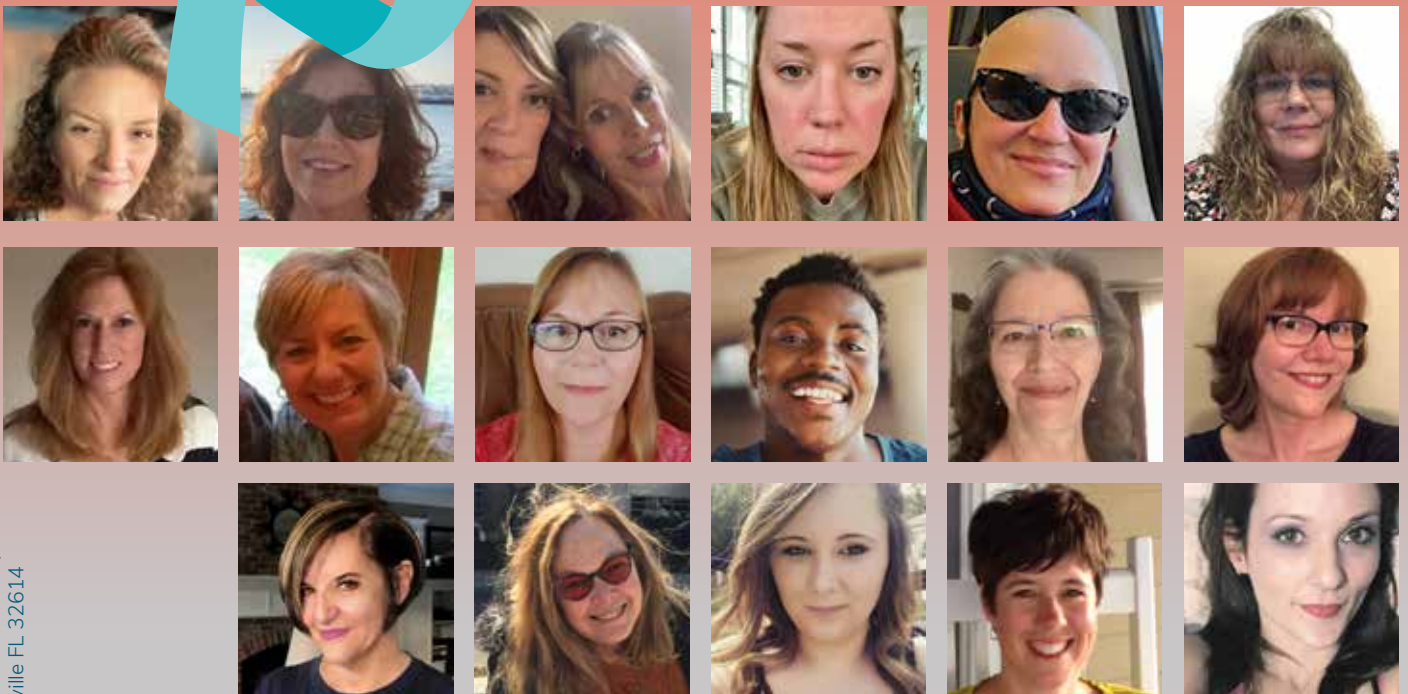


Quarterly



October is Facial Pain
Awareness Month



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From the Chairman of the Board



You probably already know that the FPA's mission entails providing information, support, and advocacy for you. Truth be told, most of the organization's focus in the past has been on providing information so you and your healthcare partners can make the best decisions, and support to help everyone make it through this difficult time in your life. With our limited resources, these focus areas were rightfully given priority.

This year, the FPA will be expanding its efforts to include much more advocacy, specifically in two vital areas. First, the FPA will significantly expand its efforts to help organizations that are developing new procedures, imaging technology, and medications that can help those of us with neuropathic facial pain. These major medical centers and pharmaceutical companies have embarked on providing more treatment options for us, and we are going to help them be successful by providing information, guidance, and participants for their research. To be clear, we are not going to duplicate the Facial Pain Research Foundation's (FPRF) efforts of raising money and directly funding research. We are going to help those who already have the funds and programs in place to be successful. Between the work that was started last year and what we hope to accomplish this year, we are striving to assist ~ 25 research efforts. In short, we are working to put more treatment options in your healthcare providers' hands so they can better serve you. And you can help. This year the FPA will be launching a patient registry so we can become the "go-to-research-partner"

for those working to help our community. Please consider joining the registry when it goes live.

The second vital advocacy area that the FPA will be focused on this year is to make dentists aware of neuropathic facial pain to help prevent unnecessary dental procedures that so many of us had to endure because of dentists' ignorance of our condition and to hasten a proper diagnosis so members of our community can get the care they need sooner. The FPA has worked on this in the past by going through the American Dental Association and other dental organizations, and we were not successful. We are taking a much broader approach this time to help ensure success. If you have expertise in marketing / communicating directly to dentists, please let our CEO, Allison Feldman, know.

We are able to embark on these vitally important efforts because last year the FPA was the recipient of four bequests (money left to us in a person's will), and we now have the resources to do this. My wife and I were so inspired by the generosity of these wonderful people that we recently amended our will to include a bequest to the FPA. (You can read an inspiring story about one of these bequests on page 22.) Please consider including the FPA in your will and join my wife and I in FPA's Legacy Society.



David Meyers, Chairman of the Board
The Facial Pain Association



A Message From the CEO



Allison Feldman,
Facial Pain Association CEO

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FacialPain
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New Year, New Objectives

With the start of a new fiscal year, FPA completed an update of our Strategic Plan. During this process, we reviewed feedback we received via the FPA Organizational Survey, 2020 Virtual Conference, and from all of you over the past year. We analyzed the successes and challenges of our program provision, and researched what new opportunities are available to organizations such as ours. The newest iteration of the FPA Strategic Plan contains several new initiatives, which we are excited to share in upcoming Quarterly journals.

This year, FPA will be embarking on a new initiative to promote and provide support to research that is relevant to the neuropathic facial pain community. This is something we have been doing unofficially in the past year to more than a dozen researchers- connecting them to patient volunteers, sharing surveys, assisting in garnering research participants, providing insights on study structure, and more. As it became obvious to the FPA board of directors that our organization was able to make a real impact on research being conducted for the betterment of the lives of people with facial pain, we decided to make these efforts one of our main objectives of this fiscal year, and beyond.

You may know that FPA previously included the Facial Pain Research Foundation (FPRF)- an arm of the organization that funded research- that officially separated from FPA in 2016. It is important to note that FPA will not be providing funding for research as the FPRF does; rather, FPA will be able to promote studies that are funded by FPRF.

You can learn more about medical research and studies, volunteer with FPA, read updates on past studies, and more at FacePain.org/Research. If you are a researcher, I encourage you to contact me to discuss ways FPA can help your efforts.

