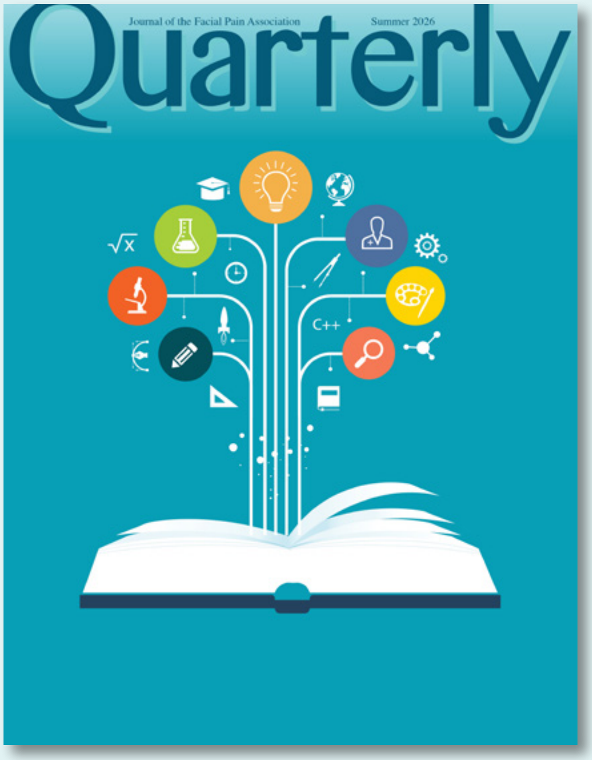
Journal of the Facial Pain Association

Summer 2026

Quarterly

THE FACIAL PAIN ASSOCIATION
7778 MCGINNIS FERRY ROAD,
#256
SUWANEE, GEORGIA 30024

ON THE COVER



At the Facial Pain Association, we believe that knowledge is one of the most powerful tools available to people living with trigeminal neuralgia (TN) and other neuropathic facial pain conditions. Education is a core part of our mission because access to accurate information can help patients move from uncertainty and fear toward understanding, effective treatment, and hope.

Through our website, patient guides, books, webinars, Quarterly journal, and bi-weekly bulletins, we provide trusted resources that help patients, caregivers, and healthcare professionals better understand facial pain conditions and treatment options. We also offer continuing education programs for dental professionals, helping improve recognition of neuropathic facial pain and supporting earlier referrals to specialists.

As technology evolves, tools such as artificial intelligence may offer additional support by helping patients organize symptoms, prepare questions for appointments, and identify experienced providers. While AI is not a substitute for medical advice, it can be a useful resource when used responsibly. Our goal is to empower every person affected by facial pain with the knowledge and support they need to advocate for their care.

Listen to our podcast, **The Nerve**, on Spotify, Apple Podcasts, Amazon Music, and Podbean!

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From the Board Chair

The mission of the FPA is Support, Education and Advocacy. In this letter, I'm going provide some real-time education about how Artificial Intelligence (AI) can help with your medical challenges.

Note: I'm not a doctor. However, this letter has been reviewed and approved by the FPA's Medical Advisory Board.

Recently I took an online course about AI & Medicine taught by three Harvard and Johns Hopkins Medical School professors. It further opened my eyes about how AI can be immensely helpful to patients. Although the AI tool can be used in many ways to be helpful in a medical situation, I'd like to focus on three elements.

Diagnosis

Getting a proper diagnosis for a rare condition like trigeminal neuralgia (TN) and similar conditions is very difficult. A common characteristic of physicians who are excellent at diagnosis is their pattern-matching skills. They recognize a pattern from their experience to help form a diagnosis. It turns out that AI is superb at pattern-matching and consequently is excellent at providing a diagnosis. Although physicians often follow different questioning patterns to get the information they need for a diagnosis, a recommended approach for providing information into an AI tool like ChatGPT is T-LICC.

Time: When did the symptoms start?
Location: Where is the pain located in the body?
Intensity: What type of pain, how long does it last, how frequent?
Change: How have the symptoms changed over time?
Context: Who are you: age, gender, other conditions, current medications?

Putting this information into AI, asking for possible diagnoses, and then asking your doctor if any of the diagnoses might be correct could be immensely helpful, especially for a rare, hard-to-diagnose condition. Don't take an AI diagnosis as a final answer and don't submit any personally identifiable information (e.g., name, address)! The warning with AI is to "trust but verify."

Doctor Appointment Preparation

AI can help make your doctor's appointments more valuable. By asking AI something like: "I'm a 55-year-old woman who was diagnosed with trigeminal neuralgia three years ago and have been on carbamazepine for the symptoms. What questions should I ask my neurologist at an upcoming appointment?" You'll have many excellent questions to choose from.

