

Brain Injury

June 2019

HOPE

supporting the
brain injury
community

MAGAZINE



SPECIAL SECTION

LOVE
YOUR BRAIN
Y O G A



Welcome

Publisher's Introduction

HOPE MAGAZINE

*Serving the Brain
Injury Community*

June 2019

Publisher

David A. Grant

Editor

Sarah Grant

Our Contributors

Lynne Brennan
Rachel Dombeck
Debra Gorman
Amanda Isley-Hatfield
Natalie McDonald
Kyla Pearce

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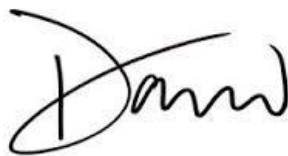
Welcome to the June 2019 issue of HOPE Magazine

Over the years that we've been publishing HOPE Magazine, I have come to find that each issue has its own personality. Some of our issues have consisted almost entirely of survivor stories, while other issues have leaned decidedly to caregiver stories.

We don't do this by intent, rather it's just been the way that things have come to pass. It's always a source of fascination to see how each issue comes into its own.

This month, we are pleased to feature a special section about LoveYourBrain Yoga. Recovery from brain injury is as much a matter of mindfulness as it is of physical recovery. You are sure to appreciate the insights of first-time contributor Kyla Pearce.

I hope you enjoy this month's issue of HOPE Magazine!

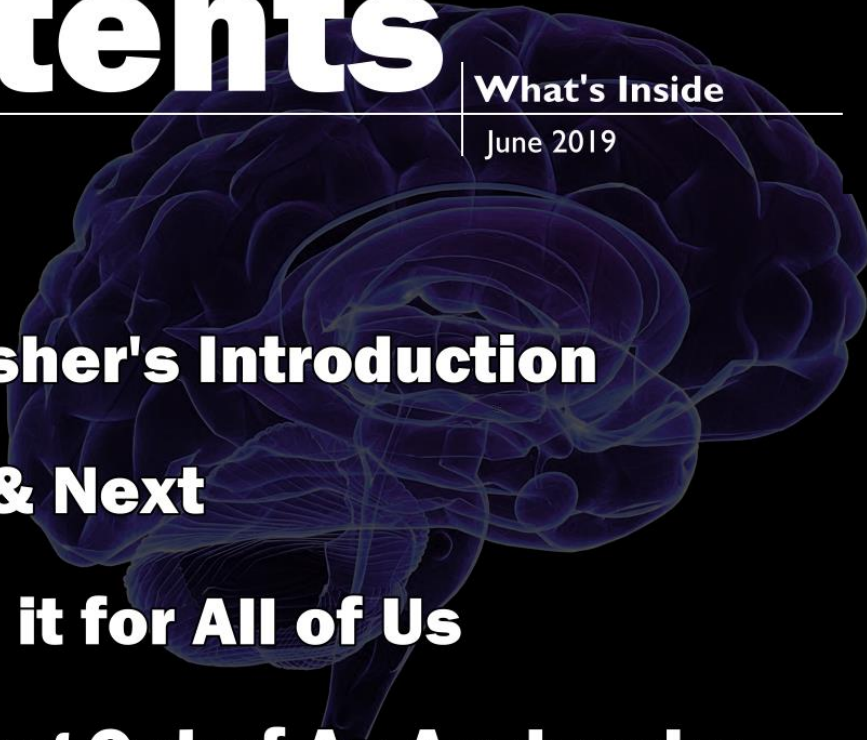


David A. Grant
Publisher

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Over and Next

By Natalie McDonald

I was listening to “Wait, Wait, Don’t Tell Me,” on NPR the other day and Norman Lear was the guest. He was the producer of such groundbreaking television shows as “All In The Family,” “Maude,” “The Jeffersons,” and many others.

He was 93 years old and about to turn 94 the next month. The host asked if he had any advice for people on “How to live to be 93 and be as spry and successful and happy as he was?”

His next words rocked my world and I’ll never forget them. He said he always lived by two simple words: “over” and “next.” He talked briefly about the need to always be looking to the future. To celebrate, fully, what good thing you have just done, but then to always be moving on.

“Depending on the severity of your injury, you may resume your previous interests and occupation, but YOU and the way you approach life will be forever changed.”

This obviously is great advice for everyone, but after a brain injury it is absolutely essential. We cannot go back: that door is forever closed. Depending on the severity of your injury, you may resume your previous interests and occupation, but YOU and the way you approach life will be forever changed.

For example, my entire life before the injury revolved around music and I spoke “piano.” I married another musician and all four of our children are musicians. My husband and I both taught music. I was also a church musician.

After the TBI everything changed. I spent a couple of years trying desperately to get my piano skills, music knowledge and singing voice back. I would sit at the piano for hours a day, holding my dyslexia reader up to the music, one staff at a time and try to decipher the notes; or I worked on scales with a metronome trying to keep the tempo and my hands playing in something resembling coordination. I had to start painfully slow, simply creeping up and down the keyboard at first.



Two or three days into this, it would never fail that I would find that I had been mistaken about some notes and had been practicing all wrong. Now, not only did I have to correct my mistake, I had to “forget” what I’d painfully memorized and start all over, which with a brain injury is incredibly difficult. It resulted in terrible headaches, deep depression and dark frustration.

I finally took some time out to evaluate what my goals were in putting myself through this: I mean, if it was going to be a worthwhile end result, I was willing to put the work in, but just what the heck were my dreams, exactly?

I realized that in my broken brain, I could not conceive of any different type of a life than what I had always had. So I took a few months out, meditated, prayed, and did other, non-musical things. I set an official “re-evaluation” date. At the end of the time, my headaches were better, my depression had improved and I felt like a burden had been lifted. The truth was, I had to face that I just wasn’t that interested in music anymore. It would never again be my all-consuming interest. When I had let myself consider a life without being good at music before, I had been filled with fear, guilt, and all sorts of other destructive emotions that were keeping me from moving forward.

My story is far from universal, I realize. But I feel we all have a tendency to idealize our former existence and see it through the lens of “all the things that we could do then that we can’t do now.” As if, when we were doing those things, they didn’t come with any problems. I truly had loved piano, that was true. But the harsh reality was that it would never be easy for me again, no matter how many hours a day and years I poured into it. I would never even approach where I had been, and it would likely never be as enjoyable for me again. So it was time to move on.

