

December 2016

# TBI HOPE

Advocacy & Education  
MAGAZINE

supporting the  
brain injury  
community

Our  
HOLIDAY  
Issue!

## The Emergency Room

## Still in the Game

## A CAGED MIND

What Are They Thinking?



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# TBI HOPE MAGAZINE

*Serving All Impacted by  
Brain Injury*

**December  
2016**

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# Welcome

Welcome to the December 2016 issue of TBI HOPE Magazine!

Later this week, much of the world will come together to celebrate the Christmas holiday. While this can be a stressful time of year for just about anyone, those with lives affected by brain injury especially feel the added pressure.

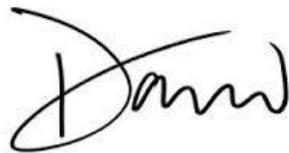
There are family and social obligations that no longer come easy to so many of us. Dwindling (or non-existent) budgets make gift-giving a new challenge, and there are expectations that we hope to live up to.

This year, like the last several years, our own holidays will be scaled down. Our world is smaller these days. We'll do a bit less, we'll spend decidedly less, and take our own focus off the commercialization of the holidays.

We'll spend time with family, enjoy the company of a few close friends, and live mindfully that this is the season of love, giving of ourselves, and spending time with those we love. As time passes, I see it for what it is – our time is the most precious gift that we can give someone.

Whatever your faith, wherever you are, it is our heartfelt wish that you find peace and can keep company with those you love.

From our family to yours, Happy holidays.



David A. Grant  
*Publisher*



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*"Christmas is doing a little something extra for someone."*

~Charles M. Schulz



# **My Miracle Boy**

**by Alicia Scott**

Our story begins back in November of 2011. I gave birth to a beautiful, healthy, blonde haired, blue eyed little boy whom I named Ethan. Now, Ethan truly is a miracle all around because his biological father was not supposed to ever have children, due to his having testicular cancer when he was younger. Needless to say, when we found out I was pregnant with Ethan it was a shock and a miracle. Ethan was born on November 4th, 2011 at South Shore Regional Hospital, in a town called Bridgewater, in Nova Scotia (Canada). He was as perfect as perfect can be and I was so very proud to be his Mommy.

A few weeks went by during that snowy, cold November, when one night I left Ethan alone with his dad while I went out to get milk for Ethan. When I came home, Ethan was more sleepy than usual, but I figured he was just overtired, plus newborns do tend to sleep a lot! The next morning, I got up as usual and was preparing Ethan's bottle when I noticed he wasn't acting like himself.

I watched in fear as my three-week old son started staring off into space and jerking his arm in a seizure-like activity. Right away, I told Ethan's dad there was something wrong and I needed to take him to the hospital and in reply, he told me I worry too much. As soon as the doctor saw Ethan, he went into sudden panic mode and started making calls to hospitals an hour away, and eventually called the IWK, the children's hospital in Halifax, about two and a half hours away.

I watched in fear as my baby continued the seizure activity and eventually stopped breathing. When the doctor came back from making phone calls, he proceeded to tell me Ethan was going to be flown by helicopter to get to the Children's Hospital ASAP. I tried to ask questions about what was happening with my son, but little answers did I receive. What took only a short time for the helicopter to come felt like hours for me, as I watched my once healthy, perfect three- week old happy son, now hooked up to tubes and barely hanging on.



While waiting for a helicopter ride, my mind raced a thousand miles a minute wondering what happened. Minutes before the helicopter showed up to take Ethan, our family doctor pulled myself and Ethan's dad aside and began to ask questions about child abuse, and asked if one of us ever hurt him, "NO!" I shouted; how dare he accuse me of hurting my child? His final statement to us before we left for the city was "they are going to question you about child abuse at the children's hospital." I couldn't believe what was happening. Never did I put it together that there was something seriously wrong with my son, nothing I thought our hospital couldn't have fixed. Boy was I wrong.

We arrived at the IWK hospital where Ethan was rushed for a CT scan. We waited inside a little room outside the PICU. While there, the pediatric doctor came in the room and asked if anything happened to Ethan, because the CT scan showed Ethan's skull "Was like a crushed egg", to quote the doctor. That statement has stayed with me ever since. My mouth dropped in disbelief, "A crushed egg? How?!" How could this be? I never did anything other than love, care for and protect my baby with every fiber of my being.

Of course, I told the doctor I didn't know how Ethan's skull could be like a 'crushed egg'. The doctor said something purposely happened to Ethan, and he wouldn't stop coming in the room until he knew the truth. Finally after a few attempts to get to the truth, Ethan's father spoke up and said he dropped him. I was so angry, so hurt. How could he not tell me that something happened to our son while in his care? Although he said he dropped him, the doctor was not convinced that a drop caused the skull fractures my son had. The doctor proceeded to tell me to prepare for my son to die. He was put into a medically induced coma to give his brain a rest, and was going to stay that way for a couple of days.

Also, if he didn't start breathing on his own, he was likely to die. My heart shattered. I wasn't sure which pain was worse: being betrayed by the man I loved, or knowing he could be so cruel and evil to hurt our son and put his life at risk.

Days went by in the hospital and while Ethan lay in a medically induced coma, I met with police officers and doctors and councilors who reassured me there was no way this was an accident, and that Ethan's dad purposely caused the injuries that Ethan sustained.



Finally, on the second day of the coma, the doctor came in and told me there was a 99% chance Ethan was going to live. I was so happy, but little did I know the damage that was done was so serious it would haunt us forever.

After a six-month investigation with the Major Crime Unit, Ethan's father was arrested and found guilty of three abuse charges. He is currently serving a two-and-a-half year sentence, while Ethan was left with skull fractures, retinal hemorrhages, hydrocephalus; a stroke which affected his left arm and leg, and a TBI. When the doctor was explaining the injuries, he compared them to those of babies who were shaken, or in traumatic car accidents. I specifically remember one doctor saying to me, "You prayed for life, but what life will he have as a vegetable?" That question was like a knife to my heart.

Here we are in 2016, five years since Ethan's TBI. Although he is not walking, he is a true miracle boy. The retinal bleeding cleared up and he is a bright happy boy, and very social. His speech has come so far! Although he is followed by a lot of specialists and doctors, he continues to amaze them with every visit.

When people see Ethan they stop and say, "well, what's wrong with him?", and I always tell them the damage is on the inside. Although not visible, and although he seems like a normal child, his brain is permanently damaged. Sometimes, there are setbacks with things, but he continues to progress at his own speed, which is far from being a "vegetable", and far from being told at 3 weeks old he was likely to die.

