



Headlines

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 **Helpline**
Toll-Free
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Creating a better future for Vermonters affected by brain injury through prevention, education, advocacy and support.

A Survivor Story

By: Theresa Tedstone

Where do I start? When my Mom was 90, she fell in her apartment during the night. She was taken to the local hospital and was treated for a weak leg. I had constantly asked if they scanned her head and was told no. She was placed in rehab for her leg and at the time I was living in NY and she was in northern VT. I called her at the rehab, and she was babbling so, I then called the nurses station, and she was rushed to the local hospital and was then transferred to UVM Medical Center where brain surgery was performed for a brain bleed. Come to find out, there were two prior brain bleeds that I wasn't aware of, she had never even mentioned hitting her head. She could no longer return to her apartment but had to reside in assisted living. She thrived and functioned quite well and actually loved the activities. I was able to find a job and moved to be near her in August 2017. She passed 4 months later on December 23rd, 2017.



I was planning for her funeral to be in May 2018. During that time, I was planning to have my Dads ashes buried with her in Stowe VT where most of her family were buried. Unbeknownst to her, I purchased a plot for her and Dad. I was preparing for the inevitable.



Survivor Story Continued

Now my turn to tell my story. July 22nd, 2018 was the day that changed my life. Let me add that I have been a Service Coordinator for a brain injury pro-program in NY for quite a few years and continued that path with another agency when I relocated to VT in September 2017. On July 16th, 2017 I went to work with a headache on my forehead. It was July and quite hot plus my phone was ringing constantly, emails to answer, there were meetings to attend and emergencies were fairly common. I was busy. The headache continued on my forehead for the rest of the week. Was it a migraine (which I get), Maybe a sinus headache or was it just plain old stress? Remember I also advocated for my Mom and she was moved up to the full care of the nursing home 2 weeks after I moved to VT. I didn't have time for myself or my week-long headache. On that Friday, the headache moved to the right side of my head. I wanted to go home, and I felt grumpy, which surprised my office mate. On Saturday morning I awoke to a banger of a headache and I spent the day on the couch with my migraine meds and a cold pack.

During the early morning hours of July 22nd, 2018, I threw up. I waited until it got light out and I called my cousin that lived nearby and asked for a ride to the local ER. Within a very short time, a scan was done, and an ambulance was called. The doctor came into the room and informed me that I had a thrombosis in my head. I was being shipped off to UVM ASAP!! Having flashbacks of my Moms journey, I panicked. I looked at him and my cousin and I informed them that I needed to be medicated or I was leaving. The doctor then appeared with two tiny white pills. I was transported quickly with the EMTs notifying the ER our time frame and to have neurology waiting. I was receiving blood thinner and lots of tests, constantly checking my cognitive reactions. So far so good, I guess, I don't think I had a stroke. The next day, July 23rd, 2018 at the UVM Medical Center, the sun came up and I had gotten no sleep. My nurses and neurology team have been testing me throughout the night. I was still "doing well," no stroke. Meanwhile, my sons were calling me, and we were trying to figure out how to handle all this.

They were not even in the same state as me. I was keeping my cousin posted, so I was alone. 4 neurologists and 6 or 7 students walked in and the room was crowded. One neurologist spoke up and informed me that I had DVST, a rare blood clot that they have only seen two of in 10 years! Great!! "So-how big is this clot?" I asked.

Survivor Story Continued

The neurologist informed me that the clot was 5 inches long. The room was silent. So, I figured that I needed to say something- "Holy shit. I have a snake in my head." Needless to say, no one spoke. This is serious, I concluded. Throughout the day on July 24th, 2018, I was watched closely and brought downstairs for all sorts of tests, scans and blood work. Then a nurse came in and informed me that I will need to learn how to give myself injections of blood thinner when I was to leave, which was the next day!!!! What?? Really? It took me 11 hours to be able to do that. I was discharged July 26th, 2018 to my son that came from MA. I continued to give myself shots while being weaned off to another blood thinner and 2 to 3 visits a week to my primary care to monitor my INR numbers, which was all over the place. The rest of this whole adventure was advocating for myself with a very supportive primary care doctor. I went through 3 neurologists over the next year. One being at Mass General. I needed a second opinion.