Allison Feldman
Chief Executive Officer

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The MAB Corner

Historical Grant Awarded to Study TN

Raymond F. Sekula, Jr., MD, MBA
Professor and Residency Program Director
Department of Neurological Surgery
University of Pittsburgh School of Medicine

Each week, my team and I evaluate patients who have often traveled great distances for help with various forms of facial pain. Over seven years of training and the past thirteen years (that figure is particularly difficult for me to believe) of practice, I've learned a great deal about facial pain from these patients. I became interested in patients with facial pain when I was a first-year medical student, during my first semester, assigned to study one afternoon each week with a general internist. In those days, ride services such as Uber and Lyft did not exist, and to get to his office in time for afternoon clinic after a morning of classes, I would hail a jitney to take me into the heart of South Philadelphia where this internist's office existed. Over the course of that semester, one patient's story stayed with me more than any other. An elderly African American man with chronic high blood pressure, cared for by this internist for years, presented early in the semester with a new complaint. He reported that "for the past few weeks, Doc, I feel like fire is shooting through my face when I eat or talk". Looking at me, he said, "The pain can bring me to my knees, son." Until that day, I had never heard of trigeminal neuralgia. This gifted (i.e., many patients with trigeminal neuralgia struggle to receive a proper diagnosis and treatment) and kind internist diagnosed him with trigeminal neuralgia and prescribed a course of carbamazepine, which he deftly titrated for the man each month in subsequent appointments. I still remember the first follow-up appointment, when the patient reported to the internist, "It's gone, Doc...it's a miracle."



Unfortunately, for many patients, the story is more complex, more nuanced. While that first patient I witnessed was likely suffering from the so-called classical trigeminal neuralgia, many patients suffer from trigeminal neuralgia of various forms, which we do not understand as well as we would like. Over the past six years and with the financial help of many grateful patients, my scientific partner, Michael Gold, PhD. and I have been investigating the fundamental mechanisms of trigeminal neuralgia. Most of our work is directed at understanding differences between pain which occurs in the face as compared to pain in other parts of the body. **Recently, our proposal "Mechanisms of Pain Associated with Trigeminal Nerve Injury" was awarded, from the National Institutes of Health, five years of funding totaling nearly \$3 million to study this devastating disease.** Essentially, this is a drug discovery grant, and we hope that the results of our work will form the basis for viable medications soon to help those who currently cannot be helped with available medications like carbamazepine and the others most of you know so well. Michael and I are grateful to our financial supporters, including my patients, the University of Pittsburgh, and the National Institutes of Health. For me, it all started with that first patient in South Philadelphia in 1996 (wow!). Something about his admonition, "The pain can bring me to my knees, son." inspired me to want to learn more. And there is so much more to learn. I hope to report back to this group with encouraging findings in the next few years! ■

Teflon-free MVD



Richard Zimmerman, MD
Neurosurgeon
Mayo Clinic, Phoenix, AZ

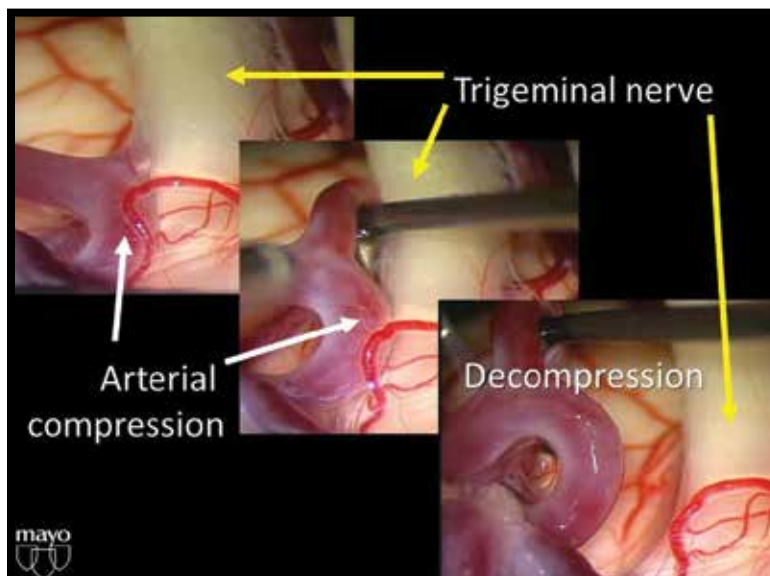
In March 2021, the article “Microvascular Transposition Without Teflon: A Single Institution’s 17-Year Experience Treating Trigeminal Neuralgia” was published in the peer-reviewed journal *Operative Neurosurgery*. The senior author and surgeon of the article is FPA Medical Advisory Board member, Dr. Richard Zimmerman, at Mayo Clinic in Arizona. The content below, provided by Dr. Zimmerman, shares some background behind the article, as well as a brief synopsis of the findings. Although copyright law prevents FPA from providing copies of the paper, for those interested in reading the complete article as published, the citation is: *Operative Neurosurgery* 2021 Mar 15;20(4):397-405.

Microvascular decompression (MVD) as a treatment for trigeminal neuralgia (TN) has been foremost championed by Dr. Peter Jannetta. Through his tireless support and work to help the facial pain community, Dr. Jannetta also made this procedure a part of mainstream neurosurgery. Furthermore, it should be recognized that Dr. Jannetta’s work helped educate the medical community outside of neurosurgery about the most common cause of this disorder. In his seminal work published in the *New England Journal of Medicine* in 1996, Dr. Jannetta was able to show that moving a blood vessel off the trigeminal nerve provided lasting relief from the terrible condition we know as trigeminal neuralgia (TN). The impact this neurosurgeon made on patients, neurosurgeons, and all physicians has been so great that MVD surgery

commonly bears his name - the Jannetta Procedure.

In the initial descriptions of this procedure, the technique used to elevate a blood vessel off the trigeminal nerve was to insert a small piece of sterile Teflon felt under or against the vessel such that the compression was eliminated. The use of Teflon felt has been very effective, demonstrated by the successful results that Dr. Jannetta and many neurosurgeons have achieved. Yet as my career treating patients with TN progressed, I began seeing patients who previously had an

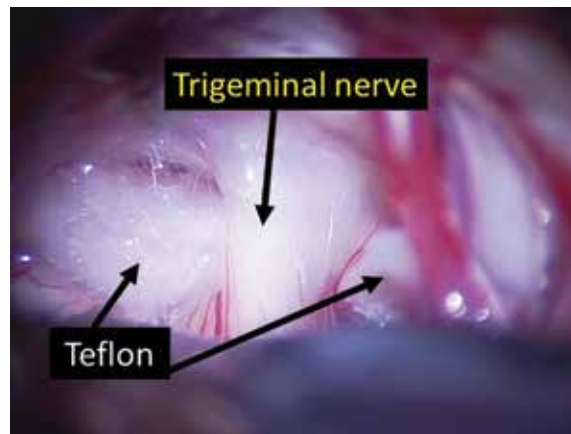
MVD but either still had pain or experienced only a short period of relief before their TN reappeared. After seeing several of these patients, I had to consider that perhaps something about the way their initial procedure was done didn’t truly accomplish



