The road to successfully treating trigeminal neuralgia can be a long one, especially if you’ve relied on medications for years with only modest success. It’s time to take a unique road: outpatient, nonsurgical treatment at The Valley Hospital’s Gamma Knife Center in Paramus, New Jersey.

And to help you down that road are Valley’s highly experienced nurse navigators who literally meet every patient at the door, taking them through each step of their treatment journey.

We are one of very few gamma knife centers in the New York / New Jersey / Connecticut area, and we have been effectively treating trigeminal neuralgia for many years.

Care is delivered in a beautiful and calming outpatient setting, off-premises from The Valley Hospital. Access is easy and direct from all main highways.

The Valley Hospital Gamma Knife Center
Paramus, New Jersey
201-634-5677

If you are searching for relief from the facial pain of trigeminal neuralgia, now is the time to learn about gamma knife.

TELEHEALTH APPOINTMENTS are available, saving you time and travel.

EVERYONE’S FACIAL PAIN IS UNIQUE.
SO SHOULD THE TREATMENT.

Learn more at ValleyGammaKnife.com/FacialPain

Care Like No Other™
Like many of you, my wife and I have donated to important causes most of our adult lives. We expect a lot from our philanthropic investments, as we believe everyone should. To sound a bit crass, we want to see a significant return on the dollars we donate. And if we don’t, we look for other nonprofits that are truly making the world a better place. For all of you who generously give to the FPA, I want to make sure that you have a sense of how much impact you are making. Typically, there are three things my wife and I assess from our giving.

First, we look for real evidence of concrete progress being made to advance the philanthropy’s mission. At the FPA, my wife and I marveled this past year at:

- the first virtual FPA conference with approximately 1,000 participants from 14 countries
- the creation of a 31-person Peer Mentor Corps
- the increase of many more webinars and Facebook Live events
- the expansion of our Support Groups
- and most recently, the launch of a new FacePain.org website to help get even more vital information into the hands of our community even faster.

And this is only a partial list. There is no doubt in our minds that concrete program additions are being made to help our community.

Second, we look at how much of our donation goes directly towards advancing the mission (e.g., doing the things above) and how much goes to pay for the fundraising and overhead.

The FPA does not have dedicated fundraising staff. Our CEO, Allison, takes the lead (along with everything else she does) and she is supported by one of her staff occasionally. Overhead? FPA is now a virtual organization so no funds go toward rent, utilities, etc. This year, we have saved close to $70,000 by moving to a remote office. In short, we feel great that our donation directly supports the programs and services FPA provides to thousands of people each year.

Finally, and most importantly, we look at the impact that our philanthropy is having in terms of how many people are helped and how much their lives are positively impacted. The number of people the FPA reaches is staggering. Our staff responds to approximately 2,500 email requests for information annually, and that is not counting the thousands who are reached by our conferences, webinars, support groups, Peer Mentors, etc. And these individuals are typically helped enormously. I have a friend of the family with TN. He was in a terrible position when he first contacted the FPA. Within a very short time, FPA supplied him with the information he needed to feel comfortable with the ablative procedure being recommended by his doctor; he had multiple helpful conversations with our staff, and he was connected to three Peer Mentors. He’s now pain-free and immensely grateful for the help the FPA provided to him at one of the lowest points of his life. No other philanthropy that my wife and I have ever supported has this kind of impact.

So, to all of you who so graciously and generously support the FPA, I hope that you more fully realize how you make the world a better place through your gifts to FPA.

David Meyers, Chairman of the Board
The Facial Pain Association
2020 was an extraordinary year for many reasons. World events impacted the facial pain community and, in turn, the Facial Pain Association. Despite the challenges presented by the COVID-19 pandemic, which eliminated the options for in-person support meetings and events, created barriers to healthcare provision, and increased isolation, FPA reaffirmed its commitment to serving everyone affected by facial pain. We pivoted to virtual support group meetings, offered more webinars and Facebook Live events, created a network of Peer Mentors to connect with virtually, and held our first virtual FPA Conference.

In 2020 we also honored our 30th year of facing facial pain together. We recognize how important it is not to forget why this organization was founded, and to continue to learn from the medical experts, longtime volunteers, and past leaders of the FPA. We retain our core mission and values as we bring FPA into its fourth decade.

We are excited to share FPA’s 2020 Annual Report with you because it is about more than numbers, it is the story of our impact in the facial pain community. If you are a donor, we want you to understand how much impact your gifts have. If you are a person with facial pain, or love someone who has facial pain, you are part of this annual report, too. You read our Quarterly journal, and you likely have participated in one of our programs or have been helped by one of our many resources as well. The annual report offers a chance for us to share all we have done in the past year, and conveys how your ongoing support directly translates to more programs, more resources, and more people helped, supported, and shown they are not alone.

FPA is dedicated to creating an environment where people with facial pain are supported through community, educated about their condition, and empowered to advocate for themselves and others. This past year brought many challenges, but it was the challenge that created opportunities for us to connect with people in new ways. We have learned valuable lessons and these lessons will help us reach more people earlier on their journey to correct diagnosis and pain relief.

Thank you for your continued support in the last year and in the years to come.

Allison Feldman
Chief Executive Officer
FPA is the heart of a diverse community with a common mission, to serve those with neuropathic facial pain through support, education, and advocacy. This year we seek to celebrate the many faces that comprise our community.

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"The only thing you can really control is how you react to things out of your control."