Find A Doctor

Finding a doctor experienced in treating TN and similar conditions can be very hard. Now it's easier. By asking AI something like: "I'm a 55-year-old woman, living in Asheville, NC, who was diagnosed with trigeminal neuralgia five years ago and now want to explore surgical treatments for my condition. Which neurosurgeons should I consider who are highly rated in treating trigeminal neuralgia in the Southeastern U.S.?" I tested this in a familiar metro area, and the results were very good. Of course, you will still need to vet the physician. The FPA has a tool to help you do that. Visit www.facepain.org/find-support/find-a-doctor.

We are all familiar with stories of patients barging into a doctor's appointment, armed with information from "Dr. Google," and believing they know the answer. Understandably, the doctor often doesn't respond well. I suggest you take your AI-generated information and questions into your doctor's appointment with respect and an inquisitive mind. The goal is to help the expert – your doctor – help you.

David J Meyers

David Meyers
Board Chair, The Facial Pain Association

A Message From the CEO

Knowledge Is Power: The FPA's Commitment to Education

One of the most difficult aspects of a facial pain diagnosis can be the journey to an effective diagnosis. Feeling the lightning strikes that are common with trigeminal neuralgia and not knowing what is happening to your body, not knowing what to call it, not knowing whether anyone else has felt what you are feeling, or if relief is possible, is incredibly scary.

I hear about that experience often. It is the reason education and awareness are at the heart of everything the Facial Pain Association does. It's why education is one of the three pillars of our mission. Information changes things and when a person in pain finally has words for what they are experiencing, something shifts. When a physician, dentist, or other health care professional recognizes the signs of neuropathic facial pain, a person's entire trajectory can change. When friends and family understand what their loved one is going through, they can engage more fully. That is the power we are trying to put into people's hands.

Over the years, the FPA has built a collection of one-of-a-kind educational resources. Our website offers clear, thorough information on many facial pain conditions, and includes symptoms, diagnoses, and treatment options. A downloadable patient guide gives patients something tangible to bring to appointments or share with the people in their lives. Our webinar library and collection of past Quarterly journal articles offer deeper exploration of topics that matter most to this community, from treatment decisions to the emotional weight of chronic pain.

We have also published two books. *Facial Pain: A 21st Century Guide* was published in 2020 and *Living Well with Neuropathic Facial Pain, Including Trigeminal Neuralgia*, was published in 2024. I consider these among our most important contributions to the field. They bring together the best available clinical knowledge in a form that is useful to both patients seeking to understand their condition and practitioners who want to deepen their expertise.

Our *Quarterly* journal offers new and updated information four times each year. The News You Can Use pullout in each issue is designed to deliver something practical and immediate. It is designed to be something you can use right now or keep it and reference it when you need it. Between issues, our bi-weekly bulletins keep our community connected and informed.

Three to four times each year, we host accredited webinars offering continuing education (CE) credits for dental professionals. Dentists are very often the first specialist someone visits when they experience TN pain. Giving their teams the tools they need to recognize neuropathic pain and to make the right referral is one of the most direct ways we can shorten the road to a correct diagnosis.

We have more to do. More people to reach. More practitioners to educate. But when I look at what this organization has built for the facial pain community, I feel hopeful - hopeful that the right information, in the right hands, at the right moment, can change someone's life.

That is what we are here for.

Melissa Baumbick

Melissa Baumbick
Chief Executive Officer, The Facial Pain Association

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MAB Corner

Orofacial Pain and Dentistry

Donald Nixdorf, DDS, MS
Director of the Division of TMD and
Orofacial Pain at the University of Minnesota

Orofacial pain is a specialty of dentistry that encompasses the diagnosis, management, and treatment of pain disorders of the jaw, mouth, face, head, and neck.

Despite its recognition as the 12th dental specialty in 2020, the number of board-certified specialists remains limited, with fewer than 287 diplomates of the American Board of Orofacial Pain serving a US population exceeding 333 million. This deficiency is due to the shortage of training programs as only 14 orofacial pain residency programs are currently available in the US, graduating around 30 new specialists annually. Compared to similar disciplines such as headache medicine with 50 fellowship programs, the sheer gap in specialty training becomes obvious.

Patients with facial pain usually see their primary dentist first. For instance, more than 50% of patients with trigeminal neuralgia present with oral or dental pain and the majority of these patients visit their dentist for consultation. Temporomandibular disorders (TMD) are the most common cause for non-dental facial pain and are common reasons for dental visits. Patients experiencing pain or dysfunction in their jaw usually consult with their dentist or primary care provider. However, since TMD can present with ear pain or mimic nerve pain, these patients are sometimes seen first by ear, nose and throat specialists, neurologists or neurosurgeons. Therefore, orofacial pain specialists collaborate with various medical and dental providers in addition to clinical psychologists and physical therapists for the diagnosis and management of oral and facial pain disorders.