“Teflon-free MVD” continued on page 6

the goal Dr. Jannetta championed. Furthermore, as MR imaging quality became more sophisticated and detailed, it became apparent that the re-imaging of these patients showed a mass of Teflon against the trigeminal nerve at the root entry zone. Could it be that in these cases, the surgery only replaced vascular compression with Teflon compression, or that the Teflon against the nerve still transmitted vascular pulsations? Finally, with fellowship training as a microvascular surgeon, I was quite familiar with options available to mobilize the blood vessels of the brain, even to the point of relocating their position. Ultimately, I decided that in my surgical cases for TN, I would try to avoid using Teflon and instead simply relocate or transpose the position of the compressing blood vessel(s) away from the trigeminal nerve. To maintain the vessel in its transposed location, I used a biologic adhesive known as "fibrin glue" that is commonly used in neurosurgery. The goal of this technique was to completely remove anything whatsoever from touching the "sensitive" trigeminal nerve. Thus, I started performing "microvascular transpositions" (MVT), otherwise known as a "Teflon-free MVD."

This concept was not invented by me, and several other neurosurgeons have written about their series of trigeminal neuralgia surgeries employing a "non-compressive" technique. Variations to the use of Teflon have been described, including the use of sponges, glue, sutures, slings, and



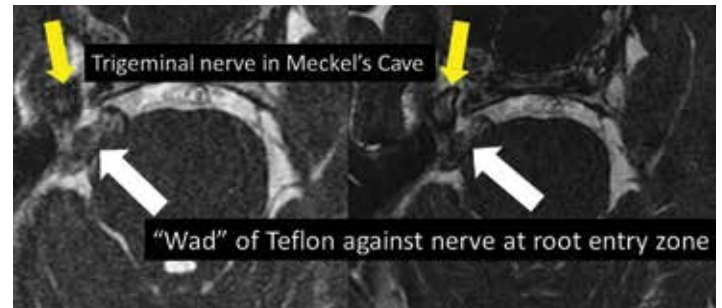
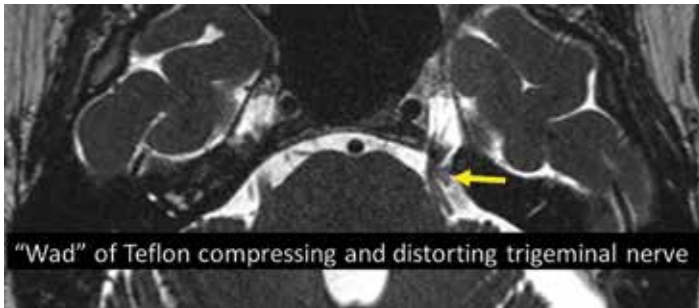
even aneurysm clips. Furthermore, this is not to say that there is anything wrong with the use of Teflon. However, the pattern that I observed in post-surgical recurrences of pain typically involved Teflon seen against the trigeminal nerve on imaging. I cannot recall seeing a failed case of MVD surgery where

Teflon was used, but where it was inserted away from the nerve - truly achieving a compression-free result.

However, I was concerned that the teaching of MVD surgery was becoming simplified to the point of "stuffing Teflon between the nerve and vessel," without necessarily achieving a good or complete decompression. This might be even more so for surgeons who do not see many trigeminal neuralgia patients or do MVDs infrequently.

Long- term, pain-free results were achieved in 89.4% of patients with a mean follow-up duration of 6.9 years.

After almost 20 years of using this technique consistently, I wanted to evaluate and compare the long-term results of this strategy to treat TN. Thus began the effort to reach out to my patients who had a "Teflon-free MVD" using the method of patient reported outcomes. Patients who had an MVT TN procedure were sent a questionnaire about their surgical outcome. While far from reaching all the patients who had this type of surgery, there were 102 patients who had contact information available, and we received 85 responses. The ages of these patients who responded ranged from 20-89 years, and the duration of time after surgery ranged from nine months to more than 17 years. Long- term, pain-



free results were achieved in 89.4% of patients with a mean follow-up duration of 6.9 years. This is a very high rate of success and compares with the best reported outcomes in the literature. We were also able to examine the outcomes divided into the patients who provided a description of intermittent attacks of facial pain alone (TN type 1) vs. attacks of facial pain with a background component of constant pain (TN type 2). While both groups did well, we did find that TN type 1 patients did better, with nearly 92.8% being pain-free at 10 years. This study certainly has limits, and they are outlined in the full article. The conclusion, however, is that Teflon is not necessary for a successful TN surgery. Achieving a good decompression whether or not Teflon is used - potentially with

no residual contact against the trigeminal nerve - arguably should be the goal of MVD surgery.

Patients should always feel comfortable discussing any plans for an operation with their surgeon, including the option of having a "Teflon-free MVD." However, given the widespread and classic teaching of using Teflon, it is not likely many neurosurgeons will be experienced treating trigeminal neuralgia with vascular transposition. One therefore needs to decide if they want to ask their surgeon to perform a procedure with a technique they don't routinely do vs. finding a surgeon who is familiar with this technical nuance. ■

Patients should always feel comfortable discussing any plans for an operation with their surgeon ...

Disclaimer:

The FPA does not endorse any product, doctor, procedure, medical institution, or its staff.

Note from Medical Editor, Dr. Jeffrey Brown

Dr. Zimmerman, a longtime member of the FPA Medical Advisory Board, should be complimented on his effort to review the results of his innovative technique in the treatment of trigeminal neuropathic pain. His results are excellent and match the highest standard achieved by other distinguished neurosurgeons. Dr. Zimmerman asks reasonable questions: "Can Teflon cause trigeminal neuralgia?"; "Can Teflon continue to transmit pulsations from arteries and thus not adequately decompress the trigeminal nerve?" These inquiries remain for us to answer through further studies like the one published by Dr. Zimmerman. The members of the FPA Medical Advisory Board remain dedicated to the task of furthering the knowledge base of this important field as well as to the provision of optimal care to those of you who suffer from a disease that saps one's energy and distracts from the joys we hope to feel each day of our lives.



MVD Patient Perspective with Tom Fenstermacher

My name is Tom Fenstermacher, and I was diagnosed with trigeminal neuralgia by my internist on June 8, 2007. Prior to that appointment, I had seen my dentist for the excruciating pain, which I initially thought might be a root canal problem. My dentist was unable to find a dental problem and thought it might be TN since my symptoms were similar to his neighbor who had TN.