Believe me, I'm not trying to preach. This is as much a therapy session for myself as it is a help for others. I have to remember all the pains that went along with the "highs" in teaching vocal music and being a church musician. I think if you'd lived with me back then, you certainly wouldn't have had the impression that my life was all perfect. I loved what I did, don't get me wrong, but there were frustrations that I simply don't deal with anymore.

Even trying to get to work: warming up my car in winter, car breakdowns, having to fill up with gas when I'm already late to a 7AM rehearsal. Then, once in a while there would be those cranky parents and ill-behaved kids.

I tend to gloss over all those things and just gloom about not being able to drive and not being able to work. Just because some, or most things, are bad doesn't mean *everything* is *all* the time.

I'm not saying that you don't need to fully mourn what's lost: not at all. Depending on who you are and what you've lost, that might take quite a while. For me the temptation is always there to get stuck on "what was" and not think enough about "what's coming now?"

The list of what I can do now, compared to what I could once do, can seem very disheartening. But one positive thing is, if you concentrate hard enough on one particular thing, you can achieve a laser-like focus on it, and it may take that now to help you achieve after a brain injury.

"Just because some, or most things, are bad doesn't mean everything is all the time."

Our pastor said in a sermon a few months ago, **“Comparison is a joy stealer.”** And it is.

For me it has not been so much comparison to other people that steals my joy but to my old self. It is a very much “idealized” picture of my former self sometimes, I admit.

So I’m concentrating on my new life as a writer. I’m still not ecstatic about it most of the time yet and it’s pretty lonely, but it’s far better than being able to do nothing and turning bitter about it. I practice my writing skills, keep my house clean, do my therapy exercises, listen to audiobooks and podcasts to keep my spirits up and talk to God a lot. It’s a pretty good life so far and I improve every year. My brain injury was a severe TBI and I’m only 4 1/2 years out. In brain injury terms it seems I’m only a baby.

Not, mind you, the life I was planning. At all. But it’s what I got. And I can work with that.



Meet Natalie McDonald

Natalie McDonald lives with her husband Marty outside of Des Moines, Iowa. They have four adult children, Alanna, Ali, Nate, and Evan, and two amazing granddaughters. Natalie suffered a TBI in a car accident in September of 2014, on her way to an evening musical rehearsal. She was in a Level 1 coma for two months. She was first in ICU then transferred to another section of the hospital. Before Thanksgiving she was taken to On With Life, a brain injury rehabilitation center in Ankeny, IA. In January, she was improved enough to come home and stay. She returns to ‘On With Life’ regularly for outpatient therapy and to speak at survivor panels.

“You cannot swim for new horizons until you have courage to lose sight of the shore.”

— William Faulkner



I Said it for All of Us

By Amanda Isley-Hatfield

It is well beyond time to say out loud that I am absolutely to the bottom of my core, my heart, my mind and all that I am, 110% down-right TIRED!

I am beyond tired and I will tell you why. I am tired of exhausting myself over opinions that are whispered behind me. I am tired of pushing myself beyond my breaking point for people that cannot be bothered to pick up a phone and call or pop by.

I am tired of breaking my own heart to fill an expectation of who I should be as a mother, a partner, a friend, a woman, a patient, or a survivor. I am tired of being too much, too loud, too quiet, too aggressive, too submissive, and too suggestive. I am tired of being judged because I am not wearing make-up, or not dressed appropriately, or over dressed and too done up.

I am tired of not looking like people think I should look because I have a chronic illness and I'm genuinely struggling. I am tired of people's opinions of what my illness is supposed to look like, despite no one taking the time to find out exactly what it is. I am tired of being told I'm not trying hard enough, asking why I am still sick, and to do this or do that, it will cure it. I am tired of feeling

"I am tired of pushing myself beyond my breaking point for people that cannot be bothered to pick up a phone and call or pop by."

like a prisoner in my own mind and my own body and having to lay still as I open my eyes and pray yet again that maybe, just maybe today will be the day it turns around. I am tired of my body having a good day while my mind is pounding from the screaming of a thousand demons with every movement, breath and sound I hear, as my ears scream like a dog training whistle being blown straight into it and having to look calm and put together because no one can hear it but me. I am tired of clothes that hurt my skin and make my muscles burn like I am being branded deep into my bones. I am tired of being so tired days upon days as I watch my children grow and not be able to push through to "be better" even with the strength that I had to birth them.

I am tired of being too thin, too out of shape, too sore, too active, too risky, or too safe. I am tired of being told what every piece of my life should look like now that I am "fragile," from my personal care, to my sex life, my traveling, my moods, my eating... seriously? Go away! I am tired. I am tired of partners that "understand" through assumptions. I am tired of being told that they don't want to hurt me or won't bug me because I am tired. I am tired of being told to settle for things because I should feel grateful. I am tired of opinions of what I should and should not say, out of being proper, only to make others comfortable. I am tired of being judged because I am tired and well, "we all get tired," so I should just deal with it.

I am tired of trying to explain what is wrong with me when I know that even I can't understand it. I am tired of the unknown, feeling lost, assumptions, ugliness in judgment, in the disgusting ignorance of belittling and shame thrown by people that have no clue what it takes to even be in their presence. I am tired of being defined by this.

“I am tired of trying to explain what is wrong with me when I know that even I can't understand it.”



I am tired of PTSD, of my brain injury, of grief, of trauma, of loss, of self-sacrifice; of trying to always be understanding when I am so misunderstood. I am tired of fighting alone. I am tired of being told who I should and should not love. Of the judgement on what my time and days are supposed to look like if I am actually sick or even a decent mother. I am tired of my disassociation, of anxiety that just won't quit.

Of my heart that won't slow down. I am tired of being in pain and of the tears that many days literally have no end. I am tired of being unreliable, even to myself, of not knowing what tomorrow looks like even though I have a schedule. I am tired of being told what to take to help me sleep. Trust me, I have probably been prescribed or tried it and it hasn't worked. I am tired of the ignorance around what has worked and the stigma cast by arrogance. I am tired of falling through the cracks with a system that cannot keep up with hundreds of thousands of us that are all simply TIRE!

Saying I am tired equates to me being completely, emotionally exhausted, to flat out neuro-fatigue, physical exhaustion, over-stimulated visually, audibly, and even through touch. It is not an excuse, but it is an attempt to explain what is happening in the best way that I can.

