

September 2016

# TBI HOPE

MAGAZINE

**HOW CAN YOU SAY  
THAT IT WAS A GIFT?**

**The Bicycle That  
Broke My Brain**

**The GIFTS of my TBI**

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# TBI HOPE MAGAZINE

*Serving All Impacted by  
Brain Injury*

**September  
2016**

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# Welcome

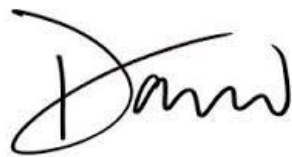
Welcome to the September 2016 issue of TBI HOPE Magazine!

For one of the first times since our publication began its journey into the world of brain injury, every one of this month's contributing writers is a repeat contributor. I find that such a living testament to the spirit of the concussion/TBI community.

So many others, kind souls who never asked to have brain injury as part of their life's narrative, have chosen to give back to our community. This they do selflessly so that others can find hope and inspiration, and come to the realization that a meaningful life is indeed possible after brain injury.

We hope that you enjoy this month's issue. If you have any suggestions about how to make our publication even better, we'd love to hear from you!

Peace to all living in the realm of brain injury,



**David A. Grant**  
*Publisher*

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*"Happiness often sneaks in through a door you didn't know you left open."*

~John Barrymore







# Hope Changes Everything

by Nicole Bingaman

After my son's fall down thirteen stairs on Thanksgiving Eve of 2012, we formed a gathering in the dimly lit corridor of the hospital. The waiting room closest to the AICU was closed, so we created our own space. Areas were available on other floors, but we needed to be near Taylor.

Around the third day of our stay, a well-intentioned clergyman came to visit. As he stepped off of the elevator and into our meeting place, he spoke, "I understand things look pretty hopeless here." Immediately, I felt our internal attack. *We were allowed to acknowledge how bleak things were however, we did not want someone who was merely an acquaintance to express it.* We had been told that Taylor may not survive, and things were leaning more that way, but we did not want to hear the word "hopeless".

After his initial words, I shut him out. My father tells me that the clergyman went on to share some thoughts that were far less callous, and that he actually intended to be encouraging. But his opening statement was not something that created a desire to hear any more of his thoughts. Looking back, I know that this man's words were not intended to deliver the blow that they did. But something else also came from his utterance of fear, and that was our collective ability to have hope.

The night before, our middle son, a college sophomore at the time, brought one of my sweatshirts into Taylor's room. He whispered, "Let's leave this by Tayl." Written on the front was one word...**HOPE**, and on the back were two words...**changes everything**. He

wanted to put it on Taylor's bed, but we had to settle for the chair that was situated closest to him.

The shirt was something I had created years before. It represented that good can arise in the most horrific of circumstances. In response to losing my stepbrother as the result of a random act of violence, hope had arisen. My brother had been shot in the head, and died immediately as a result of the trauma to his brain.

Now my son lay in the ICU, fighting for his life, with a brain injury. I again learned that hope could exist in the chasm of grief, fear and despair. The shirt was created in my brother's honor, and now we wanted Taylor to be surrounded with what it represented.

*Hope was all we had left.*

Hope is a complicated concept. It represents believing that something can improve, despite the current state of circumstances. It means that in the middle of death, there can still be life. I have come to understand the value of hope more than ever. Hope signifies that while we might be powerless to change a given situation, we are not powerless in our response to it.



About a year later, our family was gathered around the dinner table. Taylor had survived weeks in the ICU, lived at rehab for several months and was now home participating in outpatient therapies. He had relearned to walk, speak, eat and much more. We were sitting at the table with someone who embodied perseverance and determination, and yet we were depleted of hope. To say that things felt horrible would be a vast understatement. Each one of us who was able to feel, felt an immeasurable sadness, frustration, and anger about what had happened. We were stuck in the unknown space between where we had been, where we were and where we would be going.

We had to take turns sleeping in Taylor's room, because he was unexpectedly regressing, and we had just learned that his body was rejecting the piece of his skull that had previously been replaced. We were going to have to face another series of unfortunate circumstances. After surviving more than we ever imagined, the possibility was again

presented that we could lose all that we had fought so hard for. We could lose even more of Taylor.

Taylor tired quickly at the time, and he did not last long at the dinner table. We had returned him to his bedroom, right next to the dining area, and my husband and youngest sons sat at the table with me. If hope was a picture hanging on the wall of our home that evening, it would have been visibly smashed, dismantled and removed. We were too exhausted to hold on to hope, and the situation seemed to scream at us, like a military general on a tirade, “Let hope go.”

I still recall the heaviness around the table. No one really knew what he or she were feeling, or why they were feeling this way, but it was evident that we were all aching inside. Emotional turmoil, months of exhaustion, and now another huge setback, was smacking us hard, and it appeared that defeat was replacing any hope we had reserved.

My youngest son spoke amidst the silence. Tanner was a high school senior. He was an athlete, and despite his small stature and lighter weight was a respected running back, known for fighting through a tough line. Tanner knew what it meant to have your body beaten, while continuing to push forward. He shared, “If we lose hope, we lose everything. Without hope, we might as well give up.” He was putting out a challenge to our family. His strength was not clothed in any great form of courage or loud voice. It was a small, quiet whisper that seemed to remind us that we could not afford to let hope go.

We didn’t discuss how we were going to get this thing called hope back. And as life with brain injury would have it, hope would come and go, and would be tested again and again. But in time I have learned to let hope be my friend, even when I feel the most despair.

Hope changes everything. Most of all, it changes the heart in which it resides.

