

BRAIN INJURY

Winter 2021

HOPE

Magazine

support
education
inspiration

OUR SPECIAL STROKE SURVIVORS ISSUE

MedRhythms Offers
**New Hope for
Stroke Survivors**



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Welcome

Publisher's Introduction

HOPE MAGAZINE

*Serving the Brain
Injury Community*

Winter 2021

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Welcome to the Winter 2021 issue of HOPE Magazine!

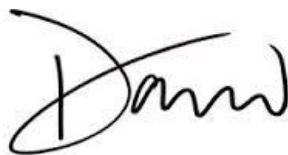
It's hard to believe that another year is behind us, and what a year it's been. While the ongoing pandemic continues to upend life, there remain bright spots on the landscape of humanity.

We are committed to profiling new technologies and protocols that have been demonstrated to improve the lives of brain injury survivors. In this issue dedicated entirely to stroke survivors, we are introducing you to Rhythmic Auditory Stimulation (RAS).

There now are over fifty clinical research studies demonstrating improvements in movement when using RAS, offering new hope to stroke survivors.

As we move forward, you can expect us to remain committed to offering forward-moving information to all affected by brain injury.

Be Safe and Happy Holidays,



David A. Grant
Publisher

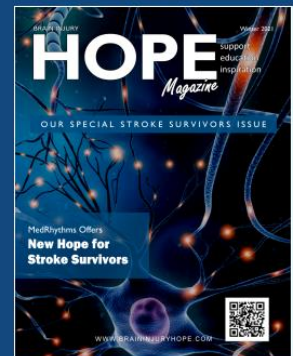
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Winter 2021



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Using Digital Therapeutics to Improve Outcomes

By Maya Pierce, Lauren Steidl, B.A., Brian Harris, M.A., MT-BC, NMT/F, and Chrissy Stack, M.S., MT-BC, NMT/F, CBIS, MedRhythms



Humans, for almost as long as we have existed, have been making and listening to music. Archeologists have discovered man-made drums and flutes that are believed to be more than forty thousand years old. Music remains an essential part of the human experience today, and we are all familiar with its unique and profound effects. It has the ability to motivate us, trigger our emotions, transport us to different times and places, and quite literally help us heal. Using music in rehabilitation is at the heart of the work at MedRhythms, a Maine-based digital therapeutics company that uses sensors, software, and music to address walking deficits caused by neurologic injury and disease.

Neurologic Music Therapy (NMT) is a research-based system of standardized clinical techniques for sensorimotor, speech, language, and cognitive training. These treatment techniques are based on the scientific knowledge in music perception and production and the effects thereof on nonmusical brain and behavior functions. Populations served by NMTs include stroke, traumatic brain injury (TBI), Parkinson's disease, multiple sclerosis, and others. Therapeutic goals and interventions address rehabilitation, development, and maintenance of functional behaviors.

“Neuroplasticity is a natural process by which the brain creates and strengthens internal connections, and it is the reason brain injuries can heal.”

Neuroscience research has shown that music has the ability to simultaneously engage multiple regions of the human brain. Additionally, there is profound evidence that engaging in music can aid in neuroplasticity. Neuroplasticity is a natural process by which the brain creates and strengthens internal connections, and it is the reason brain injuries can heal. NMTs witness neuroplasticity in

action in clinical settings every day. They frequently see people who sustain neurologic injuries that result in walking problems begin to walk faster, farther, and more efficiently after receiving NMT for several months. This important research has set a foundation for how music can profoundly affect recovery from neurologic injuries and diseases.

Over time, clinicians began to notice that patients who received NMT recovered faster than with the standard of care alone. This was the case with MedRhythms, a company founded out of Spaulding Rehabilitation Hospital that was originally started as an NMT service provider by Brian Harris, one of only 250 NMT fellows in the world. Identifying the significant need for effective, music-based interventions that could not be met by therapists alone, Harris found a technological solution.

Patients noticed the dramatic improvement, too. Unfortunately, those receiving NMT often had to discontinue the treatment regardless of whether they showed functional improvement. Sometimes the discontinuation of treatment was due to the cost of therapy, as NMT is primarily funded out-of-pocket. Sometimes it was due to patients relocating and no longer having access to NMT services. There are millions of people who could benefit from NMT and only approximately 3,000 therapists worldwide with NMT training.

The digital therapeutics industry is made up of companies that develop evidence-based therapeutics through technology, including hardware and software programs. MedRhythms is in the process of developing its first digital therapeutic, a prescription software system that uses 3D motion sensors and music to support the walking rehabilitation of adults with neurologic injuries or diseases, such as stroke. Walking rehabilitation has been the focus of this digital therapeutic because it shows the most quantitative, dramatic improvements when using music to improve walking. This intervention is known as Rhythmic Auditory Stimulation (RAS). There is substantial evidence that walking in sync with a beat can help those with brain injuries and neurological diseases walk faster, longer, and more symmetrically.

Randomized Control Trials in multiple indications, including stroke, MS, Cerebral Palsy, and PD, demonstrated improved walking when RAS was delivered.

Suh et al., 2014; Conklyn, et al., 2010; Kim, et al., 2012; Bukowska, et al., 2016).

The MedRhythms digital therapeutic system is designed to replicate RAS with a mobile app, sensors that attach to shoes, and headphones that play personalized music. Users walk to the beat of the music they hear as an algorithm and embedded sensors take in data and change the music in real-time according to the RAS protocol. Depending on how well the user is able to walk to the beat, the algorithm augments the tempo and rhythmic structure of the song being played through the headphones to drive users toward improved clinical outcomes.

The goal is for this device to make the benefits of NMT accessible to all who need it. In 2020, MedRhythms' device for chronic stroke walking deficits received Breakthrough Device designation from the US Food and Drug Administration (FDA) based on the product's potential to address a large unmet patient need in a novel way. This device for chronic stroke survivors with walking deficits is currently being studied in a multi-site randomized controlled trial at some of the top rehabilitation hospitals in the country. Along with developing this walking-focused product for stroke survivors in the chronic stage of their recovery, MedRhythms will continue its work toward gaining FDA approval, making this reimbursable by insurers, and commercializing the device as soon as possible.