Better advice has probably never been given to any of us. It is relevant to the numerous roles I play in my life and something that I consider multiple times a day. As a surgeon, I often face an unexpected set of circumstances in the operating room- a new team or a different piece of equipment. As a mother of former toddlers and now tween/teens, often plans do not go the way I had envisioned. As a patient, how a new brand of medication carried by my local pharmacy may affect my body may be highly variable.

Chronic pain affects people in so many different ways and there are so many variables that may further limit control over the condition. We often focus on the sensory experience and its treatment. Patients are often asked, what is your pain level? As the pain level as depicted on the numeric rating scale score (NRS) is then used to assess response to treatment, the focus on sensation continues. Physicians and patients are less apt to consider other markers of success. More relevant questions perhaps are- Could you stand a minute longer than you did the day before? Were you able to do the dishes? Were you able to ride in a car? Were you able to sleep better? Was your mood improved? Were you able to enjoy time with family?

Why do we still use NRS? Historically, its use goes back to the well-meaning idea of considering pain as the fifth vital sign, which unfortunately had the unintended consequence of contributing to the opioid epidemic [1, 2]. The NRS resonated with physicians as treating abnormal vital signs is something they are well familiar with. If blood pressure is high, providers give medications to reduce the value. The same is true for treating NRS values and thus the focus on sensation continues. While this may work for acute pain (e.g. a broken arm), for patients who have chronic pain, defined as greater than three months of pain in the same distribution, it does not. Chronic pain goes beyond sensory changes alone as the brain’s plasticity is altered [3].

In fact, chronic pain is a tridimensional experience that involves sensation, cognition, and emotion. However, there is
a lack of guidance and adherence to treating components of pain not related to sensation by both providers and physicians. Why is this? For physicians not specializing in mental health, we often focus on fixing values like NRS. We may advise our patients to limit their stress but without concrete guidance on how to do that or integration of these options into the formal treatment plan, patients rarely succeed on their own. Compounding the issue, patients with chronic pain have often been passed from physician to physician and because of lack of objective signs and/or lack of response to treatments, they may have been told that “the pain is in their head.” This statement marginalizes what patients are experiencing. Further, it makes patients less accepting of any cognitive or emotional components of their pain and of future treatment strategies designed to treat those aspects of their disease. Indeed, chronic pain is a disease and something that people will have to learn to manage. That is not to say people must suffer and in fact they should not. However, expecting to be pain free for a lifetime is likewise an unreasonable expectation.

We need to take into account how living in pain may affect our thoughts, our behaviors, and our moods. While we wait for our provider to aid in diagnosis and treatment, it is important to keep ourselves in the best physical and mental space possible to modulate our reactions and empower ourselves to keep moving forward. Much as we have to make good lifestyle choices when treating diabetes, we have to do the same with chronic pain. We may have to change certain behaviors. We may have to add meditation and yoga, a healthy diet that reduces inflammation, and good sleep hygiene to our lives. Changing our cognitive and emotional response to chronic pain is essential to our well-being. While working through the process of limiting pain, controlling our reactions is empowering.

As I watched Phil Mickelson, a soon to be 51 year old win the PGA championship, I was struck by the fact that this man who suffers from psoriatic arthritis was able to achieve these goals.

It was obvious that he was thinner and had worked on his swing. What was less obvious was what he shared with interviewers, the role of meditation and yoga in his life over the last few years. He truly had optimized his mind-body connection to accomplish the previously impossible. If we all did that, just think what we could do!

References


1. Department of Neuroscience and Experimental Therapeutics, Albany Medical College, Albany NY

2. Department of Neurosurgery, Albany Medical College, Albany NY

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Key Words: Chronic pain, NRS, Pain Management, Meditation, Quality of Life
My name is Erika Greenup, and I have atypical trigeminal neuralgia/idiopathic facial pain. I was 24 when the pain started, and I am now 30. Since this began, I have only had 28 pain-free days, after a trigeminal node nerve block last summer. Unfortunately, it was not effective long enough to be a long-term treatment.

The pain on the left side of my face has slowly developed from aching/crushing pain, mostly located in my mouth, lower jaw, and cheek bone, to almost the entire left side of my face. My pain is likely caused by damage from an oral surgery, but this has not been proven. I have clean scans, and my doctors and I agree MVD is not a good option. I have tried 11 medications, and only Nortriptyline has really worked without making me horribly ill. It took five months to get accurately diagnosed, and I barely slept during that time. The pain was a constant level 10, nothing really helped. The stress and lack of sleep nearly killed me.

About a year into the pain, I realized if I was going to heal emotionally from the trauma of the pain, drug side effects, and deep depression, I needed a project to change my thinking about my ATN. I began to paint my pain areas daily, took photos, and posted them to a blog called “masking the pain” (www.maskingthepain.wordpress.com).

Each time I painted, I felt that I reclaimed my face by turning the aching, crushing pain into beauty and color. It made my pain visible. I didn’t need to talk about it with family and friends because they could actually see it, so they stopped asking me how I was feeling. Strangers asked questions, and I was able to raise awareness. I also found that as meds lowered my pain levels that wind was a trigger, but touch was not. The paint sealed my skin from the air and helped keep pain levels lower. The paint patterns also became a record of where my pain was and how it was growing over time.

As life got busy again— getting married and trying to work odd jobs here and there, I painted less, but I still do it when I feel I need a lift emotionally or when I have a new symptom and need to come to terms with it.
When a person suffers from trigeminal neuralgia, many options exist that can help them manage or eliminate their pain. Both medical and surgical options exist to meet differing needs, but patients should understand that each option has risks, benefits, and relative rates of and duration of success. Choosing to have intracranial surgery is always serious, and a thorough explanation by healthcare professionals should precede making this decision. As one of the most common surgeries for treating trigeminal neuralgia, this article will discuss microvascular decompression.

