

BRAIN INJURY

Spring 2022

HOPE

Magazine

support
education
inspiration

*It's the Season
For Hope!*



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Welcome



Publisher's Introduction

HOPE MAGAZINE

*Serving the Brain
Injury Community*

Spring 2022

Publisher

David A. Grant

Editor

Sarah Grant

Our Contributors

Stacia Bissell
Kelly Buttiglieri
Davison Chapman
Virginia Cote
David A. Grant
Kathryn Paulson
Jillian Pfennig



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Welcome to the Spring 2022 issue of HOPE Magazine!

Our spring issue of HOPE Magazine is a very special issue indeed as it marks the seven year anniversary of our publication. Since March of 2012, we've been delivering hope to readers around the world. Now read in over sixty countries by thousands of readers, it remains such a thrill to be able to share stories of true perseverance of the human spirit.

The world has changed dramatically since the publication of our last issue. Worldwide pandemic numbers are on the decline – offering a reason to look to 2022 with renewed hope. Yet, at the same time, the atrocities against the people of Ukraine have captured the attention and prayers of people around the world. Here at HOPE Magazine, we hope and pray for fast resolution to all affected.

Hold those you love close and be safe wherever your travels take you.

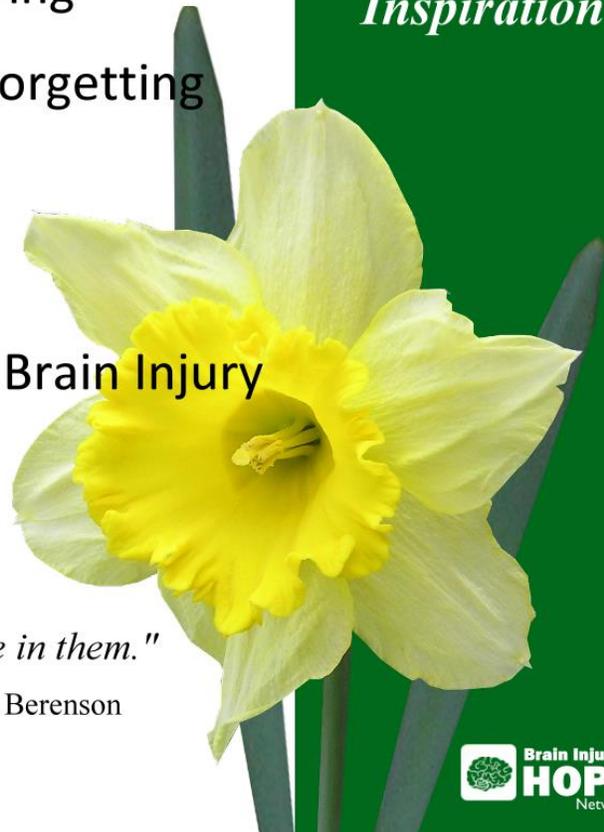
David A. Grant
Publisher

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"Miracles happen to those who believe in them."

-Bernhard Berenson



Spring 2022



Advocacy

Education

Inspiration



Three Decades of Recovery

By Kelly Buttiglieri



This year marks the thirtieth anniversary of the car accident that caused me to suffer a traumatic brain injury (TBI). As I reflect on this day, I believe my lifelong interest in advocacy, the active support of an idea or cause, played an instrumental role in my recovery. To be an advocate, one must know who they are as a person and what things in life are important.

As a young child, I became interested in politics in the summer of 1973 as I watched the Watergate hearings with my grandmother and began to learn how the government worked. I recall singing to the Schoolhouse Rock video “How a Bill Becomes a Law”. A few years later, images on the news encouraged me to write a letter to President Jimmy Carter asking him to do more to free the fifty-two American diplomats and citizens held hostage in Iran.

“My interest in advocacy and desire to become a trial attorney directed me to attend Suffolk University Law School.”

My interests in politics continued in high school when I became involved in student government. I attended Girls State, a summer leadership and citizenship programs for high school juniors, which focused on exploring the mechanics of government and politics. I also followed my representative at the State House for a day to explore the wheels of government. In college, I interned for a congressman helping to handle constituent calls. My junior year, I attended American University’s Justice Semester, allowing me to work on a project for the American Civil Liberties Union.

My interest in advocacy and desire to become a trial attorney directed me to attend Suffolk University Law School. I competed in three Moot Court Competitions and finished in the quarter finals in each one. Beginning in my Second Year, I worked part time for an insurance defense law firm and with that experience was able to work for a summer in a large law firm in downtown Boston.

During my final semester of law school, everything came to a screeching halt when my car was hit head on by a car driven by a woman that passed out at the wheel from an overdose of prescription drugs. I spent the first five days in a coma and then received six weeks of in-patient speech, occupational and physical therapy. During the discharge meeting, the reality and seriousness of my injury became real when the doctor at first discouraged me from going back to school.

I did not accept the doctor's suggestion and told my family that I was going back to school. After seeing my ambition, the doctor did suggest that if after undergoing more outpatient speech therapy I might be ready in the fall to go back to school but should only take one class at a time. Despite all the sadness and shock at this news, the doctor reinforced my ambition in the law. After two years, I did graduate and believe strongly that it was with this aspiration that I was able to slowly move on.

After the accident, I began having partial complex seizures. Periodically, I would have a grand mal seizure and I had one status epileptic seizure. The anti-seizure medications caused many side effects and did not control the seizures. As a patient, I advocated for the best treatment to control the seizures and ended up seeing three different neurologists even interviewing two of them before deciding if I would become their patient. Eight years after my accident, I underwent a left temporal lobe resection. My operation is considered a success even though I occasionally have a partial complex seizure. I will probably be on anti-seizure medication for the rest of my life.

Before the operation, I did practice law for about a year but had a lot of difficulties. Part of them were caused by the side effects of the medication. Others were caused by the deficits I have from the brain injury.

“I spent the first five days in a coma and then received six weeks of in-patient speech, occupational and physical therapy.”

Word retrieval aggravated me the most causing extreme frustration and embarrassment, it still does. I was not able to think quickly, working at half the speed that I was able to before my brain injury. Slowly I began to realize that I couldn't practice law. It took me a long time to accept this reality. When I heard of other accomplishments from fellow law school students, I was happy for them but also despondent and resentful that I was not experiencing these successes.