I know without a shadow of a doubt that I am not the only one who knows deep within their own souls this level of tired. I know that there are so many more pieces to add to this as well. That this could go on and on. But, mostly I just needed to say I still try, I still push, I still hope and dream, move and stretch, and I will always persevere.



Meet Amanda Isley-Hatfield

Amanda Isley is a Canadian mother of two teen daughters and multiple TBI survivor. While learning to find her "self", through healing, Amanda discovered her ability to connect through her writing, on a level that resonated strongly with other TBI survivors and on various mental health issues. Through multiple online support groups, Amanda finds and shares comfort with other members from around the world through writing. Her goals are to continue publicly advocating, spreading awareness and hope. She is currently also working to complete studies for certification allowing her to formerly help others through a variety of approaches through creative therapeutic methods.



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Digging Out of An Avalanche

By Rachel Dombeck

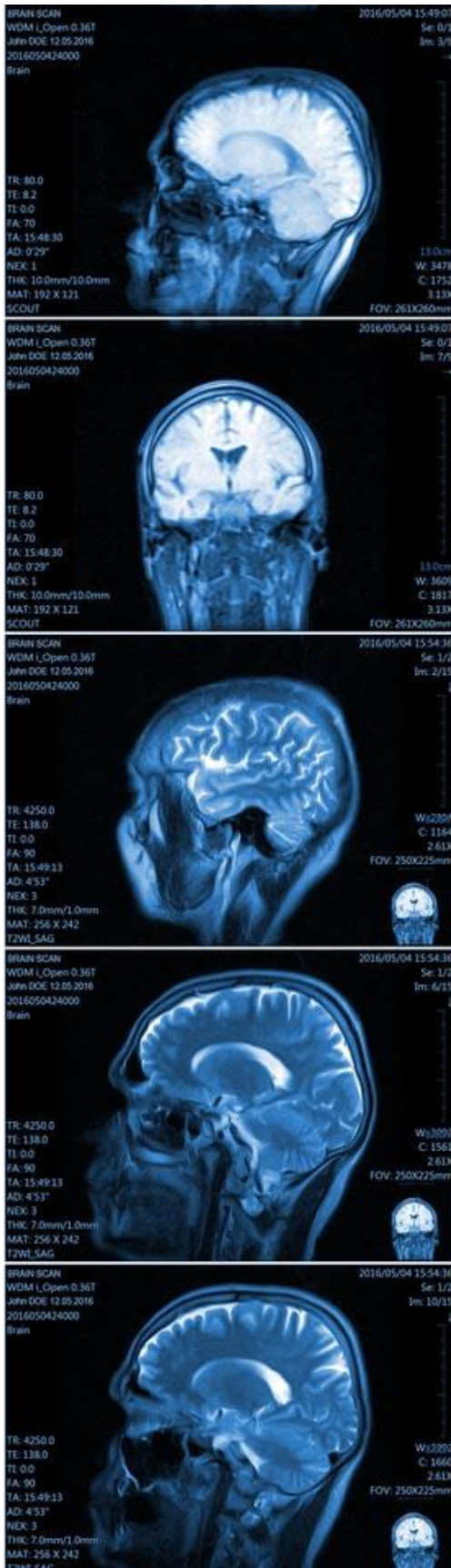
People say I am good with words and a good writer. And yet, I have tried to write this story for over a year. I sat down many times and wrote it on my to-do list many times. Why is it so hard to tell my story? Because that makes it real; that it happened. Then ...people know.

I have read others' stories for years in my recovery and found so much hope, encouragement, companionship, and validity through them that I had a deep burning desire to do the same thing for other TBI warriors through my own life-changing experience.

When people would ask how my accident happened, I used to laugh and say I wish I had a better story, because the truth is so commonplace that it seemed almost a joke to me. I slipped and fell stepping into the shower and landed full force by striking my head on the side of the inside corner shelf that wrapped around the tub. Due to the way I landed and hit, I had other injuries that took months and even years to heal, but the TBI has been the most challenging of them all.

“When people would ask how my accident happened, I used to laugh and say I wish I had a better story.”

I remember the sound of my head hitting the tub, the last flash my eyes saw before everything went to an eerie black and the moment I came to (rather quickly I believe). Holding my bleeding mouth, sitting in the tub, all I could think was, “Oh my gosh! What did I just do and how badly did I mess up my face?!” I was more scared to look in the mirror for what I might see, than ever even giving a



thought to the fact that I had just done something to my head and brain that would forever change the course of my life. In the days that followed, it became obvious that I had suffered a bad concussion, and in the weeks and months that followed, a TBI and the real effects of what that would mean in my life began to unfold.

The worst part of some TBI's is that nothing is actually seen on a test or an MRI and you basically feel like you just lost your mind, are going crazy, and the harder you try to push through it, the worse you get. I had no clue what I was in for (thank GOD) and you truly learn as you go.

