testing and Materials (ASTM)
- National Operating Committee on Standards for Athletic Equipment (NOCSAE)
- SNELL Memorial Foundation (SNELL)
- European Committee for Standardization (CEN)

Follow the instructions that come with the helmet for properly fitting the helmet to your head. You can also check out www.thinkfirst.ca for further instructions.

Take good care of your helmet and don't throw it around. Most helmets are built for a single impact, so make sure you don't damage it by dropping it on the ground. If you do fall off your bike or your helmet looks worn and damaged, get a new one before you get back on the road.

Now that you have a certified, proper fitting helmet, just a few more things to take into consideration before you get on your way:

- Make sure your seat, handlebars and pedals fit properly
- Check and oil your chain regularly.
- Check your brakes to be sure they work well and aren't sticking.
- Check your tires to make sure they have enough air and the right amount of tire pressure.
- Avoid loose fitting pants or skirts/dresses that might get stuck in the chain
- Wear bright coloured clothing so you can be seen easily by drivers and other riders.
- Don't wear headphones. You need to be alert to the sounds of cars and pedestrians.

Always remember to follow the rules of the road and have a safe and happy cycling season!

Call for Artists

Here's your chance to show what survivors can do!

Display your art at the BIAM Awareness Event

We're looking for artists to display their work at Nathan Phillip Square on June 16th 2011 at lunchtime during the BIST Brain Injury Awareness Event.

Who is eligible? All artists who are able to bring and display their work.

Do I have to be a survivor? No, all artists are welcome.

What kind of art? Any visual art that can be displayed in an open-air format (painting, sculpture, photography, etc.). You will be responsible for the transport and display your work.

How do I enter? Email BIST at info@bist.ca or phone at 416-830-1485.

What is the cost? FREE! But you must follow some rules. These will be explained when your reservation is confirmed.

Call for Personal Stories

BIST Brain Injury Awareness Event June 16th, 2011

Here's your chance to tell your story to an audience that may never have heard of acquired brain injury. We are hoping to collect enough personal stories to create a booklet for distribution at the Awareness Event.

Who is eligible? Any survivor or family member who is a member of BIST (membership is \$5/year for survivors) can submit their story.

What kind of story? Your speech must be pre-written, about 10-15 minutes in length, and convey a positive message about brain injury. Please note that the

Speakers Series will take place in a small tent, not on the main stage.

How do I enter? Submit your story in writing to info@bist.ca
Be sure to include your name and contact information.

What happens next? The BIST Awareness Committee members will choose the stories for inclusion in the booklet.

Obituary - Dr. Jane Gillett

Taken from the Globe & Mail - March 29th, 2011

Jane Gillett was on the forefront of brain injury treatment

By Noreen Shanahan Special to Globe and Mail Update

She founded the Pediatric Acquired Brain Injury Community Outreach Program, an innovative care program that became an international prototype and marked her as a mayerick.

"She was often questioned by other neurologists because she didn't really practice traditional neurology," Ladak said. "Instead, she looked at the big picture and where these patients would be in six months, one year, five years down the road." Gillett and her team worked closely with teachers, parents, other caregivers and the patients themselves.

For example, she wouldn't change medication for a condition such as spasticity until she talked to a patient's occupational therapist. And she worked directly with speech pathologists around issues related to eating or swallowing. When she attended international neurology conferences, she'd insist on team members accompanying her.

Gillett followed three tenets when designing a pediatric care program. First, it has to be based in the patient's community. Second, it has to be child and family centred. Third, it has to optimize the use of local resources. For instance, children from a native or Mennonite community would have treatment plans tailored to their circumstances.

Gillett was a media spokesperson on concussions long before they began to grab headlines. Interviewed on CBC about the death of actor Natasha Richardson after a fall on the Quebec ski hill two years ago, she emphasized the importance of wearing helmets and insisted that a concussion is a brain injury that needs immediate treatment

"My practice is in sports concussions, and Jane was the one who inspired me to do that," said Ladak. "She was chair of the Knowledge Mobilization Committee of the Trauma Foundation and one of her primary goals was to teach educators, to teach parents, to teach coaches about proper safety gear for children and young adults." She also stressed that the human brain doesn't reach maturity until the age of 25. An important bit of information, perhaps, for a parent communicating with an overzealous 18-year-old rugby player.

Ladak and Gillett were advisory board members for the Sarah Jane Brain Foundation in New York, a non-profit organization dedicated to care systems for children with acquired brain injuries.

"On the last night of the founding conference [in 2007] most of the Americans went to catch Broadway shows while Jane and I stayed behind to draw up the guidelines," he said. "We drafted the first letter President Obama received after his inauguration, on behalf of the Sarah Jane Brain Foundation."

Gillett left London in 2001 and moved to Hamilton, where she became director of the provincial Acquired Brain Injury Program at Hamilton Heath Sciences, working specifically with slow-to-recover patients – those in non-responsive or "locked in" states. It was one of her first steps outside of pediatrics.

Esther McEvoy was a health professional working alongside Gillett in the six-bed unit. "She would bring patients onto our program in hopes we could wake them up a bit. ... Maybe we could get a 'yes' or a 'no' and if we did, they could try to make some choices for themselves. It might be something as simple as asking them: 'Do you want to wear your black pants or your red pants?' "

Success in the program was measured by things such as patients moving on to a higher-level brain injury program. "They just needed a good medical workout and the time to do that," McEvoy said.

In 2009, Gillett co-founded the International Pediatric Brain Injury Society. The impact of her work stretched as far as Denmark, Sweden, Italy, Portugal, Australia, and the United States. She was working on a project in Canada's North when she became sick less than three months ago.

At one conference in New York, said Ladak, there were vociferous arguments across the table among neurosurgeons, neurologists and psychiatrists. Gillett mediated.

"She said: 'You know what? This is what it is to be Canadian. This is what we do in the world: We mediate, we keep the peace, and that's exactly what I'm doing here."

Gillette leaves her parents, Jack and Ruth Gillett, her sister Martha Pettit and her brother, Tom Gillett, as well as several nieces and nephews. She also leaves Jessica Johnson, whom she regarded as a daughter.

Toronto Brain Injury Blog

www.torontobraininjuryblog.wordpress.com

BIST has a blog! Subscribe to receive the latest news, upcoming events and other great information delivered right to your inbox.

Feel free to send submissions to info@bist.ca

Open Call for Submissions

Have any story ideas or submissions for the newsletter? Please send contributions to **newsletter@bist.ca**

Contact Us: PO Box 49999 660 Eglinton Ave. E. Toronto, ON M4G 4G1 www.bist.ca info@bist.ca 416.830.1485

First Annual 5KM Run/Walk



Saturday September 24th, 2011

Race Time: 10:00 am

Sunnybrook Park

Entry fees:

- \$35 for Individual Runners/Walkers
- \$100 for Teams (4 per/team)

Registration is limited to 250 participants so register early!

Register as a runner/walker or get your family, friends, and/or coworkers together and register as a team at www.bist.ca/run

For sponsorship and volunteer opportunities call 416-830-1485 or email info@bist.ca



Fastest Female

Fastest Male

Top Individual Fundraiser

Top Team Fundraiser



All proceeds will support BIST's program and services

Package Pickup Information

- Friday, September 23, 2011 4:00pm 8:00pm Running Room 2629 Yonge Street Toronto, ON M4P 2J6 Ph: (416) 322-7100
- Saturday, September 24, 2011 (Race Day) 7:30am—9:30am Sunnybrook Park

For more information including directions, course map, event details and fundraising forms, please visit www.bist.ca/run