I finally decided to use my skills and interest in advocacy to move on to another career. My abilities first empowered me to implement a public speaking program that educates civic groups and schools about brain injury for the Brain Injury Association of Massachusetts (BIA-MA). I recruited and then helped brain injury survivors and family members write their personal story. I marketed the program and sometimes I would share my own story to the groups.

After a few years, I became the Public Policy Manager for the organization. My legal skills allowed me to advocate for funding for state services and for various bills related to brain injury, including a cognitive rehabilitation bill and a primary seat belt bill. With advocating for the bills, I met with legislators and testified at many hearings. Before the pandemic, we hosted a yearly Advocacy Day at the State House allowing survivors, family members and professionals to learn about our policy initiatives and then meet their legislators or aides.

None of this progress and success would have been possible if it were not for the support and love of my husband, family, and friends. At times, especially when things were especially negative for me, I know I was not the easiest or most pleasant person to be around. Their positive influence and guidance allowed me to take the small steps to get to where I am today.

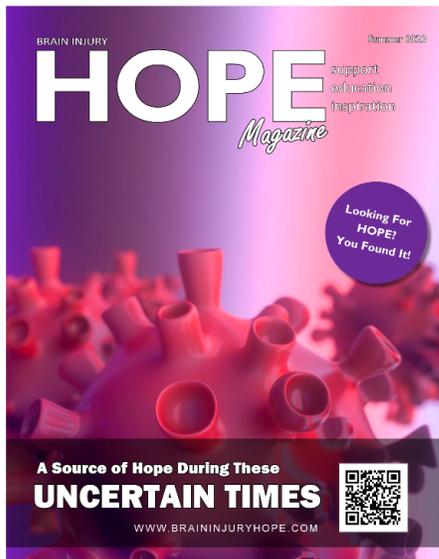
Thirty years ago, the accident changed my life's direction but my interest in advocacy enabled me to use many of the skills that I still had to make things better for TBI survivors, family members and caregivers.

Meet Kelly Buttiglieri



Kelly Buttiglieri, of Stow, is the Public Policy Manager for the Brain Injury Association of Massachusetts (BIA-MA). For a number of years, Kelly worked for BIA-MA coordinating a public speaking program for brain injured survivors to speak to civic groups throughout the state. She now advocates for services for brain injured survivors at the state and federal level. Kelly graduated with honors from Suffolk University Law School and has a B.A. in Political Science from Boston College. Kelly has been married to her husband, Rich, for the last thirty years, and has a twenty-two-year-old son and a sixteen-year-old daughter. She enjoys reading, gardening and loves doing jig saw puzzles.

Contributors Wanted!



Got A Story To Tell?

We are accepting stories for the Summer 2022 issue of HOPE Magazine!

Your story has the power to help others.

The Summer 2022 issue of HOPE Magazine will be available in June.

Your Story has Value!

And now the details...

- We prefer an article length of 800-1,000 words. Longer or shorter pieces will be considered.
- When submitting, please include a photo and short bio to be included with your piece.

Please email your submission to info@tbihopeandinspiration.com.



Unconventional Healing

By Kathryn Paulson



Most of us don't pay attention to how fast your world can be turned upside down. I didn't until December 20, 2016. I fell on black ice in my driveway and sustained a skull fracture with subarachnoid hemorrhage in my right temporal lobe. I was fortunate enough to not require surgery, but recovery has not been smooth sailing. Like many other readers of HOPE, I experienced the many highs and lows of brain injury. I had developments I had to work through, that I am still working through, that I will work through for the rest of my life.

One of the best things in my recovery, besides my amazing husband, has been my brain injury support group. We share our journeys and our struggles. We celebrate our wins and our resiliency while advocating for our future. One of our projects was a presentation for Mayo Clinic Grand Rounds, 'Understanding the Lived Experience of Brain Injury.' Currently we are working on an educational series in a local monthly publication about brain injuries.

Back in October of 2020, our group, led by Jerry Hoepner, Ph.D, CCC-SLP of UW-Eau Claire's Department of Communication Sciences and Disorders, was able to explore the benefits of poetry writing for people with acquired or traumatic brain injuries and aphasia. Brendan Constantine, LA based poet, along with student clinical speech language pathologists from UW-EC and Jerry, offered a three class opportunity to explore the basics of poetry and how, with some prompting, individuals can write out their feelings, their stories, and their experiences.

"Poetry is different from other writing because often, the rules can be broken."

Poetry is different from other writing because often, the rules can be broken. That definitely works to our groups' advantage. Previously, Brendan had worked with Jerry at a local aphasia camp. Brendan had also worked with individuals in California with aphasia and brain injuries. He made it clear from the beginning that he treated our class no different than any other of the classes he taught. We were writers, we all just happened to have our brain injuries in common as well. Personally, I had never written anything before my injury so I never really considered myself a writer, but it was mid-pandemic and I found myself with some extra time on

my hands, and a slight curiosity. What started as three classes, has evolved into working together almost weekly for seventeen months. In that time, we have all blossomed.

My poem 'Coal Smoke' will be published in June of 2022 in 'Rattle', an independent poetry publication. Our group is in the works of publishing our first poetry chapbook, "I Don't Think I Did This Right." We had our first poetry reading on Zoom for an audience of over 300 people along with Brendan and Ra Avis, another poet based in California. We are also working on another book project that will allow us to share our experiences with more people and how to use poetry in recovery.

Not all of our writing has been about our injuries, just like not all of our lives are about our injuries. It is a part of us, that will never change. But it is not all of us. I now consider myself a poet, even though those words don't necessarily just roll off my tongue. I have found some healing in writing poetry, I honestly think I would not have found without this class. I am forever in debt to Brendan and Jerry for that. Below is another one of my poems. I am grateful for so many things, and now I can add poetry and Brendan to that. You may not feel like poetry is your thing, but give it a chance to be an outlet. I hope this makes others think about how unconventional methods may help on our road towards healing.

Meet Kathryn Paulson



My name is Kathryn Paulson. I am many things, wife, daughter, sister and friend. Lover of dogs and books. I am also a brain injury survivor and advocate. I live in Wisconsin with my husband and family. I have recently discovered how healing writing poetry can be. One of my goals during my recovery has been to help others with my story. Among other things I do, I am trying my best to relay that help with my poems.