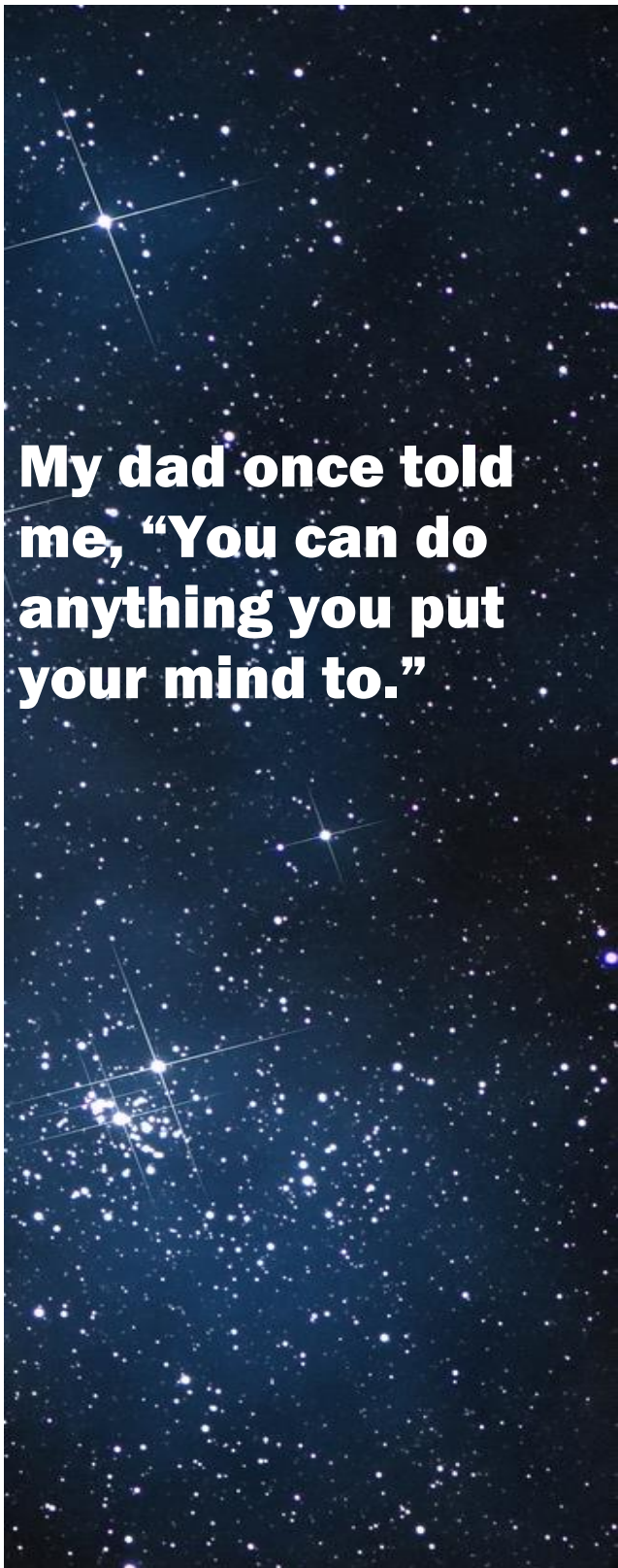
For me, I looked fine--absolutely fine--the entire time. I felt like I was having a constant out-of-body experience though and whoever's body I had been switched with, I wanted mine back. I didn't know myself anymore and I found the harder I tried to get myself "back," and get my life "back," the worse I got.

While the physical part of a TBI is truly one of the most challenging things I have faced, it was, and is, the mental, emotional, and physiological part that is the hardest to come through and recover from. And I am still working on that.

I think it is the secondary losses and challenges that are the hardest as well. I could say that it's all HARD. Everyone who is a brain injury survivor would agree. But it is the ripple effect that shakes your world the most. The losses after a traumatic event seem to pile up and gain momentum in your life if you let them, each one building on the other, and it truly becomes an avalanche, overtaking and suffocating you.

How do you dig your own self out of an avalanche, when you are hurting, wounded and scared to put your head up again because that last thing you think you can take is One. More. Blow. I am still working on that, but I will share with you the moments that defined my recovery-- each one building on each other in a positive, powerful, healing way out of that darkness and not BACK into my life, but into a whole NEW life that I am learning I love better than my life before my accident.

I remember lying on my air mattress bed at my mom's house in the weeks right after, as I wasn't able to be on my own



My dad once told me, “You can do anything you put your mind to.”

and I literally couldn't even think because that hurt too much. I didn't have the cognitive energy to form thoughts or words in my head or pray – I couldn't do any of it. I lay there and a few things happened over those weeks. I couldn't even pray for myself, but somehow the words of an old hymn sung in church growing up would come to me. "What a Friend We Have in Jesus," would go through my mind somehow, even though I was too fatigued in my brain to form the words.

Bible verses that I had learned as a kid, going to AWANA in the church where I grew up, would come to me and flow through, giving me comfort and encouragement in a very dark and scary place. I will never forget those moments--in the day, in the night, when you are too weary and mentally fatigued to even think a thought, and your mind is a scary and lonely place suddenly--but I had that comfort.

My dad once told me, “You can do anything you put your mind to.” I can still remember everything about this moment, the way he said it, where he was standing and where I was standing, the light coming in from the window, and the impact I felt as those words hit me.

My dad died three years before my accident. But those words were tattooed on my soul and came to me as I was lying there, rocking myself to comfort myself (a strange thing I never did until then and found it is a coping technique for sensory issues). I remembered, even though I was so weak I could hardly shower and feed myself in a day or do anything, and he was with me in that moment, reminding me what I was capable of.

I knew, decided, and chose in that moment that no matter what, how long, how hard, I would figure it out, overcome this and not just survive my brain injury, but rise like a phoenix from the ashes because of it.

In your recovery, wherever you are, you have some choices to make. You can focus on all you lost or focus on all you gained. You can pine over your old life and imagine how it might have gone IF you just hadn't taken that one step, or you can find the courage to imagine what your new life can look like and go after it. While I wouldn't wish this on anyone, I wouldn't trade it for anything.

Sometimes, I think I am the lucky one. Sometimes, I think I am the blessed one. I got a second chance at life. I was an inch-and-a-half away from hitting my head where it might have killed me. I am always amazed I didn't break my neck with how I hit and landed. You really only know what it's like unless it's happened to you, but when you have something happen that brings you that close to death and the fragility of it, you are changed-- hopefully for the better. You decide.

The other defining moment in my journey was at one of my follow-up appointments with one of my doctors. He looked me in the eye and said, "This will be your strength. You got something that most people don't get: a second chance; a clean slate.

Your life pauses, and you look at yourself. Who do you want to be? What do you want to do? Where do you want to go from here? Not everyone looks at themselves that closely. You see all your faults and flaws, but you get to know yourself and decide. You get to decide now who you want to be, what kind of person you want to be and how you want to recreate you and your life.

This will be your strength." Those words flat out haunted me. I walked out of there feeling like I had just been charged with some great mission to take this and use it for insurmountable good to reach others and make my life count and make sure I didn't waste it. Instead of being broken, I had been made.

“You got something that most people don’t get: a second chance; a clean slate.”

The other and last moment I will share with you for now, was when I got the movie *Crash Reel*, the story of professional snowboarder Kevin Pearce. I couldn't watch the movie all at once; not because of my head, but because of my heart--because even though our stories were different, they were the same. I had to keep stopping and walking away to cry.

I finally made it through the whole thing and knew, while it was mentally and emotionally exhausting to watch, that I had also found healing. "You need to be prepared for the Kevin who comes back not to be the same Kevin." These words were told to his parents by one of his doctors, and that was the first time I was given permission to not keep fighting to bring back the old me; and that was ok, even if it was hard and needed to be grieved before I would be able to move on to the new life ahead of me. I think this is done in process and parallel as well.