This TBI road has not been an easy one, that's for sure. Before Ethan's TBI, I had never even heard of TBI and had no clue what it was. Now our world revolves around it. When

a milestone is not met that should be at a certain age, or when we see other kids Ethan's age and younger doing things he cannot, it creeps right back up on us and reminds us just how terrible and life-altering TBI really is.

But, it has also shown us that doctors are not always right, and although they can make their predictions and suggestions, it does not mean that's what the final outcome will be. Most importantly, it has shown my family and me, along with our home town of Shelburne, Nova Scotia, that miracles really do happen, and my son Ethan is a true Miracle Boy.

## Meet Alicia Scott

*Alicia calls Shelburne, Nova Scotia home. She is a first-time contributor to TBI HOPE Magazine and hopes that others will benefit by her willingness to share her experience.*

*She is a mom and full-time caregiver to her son Ethan. Alicia is also a strong believer in miracles!*



## Living With Hope

By Patrick Brigham



# Still in the Game

by Aislinn Fallon



On what I thought would be an idyllic birthday, I felt my soccer cleats tear through the ground as I bolted toward the ball in a tournament game for my team. Little did I know that the next moment would change my life forever.

Life as a child was ordinary for me. I went to school every day and played as many sports as I could. I was MVP of diving and soccer, respectively, every year, practically living at the pool I swam and dove each day.

My life was perfect, the life every child would have yearned for. I dreamt about my future and having a flawless life. When I gazed at the dandelions outside my window, I would never see weeds, for they would always be wishes. Little did I know as a child that life isn't perfect, it's messy. Life is a trail with twists and turns; it has outcomes that always go unforeseen. Anything can happen in a second, and for me just one second turned my world upside down.

As I woke to the scent of pancakes in the air on that spring day, I sped out of bed toward my calendar. I crossed off the large square labeled March 26, 2012 with "MY BIRTHDAY" drawn in the center in a rose-colored Sharpie.

"I can't believe I'm 13, already," I thought to myself.

I began getting ready for school, making sure everything was ideal for this special day. I slung my soccer bag over my shoulder and headed off to school for my classes. The day carried on normally, with everything from Mrs. Hathaway's lectures on the shape of the globe, to Mr. G's explanation of grammar.

My soccer team gathered in the locker room after the final bell and got ready for the tournament against our rivals. When the school day was over, I was ready to hit the field. My team and I stretched, counting out in unison.

We played hard against our rivals, trying to come out victorious. As the last few minutes of the game approached, I could feel my heart pounding in my chest. I glanced at the scoreboard; the game was perfectly tied and that was not good enough for me.

I was playing right forward during the last five minutes of the game. My left forward had the ball and attempted to make the final goal, but the opposing team's goalkeeper was good. The goalkeeper shot the ball into the air and my eyes remained locked on it as it soared through the sky. I jumped into the air but right before making contact with the ball, everything went black.

The shriek of the whistle made my eyes shoot open. I rolled to my side to see another player holding her head, and, within a second, pounding traveled through my brain.

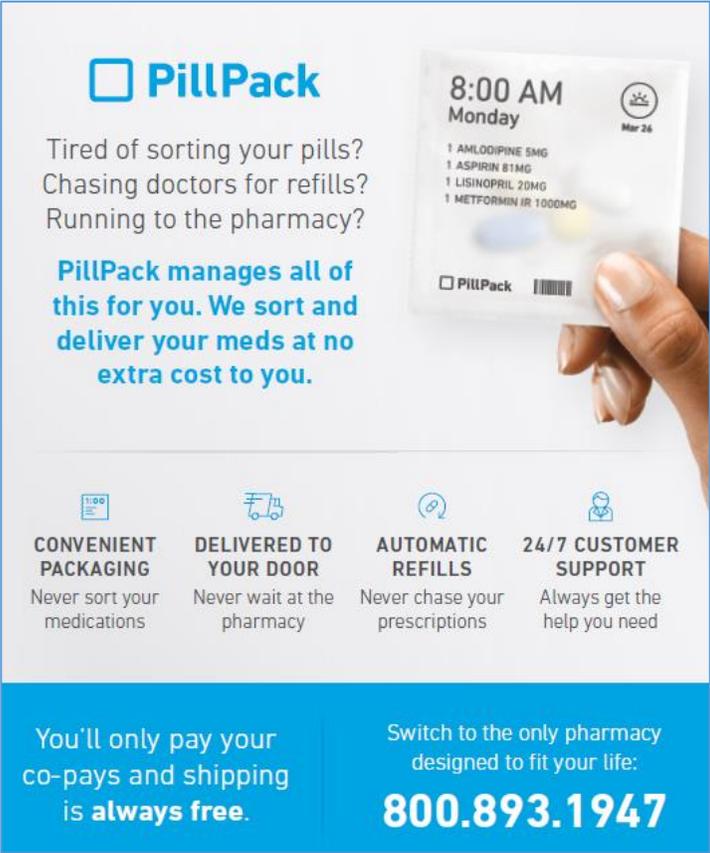
The rest of the day was normal, but everything had changed once I woke up the next morning. The pounding continued in my head; as I stood up, everything went black and, before I knew it, I opened my eyes, staring at the ceiling. I scurried over to my bathroom, violently vomiting on the surrounding floor.



Yet, I pushed myself to go to school. Lights seemed to burn my eyes; Mrs. Jenkins handed out worksheets, but as I looked at the paper all I could see were lines and circles. I couldn't read anymore, and as I tried to grasp a pencil, it dropped from my hand.

From that point on, my memory is a fuzzy mixture of short-term memories, walking sideways, blacking out, headaches, vomiting and so much more. Unfortunately, my concussion led to a multitude of chronic illnesses that changed my life forever. I have been on hospital/homebound school due to the fact that physically attending school is practically impossible due to my chronic pain.

Even though it has been four years since my injury, those few moments changed my life forever. When you have a chronic illness, you have to say goodbye to everything you once loved: school, sports, and friends. A lot of people with conditions similar to my own feel alone in their fight, which is why spreading awareness is an important cause to me.



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A few years after sustaining my injury, I came across some disturbing information: the number one cause of death for those with chronic pain is suicide, and the majority of those who are alive with chronic pain participate in self-harm. I started a blog about staying positive with chronic illness, and, within a year had thousands of followers.