To rule out any dental issues, my dentist referred me to an endodontist for a possible root canal. The endodontist did not find anything wrong with my teeth, so we were pretty certain it was TN. I was prescribed Tegretol, Gabapentin, and Neurontin at various times, with only the timed release Tegretol providing pain relief. The effectiveness of Tegretol became less and less over the next two months, and increased doses were required to keep the pain somewhat tolerable. The dosage increased to 1400 mg per day, which was near the allowable limit for Tegretol. With the high dosage, I was not able to focus on my job as Chief Financial Officer of a large organization, so I knew I needed another approach.

I explored several methods and decided that the Microvascular Decompression surgery provided the best possibility for a successful outcome. I contacted three hospitals that had extensive experience with the MVD operation and settled on UPMC in Pittsburgh. Dr. Kassam of UPMC had performed over 800 MVD

operations, which fit right in with my desire to have a highly experienced surgeon to do the operation.

I flew to Pittsburgh from Philadelphia around August 20, 2007, and was given several tests, including a hearing test. A colleague of Dr. Kassam's, Dr. Silverman, was also to be involved in the operation to monitor my auditory nerve, which I thought was impressive. On August 22, 2007, I was operated on for the MVD and woke up in recovery, then moved to my room. I was very groggy and only semi-awake when Dr. Kassam came into my room with four of his residents. He asked me if I had any pain. I responded (half in a daze), "What pain?" All five doctors got a good laugh, but I was totally honest in my response – I no longer had any pain.

Over the past 14 years, I have not had any pain from TN. I consider myself very fortunate to have done the research and selected the right surgeon for me. I finished my corporate career on January 1, 2014, and have been retired, spending time between our homes in Pennsylvania and Colorado. I would recommend the MVD surgery to anyone who has had that method recommended by their doctor. Do the research through FPA and on your own so that you can be satisfied making your own decision. If you do decide on the MVD, I hope that it is truly worthwhile for you, as it was for me. ■



MVD Patient Perspective with Neave Halvorson

My name is Neave Halvorson, and I live in the Denver metro area. In 2012, I was in graduate school, working full-time, caring for five children, a husband, and a fur baby when I was diagnosed with trigeminal neuralgia. I had been having symptoms for a few years before I was officially diagnosed. I was prescribed medication including Gabapentin and Tegrretol, and reached the maximum dosages for each. I also began receiving Botox every three months, which I still do to this day.

My neurologist is a wonderful, kind person who listens to what I say, and I appreciate this so much. I stayed on med management for a long time, against his recommendation, until I developed appendicitis. I had met my deductible for the year and decided to make an appointment with Dr. John Prall, the neurosurgeon that my neurologist referred me to.

I truly believe in my providers who have completely earned my trust. Dr. Prall is a trigeminal neuralgia expert, which was important to me. He reassured me that he would do everything possible to help me, and he has over the years. I always joke and say, "How many years are you supposed to have a neurosurgeon for?"

I had my first Gamma Knife procedure on April 24, 2014, followed by my first Microvascular Decompression on December 22, 2014. Shortly after,

I had my second Gamma Knife procedure on May 22, 2015, and my second Microvascular Decompression on May 14, 2018. I achieved three years of freedom from pain after my second Gamma Knife. I did have a couple of months after each procedure where I did experience pain-free time. After my second MVD in 2018, I was pain-free for almost a year. I always hold my pain-free years close to my heart and remember these days when I have a bad day.

I have chosen not to have anymore surgeries at this time. I consulted with Dr. Prall in 2019 when the pain returned, and he gave me options. I have chosen to keep these in my back pocket and remain in medication management for the time being. By doing this, I began a personal journey into accepting TN. This was not easy for me because I wanted to fight and "be normal" again; however, I realized that TN was given to me, and we had to learn to live together. I describe my life in terms such as my life Pre-TN and Post-TN. My life is different in a number of ways now, but I work with the tools I have available and have learned to accept and live with TN because she is a part of me now.

My advice for someone considering surgery is to weigh your options. Create a list of pros and cons. Consult with your family members and loved ones to see if they have any questions or concerns

"Patient Perspective" continued on page 10

"Patient Perspective" continued from page 9

beforehand. Sometimes, family and loved ones have valid questions that have not been previously asked. Ask questions and make sure you understand the answers. Always make the choice that is right for you. In the end, that is what matters most of all.

I would also tell someone considering surgery to do your research to know what to expect, at least on a basic level. In 2018, I sat with my children to make sure they knew what to expect when I had surgery and what they may see after the surgery. One of my sons (21 at the time) began crying and was very upset because of the way his mom looked in the ICU. My husband and dad were able to make sure my son knew that I was okay and not to be scared. During my first MVD, my children were small and were not allowed to see me in ICU, but instead, they saw mom at home, recovering.

Surgery offers hope to others, and it provided hope to myself and my family. Just because this intervention

did not work for me does not mean it won't help another person. We are all individuals, and as I like to say, "We don't have a crystal ball to predict the future." I am a therapist, so I have lots of sayings like this that I have learned to apply to my life! I have TN, and my career is to talk with other people—I always find this to be ironic.



My family has been my source of strength through the years. My husband has always been by my side to help me make the tough choices. My children have also been amazing, and I appreciate that they have tried to understand what was happening to the best of their ability. When they were little, we called this "mom's jaw pain," but now that they are older, they have a better understanding. It is so easy to feel "alone and isolated," but find those people who

love you and lean on them for support. We all need a support system in our lives! ■

Join the facial pain community on social media and help spread awareness.



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Gary Klasser, DMD	Richard Zimmerman, MD
Michael Lim, MD	Leesa Scott-Morrow, PhD, JD, LP
Mark Linskey, MD	Kenneth Casey, MD
Donald Nixdorf, DDS, MS	Wolfgang Liedtke, MD
and others...	



Breaking Through Barriers

By Candace Walkup



Ten years ago, I was an active soccer mom to my 10- and 11-year-old daughters. I worked full-time, volunteered, and loved to travel. I had a bucket list that included snuba diving and sky diving. Like many of you, important parts of my life were drastically altered once my facial pain started. The last ten years have led me to numerous doctors and surgeons, medications, and procedures. Most of these were unsuccessful, and the pain I endured caused me to give up hope of accomplishing my bucket list. If light wind and fabrics hurt my face, there was no way snuba diving and sky diving were options!

Five years ago, I discovered the Facial Pain Association and my local support group. Not only did I find people who could understand my physical and emotional pain, but I also found invaluable resources, including my neurosurgeon Dr. Mark Linskey. He has performed two microvascular decompression (MVD) surgeries for my bilateral trigeminal neuralgia and bilateral geniculate neuralgia conditions over the last four years. Both MVD's were successful in reducing my pain and giving me a lot of my life back.

Since my pain levels were better, my mind returned to my discarded bucket list to see how it could be revived. My husband and I traveled to Jamaica in October 2020 to celebrate our 25th wedding anniversary and renew our vows. We spent ten days at a beautiful resort and discovered something

called snuba, a hybrid of snorkeling and scuba diving. Snuba allows you to explore the ocean deeper than snorkeling but still be connected to the surface via a breathing tube. We decided to give it a try even though I was nervous about flares caused by either the pressure difference or the equipment.