I said before that I wouldn't wish this on anyone, and I wouldn't trade it for anything. I feel I have been given a chance to see the world and life differently. I used to say that having a TBI is like living in slow motion and everyone else is on fast-forward. I used to see that as a bad thing, as a negative, and tried to find how to speed up. THEN I realized, it was actually a gift.

When you play things in slow motion in a movie, you see more details; you pay attention and you feel a sense of more value and importance in that moment in what is happening. You soak it up and you savor it more. Living life at a different pace isn't a bad thing and I protect it vigilantly. What is truly important comes into focus, and the other stuff is....just stuff.

"I can definitely come back and win, and I know that, but it's not going to be easy. Nothing in life now is coming easy and I used to do it a lot better; but I know now that I can do it and I just have to fight a lot harder. Things are different. But things are good. And things are ok." -- Kevin Pearce, *Crash Reel*.



Meet Rachel Dombeck

Rachel is passionate about inspiring and empowering others in their journey while spreading awareness for brain injury and how to live a healthier life in all areas.

She is learning to rebuild her life every day and finding peace in accepting the past, embracing the present and starting to dream again for the future, trusting God for the unknown.

**EVEN TEXTERS
AND DRIVERS
HATE TEXTERS
AND DRIVERS.**

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Take Care of Yourself

By Lynne Brennan

I was officially inducted into the Caregiver Club in 2014 when I received a call from Boston Medical Center telling me that my fiancé, Gary had been in a serious highway crash and had suffered a traumatic brain injury. The crazy part of it is that I had been married to him for just shy of forty years at that point. His injury managed to obscure the most recent forty years of his life and he thought it was the winter of 1974-1975. He is fully back in the twenty-first century now, but it made for some interesting conversations for a while.

I also am helping to care for my eighty-eight year-old mother who lives by herself; and I help provide care for two of my grandchildren who, along with their parents moved in with Gary and me a year ago. I also assist one of my sisters who is in remission from breast cancer. Since my husband is not fully able to do so, I also act as property manager for a rental house he inherited from his mother. I am sure all of us who are caregivers have been told at some point to, “Take care of yourself!” There was a point early on in our brain injury journey when I wanted to smack the next person who said that to me. In the midst of all I was going through since my husband’s injury, the mental effort it seemed to take to figure out what that statement meant – and then make it so – felt like more than I had to give.

“Take care of yourself!” We’re told that our loved ones need us to do that so we can continue to help them. Some might even remind us of the airline rule about putting the oxygen mask on yourself before helping anyone else. But when you’re drained of nearly every drop of energy because you’ve been traumatized by what has happened to your family, when you don’t sleep at night, and you’re on autopilot to just get through every day, “Take care of yourself” becomes another item for your OMT pile (One More Thing.) So we tend to take care of ourselves by chucking that advice right in the bin!

When I was working as a classroom teacher, I used to dread the days when I would need a substitute. It was always much more work to prep for a sub than to just drag myself in to school and do it myself even if I felt lousy. “Take care of yourself,” can sort of feel like that.

As time has passed, I’ve gained a bit of insight on the concept. I’ve come to the conclusion that when we’re in the throes of crisis, we need to do what is needed for our survivor or our family because that’s what we need to do. In a sense, that is part of taking care of ourselves. We need to do what we need to do because it needs to be done. We just do it.



Over time as well, I have realized that rather than the grand, and certainly misguided, idea of taking a mountain or beach retreat each month (as lovely as that thought may be for many), I think the bottom line to taking care of ourselves amounts to at least the regular personal maintenance we would have been doing apart from our crisis.

Keep brushing your teeth twice a day, keep taking showers and using deodorant, keep doing your devotions every day (even if you have to do it in the bathroom because it’s the only

private time you get.) If you usually saw the dentist for yourself twice a year before the crisis, continue making and keeping dentist appointments twice a year going forward. Make and keep medical appointments for your annual physical, your mammogram, your chiropractic adjustments just as you would have done before the crisis. Keep taking your vitamins, keep eating good food (especially something with protein), keep enjoying maple frosted shredded wheat and Cherry Garcia, though not necessarily together! Keep doing the things you did before the crisis that make it so you can breathe and move each day.

But, truth be told, sometimes, we are so stuck in the crisis and the doing, that we literally cannot choose to take a break. When I was at that point, my friend Susan called me one day to say that I WAS going to come with her to a women’s retreat in New Hampshire the next weekend. She would help me locate folks to care for my husband while I was away. I didn’t have a choice – I was to go with her. I went and for the entire weekend, she guided me into activities and meals because I was in no shape to make choices for myself. I think we need to be aware of those around us who are at that point and then choose to step in and help that person – invite her or him for a cup of coffee somewhere; if you’re going to a retreat yourself, insist that that person come along. Be a Susan for them.

Beyond that, taking care of yourself becomes an individual thing. What works for me may or may not be the thing for you. Not everyone is able to get away for a weekend retreat. Not everyone can pay for yoga classes. But maybe you love to golf and you have an opportunity to get out there with a couple of friends and enjoy a respite time that way. Maybe you relish getting out on your bicycle or perhaps jogging and spending time that way. Only you know what you need and what personal and financial price you're willing to pay.

Over the past couple of years, I've scrounged to come up with the funds to pay for a massage therapist on some sort of a regular basis. The sessions are good, but they get balanced by the fact that insurance doesn't cover them and I feel guilty taking our limited grocery funds to pay for them. The same thing applies to going to the hairdresser. (I confess that sometimes I feel selfish for doing these things – other times not.)

Taking care of yourself might mean that eventually, maybe, you will decide it's time to talk to a counselor who will listen to how you're feeling about what you are going through. Maybe you'll come to the realization that you are dealing with depression and maybe you're now willing to use a medication that will help you have more energy so you can have a better outlook on life in general and on your situation in particular.

And, maybe you'll realize that your stress over your current normal (new normal can seem to be a moving target) keeps you from eating at all sometimes and that you need to deal with how that is affecting you. Or maybe you'll realize that all those extra snacks and all that Cherry Garcia has added so much weight that now your short grocery dollars need to stretch even further to buy new clothes that will fit comfortably, to say nothing of the effect that weight is having on your joints, your heart, and your breathing, and it's time to address the behavior.