When I began receiving messages from my followers about how my blog was changing their lives, I made the decision I was not going to just let my work with chronic illness stop at a blog. I was being asked to write for multiple websites, but after a while I decided to create my own, and that's how [www.chronicpain09.com](http://www.chronicpain09.com) was born. Running

my own website allows me to spread awareness about traumatic brain injury, chronic illness, and mental illness. I also started "chronicpain09 support" on Facebook, which is a closed group offering support to those who suffer from chronic illnesses and mental illnesses. It felt unreal that in less than a week, my support group had already hit over 100

members. After starting my support group I came to the realization that my followers and readers were spread all across the globe. Not only was my writing impacting lives, it was impacting lives throughout the world. Life with chronic illness is so challenging and is a tough mountain to climb. All of my platforms are focused around positivity and the message that I want to leave with my followers is hope never abandons you— you abandon it.

Since starting my website I have written for magazines, newspapers, and various websites. Not only has Florida Virtual School featured me on all of their social media pages, they also handpicked me as one in a group of five, out of 300,000 students, to be a featured success student in the yearbook. At age 16 I had articles accepted into a website awarded best chronic illness website three years in a row. However, this year brought my most exciting opportunity yet: being contacted to write for a publication outside the United States. On June 21st, my work was published in Great Britain, officially making me an internationally published writer at the age of 17.

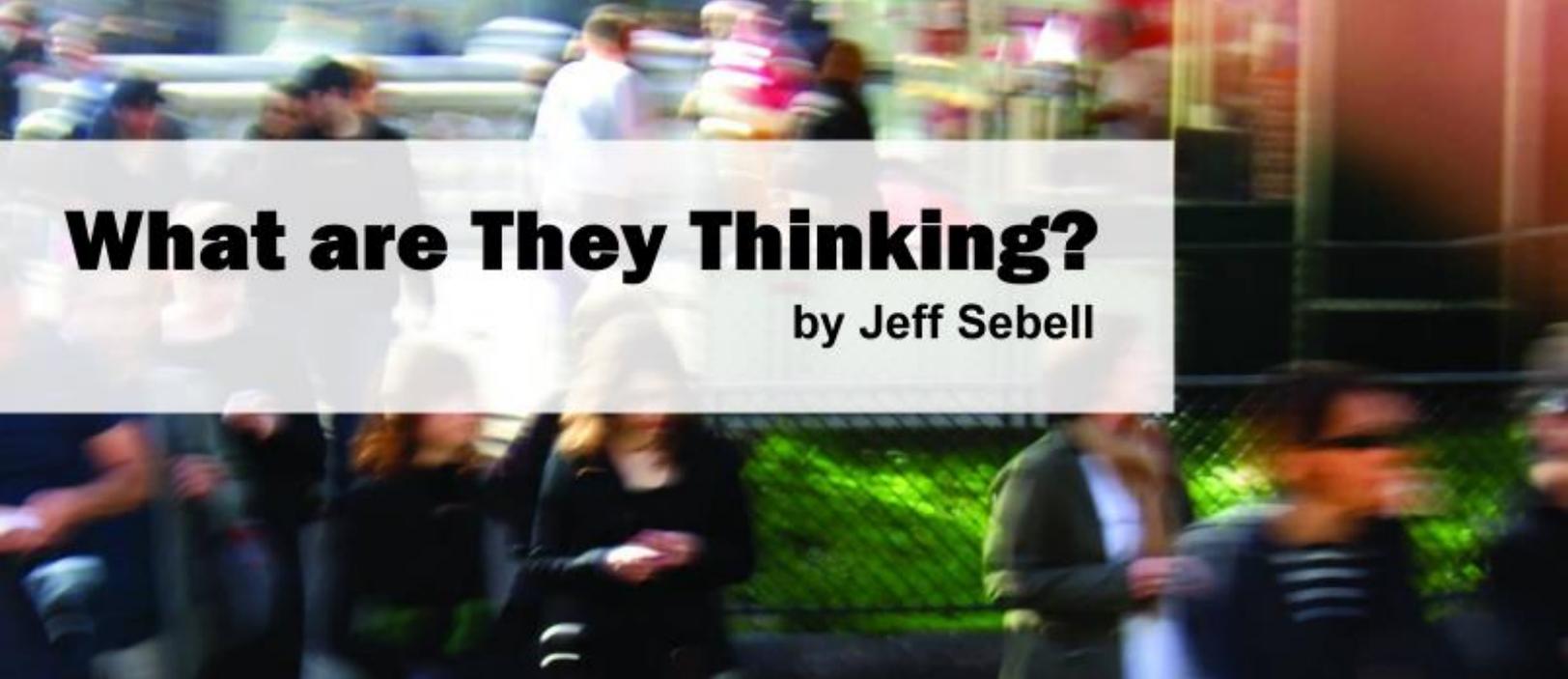
A countless number of people have the belief that one human is incapable of changing the world and this belief is especially supposed to ring true towards adolescents. I am living proof that this belief is false. With strength, compassion, resilience, determination, positivity, and hard work a single person can and will make a difference.

## **Meet Aislinn Fallon**

*Aislinn Fallon is a high school student based in the USA who hopes to go into the field of pain medicine. She runs a website at [www.chronicpain09.com](http://www.chronicpain09.com) about staying positive while fighting the battles that come with living with a chronic illness.*

*She is determined to change the way the world views those who have invisible illnesses and the way in which we see ourselves. She tweets @aislinn\_fallon.*





# What are They Thinking?

by Jeff Sebell

Sometimes people question what's wrong with us and say such blow-me-out-of-the-water unbelievable things that we are struck dumbfounded; unable to respond.

We are first made numb by the ignorance/unreality of what was just said. Add to that the fact that many of us have trouble processing information or shifting gears in conversations, and the result is we cannot think of, or articulate, a way to answer.

After a suitable amount of time has passed to figure out what actually happened, we might cry out passionately, "You don't understand!" and then get into some kind of argument. Sometimes, we might launch into an attempt to *explain*; always a bad idea given the heat of the moment and our exasperation.

## **It Happens All too Often**

We take these things very seriously. When this happens we feel as though our very essence is being attacked, and we feel a burning need to defend ourselves and clear our good name!

Only on those rare occasions when we are able to use all our power to restrain ourselves from impulsively answering, are we able to simply walk away, shaking our heads and muttering under our breath. We walk away, wondering how they could say something so ignorant, or stupid, or mean.

People's reactions to the things we say and the things we sometimes do; their quick quips and offhanded statements, reinforce all the bad stuff we think about ourselves. Rather than build us up when we really need a boost in confidence, other people often send us spiraling down into despair and depression.