This digital therapeutic for post-stroke walking deficits is just the beginning as there are many other patient populations that could benefit from RAS. These include those living with TBI, Parkinson's disease, multiple sclerosis, and Alzheimer's disease. In addition to improving walking function, NMT techniques are effective in helping people with certain neurologic injuries and diseases to regain language and cognitive skills. The possibilities are endless, and the work has only just begun.

About MedRhythms



MedRhythms is a medical device company that is developing a digital walking therapy for stroke survivors that is undergoing research in usability studies and clinical trials across the country. The device uses music, sensors, and software to provide therapy based on decades of research that walking to music can improve mobility.

To Learn More, Visit: www.medrhythms.com

Laugh When You Can, Grieve When You Must

By Donna Hafner



It's been many years since my brain injury. I have enough distance now from that fateful night to know that you can't go through this kind of gigantic, life-changing event without some continuing repercussions. That goes for both the survivor as well as those who love or care for us.

In the early months after my strokes, I was just brain numb. Though I could follow simple conversations and directions and had to re-learned the most basic activities of daily living (ADL) skills, I didn't yet have the cognitive ability to fully grasp the magnitude of my injuries or deficits.

I knew that I had a massive heart attack and a series of strokes, but I had no memory of these things thanks to my two-week coma. I had no firsthand memory of the trauma that had occurred, nor did I have any idea of what my family and friends had endured while I was "sleeping."

I often minimized my injury and exaggerated my skills when talking to everyone. I had no idea at all that I wouldn't be returning to the person that I used to be. My family may have had a clue, but I think that secretly all of us were expecting that I would ultimately "bounce back", as I always had. Heck, hadn't I already beat the House and lived against all odds?

My first year was spent in a cocoon of denial. I know now that it was a necessary part of my recovery process. It is the way that our brains protect us in stressful times. Recovery is an imperfect process that does not often happen linearly.

"I often minimized my injury and exaggerated my skills when talking to everyone. I had no idea at all that I wouldn't be returning to the person that I used to be."

“At times, I even considered suicide. It seemed like a viable option, but I knew that I didn’t want my family to suffer further because of me.”

You make some headway, then go back a step or two, then lurch forward three steps and then, unexpectedly lose a step. Many of us refer to it as the brain injury dance. Recovery rarely goes in a straight line for long.

When it happens, we and our loved ones are exhilarated by our progress and worried sick at the setbacks. Seldom are we told in advance that this is normal. This can be a period of enormous frustration and can strain relationships and all concerned. It can even feel quite hopeless and disheartening at times.

The good news is that this is also the time that insight begins to occur. For me, it was in my second year that I was starting to get some perspective. I had some “time under my belt” in this new life now. I could begin to make sense of the ebbs and flows of my recovery. The reality of my deficits was undeniable.

My second year was just plain hard. The grief was overwhelming. I didn’t want to tell anyone just how painful it was. I suffered a lot when I was home alone and felt that I didn’t want to burden my family and friends. They had already gone through so much due to my medical catastrophes. It was a really tough time. As I later learned, this grief was normal and expected - I just didn’t know that at the time.

Had I been able to think more clearly, I might have reached out and gotten some professional support, but I didn’t. I just muddled through, cried, and missed my old life and my previous skills and abilities. I had many fears about my future. Many of them I couldn’t even articulate fully, but they were there, lurking in the background. At times, I even considered suicide. It seemed like a viable option, but I knew that I didn’t want my family to suffer further because of me.

I've since learned that contemplating suicide is common among people who are newly injured. It's hard to see that a good future is even a possibility. It wasn't until I found a local brain injury support group and heard other people talk about their experiences that this thought finally left my head. There were folks there who had more time under their belt who kept saying that it would be better. I didn't believe them at first. But slowly, I began to see that there were small improvements.

They gave me hints and suggestions and I started learning how to live with a brain injury instead of fighting against my reality. It wasn't easy but I slowly started finding that I laughed more about the ridiculous stuff that happens because of our injury. You have to admit, some of the stuff that we do is just absolutely funny. This doesn't mean that grief doesn't still show up. It does and that is normal. We've lost a lot.

I've found that when the sadness comes, it's good to acknowledge it, cry, have a small fit, be mad... and move on. I know that it isn't good for me to live in that sad space for long. It keeps me from fully living the life that I have now. I'm finally grateful that I did survive, but, it took a while to feel that way. If you are struggling with this too, don't give up yet. It gets better.

The words that I've repeated to myself over the last two years are, "Laugh when you can, grieve when you must." It's helped me along my journey. It reminds me that there will be tears and sadness at times, but laughter will return. I wish you all much laughter, fewer tears, and peace.

Meet Donna Haffner



Donna is a survivor in the truest sense of the word. Coming back from near death and living life as a brain injury survivor have validated why those closest to her know her by her nickname – Resilynt.

“We all have to go through the tumbler a few times before we can emerge as a crystal.”

- Elizabeth Kubler Ross

What Do I Believe?

By Jennifer White



Immediately after I realized that I had survived a massive brain injury that kills most people, I was thankful and prayerful. This was a natural reaction from someone who spent her youth in church all day on Sunday's, nights at weekly prayer meetings, Thursdays at church lock-ins, at least one year presiding as State President of the Baptist High School Student Union, and a summer traveling internationally with a religious singing group.

Although as a result of natural attrition while in college, I started attending church less often and started wondering what I believed in. I never stopped believing in a higher power, but I started questioning my true beliefs.

“I never stopped believing in a higher power, but I started questioning my true beliefs.”

Then my world was rocked by a massive stroke, an acquired brain injury as my rehab facility called it. Honestly, it was difficult for me to rejoice in the fact that I lived despite my physician's predictions. I could not understand how I could work my fingers to the bones and become an executive at a company dedicated to raising money for health and service organizations, only to be struck down from a brain injury that forced me into early retirement in my early 30's.

Simply, I had my whole life ahead of me. Then, twenty-four hours later I was forced to learn how to walk again, how to talk again, and how to eat again. I had already gone through this learning process as a child. How could a powerful entity that I dedicated my entire life to for so many years allow this to happen to me?

I was in pain and hurt as if a friend had slapped me across the face. Then I read a book about how bad things happen to good people and I felt a little better. Honestly, it has taken quite some time to accept the fact that my surgeon recommended that I not have children. Is it fair that my husband has to

suffer because I had a stroke? The answer is no, but it is what it is, and I still believe that there is a guiding light in my life that led me here.