A quick boat ride brought us to the location where we were outfitted with fins and masks. As I jumped in and descended 20 feet or so, to the ocean floor, I noticed the ice pick pain in my ears, which lasted about fifteen to thirty seconds but nothing in my face. I was relieved but still waited for something worse to happen. We swam around a coral reef, finding sea anemone, sea urchins, and brightly colored fish. Our guide found a sea cucumber, and we were able to feel how soft it was. I saw a giant jellyfish about twenty yards away from me and so many other things. I had the same small bit of pain on the way back up, but it subsided. We enjoyed it so much we went again the next day.

It's been disappointing spending the past ten years living with most activities and adventures on hold. What I realized from the snuba experience was that I have the courage to jump back into those things in life I want to explore. Yes, it may hurt, and I may have to manage flares. But instead of saying, "I wish I could have done that," I am saying, "I did that!" ■



Paving A New Path

Charity Harris

My name is Charity Harris, and I live with multiple life-changing diseases. I was born in Tulsa, Oklahoma, and moved to Los Angeles when I was seven years old. Shortly after moving, I was diagnosed with Charcot Marie-Tooth Disease, and I have type 3, known as Dejerine-Sottas. At that time, doctors were amazed I was still able to walk and told my parents to prepare for me to use a wheelchair soon. Little did the doctors know, that was not happening...

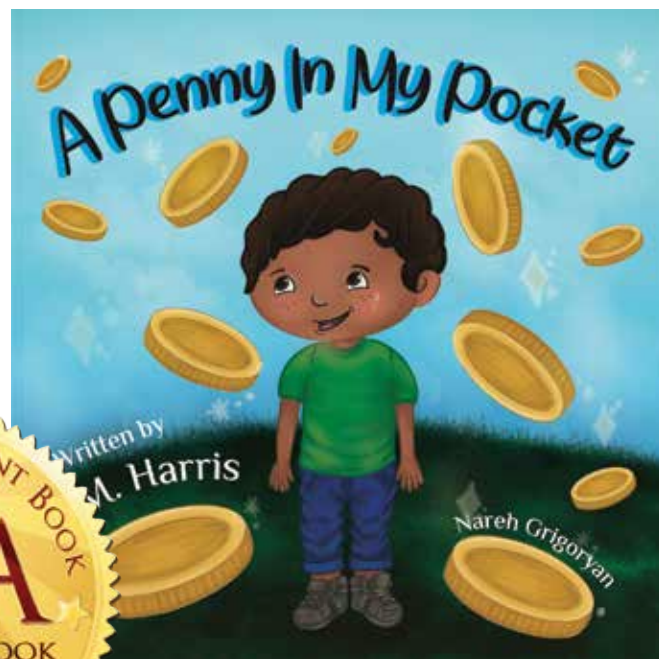
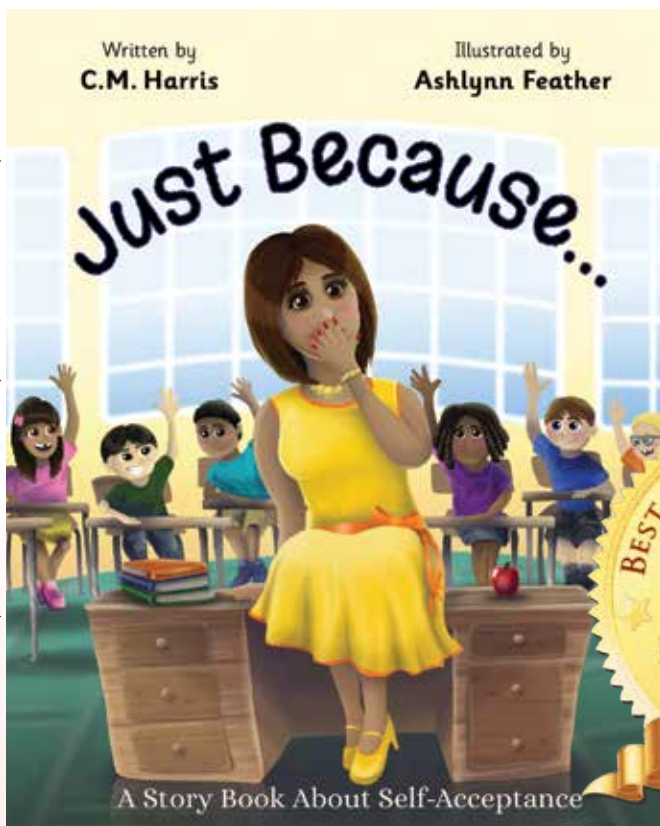
I grew up like any other child; rode my bike, went swimming with friends, Disneyland with the family, walked the dog, and any other normal activities any child would do. When I entered high school, I also did what any teen did, looked for my first job. I applied to multiple local places around my neighborhood; some pet stores, quite a few clothing stores, and office supply stores, but each one was a no.

I was young and think I assumed I didn't get the jobs because I had no prior work experience. It wasn't until after I graduated from the university and started looking for jobs again that I discovered the real reason. I attended California Polytechnic University, Pomona, and earned my Bachelor of Fine Arts Degree in Graphic Design and a minor in Marketing Management. Unfortunately, at the end of my first

semester at Cal Poly, I experienced my first shock of trigeminal neuralgia. It was debilitating and quite a nuisance for a college student, but during my last semester at the university, I had finally received a diagnosis and chose to undergo surgery and had a



"Paving A New Path" continued on page 14



"Paving A New Path" continued from page 13

Microvascular Decompression performed on the right side of my brain. I have bilateral TN, but it has been a blessing that my left side has been in remission for many years, and I currently live pain-free from TN.

Two weeks after I had surgery, I started a marketing internship that I finally landed and had two days to celebrate before quickly scheduling the surgery. Nothing was going to stop me from the opportunity to work. I was ready to work! I never told the company that I just had surgery for fear that they would change their minds. I loved the four months I spent as an intern, and I was surprised when I received an exceptional letter of recommendation that I couldn't wait to use. I was ecstatic when I graduated, thinking this was it, I was finally going to get a job, I just had surgery, I just completed an awesome internship, and I was ready for my career to start. Until it didn't.