## **It takes Two**

Now, I am not making excuses for other peoples' behavior, and I am definitely not making it okay for others to do the things they do or say the hurtful things they say, but I do want to take a closer look at what might bring these things on, so that we may be able to see what we can do to help.

We need to take a closer look at the dynamics here. The situation is this: it might help us to understand why others behave the way they do, by first examining what kind of impact we have on **them**.

Interpersonal communication is never simple, although we tend to see it as simple. In our minds, we have been knocked for a loop by a brain injury and, while not necessarily looking for sympathy, what we are asking for is some understanding and support. Something to make our lives easier.

*“Interpersonal communication is never simple, although we tend to see it as simple.”*

“What could be simpler than that?” we ask.

## **It Ain't So Simple**

Let's look at the affect we have on others. Why don't we imagine you are walking down the sidewalk and a friend of yours comes up, approaching you from the other direction. What do you think is going through their mind when they see you?

Well, this person might be feeling uncomfortable, or have concerns or pity for this friend (you), who just doesn't seem right since his injury. Maybe he doesn't know how to be a friend in this situation and because of that, he feels like he is letting you down so he feels bad and doesn't know what to say.

In the end he just really wants to help, but is not sure how. After all, he really doesn't understand why things can't be the way they used to, and this makes him feel helpless.

He isn't really sure what to do, and truthfully, some things this person says to you might be an attempt to "jumpstart" you, sort of like giving you a little, well-meaning "kick in the pants". Just something to get you moving in the right direction. He may not mean to be hurtful but it comes out sounding that way.

Beyond not knowing what to do, there is a question of expectations. You are expecting support from this friend or family member who doesn't know what to do. You expect your friend to be there to help out as you transition to normal life, but even you don't know what that means. There are expectations and confusions on both sides, and a once-clear friendship with boundaries and structure is now murky and cloudy.

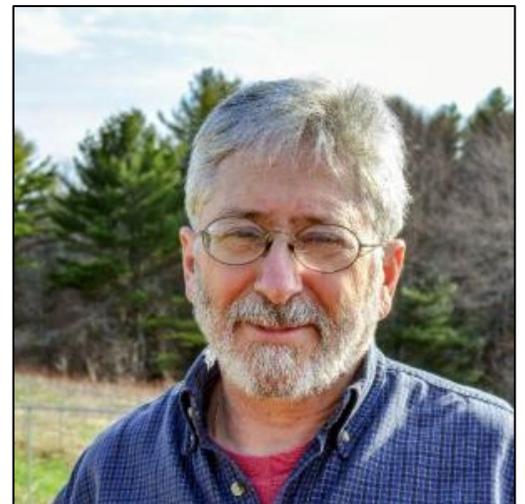
In my own situation, after my neuropsych exam, I sat down with my parents and went over the report with them in detail to help them understand what was going on with me. When we want others to understand but don't give them the tools, we are setting ourselves up for failure. The only thing that is really clear is that we cannot be relying on others to set things right in our lives. This is not their fault. The responsibility for a relationship cannot be all on one side's shoulders.

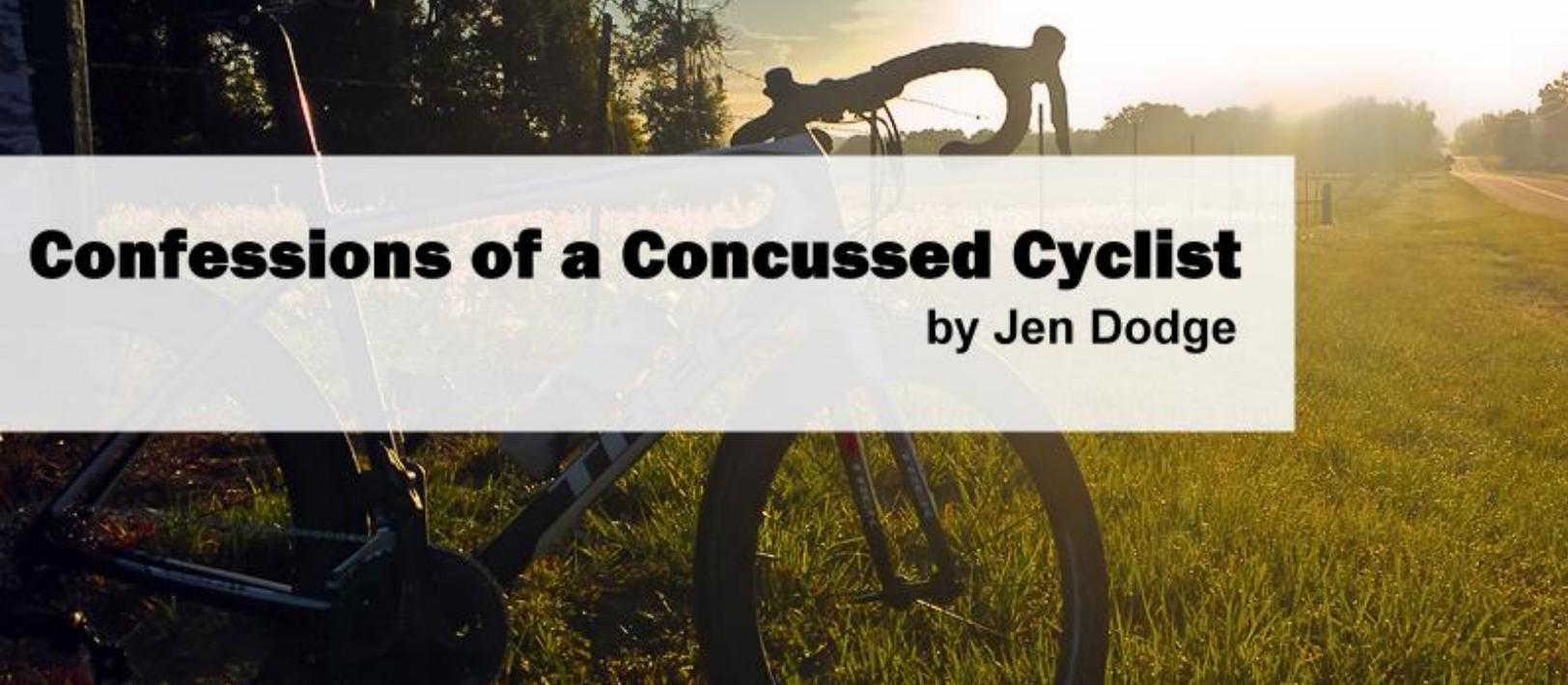
As frustrating as it might be, it is your responsibility to *teach*. Collectively, it is our responsibility to instruct.

