Journal of the Facial Pain Association Fall 2025

Quarterly

THE FACIAL PAIN ASSOCIATION
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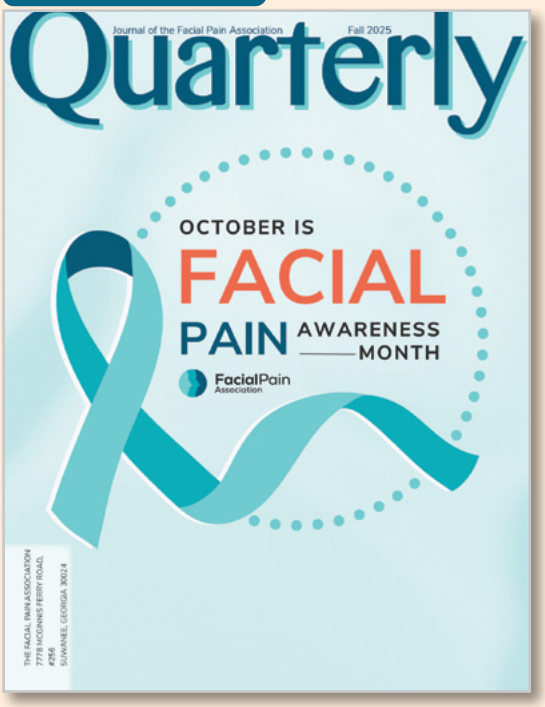
ON THE COVER



October is Facial Pain Awareness Month, and the FPA needs your help turning the world teal! On the cover of this Quarterly issue, you will find the Facial Pain Awareness Month logo that the FPA has used over the years. This logo is available to download by visiting **www.facepain.org/face-today-together** and can be used as a social media profile picture for Facial Pain Awareness Month. Help us raise awareness and educate others about facial pain by bringing a copy of this Quarterly to your doctor's office or your friend's house, changing your social media profile picture, sharing facial pain facts and patient stories, and rocking your teal clothes and accessories. Throughout October, we hope you remember that **you are not alone**. The FPA has resources to support you through every step of your facial pain journey. Whether you need information on a possible treatment option, a peer mentor to confide in and provide support, help finding a doctor, or joining a support group to build community, the FPA is here and ready to help.

From the Board Chair

October is Facial Pain Awareness Month — but what does that really mean for those of us living with rare medical conditions like trigeminal neuralgia (TN), which affects fewer than 1% of the population, or other rare facial nerve pain conditions that might even be more rare? It is crucial that we raise awareness about our conditions and the Facial Pain Association (FPA). It seems that there are three particularly important groups that need to be reached, all with different messages.

Healthcare Professionals
Since our condition is so rare, many healthcare professionals are not aware of TN and other facial nerve disorders. We must continue to reach out to dentists to make them aware of neuropathic facial pain (they aren't dental problems!) so that unnecessary and painful dental procedures are avoided and proper medical help can be rendered sooner. Some primary care physicians and neurologists are undoubtedly aware of TN, but most are not knowledgeable about all the medications, complementary and alternative therapies, and surgical procedures that can help us. And they certainly aren't aware of the FPA and all of the resources available to help them support their patients. And even many neurosurgeons who perform ablative procedures (e.g., damaging a nerve) to help reduce/stop the pain are not aware that a microvascular decompression (MVD) procedure may be a much better option for many of us.

Family, Friends & Co-Workers
Many of us are reluctant to share our medical situation with others, choosing instead to "suffer in silence." Sometimes we even wonder if we're somehow to blame for what we're going through (we're not!). Letting the people we spend time with know about our condition can help them understand our behavior and, in some cases, be there to offer emotional or practical support when we need it most. Even a simple conversation — along with a link to the FPA website or other reliable resources — can go a long way toward building the understanding and support we need.

Those With TN and Other Facial Nerve Pain Disorders
The FPA serves thousands of people every year. However, it breaks our hearts knowing that there are tens of thousands more living with severe pain whom we have yet to reach. As the world's leading organization for those with trigeminal neuralgia and other facial nerve pain disorders we offer an extensive range of invaluable information — including our staff, 119 trained volunteers, nearly 60 Peer Mentors, approximately 40 Support Groups, and an amazing Medical Advisory Board — all ready to help. Our challenge is clear: we must reach everyone who could benefit from the information and services the FPA provides.

What can you do? Make sure every healthcare professional you encounter becomes more aware of TN and the FPA. Consider sharing your condition with more people who are important to you. And do whatever you can to point people in need to the FPA.

David Meyers
Board Chair, The Facial Pain Association

A Message From the CEO

October is Facial Pain Awareness Month — a time to shine a light on a condition that is too often misunderstood, misdiagnosed, or dismissed. For those who live with facial pain, every day is a reminder of its challenges. For the facial pain community, this month is an opportunity to raise awareness, educate the public and healthcare professionals, and a chance to reaffirm our commitment to supporting one another.

The Facial Pain Association (FPA) is honored to be a part of this important effort and everything we do this month will be about elevating these messages and telling your stories. Several volunteers have spent the last 12 months working in cities around the country, asking them to "Light It Up Teal." There are over 50 bridges, buildings, and towers that will honor those living with facial pain by lighting up teal for at least one day in October. We've sent a press release to major news outlets to let them know why they see teal structures in their cities, and we have awareness month shirts and hoodies that can help to spread awareness.

This year's awareness month carries special significance for the FPA. In June, we proudly launched the Facial Pain Registry — a groundbreaking initiative designed to collect real-world data about the experiences of people living with trigeminal neuralgia and other facial pain disorders. By capturing patients' voices in a structured, meaningful way, the Registry will help researchers identify trends, improve treatment options, and—most importantly—move us closer to better outcomes.

Your participation is vital. If you live with facial pain, I encourage you to enroll in the Registry. If you are a loved one, caregiver, or healthcare provider, please help spread the word. Together, we can build the evidence base needed to drive progress in research, clinical care, and advocacy.

As we mark Facial Pain Awareness Month, let's remember: every shared story, every new data point, every effort to educate others is a step toward a future where no one has to suffer in silence. Thank you for standing with us, for lifting your voices, and for being part of this strong and determined community.

Melissa Baumbick
Chief Executive Officer, The Facial Pain Association

To purchase awareness merchandise click below.

Journal of The Facial Pain Association
Quarterly

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The MAB Corner

5 Questions for 35 Years with Kenneth Casey MD, FACS

Kenneth Casey MD, FACS

Dr. Casey is nothing short of a force to be reckoned with. As if being a renowned and respected neurosurgeon were not enough, Dr. Casey is also a U.S. Army veteran, co-author of the FPA's first book "Striking Back," associate professor at Michigan State University, and associate professor at PM&R Wayne State University. He is actively involved in multiple local, state, national, and international professional organizations, including his service to the FPA as a member of the Emeritus Medical Advisory Board.

A patient with several serious conditions himself, his perspective on the patient-physician relationship is unique. He shared his insights on the importance of listening to patients—of allowing them to tell the story of their journey before acting on any preconceived notions of a potential treatment path. His genuine sense of humor and true love for the art of surgical care, his patients, and his colleagues are just a few of the qualities that set him apart from other healthcare professionals. The FPA is honored to have him as a long-standing advocate for the organization and those it serves.