Since general dentists are frequently the first point of contact for individuals with facial pain, substantial efforts have been made to integrate orofacial pain into predoctoral dental education over the past two decades. In 2005, instruction was present in only a subset of US dental schools and was largely limited to didactic teaching with minimal clinical integration. Since then, meaningful progress has been achieved. By 2025, dental schools reported inclusion of TMD-related content, with increased average instructional time of about 16 hours and broader coverage extending to neuropathic pain, atypical dental pain, and primary headache disorders. However, variability remains high across dental schools, often more impactful educational offerings depending on the presence of dedicated orofacial pain faculty or an affiliated postgraduate orofacial pain residency program. Despite improvements with didactic education, a persistent gap is the limited clinical orofacial pain exposure dental students have to patients during their predoctoral training. This limitation constrains skill acquisition, including diagnostic confidence and clinical competence. Evidence suggests that students who combine didactic learning with experiential training demonstrate significantly higher scores in knowledge retention and confidence in TMD-related skills.

In summary, while progress has been made in incorporating orofacial pain into dental curricula, significant gaps remain, particularly in providing students with opportunities for standardized clinical training and experiential learning such as structured clinical rotations, peer-to-peer hands-on activities, case-based discussions, and simulation-based approaches. Addressing these deficiencies is essential to ensure that future dental professionals are adequately prepared to screen, diagnose, manage, and refer this underserved patient population. Ultimately, strengthening predoctoral dental education is a critical step towards improving access to high-quality care all patients suffering with chronic pain deserve. ■

Facial Pain Registry

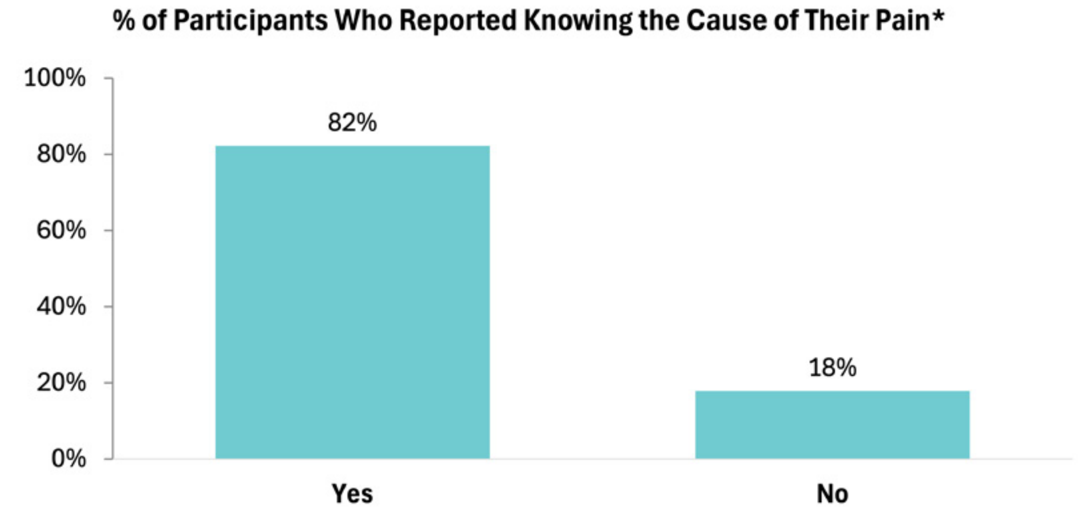
Data Speaks: The Power of Information

By Liam Winters, Tristan Olinger, and David Ciemnecki

In our Spring 2026 Quarterly, we explored how registry participants described their pain, including its severity, location, and whether they experienced a range of neuropathic symptoms. In this issue, we turn to what registry participants told us about the causes of their pain. With more than 700 participants now contributing to the Facial Pain Registry, these responses offer a detailed look at the many paths that lead to facial pain.

Most Participants Identified a Cause of Their Pain, and Many Cited More Than One

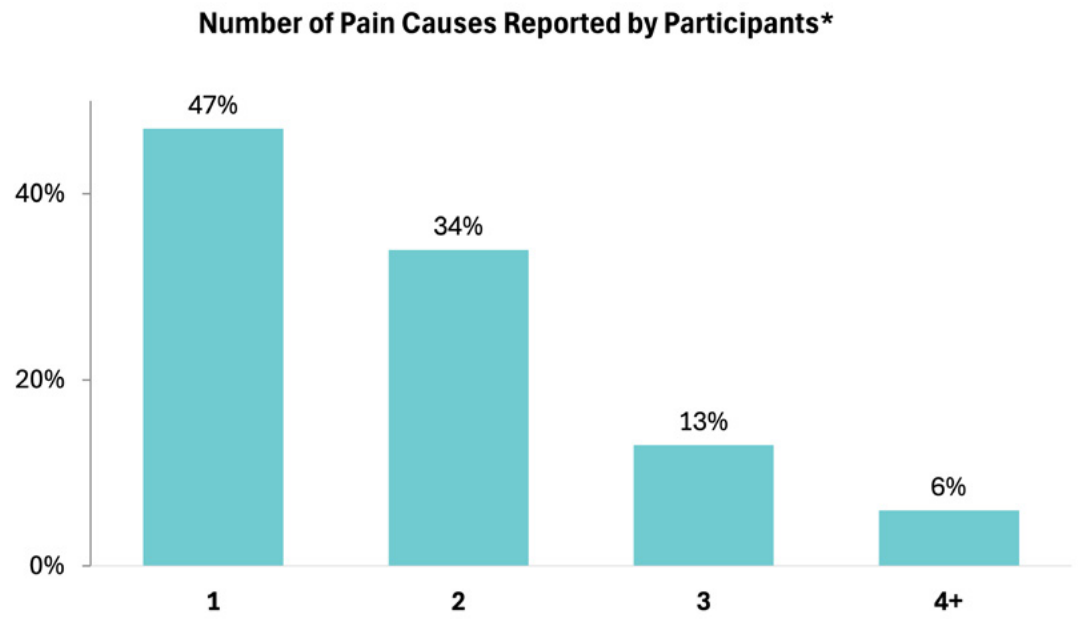
When asked whether they knew the cause of their facial pain, 82% of participants said yes, while 18% said they did not know. The high percentage of people who have identified a cause is encouraging, and it suggests that many people have worked with their healthcare providers to reach at least one explanation. At the same time, nearly one in five participants remain without a known cause, a reminder that diagnosis can be a long and difficult process for people with facial pain conditions.