“In a gentle way, you can shake the world.”

- Mahatma Gandhi

Empty Bottles

By Kathryn Paulson

I lost a dinosaur painting
a lemon shaped piñata and
a piece of the World Trade Center/

I lost the lid
to my favorite Tupperware
I also lost my sisters headstone,
it's already been engraved/

I lost my first love,
but found my last love/

I lost my innocence,
a home,
a high stress job and
gold glittery hoop earrings/

I found out that stepping on a crack
really won't break mama's back/

I lost a backpack
filled with bundt cake and macaroni,
a single lonely mitten
an empty bottle/

When I was ten
I found a twenty dollar bill
on the way to the county fair,
I thought I was rich/

I lost my dog,
Actually, my parents lost my dog/

the police were called
dad rode the streets
on his yellow bicycle to find her/

I lost a bottle of aspirin,
but found it in the refrigerator
I lost a gallon of milk,
but found that in the kitchen cupboard/

I lost a camera
filled with once in a lifetime pictures
And golf balls
many, many golf balls/

I lost friends,
the ones I thought
would be there for me/

I found too much darkness,
too much light
too much of too much/

I lost my concentration,
my memories,
my chance to remember what I remember,
and my chance to forget how/

I lost my opinions,
I lost my voice
I lost my will to live/

And then there are the lost
empty bottles,
the keys
the puzzle pieces
and words/

I have lost so many words
but I have found so many more/

I found poetry
In that,
an ability to create/

I found sanity and resilience
and a voice to express how I feel/

I found ways to look at life in a different light,
I found situations where I handle myself
gracefully
and situations I blow out of proportion/

I found I will have days
that I will lose it all again
Except the stubbornness in me
I never realized existed/

I have found empty bottles
and filled them with my stories

Losing Someone

By Stacia Bissell



It was May 1987. I stood on the balcony of my college ballroom facing the love of my life, reciting my marriage vows, while a few dozen of our friends and family sat behind us on folding chairs. Soon the college bell tower would ring a cacophony of booming melodies to celebrate the union of our lives and families in holy matrimony.

Our thirty year marriage would play out in a flurry as we focused our energy on the three children we had, and our two immediate families that lived in town with us. Our careers would eventually take up more space in our lives, too. As a couple we never missed an opportunity to host a holiday, anniversary, or birthday, and we celebrated everything with fervor and perfection. Our home was the official “gathering place” as the wooden sign in our dining room stated.

As we entered our forties, my love for my husband was solid. However, our methods for staying busy - entertaining, working too much, signing our kids up for more activities, and socializing with other couples instead of going on dates alone - were signs that we were riding a wave of relationship avoidance.

“We were dreadfully disconnected and exhausted. That’s a tough place to be in when a brain injury assaults you.”

The more stretched thin we were with this absurdly distracted existence, the lonelier I noticed I became. My husband must have felt the detachment, too. He became obsessed with keeping himself preoccupied. He would chop more wood, build another shelf, or sign up to go on more overnight camping trips with our son’s boy scout troop. We never stopped long enough to sit on the couch together just to talk or hold hands. The dinner table wasn’t for checking in on the highs and lows of each person’s day. It was for planning the evening’s homework agenda and shower schedule, or the

next day's carpooling duties. We were dreadfully disconnected and exhausted. That's a tough place to be in when a brain injury assaults you.

When I flew over the handlebars of my bicycle in 2011, it caused a hole on the outside of my helmet and a life-altering brain disturbance inside. When my husband arrived at the ER and drew back the curtain of my hospital cubicle, what came out of my mouth was uncontrollable and unrecognizable. Although I don't remember it, apparently, I said, "I don't like you!" That's not a promising start for keeping someone around to love and cherish you in sickness and in health.

Because of my brain injury, I now resided in a world reserved for folks who have become trapped in their own quiet, dazed memory of who they were without access to that person. The new lens through which I viewed the world and people was suddenly very different. I could discern fairly quickly who would offer healing and sanctuary to my body and spirit, and who would bring insincerity, unkindness or abandonment. And some did. But I have come to realize that sometimes, when your circle decreases in size, it often increases in value.

Just fourteen days after my accident, as I sat sobbing because I didn't have an ounce of energy to get dressed up to accompany my husband to a friend's birthday celebration, he told me he was moving out. Then he left to go enjoy the party. He reluctantly stayed for another year, after realizing how injured I really was, and that year was marked by a roller coaster of emotions, including a perpetual fear of impending abandonment and upheaval. Unfortunately, this negatively impacted my capacity for optimal acute healing. While my husband's time was spent apartment hunting that year, mine was spent wondering how I could do something as sizable as initiate the restoration of a marriage with blurred cognition, emotional dysregulation, persistent, pounding headaches, and little stamina for anything but getting dressed each day.

“Because of my brain injury, I now resided in a world reserved for folks who have become trapped in their own quiet, dazed memory of who they were without access to that person.”

“I was left with a void in my heart for my precious family that was no longer a unit and grieving the loss of the life that we started together.”



A year after my accident he moved out. I was alone, struggling terribly at work and handling finances and home repairs by myself for the first time. I was still years away from feeling even 70% of my old self. I was a mess physically, psychologically, and emotionally from being left to cope on my own with my disability.

I resented that I lost precious years with my kids because I spent every waking moment trying to keep up with work, chores and medical appointments. Meanwhile, he was able to do things like hike, raft and ski with them. I lost weight, didn't eat or sleep well, and simply could not get my bearings.

Who understands brain injury when one hits? My husband didn't. He didn't understand that I needed him more than ever. He didn't grasp that we really still loved each other. Or maybe he did, and moving out was his way of trying to get me to “snap out of it”?

Of course, people don't just snap out of a brain injury. Perhaps this was just the excuse he needed to finally bolt. What I desperately needed him to know was that even though it may have looked as though I wasn't trying to improve or repair the relationship, I *was* giving 100% and I couldn't try any harder with my impaired brain. I also couldn't reach out to him for reconnection because I was disconnected from myself.

For at least a little while, I needed him to step up and initiate hitting the reset button. I needed him to dig deep inside himself for more kindness, patience and love toward the new, unidentifiable me. But he didn't. He fled. Losing someone you love who just doesn't understand brain injury is like trying to hold onto water.