For two years, I applied to over 100 jobs, went on over 30 interviews. Some interviews were by phone, but many were in person. I never indicated that I was in a wheelchair. By this time, I had become fully reliant on needing a wheelchair after graduating high school. Many

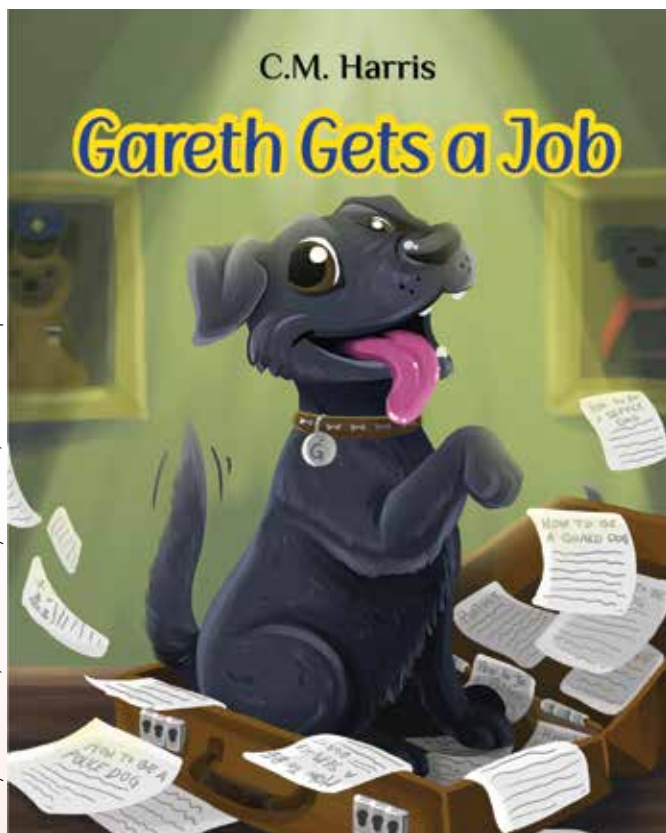
"... I'm going to face many battles as someone born with a life-changing disability, but I never allowed it to prevent me from doing what I wanted."

employers were impressed by my resume, so I thought for sure when I show them my portfolio in person, they'll have to hire me. I went all out on my portfolio, had it custom-made

acrylic, and printed high quality with my designs. But there was the same surprised look on their faces when they saw me.

I received great remarks about my work and how qualifies I was and whatnot, but I was never officially offered a contract to sign and join a company, and I believe it was due to using a wheelchair. There is an unspoken and unfair bias towards individuals who are disabled, and although there are laws to protect against discrimination, it still happens. It's not fair, and something absolutely needs to be done to change the bias.

In 2018 I received my certification as an ADA (Americans with Disabilities Act) Coordinator and decided I wanted to bring a change in some way to how employers hire fully trained and qualified individuals. Just because someone may have mobility limitations, it doesn't mean they will not be able to accurately get the job done when they have the qualifications and the desire to work. Everyone should be given the same and fair opportunities when employers hire. I have been to many places, and never have I seen a wheelchair user employed in a store, a theater, a



restaurant, or anywhere else, and that should change, a change I hope to focus on shortly. After many years of unsuccessful networking and interviews, I decided to create my own job and started my own business.

In 2019, I started Purple Diamond Press, LLC, and published my first children's book. I wrote, "What If We Were All the Same!", a children's book about

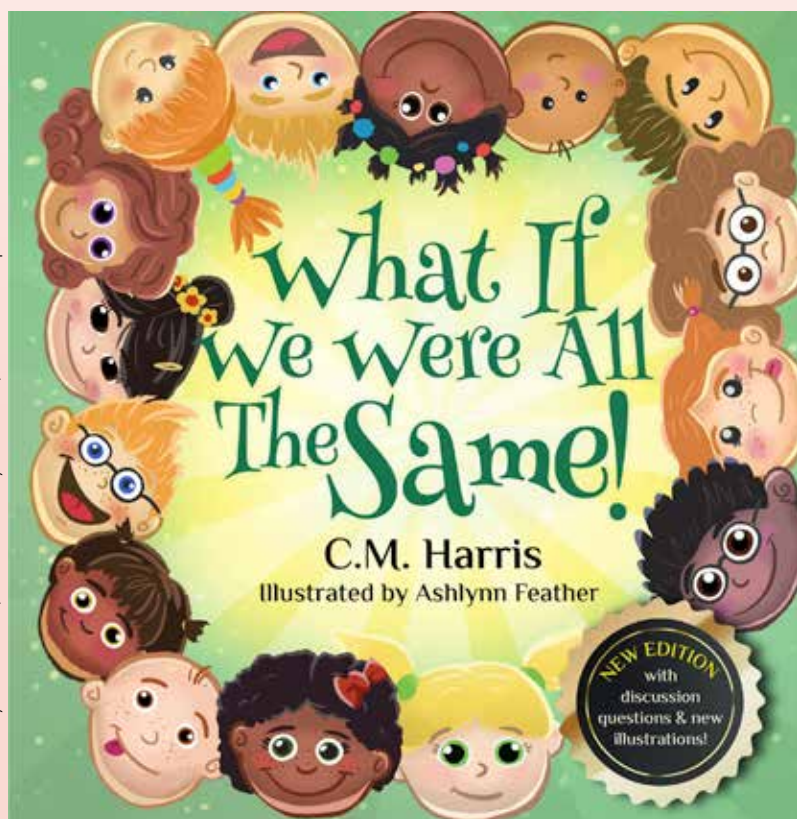
diversity and inclusion. I wanted to write a fun story that embraces equality. Growing up, I learned I'm going to face many battles as someone born with a life-changing disability, but I never allowed it to prevent me from doing what I wanted. I've faced many people who doubted me and told me I could not do something, but I live my life not to prove to anyone they were wrong about me, but I live my life to prove to myself how strong I know I can be.

When I had my first sting of trigeminal neuralgia, I did not see a light on my dark days, but thankfully I was mentally prepared to keep moving forward. To date, I've written eight children's books, and I focus on embracing differences and acceptance. I write for children and hope my collection of C.M. Harris Books encourages readers to treat people who rely on mobility aides the same as anyone else. Our differences are good, and everyone is different in one way or another, and we should all be accepted. My latest story is in memoriam to my service dog of ten years, Gareth. Gareth was with me and encouraged me as I battled through my job hunt. "Gareth Gets a Job" will be available on December 21st. Today, I am very grateful for the job I have but I hope to help others who have faced similar employment experiences. ■

Author site : <https://cmharrisbooks.com>

Publishing site: <https://purplediamondpress.com>

Amazon: www.amazon.com/author/harriscm





Awareness Conversation Starters



By Stephanie Blough

Living with a rare disease like trigeminal neuralgia or any of the many facial neuralgias we all experience can be isolating. One thing that 2020 taught the world is the importance of human interaction. This year, we encourage you to foster knowledge. For those who don't live with a rare disease, research leads to knowledge which breeds empathy.

Empathy is a very strong emotion that can help us not feel as isolated in our pain. Having those difficult conversations can be the first step to bridge the gap between those who experience pain and those who do not, such as when you are explaining your experience to family or spreading awareness.

Kickstarting these conversations

can be challenging; they require us to lean into our vulnerabilities and share something very personal. We've come up with a few tips and conversation starters to help with these conversations.