So... what do YOU do to take care of yourself? Find a caregiver support group in your area or online and then please do share what YOU do to take care of yourself. Maybe what works for you will give others an idea of what might work for them!

Meet Lynne Brennan

Lynne Brennan was a teacher and school administrator for nearly 40 years. She began a new life as a caregiver in early 2014 when her husband, Gary suffered a traumatic brain injury in a highway vehicle crash caused by an inattentive driver. In addition to caring for her husband, Lynne is active in support groups with the Brain Injury Association of Massachusetts and also serves a co-facilitator for a caregiver support group at Spaulding Rehabilitation Hospital Cape Cod. Lynne and Gary have been married for 44 years and have two wonderful sons, two amazing daughters-in-law, and three precious grandchildren.





Four Steps to a Joy-Filled Life

By Debra Gorman

There are ways to navigate life that make it more beautiful. I have found four reasonable steps for managing life that will deliver not only beauty but meaning.

I certainly have been put to the test since my brain hemorrhage on August 20, 2011. Physically, I have changed much since that fateful day. Although I have little control over my circumstances, the real power I have is over my attitude. My stance is something I am very purposeful about. I watch it, monitor it daily, and try to improve on it. I'm not always successful.

There are hours or even days when I grieve. Even on those days, I know I'm passing through a short phase. Soon the sun will shine again. Usually, I'll allow myself a limited period of time to go all out as I bask in sadness. For a brief time, I'll savor it. If grief was mud, I wallow in it and cover myself with it until I barely recognize myself. Soon enough I'll realize that I feel worse, not better. At that point, I'll pick myself up and remember that attitude is everything.

“At that point, I’ll pick myself up and remember that attitude is everything.”

You don't need a brain injury to feel emotional, spiritual or physical pain. It's inescapable. As long as we tread this earth, we will experience hardship. We can use it to our advantage.

Here are the four easy steps to a joy-filled life:

1. Accept what you cannot change; change what you can.

Bitterness or anger at our circumstances will not improve them. The sooner we accept the cards we have been dealt, the sooner we can experience joy. The Serenity Prayer is an excellent mantra for anyone:

God, grant me the serenity (peacefulness) to accept the things I cannot change, Courage to change the things I can, and wisdom to know the difference.

Being as physically active as possible is important, not only for physical, but also for mental health. I recently spent five weeks in physical therapy. It's been years since I had formal sessions, but I did make some improvements.

2. Find purpose in and for your life.

I heard someone say, "If you have a pulse you have a purpose." You and I share space on this planet for a reason. Our circumstances are no surprise to God. If God didn't plan to use us and our particular circumstances to somehow better the world, we wouldn't be here.

Think about ways to serve. One result of serving is personal joy. Wherever your interests lie, whatever you can do, consider sharing them with someone. It feels good to contribute in some way. List your talents and abilities. What have you been uniquely gifted to do? What gives you pleasure? How can you share it? You are one-of-a-kind, like a snowflake.

With life comes suffering. It's a given. It's easy to become discouraged if we believe this life is all there is. However, my faith and all the wisdom I can glean tells me that this life is a classroom for what lies ahead. It's to our advantage to be good students.

3. Make goals, even just one.

A goal gives you something to look forward to and to work toward. A goal is measurable. You'll know when you're getting close and you'll know when you've achieved it. Write down your goals

God GRANT ME THE serenity
TO ACCEPT THE THINGS I CANNOT CHANGE
THE courage TO CHANGE THE THINGS I CAN
AND THE wisdom TO KNOW
THE DIFFERENCE

with the date and put the paper in a safe place, but somewhere you will occasionally come across it and be reminded.

Here are some examples: Learn something new. Have you always wanted to learn a foreign language? Or learn to play a particular instrument? Or get in better shape? The point is to be engaged in your life, try something new that interests and inspires you. Enjoy your life.

4. Practice gratitude

Research shows there may be no other attitude as powerful in its potential to improve our thinking as gratitude. Write down three things for which you're thankful daily. It's a powerful way to cultivate awareness, determination, enthusiasm and energy.

My husband and I used to keep a gratitude journal. We would write in it every evening after dinner. I mostly do it in my head now, but I think we should get back to writing it down. It doesn't take long, and it has proven benefits.

With gratitude comes joy. Joy is not dependent on happiness. Happiness is fleeting, joy abides. Joy is defined as, "a state of mind and an orientation of the heart. It is a settled state of contentment, confidence and hope."

I actually felt encouraged as I wrote this article. I plan to employ more effectively some of my own recommendations. If it works for me, it will work for you. I encourage you to try... you have nothing to lose, and everything to gain.

Meet Debra Gorman

Debra Gorman was fifty-six years old when she experienced her brain injuries. The first was a cavernous angioma, causing her brain to bleed, and four months later, a subdural hematoma. She later learned that she also had suffered a stroke during one of those events.

She finds a creative outlet in writing. She is able to use a keyboard, tapping keys with her non-dominant forefinger and thumb. She enjoys writing for her children and grandchildren and has written articles that have been published for hospice. Currently, she writes for her blog, entitled Graceful Journey. debralynn48.wordpress.com.



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BY HER SIDE,
EVEN IF
SHE'LL HARDLY
REMEMBER.**

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LOVE YOUR BRAIN Y O G A

By Kyla Pearce



In the blink of an eye, Kevin Pearce went from being an Olympic gold medal hopeful to suffering a near-fatal TBI. By drawing upon his own unwavering optimism, the resilience that he developed as a world-class athlete, the love of his family, and the support of numerous healthcare professionals and caregivers, Kevin made amazing progress that continues to this day. His journey led him to found the LoveYourBrain Foundation in 2014 alongside his brother, Adam Pearce, to serve others affected by TBI through programs that build community.

Kevin's TBI gave the Pearce family a glimpse into a new world—one where many people affected by this injury are plagued by intense isolation and disempowerment. This revealed the need for programs to rebuild community and resilience for healing. Post-injury, Kevin attended a yoga class and personally realized the potential of this practice to transform people's wellbeing, both physically and through the community connection. Yoga, a mind-body healing modality, has been shown to improve outcomes in a broad array of clinical populations, yet has not been used widely among the brain injury population. The practice of yoga integrates physical movement (asana), breathing exercises (pranayama), and meditation practices to promote strength, coordination, stress reduction, and self-regulation. Several studies have examined the benefits of yoga for brain injury, which found improvements in attention skills, memory, mental fatigue, self-esteem, and quality of life. However, at the time, no organization was offering accessible yoga to people with TBI and their caregivers at a national level.