I was left with a void in my heart for my precious family that was no longer a unit and grieving the loss of the life that we started together. I often wonder whether our marriage would have survived if the brain injury had occurred when the kids were younger and when we were happier. Would it have forced us to slow the pace of our excessive busyness and avoidance before the damage was done?

Over the years he and I sometimes appear to grow closer over some crisis or celebration in the family. For me, this can sometimes accentuate our long history and the lost love for one another. But when he invariably pulls an escape artist's act again, I silently thank him because it emphasizes the stark contrast in our personal growth since my accident. It is also a good reminder

that the new lens through which I viewed the world was - and still is - operating well enough to make good decisions for myself when it comes to people who don't consistently show up.

I'm glad I'm on a train that's facing forward. It feels good to be upright and alert in my seat waiting for the train to stop at my station, wherever that is, and with whomever it is. I do know it's warm and welcoming there and that I will belong. I urge survivors to continue to learn and do new things, and to find kind and supportive people to spend time with. This is what will bring you back from being a flickering candle flame to the roaring campfire you are meant to be.

Be patient. Have hope. Most people who suffer a brain injury lose a few people along the way. It isn't easy and it hurts, but you will meet those who were meant to come into your life. And they will understand.

“I urge survivors to continue to learn and do new things, and to find kind and supportive people to spend time with.”

Meet Stacia Bissell



Stacia Bissell, M.Ed. is a brain injury coach, educator, public speaker and survivor. She specializes in personal and professional growth relating to brain injury. Passionate about education, Stacia spent much of her career as a secondary math teacher until taking on roles in administration and academic coaching. Stacia is a Program Leader for LoveYourBrain. She was co-founder of the Northampton, MA brain injury support group, and was instrumental in the creation of the Berkshire Brain Injury Collaborative in Massachusetts that was designed to provide professional development to teachers on “return-to-learn” strategies after a student suffers from a concussion, and which has now become part of the BIA-MA. She has three grown children who live in Virginia, Colorado and Vermont.



BRAIN INJURY IN KIDS

ALMOST *half* A MILLION KIDS

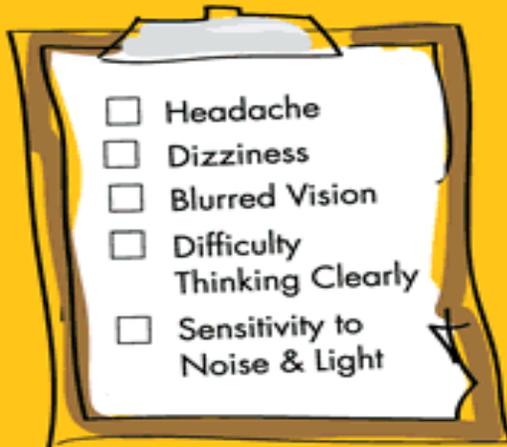
are treated in an emergency department each year for traumatic brain injury*, including concussion.

* alone or along with other injuries or conditions.

THAT'S MORE THAN 5,000 OF THE NATION'S LARGEST SCHOOL BUSES FILLED TO CAPACITY.



SOME BRAIN INJURY SIGNS AND SYMPTOMS



- Headache
- Dizziness
- Blurred Vision
- Difficulty Thinking Clearly
- Sensitivity to Noise & Light

LEARN MORE SYMPTOMS @

www.cdc.gov/TraumaticBrainInjury



50%

of BRAIN INJURIES AMONG KIDS

ARE DUE TO FALLS

WHAT TO DO
if you think a child has

A BRAIN INJURY

- A** ASSESS THE SITUATION
- B** BE ALERT FOR BRAIN INJURY SIGNS AND SYMPTOMS
- C** CONTACT A HEALTH CARE PROFESSIONAL



From Surviving to Thriving

By Davison Chapman



On November 3rd, 2018, my mother and I were leaving my elementary/middle school alma mater's fall festival where we had volunteered for the afternoon. Before crossing the street, or attempting to anyway, we turned on the pedestrian crossing light and stepped out into the clear school zone crosswalk. We, however, never made it to the other side. We were hit by a reckless driver in a blue Toyota Tacoma with a bull bar on the front - or so I've been told. I have no recollection of it.

We were hit on our left sides but landed on our right, having been thrown by the impact. Mom sustained a broken bone in her leg and torn tendons in her arm and shoulder while I was hit directly in the head. A scan at the hospital would later reveal brain bleeds on both sides of my head and subsequent diagnosis of severe traumatic brain injury. I had to have a third of my skull removed on the left side and a hole drilled on the right, all to allow my brain to swell unencumbered. Reimplanting my skull flap would not go smoothly. In fact, it would require two additional surgeries to get me to where I am today. The three years since then have been a roller coaster physically, mentally, and, most of all, emotionally.

"I had to have a third of my skull removed on the left side and a hole drilled on the right, all to allow my brain to swell unencumbered."

I spent one month at a nearby hospital following the accident. For the first ten days or so, I was in a coma, at which time the doctors expressed concern about whether or not I would survive. When I woke up, I understood very little of what was going on around me. I asked Mom innumerable times what had happened. When a therapist came in and asked me whether I was in a hospital or on a farm, I told him/her that I didn't understand the question; and apparently, I once asked Mom to "cut my lunchbox in half" when I wanted her to unfold my blanket.



I couldn't control the right side of my body, and the doctors and my parents feared that this partial paralysis might be permanent. I endured physical, speech, and occupational therapies during in-patient rehabilitation, the worst of which was learning to walk again, but all of them felt like pure torture. I vaguely remember waiting desperately for the weekends, my only respite.

There were, however, some events that provided joy during this otherwise dark time. When the accident took place, I had just finished the first quarter of my ninth grade school year (now referred to as ninth grade, take one) at Maggie Lena Walker Governor's School. This was my first year at the school, and my family and I were thus overwhelmingly touched by the support and gifts we received from the students, teachers, and administration there, including cards, stuffed animals, and a picture of the school mascot (a dragon) holding a heart which said "Get well soon! I hope you feel better, Davison!"

Unfortunately, my return home coincided with the worst physical pain of my entire life. My right ankle began to hurt. We, of course, thought nothing of it initially, but as time went on, it got progressively worse, until it was excruciating to so much as step on it, let alone walk. My father, who himself had battled Acute Lymphoblastic Leukemia and survived cardiac arrest about seven years prior, had to start carrying me around. We saw two different doctors, one of whom said to rest while the other said to walk.