I did begin with a hematologist in VT that has been the best thing since sliced bread. I am now on a medication that does not need my INR numbers checked. I spent the better of 2 years in and out of doctor's offices and hospitals looking for an answer. Guess what? There aren't any answers, only speculations. One thing that was for sure, brain swelling takes up to a year to heal, and having a medical issue that only 3-4 people out of a million have, is something I am still dealing with. I have seen a neuropsychic counselor and now a counselor to just sort out issues that I've struggled with. It hasn't been three years yet. I've had to keep up with scans and tests and I did struggle with this. You have to be aware of how you feel and don't downplay it because you're tired of the whole ordeal that has turned your life upside down. Thanks to my skills from my career of choice, I knew the ins and outs of navigating the healthcare system. What I wasn't ready for was the physical and mental side effects that interfered with self-advocating. My support system, my family and my sons have been there for me. My team of doctors that I finally felt confident with have been superior. There is a very overused phrase that I've always disliked but pretty much sums it up- "It is what it is." I really am very lucky it could have gone very differently. In May of 2020 I got clearance that the Snake in my Head was gone. My mental health and everyday living have been impacted. I am no longer working but, the funny thing is, is that I kept telling my director at the agency I was with that I'll be back. I started that conversation a month after my incident. My personality is to deal with things and keep going. Little did I know that this was bigger than I wanted to accept.

Did You Miss Our Conference? You Can Still Register!



Get access to a dozen recordings from our 32nd Annual Brain Injury Conference. View presentations from amazing speakers such as renowned speaker, Dr. Kim Gorgens, as well as inspirational speaker and American former professional snowboarder, Kevin Pearce.

To learn more & register to receive immediate links to recordings, head to:

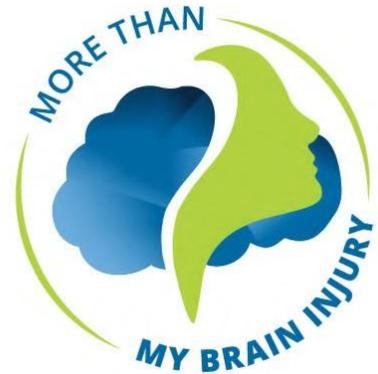
give.classy.org/BIconference2020

March is Brain Injury Awareness month!

The theme for the 2021 campaign is
More than my brain injury!

How to Get Involved During Brain Injury Awareness Month

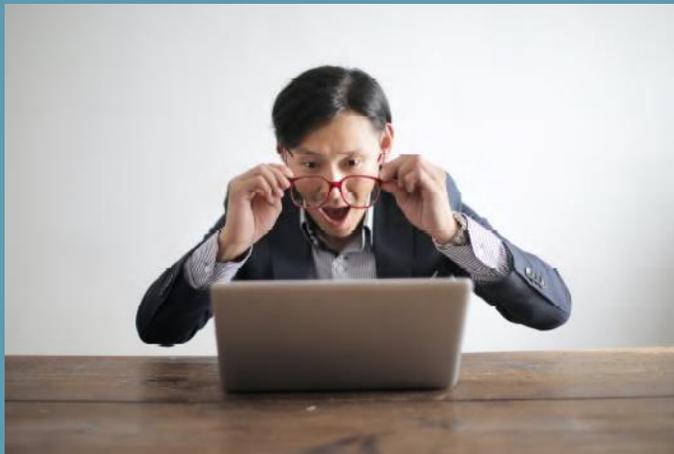
- Talk with someone with a brain injury and listen to their story;
- Share your brain injury story on your social media accounts using the hashtag #MoreThanMyBrainInjury
- Send a letter to the editor of your local newspaper explaining to your community why they should care about brain injuries (See downloadable template, below!);
- Talk to your employer and businesses you patronize about their practices for recruiting and hiring people with brain injury; and
- Contact your legislatures, today, and let them know you expect them to enact public policy to assist people with brain injuries.



Join the Brain Injury Association of Vermont & America, during the month of March, to help raise awareness. Find out more about brain injuries and what you can do at:

<https://biavt.org/advocacy/biawarenessmonth/>

We Have a New Website & Resource Directory!



Check out our new website! Additionally, we have a wonderful new resource directory with an abundance of resources that are available to TBI survivors and their family.

<https://biavt.org/support/resources/>

Don't see your organization listed? Head here to learn more about becoming a part of it!

<https://biavt.org/support/professional-membership/>

Caregivers' Corner

Coping with Stress During COVID-19 Tips from American Red Cross

For many of us, COVID-19 has disrupted our routines and made everyday activities, such as work and caring for loved ones, challenging.

These changes, on top of the general uncertainty around this pandemic, can create feelings of stress, fear and nervousness. These feelings are normal, and people typically bounce back after difficult times.

Children and teens may respond more strongly to the stress and anxiety caused by COVID-19, and become frightened that they or their loved ones will get sick. Take time to talk calmly and reassure children about what is happening in a way that they can understand.

The following information can help you cope with stress and support others during this emergency:

It's normal for people to have these types of feelings right now:

- Fear about running out of essential supplies.
- Anxiety, particularly about being separated from loved ones.
- Uncertainty about how long you will need to shelter at home.
- Concerns for your physical safety and that of others.
- Fear of getting sick.
- Guilt about not being able to fulfill responsibilities, such as work, parenting or caring for dependents.
- Boredom or isolation.
- Thoughts of blame, worry or fear.
- Worry about loss of income.
- Fear of being stigmatized or labeled if you become sick.