## **Meet Jeff Sebell**

*Jeff is a nationally published author, keynote speaker and blogger - writing about Traumatic Brain Injury and the impacts of his own TBI which he suffered in 1975 while attending Bowdoin College.*

*His book "[Learning to Live with Yourself after Brain Injury](#)," was released in August of 2014 by Lash Publishing. Jeff is a regular monthly contributor to TBI HOPE Magazine.*





# **Confessions of a Concussed Cyclist**

by Jen Dodge

The image is still very vivid in my head...perhaps it always will be.

It is impossible to put into words the fear you feel, knowing you're about to be hit, and there is nothing you can do about it.

Tuesday, August 19, 2014...an ambulance is called at 19:51 with the report of a cyclist being hit by an SUV on the corner of Hillside Avenue and Willard Street, in Berlin. I don't remember the time of the call or the call being made at all for that matter, I know this simply from the first responder's report. What I do clearly remember is how much my body hurt and how angry I was! I remember saying to my brother repeatedly "I've never been so mad in my life!"

Adrenaline is an amazing thing. Within hours of the crash, I felt...okay...I didn't feel perfect (my shoulder and hip hurt a lot, my head ached, and I felt sick), but I felt like everything would be fine, that after a good night's sleep, I would be back on the bike. This was not to be the case. Not only did I NOT get a good night's sleep, but in the morning my body let me know that all was not okay and that I would not be back on my bike that day, that week, or even the week after. When people would ask me "how do you feel?" there were no words adequate enough to describe it. "Hurt", didn't begin to express how I felt. "Uncomfortable", was an understatement. "Dizzy and nauseous" were just a part of a bigger problem. So, I could truly only respond with "I feel like I got hit by a car!"

Despite first responders and ER doctors the night of the accident, my PCP, the MRI technician, and the ER doctor I saw the day after the accident all saying to me “how did you ever survive?” I still felt that this was going to be short-lived; a nasty speed-bump in life. This ignorance of mine was confirmed when I saw my first neurologist and he confidently told me that despite the diagnosis of a traumatic brain injury, within three months I’d be back to my old self.

Three months came and went. Then six months came and went. That whole time I remained in denial about the severity of the head injury and my neurologist continued to reassure me that this would fade quickly. Despite my ignorance of the truth, I would become depressed and frustrated when the “deadline” (given by the neurologist) came



and went and I had not met the expectations. I finally asked him to stop giving me a timetable - it wasn't helping. Around month eight post-accident, while meeting with another neurologist, I asked her to be brutally honest with me, to not sugar-coat a thing, and to tell me what to expect.

See, there's a “rule” out there that I'd never before been aware of. The general rule of thumb says “whatever you are one year after the accident, is what you'll most likely always be.” I was informed of this rule very soon after the crash and it haunted me; I counted down days to the “one year mark” willing my brain to improve. So when three months passed, then six months, then eight, and I still was not better, I began to really lose hope that this truly would just go away. At month eight, when I asked for the honest truth, I got it: what has improved will most likely continue to improve. What hasn't improved, will most likely remain the same. I knew what had improved (the nausea, the dizziness, and the weak legs) but I also knew what had not improved over the past eight months (my short-term memory, my ability to multi-task, and my occasionally slurred speech, my trouble with word-retrieval, and most debilitating: my migraines.)

Back when I was first told I had a traumatic brain injury, I researched it. I needed to know all I could. If you Google “T.B.I.” one of the first things you will see is “your new reality”, what life is like after a brain injury. Much like everyone else that commented when “your new reality” was mentioned, I too refused to believe this would happen to me, I kept telling myself “I won't have a new reality, I will go back to my old one.” But as months passed

and things were not improving I began to wonder “will I be one of those people? Am I in denial that things will return to normal?” Remember I said at month eight, I asked my neurologist to be honest with me and tell me what to expect? Her brutally honest answer was what I needed to hear: to begin to accept that I too would now have a “new reality”.

So, what is my “new reality”?

- I have difficulty with noise, lights, multi-tasking, short term memory, processing, and a few other cognitive functions.
- I see a neurologist every two weeks to receive two, not so comfortable, injections into the back of my head to “numb” it as an attempt to mask the migraine. Every ten weeks, I also see the neurologist for thirty-one injections around my head, neck, and shoulders, to also numb the area and mask the pain.
- I have three different prescriptions to take as well, to try and make it so I can just function each day with the headache/migraine.
- I have cognitive therapy once a week; I see a TBI specialist once a month; I have speech therapy once a month.
- More so when I'm tired, I have trouble having conversations, focusing, word-retrieval, keeping my train of thought, depth-perception, etc. These troubles almost look like being drunk and I have been accused of it (despite having no alcohol in my system), on more than one occasion.
- Some friendships have suffered since the accident because people can't comprehend what it's like for me and I've had many arguments with family/friends to try and get them to understand.
- I need to greatly limit my activity because I become too tired. One year ago, I could have gone for a hike, a swim, and bike ride in the same day and still be fine to meet up with friends for a meal after. Now, I can ride my bike and that's about it. Some days I can ride my bike and one other activity, but I need to choose wisely.
- My ability to fully do my job is in question.
- I can only be around family/friends for small periods of time because I become too tired and overwhelmed by everyone and all the noise. I'm losing time with my young nieces and nephews. And when I am around them, they are always being told to "be quiet...T has a headache".
- Although I am back to riding, I do not ride as often as I'd like because my head doesn't allow for it. I remain nervous around cars as well, which adds a new challenge to riding on the road. And anyone that knows me knows that biking is my world!

Today is my one year mark. It saddens me that if the “rule” I mentioned earlier is true, this is now my life. Migraines and a rattled head. I know the accident could have been much worse and I made out better than I should have considering the circumstances, but that doesn’t make the bad days easier. I try not to be angry about this, bad things happen. But some days, the anger is all-consuming. I say that I would love for just one day to feel “normal” again (no migraine, no cognitive issues, etc.), but truth be told, over the past 365 days, I’ve forgotten what “normal” feels like.

If nothing else comes from this accident, take this...share the road. That cyclist that you’re driving too close to could be me.