After much frustration and suffering, a wonderful doctor confirmed the first's diagnosis, tarsal tunnel syndrome. Some special cream, a compression sock, and a brace finally offered some relief and the pain gradually subsided. Shortly thereafter, however, I started having weird episodes where I'd lose motor control in my right hand and slur my speech. At first, Mom thought I was just tired, but then it started happening more frequently and severely, and we wound up in the emergency room more than once.

Doctors thought I was having small strokes, but the images they took of my head didn't indicate that. We lived in fear of when it would happen again. After a

few months and several terrifying incidents, we realized that I was having seizures. The pediatric neurologist, or as I refer to her, seizure doctor, tried a few different medicines until we found one that completely controlled the seizures without slowing down my thinking too much more.

Throughout the leg pain and seizure ordeals, I continued going to the children's hospital for my outpatient therapies. In fact, I spent the remainder of the 2018-2019 school year, and the summer after, continuing to recover. When I wasn't at the hospital, I was at my former school, where my mother was still teaching. This allowed me to become reaccustomed to an educational environment. As the 2019-2020 school year approached, however, Mom decided to follow me to my new school, where I would start my high school career over again, in order to provide any supports that I might need.

Returning to the rigors of school was a big adjustment, not the least of which was Spanish. I had taken Spanish 1 in sixth through eighth grades and was moving easily through Spanish 2 at Maggie Walker. However, because the majority of the damage was on the left side of my brain, language and memory were heavily affected, rendering Spanish almost impossible. Due to this, and the emotional turmoil that resulted from it, I decided to take Latin instead, but since that was even less familiar, I was back to Spanish within two weeks, but this time starting from scratch with Spanish 1.

Even more devastating was the fact that my right visual field loss made reading extraordinarily difficult and tiring. Not only is reading essential for all subjects, but it had been my favorite hobby as well, so I shed many a tear over that one. Thanks to my English teacher, who had us read (and do a small project on) a book every quarter of the year, I began to listen to books and now do so for pleasure as well.

I'm now a little over three years out from my brain injury. Physically speaking, I've completely recovered - and am actually stronger than I was prior to the accident; I'm more flexible and have better balance. Mentally I analogize my brain to Swiss cheese; the "holes" are memory, word retrieval, and thinking speed. These "new" deficits are exacerbated by stress and fatigue. I now study a little more and differently (a "shout out" to flash cards), have some accommodations at school, and



have to repeat things to myself or ask people to repeat them more slowly. I have a special prism in my glasses that helps me see to my right, and I'll likely take anti-seizure medicine for the remainder of my life. I'm still not the reader I used to be, but my reading has gotten better. In fact, I now read aloud again with a degree of confidence.

While I still struggle emotionally from time-to-time, I'm more at peace with what happened as days go by. In fact, the brain injury itself no longer upsets me as it's squarely in the background. It does, however, make me more emotionally vulnerable in some situations, which is why I am thrilled to report that at the end of last year, I transferred to a wonderfully warm and supportive school, Richmond Christian, where the vast majority of students, teachers and administration are happy to help me. I can honestly say that I'm the happiest I've been since the accident and perhaps even the end of eighth grade.

Meet Davison Chapman



Davison is now in his fourth year as a brain injury survivor. He hopes that by sharing his story with readers of HOPE Magazine, that others can learn from his experience that a meaningful life after brain injury is possible. He is grateful for the opportunity to share with others who understand.

Join Our Facebook Family

What do over 30,000 people from 60 countries and five continents all have in common? They are all members of our vibrant Facebook family at [f/braininjuryhopenetwork](https://www.facebook.com/braininjuryhopenetwork)



Brainy Word Search

Q K D T T J P Y Y G N L R
B G Y R S N E U R O N E X
V K J K P I J S I D C Y G
A B M T T D G T I O Y M Q
P Q R M Y M P O V S Y P N
H T L Z Y E U E L H O D Q
A W A A C T R I O O V N F
S L R R N Y I P N Y R F G
I Z E T X T E L T A U U O
A P T N H G E P I S R X E
D J A Y P E J R E B A C R
R M L V N R R L I L A Q K
G P M Y Q B D A D O N S Z
R G Y P M J R L P Y R Z I
K P M T L T R W B Y D M Y

Answers
on page
18!



Find the Words!

Cranium	Neuron
Anterior	Perception
Aphasia	Neurologist
Axon	Prognosis
Diffuse	Hope
Disability	Recovery
Lateral	Therapy

Look for the Answers on Page 32!

Forgetting That I was Forgetting

By Jillian Pfennig



It took me months to realize I had retrograde amnesia after my TBI. It's almost as if I kept forgetting that I was forgetting. The day that I fully realized a huge part of my memory was gone, I was with my extended family for the first time since the accident. It was Christmas time, and I looked forward to this day with all of them all year. I tried my hardest to pretend I wasn't as hurt as I really was, since I was raised to push through the pain. Everyone started sharing inside jokes and looking at me as if I should be in on the joke, but I wasn't. I did my best to hide my terror and smile through the festivities.

"In that instant, it was so apparent I was missing something I once had - memories, and the joy that came with them."

But it was an exhausting experience because I was holding back tears inside the entire time. It had always been the happiest time of the year for me, yet I started to dread these once joyous moments. In that instant, it was so apparent I was missing something I once had - memories, and the joy that came with them.

The following days were filled with me searching my mind for what I could remember and what I couldn't. I knew things like math, how to ride a bike, and people's faces. I knew a lot of facts, like where I lived, what objects were, even history, except dates, but to be fair, that was something I was never very good at remembering. However, countless moments with my family and friends - those were gone. Sometimes, I would close my eyes and literally walk through a friend's house, a house I had been to hundreds of times. I tried visualizing the entire set-up, attempting to remember any and every detail. Where was the kitchen from the front door? Where were the stairs? Was the couch on the left or the right? Some houses I could remember, others not at all. Some houses I could get up the stairs and then I'd lose the memory.



Once I mustered up the courage to actually say the words out loud—that there was so much of my life I had forgotten—it was confusing for others because I did remember certain things. This made me begin to doubt myself and isolate even more. I started looking at a lot of old photos, so when people talked about things, I could at least reference the photo of the event they were talking about.