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Caregivers' Corner, Continued

Coping Tips:

People's reactions appear in different ways, not only in the way someone feels, but in the way they think and what they think about — their sleeping habits, how they go about daily living and the way they interact and get along with others. Here are a few steps to help people cope:

- Connect with loved ones through video calls, phone calls, texts or social media.
- Stay informed with accurate, reliable information from trusted sources. Avoid social media accounts and news outlets that promote fear or rumors.
- Take care of yourself and monitor the physical health needs of your loved ones.
- Eat healthy, drink plenty of water and get enough rest.
- Unless you are showing signs of illness or have tested positive for COVID-19, going outside to exercise and walk pets is okay. But don't forget to practice social distancing by keeping at least 6 feet away from others and wearing a [cloth face covering](#) when in public.

Be patient with yourself and others. It's common to have any number of temporary stress reactions, such as fear, anger, frustration and anxiety. Hold an image in your mind of the best possible outcome. Make a list of your personal strengths and use these to help both yourself and others stay emotionally strong.

- Relax your body often by doing things that work for you - take deep breaths, stretch or meditate, or engage in activities you enjoy.
- If you are religious or spiritual, follow practices at home that provide you with comfort and emotional strength.

Support Groups

Living with a brain injury can feel isolating. A group of people that share similar challenges can be a way of once again feeling connected to those around you and not so alone in your journey. Gathering with people that are experiencing similar challenges can help you find ways of adapting that are practical and empowering. Insight from others that face a common problem can help you heal and grow.

For virtual support groups, visit: <https://biavt.org/support/>

BIAVT Support Groups
More Information: www.biavt.org

Bristol

Howden Hall
19 West St, Bristol
3rd Monday
5:30 - 7:00 PM

Burlington

Department of Labor
63 Pearl St, Burlington
Last Friday
12:00 - 1:00 PM

Non-BIAVT Affiliated Support Groups
More Information: www.vcil.org

Rutland

Rutland Free Library
3rd Friday
2:00 - 3:30 PM

St. Johnsbury

Grace Methodist Church
36 Central St,
St. Johnsbury
3rd Wednesday
1:00 - 2:00 PM

Colchester

Fanny Allen Hospital
790 College Pkwy
1st Wednesday
5:30-7:30 PM

New Hampshire (Border) Support Groups
More Information: www.bianh.org

Manchester

Catholic Medical Center
100 McGregor St
4th Tuesday
4:30 - 5:30pm

Lebanon

Dartmouth Hitchcock
Medical Center
2nd & 4th Wednesdays
6:00 - 7:30pm

Keene

Monadnock Pacers
63 Community Way
4th Tuesday
6:00pm-7:30pm

BIAVT will provide assistance in forming support groups in areas that are not currently being served. For more information or to facilitate a group contact support@biavt.org.



Survivors' Segment

COVID-19 Vaccination for Individuals with Brain Injury: A Webinar & FAQ

Earlier this month, the Brain Injury Association of America invited [Gregory J. O'Shanick, M.D.](#), BIAA's medical director emeritus, to talk about the COVID-19 vaccine. In a one-hour webinar, Dr. O'Shanick discussed the increased risks associated with COVID-19 and brain injury, what you should know about chronic inflammation, and an overview of vaccine safety, efficacy, and common myths.

[Click here to watch the webinar recording](#)

The CDC and the Food and Drug Administration (FDA) are tracking information through the V-safe app and the Vaccine Adverse Event Reporting System (VAERS). Both the V-safe app and VAERS collect information about adverse events (possible side effects or health problems) that occur after vaccination. [Download the V-safe app](#) to tell CDC how you're feeling after getting the COVID-19 vaccine or [click here](#) to share your information through the VAERS online.

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COVID-19 Vaccination: Frequently Asked Questions

Should I get the vaccine?

The medical leadership of the Brain Injury Association of America (BIAA) wrote an [open letter](#) encouraging all individuals with brain injury to get vaccinated in order to avoid additional neuroinflammatory issues and keep themselves, their families, and their communities safe. For immediate questions or concerns, please seek the advice of your physician or other qualified health provider.

How do I get the vaccine in my state?

Although each state is setting up its own priority sequence for vaccination, individuals with chronic health conditions are generally placed among the higher levels. Many in the medical community recognize brain injury as a chronic condition – see our position paper on Conceptualizing Brain Injury as a Chronic Disease [here](#). Some individuals in our community have had success advocating to receive the vaccine by showing our [vaccine statement](#) and [open letter](#) to their doctors and/or vaccine administrators in their states. For information about getting the vaccine in Vermont, [click here](#).

What should I do if I have a reaction after getting the vaccine?

According to the Centers for Disease Control and Prevention (CDC), you may have some side effects, which are normal signs that your body is building protection. These side effects may affect your ability to do daily activities, but they will likely go away in a few days. For immediate concerns, please contact your physician.