By Danielle Clements
The Facial Pain Association's 35th Anniversary Special Correspondent
Diagnosed with hemifacial spasm in 2023

You have a very broad and impressive background, not only in medicine, but in publishing, and your involvement with so many important organizations. Can you talk a little bit about what brought you to the FPA, and how you became involved?

If you think about it, it's not really the 35th anniversary [of the FPA], because the organization started on December 1st, 1987. Do you know why? That's the day that Claire Patterson (*the Founder of the FPA, originally called the Trigeminal Neuralgia Association, or TNA*) had a successful MVD (microvascular decompression surgery) with us at Pittsburgh, Dr. Peter Jannetta (*under whom Dr. Casey studied at the University of Pittsburgh*) and I. And that famous conversation that she had at post-op, where she said to him, "You know, gosh, I need to do something."

And Dr. Jannetta said, "Well, why don't you start an organization? Start a support group." She thought, "Why not?" So, over the next couple of years, we were back and forth, and then she came to Dr. Jannetta and said, "I need medical professionals [to help]." And at that point, Dr. Jannetta, myself, Dr. Jeff Brown (*neurosurgeon, former Chairman of the FPA Medical Advisory Board*), some of the other original members, decided that a patient-to-patient support group was very important, because no matter how much empathy you have as a physician, you just don't have the pain.

With hemifacial spasms, those patients, like yourself, whether you work in a bank or you're a customer, you're just so self-conscious. But the docs can't feel that. Only you could, and only you could tell another patient how that felt. At the same

time, though, we knew support groups could be vulnerable to misinformation. So, we knew that if this was going to work, we needed to have a really solid, first-class source of information.

It was kind of easy to talk to other neurosurgeons who were interested in MVD and say, “How about we make sure that these folks [patients] have good advice? And in fact, why don't we actually go to some of these meetings?”

So that's how it got started. Dr. Jannetta, myself, Dr. Brown, and others too, said, “You know what? Maybe we should have a national meeting.” To me, that's really where it went from being kind of talked about to emerging on the national scene as a viable, important information source.

It seems like a lot of your focus is on trigeminal neuralgia. Is there something in particular about that condition that drew you in? What do you find to be the most challenging in treating patients with TN?

I was working in a trauma hospital in New Jersey and a guy there knew Dr. Jannetta and said, go see this guy. I didn't realize that was the number one training program in the country. And he hired me. He imbued in me this sense that we're basically plumbers and electricians and carpenters. We open things and then we try to fix it. And we fix the electrical system or the plumbing system or whatever. But we're service people. That's what we do. We're here to service people.

Claire Patterson with Dr. Peter Jannetta (upper right)

Claire Patterson with Dr. Peter Jannetta

And like any service person, you act like it. The person is your patient, but they're your friend. They're a customer. And more importantly, they're your colleagues because they've got to tell you how to get it right. If you don't listen... People are getting MVDs and operations when that's not what they need. If the doctor had just listened a little longer and didn't just jump to, “here's what I think...”

We knew that educational information was important. And who is better than the patient? If the patient speaks knowledgeably, challenges that old patriarchy where the doctor pats you on the head and says, “I know better.” Well, we've [physicians] never known better.

Who knows their symptoms better than you? You can see my passion for it. Just now I answered about four or five Facebook questions from around the world because people sometimes get told, incorrect things. You've probably been exposed to them [as a patient yourself] saying, “you know, you have something else, or you have something different, you're doing this.”

And then it's never like, hey, how about you be quiet and listen to their story? In our office we sit there when we first meet a patient. We let them sort of get over the fear of all the things happening and then I let them go because how they say the first 8 or 10 sentences usually gives me the entire picture. And who

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was it, English physician, who said the patient knows the diagnosis, let them tell you in what they say.

It's watching and listening and then hearing your burden as a patient tells me and you, where you are willing to go. Like a hemifacial spasm, it is always difficult because those patients say, “Isn't there a medicine?” I'd say, no. They'd say, “Well, what about Botox?” I'd say, bad idea, because ultimately, Botox sets you up for weakness even after a successful MVD. And then now there's data to prove that.

The FPA is technically celebrating the 35th year in existence this year. What would you like to see for the future of the FPA?

I think social media is very useful. But we need to control the educational world, we need to reel in the craziness that occurs. I don't have a good way to do that. I go on the internet two or three times a week on the four sites, FPA France, FPA New Zealand, FPA Australia, all of which I've visited, and I know their readers. I look at their questions and then try to put answers or give references. I try to always avoid actual medical advice but there's a great deal of misinformation out there.

So that, to me, is the goal of the FPA, information. Make sure that more and more patients are informed, I'm sure you know about the Dentist Initiative, but when we started in ‘95, Dr. Jannetta and I saw that patients were losing on average 8.4 teeth before they got a diagnosis. And then around that time, if you look, that's when Claire and the others started, we got to talk to dentists, and they pushed the dental campaign, which as you know is still going. Three years ago, in a much smaller survey, we saw it's down to 2.8 teeth.

When you're talking to patients about surgery, how do you approach that? It's such a hard decision. How do you help patients keep their anxiety level down?

Actually, I tell each of my residents the same thing: You start with the patient. “Do you think you're in the right place? And do you think I gave you the right diagnosis?”

If they say yes, you'd say, “Do you think it's the right time for a next step?” Because that's the question I ask them in the operating room in the pre-op. “Are we in the right place with the right people at the right time for you?” If the patients say yes, we're going. Right after that, I'll say to them, “I know it's a big deal, but obviously, we think your pain is so bad that you're willing to even think about having somebody roam around inside your head.”

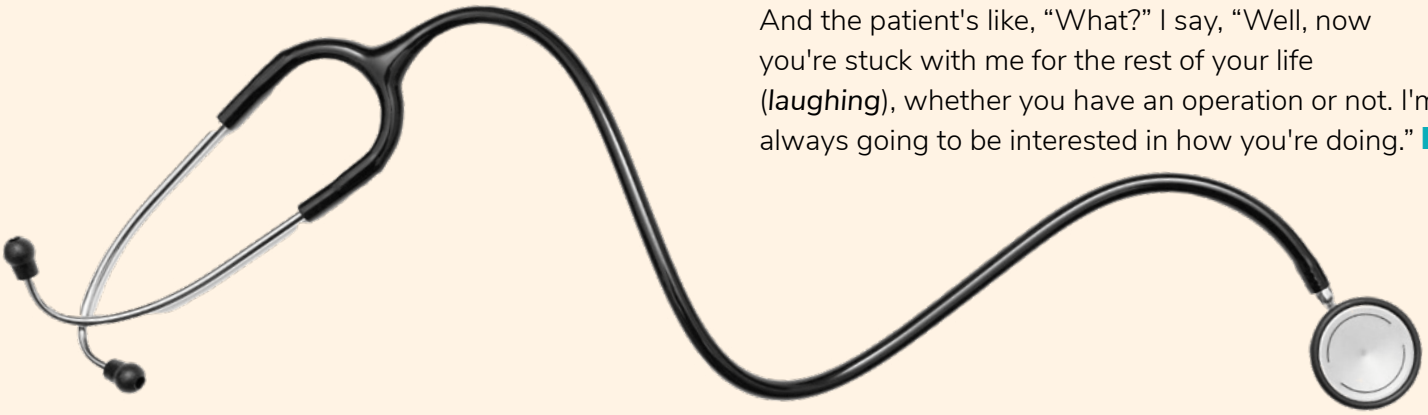
With Dr. Jannetta, we always had this thing. Dr. Jannetta and I, we used to say to the patients, “This is no joke,” and we’d pray every night because to us, we're going to get lucky the next day. We never start with, “We're good.”