Utilize Plural Pronouns

If you aren't comfortable sharing your own personal experience, use plural pronouns like 'us,' 'they,' or 'we' to share the experience of facial pain. Phrases like "when we feel pain it comes in the form of electrical shocks" or "taking lots of different types of medications is normal for us" can be just as powerful as "I feel electrical shocks" or "I take four types of medications for my pain."

...use plural pronouns like 'us,' 'they,' or 'we' to share the experience of facial pain.

Using broad statements like this won't take away from the impact of what you're saying, but it does give you the opportunity to avoid complete vulnerability. We should have the choice of what to share with the world about our pain while still being able to bring awareness to those around us.

Start with a Question

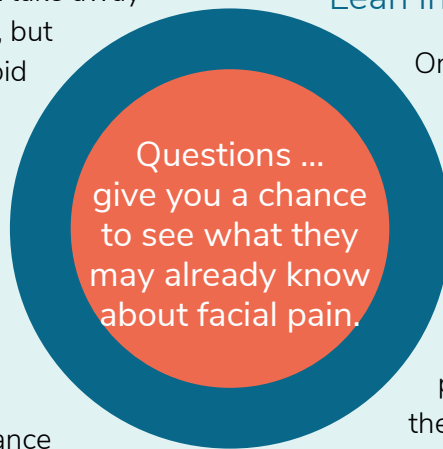
Questions are an easy way to start conversations, and they give you a chance to see what they may already know about facial pain. When dealing with difficult conversations, you want to give the other party a chance to speak too. Asking questions pulls people into the conversation. It also gives the other person permission to ask questions.

You can start with, "Have you heard of Rare Disease Day?" or "Did you know that October 7th is International Trigeminal Neuralgia Awareness Day?" to start a broad conversation. But questions like, "Did you learn about facial pain in your college health class?" or "Have you ever noticed that sometimes I need to wear face coverings outside?" will draw the other party into more specific conversations about facial pain.

Lean Into Your Emotions

One of the hardest things to do when talking about difficult things is to have a constructive conversation while trying to hold in your emotions. Showing an emotional side of things, whether it be anger or tears, doesn't take away from the validity of your words. In fact, it only heightens the power you show. People will remember the conversations that made them feel something. Allowing yourself to feel and show how you're feeling gives the other person a chance to step into a sphere of understanding. Facial pain is an emotional rollercoaster, lean into the rollercoaster and see where it takes you!

Hopefully these tips will help you share with those around you about facial pain and to help us bring awareness to our experience. Whether you lean into your emotions or choose to speak broadly about facial pain, speaking up is an empowering phenomenon. We are proud of your strength! ■



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YPC Member Q&A

Meredith Hedrick

How old are you? 35

Where do you live? Katy, Texas

What is/are your diagnosis? Occipital Neuralgia and Trigeminal Neuralgia

When did you first experience your facial pain? 2016

What do you do in your free time? Spend time with my family.

What has TN/facial pain taught you? To enjoy all the low pain moments as you can and to make the best of those moments. I was already a Mom when I first experienced pain, so my perspective maybe a bit different. I have been very focused on showing my girls that life may throw you a curve ball, but to be a "Positive Polly" even when you don't feel so positive. I also want them to understand what is going on, appropriate to their age of course, so they can express their feelings. It is scary for a child to have a Mom who is in pain and not feeling well. We came up with fun ideas like special dinner and tv show night in Mom & Dad's bed so I can spend time with the family and so I can try to be as comfortable as possible. Unfortunately, my oldest daughter experiences migraines so she understands the pain and discomfort.

What non-surgical procedures have you tried?

Every medication in the world...acupuncture, physical therapy, rest, ice, heat, massage, showers, baths.

Have you had any surgical procedures?

Decompression of occipital nerves – 2017 & 2019 and decompression of trigeminal nerves 2019

What is something you would share with a newly diagnosed young patient? Find a doctor that listens and understands you. It is important to advocate for yourself or to have someone with you advocating for you. My husband has been vital in helping me find a doctor and finding the right surgeon for me. He pushed me and pushed my doctors when I needed it most.

Do you have anything to share with other parents with TN/facial pain? To do the best you can at that exact moment. Be honest with your kids and spouse. Communicate to your spouse or others around truly how you are feeling so they know how best to help. Your kids love you no matter what and want you to be happy and healthy. Always keep a special treat in your purse or game on your phone for them when a sudden attack happens so you can give them something to do until it calms down. ■

Remembering Jenny LeCompte



As a beloved member of the facial pain community, Jenny LeCompte made many contributions, and one that brought her great pride was an article she wrote for the 2016 fall issue of the Quarterly journal. Please enjoy reading “How Neuroplasticity Changed My Brain”, by Jenny Lecompte as told to Melissa Anchan.

This year marks the 24th year I have been dealing with TN type 1 and type 2 and Bell's Palsy. Before you ask “have you tried...?” Yes, I've tried it. I've tried it all, it seems. Over a dozen neuropathic medications, a dozen more pain medications like narcotics. I've tried microvascular decompression surgery, rhizotomy, motor cortex stimulator, injections, nerve blocks, lidocaine and ketamine infusions, chiropractic care, cranio-sacral massage therapy, medical marijuana, acupuncture... you get the point. And each of these options has been met with various degrees of success, but many brought on more problems than I had before. For instance, the rhizotomy left me with severely slurred speech. I developed vertigo, which left me walking with a cane for two years. And this was all before I turned 35.

After the rhizotomy, my pain specialist introduced me to a nurse who teaches neuroplasticity at Pain Consultants of Oregon. I'm sorry, neuro-pla-what? Something I haven't tried! I embraced the opportunity to learn something new. And neuroplasticity allowed me to hone in on the things that I can influence, since so many of the other treatment options were dependent on factors out of my control.

With sadness, the Facial Pain Association announces the passing of Jenny LeCompte, FPA Peer Mentor, and former FPA YPC Committee Member. Jenny passed away from non-TN related causes. We send our sincere condolences to Jenny's son and host of family and friends.

I had never heard of neuroplasticity, so perhaps you haven't either. Let's break it down. Neuron + plasticity = neuroplasticity. It is also known as “brain plasticity,” an umbrella term that describes lasting changes to the brain over the course of a person's life. It gained popularity in the back half of the last century when medical research indicated that there are parts of the brain that remain changeable (or “plastic”) even well into a person's adult life. Previously, consensus had been that the brain develops during a critical period in one's childhood and then remains unchanged throughout adulthood.

Wait, what? I can change? My brain can still change? Therefore my perception of the pain can change? Sign me up.

Imagine my surprise when I learned that I've been incorporating neuroplasticity into my daily life all along. I can drive from my house to my son's school without thinking about where I'm going. I'm on autopilot, if you will. My brain has adapted to just know how to do this, thereby freeing up space in my brain for other information. Another example: a friend of mine works in a hospital, and she can tune out all of the constant beeping.