“Kevin attended a yoga class and personally realized the potential of this practice to transform people’s wellbeing.”

Serendipitously, as Kevin was experiencing the profound benefits of yoga, Kyla Pearce, Adam Pearce's wife and Kevin's sister-in-law, was completing her certification to be a yoga teacher and Adam was using vipassana meditation to support his own healing. Together, they chose to focus one arm of LYB's programming on yoga because they believed its holistic and dynamic nature could meet the individual needs of each person with TBI, from wanting to rebuild strength and balance, to manage stress, and to find comfort in a community of people with shared experiences.

As Adam shared, “a big part of our motivation to create LYB Yoga stemmed from the transformation we saw in Kevin from his own practice. After a yoga class, Kev would share that, for the first time in a while, his mind felt calm and he was able to take a break from the race of trying to keep up. I also noticed that he loved the feeling of accomplishment that he received from engaging with what he deemed was a fitting challenge (be it focusing his mind in meditation or holding a strength-building yoga posture), instead of assessing his progress based on some medical benchmark. When he practiced yoga, he no longer felt defined by his injury.”

To address the unmet need for TBI-friendly yoga, LYB partnered with Dartmouth College to conduct a study that Kyla designed to evaluate an 8-week gentle yoga pilot program for this population (Donnelly et al., 2017). This study found that 16 people who participated in the yoga intervention reported significant improvements in their quality of life, most notably in their self-esteem and future outlook and in their ability to manage negative emotions like loneliness, anxiety, and anger. In contrast, the 15 people in the control group did not experience any significant improvements. Other feedback revealed that participants also valued opportunities to connect with other students in the class to learn from each other and normalize their TBI experience.



Based on the positive results of the pilot study, LoveYourBrain finalized the curriculum and officially launched the LoveYourBrain Yoga program in November 2015. This 6-week program is offered free of cost for both people with TBI and caregivers. Each 90-minute class integrates breathing exercises, gentle yoga, meditation, and group discussion based on empowering themes. LoveYourBrain partners with yoga studios across North America and trains and compensates their yoga teachers to offer LoveYourBrain Yoga in their respective communities. Teachers are trained to address a range of TBI-related symptoms by adapting specific poses to prevent dizziness and headaches, offering similar movements in a similar sequence to support learning and memory, using soft lighting and no or soothing music to mitigate hypersensitivity, and incorporating strategies to focus attention and release negative thoughts.

Once people complete the program, they can access other gentle yoga classes taught by LYB-trained teachers at a discounted rate so that they can sustain their practice and community connection. LoveYourBrain Yoga programs are run four times a year (i.e., January, April, July, October) and people sign up directly on their website.

Kyla Pearce, Senior Director of the LYB Yoga program, shared that, for her, the “aha” moment was the first time she taught LoveYourBrain Yoga at a wellness center in New Hampshire for a group of

10 people with TBI. “Based on feedback from our pilot study about the need for more community connection, we changed the structure of our program to incorporate 20 minutes of group discussion at the end of each class. This was somewhat of a gamble, since people with TBI often struggle with attention control, information processing, and emotional regulation, so I wasn’t sure whether our participants would want or be able to engage in group discussion. How wrong was I? As I listened to the story sharing and cross-learning in the group discussion, I witnessed participants regain their agency, feel accepted and understood, and experience the possibility instead of the limitations of their body and mind for the first time since their injury. I realized that people were gaining so much more than the physical benefits of yoga. We were helping to rebuild community for a group of people that so often experience intense isolation, which was incredibly powerful.”



LoveYourBrain is trying to address one of the major issues for the TBI community—the gap in ongoing support following inpatient and rehabilitation services. Because TBI is often an “invisible” injury, many people are unaware of the effects of the injury and thus are unable to act with understanding and compassion. Therefore, yoga studios offer an important community-based avenue for ongoing rehabilitation, in particular because they support holistic—physical, emotional, social, and spiritual—healing. Kyla shared that ultimately, their vision for LoveYourBrain Yoga is to create a more seamless continuum of care for people with brain injury. “We host comprehensive 20-hour trainings for

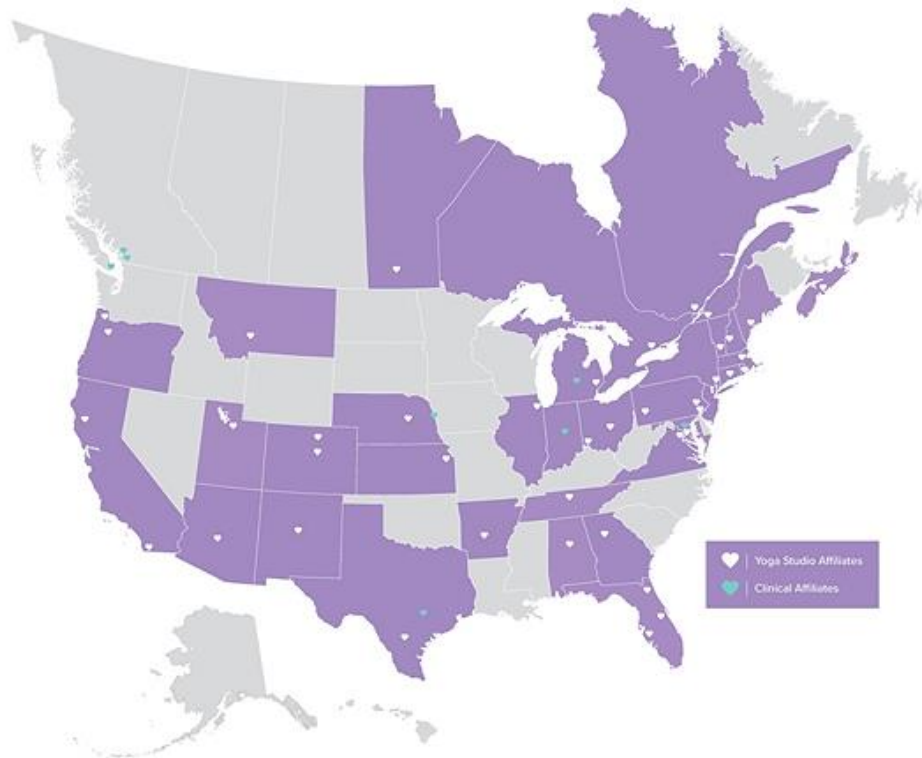
yoga teachers and clinicians working in brain injury rehabilitation to learn best practices for adapting yoga for brain injury, and how to offer our program in both community and clinical settings.