We start with, “We're going to get lucky.” So, you pray for us tonight. We're going to pray for you.

And then I tell them to go home and sleep on it, and in the morning, I'm going to ask you the same questions. And I tell them [the patients], it's not a contract. If in the morning, you get cold feet on me one hour pre-op, I'll buy you breakfast, and you'll go home.

We're in this together. It's a deal. And we always tell the patients, “By the way, you just made a fatal mistake.”

And the patient's like, “What?” I say, “Well, now you're stuck with me for the rest of your life (*laughing*), whether you have an operation or not. I'm always going to be interested in how you're doing.” ■



The Surgical Management of Glossopharyngeal Neuralgia

Mark E. Linskey, MD
Professor of Neurological Surgery, UC Irvine
Medical Advisory Board, Facial Pain Association

Glossopharyngeal neuralgia (GPN) is the least common of the four major cranial nerve (CN) vascular compression syndromes [trigeminal neuralgia (TN), geniculate neuralgia (GN), hemifacial spasm (HFS) and GPN]. In my surgical series over the last 19 years, GN was 10.8 times less common than TN. It is characterized by paroxysmal (sudden and intense, intermittent) attacks of pain on one side, at the back of the throat and tongue (**Figure 1**). Just like TN and GN, GPN pain can be typical neuralgic pain (brief, sharp, stabbing, electric attacks), atypical neuralgic pain (dull, aching, pressure, burning, and occasionally constant, with episodic flares), or hybrid syndromes where both types of neuralgic pain are present but to different degrees. Just like TN and GN, GPN is often associated with tactile triggers such as swallowing, coughing, yawning, talking, or different-temperature liquids touching the back of the throat. The name is to some degree a misnomer, as GPN implies that only CN 9 is involved in the syndrome, which is incorrect. We learned long ago that the upper fascicles (parallel contributing nerve fibers) of the multi-fascicle Vagal nerve root (CN 10) are also routinely involved. There are other names sometimes used to distinguish variations of the syndrome such as “vasoglossopharyngeal” neuralgia, or “HeLPS” (GPN with concurrent hemi-laryngospasm or spasmodic dysphonia). This varying nomenclature can further confuse both patients and physicians. It is best to realize that despite its name, GPN is a disorder of the 9th AND 10th CNs.

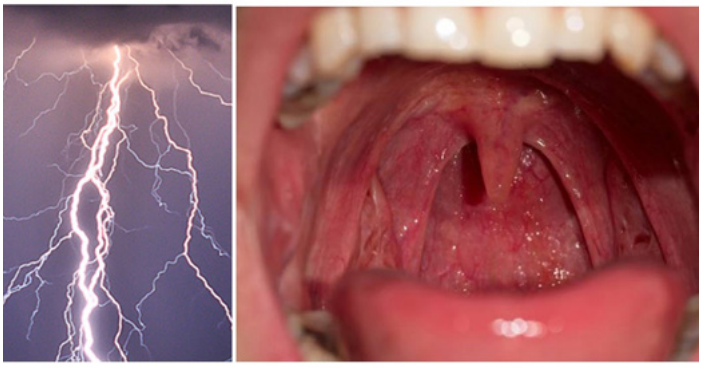


Figure 1: Glossopharyngeal Neuralgia. Paroxysms of pain on one side in the back of the throat. Often triggered by swallowing

Based on empiric results from surgery, GPN is usually the result of vascular compression of CNs 9 and 10, between the nerve root exit from the brainstem and where they exit the skull through the jugular foramen. Nevertheless, a careful search for other possible causes is always warranted. These other potential causes include oropharyngeal cancer, perineural spread of cancer, peri-pharyngeal benign tumors such as nerve sheath tumors,

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TABLE 1				
Demographic Characteristics for 62 Surgical GPN Cases in 55 Patients over 19 Years				
Sex	Female – 47 (85.45%)	Male – 8 (14.54%)	F:M Ratio 5.875 / 1	
Laterality	Left – 32 (58.2%)	Right – 23 (41.8%	Bilateral @ Presentation – 16 (29.1%)	Eventually Bilateral – 18 (32.7%)
Age @ Presentation	Mean – 43.3 y.o.	Median – 43 y.o.	Range: 14 – 71 y.o.	
Age @ Symptom Onset	Mean – 40.7 y.o.	Median – 40 y.o.	Range: 7 – 65 y.o.	
Symptom Duration @ Presentation	Mean – 33 m (2.75 y)	Median – 60.4 m (5y)	Range: 2 m – 20.5 y	
Sudden Pain Onset?	50/62 (80.6%)			
Memorable Onset?	35/62 (56.45%)			
Initially AED Responsive?	50/62 (80.6%)			
Triggers?	50/62 (80.6%)	Swallowing	40/62 (64.5%)	
		Temperature of Liquids	11/62 (17.7%)	Cold Liquid – 8 (72.7%)
				Hot Liquid – 3 (27.3%)
		Talking/Singing	7/62 (11.3%)	

per-tonsillar infection, demyelinating disease, cerebellopontine angle lesions (Cysts, tumors, aneurysms, arteriovenous malformations), brain stem tumors, auto-immune or connective tissue disorders, as well as hereditary neuropathies. The neuro-imaging protocol for workup includes with-and-without contrast magnetic resonance imaging (MRI), including volumetric T2 acquisition with submillimeter secondary slicing, ideally in more than one plane (**Figure 2**). This T2 volume acquisition is often referred to as "CN protocol MR" and, depending on the manufacturer of the MRI machine, is known variously as "Fiesta protocol," "CISS protocol," '3D Fast Spin Echo (FSE)," "SPACE," or "VISTA."

The demographic characteristics of our 62 surgical GPN cases treated in the 19 years leading to 2024 are presented in **Table 1.** The high incidence of bilaterality likely reflects the referral bias in our surgical practice for patients with pediatric onset of CN pain syndromes. All seven GPN patients that experienced syndrome onset younger than age 21 were bilateral, while only 12/48 (25%) that experienced syndrome onset over the age of 21 were bilateral ($p = 0.0207$). It is very important to realize that, as shown in **figure 2**, GPN occurring in isolation is extremely rare (only 7/62 operative cases – 11.3%) (**Figure 3**). In the remaining cases, GPN co-existed with either GN, TN, or both. In fact, GPN was not the major pain syndrome in 69.35% of cases. As a result, it is extremely important to ask about GPN symptoms and triggers when working with TN and/or GN patients. Abnormal findings on neurological examination are rare, with only 4 cases (6.45%) demonstrating uvula deviation, reduced one-sided pharyngeal sensation, or gag reflex.