*706 Participants

Among those who did identify a cause, most pointed to more than one. We found that 47% cited a single cause, 34% cited two, 13% cited three, and 6% reported four or more. This means that more than half of registry participants are dealing with multiple, overlapping contributors to their facial pain.

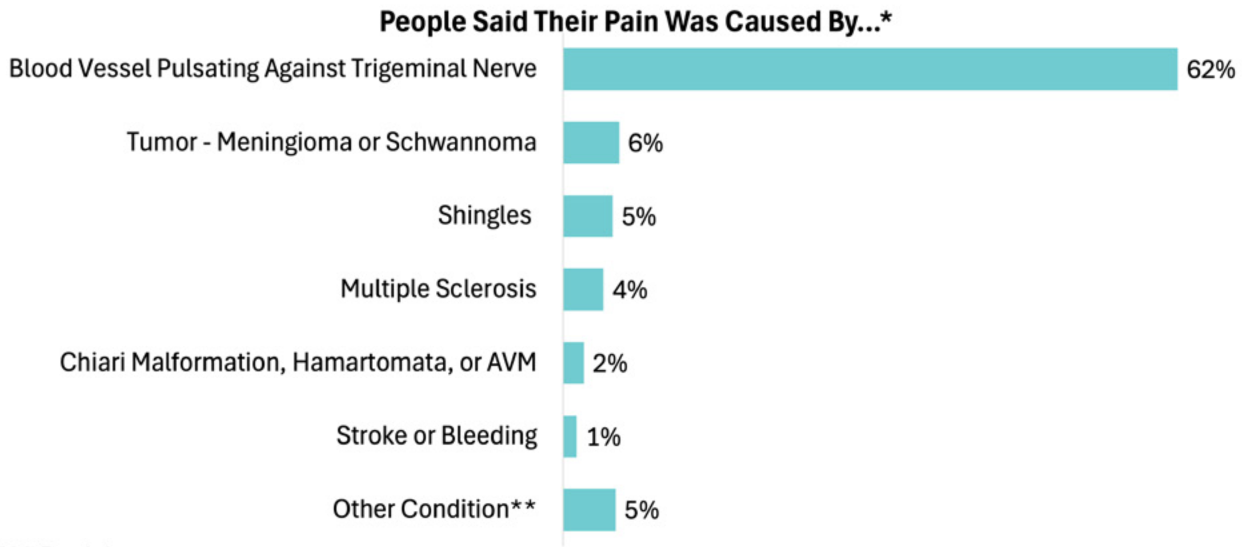
It is also worth noting that not all reported causes were the initial triggers for the pain. Some factors, such as stress, illness, or subsequent medical procedures, may have acted as exacerbating events, reigniting symptoms rather than serving as the original source of pain. This distinction between root causes and contributing triggers is one more reason why a comprehensive evaluation by an experienced healthcare provider is so important.



*580 Participants

Reported Causes of Pain Vary Widely

Among those who identified a cause of their pain, the most commonly reported was a blood vessel compressing or pulsating against the trigeminal nerve. This is consistent with what we know about classical trigeminal neuralgia. That said, survey participants also reported a wide range of other causes, including tumors, shingles, and multiple sclerosis causing pain.



