THE VOICE
BRAIN INJURY SPEAKS NEWSLETTER
ISSUE NO. 3 | SEPTEMBER 2021

SHINING A LIGHT ON BRAIN INJURY

NEW AND UPCOMING EVENTS

Now Available @ OBIA.CA
- Share your story with Voices of Brain Injury

Coming Soon @ OBIA.CA
- Upcoming Brain Injury Speaks Projects
- Results from the Brain Injury Speaks Social Isolation Focus Groups

Upcoming Events @ OBIA
- 2021 Virtual Provincial ABI Conference, October 28-29.
Dear Members of **Brain Injury Speaks**,  

We are pleased to present our first theme-focused issue of *“The Voice” Brain Injury Speaks Newsletter*. These themes will highlight the issues you, our *Brain Injury Speaks Members*, indicated are most important to the brain injury community.

This issue spotlights the theme **Shining a Light on Brain Injury - Increasing Awareness**, which directly echoes the 2021 National Brain Injury Awareness Month Campaign. In June 2021, Brain Injury Associations across Canada came together to share a universal message of making an invisible injury visible to all.

For the many who have been misdiagnosed, under-diagnosed, or told, "but, you look great?" as they face the unique challenges a brain injury presents, we want you to know there is help and hope! Through the September issue of *“The Voice,”* OBIA hopes to offer support.

To empower you to increase awareness about the incredibly complex and unique challenges associated with brain injury, this month's issue will focus on providing practical tips, up-to-date news and research, and shared experiences related to **Shining a Light on Brain Injury - Increasing Awareness**.

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**Let’s Talk About Brain Injury**

While sometimes “hidden” in nature, brain injury can be misunderstood by those who have not experienced it. Although often well-meant, misguided comments from friends, family, or strangers can make an already challenging situation more difficult.

To alleviate some of this frustration here is some helpful information on speaking about brain injury to those who may not understand. We hope that this information will help resolve some of the common misunderstandings you have experienced and help to promote awareness in your everyday conversations.

(Cont’d on next page).
Let’s Talk About Brain Injury

What Should You Share?

Of course, what you feel comfortable sharing about your injury is entirely up to YOU. It can be helpful to think of past conversations and revisit some common misconceptions that you’d like to offer information about in the future.¹ Think about examples that would be important to understanding YOUR experience!

Practicing Thoughtful Responses

Let’s use challenges with information processing as an example. Someone who does not know much about brain injury may interpret pausing a conversation to gather your thoughts as rude.² Sharing information about why this is difficult for you can help prevent future misunderstandings.

In response to the above example, you might say:

“If I seem “stuck,” my brain may be struggling to understand the information. Coaching me, suggesting other options, or asking what you can do to help, may support me while I figure it out. Taking over and doing it for me will not be helpful, and it will make me feel inadequate.”³

Practicing thoughtful responses like this is a great way to promote awareness & increased understanding. The above example may not apply to you, but telling your loved ones about your injury and your challenges is a powerful strategy to help them understand what you are experiencing. For more examples of thoughtful responses, CLICK HERE.

While you may talk with your loved ones about your personal experience, it can also be helpful to explain that no two brain injuries are the same. This can promote awareness about the diversity of brain injury and an understanding that other individuals they speak with could have a different set of challenges.

Encourage your friends, family and strangers to ask questions if they are unsure of something. The main takeaway is that practicing thoughtful responses to assumptions or misunderstandings with those around you can significantly increase awareness and foster a deeper understanding of brain injury.

An integral part of Brain Injury Speaks is its Provincial Advisory Team (PAT). The “PAT” is a team made up of 7 Brain Injury Speaks Members from across the province, who offer their thoughts, opinions, and guidance on network initiatives. Collectively, their voices aim to reflect the needs of this community, and to better inform future work of Brain Injury Speaks.

To showcase their passion and dedication to this network, we are pleased to introduce to you a few of your “PAT” members!

Meet Butterfly!
Why did you decide to join the “PAT”?
“I decided to join Brain Injury Speaks’ PAT, because I like to think that I am able to speak up for myself, as well as those who cannot speak for themselves. I think that everyone’s voice is important. It is important to continue to share and learn, to help the right people hear our voices.”

Anything else that you would like Brain Injury Speaks members to know?
“I am a lifelong survivor of multiple types of brain injuries.”

Meet Russ!
Why did you decide to join the “PAT”?
“As a survivor of a TBI more than 12 years ago, I want to assist in raising awareness of ABI, and offer support to other survivors and erase the stigma surrounding ABI.”