## **Meet Nicole Bingaman**

*Nicole has worked in the human service field for over twenty years. Since Taylor’s injury Nicole has become an advocate and spokesperson within the TBI community. Nicole’s book “[Falling Away From You](#)” was published and released in 2015. Nicole continues to share Taylor’s journey on Facebook. Nicole firmly believes in the mantra that “Love Wins.”*







## **Eat, Drink & Rest** by Tris Greenman

“I am not paying \$20 for food that I cannot taste,” advised my husband, Tim, adamantly. This was our first attempt at going out to eat since the June 2013 accident that left him with a TBI. Amidst the damage his skull had suffered, his olfactory nerve was severed leaving him with the inability to smell, and without smell, one cannot taste. Anything. There is a word for that as well. Anosmia.

Prior to the accident, we were the couple that tried out new restaurants in the area and reported back to friends on whether or not they were 5-star, so-so, or scary. I collect cookbooks and would often use Tim as my guinea pig for a new recipe. His appetite was infamous and contradicted his lean, 6’5” frame. He would drink a gallon of milk almost every day and in the early days after his accident, one friend joked that somewhere a dairy was going out of business. He loved food

He came home with a stomach tube. The hospitals had all tried to get him to eat after he came out of his 8 week coma however, his jaw had been broken and wasn’t discovered until after it healed crookedly. Cracking and popping sounds emanated from his head the first few bites he took, and threw him into hysteria. He didn’t know what was wrong with him.

Nutrition drinks and soft food helped him lose the tube, but then came the challenge of getting enough calories into him to nourish and heal. The brain needs food. With the

anosmia came a total loss of appetite and no sense of thirst. Tim can go for days without eating or drinking; exactly what the brain does not need when healing.

Eat, drink, rest. This mantra is written down all over our house so Tim will have cues to eat and drink throughout the day. Bottles of water, protein bars and candy bowls are strategically placed hoping to be spotted and consumed.

Not too long ago, our best friends were having an anniversary and I asked Tim if he would be okay with taking them out for dinner, like we used to. He agreed and promised to eat



whatever was soft on the menu. At our favorite restaurant, everyone was overjoyed to see Tim and promised him the best of the house. He held up the menu and said “I can’t taste food, give me bread and water”. We all tried to get him to order soup, pasta, cake even, but it only made the situation worse. I was ashamed that I had tried to do something normal again. I cannot imagine what it must be like not to be able to partake in an

experience so enjoyable for him in the past.

Meals are the most challenging now. Tim must have soft food and now is sensitive to the texture of food. He cannot tolerate crunchy bits, fatty gristle, and gummy, gluey or greasy bites. Smoothies with fiber powder, veggie powder, protein powder and vitamin supplements help out at breakfast and lunch. For dinner, I still try to find something solid and palatable for Tim, but often whatever it is goes into the blender with ice cream and he ends up drinking it. Yes, even tacos have gone into the blender.

Food and drink is only a part of this loss. Tim cannot smell gasoline or toxic substances. He had a mason jar of paint thinner in the garage that he attempted to drink, thinking it was water I set out for him. He could not smell smoke if there was a fire. There are special alarms that can be purchased that sense propane gas leaks in one’s home. Our senses are there to protect us. Tim now needs protection. All dangerous chemicals are locked away, smoke and gas alarms in place, and food containers dated and monitored so he doesn’t eat or drink something that may have spoiled.



Personal hygiene has also become a topic at our house. Carefully crafting suggestions to brush his teeth, take a shower and use deodorant, generally work without hurting his feelings. Yet, there have been times when I have had to insist on mouthwash. Can you imagine taking a swish of Listerine and tasting nothing?

I am humbled by the fortitude Tim exhibits in getting up every morning and facing another day with his aches and pains and loss of smell and taste. Wet spring mornings, wild roses around the lake, leaves burning in the fall, and Thanksgiving dinner are but a handful of the ‘smell’ memory triggers lost. People with anosmia are often depressed and feel a lack of connection with home, loved ones and one’s self. Add this to the complexities of traumatic brain injury and you have a challenge as a patient and a caregiver.

Finding reasons to celebrate the life that has been saved can help replace the losses sustained as a result of suffering a brain injury. Eat, drink and rest. The reasons will come. Eat, drink and rest. You are alive. Eat, drink and rest. We are together in this.

## Meet Tris Greenman

*Tris Greenman is caregiver to her husband, Tim, in Southwest Michigan. Continuing to work full-time along with overseeing Tim’s care and challenges has kept her ultra-busy. Tris and Tim replaced eating out with listening to music and playing cards together nightly. “TBI has taught me to be thankful for what we have not lost rather than dwell on what we have!”*



*“Happiness can exist only in acceptance.”*

*~ George Orwell*



# **A Living Grief**

by Dr. Katherine Kimes



The media overwhelms us with the sound-bite of death in this country. We are bombarded by the images of demolished vehicles empty along the side of America’s roads and the voice-overs announcing how many fatalities occurred or if people were lucky enough to survive these accidents. What is seldom, if ever, reported by the media are how many of those individuals were lucky enough to have survived, and sustained a traumatic brain injury (TBI). Little reporting is done on those survivors or the impact the brain injury had on their life. I am one of those survivors.

It wasn’t until several years after my TBI, while I was still trying to reclaim some semblance of my older self, my mother commented to me that there are worse things than death. She confided, “It is one thing to have your child die in a car accident, but it’s another thing to have your child sustain a TBI and live.” Was she saying that it would have been easier if I had just died that August night in 1989? I was speechless—not only because I was still unable to move my tongue and articulate, but I couldn’t believe what had just come out of my mother’s mouth. I simply nodded in compliance.

It is difficult to rationalize emotions, but I now know what she meant. I understood her pain as I understood my own pain. I was still present in her life, but the child she had known for 16 years was no longer there. I was alive, but not really alive; not my “self”. My mother was experiencing a living grief. My soul, my personality, momentarily died the night of my TBI, but my physical body managed to live. As a result, I would never be 100% the same person.

In hindsight, however, my mother wasn't talking about me or the reality I now found myself in. Rather, she was referring to the individuals she saw, day after day, at the rehabilitation center who sat in wheel chairs with blank looks on their faces, unable to communicate.