*580 Participants

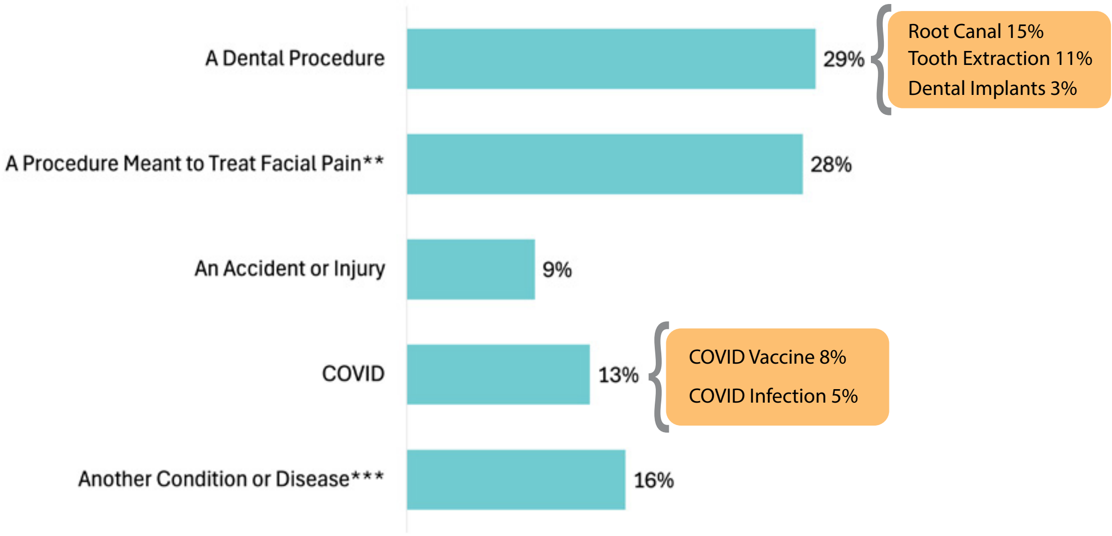
**Other Conditions Include Lupus, Sjögren’s, and Hashimoto disease

Many Participants Report That Their Pain Followed a Specific Event

We also asked participants whether a specific event preceded an episode of facial pain. Dental procedures were the most frequently reported, cited by 29% of respondents. Twenty-eight percent of survey participants reported that a procedure intended to treat their facial pain worsened their symptoms or caused the onset of different facial pain. This is concerning, as no one wants to be in pain following a procedure. People considering a procedure should take special care to find an expert who can prescribe an evidence-based procedure for their specific type of pain and perform it impeccably.

Notably, 13% of respondents reported that their pain began after COVID-19. This is consistent with a growing body of research demonstrating that SARS-CoV-2 can directly affect the trigeminal nerve[1]. Accidents and injuries accounted for 9% of responses, and 16% cited another medical condition. These results confirm that facial pain can emerge from many different starting points, making accurate and thorough evaluation by an experienced provider essential.

Some Reported Their Pain Began Shortly After an Event Such As...*



*580 Participants
**Includes Surgery, Rhizotomy, Balloon Compression, Gamma or Cyber Knife Procedures
***Includes Jaw/SurgeryTMD/TMJ, Bell's Palsy, Encephalitis, Neck Degeneration, Ramsay Hunt, Tightness in Shoulder and Neck, Ehlers-Danlos Syndromes (EDS), and Lyme Disease

Looking Ahead

Every response in the Facial Pain Registry helps build a clearer picture of what our community experiences. The more individuals who participate, the more valuable the data becomes for researchers working to develop better treatments. If you have not yet completed the registry surveys, we encourage you to do so. It takes most people no more than 15 to 20 minutes, and all responses are confidential. ■

Reference: 1. Al Talalwah W, Al Dorazi S. Trigeminal neuralgia in COVID-19: a meta-analysis. Int J Odontostomat. 2023;17(1):70-76.

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Weighing Surgical and Non-Surgical Options for Facial Pain

For people living with chronic facial pain, simple everyday moments like talking, eating, brushing teeth, or even a light breeze across the face can trigger intense discomfort. The pain often comes in sudden, lightning-like shocks. For others, it is a constant, heavy burn that doesn't fully subside. Regardless of how it shows up, its impact extends beyond a medical diagnosis and shapes people's daily lives in profound ways.

As Mayo Clinic neurosurgeon Dr. Rushna Ali puts it, *"Chronic pain is a beast; it takes away the best part of us."*

While medications and other non-surgical treatments help many patients, some continue to experience significant pain despite these approaches. When that happens, surgical options are often considered, but the path is not a simple or immediate one.

According to Dr. Ali, determining whether surgery may help begins with a critical first step: understanding the exact type of facial pain a patient is experiencing. From there, care follows a thoughtful, step-by-step process designed to ensure the right treatment is matched to their condition.

When to consider a surgical consultation

Most patients with facial pain begin treatment with medications or other non-surgical therapies. Surgery is usually considered only after those options haven't proven effective.

"If you're dealing with facial pain, the right time to speak with a surgeon is usually after you have already worked with a neurologist who specializes in facial pain or headache disorders,"
Dr. Ali explained.

Patients may have tried several medications or interventional therapies. If those treatments have not provided meaningful relief and the pain remains moderate to severe, it may be appropriate to seek a surgical opinion.

That evaluation doesn't necessarily mean surgery will be recommended. Instead, it allows specialists to determine whether a surgical approach could help based on the patient's diagnosis and symptoms.

The importance of the right diagnosis

Facial pain is not a single condition. Instead, it is an umbrella term that includes several different disorders, each with its own causes and treatments.