I will deal with the loss of old friends that I had before the stroke because we have little in common relative to raising children and I will deal with the inability to acquire new friends because of our incompatibility regarding child-rearing. It is because I will not define the quality of my life based on my ability to raise children.

After feeling sorry for myself for quite a while and feeling guilty that I had lived when others had died, I decided that even though I didn't have the answers I would continue to believe in something greater than myself. My faith has gotten me through a lot of hard times, and I believe it helped me survive this brain injury when all I wanted to do was sleep.

The truth is I have always believed in a higher power -when my mother died of cancer when my father died of cancer and throughout my life when there were times that seemed unbearable. I realized after the stroke that I did not have to have answers to every question. It is okay not to know the answers. It was simply hard for me to accept what I had learned all my life, (believing in something greater than yourself and more powerful than you are) is having blind faith. Believing in something that you can't necessarily touch physically is very powerful and gives you strength when you need it most.

Although I always felt very guilty for questioning anything religious, I learned throughout my life that much of my strength comes from questioning things that I do not understand. I realize that it is okay to question things. Questions bring answers, and I believe they make us stronger. I was raised in a fire and brimstone church where I felt guilty for questioning my religion. I feel guilty no longer. The God I believe in is fine with my questions!

Meet Jennifer White



Jennifer White is a traumatic brain injury survivor from St. Louis, Missouri. When she's not writing about her life as a survivor, she enjoys spending time with her family and of course, quilting.



American Stroke Association
A division of the American Heart Association

Together to End Stroke®

F.A.S.T. is how we come together to end stroke®

Learn the stroke warnings signs

F.A.S.T.

Face
Drooping

Arm
Weakness

Speech
Difficulty

Time to
Call 911

Every 40 seconds, someone in the U.S. has a stroke.

It could happen on your street, in your workplace, at a store where you shop — anywhere. Your readiness to spot the stroke warning signs and call 911 could save a life or make the difference between a full recovery and long-term disability. That's why it's so important to learn the stroke warning signs and urge everyone you know to do the same.

The faster stroke is treated, the more likely the patient is to recover.

In fact, stroke patients who are treated with the clot-busting drug IV r-tPA Alteplase within 90 minutes of their first symptoms were almost three times more likely to recover with little or no disability.

In some cases, a procedure to remove the clot causing the stroke is also recommended. Ninety-one percent of stroke patients who were treated with a stent retriever within 150 minutes of first symptoms recovered with little or no disability.

The thing to remember is that stroke is largely treatable. It's a matter of getting the right treatment, right away.

[Stroke.org](https://www.stroke.org)

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No Was Never an Option

By Brian Maram



The year 2011 started full of promise for me. Out of the blue and with no warning, a week into the New Year, I was struck down by a near-fatal hemorrhage in the pons area of my brainstem. Surviving such a deadly stroke came with a very high price tag. I was given a 1 – 5% chance of survival.

My family was informed that if I survived the first forty-eight hours, I would need to come to terms with the fact that I would never walk again. The thought of being wheelchair-bound for the balance of my now unnatural life scared the living daylight out of me. With the odds stacked against me, I was determined to prove them all wrong.

After having spent some time in ICU, I was transferred to a semiprivate ward, wherewith the aid of a speech therapist I was taught to speak coherently again. Still numb, disorientated, and overwhelmed by what had just happened to me, I was transferred to a rehabilitation facility where I would have to spend the next two months.

On admittance to the rehabilitation center, I was examined by a doctor and placed on an untold amount of medication. For someone who had never taken so much as a pain killer before, I was suddenly on more medication than I care to think about, not to mention all the serious side effects that all these medications were causing me.

“My family were informed that if I survived the first forty-eight hours, I would need to come to terms with the fact that I would never walk again.”

Accepting the reality of my future as a stroke survivor was the hardest thing I have ever had to contend with. This meant accepting that my life would never again be the same as it used to be. Disabled and filled with uncertainty, I was determined to learn to walk again. Against all the odds, I



embarked on an intensive rehabilitation program. There was no stopping me now and I would spend every possible moment in the rehab facilities gym, working on those flaccid muscles of mine.

Six weeks after entering rehab, I was able to walk short distances with the aid of a four-prong crutch. One step at a time and with pure determination and perseverance, I eventually progressed to a single-prong crutch. Once discharged, I continued my intensive program as an outpatient at a local neuro-physiotherapist.

Soon after returning home, my marriage of fourteen years crumbled and fell apart when my wife took our two children and moved out. At the lowest point in my life, my family and friends abandoned me. With nowhere and no one to turn to, I was left desolate, without a support system. I was suddenly forced to face the daily challenges that the stroke threw at me on my own.

My stroke ultimately revealed the true colors of those around me. Through all the trials and tribulations, I have grown into a wiser, stronger, and better person. I came to learn who and what is important in my life. Wherever possible I try to motivate and inspire other stroke survivors and their families.

Each year I have entered a fun walk, which is held by a popular local radio station, on the roads of Johannesburg and meanders through the scenic suburbs. At first, I would walk as far as I could and use my wheelchair when I got tired. Last year I completed the full five-kilometer walk without the use of a wheelchair or crutch. This was a huge achievement for me, especially after being told that I would never walk again.

Not once did I ever doubt that I would never be able to walk again. With the right attitude, I kept pushing on. A very large contributor to my success was the hours I spent in a Hyperbaric Oxygen Chamber (HBOT). I purchased and imported a portable chamber that I could use at home. Daily use with the recommended breaks saw enormous changes. Slowly sections of my brain and body appeared to wake up. After a while, I was able

to read more than a page of a book without getting exhausted. Combined with my intensive physiotherapy, the high tone started to ease off a little, allowing me to regain some gross movements back into my motionless limbs.

Five years later and after thousands of hours in the gym, I can get around, independent of a wheelchair or crutch. Although my balance is still severely affected, I do take things slow and those around me have learned that when we walk, we get to do a high definition walking as we appreciate more of the scenery around us.

Life has been an uphill battle, but through it all, I have learned so much. This world is full of people with ugly characters, but thankfully they are the minority. They are outnumbered by those with good hearts and who are willing to be there for you. A positive attitude attracts positive people. Even with the limitations that I have, I have come to realize that the new people in my life are there for me and not for what I can offer them.