These were young men and women whose physical and mental conditions literally broke her heart. They would sit with blank looks on their faces—some eyes would flutter around the room and other eyes would stare straight ahead. Many smiled, while many did not. When these young men and women were spoken to, their faces showed no signs of emotion—neither love nor detest. They sat in wheelchairs. They showed no sign of recognition or comprehension. All wore diapers and had to be waited on: fed, bathed, dressed and groomed.

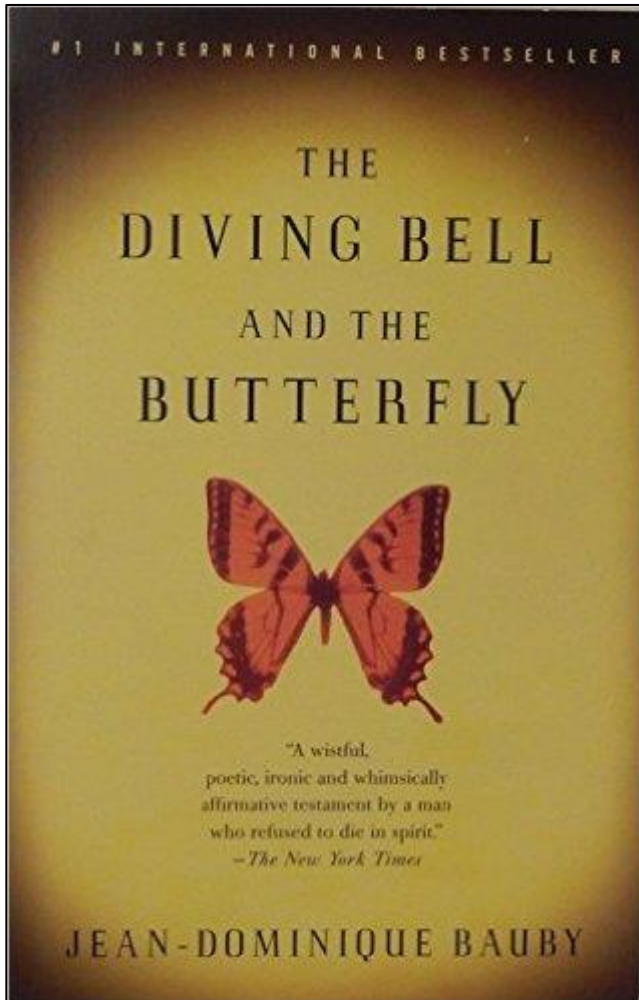


My mother wondered if these young men and women were as “dead” on the inside as they appeared to the outside world. These young men and women are the ones we never hear about. Their stories never make the 5 o'clock news. To my mother, their realities were worse than death. She knew if this had been my life after my brain injury, empty on the inside, she would rather I had not lived. But my mother refused to believe that their realities would be my reality. My mother, as usual, got it right.

It is one thing to be able to grieve over the death of a child, but it's another thing to grieve over the death of a living child, a child who's present, but no longer “there.” I'm not exactly sure how my mother would have reacted if I had been one of those women who showed no signs of emotion; no signs of recognition, and no signs of comprehension and had to be fed, bathed, dressed and groomed until the day I died. Fortunately, for both of us, their realities were not my reality.



Regardless of whether or not you, the reader, can believe or even fathom how a mother could make such a statement, I believe my mother's emotional response was completely authentic, even though it may not have been politically correct. I know for a lot of you the thought is inconceivable—to actually wish your child dead rather than alive. But to my mother, these young men and women were not living, at least not a functional life. I don't think it matters what your pre-existing capabilities are if your brain is damaged beyond repair and you become "locked-in." There is not much hope for your recovery.



Jean Dominick Bauby dictated the memoir, "The Diving Bell and the Butterfly" by blinking his left eye after he suffered a massive stroke to his brain stem. The stroke, which is another term for brain injury, caused him to become "locked-in" a motionless state. He confesses, "Something like a giant invisible diving bell holds my whole body prisoner" (3). The book was published in Europe in 1996, almost a decade after my accident and experience with traumatic brain injury (TBI). Bauby summarizes for his readers the experience of being confined to a life of locked-in syndrome, in relation to a world where human connection is maintained through personal interaction, humor, and physical touch. He narrates that he is, "paralyzed from head to toe...his mind intact...imprisoned inside his own body, unable to speak or move" (4).

What if those young men and women my mother saw at the rehabilitation facility, had the mental capacity to understand just like Bauby, but did not have the physical capacity to express themselves? Could they have been "locked-in" too? Bauby's personal experience, as recounted in his memoir, only confirmed to my mother her deepest fear—those young men and women were aware of their situations. He writes, "My old life still burns within me, but more and more of it is reduced to the ashes of memory" (77).

Prior to my TBI, I was a very independent, self-sufficient and highly motivated and determined child. My mother and I had always had similar personalities—I always considered myself my mother's child. There had always been a bond between us, but my

injury seemed to me to sever this bond for many years. But what if I had been one of those women my mother tearfully speaks about? How would my mother have handled it? Would she have had been able to handle it? Could she have handled it? I'm not sure.

Even 27 years later, my mom has difficulty talking about my brain injury and what happened to me. She doesn't believe it is good for me to hear how she felt or how she still feels. She won't talk about it unless forced. She grieves still. She will always grieve. For many weeks after my injury, she could not eat, sleep or drive a car. It was as if her ability to function stopped the night she picked up that telephone receiver. It was 2am. My father was out of town on business. The telephone rang, but my mom was awake. She couldn't sleep because she knew something was wrong, but had no one to call. The driver's mom was on the other end of the line. She told my mother that there had been an accident and she thought my condition was serious. She told my mom that she needed to get to the hospital as soon as possible.