Introduction

Microvascular decomposition (MVD) is a surgical procedure utilized to treat trigeminal neuralgia (TN), both TN Type 1 (attacks of pain) and TN Type 2 (some constant pain and attacks of pain). It is also effective to treat other related disorders such as glossopharyngeal neuralgia, geniculate neuralgia, and hemifacial spasm, but for this discussion we will limit the topic to TN. Of the surgical/procedural options, MVD has the distinction of being the most effective treatment for TN. This holds for general success rates as well as longevity of success, and with preserved nerve function (no numbness). Most believe this is a logical outcome as MVD is the only treatment for trigeminal neuralgia that:

• Corrects the anatomic problem causing the pain—vascular compression of the trigeminal (5th) nerve
• Does not include deliberate nerve damage as part of the procedure (all other procedures do, including radiation)

However, while the most effective, it is also the most invasive. Let’s take a closer look at the details behind TN and MVD surgery.

The trigeminal nerve is the 5th of 12 cranial nerves— which are 12 pairs of unique and special nerves of the head and neck. The major function of the 5th nerve is to provide the sensory connection to the brain from the face and related structures. The trigeminal nerve joins the brain in an area called the pons, the mid-portion of the brainstem. From this location, it travels forward through the spinal fluid space, and the nerve root enters a fold of dura (the thick covering that protects the
brain) called Meckel’s cave. The nerve root then separates into the three main divisions (V1, V2, V3) and moves through openings in the front and base of the skull to reach the tissues of the face (including the eyes, teeth, tongue, and inside of the nose and mouth). The nearest named blood vessel that usually runs above the trigeminal nerve root is the superior cerebellar artery (SCA). This artery (and sometimes other vessels) can elongate (common with aging) and can form a loop or assume a similar position physically against the trigeminal nerve. Unfortunately, when a vascular loop compresses the trigeminal nerve at or near where it leaves the brainstem, symptomatic vascular conflict can occur.

The trigeminal nerve undergoes an interesting structural change as it leaves the brain (as do all nerves as they leave the brain or spinal cord). To visualize this, picture nerves like wires in a circuit—just like wires connecting electronic components, the long segments of nerves (axons) provide the connections between brain and body. And just like our wire analogy, all nerves have insulation for protection and help them conduct impulses normally and efficiently. This protective insulation is composed of a fatty compound called myelin. Now is where we get to the fascinating (and potentially terrifying) part of the trigeminal nerve: the mysterious “root entry zone” (REZ).

The REZ describes the location where the nerve is just outside the brain. At this location, the myelin that surrounds the axons transitions from being made by one cell type to another. Very specifically, the myelin covering the trigeminal nerve in the central nervous system (inside the brain) is produced by oligodendroglia cells. When the trigeminal nerve leaves the brain to become part of the peripheral nervous system, the myelin changes over to that produced by the Schwann cell. Something about that transition that makes the nerve vulnerable to compression. This is why caregivers who understand TN make a big deal about finding “a vascular loop inside the root entry zone.”

While it is not known why the REZ is vulnerable, we observe that compression of the nerve at this location can certainly create “abnormal conduction behavior” —a.k.a. terrible face pain— yet there is nothing wrong with the face. While the cause of the problem is pressure or pressure pulsation near the trigeminal nerve REZ, few patients describe their TN pain in the character we would consider “pressure” or a “pressure sensation.” The pain of TN is typically a sudden, sharp, electric, or stabbing pain. Now that we have a basic understanding of the trigeminal nerve when it isn’t functioning correctly, we can now explore the journey of having an MVD.

Microvascular Decompression continued on page 10
Discussing an MVD with a surgeon

In most cases, pre-op imaging with thin-cut MRI and 3D “Fiesta” or “CISS” sequences will nicely show the compression before surgery. Imaging technology, while improving all the time, is not perfect, and sometimes an MRI may not appear to show vascular compression. It also happens that if the neuroradiologist looking at your MRI is not familiar with vascular compression, they may fail to recognize it. In addition to having an expert surgeon who knows what to do on “the inside”, the experienced surgeon will help determine whether to offer you an MVD versus other choices based on the MRI as well as other considerations.

When selecting a surgeon, the best place to start is with a provider that has the time to speak to you and answer all your questions.

Do your homework and research your provider. Nearly all neurosurgeons complete their training and have had at least a little experience doing a microvascular decompression. However, finding someone who is an expert and focuses their practice on this condition and this specific operation will serve you well. Unfortunately, we do see MVDs that have not been done well. After surgical and non-surgical options are reviewed to your satisfaction, and you feel an MVD by an experienced surgeon is for you, it’s time to prepare for surgery.

The Surgery

All MVDs are done under general anesthesia, so routine preparation common to contemporary surgical techniques and precautions are necessary. During MVD surgery, an opening is created in the skin and bone behind the ear. Some spinal fluid is removed, and the space over the brain (cerebellum) is followed to the location where the nerve is leaving the pons to the location of vascular compression.

