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
- Awards of Excellence in Brain Injury Rehabilitation
- 2021 Virtual Provincial ABI Conference
  A Scholarship rate is available thanks to the generosity of Thomson Rogers. A limited number of delegates will receive a subsidized conference rate of $50 per person!
As we move forward with Brain Injury Speaks, we want to ensure that we keep the voices of individuals with brain injury and their family members at the centre of everything we do. On August 4th, 2021, we sent out a survey to get your input on themes for future issues of "The Voice: Brain Injury Speaks Newsletter".

Members of the Brain Injury Speaks Network were asked to select five topics that best reflect their experiences and are of greatest importance to them from a list of thirteen choices, or they could offer their own ideas in the other category.

We are happy to announce that we had 168 members participate in this survey over the last few weeks. The most selected topics by the Network were: Lack of Awareness about Brain Injury in the General Population, Mental Health, Social Impacts of Brain Injury, and Identity Change Following Brain Injury.

The results of the survey were taken to the Brain Injury Speaks Provincial Advisory Team during our August meeting. The team applied their experience and knowledge to narrow down the topics to eight themes that will be used for “The Voice: Brain Injury Speaks Newsletter” over the next several months.

The final topics are:
- Lack of Awareness and Stigma about Brain Injury in the General Population
- The Cost of Care and Accessing Financial Support after Brain Injury
- Identity Change after Brain Injury
- Long-term Effects of Brain Injury
- Social Impacts of Brain Injury
- Mental Health
- Interdisciplinary Care
- Caregiver Supports

Thank you so much to everyone who participated in this survey and shared their opinion about what matters to them!

We are truly looking forward to future issues of “The Voice: Brain Injury Speaks Newsletter” being focused on these important themes. ♦♦♦

DISCLAIMER:
The opinions expressed in “The Voice: Brain Injury Speaks Newsletter” are those of the respective authors and not necessarily those of the Ontario Brain Injury Association (OBIA). OBIA will not be liable for any damages or losses howsoever sustained, as a result of the reliance on or use by a reader or any other person of the information, opinion, or products expressed or otherwise contained herein. Where appropriate, professional advise should be sought.
Do Not Give Up on Yourself, Even When Everyone Else Does!

By: Sarah Silvester

Here I am, two weeks out of the hospital with another bag of ice on my head. In 2005, there was little information about concussions and less advice about recovery. I had been tackled in rugby and my head hit the hard dirt below before any other part of my body. My head buzzed, my neck torqued, and I lost vision for a few moments. My bell had been rung and the reverberations continue to this day. I went back to rugby after the two weeks the doctor had told me to take off. Of course, my head was hit again. I'm smiling at this moment, happy that I don't have to leave in an ambulance. Happy that I'm 18 years old and captain of the rugby team, on the cusp of adulthood with no idea how difficult the path forward was about to become.

The buzzing returned, louder than ever. The memory gaps continued. I quit sports. Gained weight. I went into exams with near-perfect grades and failed most of them. I lost my spot at the top of the class. Lost myself and my identity and my path forward. I withdrew from university tryouts in hockey and rugby. I withdrew from friends. I withdrew from myself. My family doctor, who had always been supportive and helpful, couldn't offer relief. I grew angry. Ostracized. University was hard. Harder than I imagined. I looked for help in my struggle and found nothing. Disability services excluded me. Counsellors had no advice to give. It took years before I sought mental health assistance, out-of-pocket, as my vibrancy and ambition dwindled to nothing. I didn't go willingly. My mental health deteriorated to the point that I was wandering in traffic, looking for evidence that I was real, that I could feel something again.

Years later, I suffered another concussion. This time, I woke up petting the first responder's beard, uttering nonsense, and growing flustered when they asked over and over what day it was. Only later did I find out that what I thought were flawless answers were actually strings of irrelevant words. Although this time the care in the ER was somewhat more involved, there was still no aftercare and zero follow-ups. Once again, I was sent off on my own in a mind I couldn't recognize. While I am learning to love my restructured brain, it has taken years of loss, heartache, despondency, and hard work to get here. Accepting myself and my new way of being without the world accepting me back has been a challenge. But, at least the smile is back on my face.