My mom knew she wouldn't be able to drive herself so she called the next door neighbor and asked if she would be willing to drive her to the hospital. My mom hung up the phone. She went upstairs to change out of her nightgown. She stood in her closet dumbfounded, trying to figure out what she should wear. After several minutes of staring at her wardrobe, she "sort of shook"

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herself back to reality. She realized it didn't matter what she wore. She grabbed a pair of shorts and a t-shirt.

My mom's life irrevocably changed that night when she answered the phone at 2am on August 28, 1989. Her mind set on auto-pilot. Her actions were mechanical. Her complete focus was me. When I was in the intensive care unit, she spent every night, in vigil, in a spare room at the hospital. When I was out of intensive care, she came to the hospital every morning and left every night—only to return the next day. Her days were cyclical, habitual. Once I went to a rehabilitation facility, she came every morning and left at the end of a long day after I was put to bed for the evening—only to return the next day. She knew this behavior was unfair to both her husband, my father, and her daughter, my older sister, but she could not function in any other way. All her attention had to be focused on me. It was the only way she could handle the situation. This was how she dealt with her grief.

She grieved not only because she couldn't make me better or well again; she grieved because she couldn't trade places with me. She still grieves because I am not the "charmer" she once knew me as. She told me, as my mother, this is something she will never get over. Her grief is a living grief that will not go away. She grieves for the person I will never become; the husband I never met; the children I never had. She grieves for the life I was never given the chance to live. She still grieves for the life I lost. I grieve over those same things.

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My mother's coping mechanism—when at all possible—is to avoid, avoid, avoid.

While I was in the hospital, my mother avoided the doctors whenever possible. She conveniently timed her exit at the time of their routine visits. She carefully planned her escape. She did not want to hear what the doctors had to say. Every word that came out of their mouths was negative. My mother did not believe it. She would not believe it. She could not believe it. She was repeatedly told things like, “Your daughter will be bedridden for the rest of her life,” or “She doesn't have much chance for any significant recovery,” or “She won't be able to graduate from high school without major assistance, and higher education is out of the question.” My mother refused to believe the doctors' words. She didn't want to hear it. She was repeatedly told that she was not realistically dealing with her daughter's TBI. My mother's mantra: avoid, avoid, avoid. Avoid the issues she does not want to hear or discuss.

I know that after my brain injury, I did not feel alive inside. I don't think my mother did either. I guess a lot of that had to do with my inability to speak. I couldn't move my tongue, so I didn't talk. Day after day went by and I felt I was just going through the motions of life. Like Bauby, “something like a giant invisible diving bell holds my whole body prisoner” (3), but in my case my

“I know that after my brain injury, I did not feel alive inside.”

tongue was being held “prisoner”. I was a prisoner inside my body. In my thoughts I could communicate and knew what I wanted to say, but I could not make my tongue physically move to verbally express those thoughts. Even when I would talk, no one but my mom could understand a word I was saying. Yes, I was not “locked-in” like Bauby, but my brain was severely injured and it functioned differently, which caused me to physically function and behave differently. The physical struggles I endured created deep emotional struggles within myself. There were times I was depressed and had suicidal thoughts. Isn't it only natural that my mother felt loss and experienced similar emotions too? She did give birth to me. She had hopes and dreams for me just like I had hopes and dreams for my own life.

The world moved past me and I was unable to participate. The world kept moving on without me. Was this the life I was meant and destined to live? I grieved for what could have been.

I now had physical limitations. I oftentimes behaved irrationally, but it got better day by day. I know I struggled with the person I had become and all of the obstacles I faced; still face, and have yet to face. After my injury, I could not walk, talk, hold up my head, or even feed myself. I was like a helpless infant.

There was a time, after I graduated from college, when I would just cry and cry as I lay on my bed, grieving for the life I would never live and what my life had become. I learned the hard way that dreams do fade away. The dreams from my adolescent years were never realized. It's only rational that the dynamic of my brain injury affected my mother in a comparable way. We both experienced the loss of a loved one. Society doesn't seem to



understand, or perhaps doesn't want to understand, how brain injury impacts the individual and the family as a whole and causes the family dynamic to shift.

Since the accident and thus my injury, I've had to try my best to live my life in spite of my injury. My desire and determination have helped me in the long run to reestablish a sense of myself and allow me to recover as much as I have. My mom has told me that she is "very proud of my determination and so many accomplishments." She believes it was "this drive and determination that the accident didn't take away," and I would not be where I am today without it. However, despite my successes there have been times when life and the people in the world have not been very kind to me.

Despite the complete detour my life took after my TBI, I have learned to accept brain injury as my reality. I now live with a brain injury—it will never go away. It has taken almost 23 years, but I have come to accept that this is my life. I've tried my best to move beyond this obstacle. I have accepted that the dreams from my adolescence are unrealized and by no fault of my own. No one is promised that their life would be easy. We are not given a free pass, but we are responsible for making the most out of our situations the best we can. It is just the luck of the draw, the cards I was dealt with in life. I still grieve over those lost dreams everyday—at least in the back of my mind I do.

I have learned to accept that this reality is my life. I have learned to move past my grieving. The life I have is now. What type and quality of life would I be living if I incessantly

grieved over the life I lost, that was never meant to be? My mother still grieves over the life I now find myself in. I know she wishes my life would have been different and not so full of so much pain and so many obstacles. It's not a life's path that you dream of for your child, but it's my life none the same. Bauby's grief for his past life is quite evident in his memoir. My mother's grief is a living grief that she honestly admits that she will never get over. There are many dimensions of living grief. My mother and I have experienced two spectrums. My mom's grief is the living grief experienced by a mother for her child who has not died, but has lived through a TBI. My grief is the experience of surviving and learning to function independently after a TBI. I have come to learn that while my life has irrevocably changed, I need to move beyond my grief to make a new life for myself. I owe this to myself.