Anything else that you would like Brain Injury Speaks members to know?
“I believe that Brain Injury Speaks has the opportunity to improve the lives of survivors and their families. Brain Injury Speaks allows us to have a powerful voice in raising awareness among the general public and government. The only way this happens is with the participation of the Brain Injury Community, so, please participate in the surveys and read the newsletter. When combined, our voices can become powerful towards advocating for ABI. It’s time we are recognized!”

Meet Biplob!
Why did you decide to join the “PAT”?
“So that I could speak for myself and for others who have lost their voice after sustaining a brain injury!”

Anything else that you would like Brain Injury Speaks members to know?
“I am a Canadian Veteran!”
“I am Alive, Strong and Unbreakable”
By: Shreena Dew

“This photo represents my story and how that one day has changed my life forever. In a moment your life could change. We don’t always get to choose what happens to us but we can choose how to react to the things that happen to us. Living with a brain injury is my new normal, even though everything is a bit more difficult now and I have days where it’s hard to accept what happened and I wish I was ‘normal’ again. I am learning that there is a light at the end of a dark tunnel and I am so thankful for all the amazing people who have come into my life since my brain injury and how much closer I am with my parents. Knowing that I am Alive, Strong and Unbreakable!”

Additional Information that the Participant would like BIS to Know:
“I wrote a book telling my story!”

Interested in Sharing Your Story?
You can submit your story and photo to the “Voices of Brain Injury - A PhotoVoice Collective” for a chance to be featured in The Voice: Brain Injury Speaks Newsletter!

CLICK HERE TO SUBMIT YOUR STORY

IN THE NEWS

Centre for Addiction & Mental Health, Becoming a Global Leader in Brain Injury Research

The Concussion Legacy Foundation Canada (CLFC) has partnered with Dr. Vasdev’s team at the Centre for Addiction and Mental Health to focus on chronic traumatic encephalopathy (CTE). This condition occurs as a result of multiple concussions. Dr. Vasdev and his colleagues are exploring the progression of traumatic brain injuries through brain imaging in patients. In addition to collaborating with the CLFC, CAMH is also partnering with the Canadian Military to investigate whether specific military training exercises negatively impact long-term brain health. Through these partnerships, CAMH is moving to the forefront of research on head injuries and the mental health effects that are often associated with them.

To Read the Full Article on CAMH & Their Research: CLICK HERE
For More Information on the CAMH Brain Health Imaging Centre: CLICK HERE
A Look at The Hidden Disability Symbol Movement in Canada

After sustaining a significant brain injury due to a motor vehicle collision, Laura Brydges’ life changed forever. Laura grew frustrated by the lack of understanding from the public about her invisible disability, so she designed a symbol and tool to raise awareness and understanding about hidden disabilities. With a large petition and the support of Brain Injury Canada and The Brain Injury Society of Toronto, Laura hopes to display the Hidden Disability symbol alongside the universal accessibility (or wheelchair) symbol.

To Join the Movement, You Can Sign Their Open Letter: CLICK HERE
To Learn More About the Hidden Disability Movement in Canada: CLICK HERE

“COVID-19 and Disability: The Impact of a Societal Lockdown on Those with Spinal Cord and Brain Injuries” - Lawson Health Research Institute

Researchers are looking at the impact of COVID-19 on the physical and mental well-being and quality of life of individuals living with spinal cord injuries and brain injuries. They are recruiting participants who are 18 years of age and older, live in the community, diagnosed with a stroke, spinal cord, or acquired brain injury (of all severities, including concussion). Participation requires completing an online survey upon enrollment into the study at three and six months. The findings of this study will be used to improve the quality of life for individuals with disabilities during this challenging time.

To participate or for more information please contact the Principal Investigator:
Eldon Loh, MD at: eldon.loh@sjhc.london.on.ca or 519-685-4292

“Employment and Accommodation Needs in Individuals with Traumatic Brain Injury (TBI): A Pilot Study” – UHN & Rehabilitation Sciences Institute University of Toronto

Researchers at the University Health Network in Toronto are looking for adults with a traumatic brain injury, who currently live in a community setting. Participants also need to have worked full-time, part-time, or casually with a TBI, or be currently working. The goal of this study is to understand:

1. Gender differences in the use of support services and quality of life.
2. Workplace accommodations.
3. The impact of COVID-19 on employment and mental health post-TBI.

Participation time is around 30-45 minutes and is done by completing a survey. Gift cards will be given as a token of appreciation for participating.

For More Information About the Study: CLICK HERE,
To participate please contact Sara Hanafay: sara.hanafy@uhn.ca or 416-597-3422 x7829.