At this point, the magic occurs under the surgical microscope as the vascular compression is relieved. In the classical operation popularized by Dr. Janetta, a piece of Teflon felt was used to separate the blood vessel and nerve. In my particular practice, I try to avoid using Teflon, and employ a variation I call a microvascular transposition.* More on this “Teflon Free MVD” will be shared in a future article. The risks of MVD surgery include the need for general anesthesia, the possibility of bleeding and infection as in all surgeries, and risks that are related to a patient’s overall medical condition. Because the surgery takes place next to other cranial nerves, there is a small chance that hearing can be affected on the same side as surgery. To prevent this, monitoring the nearby nerves is done routinely, and is known as intraoperative neuro monitoring or intraoperative EMG (Electromyography) and BAERs (Brainstem Auditory Evoked Response).
After the decompression is complete, the covering (dura) of the brain is closed. Sometimes the bone removed can be replaced and held in place with miniplates, screws, or cement. If the opening is small, it can be completely covered with a titanium plate and screws. The muscle and scalp are closed in anatomic layers.

The Recovery

Recovery from MVD surgery should focus on mobilization. I prefer getting my patients walking the night of their surgery. This helps reduce muscle spasms and prevents other problems like blood clots in the legs and lungs, and pneumonia. These latter two issues are risks after any surgery with a general anesthetic. Some patients do have some nausea and vertigo (dizziness) after MVD surgery. These symptoms usually resolve in two days when it occurs and can be treated with a medication patch worn behind the non-surgical ear. Once the facial pain has stopped, we will begin tapering the patient’s medications. We are cautious not to stop the facial pain medications cold turkey since this can cause significant side effects. Around 75% of our patients are able to leave the hospital the next day and return home. Post-operative pain management is used for the discomfort at the surgical site behind the ear. Early mobilization and pain medication are the main stay to support this recovery.

In conclusion, MVD is a very successful surgery for TN. The first steps are obtaining a correct diagnosis, seeking good information prior to making a decision, and of course, choosing an experienced surgeon.


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

What We Do

We provide personalized support:

Support Group Leaders offer a group forum for those in the facial pain community to experience an encouraging, sympathetic group in person, virtually, or in a combination of both.

Peer Mentors offer one-on-one support by sharing their experiences and lending a compassionate ear by phone or email.

Social Media Ambassadors use their voice on various social media platforms to actively, and positively promote what the FPA means to them.

Special Projects Volunteers provide their expertise to assist with projects such as: translating materials, event planning, grant writing, patient advocacy, patient research advisory panels, and social media moderation.

We provide education:

FacePain.org includes the latest information about diagnosis, symptoms, treatment options, pain management, medication, mental health, doctor, and medical center information. Our website houses a library of educational webinars, medical articles, and links to a variety of additional helpful resources.

Webinars, Quarterly journals, and Bulletin updates provide ongoing information from top medical professionals, event notifications, research updates, and more.

We promote patient advocacy:

FPA is dedicated to creating a community that fosters collaboration through outreach to the medical community and supporting research efforts.

Social Media - FPA maintains an active Facebook Page, Facebook Group, and accounts on Twitter, Instagram, YouTube, and LinkedIn.

The FPA Young Patients Committee (YPC) recognizes the unique issues faced by people under age 40. YPC gives a voice to younger patients and raises awareness that neuropathic facial pain does not only affect older adults. YPC also has a Facebook Page and Instagram account.

Who We Are

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-lead 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.

Mission

Our mission is to serve those with neuropathic facial pain, including trigeminal neuralgia, through support, education, and advocacy.

2020 Annual Report

FPA’s 2020 Annual Report focuses on the three core components of our mission: support, education, and advocacy, providing a snapshot of FPA’s impact in each category.

Our Annual Report is more than numbers, it is the story of our impact, and we invite you to read our story through the words of many members of the facial pain community.

Facial Pain Association 2020 Annual Report
Support through Volunteer Programs

Support Group Leaders (SGL) & Peer Mentors (PM) by State

- SGL
- PM

AZ......
CA.....■■■■■■■■■
CO.....■■■■
FL.....■■■
GA.....■■■
ID.....
IN.....
KS.....
KY.....
LA.....
MA.....
MI.....■■■■■
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NV.....
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OH.....■■■■■
OR.....■■■■■
PA.....■■■■■■■
RI.....
TN .....■
TX .....■
VA.....■■■■■
WI .....■

32 Support Group Leaders
31 Peer Mentors
26 Support Groups
26 US States & Canada

Living with a rare disease can be lonely and isolating. It took ten years since my first trigeminal neuralgia attack to meet anyone else with the diagnosis. Our support group is a community diverse in background but unified in helping each other understand the disease and cope in positive ways.

—Kim

I just wanted to thank you for the virtual support group meeting. Ever since I was diagnosed I felt alone with this. It was good to share with others who understand.

—Bettyann

Thank you for your response, I will be contacting the Peer Mentors. It is a relief to have the sense that I may have some support with this awful condition.

—Gwendolyn
Volunteer

Being a volunteer in other organizations may mean planting a garden, serving a meal, reading to a child, decorating for a gala, or a hundred other practical, physical tasks. Every act is worthy, and appreciated by the organization. However, being an FPA volunteer means something different.

Our volunteers are called to lessen someone’s isolation, confirm their humanity, provide empathy when seemingly no one else will listen, or be there when loved ones are numb from the ordeal. To paraphrase Michele Cohen, LCSW, a licensed psychotherapist, and FPA Support Group Leader: ...people suffering from neuropathic facial pain often feel quite alone and misunderstood. Many have never had the opportunity to speak to someone who personally understands the condition.

FPA volunteers serve fellow members of the facial pain community in a deeply felt and personal way. The saying, “You can’t understand someone until you’ve walked a mile in their shoes” is a reminder how important empathy is in living a meaningful life. The most important aspect is to be present, and actively listen... Each one of our dedicated volunteers makes a positive impact on the facial pain community and, in turn, makes it possible for FPA to fulfill its mission of support, education, and advocacy.