Like a night at the drive-in to start the summer off right. I studied these pictures often to try to remember at least who was there and what the car looked like. That way, if it came up in conversation, I'd have comments to add. Like, "Oh, that's the night we played Hackysack in between the feature movies."

Even if I didn't remember being there, I had proof from a photo that it happened. It was draining to be around the people that meant the most to me without knowing how to explain all the things going through my mind. All my feelings and emotions about these people I loved was there, but the memories were blank.

I had basically given up on my missing memories ever returning to me as the years went on. I began opening up to people and sharing some of my story, however, I was still very isolated most of the time. It wasn't until a couple years later that I was with some new friends, and we were watching "Now and Then."

It was a movie my sister and I had watched over and over during our childhood.

During a specific scene, I had a memory... I real memory (not just that I remembered having a crush on the main actor, which is one of the reasons we watched it over and over.) But a real memory from the years that were previously lost to me: My sister and I had friends sleep over in a tent in our backyard and

then it started downpouring. We all got out and started playing and dancing in the rain. As we were running around splashing, one of us tripped near the gutter and freaked out, thinking we were going to get stuck in the sewer, just like the movie. I was transported to that night, and I had actually remembered it. I immediately texted my sister and asked if I was remembering correctly, or could I have somehow made this up? She confirmed. It was official—I had a memory return to me!

As time went on, I had more and more of these moments pop-up, but many of them included people I had lost contact with, so it was hard to rejoice in these memories alone. I still have a lot of issues with my memory, but now I have become much more comfortable voicing my needs to people. If someone takes the time to explain things more thoroughly, or describe the memory in detail, I have a much better chance of remembering.

But I am incredibly grateful every time I have a memory recall of my “Now and Then”, especially those that occurred during the years that had previously vanished. But my main focus moving forward is making new memories.

Meet Jillian Pfennig

Jillian Pfennig suffered her TBI in 2007. She is grateful for all the ways she’s healed and wrote a children’s book, [Brian the Brain Falls Down](#). She hopes it can be the resource she wishes she had at the time of her TBI, helping survivors explain their feelings and frustrations in a way their loved ones can easily understand.



**WHEN APPROPRIATE MAKE SURE
AN ATHLETE USES THE CORRECT
HELMET FOR THEIR ACTIVITY.**



**Wearing a helmet
can help protect
athletes from
serious brain or
head injuries.**

THERE IS NO “CONCUSSION-PROOF” HELMET.

Finding Your Therapy

By Virginia Cote



My son Rod had his AVM brain injury in December 2014. That is when his life completely turned around. As his mother it has been hard watching him struggle through his loss and fight trying to find himself again. I found reading Hope Magazine gave me an insight on his struggles and it helped me to find a way that I could best help him. The trials and errors in the beginning developed into me learning what he needed most from me. First: he needed my support behind him in whatever decisions he would make, whether I agreed with him or not I would support his right to make his own decisions. Second: I would repeatedly remind him how smart he is: he may be slower but the smart is there. Third: I would thank him for all the things he does for me, this makes him feel useful, which he most certainly is.

“I found reading Hope Magazine gave me an insight on his struggles and it helped me to find a way that I could best help him.”

Rod has always found his own way to work on improving his brain. He started with a support group and when that folded he found a senior group to join at our community center. They all enjoyed Rod's company and even though he wasn't a senior they welcomed him each week. When Rod first returned home we did a lot of walking as his therapy. We have a lot of woodland trails in our area and we walked them all. Every day we would walk. One day we met a man and his wife and while talking found out about a group that met each week to maintain the trails. Rod volunteered. This gave him his first purpose. His next purpose came from a friend that needed some help.

Rod knew Dan from construction work, which was Rod's work from his past life. Dan has become a very good friend and understands Rod's needs. Some days they work on a job, and other days they ride around sightseeing or going to museums, air shows, concerts, etc. They joke with each other and brighten each other's moods. Dan is a real friend.



Things were improving for Rod but he was not satisfied. He was always looking for more and different things to do. He doesn't think of them as therapy but they are therapy. In Rod's search on the internet he found something called Geocaching.

He decided to give it a try. Geocaching is using coordinates to find caches hidden in the woods. They come in different sizes, shapes and colors and each one has a paper inside to be signed after which the find has to be recorded on the computer site. At first it just sounded like something different to try but the more he worked at it the more we realized this was a great therapy for him.

It worked on his problem solving, his reading, computer skills, following charts, and even finding new friends. At first he hunted the woods but soon he expanded to towns and road sides. The more we traveled around the more

interesting sites we found in our state; water falls, parks, covered bridges, dams, cemeteries, cellar holes, etc. Some of these caches are very creative hides.

I am Rod's driver also I am a second pair of eyes. Rod's AVM caused eye nerve damage so I sometimes spot the caches first. But Rod does all the figuring and planning.

Rod's first accomplishment was when he found his one thousandth find. Geocaching provides many different challenges. Rod is working on finding a cache on every day of the calendar as well as in every town in NH. He also hopes to hit 1500 finds by the end of the year. Rod just finished his 17% puzzle finds. Puzzle finds you must first solve a puzzle to get the coordinates to find the cache. Wow, more brain work. Rod is the one that found his therapy and this is what works for him. Don't be afraid to try new things. Don't be afraid to look for something that interests you and let it be your therapy.

Meet Virginia Cote

Virginia writes... "I am a soon to be a retired grooming and boarding kennel operator. I have been working with dogs for 60 years and have learned much from my training of them. Over the years I have learned the three most important hints to training dogs are Patience, Repetition, and Praise. In helping Rod with his struggles to find his new self these same hints have proved to be valuable."



The Ultimate Goal

By Lisa Rainaud



My therapist once asked me what my current goals were. My long-term goal is always to return to work to earn an income. I usually say, “That is the ultimate goal,” but to be honest I am finding it is not the one that will bring me the most joy. It will certainly feel like the biggest success in terms of triumphing in the process of rehabilitation, but pure joy comes from the smaller successes-most of which have to do with my children and enjoying the simpler parts of daily life.

Today, the sound of a cow mooing was the loudest noise I heard for three hours. The wind was slight, and the sun was warm on my arms. My children, ages four and eight, were alternating between holding my hands and running ahead to see what they would discover next on the dirt path. It was the week of April school vacation, I was almost three years post-injury, and we were spending the morning at Old Sturbridge Village, a living museum depicting life in New England in the 1830’s.