Meet Brian Maram



Brian Maram is a stroke survivor from Johannesburg, South Africa. Brian takes pleasure in motivating other stroke and TBI survivors. He is in the process of writing a book about his journey or recovery.

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Taking That Small First Step

By Ralph Poland



On November 3rd, 2006, I went to the emergency room of York Hospital. Hours later, I suffered a heart attack. Then, I was transported to Portsmouth Regional Hospital to undergo open-heart surgery. Due to complications, I was then transported to Tuft's Medical Center in Boston, Massachusetts where they re-performed the surgery. During the second operation, I suffered two debilitating strokes, which landed me in a coma for the next two and a half weeks.

During my coma, there were times of hearing strange voices talking about cabbage. Much later in my recovery, I learned that cabbage is a medical term that means CABG, an acronym for Coronary, Artery, Bypass, & Graft.

I came out of my coma shortly after being transported back to Portsmouth Regional Hospital and discovered I had no feeling below my knees, elbows, or use of my hands, as well as being unable to speak, finding myself in a kind of vegetative state. I was left only to peer out into the limited world around me. My whole body felt foreign to me and, even my thoughts were a hopelessly jumbled mess, I was surprised that it was almost Thanksgiving Day.

“As my two neurologists were leaving, one of them posed by my bed just long enough to say: “You’ll be lucky if you are confined to a wheelchair for the rest of your life.”

As my two neurologists were leaving, one of them posed by my bed just long enough to say: “You’ll be lucky if you are confined to a wheelchair for the rest of your life.” At some point, I realized that I needed to try to only think positive thoughts. I felt I had to try to put a positive spin on things because I couldn’t afford to allow my mind to discourage me from even trying. I finally came up with simply adding ‘Yet’ at the end of my ‘can’t’. For example, my self-talk became “I can’t do it yet,” from that moment on.

Meanwhile, after five weeks in Portsmouth, I was moved to New England Rehab, in Portland Maine. There I began intensive Physical, Occupational, and Speech Therapies. When I first arrived, I couldn't feed myself and had to continue to be lifted in and out of bed by a lift that was bolted to the ceiling.

After many OT sessions, my therapist had me try to support myself enough to stand with the use of a walker. One day while having me do this exercise (feeling that I could confide in him), I told him that I wanted him to help me walk again. He replied, "I understand that you have no feeling below your knees, is that right?" I answered yes! Then he said, "Because you have no feeling in your lower legs, you wouldn't be able to learn to walk again." I was devastated when hearing that, so I asked him to do me a favor.

First, I asked him to let me know when my left foot was firmly planted on the floor, indicating that my right foot was ready to take a step. He agreed. Then, I asked him to do the same with my right foot. Once he did, he asked, "What was that about?" I told him that each time I had made a mental note of how each upper leg felt, and now I am ready to walk! He replied, "You are determined to walk?" I answered "yes!" He then said, "Well, not today! We're at the end of this session and you are well spent. But, if you are so determined to try, then at some point we can try again."

About a week later, while my OT was wheeling me out through my room, he asked if I still wanted to try to walk. Of course, I said yes! So, he stopped my wheelchair at the doorway of my room, then he placed my walker in front of me and said, "We'll try it right here." I struggled very hard to slowly take the first small step. Then after a short pause, I continued with the next step. Due to being exhausted, I let myself drop back into my wheelchair. I heard my OT mutter, "Boy, you are determined!"

"When I first arrived, I couldn't feed myself and had to continue to be lifted in and out of bed by a lift that was bolted to the ceiling."

By the time I was discharged, I could walk one hundred feet with the use of my walker, before tiring.

Through Northern New England Goodwill's Neuro Rehab services, I was assigned to two PTs. Over time they tried introducing me to using every assistive device in their arsenal. One day while I was (again) trying to use a cane, that PT and I passed my other PT in the hallway. I stood nearby as they whispered to each other. I saw them nodding their heads and both PTs turned to me. One of them asked me to explain why I couldn't use the assistive devices.

I explained that I had to concentrate on maintaining my balance. While standing on one foot, I have to move the other foot and the cane at the same time. There were too many motions, all at the same time. With that, they both turned away while again negatively shaking their heads. At that point, I made the statement: "We haven't tried me walking without anything!"

Upon hearing that, they both began shaking their heads. One said, "You can't just go from walking with the assistance of a walker to walking without anything!" At this time, the other PT spoke up and explained that they were trained to use other assistive devices before letting the patient walk on their own. I asked them to give me a week. Both PTs remained skeptical of me ever being able to walk without any assisted devices however, with their expertise and my determination, I went on to walk as I do now. I wholeheartedly credit my ability to walk today to my OT at NER, and the two PTs at Westside, for allowing themselves to think outside of the box, so I can walk as I do now. In August of 2009, I was discharged from Westside.

Since then, my life has pretty much gotten back on track. Had it not been for rehabilitation after my heart attack and subsequent strokes, I wouldn't be alive today. I know that people who are left in a vegetative state don't live long. Despite many months of hard work, Goodwill also taught me how to go from my disability controlling my life, to me taking control of my disability. Today, my life would never be as productive as it is now, had it not been for the rehabilitative care I received, and for that, I am truly grateful.

Meet Ralph Poland

Since re-inventing himself since his stroke, Ralph volunteers at a local hospital. His real passion is volunteering at the Rehab where he recovered. There, he shares his story with patients, offering them hope and inspiration.

Ralph also serves on the BIA-MAINE Chapter, as well as on CMMC's Patient Advisory Council. He continues to offer insight from a brain-injured survivor's perspective to support groups, Neuro OT students at UNE, and staff members at CMMC.



Happiness is a Choice

By Debra Gorman



On August 20, 2011, my brain started to hemorrhage from a condition I was born with, called a Cavernous Angioma, on my brainstem. It was considered inoperable and the bleeding in my brain led to a stroke. My life hung in the balance for several days, but survive, I did.

I worked very hard those first years at all sorts of therapy. I was determined I would return to my former state of being and recover my past abilities. Otherwise, I didn't know how I would face life. I didn't know if I could face life. I was fifty-six years old at the time of the event. I had spent nearly a lifetime being one way.