Currently, there are two active community volunteer roles: Support Group Leader and Peer Mentor.

Support Group Leaders offer a group forum for those in the facial pain community to experience an encouraging, sympathetic group in person, virtually, or in a combination of both.

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By Regina Gore, FPA Volunteer Coordinator

FPA Volunteers

<table>
<thead>
<tr>
<th>PEER MENTOR</th>
<th>SUPPORT GROUP LEADER</th>
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<tr>
<td>Claude Aldridge</td>
<td>PM</td>
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<td>Sarah Ancell</td>
<td>PM</td>
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<tr>
<td>Anna Beard</td>
<td>SGL</td>
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<tr>
<td>Carol Bloom</td>
<td>PM</td>
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<tr>
<td>Stephanie Blough</td>
<td>SGL</td>
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<tr>
<td>Chyrl Bowers</td>
<td>PM</td>
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<tr>
<td>Diane Boyd</td>
<td>SGL</td>
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<tr>
<td>Joan Cannelli</td>
<td>PM</td>
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<tr>
<td>Anne Ciemnecki</td>
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<td>Christine Cohen</td>
<td>PM</td>
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<td>Michele Cohen</td>
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<td>Teresa Cordonnier</td>
<td>SGL</td>
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<td>Diana Crites</td>
<td>SGL</td>
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<td>Vickie Dance</td>
<td>SGL</td>
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<td>Hosanna Derderian</td>
<td>PM</td>
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<td>Lisa East</td>
<td>SGL</td>
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<td>Allan Enis</td>
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<tr>
<td>Thomas Fenstermacher</td>
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<td>Jeffrey Fogel</td>
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<tr>
<td>Darrell Fryer</td>
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<td>Stuart Gause</td>
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<td>Kurt Goodman</td>
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<td>Tim Guith</td>
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<tr>
<td>Neave Halvorsen</td>
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<td>Megan Hamilton</td>
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<tr>
<td>Sarah Hawbecker</td>
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<tr>
<td>Jeanne Tarullo Hays</td>
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<td>Kathleen Hays</td>
<td>SGL</td>
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<tr>
<td>Vince Holtmann</td>
<td>PM</td>
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<tr>
<td>Rosa Jimenez</td>
<td>PM</td>
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<td>Rene Johnson</td>
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Peer Mentors offer one-on-one support by sharing their experiences and lending a compassionate ear by phone or email.

FPA regularly receives feedback from volunteers and members of the community they are in contact with. Here are three heartwarming examples:

Heidi Wittgren, a Peer Mentor, made a point of sharing her experience: “I did a lot of listening and found that the people who called me really just wanted to feel comfortable with what they are feeling and that they are not alone. TN makes us isolate sometimes, and it’s nice to know there are people out there who completely understand what it feels like to wake up and face a day of pain. I am learning a lot from this experience and I have met so many wonderful people. I can’t thank you enough for this opportunity. I am humbled by this experience.”

A participant in a recent Suburban Detroit Support Group Meeting co-led by Tim Guith and Lynn Ruppe wrote to say: “I was so happy to attend your meeting yesterday…and speak to people who really understand.”

Tim and Lynn have been holding monthly meetings since 1998. Tim, now retired from GM, says the regular meetings have helped him over the years. He credits Lynn, a registered nurse, with keeping things going with her warm personality and ability to comfort members.

Another Peer Mentor shared the following text message from a person who was connected to them by FPA’s Peer Mentor list: “Bless you! I am so glad I have a relationship with you. You are always so comforting...you have helped me so much in my short time getting to talk with you. You are better than medicine for me. I look forward to our talks and I am blessed to have a resource like you to help me along this difficult journey.”

FPA welcomes volunteers from varied backgrounds, life experiences, and medical histories. No specific skills, educational background, or experiences are required. Potential volunteers are asked to complete an application and screening process. FPA provides training, educational opportunities, and ongoing support. If you are interested in volunteering please contact Regina Gore, Volunteer Coordinator, rgore@tna-support.org.
My name is Rosa Jimenez. I am a licensed massage therapist working in Eugene, Oregon. I am 45 years young and have dealt with chronic pain since childhood. I am inspired by beautiful things, my fulfilling work as a licensed massage therapist, working in the garden alongside the hummingbirds and my cat.

My goal is to live happily, even with facial pain. I am choosing every day to engage in the things that create joy and fulfillment for me. In the next few years, I hope to travel frequently when my daughter begins to have my grandchildren. I hope to return to outdoor photography, cycling, hiking, and teaching in the local community college massage therapy program. I hope to be able to tolerate cold weather and wind more.

Over the years many providers gave me differing opinions of what was causing my pain. Finally, early in 2018, I was diagnosed with TN1 but I sought out different opinions as recently as December 2020.

I have tried over 30 different pain relief treatments including topical and nasal lidocaine, hyperbaric therapy, 12 different modalities of bodywork, several types of breath work, meditation, stress management, light therapy, ice/heat, nutritional supplementation, essential oils, Chinese medicine, various modalities of physical therapy, chiropractic, acupressure, prolotherapy and platelet rich plasma therapies, nerve suppression injections, high frequency micro-current, and dental work.

Hyperbaric therapy has always given me the fastest and most lasting pain relief. After a session, I may have up to five weeks without pain. Massage has been less successful; although I know many talented bodyworkers and physicians, only occasionally would I get short-lived temporary relief from massage therapy.