We also give scholarships to people with TBI and caregivers to attend our training so that they can be advocates for the benefits of yoga in their communities. We want people to experience the benefits of yoga-based tools early on in their rehabilitation, then, when they’re ready, to transition to our program at a yoga studio in their community to continue their healing. At its core, yoga is a practice of deep listening to—and honoring of—our vast capacity to be with whatever life throws at us without resisting it. I believe touching into this capacity leads to more authentic and compassionate self-expression and to regaining a sense of purpose, which are critical to any healing process.”

Over the past four years, LoveYourBrain has been working tirelessly to expand access to LoveYourBrain Yoga across North America. Currently, the program is offered through partnerships with 50 yoga studios and 8 clinical facilities across 29 U.S. states and 4 Canadian provinces. Altogether, 244 LYB Yoga programs have been offered for nearly 2,500 people with TBI and caregivers. LoveYourBrain is proud that their program is serving people from TBI across the

spectrum of severity, including mild (concussions), moderate, and severe injury, and with variable symptoms and comorbidities, including light sensitivity (44%), post-concussion syndrome (30%), and PTSD (15%). To ensure equity in access to their program, LoveYourBrain has an ambitious goal of expanding LoveYourBrain Yoga to all 50 states by 2021.

A small team of passionate and dedicated staff conduct extensive outreach to generate awareness among the TBI community about their local LoveYourBrain Yoga program.



Kim Baker, Director of Implementation, shared that “we’ve found about 25% of people who sign up for our program are referred by clinicians specializing in TBI rehabilitation. So, our team hosts in-service presentations at clinical facilities and presents at conferences like Brain Injury Association’s annual state conferences to engage clinicians and other TBI advocacy organizations. We also have established a network of volunteers called Clinical Connectors who are clinicians working in TBI rehabilitation that have agreed to raise awareness in their health service about LoveYourBrain Yoga. We believe partnering with health professionals is critical to the sustainability and expansion of our program.”

LYB is also dedicated to designing rigorous research to evaluate the impact of their programs. They feel that by contributing to the development of evidence-based practices, the medical establishment will recognize yoga as a viable healing modality and increasingly integrate it into the healthcare system. This way, people affected by TBI will experience a more seamless continuum of care where they can access ongoing support and participate in their community. For example, LoveYourBrain

Yoga was evaluated in a qualitative research study (Donnelly et al., 2019), which demonstrated improvements in strength, balance, flexibility, and attention control and greater sense of belonging, community connection, and ability to move forward with their lives. As one LoveYourBrain Yoga program participant shared, *“LYB yoga gave me something to look forward to in contrast to so many days that I feel I have no purpose, (and the things I want to do I cannot tolerate or do not have the energy or ability.) My “best” days (or parts) are always followed by my “worst”. Yoga helped me with balance. It is a good day that is not followed by a bad day to recover. Knowing I was likely to have a positive experience one day/week for six weeks was reassuring. The classes helped me feel more optimistic and relaxed. The yoga improved my strength and flexibility.”*

LoveYourBrain also implements two other program areas. The LoveYourBrain Retreat program includes week-long holistic health retreats for people with TBI and weekend retreats for caregivers. The Retreats are designed with an integrated approach using their core pillars of community, mindfulness, movement, and nutrition. LoveYourBrain believes these pillars help people cultivate the resilient mindset, physical capability, and support system essential to one’s health and happiness. The Education program teaches youth about key concepts related to traumatic brain injury—what it is, how often it happens, and the potential consequences—to give youth important perspective about their brain health. LoveYourBrain also uses The HBO documentary, The Crash Reel, which showcases Kevin’s TBI experience and healing journey, as a powerful platform for raising awareness about TBI.

More information about LoveYourBrain and the LoveYourBrain Yoga, Retreat, and Education programs can be found on their website at www.loveyourbrain.com. To sign up for LoveYourBrain Yoga, please visit their website (www.loveyourbrain.com/yoga/practice), or if you don’t live near a LoveYourBrain Yoga program, you can access their library of free yoga and meditation recordings here: (www.loveyourbrain.com/resources-overview)

Meet Kyla Pearce, MPH, PHD, CBIS, RYT-200

Dr. Kyla Pearce serves as the Senior Director of the LoveYourBrain Yoga program, overseeing the design, implementation, and evaluation of the program on an international level. She has been part of the Pearce family for years and, following Kevin's accident, played an integral role in the launch of LoveYourBrain. Kyla has blended her expertise as a yoga teacher and researcher to develop a TBI-focused yoga curriculum, train yoga teachers and clinicians to deliver this curriculum, and lead ongoing evaluations of its impact. As a Post-doctoral Research Scholar at Dartmouth College, Kyla leads a research portfolio in the application of yoga and meditation for community-based rehabilitation for populations with neurological conditions.





Over the last few years, there has been a clear acceleration in both diagnosing brain injury as well as a virtual well-spring of new treatment protocols. My recent experiences with EMDR have been transformative with my PTSD.

Early on after my brain injury, the only treatment recommended was a few days of rest. I was told by a well-intentioned doctor that I would be back to 100% and back to “normal” in a few short months.

That was over eight years ago. Over that time, we have learned more about the subtle (*and often not so subtle*) nuances of life after brain injury. Though our experience has been that of laypeople, living as a survivor family has been an eye-opening experience. At times heartbreaking, at times wondrous, brain injury will forever be part of our lives.



This month’s issue of HOPE Magazine touched us both deeply. Caregiver stories often offer the end to isolation that so many people feel when brain injury strikes. Our survivor stories give others a voice and a platform to share their day-to-day struggles and victories. This month’s special section about LoveYourBrain Yoga shows that meaningful recovery truly requires a body, mind, and spirit approach.

HOPE Magazine is now read in over sixty countries, something we marvel at. Every one of us, however, can be an advocate, sharing when appropriate, to help end the isolation and silence that surrounds brain injury.

Peace,

~David & Sarah