So how have I done it? Well, I'll admit - I was a bit hesitant and it wasn't easy. It still isn't easy, even with a lot of practice. It's a daily effort and it took me a good 12-18 months to really learn the process for me to be able to find the tools I keep handy in my toolbox in order to live a pretty productive life. Learning to

“Remembering Jenny LeCompte” continued on page 20

meditate has for sure been the most difficult part for me. As simple as it seems to learn breathing techniques, they take a lot of mental energy to keep going.

Neuroplasticity techniques, mindfulness and lots of self-care have helped me to not only regain my ability to speak, I've also gotten my vertigo issues under control to the point I can walk without a cane. My pain levels generally stay low so I can go on with my day. I am able to volunteer within the community and have lots of family time. My favorite byproduct of incorporating neuroplasticity in my daily routine has been finding all the fun and pleasures in life. My biggest joy is my son; I try and make sure we have some kind of adventure on a regular basis so I get to see the world through his eyes. Even on days I have increased pain, I find myself able to force the pain aside and enjoy the day instead.

It's been important to find the main triggers that cause the pain and act in a way that intentionally fights them. Don't get me wrong, I still avoid intense triggers, for instance hot days with the direct sunlight on my face, freezing cold weather or gusty winds. I try to go out in the overcast sunny days and enjoy my wind chimes on my patio. I go for walks with my son, even when it's a little breezy outside. On days I choose to stay in, I love writing, reading, scrapbooking and baking. I keep a list handy of ways I can care for myself, either outside or inside. The better I feel, the more I find to add to this list - just more tools for the toolbox.

With enough practice, it's said neuroplasticity could be seen as a "cure" or a way to heal what ails you. I think that's a stretch. Of course someone who has lost a limb is not going to regrow it. The arteries that are wrapped around my trigeminal nerve are not going to magically unwrap themselves. I do believe, however, that neuroplasticity can get me to a state of remission. When I have an attack that's more than I can handle, it's a sure sign I haven't been working on taking care of myself as well as I should have been. Of course there are some stressors and triggers in life that are beyond

my control. What's most important is I refuse to let the attacks get me down. I now know I'll have more good days than bad, it takes work and persistence for it to become a way of life.

If I could give anyone advice on pursuing neuroplasticity as an option, it would be to not give up. Even with painful conditions like trigeminal neuralgia, neuroplasticity

gets easier the longer you practice it. Attacks are not uncommon for me but the duration and intensity of the pain have been reduced significantly since I introduced neuroplasticity into my treatment.

Look, let's be real here. I'm not a doctor - none of us on the YPC is. We're all patients, just like you. And just because this has worked for me doesn't mean it will work for you, or work in the same way. If there's only one truth about facial pain patients it's that each of us is different and has a unique story. The tools in my neuroplasticity toolbox will differ from yours. But if you're like me and feel like you've tried everything, why not give it a shot?

For more information on neuroplasticity, here are a few resources we've found helpful:

Neuroplastic Transformation Workbook by Michael Moskowitz and Marla DePolo Golden

The Brain's Way of Healing: Remarkable Discoveries and Recoveries from the Frontiers of Neuroplasticity by Norman Doidge ■

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to pain relief,
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you want and the
rest will follow."*

*—Peter Abaci, M.D.
Huffington Post,
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Our parents, Arlene and Bernard Richards, started life in fairly humble circumstances, growing up in New York City during the great depression. They met each other on a City College stairwell in 1947 and were blessed to spend the next 65+ years together, working hard and building a wonderful life for themselves and for us, their children. Through it all, they always cared for those less fortunate than they were, and charitable giving played a central role in their lives.

Our dad, who passed away five years ago, was a healthy, vigorous man who developed trigeminal neuralgia sometime in his middle years. Although he was in a tremendous amount of pain, he rarely complained and never allowed it to dominate his life. That was the type of person he was.

That said, he really suffered and understood how difficult this condition could be, which is why he designated a portion of his Charitable Remainder Trust to the Facial Pain Association. It was an honor to inform the FPA of his generous gift, and we look forward to hearing how it will be used to help others who are suffering as our father did.



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If you would like more information on joining the FPA Legacy Society, please
call 800-923-3608 or email Brandi at bunderwood@tna-support.org.

Acknowledgements



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Every effort was made to ensure the accuracy and completeness of our supporters' names listed in the 2020 Annual Report.

We apologize for errors or omissions that occurred and we give special recognition to the following individuals and organizations. If you see something incorrect, please contact Regina at info@tna-support.org.

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The Facial Pain Association is the largest patient organization supporting all people affected by neuropathic facial pain, leading the world in resources for information and healthcare guidance. Through programs of education, personal support, and advocacy efforts, FPA supports patients, their loved ones and caregivers, and healthcare professionals who diagnose and treat people affected by facial pain.

FPA is volunteer-led and community-focused. Guiding the FPA is a volunteer Board of Directors and a Medical Advisory Board which is composed of experts in neurosurgery, neuroscience, pain management, and dentistry.

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Partnering with FPA connects you to a community of over 55,000 patients. If you provide services to people with neuropathic facial pain, we have many opportunities for you to partner with us:



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FPA's Professional Membership Program connects the facial pain community with specialists diagnosing and treating neuropathic facial pain and related health care conditions. Connect with the worldwide facial pain community through an annual individual or center FPA professional membership.

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The FPA promotes and supports medical research that is relevant to the neuropathic facial pain community. While FPA does not provide funding, we support research in a number of ways for the betterment of the lives of people affected by facial pain. To learn more contact Allison Feldman at afeldman@tna-support.org or visit www.facepain.org/Research.



FPA Support Groups

Our national network of virtual and in-person support groups welcomes you to share your expert knowledge on any number of relevant topics.

Contact Regina Gore at rgore@tna-support.org.



FPA Quarterly Journal

The FPA Quarterly print edition is mailed to several thousands of our members and the digital version is sent to approximately 30,000 four times per year. If you would like to contribute an article, contact Brandi Underwood at bunderwood@tna-support.org.



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Michael Brisman, M.D.

Dr. Brisman has served as Chief of Neurosurgery at NYU Winthrop Hospital, Mineola, NY, and is Co-Medical Director of the Long Island Gamma Knife® Center at Mount Sinai South Nassau in Oceanside, NY.



Jeffrey Brown, M.D.

Dr. Brown is the Facial Pain Association Medical Advisory Board National Chairman. He serves as the Neurosurgery Director of the NYU Winthrop Hospital CyberKnife® Program in Mineola, NY.



Alan Mechanic, M.D.

Dr. Mechanic served as Chief of Neurosurgery at Huntington Hospital, in Huntington, NY, from 1996 to 2014. He has served as Chairman of the Nassau Surgical Society Section of Neurosurgery.



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