I was prescribed Oxcarbazepine, on which I function well. For the most part, medications did not help as much as they harmed. Although I have had some temporary and minor pain relief, I have also suffered multiple side effects. It amazes me how intent I am on taking medications to relieve facial pain flares. I have avoided pharmaceuticals before this time in my life.

It’s very important to me to advocate for my own health and bring as much information with me when I see doctors. Recently, I went to an appointment with my neurosurgeon, carrying my copy of the new FPA book, and wearing my TN Warrior t-shirt with

Volunteer Spotlight - Rosa Jimenez
its white ribbon on the front and “Keep Calm and Fight On” on the back. As my doctor leafed through the book, he said he has known and/or has worked under all the physicians mentioned. I had no idea! At the beginning of his career, he even worked under the doctor who created the balloon compression surgery I had in June 2020. I thought to myself, “No wonder you are so good with this and with me!” It made me want to hug him.

To anyone who is newly diagnosed, I would say there is hope. You are not alone, and you have this whole community who loves to be here for you. Perhaps the first things you try may not work but there are still many solutions for you out there. Don’t give up trying for relief and solutions. Please be kind to yourself with your incredible suffering. Use any coping mechanisms you have and try to learn new ones. They help!

I connected with the FPA while I was doing a national search for resources for facial pain sometime in 2019. I called the FPA office at a time when I was feeling desperate for solutions. When I called, I felt so very supported. They really live up to their goal of education, advocacy, and support. They really do care and they really do help!

I volunteer with the FPA so I can offer support, friendship, and advice on pursuing care to those also suffering with this horrible monster. I have immense fulfillment from supporting those in a pain crisis and living with this disease. I have felt such honor in being there for those like me who are suffering with this mysterious and difficult disease.

I fill my dance card daily and have never felt over-used as a Peer Mentor. FPA appreciates any time and energy you are able to give. The times I have been able to offer my support and listening heart were convenient, and the folks who have reached out to me have been wonderful to connect with.

I feel like what I can do best is offer validation, treat other facial pain sufferers with credibility, and honor the vast effects facial pain has on a person’s life. Those have all been things that have helped me through the hard times with this pain. Sharing our stories, validating each other’s experiences, and offering one on one support to help— these are the things that keep us going.

Nowadays, I experience extra fulfillment when I can treat a client’s pain I relate to with massage therapy, and I get “extra-extra” fulfillment when I can support someone who is living with this terrible suffering.
In 2020, the FPA hosted a virtual conference with 1000 attendees from 47 states and 14 countries.

“I just wanted to say that this conference for me personally was life changing. I felt for once not alone. Like there were doctors who understood me, like I shouldn’t be afraid to be the expert or to fight for what I need.”

— Melanie

“I was able to view the virtual conference and learned so much. I feel I have a better idea of the next step in my treatment.”

— Jane

<table>
<thead>
<tr>
<th>Educational Programs</th>
<th>Website visits</th>
<th>Bulletins emailed</th>
<th>Facebook Group Members</th>
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<td>Webinar/Facebook Live registrants</td>
<td>Calls for information</td>
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Dear Friends,

We recently launched our new website to better serve the facial pain community. The realization of this dream would not have been possible without the generous support of people like you! As we envisioned, the website is faster, easier to navigate, and more accessible, with up to the minute information available at your fingertips. You can search for an upcoming FPA Support Group meeting, contact a doctor in your area, or research treatment options.

The Facial Pain Association website is here to support, educate, and empower you to take charge of your health. We have come so far, but the work is not finished. Join our mission to reach more people earlier in their journey to accurate diagnosis and relief from facial pain. Make a gift today.

Thank you for your support!

Allison Feldman, Chief Executive Officer
“I just wanted to say what an absolutely wonderful website you have. The Facebook group has helped me so much. I am so grateful I found your group.”

—Member in Western Australia

Advocacy through community engagement: outreach to medical community, research support, and creating a community to foster collaboration and partnerships.

Community Of Collaboration

Biohaven Pharmaceuticals
Coalition for Headache and Migraine Patients
Facial Pain Research Foundation
Geo Pain App
Harvard Brain Integrative Health Clinic and Research Program
Migraine World Summit
Noema Pharma
PRAXIS Precision Medicines
Rare Disease Day
Stanford University Byers Center for Biodesign Innovation
TMJ Association
University of Minnesota Health

Reach/Impressions: 720,000
Likes/Follows: 15,000
Reactions: 13,000
Shares/Retweets: 3,000
Comments/Mentions: 2,000

Reach/Impressions measures the people who see FPA’s content.
Likes/follows measures the people who support FPA on social media.
Reactions measures engagement with FPA’s content.
Shares/Retweets measures the amplification of FPA’s content.
Comments/Mentions measures interactions with FPA content.
Meet the YPC! With the launch of the new FPA website, logo, and branding, we thought it best to reintroduce ourselves. We are the Young Patients Committee, a committee designed to advocate for people with facial pain under the age of 40.

Our primary goal is to make sure that no one ever feels alone in their diagnosis. From our new monthly support group, to supporting young patients at facial pain events, to everything in between, we are here for you.

On the new FPA website, we have our own page that has links to all of our social media accounts and articles our board members have written through the years to make the world of chronic pain more manageable. Make sure to follow us on Instagram, Facebook, and Twitter! We also have an Etsy store with tons of items that help to start the conversation about trigeminal neuralgia. After all, awareness starts with one conversation about a cute teal ribbon decal!