“I developed panic attacks post-injury. I was straight up nervous. I was taking my children on an extended outing alone - with no back up escape plan.”

That morning I had trouble eating. At first, I was sent into thoughts of having the dreaded belly-bug that seemed to plague our friends and family this winter, but mercifully spared us. Then I recognized that this was actually an old familiar feeling. I developed panic attacks post-injury. I was straight up nervous. I was taking my children on an extended outing alone - with no back up escape plan. “Fun day with mom,” as we had been calling it, was not so fun for mom’s nerves.

And if I didn’t eat my waffle with peanut butter, almond milk, and pickle (need that salt for my low blood pressure) - I would be weak and lightheaded, lacking energy and feel about pass out - exactly what I feared. I forced the food down slowly over the next hour, taking bites in between getting the



kids dressed and doing my hair. I WAS DOING THIS. Through sheer will or just plain stubbornness, I made it.

Walking down that dirt path, I stood tall and proud. I was feeling the small stones crunch beneath my feet and, taking a deep breath, I thought to myself, “*I am here.*” I am here at Old Sturbridge Village, but I am also here in my body, no longer a floating head. I am here with my children, and I am so full of joy, because in this moment there is nowhere else I want to be.

This is my definition of joy - being so full of life and love in the present moment that you want for nothing and allow yourself to soak it all in.

I wonder, walking through OSV, why it feels like so much of a respite here, but it quickly comes to me as we stand in a kitchen, and I ask my children to notice what is missing. No fridge! No microwave! No sink! All of these modern inventions that no doubt make my life more convenient also come with a price: humming, beeping, buzzing, swishing. It is not just the lack of cars and screens and electricity, but noise in general that I find so intoxicatingly peaceful.

As I write this, my children pull out their electronic keyboard with keys that meow, play music, and a background rhythm simultaneously. Why can it do all three at once?! It's maddening. In addition, I can hear my bathroom fan humming at the same time a dump truck drives down the length of the yard to our neighbor's house, growling, roaring, beeping as it backs up, finally slamming its dirt contents onto their driveway, metal door crashing back into place.

Down the street, a road construction crew has been jackhammering into boulders all day. The term “noise pollution” actually feels legitimate. But back at OSV, being inside a house is so similar to being outside in the woods. The lack of artificial noises makes me long for the quiet of a life in the 1830’s. Would I even be considered disabled here? If I never had to look at a screen, drive a car, spend time in fluorescent lights or even read past a third grade level - might I be just fine? This thought makes my eyes well with tears. Maybe I am okay just the way I am. Maybe it is the world that cannot tolerate my simplicity.

So I rethink my current short-term goals. Do they serve me or do they serve the modern world?

- Tolerate more computer and TV time - especially reading on the computer
- Read for more than 20-30 minutes without fatigue or pain
- Not be exhausted by processing thoughts with background noise (ex. restaurants)
- Reduce/eliminate neck pain
- Be able to participate in cardio exercise - specifically that new beach body DVD I ordered that is still in the packaging
- Take my kids to the movies

Is it possible that the answer to my question is that they serve both, neither, or some complicated combination of the two? I am reminded of a quote by author Howard Thurman that I like to paraphrase: “Don’t do what you think the world needs from you. Do what lights you up, because what the world actually needs is your light and the best version of you.”

Meet Lisa Rainaud

Lisa is an information seeker and therapy enthusiast. She is relentless in her pursuit of anything related to the brain that will help her better understand her injury and assist her in her rehabilitation. She has found writing to be a creative outlet to deal with the emotional difficulties that come with a traumatic experience. In addition to writing, she enjoys listening to audio books, practicing yoga, walking, and spending time with her family and friends, especially in the outdoors!



Ambiguous Grief After Brain Injury

By David A. Grant



To be human is to grieve. As shared members of the human family, we all experience great joy – but to be human means that we live with the flip-side of the coin. We all experience grief.

My first real experience with grief came to me after the sudden loss of my sister-in-law. She was taken from us by a brutal murderer. I was only twenty-eight at the time and had never even heard of the five stages of grief. The only thing I knew was that I had an inner pain that I didn't understand and could not have prepared for. It took me many months to get my emotional feet under me, only to lose that footing – again. To this day, over thirty years later, if my mind bends to that October day back in 1990, my eyes still fill with tears. Today I know that grief never ends, it just changes form.

“To this day, over thirty years later, if my mind bends to that October day back in 1990, my eyes still fill with tears.”

If there is any such thing as traditional grief, our family had a full-on crash course in 2019. It was in 2019 that both my mother and my wife Sarah's mother passed away. My mom sustained a stroke the year prior and spent her last year in a rehab. My mother-in-law passed away completely unexpectedly in her sleep. One death we knew was coming, and one death blindsided us. Both were painful as we grieved the loss of our moms. 2019 will not go down as a year that I have any fondness for.

Like it or not, the losses of these two beloved souls are part of the natural path that most of us follow. Parents age, they die, and we grieve, profoundly affected by their passing.

But there is a type of grief that many people experience that is less common, less talked about, but none the less real and painful. It's called Ambiguous Grief or Ambiguous Loss.

“Fate altered the very course of my life that day as I was broadsided by a newly-licensed sixteen year old driver.”

Ambiguous loss, by [definition](#) is “a loss that occurs without a significant likelihood of reaching emotional closure or a clear understanding. This kind of loss leaves a person searching for answers, and thus complicates and delays the process of grieving, and often results in unresolved grief.”

In 2010, I was about to get a front row seat to living with ambiguous grief. On a sunny November day, I went out for my daily bike ride. A fitness enthusiast at the time, I was cycling close to thirty miles daily in our southern New Hampshire town. I could be seen regularly on many of the streets near our home. I had a passion for being outdoors, and a passion for all that encompasses the immersive experience of simply being outside on a bike.

Fate altered the very course of my life that day as I was broadsided by a newly-licensed sixteen year old driver. Local authorities estimate his speed at over 30 MPH when he t-boned me. He never even hit his brakes. I went through his windshield and was catapulted into a strange new existence. In addition to broken bones, bruises, and lacerations, I had an unseen injury. Though I was wearing a helmet, I had sustained a traumatic brain injury. From that day forward, everything I knew about life, and about myself, was to change forever.