Like TN, the initial treatment for GPN centers on anticonvulsant medications (AEDs). The most utilized are from either the carbamazepine family (carbamazepine, oxcarbazepine, eslicarbazepine acetate) or the GABA agent family (gabapentin, pregabalin). While an initial positive therapeutic response to one of these agents is very gratifying for confirming a correct diagnosis, not all patients with GPN will respond. In our series, 80.6% of cases

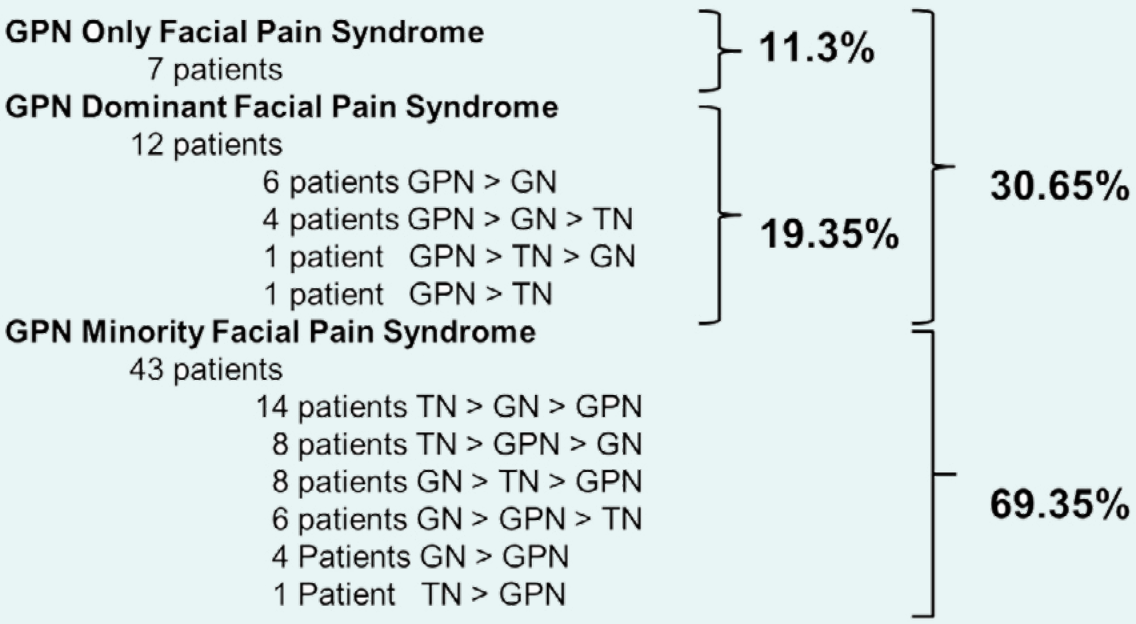

Figure 3: Diagrammatic breakdown of 62 cases of GPN demonstrating how often the GPN was present in isolation and how often it was present as the dominant syndrome associated with other CN pain syndromes versus present is a minor syndrome associated with other CN pain syndromes. Abbreviations: CN – cranial nerve; GN – geniculate neuralgia; GPN – glossopharyngeal neuralgia; TN – trigeminal neuralgia.

initially responded to AEDs, but 19.4% did not. In our experience, GPN is even more debilitating to patients than TN or GN. This observation is linked to the swallowing triggering mechanism, which is even more likely to lead to diet modifications, weight loss, and malnutrition (**Table 2**). Unfortunately, while spontaneous remissions can occur, GPN is generally a progressive syndrome and due to the issues emphasized in Table 2, patients usually come to surgical treatment earlier than TN or GN patients.

The initial surgical treatment for GPN was surgical exploration for a section of CN 9. This procedure was first reported in France in 1920,[1] and in the U.S. by Walter Dandy at Johns Hopkins.[2] However, it was largely championed in the U.S. at the Mayo Clinic in Rochester, MN where they soon learned that their best results also required sectioning of the upper 1/3 – 1/2 of the fascicles of cranial nerve 10.[3] Unfortunately, this led to a 19% permanent dysphagia (trouble swallowing) rate. Hoarseness from vocal cord (VC) weakness was a problem that was less well documented/characterized. Because of the anatomy of the jugular foramen (a natural opening, hole, or passage — usually in bone — through which nerves or blood vessels pass), percutaneous, partial, selective, palliative destructive procedures available for TN [radiofrequency lesion (RFL), glycerol rhizotomy, balloon compression rhizotomy], are not feasible for GPN. The one partial, selective, palliative destructive procedure that is available for GPN is Gamma Knife® stereotactic radiosurgery (GKSR). The experience with GKSR has been relatively small, with the largest reports including 21 and 22 patients, respectively.4,5 The results demonstrated an approximately 65% chance of initial complete pain relief, but this result rapidly falls to 35% at 3 years and 20% at 6 years. However, neither study reported any permanent neurological damage from initial GKSR rhizotomy, and the risks appeared to also be acceptably low for the few patients who went on to have a second procedure.

"Glossopharyngeal Neuralgia" continued on page 10

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TABLE 2

Severity of Debility for 62 Surgical GPN Cases in 55 Patients Over 19 Years

- **Median Karnofsky Performance Score (KPS) - 80 (Range: 60-90) versus Median KPS 90 for isolated TN or GN**
- **5/55 (9.1%) - Significant weight loss**
    - Liquid diet only
    - 2 – required a gastrostomy tube (PEG) for nutritional supplementation prior to surgery
- **Significant Incapacity**
    - 3 patients ≤ age 21 homebound/bed-couch-bound, unable to participate in school
    - 2 patients > age 21 homebound/bed-couch bound
    - A significant number of patients > 21 age unable to maintain employment
- **1 patient had to be admitted as an inpatient in clinical extremis**
    - Acute dehydration requiring IV hydration
    - Uncontrolled pain despite narcotic Patient -Controlled Anesthesia (PCA) pump IV
    - Pain eventually broken with IV Dilantin load associated with transient arrhythmia
    - Eventually required urgent MVD
- **1 Suicide**
    - 40F, with constant ipsilateral throat pain characterized as constant (atypical), but sharp & stabbing. S/P both unsuccessful CN IX/X MVD @ another academic medical center & unsuccessful styloidectomy at another institution. Living on her sister's couch unable to go outside or work. Treated by us with re-exploration MVD & section CN IX & upper fascicles CN X which unfortunately was also unsuccessful. She committed suicide 5 months after her UC Irvine surgery

The major breakthrough in effective nerve-sparing surgery for patients with GPN came in 1977 when Peter Jannetta reported on the use of microvascular decompression (MVD) for GPN in six patients.[6] Our series of 62 cases in 55 patients is the second largest in the U.S. Of these, 19 (30.6%) had already had prior surgical procedures for CN 5 only (TN), and 9 (14.5%) had already had prior surgical procedures for CN 9 and 10. We performed MVD of CNs 9 and 10 in all but two patients, where sectioning of CN 9 and upper fascicles of CN 10 was performed. The most common etiologic blood vessel was the posterior inferior cerebellar artery (PICA) in 48 cases (77.4%), but multiple vessels were identified and dealt with in 49 (79%). While veins contributed to the CN compression in 21 cases (33.9%), veins were never the sole compressing vessel(s). All cases were performed with intra-operative auditory brainstem evoked response (ABR), facial nerve electromyography (EMG), as

well as CN 9 and 10 EMG monitoring. Stimulation thresholds of CN 9, as well as upper and lower fascicles of CN 10, were recorded at the brainstem both before and after CN decompression.