Our email account and social media accounts are always open for conversations and questions. Feel free to send us a message if you need some extra love. Always remember that you are never alone. Each of our board members have experienced different paths since our diagnosis, so we’re always here to help you through what you’re experiencing. Even though no two diagnoses are the same, if we have each other, we can get through anything.

If you’ve known about us for a while, we’re glad you’re here! And if you’re just being introduced to us now, welcome to the family!

All our love and support,
The YPC: Steph (Chairwoman), Emmy, Lindsey, Meredith, Kenzie, and Rachel
youngpatientscommittee@gmail.com
I was diagnosed with atypical trigeminal neuralgia a little over six years ago. I have it primarily on the right side but also on the left side. I first started experiencing pain in March of 2015 with a sharp stabbing through my right eye. After many scans and quite a few doctors, I was finally diagnosed with trigeminal neuralgia. As the pain was so severe, I went right for the microvascular decompression. When I woke up still in pain, I was fearful it did not work, but I tried to be optimistic. I was also quite numb along the right half of my head, but after some time, the feeling came back except for the area from my cheekbone to my jaw, and still to this day, I have sensory loss on the right side of my face.

Unfortunately, as the weeks went on, the pain continued, and my fears were correct—the surgery was unsuccessful. My surgeon at the time did not have experience with other treatments, and I did not want to be his guinea pig, so I sought another opinion. After multiple physicians and what I like to call a rollercoaster of events, I had been through a lot. I had tried countless medications, outpatient procedures like injections and nerve blocks, and too many doctors and teams telling me they just cannot help me. I felt pretty defeated after a while. But looking back, yes, some doctors were completely rude and not helpful, but some were just frustrated that they couldn’t help, so the only option was to turn me away. For that, I can’t be mad because it wasn’t their fault that I am an “interesting” case, as most physicians called me.

At the time, I was quite upset, but looking back, I had to get through those people to get to the ones that truly wanted to help. I ended up having a second microvascular decompression with a great surgeon with whom I felt super safe and comfortable. Unfortunately, that one did not “take” either. This time however, he did not want to give up and gave me more options. We tried more medications together and Gamma Knife radiation, but alas, nothing seemed to help. As he is a surgeon, and I was out of surgical options, I had to find another doctor but always stayed in touch. My pain management doctor and neurologist that I settled on have become my team that listens to me and works with me. They are the backbone to my disorder, and even though it took a while to find them, and I have had my share of ups and downs with them, they haven’t given up on me.

Struggling with this disorder all these years, I have learned that you need to find doctors who will listen to you and hear what you want to do. I learned that I will always have this and be in pain, so how can I make it better, and what do I need to do to live with it in a healthy way.

Learning to find balance with this disorder has been difficult, but when it hit me, I realized I had to learn to live with it. I just had to. I wake up and go about my day, and sure I have some bad days where I can’t get out of bed, and that is my reminder that I need the day to rest my body and mind, so I take those days. But when the pain is tolerable, I get up and go about my day.

Hi! My name is Kerrin Heaney, and I am 32 years old from Long Island, New York.
I work in cancer research and enjoy what I do. It was almost a blessing starting to work in the healthcare field prior to getting this disorder because when I was diagnosed, I realized my life could be worse. I don’t consider myself “sick” because of what I do and where I work, so yes, it is a disorder, and yes, I struggle in pain every day, but I try to hide it because I know things could be worse. I also know everyone is battling something, so never judge people because you never know what is going on, and some people are good at hiding what they are going through. It may not be the best approach, but my closest family and friends know what is going on with me, and I know I can reach out when I need to, but most of the time, I go about my day as normally as I can.

When I am not working, I love to cook or bake or binge the latest shows. I also love meeting family and friends out or at their places to catch up or have a fun game night. It takes time, but I eventually found a good balance between life and this disorder. Sure, the pain is still there, but I do have a job and family and friends, and I am able to balance it all in a healthy way because I have learned when I need to take time to rest and when I can push myself just a little bit.

For newly diagnosed people, it takes time. It sucks to hear that, but it does get better. I have had countless procedures, surgeries, medications, and doctors who have all failed me. While I might still be in pain, I have been able to find balance in my life. I call my journey a roller coaster because that is exactly what I went through and still go through. Now, six years later, I can look back and realize that I went through so much because I had to try everything to see if I could get better. I am still playing with medications and trying to find new ones, and my doctors have ideas on more outpatient procedures if it comes to it, but the pain is tolerable. The hardest thing, and I struggled with it too, is acceptance. Once you accept this condition, then find the team of doctors you are comfortable with, you will be able to balance this ever-changing disorder with life.

Let Gamma Knife bring back your smile.

If you suffer the excruciating pain of trigeminal neuralgia and medication no longer provides relief, ask your doctor if Gamma Knife could be right for you.

For information or referral, call (866) 254-3353 — and see our videos and patient stories at endtrigempain.com
The FPA Annual Report is more than numbers, it is the story of our impact in the facial pain community.

### 2020 Sources of Revenue

- **Donations**: 86.5%
- **Professional Membership**: 8.4%
- **Conference**: 2.1%
- **Advertisement**: 1.4%
- **Sale of Material**: 1.0%
- **YPC**: 0.6%
- **Donations**: 86.5%

### 2020 Expenses

- **Programs**: 73%
- **Support services**: 11%
- **Fundraising**: 16%

### 2020 Levels of Giving

- **Donation Range**
  - $1—$25
  - $26—$50
  - $51—$100
  - $101—$250
  - $251—$500
  - $501—$1000
  - $1001—$5000
  - $5,001—$10,000
  - $10,001+

We retain our core mission and values as we bring FPA into its fourth decade.
LEGACY SOCIETY

Your story. Your values.
Leave a Legacy with the Facial Pain Association.