## Meet Jen Dodge

*Jen is a 34 year old resident of northern New Hampshire. On August 19, 2014, she was hit by an SUV while riding her bicycle on a group ride. Since the accident she has written several articles titled "Confessions of a Concussed Cyclist" to help inform others and as a form of therapy for herself. She is a certified Special Education teacher, and an avid cyclist. Jen uses her own story to encourage people to become informed about the invisible disability of a brain injury and to be kind to cyclists and Share the Road!*



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## **An Interview with Barbara Webster**

### **Brain Injury Survivor and Author**

Barbara Webster, who penned [Lost and Found – A Survivor’s Guide for Reconstructing Life After a Brain Injury](#), shared about her own experience as a brain injury survivor and as a facilitator for hundreds of support groups in a recent interview:

**Question:** *Why did you feel compelled to write Lost and Found?*

**Webster:** I needed to educate myself. After my injury (20 years ago), there were no resources available for survivors of brain injuries. The first time I heard about “strategies”, it was from another support group member and it felt like a “light bulb moment”, a little miracle. It gave me a tool to start figuring my way out of the terrible place I was in. It gave me HOPE. Figuring out strategies to help me do whatever I was trying to do became my MO, my method of operation. Figuring out tips, tools and strategies changed my thinking from “I can’t do this” to “HOW can I do this?” As a support group member and facilitator it became my mission to share strategies and this way of thinking with other survivors, to promote the concept of extended rehabilitation, to foster HOPE. I hope the book will help many more survivors in that way.

**Question:** *Looking back, what would you say made the biggest difference in your rehabilitation and healing?*

**Webster:** I was so amazed to discover the existence of the Brain Injury Association and the support groups for brain injury survivors and their families that sprung up everywhere. Finding out that there were other survivors who were dealing with the same challenges was such a relief. Finally, I was not alone in what felt like a death struggle. I learned about available therapies and started getting the help I needed. And once my husband attended

a support group meeting and understood what I was going through, he became much more supportive – he got it!

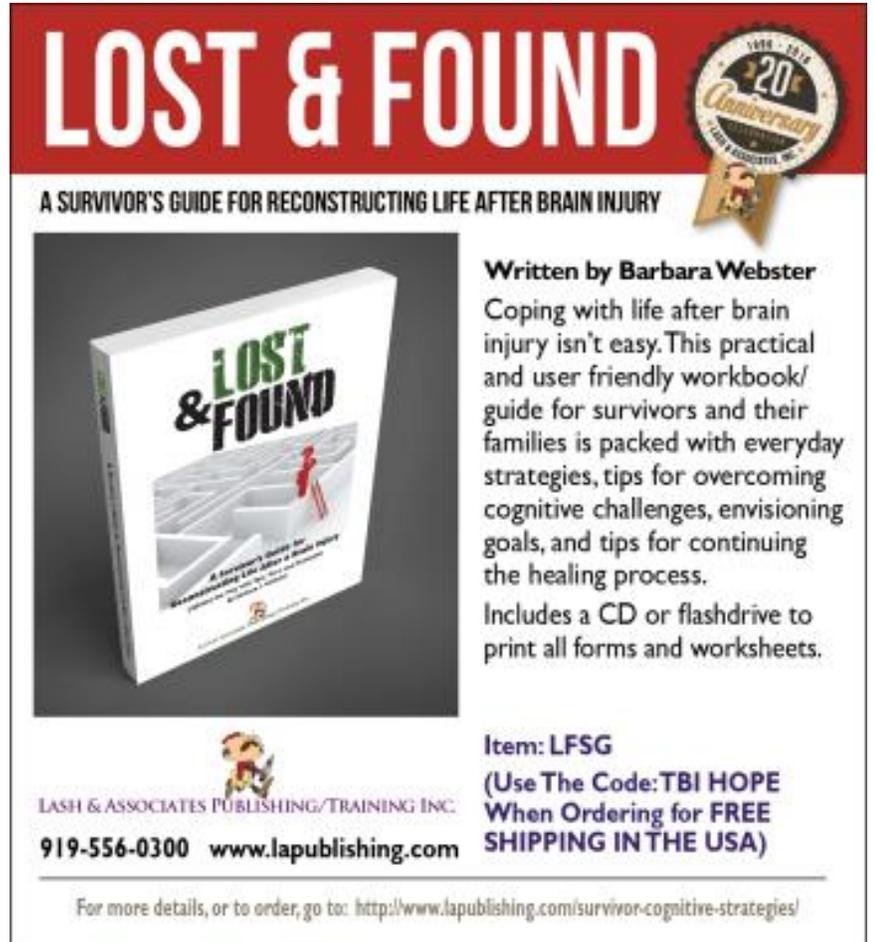
**Question:** *Knowing what you know now, what would you have liked to have known then that could have made a difference in your healing?*

**Webster:** I really wish the staff in emergency rooms were more familiar with brain injury protocol, specifically closed head injuries. It would have been so helpful to have information to refer to when my symptoms persisted. This could have minimized the frustration and despair we had with not knowing what was wrong with me or what to do about it.

**Question:** *Let's talk a little about family dynamics. How did your injury affect your relationship with your husband and other family members? What about your career?*

**Webster:** Outside of taking care of ME, my focus has always been taking care of my family. We already touched on my husband's frustrations and that after attending a support group meeting with me, he finally knew what I was going through. My son was young at the time of my accident and really did not understand the magnitude of my brain injury. As for other members of my family, they really were not involved with my rehabilitation. Some lived away from us, some chose to remain outside of the situation. Interestingly though, I found that when I was able to help myself, I was then able to help others in my family. Returning to work was out of the question. I simply was incapable of performing all the tasks related to my previous job. Instead, I started to lead support groups, which was something I found I was good at and could do easily.

Initially the injury turned our lives inside out, threatening our marriage and my ability to be a parent, as well as our financial stability when I could not return to work. In the beginning I could not do most of the things I used to be able to do, even everyday tasks.



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We had to figure out new ways to function as a family as I figured out new ways to function as myself. We had to simplify our lives and my husband and son had to take on more responsibilities and become more independent. I was very lucky in that my husband was supportive once he understood more about brain injury. We began to work together to figure things out and it made all the difference. Many survivors are not that fortunate, creating a huge handicap for the survivor.