With a mean follow-up of 2.6 years ranging up to 11 years, we were able to achieve complete pain relief for pre-operative typical neuralgic pain in 82.25% of cases. We were able to achieve 50% improvement in frequency and severity of pre-operative atypical neuralgic pain in 70.8% of cases, and complete relief of pre-operative atypical neuralgic pain in 50% of cases. CNs 9 and 10 are very sensitive nerves, as demonstrated by our 14.5% risk of temporary dysphagia and 22.5% risk of temporary hoarseness in the first weeks to months after surgery. However, the rate of permanent dysphagia was 0%, and the rate of permanent hoarseness was only 6.5%, demonstrating the CN function-sparing advantage of MVD over cranial nerve sectioning. There was only one case of hearing loss, and none of facial weakness. There were no cases of stroke, intracranial or intracerebral hemorrhage, or mortality.

While the rarest of all CN pain syndromes, GPN is arguably the most debilitating of them all. It is overwhelmingly more common in woman than men and most commonly effects the left side. It is bilateral in up to 29.1% of patients, particularly in patients that develop their symptoms before age 21. It is rarely encountered in isolation, most often existing in association with other CN pain syndromes. It can be associated with other non-pain CN compression syndromes as well. While venous compression may contribute to the pathology, venous compression is rarely, if ever, encountered in isolation. We do not currently have very successful or durable selective, partial, palliative destructive procedures as an option to open cranial microsurgery under general anesthesia, but GKSR does appear to be safe, and may be able to be safely repeated. The current "gold standard" for surgical treatment of patients with GPN is CN-sparing MVD of CNs 9 and 10. In properly trained and experienced hands, MVD of CNs 9 & 10 is very effective and has a much lower risk of permanent neurological dysfunction than CN sectioning. ■

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Learn more about glossopharyngeal neuralgia

Read Jeffrey Brown, MD's article about glosspharyngeal neuralgia from the Spring 2023 Quarterly

The Facial Pain Association

Formerly known as the Trigeminal Neuralgia Association (TNA)

2010-2019

2010:

The Facial Pain Association celebrates its 20th anniversary.

Our 8th National Conference is held in Rochester, MI, sponsored by the Mayo Clinic, and hosted by Dr. Bruce Pollock.

2011:

The inaugural issue of the TNA Quarterly (known today as the Quarterly journal) is published in March.

The Young Patient's Committee (YPC) is formed to represent and serve patients under 40 years old.

The Facial Pain Network, an interactive patient social media site, debuts.

More than 200 people attend an FPA conference in September held hosted by Dr. Mark Linskey at the UCI School of Medicine.

2012:

Art McHaffie joins the Board of Directors.

Celebrity Dr. Mehmet Oz publishes book to manage facial pain through healthy eating. He is motivated by the pain his mother-in-law, Gwen Asplundh, experiences.

The inaugural Annual Matt Redwine Charitable Gold Tournament raises money for the FPA. Director Gary Redwine produces the tournaments in honor of his son, Matt, a person with facial pain. The Redwine family held five tournaments from 2012 to 2016 and altogether, the tournaments raised ¼ million dollars for the FPA.

An FPA regional conference is held in May in New York, NY, sponsored by Winthrop University Hospital, and hosted by Dr. Jeffrey Brown.

2013:

Mike Bukaty, Anne Ciemnecki, and Gary Redwine join the FPA Board of Directors.

A Regional Conference in held in Richmond, VA in May.

Our 9th National Conference is held in San Diego, sponsored by the University of California San Diego Division of Neurosurgery, and hosted by Dr. John Alksne.

Devor, Selzer, and Burchiel hypothesize that a genetic co-factor is the most likely explanation of why only one in every 2,000 people with a nerve compression also has classic TN.

October 7th is the first Official International Trigeminal Neuralgia Awareness Day.

Click to view the FPA's 35th Anniversary timeline in its entirety

Meet Rose and Susan!

We are delighted to announce that two new staff members are joining the Facial Pain Association team. Rose Gaffney is the new Social Media Coordinator and Susan Mills is the new Data Entry/Database Coordinator. Melissa Baumbick, CEO, with guidance from the Board of Directors, created both part-time roles to support current staff and enhance the resources we provide to the facial pain community.

Rose Gaffney is an award-winning freelance filmmaker and screenwriter based in New York, New York with over ten years of experience. Her work includes filming for national nonprofits, local businesses and network shows. She also consults on media strategy and specializes in the production of social media video content. She will work closely with Natalie Merrithew, Marketing, Communications & Events Manager, to promote events and highlight personal stories.

Rose is already an enthusiastic supporter of the FPA having served as a volunteer since 2023. Her volunteer efforts included producing videos to promote Facial Pain Awareness month and Holiday Help Line. Rose is a member of the facial pain community who lives with atypical neuropathic facial pain. ■

Susan Mills, based in Sonoma, California has an extensive professional background as a paralegal, insurance loss consultant, real estate advisor, and office administrator where she specialized in document control, case tracking, and database accuracy. She will be working with Regina Gore, Manager of Community Volunteer Programs, to ensure accurate record keeping, track donor recognition, and provide administrative support for a variety of initiatives.

Susan lives with facial neuropathy due to dental injury. She has been involved with the FPA for over 10 years and started by attending conferences and joining the Northern California Support Group. She then became a volunteer taking on several roles including Peer Mentor, Support Group Leader, Conference Support, Holiday Help Line, and Special Project Volunteer, as well as being featured in the Spring 2021 FPA Quarterly journal. ■

OCTOBER IS

FACIAL PAIN AWARENESS MONTH

Let's Face Today Together

October is Facial Pain Awareness Month, an annual grassroots campaign to raise awareness about neuropathic facial pain. Throughout October, the FPA will share facts about facial pain and lift the voices of our community by sharing stories and promoting grassroots awareness events.

- Oct. 7: Trigeminal Neuralgia Awareness Day
- Oct. 10: Geniculate Neuralgia Awareness Day
- Oct. 14: Glossopharyngeal Neuralgia Awareness Day
- Oct. 25: Occipital Neuralgia Awareness Day

Share Your Story

If you are ready, we encourage you to share your story to help others on their journey with facial pain. When you share your story on social media, please tag the Facial Pain Association, and use the following hashtags:

#FaceTodayTogether

#MyTNStory

#MyGNStory

#MyGPNStory

#MyONStory

Sharing your story not only empowers you — it also empowers others. You can also wear your teal ribbon and facial pain apparel. Take a photo and share on social media with the hashtags above. Don't have a shirt? Visit the FPA online shop to purchase one. Every purchase helps to support our mission to serve all people living with neuropathic facial pain.

