Brain injuries aren’t obvious, but they affect 13.5 million Americans

By Sarah Kilch Gaffney, Special to the BDN
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Growing up, I loved playing soccer and from age 13 on I was a goalkeeper on numerous school and club teams. I ended my soccer career during a midseason game my sophomore year of college, when I caught a knee under my chin during a collision with a player from the other team.

I was dazed and my tongue swelled so badly that the student athletic trainer had to crush up ibuprofen so that I could actually swallow it. When I saw the athletic director the next day, I was told I didn’t have a concussion because, “he saw concussions every day in football,” and I was denied treatment. Meanwhile, over 1,100 miles away, my parents were frantic. As former EMTs, they knew that every head injury was potentially fatal.

After over a week of nearly continuous sleep and constant headaches, I was finally allowed to seek medical help and was diagnosed with “classic” post-concussion syndrome. It took me months to recover and I took incompletes in all of my classes that term, finishing the necessary academic work over my winter break. Looking back, we estimate that last concussion was my eighth. I was 19 years old at the time.

I was fortunate to fully recover, and a little over six months later I met my future husband, Steve, while serving as an AmeriCorps volunteer on a backcountry trail crew in the Maine woods during my summer break from school.
Three years ago, Steve died from a terminal brain tumor at the age of 31. Throughout his nearly five years of treatment, he sustained numerous brain injuries as a result of his surgeries, chemotherapies, and radiation therapies. He went through years of treatments, rehabilitation, and debilitating cognitive decline before the tumor entirely robbed him of his ability to walk and speak and eventually took his life two months shy of his 32nd birthday.

During the time he was sick, there was no brain injury advocacy organization in Maine. His doctors, though wonderful at the medical side of things, did not mention brain injury directly. We were not connected with outside support until Steve started hospice and in the years leading up to that, we were left to wade through the challenges and obstacles almost entirely on our own.

Our knowledge and awareness of brain injury has come a long way since my college soccer days and even since Steve’s death, but there is still so much work to do.

A little less than a year after Steve died, I started working for the Brain Injury Association of America’s new Maine Chapter as their program coordinator. It makes my heart absolutely full to be able to take my experience and do something positive and meaningful with it by helping Maine survivors and family members navigate the often difficult and disorienting world of brain injury.

Brain injury can be an incredibly isolating experience for both the survivor and the caregiver/family members, and I’m so grateful to help make that experience a little easier for those I work with. Often times, brain injury is also an “invisible” injury; it’s not like a broken leg or arm where the damage is obvious and there are other signs like a cast or crutches to indicate that someone is healing from a significant injury. Brain injury is also often a lifelong challenge for survivors and families.

Brain injury can affect anyone at any time. Chances are, you already know someone directly who has had a concussion, stroke, or other brain injury.

According to the Brain Injury Association of America, every 13 seconds someone in the U.S. sustains a traumatic brain injury, or TBI. The risk of another TBI increases dramatically after the initial injury: after one brain injury the risk for a second is 3x greater; after the second injury, the risk is 8x greater. Acquired brain injury (which includes TBI, as well as other injuries such as stroke, aneurysms, anoxic injuries, and tumors like Steve’s), is the second most prevalent disability in the U.S., estimated at around 13.5 million Americans.

March is Brain Injury Awareness Month and the Brain Injury Association of America – Maine Chapter (BIAA-ME) is hosting its 2017 Maine Brain Injury Resource Fair on Thursday, March 30, 2017, from 1-4 pm at the Calumet Club in Augusta. This event is FREE to attend for everyone.

The Resource Fair provides one-stop shopping for Maine brain injury survivors, family members/caregivers, friends, professionals, and anyone interested in learning more about brain injury supports and resources in Maine. There will be 35 exhibitors, including organizations specializing in veterans’ support, advocacy/legal, recreational opportunities, brain injury rehabilitation programs, assistive technology, brain injury support groups, and more!

We hope you’ll stop by and gather resources and information from our exhibitors, meet BIAA-ME staff, and pick up a copy of our new Maine Brain Injury & Stroke Resource Directory. Attendees will also have the opportunity to meet brain injury survivor Sadie Tyler, who is Mrs. Waldo County and is running for the 2017 Mrs. Maine title. The event is totally FREE for exhibitors and attendees (though exhibitor space is limited). We are asking attendees to register ahead of time if at all possible. Any questions can be directed to Sarah Gaffney at sgaffney@biausa.org (mailto:sgaffney@biausa.org) or (207) 522-6601.