Time passed and I struggled. I applied tremendous effort for improvements that either didn't come or were so minor I didn't want to count them. It was slowly becoming clear to me that I was never going to be who I was before.

“It was slowly becoming clear to me that I was never going to be who I was before.”

I turned my efforts to accepting my new limitations. I believed the key to my acceptance was to carve out a satisfying life around the interests and abilities I had always had, approaching them in a new way; a way more accessible to me now, as my methods had to be different from before.

I missed my old life terribly. Formerly, I had built my life around a fairly new marriage, other relationships, my career, hobbies, and interests. For example, I had been a long-distance runner, backpacker, bodybuilder, and long-distance cyclist. I was also a nurse, a do-it-yourselfer, a decorator, traveler, actor, and director. I took pride in all those things. They were all activities that I felt somehow defined me, but which were out of the question for me now. Recently, however, I recalled



that while backpacking many years ago I decided that when I became old and feeble, I could take up canoeing and do some primitive camping on various islands. Perhaps I would even take up fishing, which I had pursued and enjoyed in my twenties. When I made that future decision, I had in mind my eighties, but now might be a good time to explore those options.

I also enjoy writing and have more time for it. More time is needed because I must peck at the keyboard with the thumb and forefinger of my non-dominant hand. I have written several stories for the grandkids and plan to write for my grown children as well.

I like to cook and entertain, although I can no longer taste food. I cook from tried-and-true recipes and memory, and it helps that my husband is a good taste-tester. It's the nurturing aspect of entertaining I find so satisfying. I try to provide a pleasant setting with flowers, candles, music, and linens and then plan for conversation that engages the guest(s) and shows interest in their thoughts and opinions. For my part, I must plan on at least three times the actual time and effort I might have spent on such an occasion another lifetime ago.

As much as I enjoy people, I have trouble thus far striking a balance between the right amount of hustle and too much. I fatigue easily and profoundly, so I need to care for my rest needs. I must become better at recognizing the need for rest, and then be disciplined enough to go lie down.

I think the most significant thing I've learned post-brain injury is that life goes on—provided life goes on. One can be happy again. Many years ago, I was given a book entitled *Happiness is a Choice*. I don't think I ever read the book, but the title stuck with me. I find it to be true: happiness IS a choice. I CHOOSE to be happy. I wasn't always able to make that choice.

There was a point in time when I was so disappointed and so hurt, that I seriously contemplated going to bed and waiting to die. I had a decision to make.

I could give up or go on. Something told me, an inner voice, that there is purpose in all of this. The best is yet to come if I will do my part to be available, to be hopeful, to have gratitude, and to have faith. I find much to be thankful for each day, which helps my attitude.

I have done the hard work that allows me to say I'm happy. I have grieved my losses. Sometimes I still grieve, but more often than not, I feel gratitude for the people in my life, the abilities I still possess as of this moment, and more than anything I'm grateful to give and receive love.

I think I'm better at both the giving and receiving of it since my brain injury.

Meet Debra Gorman

Debra Gorman survived a brain hemorrhage from a brain stem cavernous angioma (a congenital condition), August 2011, at fifty-six years old. Three months after the first brain bleed, she experienced a subdural hematoma, resulting in a craniotomy. She nearly died several times during those two episodes and family members arrived from all over the country to possibly say goodbye. She is convinced her life has a new, more focused, purpose. She is grateful to be living, and for the abilities, she has retained.



When it comes to a stroke,
TIME = BRAIN



Coming Back From Beyond

By Ted Baxter



Having held the position of a global financial executive for a prestigious global investment hedge fund, flying was not a new experience for me. On top of that, there were the exotic vacations I took with my former wife, Kelly. When I wasn't flying for work, I was flying for pleasure. So, perhaps I should have realized right away that the pain in my leg wasn't a result of exhaustion and too much sitting on a plane. It was when Kelly asked me a question and I didn't respond that she realized something was seriously wrong.

I heard her questions and sounds from the paramedics and doctors, but I couldn't comprehend what they were saying. It was almost like having quick flashes of information in my eye, gradual shading of comprehension from one side like a curtain being drawn. I couldn't respond, I couldn't talk, I had a huge headache, and my body was starting to shut down. That sense of clarity abandoned me by the time we arrived at the hospital.

“My stroke was caused by a blood clot, a deep vein thrombosis (DVT), in my right shin which travelled to my heart and eventually landed in my brain.”

My blood pressure plummeted well below what was deemed low blood pressure and at one point, fell to 32. I did become lucid again because I remember choking on a chewable aspirin and being disturbed by the lack of sensation in my arm.

My stroke was caused by a blood clot, a deep vein thrombosis (DVT), in my right shin which traveled to my heart and eventually landed in my brain.

Motivation and Determination

I was transferred from the hospital in Evanston, IL to the Rehabilitation Institute of Chicago (RIC) and began working with highly trained physical, speech, and occupational therapists. At the beginning of my stay in RIC, the weekends were quiet with nobody around except the nurses and Kelly. I knew that time is the essence of recovery. Saturdays and Sundays became days when I went to the exercise room down the hall to attempt sit-ups and stretches. Kelly put me in a wheelchair with the aid of the nurses and rolled me into the exercise room.

I continued to struggle to form intelligible words. I couldn't read or write. It took three or four months for me to remember Kelly's name. It was while I was at RIC that I was first introduced to the term "aphasia." I had lost a great deal as a result of the stroke, including my abilities to walk and talk, but I had not lost my will and determination. By the time I was released from RIC, about two months after having the stroke, I was walking, albeit with a limp, something that most never thought I would do again. As good as that felt, I left the facility aggravated by my aphasia and determined to find a solution. I managed to communicate to Kelly that I wanted her to purchase for me flashcards meant for toddlers. I needed to retrain my brain, and that meant starting at the beginning.

She would hold up pictures of everyday objects and I would fight my way through the words, often attempting numerous times before I could mimic the way Kelly would say them.

A few minutes later, when shown the same picture, I would have completely forgotten the associated word. Short-term memory became my biggest foe. But I was determined, and I continued my methods of recovery between sessions with speech therapists at the RIC Outpatient Program.