"Awareness Month" continued on page 16

Raise Funds and Awareness

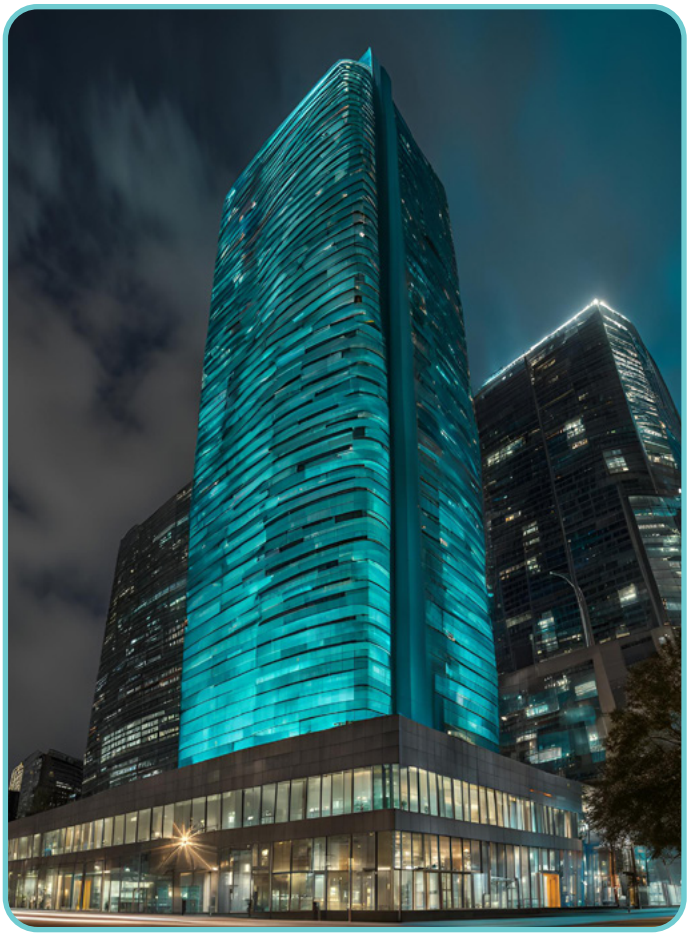
Stream for Charity You can raise funds and awareness while live streaming your favorite activity! Select the Facial Pain Association as your intended charity on Tiltify.

Fundraise Your Way

Facebook and Instagram Fundraisers Share your story and raise awareness and funds to support the facial pain community.

Purchase Facial Pain Awareness Merchandise

"Awareness Month" continued from page 16



Light It Up Teal

FPA Awareness Ambassadors have been leading the effort to light it up teal! At the time of this publication, over 50 buildings, public works, and monuments all over the world will be lit up teal on either October 7 for Trigeminal Awareness Day or in October for Facial Pain Awareness Month.

Leading the Light It Up Teal Team is Jessica Mortensen, an FPA Peer Mentor & Awareness Ambassador volunteer. Jessica says of the effort: "The goal is for awareness to spread and for those living with facial pain to feel supported... Light It Up Teal is a project aiming for international and national landmarks to bring forward facial pain awareness by shining teal throughout October."

Be on the lookout on social media for these teal-lit buildings!
Scan the QR code below for the full list.

Please share or repost any photos you see, tag the Facial Pain Association, and use the hashtag **#FaceTodayTogether!**

SPONSOR SPOTLIGHT

Developments in the Management of Trigeminal Neuralgia

Michael H. Brisman MD, FACS
Attending Neurosurgeon, NSPC Brain & Spine Surgery

Trigeminal neuralgia (TN) is a very specific type of facial pain condition. TN causes patients to suffer from recurring episodes of sudden, brief, severe, sharp pains on one side of the face. The pain is described as electric shock or stabbing in nature, and patients will experience spontaneous remissions over time. Rarely, patients will experience pain on both sides of the face, but not at the same time. The pain is usually triggered by light touch to the face, and usually responds to anti-seizure medicines, in particular, carbamazepine (Tegretol). Sometimes there can be some "atypical" features such as a dull or constant pain as well. Trigeminal neuralgia can be caused by multiple sclerosis (MS), or compression on the trigeminal nerve root by a blood vessel or other mass. But often the cause is not known. Treatments include medicines (primarily anti-seizure medicines), nerve injuring procedures (such as percutaneous trigeminal rhizotomy/PTR and stereotactic radiosurgery/SRS) and nerve decompression (such as microvascular decompression/MVD). There are many other chronic craniofacial pain syndromes besides TN, and these are generally not treated with surgical procedures.

There are several current areas of investigation underway to try to offer better treatments for people with trigeminal neuralgia. For one, there are increased efforts being made to correctly diagnose TN as quickly as possible. Part of this involves educating doctors, dentists, and the public. But there are frequently instances in which a diagnosis is uncertain even for the experienced professional. To address this, better efforts are underway to determine exactly which constellation of symptoms can most definitively establish the diagnosis of TN.

Efforts are also ongoing to determine the optimal medical regimens for patients. Furthermore, different types of patients may do best with different medical routines. For example, older patients generally require lower doses of medicines than younger patients. Investigations are also underway to better establish which patients will do best with which surgical procedures.

Current thinking is that vascular causes of TN are usually arterial (such as the superior cerebellar artery/SCA, the anterior inferior cerebellar artery/AICA, or the basilar artery) and that a vascular compression is more likely to be causative than a mere vascular contact. As such, it seems that the best candidates for MVD will be healthy patients with trigeminal nerve compression from smaller vessels such as the SCA or AICA vessels — the basilar

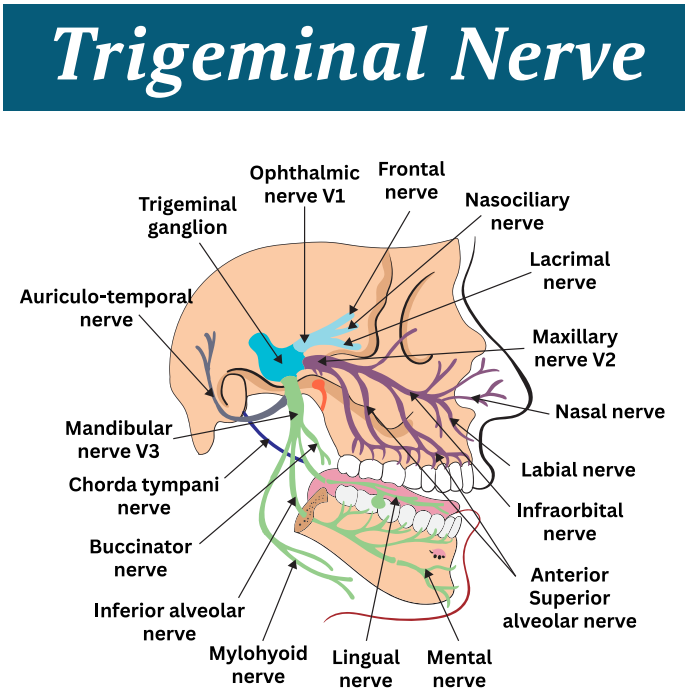
artery is larger and much more difficult to mobilize from the nerve at surgery. Many surgeons are now considering using materials besides the traditional Teflon felt for the actual decompression, including muscle and fibrin glue. The Teflon felt can cause a chemical meningitis as well as delayed granuloma formation, that may itself contribute to recurrences. There is also a much stronger preference being expressed for “transpositional” MVD procedures over “interpositional” procedures, that is, procedures that move the blood vessel away without leaving the foreign body contacting the nerve itself. For MVDs there is also a trend towards using smaller incisions, smaller bone openings, and incorporation of the surgical endoscope into the procedure for better viewing of distal nerve segments that might be hard to see with the microscope alone. There is also a trend towards sending patients home the day after surgery.