**Question:** *What about your sense of self?*

**Webster:** It's been quite a journey...20 years' worth. I know that my rehabilitation and healing are ongoing processes and that every day I am recreating my life. I know that I have a strong support system for which I am always grateful. I now celebrate every little daily success and have found that simplifying my life has brought about a comfortable balance, most of the time. My family and I have all learned to be more patient and supportive of each other. I believe that my brain injury brought my family closer together. Like many who have had a disease or injury, not being able to do everything I wanted to do caused me to re-examine my priorities and determine what was most important to me. I measure time and effort carefully, to this day. Not having much to spare, I try to measure what tasks are a good use of my limited energy. I live each day more deliberately, focusing on what is truly important to me and try to let the rest go without feeling like failure. It is really a gift, a gift of perspective not usually gained until late in life when you contemplate your limited time left on the planet. For me, like many who have had similar experiences, my focus became the important people in my life, my family and friends.

**Question:** *Any last words?*

**Webster:** Have faith in yourself and don't give up. Know that healing from a brain injury takes a long time and you have no way of knowing what the future will bring. Treat yourself like you would treat your best friend if he/she were dealing with a serious illness. Make time to do something that will make you smile, every day!

## **Meet Barbara Webster**

*Barbara J. Webster is author of [Lost and Found, A Survivors Guide for Reconstructing Life after a Brain Injury](#), Lash & Assoc. Publishing and a contributor to [Chicken Soup for the Traumatic Brain Injury Survivor's Soul](#).*



# **A Caged Mind**

**By May Mutter**



It all started in February, 2013. I slipped on the ice while curling, hitting my head on a rock. I laughed it off, and carried on. Two weeks later while playing volleyball, I got hit directly between the eyes, which knocked me out before my head hit the floor. When I got up, I was still dizzy and couldn't see straight. I know now that I should have sat down and given myself a chance to recover; it could've made all the difference.

I looked at this way: you don't run to the doctor every time you hurt yourself. Yeah it hurts, but you suck it up and keep going - so I ignored the pain. The following week, I continued to play volleyball out of stubbornness, which further aggravated my brain, and just the movement of diving around the gym floor subjected it to yet another concussion. Like with a bruise—you don't keep poking at it to see if it's healed because that slows down the actual recovery process, but since everything we do is constantly poking at our bruised brain, no wonder it wouldn't heal.

The next day, I remember sitting at work with a bag of ice on my head and a bottle of wine in my hand to numb the pain. Eventually, my coworkers forced me to go to the ER where I was dismissed almost instantly. I was given painkillers and told I'd be fine in a week or two. I wasn't. I spent the first month and a half in complete darkness, and couldn't even carry on a conversation with my husband.

It wasn't until late May of that year that a story hit the news: a local high school girl died from getting a second concussion after ignoring her first. Only then did my doctors decide

to even send me for an MRI, actually start paying attention to me, and even referred me to a concussion specialist.

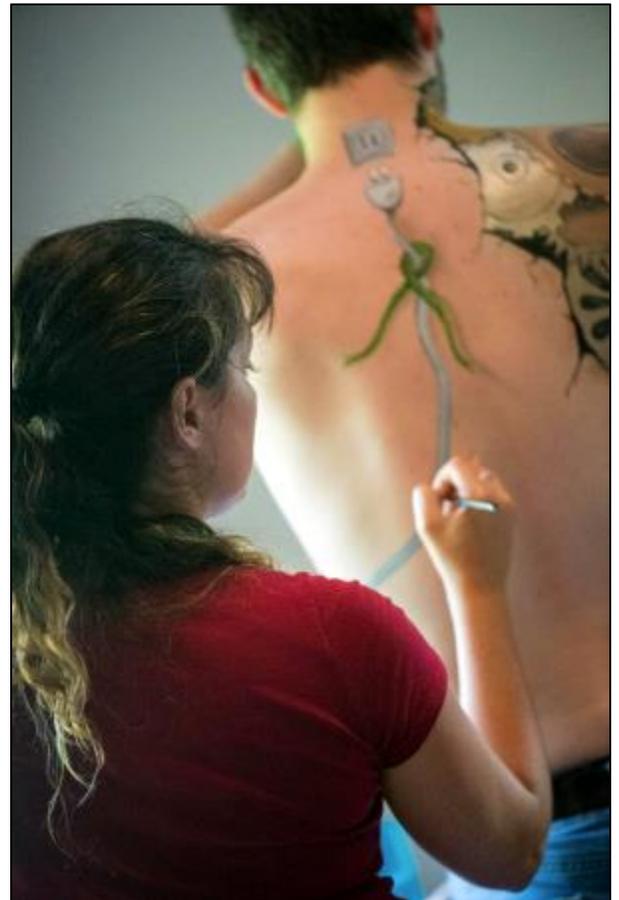
I couldn't do my job and realized I couldn't even find new work that would accommodate my new situation. Insurance eventually agreed to short-term disability, but refused for almost three years to pay for long-term. I'm lucky that's changed because I had an amazing team behind me who encouraged me to get a lawyer involved and fight. According to the insurance company, a board of doctors on the other side of the country claimed head injuries are a problem for a maximum of three months, after which you should be back on your feet.

They requested letters from all of my doctors and therapists, but then stated it was "just an opinion" and continued to refuse my appeals. Between that and no one being aware of my invisible injuries, I felt so alone. I'm considered a high-functioning survivor, yet getting through the day is constantly a challenge which you would never know by just looking at me; so much of it is an act. The headaches, lack of concentration and focus, the light and noise sensitivities, my mood, and irritability level all spiked. To this day, only those close to me understand what I'm going through, and this is because I finally hit a point where I considered ending my life—me, the so-optimistic-you-can-call-me-naive person.

I felt so alone...so caged. There were so many things I wanted to do but couldn't because of my concussions.

I starting drawing and was asked to draw how the concussions affected my life: caged in a prison that happened to be my head. So I drew a picture of me with a bandaged head behind bars to make the invisible visible.

Then I wrote a blog post about what went through my mind, and the number of people who reached out to thank me was unbelievable. So many people felt so alone and so trapped, and they said that I put into words what they haven't been able to, allowing them to share their feelings with their significant others



and to even understand it themselves. So I started focusing on my message, "You are not alone," and thus, *A Caged Mind* was born.

Most information about TBIs is overwhelming and requires more reading than our injured brains can handle. So if I, the high-functioning survivor that I am, couldn't handle it, how is everyone else dealing with it? So I've decided to combine my previous life, where I was a body painter, and my current broken one, to create *A Caged Mind*. I am currently body painting people impacted by concussions to give a visual story of what a concussion is and how it affects us. It's about the symptoms, what to do, and what really goes through our minds, brought to life for people without TBIs to visualize and understand, but also for people with a TBI to know they're not alone. I'm working on publishing this as a beautiful coffee table book that people would be proud to have in their homes; it serves to spread the word and raise awareness about concussions, as well as reach out to concussion survivors so they know they're not alone.