It's quite understandable that the media never discusses TBI or acquired brain injury. The dimensions of injury are quite complex. Not only is there the physical aspect, but there is an emotional aspect that affects the individual with brain injury and all members of the family. People do not want to think about what could or would happen if they sustained a brain injury. However, TBI does not discriminate. It does not care what race or ethnic group you belong to. It's an equal opportunity disabler.

We live in a world that is not very kind or understanding to those of us who are different. It has been a very difficult road for me to travel not just because of other's judgments, but because I had to find a way to move beyond my living grief and learn to live life. I can honestly say, however, this is not what I had wanted my life to be. I had dreams for my future, full of possibilities. I can honestly say, TBI was not supposed to have been a part of it. I think I can safely speak for my mother too when I say this.

## **Meet Dr. Katherine Kimes**

*Dr. Katherine Kimes has a Master's Degree in Literary and Technical Writing from DePaul University. She also has a Master's degree in Transition Special Education with an emphasis in acquired brain injury and a Doctorate in Special Education also with a concentration in acquired brain injury. She has worked as a CSPPPD Service Coordinator and is a Certified Brain Injury Specialist. Please visit her website, [www.ABI-EdServices.com](http://www.ABI-EdServices.com), for more information.*







# **A TBI Moment to Top All Others**

by Jeff Sebell

Just as when I was born, I don't remember the moment my life changed forever. That's all it took: one moment. It is amazing to think that if I had done just one thing differently, or if the timing had been altered by a second or two, that huge moment might have been one more forgettable thing in my life; but it wasn't.

A string of events played out perfectly (or imperfectly): some kids had taken the stop sign that was meant for me and my car crossed the intersection at the perfect moment for another, speeding, car to broadside me.

Most of us probably don't have a clear memory of "our" moment, although some of us might remember the time leading up to "our" moment. We may even go through those fateful, pre-TBI events, wondering what we could have done differently; but it doesn't matter now. What's done is done.

What does it all mean? Well, "my" moment, despite the fact that I don't remember it, has become the most talked about and thought about moment in my life. But I have a strange question which just occurred to me.

If I can't remember it, did it really happen?

Here's a scary thought: what if I'm dead? What if I died as a result of that accident, and don't realize it?

I was told when I woke up that I had been in a coma for a month. How can anyone be unconscious for a month? Those are all just words.

Maybe I have been removed from the world I used to live in and transported to an alternate universe. That would be a hoot; put into



an alternate universe where everything is the same except for yours truly. This is where I spend my life treading water, trying to keep my head in the air so I can breathe; because, in many ways, that is what my life has become.

This is my life.

I've come to terms with the fact that life is made up of moments; great and bad, happy and sad. All moments are full of things happening; either one thing happens or another happens. Each moment represents the passing of time and we are the ones who make it mean something.

Just as we might have cataclysmic, scary or hurtful moments in our lives, we also have moments that are supremely satisfying, rewarding or make us glad to be alive. We get to decide what each moment is. Some are worthy of being forgotten and quickly slip away. Some are indelibly engraved in our minds.

We get hung up on the fact that it only takes a moment to have a brain injury, but in reality, it really isn't such a strange occurrence for one moment to change everything in our life. The trick is not to get hung up on the fact that those moments happened and affected us, but to come to terms with them by focusing on how we can adapt to life after them.

The first thing we can do that might help is to tell ourselves that these are just *moments*.

Of course, one thing about those *moments* is that the changes they bring can be hard to accept and understand. That makes the adaptation process difficult and time consuming. But eventually we need to find our way out of the woods so we can begin the process of "renewal", or adaptation to our new circumstances.

After forty years of reflection on that *moment* and its consequences, I have come to the conclusion that the only thing I can say with certainty is that my life would have been different if I had not had my *TBI moment*.

I would be doing myself a disservice to say that moment was either good or bad. It was just a moment.

That said, what would my life have been like if I had not had a brain injury?

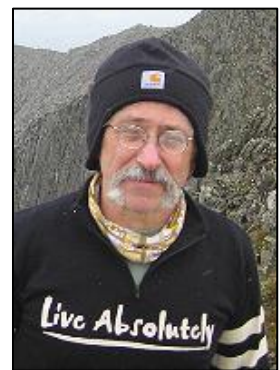
I can't answer that, nor will I ever be able to. I might like to think my life would have been great if things had gone along as I was expecting; but I will never know.

That brain injury certainly had an impact on the things I can *do* or how I can perform, but it didn't really impact *what I could be* as a human being. Becoming the best human being I could be became my goal, as I saw that "achieving", as I defined it before my TBI, was no longer relevant.

That moment changed my life like no other, but even so, I am determined to make that one, singular, defining moment no more important than any other moment in my life. To give it too much importance would distract me from living my life and learning to flourish under my new circumstances.

## Meet Jeff Sebell

*Jeff is a nationally published author, 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.*







# **The Bicycle that Broke my Brain**

by Sandra Madden

I have been slowly working on purging the attic, and closets, cabinets, drawers and bookshelves, of the “accumulations” of life. Certainly, there are many things that are easy to part with: old clothing and crafting supplies, expired medicine and old first aid supplies, expired food (have you seen how disgusting a bottle of lemon juice from 2010 looks like?), tattered holiday decorations, old paperwork and books I’ll never read.

My husband would bluntly call everything I have saved in my life “junk”, and would no doubt throw it all out in a heartbeat. He has no collections to speak of, no connection to his childhood that is visible. As for me, I have a hutch filled to capacity, walls covered in framed photographs, bookshelves full of antique cameras, a small collection of old photographs, and even my high school letter.

When my mother died, I packed up the old photographs, her recipes, knickknacks, decorative plates, the green glass parfait glasses that only graced the kitchen table on holidays, and the Christmas ornaments I loved to hang year after year, and these memories moved with me - to several apartments and two houses.