The percutaneous trigeminal rhizotomy (PTR) remains an excellent procedure for trigeminal neuralgia as well. This procedure involves placing a needle in the cheek, under sedation, into the trigeminal nerve close to where it exits the brain and producing a small injury in the nerve. It is outpatient, low risk, provides quick pain relief, and usually allows for a quick tapering off of anti-seizure medicines. It can also be repeated an unlimited number of times. There are three methods for this procedure—a radiofrequency, glycerol, and a balloon technique. Each variation has its advantages and disadvantages. Surgeons are looking at ways to optimize the results of these techniques. Considerations include set ups to perform any of the three variations at the same sitting, using different times and temperatures for the radiofrequency procedure (which may vary by the type of needle and machine used), using different volume glycerol injections and different times seated upright for the glycerol procedure, using different balloon inflation times and pressures for the balloon procedure, and using combinations of two variations at the same sitting. Ongoing assessments are also continuing as to which patients might be best for which rhizotomy procedure, or another procedure entirely.

Stereotactic radiosurgery/SRS (such as Gamma Knife), a one day, outpatient, super-focused radiation procedure, is the least invasive of the procedures to treat TN. This technique can also be very effective at controlling TN pain. It is the preferred procedure for patients who cannot come off blood thinners. Repeat procedures can be performed, but only after

"Management of TN" continued on page 20

"Management of TN" continued from page 19



long waiting periods, and ideally at least 2 years from the first procedure. Radiosurgery is also usually the preferred method for treating masses that may be causing TN, such as acoustic neuromas and meningiomas. Considerations for optimizing these treatments include consideration of the dose given, the time for the dose (which may be related to the age of the radiation sources), the proximity of the treatment to the brainstem, the shape/contour of the treatment, and the particulars of the patient's nerve anatomy. Again, studies continue on which patients will do best with this versus other treatments.

A final topic of study is which treatments (MVD, PTR, SRS) might interact in what ways with other treatments, and how such treatments might be optimized for particular patients. Again, TN patients are quite varied, in age, health, cause of the TN (MS, tumor, large vessel, small vessel, unknown), presence of only typical versus some atypical features, history of prior procedures, presence of facial numbness from prior procedures, tolerance of medicines, etc.

It should also be mentioned that we are constantly learning more about medical treatments for TN and other types of chronic facial pain, so as best to treat our patients. Exciting new developments are rapidly evolving to help patients with cranio-facial pain live more comfortable and better lives. ■

The YPC is Growing!

We have exciting news to share! The Young Patients Committee is expanding and has added two new members to our committee. Help us welcome them by learning more about them below!

"Hello! My name is James, and I am so happy to be joining the YPC as a Committee Member. My facial pain journey began in 2014 as a freshman in high school, where, after an ear infection, I began having shock-like, searing pain from the middle ear. This first episode seemed completely out of nowhere, and I was eventually hospitalized after a week or so of almost continuous pain, which included minute-long "pain attacks". The triggers for this pain, which have been consistent throughout my journey, were swallowing, talking, and sometimes moving my head. I had the same symptoms and timeline in 2018, and was prescribed effective medication. After the pain recurred for the third time in 2020, I was finally diagnosed with geniculate neuralgia, a rare form of facial pain that affects the geniculate ganglion right around the ear. 2020 was the worst pain I experienced, and I was hospitalized again, but luckily, I started a new medication and had the resources I needed to get through that episode.

I have had various bouts of pain come and go, but I am taking my medication and numerous supplements, which have greatly helped me out. In addition, I underwent perineural injection therapy in 2022, which helped to calm the pain.

My Dad found the YPC on Facebook and suggested that I take a look at joining the group. This has ended up being an incredible space for me to share my own insights while empathizing and listening to others with their journey. Pain anxiety is still present in my life, but the YPC has helped me share these feelings and realize I'm not alone.

I love the great outdoors and almost anything therein, especially camping and hiking! I also love gaming, reading, running, and spending time with my family and my girlfriend, Sam. A fun fact about me is that I can name any U.S. state Capital on command!"

"Hi, all, my name is Alessandra! I'm a new Young Patients Committee Member and Peer Mentor with the Facial Pain Association. I was first diagnosed with true bilateral occipital neuralgia in January 2023, after experiencing occipital pain on top of my history of migraines. Since then, I have experienced bouts of trigeminal nerve pain as well, without an official diagnosis.

I graduated with a degree in International Affairs and have lived abroad in two different countries. From a research perspective, I am interested in international healthcare equity and human rights. In my free time, I volunteer with other advocacy organizations, enjoy dancing, travelling, and learning languages!

I hope to be a point of reference in terms of support for those suffering from all forms of neuralgia, due to its intensity and impact on quality of life."

We are incredibly excited to continue to grow our committee. More people on our team means more that we get to do to help our community! We are honored that so many of you want to get involved. We can't wait to see where we go from here!

—The Young Patients Committee
Kenzie (co-chair), Lindsey (co-chair), Laura, Elaina, Rachel & now with James and Alessandra

Patient Perspective: My Experience with Facial Pain

My name is Jennifer Dinet, and I have trigeminal neuralgia. I was first diagnosed when I was 25 years old, and it completely changed my life.

I had to adjust to a new normal while my hopes, dreams, and aspirations felt like they were being stolen from me. At the time of the onset of my pain, I was excited to start my first full-time elementary school teaching position. The month I signed the contract I began having sharp shooting pain from my temple to my jaw. After brushing it aside and thinking it was a crazy migraine symptom or due to stress, my mom finally convinced me to go to the doctor. I was very fortunate because I was correctly diagnosed by my family physician during my first visit regarding the pain. He admitted that he didn't know much about it, and was confident in my diagnosis, but wanted to send me to a neurologist just to make sure. Over the next year I tried different medications, all of which did not help with the pain or gave me debilitating side effects.

The next option he gave me was microvascular decompression surgery (MVD). By this point I was so desperate to have the pain gone, I didn't really care to ask many questions. I woke up with worse pain than I had prior to surgery. During my recovery, the doctor who performed the MVD said that his surgeries 'would not fail' and that the pain must all be in my head.