One of the most well-known conditions is trigeminal neuralgia (TN), which typically causes sudden, sharp, electric shock-like pain in the face. Other forms of facial pain may involve nerve injury, chronic neuropathic pain, or pain that develops after infections such as shingles.

Because treatments vary significantly, an accurate diagnosis is essential. Specialists sometimes see patients who have been given one diagnosis elsewhere, only to find that their symptoms actually fit a different category of facial pain. This distinction matters because certain surgeries that help one condition could make another type of pain worse.

That's why evaluation by an experienced team that includes neurologists and neurosurgeons who focus on facial pain is an important step before considering surgery.

Who may be a good candidate for surgery?

Whether surgery may help depends largely on the type of facial pain and how it behaves.

For example, patients with typical trigeminal neuralgia often describe pain that is:

- Sharp, shooting, or electric shock-like
- Brief but intense
- Triggered by everyday activities such as talking or chewing

Patients who have this classic pattern, have responded to medications in the past, and have no facial numbness may be good candidates for certain surgical procedures.

In some cases, imaging may also show a blood vessel pressing on the trigeminal nerve, which can help guide treatment decisions.

However, patients with other forms of facial pain such as trigeminal neuropathic pain or post-herpetic neuralgia may require very different approaches.

Surgical options for facial pain

Several procedures are available today to treat facial pain, but the right option depends on the underlying condition.

For patients with trigeminal neuralgia, one commonly performed procedure is microvascular decompression (MVD). During this surgery, a neurosurgeon carefully separates a blood vessel from the trigeminal nerve to relieve pressure.

Other procedures work by disrupting abnormal nerve signals. These include techniques such as balloon compression, gamma knife or radiofrequency lesioning treatments that intentionally affect the nerve's ability to transmit pain signals.

For patients with chronic neuropathic facial pain, surgeons may take a different approach called neuromodulation. These treatments use implanted devices that deliver small electrical signals to alter pain pathways in the nervous system.

- Examples include:
- Peripheral nerve stimulation
- Spinal cord stimulation
- Deep brain stimulation
- Motor cortex stimulation

Rather than damaging the nerve, these therapies aim to interrupt pain signals as they travel from the face to the brain.

"Surgical and Non-surgical Options" continued on page 10

"Surgical and Non-surgical Options" continued from page 9

Understanding the risk of facial numbness

One topic that often comes up when discussing facial pain surgery is numbness in the face.

In some procedures, especially those designed to treat trigeminal neuralgia, surgeons intentionally injure part of the nerve to stop it from sending abnormal pain signals. Because the same nerve also carries normal sensation, this can result in some degree of numbness.

The amount of numbness varies. It may be mild or more noticeable, temporary or permanent, and it may affect a small portion of the face or a larger area.

Many patients describe the sensation as similar to the lingering numbness after dental anesthesia, when the feeling hasn't fully returned.

Many people with severe facial pain report that they would prefer some numbness over ongoing pain. Still, surgeons carefully consider this trade-off and work to avoid complications such as painful numbness that can occur if a nerve is repeatedly injured.

What recovery typically looks like

Recovery time depends on the type of procedure performed.

Less invasive procedures may involve two to three weeks of recovery, while more complex surgeries, such as microvascular decompression or certain neuromodulation procedures, may require four to six weeks.

Overall, most patients recover within weeks rather than months, although individual experiences can vary.

Looking ahead: new directions in facial pain treatment

Mayo Clinic neurosurgeons and neurologists continue to explore ways to better understand why facial pain develops and how it can be treated more precisely.

"One promising area of study involves identifying biomarkers for chronic pain," Dr. Ali says. "These biological signals could help physicians determine which treatments are most likely to work for a particular patient and enable more personalized surgical approaches."

New advances in neuromodulation technologies are also expanding the possibilities for people whose pain does not respond to traditional treatments.

At Mayo Clinic, a full range of treatment options is available. Dr. Ali explained that each person's situation is carefully evaluated to determine whether surgery is appropriate and, if so, which approach is likely to provide the most benefit with the help of a multidisciplinary team of experts.

Even when standard treatments haven't brought relief, there are still options to explore, and hope for a path forward that addresses the type of pain each person is experiencing. ■