If only I had known to take it easy after my first hit, I may not have become disabled for life.

## **Meet May Mutter**

*May sustained four consecutive concussions within three weeks in sports. With the belief that the invisible injury is an isolating journey, she is an advocate for brain injury awareness one body painting at a time.*

*For more information on her project, 'A Caged Mind,' check out [Facebook.com/thecagedmind](https://www.facebook.com/thecagedmind) and her blog at [www.caged-mind.com](http://www.caged-mind.com).*



*"Without the dark, we'd never see the stars."*

-Stephenie Meyer



# **The Emergency Room**

**By Michele Alvarez**

I search frantically for the hospital that I only heard of an hour ago. Oakwood Southshore. Why would they bring him here if it was so far away from the accident site? Don't get me wrong. I am thankful they did not bring him to the closest hospital. That one is not known for the highest of patient care so that makes me feel marginally better. Trouble is I can't seem to locate it and I'm afraid if I don't get there soon, I will start to cry.

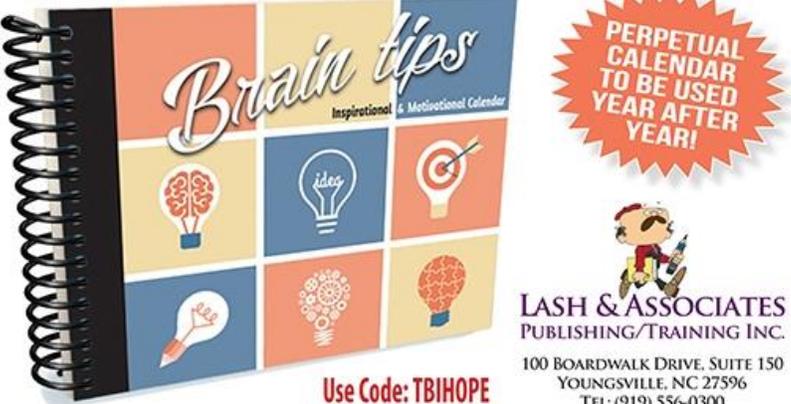
Sitting at a stop light, I am beginning to panic. No signs for a hospital and I am unfamiliar with this whole area. I spot a small ice cream shop with a neon 'OPEN' sign and tear in the driveway. I dash from the car leaving it running-door wide open. Inside, people are laughing and enjoying their cold treats. Don't they know something terrible has happened? It's Friday afternoon. Many schools just let out and you can tell the relief on the faces of those inside.

I desperately search the brightly decorated room for a sign of help. A man in his mid-fifties catches my eye and holds my gaze. Approaching him quickly I pant, "Do you know where Oakwood Southshore is? I need to get there. Now." He must notice my frazzled appearance but says nothing. I am still in my pajama pants and old tee shirt from school. It was PJ day today and I never even changed when I got home. My hair is coming out from a loose bun and sweat is pouring down my spine.

"You are very close. Go straight through this light and turn left at the apartment complex. Follow the main road all the way to the end," he gestures with his hand the way. "The

Emergency Entrance is on the right. This way you avoid the Michigan Left further down the road.” He smiles gently as if he understands my need at this moment. I want to explain what has happened. To tell him my life has changed so drastically in the last hour. He seems ready to listen, calm and patient. It would be nice to get a waffle cone filled with chocolate chip mint, sit and watch the cars drive past, and pretend there is no rush.

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to the receptionist and sign the “Permission to Treat” form.

Thelma leads me past a general waiting room and to a smaller room off to the side. The contemporary artwork on the walls and dark grey utilitarian carpeting are probably meant to speak ‘comfort’ but it all makes me feel terribly out of place. This is a room where people get bad news.

I am shocked to look up and find it is filled with people who are talking and clutching one another. Harley jackets and American flag bandanas are mixed with what I recognize to be Ford work clothing. Of course-we are only miles from where he works and it appears word has spread quickly.

The lot is smaller than I expect. I see an open spot and dart in. Both hands on the top of my steering wheel, I rest my head on the backs of my hands. This is where he is and I have no idea how bad it is. I peer up at the entrance doors and see Thelma, Jimmy K’s wife waiting for me. She looks regal as ever, perfectly groomed and looking like she is ready for Sunday services. She is expecting me, I know. We spoke several times on the phone already.

I gather my purse and phone and make my way across the scorching hot parking lot. Thelma opens her arms to me and I fall into her. She is petite and slight but stronger than she looks. She holds me close and gently guides me inside where I show my ID

There are not enough seats it seems and my anxiety rises. There are some faces I know but many I do not. All talk stops when I step into the room with Thelma. Eyes are glued to me, filled with pain and sympathy. All I want is to see my husband and take him home. This is not what I bargained for.

## Meet Michele Alvarez

*Michele Alvarez is a middle school teacher in a small, rural district. She graduated from Eastern Michigan University with a bachelor of science in emotional impairment and a master's degree in learning disabilities.*

*You can follow Michele and learn more about her journey at [www.malvarezathome.wordpress.com](http://www.malvarezathome.wordpress.com)*



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# TBI HOPE Back Page

As we turn the page on 2016, it's hard not to look to the future with optimism. Science continues to reveal that brain injury recovery is indeed a lifetime experience. More survivors than ever are exceeding expected outcomes.

Every year at this time, I like to look back over the year prior and reflect on what has come to pass. This past year, our [Facebook community](#) has grown to well over 20,000 members. Our community is active, engaged and supportive with most months averaging a quarter-million to a half-million user engagements per month. Think about that number for a moment. Up to **half-a-million** likes, shares or comments a month. There is such an unfilled need for meaningful content from within the survivor community. We are grateful to have played a small part in filling that need.

This past fall, we launched our [Brain Injury Book Directory](#), a single place where those in need can find the-best-of-the best in titles that help those trying to best navigate life after brain injury. We feature books from fellow survivors, caregivers and members of the professional community.

TBI HOPE has become larger than any one member. It is a "we" community in the truest sense.

My wife Sarah and I are already looking forward toward 2017, asking the same question we did a year ago. "How can we bring more information and resources to those who need it?"

If you have an idea, a thought, something that YOU think might be a natural addition to our ongoing brain injury advocacy work, I'd love to hear from you. You can email me directly at [david@tbihopeandinspiration.com](mailto:david@tbihopeandinspiration.com).



*David*