I found a computer application that featured a woman carefully forming words and I would mimic her sounds and how her mouth moved when the right pronunciation was used. I was given crossword puzzles, which I would do on my lunch break. In my mind, I didn't have time to waste. It might be because of my haste that I found the group therapy sessions so torturous, but I also hated being unable to answer the questions asked. I like to be the best in everything, and aphasia was robbing me of that ability. I didn't have the words yet, but I had my memories, and I knew that I had given speeches at important international conferences, did impromptu pep-talk speeches to my employees, and interacted with businessmen from all over the world.

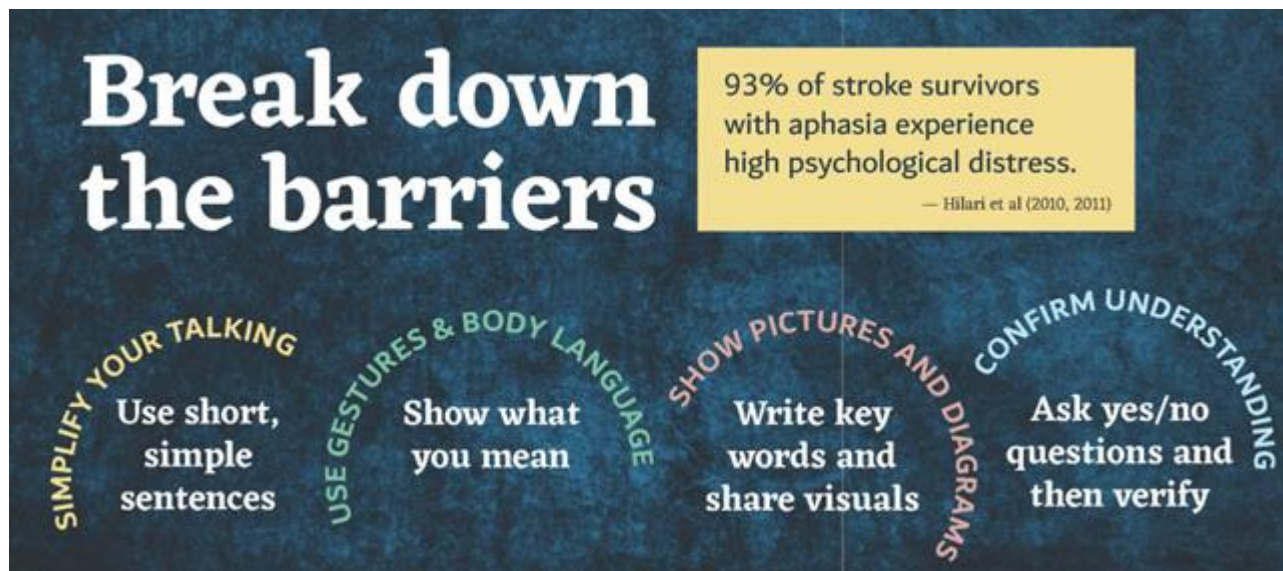
“I had lost a great deal as a result of the stroke, including my abilities to walk and talk, but I had not lost my will and determination.”

Aphasia Training in Ann Arbor

Kelly was always trying to learn more. She researched other programs in the country and discovered the University of Michigan Aphasia Program (UMAP). I willingly made the trek from Chicago to Ann Arbor to enroll in UMAP. During my first conversation with the speech therapist, she told me that it

was very clear that I wasn't always comprehending what others were saying to me. That was an eye-opening moment for me. I knew that I had trouble speaking sensibly, but I hadn't realized that I was confusing what others were trying to communicate to me.

The therapists at UMAP tried to cater to my specific needs. In one session, the primary speech therapist pulled out the financial page of the Wall Street Journal and proceeded to ask me questions related to the financial world that I had once lived in. This jogged my memory to know terms I had used frequently before my stroke. This became a regular part of the therapy routine, with her challenging me to relearn the familiar terms.



Variety of Activities to Avoid Boredom

Frustrated but determined, I did simple things like practicing writing my name twenty times every day and trying to speak clearly and fluently using a tape recorder of my voice. I then went back to a deck of flashcards and started practicing using a different form. I read the question on one side and then flipped it over and read the answer on the other. My goal was to recall what I had read. Practice, practice, practice!!!

I participated in a speech program at Northwestern University in Evanston, IL. While I was there, I was encouraged to consider participating in a book club, which I agreed to try. Each week, we were assigned a few pages of the designated book to read, and clinicians would ask us follow-up questions. I changed the rules for myself, though, and made it a goal to ask at least two comprehension-based queries every week. If I could do that, it meant that I was understanding what I was reading. Around this time, I started carrying a dictionary with me and challenged myself to learn five new words each day. That meant not only reading and understanding them but also using them in sentences throughout the day and writing them out on flashcards.

This provided me an atmosphere where part of the speech program involved working with doctoral students, completing a variety of different tasks. They would show me pictures of people doing

activities, speak the corresponding verb, and then ask me to use the word in a sentence. I enjoyed this, and it was very beneficial to my recovery. The accomplishments were great self-esteem boosters.

Recovery Moved to A Change in Perspective

After I had spoken to a variety of people, some friends, and some strangers, I decided that I needed a change.

In 2010, I moved to Southern California, even though I knew no one there. All of my life, I had been a risk-taker, so I took a chance. I was scared, but I had never let fear stop me before. Slowly but surely, I volunteered myself to the hospitals near where I lived. I was introduced to several medical doctors at the University of California – Irvine, and I attended a speech program at San Diego State University. I took it upon myself to make connections going forward.

Today, I am involved in a volunteer communication recovery group at St. Jude’s Hospital, where I provide therapy to stroke survivors and train students to be better clinicians. I’m involved in philanthropic matters of UC Irvine - Health, and I’m a member of the Board of Directors of the American Heart and Stroke Association in Orange County.

I wrote my memoir, *Relentless: How a Massive Stroke Changed My Life For The Better*, which was published in July of 2018.

It would have been much easier to have given in to the effects of the stroke and to admit defeat to aphasia, but it is so much more rewarding to know that I did what so many believed I wouldn’t be able to do.

Meet Ted Baxter

After spending 22 years in the financial industry, Ted W. Baxter retired as a global finance executive with a large hedge investment firm based in Chicago. Ted now resides in Newport Beach, CA where he volunteers at several health-related institutions and hospitals in Orange County, leading groups in a stroke-related communication recovery program, and is a member of the Board of Directors at the American Heart and Stroke Association. He is the author of “Relentless: How A Massive Stroke Changed My Life for the Better.”