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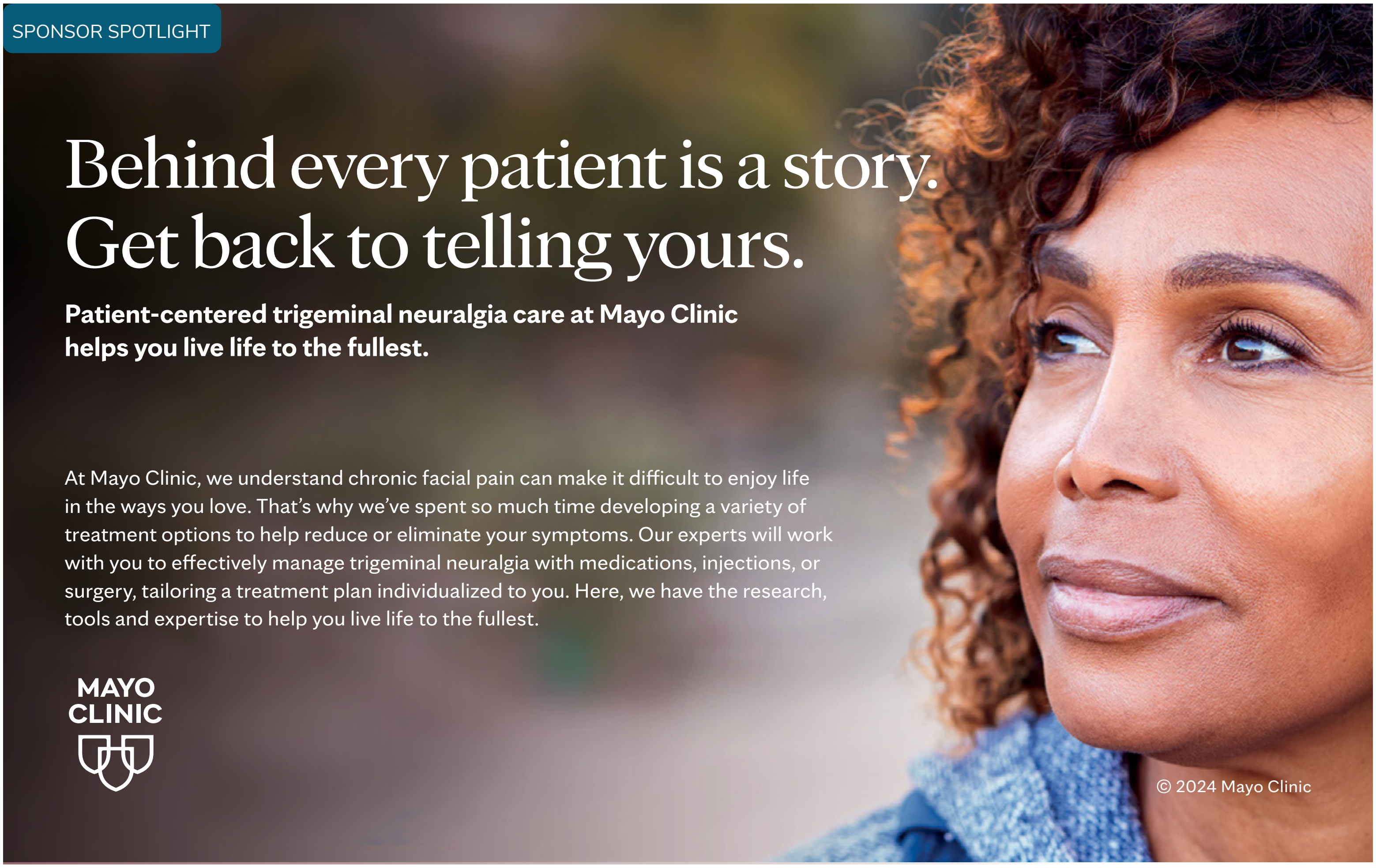

Behind every patient is a story. Get back to telling yours.

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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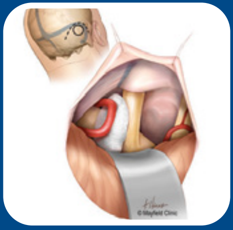
Brain & Spine

Mayfield offers several treatment options for patients with trigeminal neuralgia, glossopharyngeal neuralgia, hemifacial spasm, and other types of facial pain.

Our treatments include:

Gamma Knife radiosurgery

Microvascular decompression surgery (MVD)

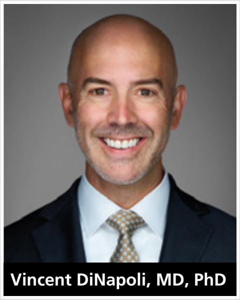


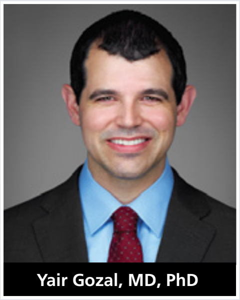
Percutaneous stereotactic rhizotomy (PSR)

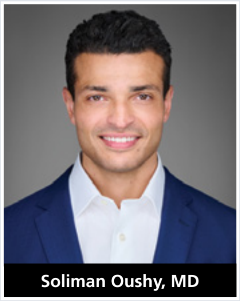
Balloon compression rhizotomy

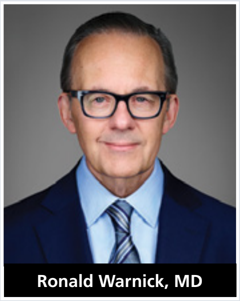
Mayfield's Nationally Recognized Trigeminal Experts