Our Legacy Society members are an instrumental group of supporters who have included a gift to FPA in their estate planning.

Anne and John Ciemnecki
Doris Gibson
Carlin Lagrutta
Miriam Leinen
Mary Ann McCann
David and Jody Meyers
Charles Muchnick
Mary-Ann Neri
Paula Rosenfeld
Arthur and Ann Schwartz

Facial Pain
Association

Sustainer Circle

The Sustainer Circle is an incredible community of monthly givers who help ensure that FPA meets our mission of support, education, and advocacy of the facial pain community.

William Albert
Cynthia Bennett
Jennifer Byram
Douglas Caldwell
Joey Callahan
Robert Camp
Daniel Desmedt
Allison Feldman
Stephen Fleming
Irene Fulk
Margaret Gallo
Lorri Genack
Kelly Glass
Sherry Henseler
Warren Huss
Ally Kubik
Isabella LaGrego
Audrey Martinuzzi
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Bahr Family
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Zelda Benson
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Brett Hodess
Andrew Kane
Janet E. King
Joseph Leonard
Kathryn Lindahl
Mark E. Linskey, MD
John L. MacKenzie

I am deeply grateful for the education and hope the FPA has provided to me. It is a privilege to give a few dollars each month to say thank you and to help sustain this crucial organization.
— Cynthia

As a third generation woman with trigeminal neuralgia, the Facial Pain Association has helped my ancestors. I joined the Legacy Society to be sure the association can continue to educate and advocate for future generations.”
—Anne

Chairman’s Club, Platinum, Gold, Silver, Patrons, Friends
I can operate, but FPA gives hope and support to so many people. That is priceless. Thank YOU!
— Dr. Chang
I appreciate you and your help very much. Our chat yesterday was like a ray of sunshine for me. I have been suffering alone for too many years so your kind words of encouragement mean a lot to me.

— Bob
Something really special is happening in the FPA and it is thrilling for me to be part of it. I have also gained a great deal of wisdom from the people in my group. Moderating the group has helped me in surprising and unexpected ways. Thank you for giving me the opportunity to be part of this worthy endeavor.

— Michele, Support Group Leader and Peer Mentor

Mary Rehmann  
Sue Remmey  
Matthew Renn  
Wayne & Elaine Retzlaff  
Jeanne Reynolds  
John Rice  
Carolyn Richter  
Rose Marie Roach  
Angela Rodgers  
Norah Rodgers  
Risa Rose  
Joyce Rosenbaum  
Paula Rosenfeld  
Cyrilla M. Royce  
Aaron Running  
Norma J. Sacca-Antonakos  
Jerry Sachs  
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Shirlene Sears  
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Judy Simpson  
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Kathleen Sommer  
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Jane Wenger  
Nancy Westlake  
Ken White, CPA  
Stephen White  
Judson Williford  
Jennifer Wilson  
Linda Wilson  
Floyd Winslow, Jr  
Mark Woelke
Thank you so much for the info! That will give us a peace of mind. What you are doing is really great. May God bless you more so you can continue helping others with this condition.

—Rachel
It was a pleasure speaking to you over the phone today. Thank you for your time and kind words. I truly appreciate your help. I will go over everything one by one and I will let you know if I have any questions. Thank you again for being so kind and helpful. The Facial Pain Association is definitely the right place for me to seek medical help with regards to my facial pain.

— Mohammed
Thank you for your email. I have a friend battling trigeminal neuralgia and it’s horrible. I feel helpless so thought this was a way to help her and others dealing with this.
I appreciate your reaching out and all the work your organization is doing.

— Sarah
Memorial Tributes:

Hope Albert
William Albert
June Dowell
Johnny Guttridge
Angela Rodger
Alma Amey
Mary Mattonni
Helen Baker
Theresa Lloyd
L. A. Barfield
Roy McKay
James A. Blodgett
Andrew Pensavalle
Pamela Boone
Claude Aldridge
Keith Boone
Gwendolyn Boone
Lloyd Boone
Richard Boone
Sherry Henseler
Illinois Tool Works
Jeri Knight
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William Fleisch
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Janet Burke
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Michael Cohen
Judith Cohen
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Nikole Chesley
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Dorothy Cope
Kathleen Everlove
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Pam Horowitz
John Kraus
Margaret Knauz
Gregory & Nancy Kucera
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William Mueller
Roni Waters
Joan Weidner
Kristie Wette
David Yagley
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David Collard
Michael O’Boyle
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Dorinda D’Agostino
Bessie Elledge
Loretta Lockett
Nancy Anne Enis
Allan Enis
Charles Everts
Carol Kirkbridge
Anita Fabricant
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Bridget Garvin
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Rohn Harmer
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Mary P. Wampler
Phil Wampler
Colleen Weiler
Edgar Weiler
Arthur E. Wermann
Barbara Pagliocca
Dorothy Willis
Dorothy Rainwater
Mi Young An
Jerome Newman
Norma Zimmerman
Ida Ashby
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Donald Behrmann, MD, PhD
Melvin Field, MD
Ravi Gandhi, MD
David Rosen, MD

The Boston Gamma Knife Center at Tufts Medical Center
Julian K. Wu, MD

Emory Saint Joseph’s Hospital of Atlanta
David J. Gower, MD
Shannon Kahn, MD
Alexander M. Mason, MD
Murray D. Robinson, MD

Hoag Hospital
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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.

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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.