My godmother gifted so many lovely collections to me during my childhood, and I still have them today, mixed with the memories of my mother’s possessions. These collections, reminiscent of my childhood, are lovingly displayed in my hutch and are in my line of sight every day. There is comfort in these memories as the years pass since my mother’s death.

After the births of my children, I became a bit obsessed with the memories of their lives. After all, I have only one photograph of my mother holding me as an infant and two elementary school projects that she saved. I hang them up every Christmas – a construction paper Santa Claus with a beard and cap dotted with cotton balls, and a crayon drawing of Santa pulling his sleigh of reindeer.

My mother was so busy raising four children by herself, left widowed when I was four months old, there wasn't time for photographing her children and saving artwork and school papers. This understanding helps me to cherish the photographs I am fortunate to have found after she passed away. Yet, it's how I explain the reason I have huge crates full of photographs from the minute my children were born, thousands of digital photographs, and every paper they brought home from school from pre-school to sixth grade!

Over the last three weeks, we moved 15 buckets out of the attic, filled with the kids' preschool and elementary school papers. Yes, 15 buckets! Typically, cleaning out attics and closets can be quite a wearisome and laborious job, but despite the huge job ahead of me I was looking forward to a trip back in time. This project was truly a labor of love, as I culled 15 buckets down to two, and spent a week in love with my children's innocence and loads of artwork.



My “over-saving” led to the discovery of many calendars, including the year 2006, when a bike accident is marked quite simply on June 11th, right next to a notation of a Girl Scout meeting on June 12th. Missing are calendars for 2007 and 2011, the years where I sustained a fall head-first into the boards at the ice rink, and a trip over a garden hose falling face first into the cement driveway, breaking my fall with my chin.

Unknowingly, the bicycle accident in 2006 was my initiation into the world of traumatic brain injury (TBI), yet no one would realize I sustained a TBI until 18 months passed by.



My symptoms “flew under the radar” when cognitive issues were deemed a side effect of medicines that were being tried to treat neuropathic pain. Ten years has passed and the cognitive issues from the culmination of three falls still plague me on a daily basis.

Concurrent with an injured brain is chronic pain that affects me every waking moment: headaches, neuropathic pain, muscle pain, tendonitis, recurring hip pain and arthritis throughout my body. The pain issues have increased in ten years, the doctors’ visits have increased in ten years, and the frustrations have increased in ten years. The invisibility of all of it has remained the same.

The choice to purge my belongings was easy, after all, I can’t take it all in my move to Australia after the Presidential election. However, the realization of the many joys, abilities and everyday experiences that TBI and chronic pain has purged from my life is becoming more difficult to manage.

From the loss of the ability to work, athleticism and stamina, to the simpler joys of music, reading, and watching movies with my children or friends. I can no longer remember “me”; the “me” that was smart and could multi-task effortlessly, the “me” who ran two half-marathons and someday planned to train for the Boston Marathon, the “me” who could bike 40+ miles a day, flying down those big hills in the Blackstone Valley at 40 mph, the “me” who could garden for eight hours, and the “me” who didn’t have to write down absolutely everything.



Recently, as I headed home from Whittier’s farm stand and passed through an intersection, I caught a glimpse of two beautiful horses grazing in a pasture, side by side, one-quarter of a mile from where my bicycle accident occurred.

I’m not sure why, but in a split second I turned the car around and stopped to take a few photographs of the two, returned to my car, and decided to drive home on the same route that I biked so many times – the same route that 10 years ago ended in an accident that would change my life forever, the same route that I typically have avoided since the accident. As I headed down the hill, I caught a glimpse of a shape that has defined my life and my photography for many years. In utter amazement, there was a huge pink



heart painted on a tree at the site of my accident, stopping me dead in my tracks and bringing me to tears. I believe the two horses were angels, guiding me to this heart. I truly believe this pink heart was meant for me, placed there to remind me to reflect on all of my blessings when confronted with all of the pain and heartache of change and loss.

A "sign" at the bicycle accident site on Wallis Street in Douglas

In the same instant, I knew it was time to purge my life of one more possession, my Trek bicycle. If you want to buy it, I'll make you a great deal! No matter what your age, PLEASE wear a helmet on your bicycle because *"In an Instant, Your Life Can Change."*

## Meet Sandra Madden

*Sandra A. Madden, a graduate of the S.I. Newhouse School of Public Communications at Syracuse University is a photographer and writer, a Special Events Coordinator at the Brain Injury Association of Massachusetts (BIA-MA), and a brain injury survivor. We encourage you to support Sandra and [her book project](#). A portion of the proceeds from the sale of her book will be donated to the Brain Injury Association of Massachusetts.*



**TBI HOPE**

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## **How Can You Say That it was a Gift?**

by Deborah Schlag

**H**ave you ever had the feeling something was about to happen, but just couldn't quite put your finger on what it was or when it might happen? That was the feeling I had been experiencing for over six months prior to the auto accident I was in on January 23, 2003. When I spent any time praying about or looking for answers to the feeling, what I felt wasn't bad, scary, or even a cause for concern, just a very matter of fact feeling. It was sort of like my mind was reminding me that something was coming up. It was nothing to worry about, just a change or shift in my life. I had a sense of peacefulness about it. I somehow knew, no matter what was about to take place, I was going to be okay.

I thought perhaps the feeling had to do with the fact that our two youngest children were about to graduate. In my mind I reasoned away the feeling with maybe the graduation and all that goes with it was bothering me more than I thought. I would be, for the first time in twenty-six years, without children, as I knew it. I had a plan I thought, one I had been working on for some time – years – to prepare me ahead of time; allowing them to move to the next level of adulthood while allowing me to do something enjoyable, all while skipping that empty-nest missing- them thing that others suffer through and talk about. I've always tried to learn through others and find better ways to deal with life's difficulties; much can be learned through watching others or reading their stories. Learning this way has helped me many times throughout my life.