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 February 2021, the Brain Injury Speaks Network held focus groups facilitated by Dr. Lesley Ruttan to better understand experiences of social isolation following a brain injury. Sixteen individuals with brain injuries and one spouse of a person with brain injury participated, and all of the participants reported experiencing social isolation.

During the groups, members talked about common barriers and factors that influence social isolation. They also discussed what has helped keep them socially connected since their injury.

Group members shared barriers to socializing, each of which led to their experiences of social isolation. Some of these were:
- Avoiding situations due to discomfort from symptoms
- Changes in their ability to socialize
- Feeling like they are not the same person
- Difficulty accessing services
- A loss of friendships and work colleagues

One group member stated:

“They treated me like I wanted [pity] when all I wanted was someone to listen. I kind of went from more friends than I could count, to two, and then to none.”

Group members said that programs offered by OBIA and their local association, community programs and volunteer work helped them stay socially connected. Although COVID-19 has taken some of these opportunities away, members reported staying connected through peer support groups, mentoring programs, family support, social media, Zoom, and phone calls. A member said about support groups:

“I think it’s important to talk to people that are experiencing the same thing as what you’re going through because they offer the best advice.”

Additional strategies participants reported using to help them remain connected include:
- Adapting their usual practices in social settings to minimize distraction
- Being selective with activities and who they see
- Using musician’s earplugs to limit background noise
- Informing their support systems about their needs
- Being open and honest about what they are going through

We are so grateful to the Brain Injury Speaks members who participated in these focus groups and shared their experiences with social isolation. Also, we would like to thank Dr. Lesley Ruttan for facilitating. A more extensive summary of the findings from the social isolation focus groups will be shared in the next few weeks online at https://obia.ca/get-involved/brain-injury-speaks/.
**Moving Ontarians More Safely (MOMS) Act, 2021**

The Government of Ontario developed *The Moving Ontarians More Safely (MOMS) Act* to protect people from sustaining injuries by targeting those who engage in unsafe, high-risk driving behaviours. This act acknowledges the importance of road safety and takes steps to protect young drivers and vulnerable road users such as pedestrians, cyclists, highway workers, and emergency services. Ruth Wilcock, Executive Director of OBIA, represented the brain injury community at the Standing Committee on General Government in consideration of the MOMS Act, also known as Bill 282. At this committee, Ms. Wilcock expressed OBIA’s support of this bill and the desperate need for safer roads in our province to reduce the risk of brain injuries. Some of the changes this act will implement include increasing the penalties for unsafe driving behaviours, reducing the speed limit threshold for stunt driving, allowing photo evidence of vehicles passing streetcars illegally, and allowing MTO Transportation Enforcement Officers to close a road and direct traffic in response to emergencies. ♦♦♦

To Read the Full Article about the MOMS Act: CLICK HERE
To Read the Committee Transcript: CLICK HERE

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**RESEARCH INITIATIVES**

**“Impact of Gender on Knowledge Translation Interventions”** - CIHR Institute of Gender and Health

Researchers at the Canadian Institutes of Health Research are looking for adults living with traumatic brain injury, their family members, and clinicians to participate in a study that aims to improve outcomes and equity for persons with traumatic brain injury. The researchers are investigating whether education can increase the knowledge and change attitudes of patients, their family members, and clinicians about the importance of sex and gender in traumatic brain injury. Participation requires approximately two hours of time and involves completing an educational session and two questionnaires. ♦♦♦

To Learn More or Participate in this Study: CLICK HERE

**“Engagement on the Disability Inclusion Act”** - The Government of Canada

The Government of Canada is asking all Canadians how they can improve the lives of individuals with disabilities. They’ve launched a survey focused on financial security, employment, disability-inclusive spaces, and modern approaches to disability. Your feedback will support the development of the new *Disability Inclusion Action Plan*. This project is part of a larger initiative related to creating a new Canada Disability Benefit. For more information about the new Canada Disability Benefit see “In the News”. ♦♦♦

To Learn More or Participate in this Study: CLICK HERE

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Funding for Brain Injury Speaks is generously provided by the Ministry of Health/Ministry of Long-Term Care, Strategic Policy, Planning and French Language Services Division. The views expressed in this publication are the views of the Ontario Brain Injury Association (OBIA) and do not necessarily reflect those of the Province of Ontario.