Twenty Years Out

By John Richards



What does anybody really know about brain injury, anyway? I thought that I had some idea, having been a social worker with folks who had sustained brain injuries, and being married to a survivor, but no, nothing, nothing at all compared to having my very own brain injury, which was a cerebral cavernous malformation, also known as a brain bleed, now twenty years ago. I have learned a lot since then and have been able to again live a full, differently able life that I love.

And for those of you who are “newer” survivors, what advice do I have beyond “hang in there”? Having a brain injury really and truly is a nasty, awful experience. For those of you who have never had one, DON'T. And for those of you who have experienced brain injury, in my twenty years of experience, I have learned that there are a few things that can make a difference:

“In my twenty years of experience, I have learned that there are a few things that can make a difference.”

Allow your friends and family to help you through this ordeal. If you're fortunate enough to have friends and family who stand by you, trust them and thank them, be good to them and let them know how much you appreciate them.

Look for the positives. You are still alive and that gives you the potential for growth and change. True – recovery takes about 10 times longer than you think it should and that's annoying, to say the least. but recovering comes along bit by bit every day.

Do the best you can, which may seem impossible at times. Another sad reality is that no one wants to spend their time listening to you complain anyway.

Figure out what to do with yourself. A little-known fact: daytime television is a secret government plot to encourage people to get out of the house, get a job, do something, anything besides watching it. So whatever it is that you can do, be it large or small, get out there and do it.

Develop compensatory strategies. Set your sights on things that really could be attainable and are things you really can and would like to do. The tough reality is there will be some things after your injury that you will not be able to do again. Ever. For example, the chances of the Celtics drafting me after my injury, considering that I couldn't dribble, couldn't run up and down the court, couldn't sink a basket are extremely remote. Of course, my chances of being drafted by the Celtics before my injury were exceedingly remote as well. My odds of my being on the Celtics are comparable with my odds of getting eaten by a shark while getting struck by lightning at the same time!

The point is this: we need to readjust our expectations and set our sights on things that really could be attainable, and make sure that our goals are things we really can and would like to do. The most successful survivors have learned and created some pretty good workarounds and compensatory strategies to get through life... Things like using a daily calendar, to-do lists, a PDA, and organized systems – the keys always go in one place, etc.

And you know what, something else happens if we are fortunate enough. We get older and that injured part of our brain gets older along with us. We integrate the new “me” into our personality and entire life so that “brain injury survivor” is no longer the dominant characteristic that defines us. I am also a husband, father, friend, brother, son, and a bunch of other things that now are much more important than “survivor” on a day-to-day basis. I still have some “stuff” that has hung on for more than twenty years ago now, but it no longer dictates who I am, nor should you let it dictate to you.

Meet John Richards

John Richards is a stroke survivor currently living in Peterborough, New Hampshire. John is the former president of the Brain Injury Association of New Hampshire's board of directors and a current board member. He is also a member of the New Hampshire Governor's Commission on Disability. He's known by those close to him for an occasional epic road trip.





Walking Therapy for Stroke Survivors is Here!

MedRhythms is a medical device company that is developing a digital walking therapy device for stroke survivors that is undergoing research in usability studies and clinical trials across the country. The device uses music, sensors, and software to provide therapy based on decades of research that walking to music can improve mobility. Reach out to us at hello@medrhythms.com to learning more!

www.medrhythms.com

The Man in the Dark

By Vanessa Garza



“Can you talk?” I typed anxiously. “I’m confused and want to talk to someone who’s been through this before.”

I lay awake next to my sleeping husband while record-breaking snow accumulated on our lawn. From the exterior, my house resembled others on my street - 1920’s colonials, sparkling with fresh snow, filled with families snuggled in warm beds. From the interior, a different scene unfolded. I had met someone online. I was engulfed in a chat with a stranger, on my computer, under the covers, in the dark, in the middle of the night.

As my lips tingled and chest tightened, I heard snowplows rumble outside. I felt the hot breath of my 75-pound dog sleep-panting at my feet. And the smell. It was the familiar scent of my husband’s crusty white t-shirt. I breathed forcefully to prevent a panic attack, but the blizzard inside me raged stronger than the white flurries dancing outside on that wintry night.

“I also had a malformation in my brain, a tangle of blood vessels that could burst, cause a stroke, and kill me.”

I could feel tears running down my cheeks. I don’t remember if I was audibly sobbing, but my heart broke. This man. His words. I couldn’t believe it. He didn’t know, and I didn’t know, but he was about to change my life. Our conversation took place on a Facebook page. It was not a dating site, a cheating page, or a page to meet people, single or married. The site was an online support group for anyone impacted by brain Arteriovenous Malformations (AVMs), an affliction that had consumed my life over the prior year.

I was 36-years old. I had it all - a devoted husband, two healthy children, a career, a red brick home, even the quintessential yellow Labrador frolicking in fresh snow. I also had a malformation in my brain, a tangle of blood vessels that could burst, cause a stroke, and kill me.

Leading up to that conversation in the dark, I had met with a dozen neurosurgeons on the East Coast. The doctors said my condition was rare, that I could not be fixed, that I should not be fixed. “There are too many risks,” they said. “If you elect brain surgery, you could end up blind, among other unpredictable deficits, including a brain bleed in the operating room. You’ll likely go into surgery with 100 percent of your senses but awake with some missing.”

They told me I had to live with, but try to ignore, my ticking time-bomb. Doctors treating AVMs often suggest a watch and wait approach, due to the rarity and complexity of these congenital defects.

Except for one doctor in the Southwest, who said he could safely remove the web in my brain. He said it with confidence, with gusto. How I wanted to hear those words, I think. But fixing me would require surgery, several of them, the longest-lasting twelve hours. First, he would inject glue into my brain, then rip open my head, crack open my skull, resect a piece of my brain, secure it with plates and screws, and staple it back together, a couple of times. But every step risked a stroke in the operating room and the chance of death on the table.

I initially assumed early detection of my AVM was a blessing until I realized it was a curse. I faced an incomprehensible decision: to elect multiple complicated brain surgeries against the advice of all but one doctor or to gamble that my brain would never explode in my lifetime.