The day of the accident, after our car came to a halt, we each took a few minutes to breathe, and calmly take inventory of what might be going on or needing tended to before calling

for help. Was anyone hurt? Was anyone broken? Was anyone bloody? I was so thankful no one was REALLY hurt, or so I thought. I knew my prayers of protection over the years for the children's safety had been answered. The feeling of relief that they were safe overrode any concerns for myself. It was a gift and there were more to come.

The emergency operator had asked if we needed a tow truck or an ambulance and I assured her we did not. She sent them anyway – what a good thing! Our car was sitting on an electrical box with the wheels broken off. It wasn't going to be pulled back onto the road by anyone and my head and neck were in incredible pain. Afterwards I thought the pain would pass quickly, maybe a week or so. In the moment though, I wasn't thinking of that and I certainly had no idea it would be years before it came under control.

In those years I learned a lot about myself, anything and everything I could to help myself move forward, and more. Having and recovering from brain trauma was, to me, like skipping college and getting the degree based on experience. There was so much more to it than could ever be read in a book. It was a more thorough understanding I didn't know I wanted or needed and I'm still learning. Who knew the trauma I experienced was a gift. It would take me to new places; meet the most loving and wonderful people, and call me to move in a completely different direction in my life, exposing and strengthening gifts I already had, but never really understood, as well as discovering more that were just waiting for the right moment to come through the door for me to embrace and develop. I found my voice, which strengthened me, so I could do what I was called and meant to do.

With each step I took, I gained confidence, allowing me to step out into that calling, where I was reinforcing and educating myself even more by taking classes and associating with those who could help me find the answers I needed to understand the changes I was experiencing. Once I could put it all together, my plan was to help others with that new knowledge and understanding. I wasn't really sure what this plan was, how to accomplish it, or what it was going to look like in the end. All I knew from the beginning was that I had to help people. There was no doubt in my mind there were many like me who never had a clue of the intensity, duration, and variables of traumatic brain injury or the amount of work needed to recover.

By 2012 people started asking me to write articles for different publications, both for those seeking healing and as guidance for other healers, and so I did. It was a busy year with the release of my first book "[Becoming the Healer, The Miracle of Brain Injury](#)." The book took seven years to complete and I felt was a huge part of the healing process for me. The book was released in October 2012 and later a finalist at the International Book Awards



in the category of health, opening even more doors for me to reach out to others. Writing the book was something I would have never thought I would have done previously. 2012 was also the year, which with the help, love, and support of my husband we created Awakenings: Center for Inner Healing & Empowerment. Awakenings is a non-profit organization and we believe we are more than the physical body and each part, mind, body, and spirit must be addressed in order to heal. We help others move forward in the healing process, empowering them to confidently continue their journey with joy.

Creating Awakenings Center wasn't just an on-paper process. We purchased land and built the road to it; we purchased a building and moved it to the land; and, we are continuing to develop the land while at the same time participating in speaking engagements, book signings, support groups, radio shows, phone consultations, and tending to guests who come for healing.

There is much to do to help the injured, their friends and family as well as sometimes professionals in the health care field. I continue working with others in a healing capacity and I continue to write, to create those things needed for others. It's so easy to get off track or stuck when faced with trauma, pain, suffering and especially loss or what we perceive as loss. It's okay to grieve for a time. Set your timer, have your cry, then get back up and make a new life. You are here for a purpose, unique to you, that only you can complete. Find ways to put Joy back into your life.

If you thought you would be doing less because of your injury, think again. Use what you know. Reach out to others, no matter how large or small your reach; it will enrich your life beyond your imagination.

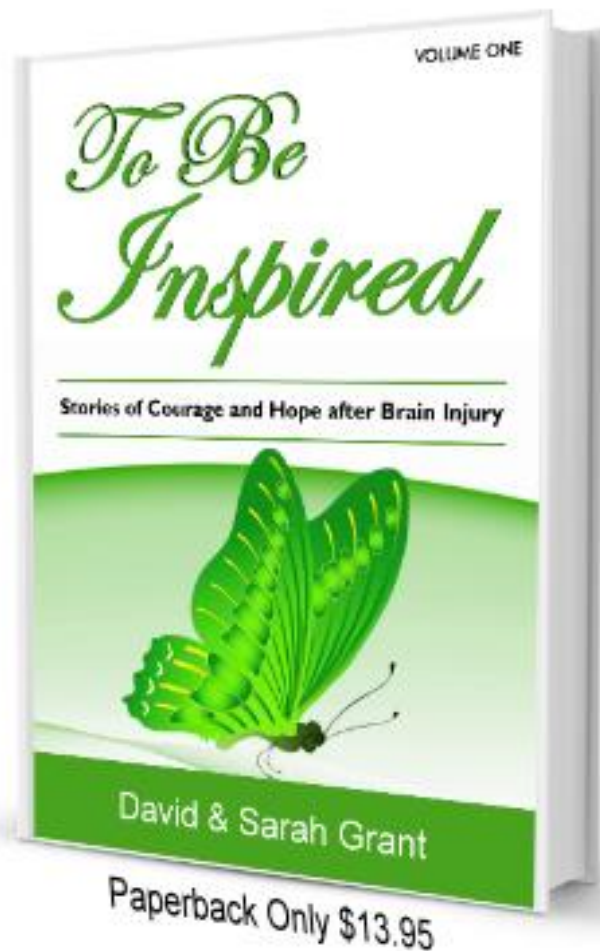
## Meet Deborah Schlag

*Deborah Schlag is the author of the award-winning book "[Becoming the Healer, The Miracle of Brain Injury](#)." Deborah lives in North Carolina with her husband where she has founded Awakenings Center For Inner Healing & Empowerment – a non-profit healing center to bring healing to others and empowering them to move forward in their own healing process.*





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## Meet David and Sarah Grant

David A. Grant sustained a Traumatic Brain Injury in 2010 when he was struck by a teenage driver. In the years since, David and Sarah have become outspoken advocates - doing their part to help end the silence that surrounds TBI.