Trying to describe to the uninjured what life is like after a brain injury is exceptionally difficult, but I’ll do my best. Just imagine if the person you have grown to know as yourself one day completely disappears, almost as if they died. My challenges after my brain injury included a very abrupt change in my personality. This is common within the brain injury community. I acted differently, I thought differently, I spoke differently, and my behaviors were not the same as they were before my injury. Literally in an instant, I was a completely different person.

One of the biggest challenges of all was that I still remembered the person who I was before my injury. I saw his face every day in the mirror. His voice sounded just like mine. We wore the same clothes and had the same address. And in what amounts to an epic heartbreak, I missed that person with every fiber of my being. I was grieving the loss of who I used to be, although it would take me many years to be able to both understand and articulate this.

My grief was as real as any grief I had ever experienced. I went through denial and anger. The bargaining was tough. What I wouldn't give to have a do-over on that fated day. What if I opted to take a right turn that day instead of a left? I never would have had my life so abruptly ripped away from me. And how about the depression? With a personality change, I was a stranger to people who knew me. The loss of personal relationships was staggering – including the loss of most of my children. They no longer knew who I was.

Depression was unrelenting. I contemplated suicide for close to a year, firmly convinced that the world would be better off without me. The very act of just existing was painful. I sought professional help through the services of a grief counselor. Over the years since, I have told her fondly, many times, that she quite literally saved my life.

But I underestimated my own personal tenacity. I was about to get another firsthand lesson: The power of healing that comes with using life experiences to serve a greater good.

During my first year – when loss and sadness defined the very fabric of my being – I attended a support group for brain injury survivors. For the first time ever, I was in the company of others who understood the loss, the sadness, and the grief that comes with the loss of self after brain injury. I had found a home, and with that a new footing.

Thinking that others might benefit from contact with others with similar experiences, I started what I expected to be a small social community online. That was nine years ago. Today, that same community, the [Brain Injury Hope Network](#), now serves more than 35,000 members from over sixty countries. It is one of the world's largest group of its kind. Such was the unmet need for others to connect with people who understood.

In the years since my injury, I have, at least in part, become a writer and realized a lifelong goal. My work, as published in a number of *Chicken Soup for the Soul* books, has been read by millions. In what amounts to something you can never plan for, I was asked to keynote at a brain injury conference. Then another, and another. My written voice was helping readers to chart their own paths to a new normal, and my spoken voice did much the same.

As the years passed, I changed. No longer do I look at my 2010 accident as the most terrible day of my life. It will always be the day of the biggest changes in my life, but so much good has come from it. I have learned that if I am sincerely trying to help others, to serve humanity by the sharing of my own experiences – no matter how difficult – that my own life becomes livable. I have a sense of purpose that I never had before my injury.

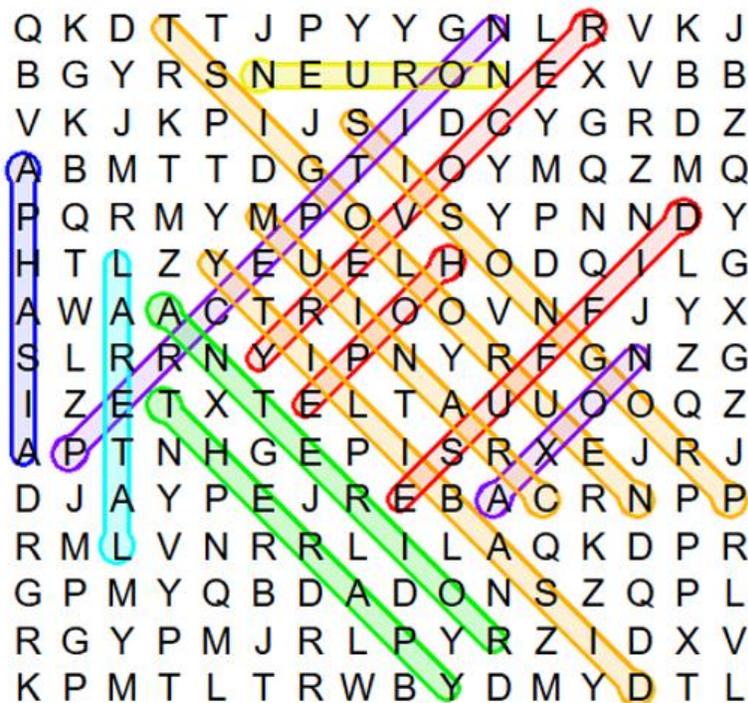
So, what about the ambiguous grief that paralyzed me for many years? I find myself today not looking back like I did in those early years. It's been long enough that I have forgotten who I was before my injury. Today, I choose to focus on who I am – and who I am becoming. And in that shift of focus, I have found acceptance and a measure of peace – both of which I wish for you today.

Meet David A. Grant

David A. Grant is a brain injury advocate based out of southern New Hampshire and the publisher of HOPE Magazine. In 2013, David founded the Brain Injury Hope Network, one of the world's largest online social communities that supports those affected by brain injury. David is also a regular contributing writer to Brainline.org, a PBS sponsored website.



Brainy Word Search Solutions



News & Views

By David & Sarah Grant



As the end of March nears, so does the end of another Brain Injury Awareness Month come to a close. This year marks the twelfth such month for my wife Sarah and I. While I am grateful for the dramatic uptick on exposure to the fact that brain injury affects millions, once I tread outside my own social spheres, I have heard surprisingly little about it.

Not a single mention of Brain Injury Awareness month was made on any of the local news channels that I watch regularly. Long a fan of watching the national evening news, I didn't see any stories about our month-long awareness event. Local news apps, and other trusted sources of information I rely, on failed to mention Brain Injury Awareness Month. I'm not saying that there was no coverage, but nothing was on my radar screen.



It's all too easy to think that we have done a good job in advocating, but I remind myself that my social feeds are chock full of people who share my fate, and organizations who support us. My "news" leans decidedly toward being rife to show stories about brain injury.

While we've come a long way in the eleven years since my own injury, we still have a long, long way to go. Each of us has the power to advocate- to help demystify and destigmatize brain injury. The big question is this: What are we going to do with that power?

Be well, and stay safe,

-David & Sarah