I viewed both scenarios as equally devastating. Either cracking my head open from the outside on purpose, or from the inside on its terms, could kill me or leave me disabled. Every direction I looked pointed to signs of death, blindness, paralysis, memory loss, stroke.

I spent sleepless nights on this Facebook page. Previously, I had met a mom whose young daughter suffered an AVM hemorrhage. She did not escape unscathed; she suffered paralysis and is destined for a lifetime of therapy to regain

skills like feeding herself and tying her shoes. I hoped this mom was awake that night. I needed to talk to someone, anyone who knew about brain AVMs.

But then I found a different man online. I asked directly, “I have seen many doctors about my AVM. Most of them say it is too dangerous to remove, but one doctor says he can do it. Do you have any advice?”

I shivered under the blankets. I didn’t know this man, but I was desperate for advice. My heart nearly barreled out of my chest.

“Please, if you have the chance, remove that beast,” he wrote. “It is a killer.”

I stared at the screen feeling like my eyes might pop out of their sockets. I did not expect his adamant response. I fixated on the text box but did not reply. I wondered if he had more to say. I hoped he would explain his answer, but I was not prepared for his next response.

“I would do anything to have my wife back.”

Three little dots lit up, indicating he was continuing to type.

“She died from her AVM, and I cry my sons to sleep every night.”

I waited for more dots to illuminate but none appeared. Tears bubbled up in the corners of my eyes.

I blinked a few times to clear my tears. More dots. He shared more.

“She had brown hair and olive skin tone. She didn’t know, no one knew, she had a brain tangle, nor had they ever heard of an AVM, until it killed her. There was no warning. It ruptured, and she died. Just like that.

We wish we would have known. I would have done anything to save her.”

Then he told me the date of her birthday.

I sat straight up in bed with a jolt that frightened our sleeping dog. This man’s beloved wife and I share the same birthday, St. Patrick’s Day, the luckiest day of the year. And our children were the same ages, 5 and 3. I wanted to wake up my husband and shake him. I wanted to yell, to tell him how I felt sad and simultaneously ashamed and ungrateful. It was not fair to this man that when doctors discovered my AVM, my husband comforted me. It was not fair to this man that once when I thought my brain exploded, it was merely a panic attack. It was not fair that I lay alive next to my husband, still unsure about a credible treatment option from a world-renowned neurovascular surgeon, while this man slept alone.

For a moment, I wished I had died instead of her. She didn’t deserve to die, and I wasn’t sure how or why doctors incidentally found my AVM before it ruptured. None of it made sense. Why her and not me?

I blankly stared at the screen, still unable to reply, drowning in my tears, suffocating in my spoiled world filled with love, support, and second chances. This man and I were online in the middle of the night to discuss the same affliction, but our situations were vastly different. His wife, the mother of his kids, was dead.

I felt the worst kind of survivor's guilt that night. I wasn’t a survivor yet, but I had the chance to attempt survival that she never had.

I finally replied. “I am so sorry. I wish I had words to give you peace. This is not fair, and I am so mad at myself that I feel scared to have brain surgery.” I worried my words were not kind, loving, or compassionate enough to comfort this man in the dark.

I waited a moment, then I saw the three dots again as his words materialized on my screen. “You should seek treatment if you trust your doctor. Your family wants you to be with them. And someday your kids will understand you did this for them. You are strong. I just hope I am strong enough for my boys because I know she would be strong for them.”

I closed my eyes for a few seconds, taking in his words. I felt the soft pillow behind my back and the warm blanket over my legs and cried a bit more. I finally wrote, "You are strong, and I know you are a great dad. Please know that I send your family all my love and best wishes. I will celebrate your wife every March, always. May she rest in peace."

I didn't know what else to say, and he did not respond again. I scrolled through our typed conversation in disbelief and re-read the words about March birthdays, young children, and brain bleeds. I looked over at my husband and adjusted the blankets to cover his left shoulder. Although I cried myself to sleep, I knew my tears did not compare to a widower's in mourning.

What if I had died from my AVM and she lived instead? I envisioned my babies crying, sleeping in my husband's armpit nook, still crusty and blue from my favorite deodorant. I wondered if they would sleep on my side of the bed or if they would leave a space for me. How long would my pillow smell like my shampoo? Would they be angry if they knew I had a chance to remove my AVM, but chose not to undergo surgery because I was afraid?

The man I met in the dark changed my life and set me on a course, an uncertain course, to remove my AVM. He showed me that discovering my AVM before it hemorrhaged was not a misfortune; it was an opportunity to live. My decision to elect multiple brain surgeries became clear. I knew surgery would be risky, but I had to move forward for my family, and for his family too.

I went back to see that doctor. Four brain surgeries later, I am now AVM-free without complications, thanks to a man in the dark, and his wife in the light.

Meet Vanessa Garza

Vanessa is a Boston-based novice writer, mother, former corporate America consultant, and survivor of a brain arteriovenous malformation (AVM), a very rare neurological condition. In the summer of 2017, she elected to have four brain surgeries to remove the AVM. Thanks to successful therapies and her newly minted brain, secured with titanium plates and screws, she is motivated to heal, recover, and write. She hopes to inspire anyone at risk for stroke, to raise awareness for this very rare neurological disease, as well as to honor all TBI warriors with both good and devastating outcomes.



News & Views

By David & Sarah Grant



While there is never a good time to sustain a brain injury of any type, we are at a very exciting crossroads. New tech solutions like those offered by MedRhythms can mean outcomes not possible a few short years ago.

The exponential growth of social communities means that survivors with an internet connection can be part of vibrant online communities of like-minded peers. And this is just the beginning. Our first-ever stroke survivors issue profiles one type of brain injury, but the causes of brain injury are as unique as the individuals who sustain them. Like snowflakes, no two injuries are alike.

As we move forward into 2022, we have more amazing things to roll out to our readership. One of our special issues will be devoted entirely to family members of brain injury survivors, those heroes who also have lives that are forever changed.



A heartfelt thank you to the contributing writers who made this issue possible. If you are the family member of a survivor and would like to submit a story of publication consideration, we'd love to hear from you. Send us an email at info@tbihopeandinspiration.com.

Be well, and stay safe,

-David & Sarah