Their monthly magazine, TBI HOPE Magazine, is now read worldwide as their advocacy work continues.



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# **The Gift of my TBI**

by Amiee M. Duffy

It was a beautiful sunny afternoon at the end of January. I had just picked up my youngest son from school and was on my way to bring him to his father so I could attend a meeting. We were driving straight down a road we had traveled every school day for years. There was no snow, and the roads were dry. Out of the corner of my eye I saw a car driving toward my driver's side door and I thought, "This doesn't make sense. Where are they coming from?" SLAM! The car plowed into my driver's side door and my head bounced off of the window.

My hand immediately went to my head expecting it to be covered in blood. It wasn't. I was dazed and remember feeling like everything was moving in really slow motion, as if I was attempting to walk and talk underwater. I looked in the backseat and asked my nine year old if he was okay. Luckily he was seated on the opposite side of the impact and was wearing his seatbelt.

I tried to get out of the car, but the door was damaged. I was able to crawl over the center console and out of the passenger door into a foot of snow. My Honda Pilot was now in the middle of someone's front lawn. My feet were unsteady and everything was spinning. I felt sick to my stomach as I sat with the door open and my head between my knees.

I could hear people coming while yelling that an ambulance was on its way. I remember trying to not pass out so that my son wouldn't be afraid, as I was carried into the back of the ambulance on a backboard in a neck brace. The emergency room was packed and there

was no space for me besides in the hallway. The lights, sounds, and smells were overwhelming. I just needed to get out of there and go home! The doctor finally saw me and prescribed me some Tylenol and told me I would probably be sore for a few days, but essentially I was fine. My ex-husband arrived to pick up our son and to drive me home. He was the first person to notice that I was not fine. "Amiee, you are not okay. Something is wrong."

I didn't realize it at the time, but I was on my way to learning about Traumatic Brain Injury. As the days went on, I not only had headaches but I had difficulty speaking. I knew what I wanted to say but the words either wouldn't come out, or they would come out slurred or stuttered. Even worse was when I believed I was talking normally and making



perfect sense and my children would look at me and say, "Mom, what are you talking about?"

I had a CAT scan and MRI, and everything was "fine." But I WASN'T. I wasn't fine at all. I was sleeping 12-15 hours a day and not feeling rested. I couldn't communicate with the car insurance company or doctors' offices because I couldn't understand the questions they were asking. I was unable to

spontaneously develop questions and ask them in a timely fashion. I was not able to function on my own and I certainly was unable to take care of my three children. When I wasn't sleeping, fear began to creep in.

I was unable to work and initially took just two weeks off. I don't think I truly understood the shape I was in. I began to have issues with short term memory. I couldn't remember a thing. I wrote down everything I needed to remember but, because I often forgot to look at the post-it's that were littering my kitchen counter, it didn't really do me any good. I went back to my Primary Care Physician and advocated for speech and cognitive therapy with a speech and language pathologist.

I went to Speech/Cognitive therapy three times a week. I struggled to remember three item lists after a 10 second delay. I could not do third grade math. I still stuttered. My short-



term memory was nonexistent. I remained in therapy for six months - this was a far cry from the original two weeks I thought I would be side-lined.

Over the course of a year, I had many appointments. Appointments with neurologists, physical therapists, orthopedists, lawyers, and ophthalmologists. I was seen for cognitive delays, executive function problems, memory issues, tinnitus, and partial loss of hearing in one ear, sensory issues, anxiety, muscle tension, poor balance, and almost constant migraine pain. As I navigated my way through the variety of appointments that year there were small victories, such as being able to drive to familiar places without having to rely on GPS and being able to complete grocery shopping without getting sick to my stomach. And finally there were larger victories - I was able to return to work full time and make a five hour car trip on my own in order to visit my parents!

It has been a year and a half since the motor vehicle accident that changed my life. I still mourn my previous life at times. There are so many things that I took for granted. I wish I had appreciated my body and brain more. I wish I didn't sweat the small stuff as much as I did. However, as with any difficulty that comes slamming into you without warning, there have been gifts.

I am getting better at accepting what is. I rush through life less. I have much more patience with others now. Even better than that, I have much more patience with myself. I am better at giving myself care. I ask for help when I need it. I am getting better at listening to my body. I invest in quality sleep and take time for massages. I make time for activities that bring me joy. I savor the good days when I am pain free. I am using the gift of my mTBI to appreciate all that I have and look forward to continued recovery and promoting awareness.

## **Meet Amiee Duffy**

*Amiee M. Duffy is the proud mother of three children. She has been teaching for over twenty years and is looking forward to using what she has learned about Executive Function and Working Memory in order to better serve all students in her classroom.*



*Check Out The All New*

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# TBI HOPE Back Page



A few years ago I was introduced to a new concept. Most of us have heard of Post Traumatic Stress Disorder. PTSD is now a very familiar condition to most. In fact, I live daily with PTSD.

But this new concept intrigued me. Called Post Traumatic Growth, it happens when someone takes what may seem to be a tragic life event and use that experience to not only reshape their own identity, but to help and to serve others who share the same fate.

It had a familiar sound to it. I started to look around at those I now call friends, people that I would not have met had it not been for my own TBI, and I realized that the landscape of my life is overflowing with PTG'ers.

This past September 16<sup>th</sup> was the first ever National Concussion Awareness Day. A young TBI survivor, local to us here in New Hampshire, founded this event. Brooke Mills was only fifteen when she sustained her brain injury. She now advocates for others who share her fate.

Years ago, I heard something like “you will find what you look for.” Rather than focusing on all the suffering in the world, today I am making a choice to seek out – and keep company with – those who are lifting humanity higher. To Brooke, and all the others like her, a grateful thank you. The world is a better place because of what you do!



*David*