Confused and frustrated, I knew this was the time that I needed to advocate for myself. I found a support group that was about an hour away and attended some meetings; I also found some people online that were going through similar struggles. Through the meeting, I was introduced to the doctor that performed my second MVD surgery. Although this second surgery was not a success, I finally had a doctor talk to me like I was a human. After the surgery I went to a pain management doctor, where I felt like I was just a number and was not taken seriously. I took action and wrote a letter explaining all the reasons I would not be returning to their office.

By this time, I realized that I could no longer be the teacher that school children needed, so I resigned from my teaching position. I needed to apply for disability benefits since my pain was increasing and unpredictable from hour to hour. I applied and was denied five times — I completed every task and form they asked for and it still wasn't enough. I knew I had to fight for myself to get what I needed. I contacted any doctor I had seen over the years and asked for all of my records and asked my current doctors if they would write letters to help explain my diagnosis. I even asked my colleagues, training coach, and boss to write letters explaining how my pain affected my work performance.

I did everything I could think of to make them understand my situation; they did not.

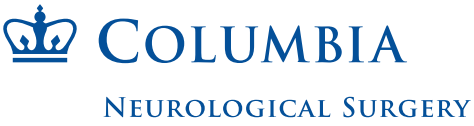
I finally called a disability lawyer and was granted full Social Security Disability Insurance (SSDI) the following year. I am still searching for different doctors and resources that can aid in my search for less pain. I have consulted different doctors from across the country to inquire about new techniques or treatments that could benefit my personal needs.

By advocating for my own health, I have been able to keep the pain somewhat manageable with medication and different therapies.

After 14 years of searching for answers, I am eager to help others struggling through their facial pain journey and help them advocate for what they really need. ■

The Facial Pain Association is hard at work curating resources for members of the facial pain community who need to receive Social Security Disability Insurance. Keep an eye on our website, www.FacePain.org, and sign up for our biweekly newsletter to receive the latest updates on our efforts.

Sponsors



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If you care for patients with neuropathic facial pain, we want to partner with you. The FPA's new sponsorship program is designed to meet you where you are as you build a robust facial pain program at your center.

Email development@facepain.org or call 800-923-3608 to join the FPA annual sponsorship program and add your center as a valued resource for those living with facial pain.

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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.

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Ann & Arthur Schwartz

If you would like more information on joining the FPA Legacy Society, please call 800-923-3608 or email development@facepain.org.

FacialPain 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.

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Nicole Aiken
Melissa Baumbick
Joan Beelen
Carol Bender
Carol Berardi
Erika Blumberg
Joe & Tatiana Christian
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If you would like more information on joining the FPA Sustainer Circle, please call 800-923-3608 or email development@facepain.org.


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Behind every patient is a story. Get back to telling yours.
Patient-centered trigeminal neuralgia care at Mayo Clinic helps you live life to the fullest.
At Mayo Clinic, we understand chronic facial pain can make it difficult to enjoy life in the ways you love. That's why we've spent so much time developing a variety of treatment options to help reduce or eliminate your symptoms. Our experts will work with you to effectively manage trigeminal neuralgia with medications, injections, or surgery, tailoring a treatment plan individualized to you. Here, we have the research, tools and expertise to help you live life to the fullest.
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Low Dose Naltrexone (LDN) for Facial Pain

Dear Doctor,

Your patient, who suffers from a facial pain disorder such as Trigeminal Neuralgia (TN)-either typical or atypical, Geniculate Neuralgia (GN), Glossopharyngeal Neuralgia (GPN), or Occipital Neuralgia (ON), may derive benefit in their pain management therapy with Low Dose Naltrexone (LDN) treatment. Although this drug has been found to be safe and effective in thousands of real world cases, and successfully used for over 15 years for treating these conditions, most physicians are unaware of its applicability.

By way of background, regular strength naltrexone is used to treat alcohol and drug addiction. It is not a narcotic and is not habit-forming. It is an opiate antagonist that works by blocking opioid receptors. Low Dose Naltrexone works by an as yet unknown mechanism of action.

LDN is to be used as a chronic therapy, it is not effective for acute pain attacks. Further, it has been shown to be effective only in those patients who are on concomitant treatment with other medications for facial pain. In fact, for those patients on either sodium channel blockers such as carbamazepine or Lacosamide, Gabapentin, or SNRIs (e.g. Cymbalta), who have achieved only partial relief of their pain, the addition of LDN has been shown to make those medications resoundingly more effective. The following information will hopefully allow you to feel more comfortable in prescribing LDN for your patients.

- LDN is not a controlled substance.
- Although regular strength naltrexone is commercially manufactured, LDN must be made by a compounding pharmacy, either locally or online. It can be formulated as a 1-6 mg single dose. Dosage forms are either capsules, tablets, or liquid.
- The regular dose of naltrexone is 50 mg/day. In contrast, LDN dosage is only 2-4.5mg/day.
- The usual starting titration is 1mg/day for 2 weeks, then 2 mg/day for 2 weeks, then 4.5 mg/day ongoing.
- LDN therapy cannot be considered to have failed before 2 months of use at full dose. The success rate can be significant, with greater than 2/3rds of patients remaining on the medication.
- Side effects are few and do not differ much from placebo in clinical trials. They include stomach upset, diarrhea, sleep disturbance, and infrequently, constipation. These side effects are rarely significant enough for patients to discontinue therapy.
- LDN is best taken in the evening, shortly before bed, however morning dosing can be a suitable alternative.
- Since LDN is a maintenance therapy, if effective, it should not be stopped. No drug tolerance requiring increased dosage has been seen.
- LDN can NOT be used in patients on chronic opioid therapy.
- If medically indicated short-term opioid use should become necessary (e.g. post surgery), LDN must be temporarily interrupted, then may be resumed after discontinuation of the opioids. When LDN is re-started after discontinuing opioid therapy, it should begin again with the above tapering schedule.
- LDN may be covered by commercial insurance drug plans. If not, the typical cost is $0.50 to $1.50/day.

.Jeffrey Fogel, MD

Wolfgang Liedtke, MD, PhD

$70

Facial Pain Book Bundle

Our newest book, ***Living Well with Neuropathic Facial Pain*** takes a comprehensive, "whole-person pain relief" approach, focusing on proven medical treatments, the psychology of pain, and accessible solutions to eliminate or mitigate the pain. The book aims to empower individuals to live their best lives by providing insights into various types of neuropathic facial pain, finding the right medications and surgical solutions, and navigating the challenges of affording medication and disability. It also dives into the more personal aspects of pain that can impact daily life. It provides coping strategies, including important and less frequently discussed areas such as mental health, support groups, sleep, relationships, and more.

This book is a companion to the FPA's first book, ***Facial Pain, A 21st Century Guide: For People with Trigeminal Neuropathic Pain***, which provides essential information across a broad set of subjects to serve as an introduction to this condition. Both books are valuable resources for individuals living with neuropathic facial pain, as well as caretakers and loved ones.

Purchase your copies today!

YOUR VOICE MATTERS

Let Data Tell Your Story

THE FacialPain REGISTRY

Join the Facial Pain Registry Today!