Steven Bailey, MD


Vincent DiNapoli, MD, PhD


Yair Gozal, MD, PhD


Soliman Oushy, MD

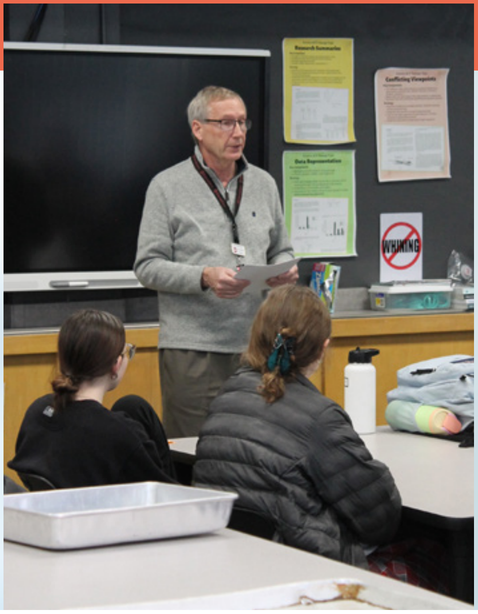

Ronald Warnick, MD

For more information, visit **mayfieldclinic.com/trigeminal** or call **513-221-1100** to make an appointment.

Patient Perspective

SEA of Hope in Education

Vince Holtmann,
FPA Support Group Leader
and Board Member



On June 11th, 2008, I got a do-over in life. I underwent 6 ½ hours of surgery to remove a meningioma that had been pressing on five of my cranial nerves, including the trigeminal nerve. After living with trigeminal neuralgia for just over two years, I woke up from surgery completely pain free and remain pain free to this day. There had been several pitfalls through the course of my treatment. However, once I finally discovered the FPA website (TNA at the time), it put me on a better path and gave me the one thing that no one else had been able to provide – hope!

As you can imagine, I was quite excited about my new pain-free existence in 2008. At the time, I was a full-time math teacher on summer break at a local college. When the fall semester arrived, I couldn't help but tell the students my personal story of hope and overcoming trigeminal neuralgia. From that semester on, I repeated my story to the students in each of my classes. Until one year - when I decided maybe it wasn't worth repeating anymore. But finally, at the end of the semester, I proceeded to tell my story. That's when a young woman raised her hand and said "Mr. Holtmann, I wish I had heard your story about hope and the FPA sooner. My husband's best friend had trigeminal neuralgia and just ended his life two months ago." I had a sick feeling in my stomach.

I knew from that moment on, I could not stop telling my story. Because if I wasn't going to help spread hope and awareness, who would?

I continued to tell my story every year at the college. But by 2024, I had retired and was looking for a part-time teaching position. Amazingly, a part-time position opened up at the high school I once attended, Bishop DuBourg High School in St. Louis. I was hired and began teaching there in the fall of 2024. But telling my story there would be a bit different. These students were a lot younger - 14 to 18 years old. I reached out to our Head of Academics and received permission to tell my story. Then, in what turned out to be a pivotal move, I reached out to Ms. Upton, our biology teacher. I explained to her the story that I was about to tell my students. I wanted her to be aware that there might be some students coming to her with questions or concerns about the trigeminal nerve. She was very intrigued. So much so, that she asked if I could tell my story to her Anatomy and Physiology students in the spring - when they would begin studying the cranial nerves. She mentioned that many of these students were preparing for careers in the medical field - hearing a firsthand account of my experience with diagnosis and treatment of a cranial nerve condition might prove invaluable to these students in their future careers.

That fall, I told my story to all of my students and then again to Ms. Upton's students in the spring. All of the students were very receptive to my story, especially Ms. Upton's students. They asked many questions up until the end of class. In addition to telling my story, I explained the many resources that are now available through the Facial Pain Association to assist those who might have trigeminal neuralgia or other types of neuropathic facial pain. I offered students a wristband that has the FPA website embossed on the inside. The students quickly stormed the front of the classroom to get a wristband - almost every student took one. I asked that in return for receiving the wristband, if they ever come across a person with trigeminal neuralgia or neuropathic facial pain in the future, they turn their wristband over to that person. By passing it along, the person receiving the wristband should gain a quicker path to the FPA website and know the meaning of "You're Not Alone," as imprinted on the band.

Again, this school year, I told my story to my new students in the fall and to Ms. Upton's students this spring. But this spring, I happened to mention these high school talks at a family gathering. I was unaware that a relative of mine was working part-time by teaching a class in the nursing program at a local community college. She felt it would be very impactful if I could give the same talk to her nursing students. I spoke to her students this spring, too, and the talk and wristbands were well-received.

I keep telling my story, even though sometimes it can be difficult and sometimes it can be emotional. From time-to-time, I see a student in the hall still wearing their wristband - students I had last year or were in Ms. Upton's class last year. It's moments like these that I realize I will never be able to measure the full impact of telling my story or handing out wristbands. If it helps just one person – it will be worth it. ■

Helping Facial Pain Patients Tell Their Story:

How AI May Support Education, Diagnosis, and Access to Care

Xiang Qian, MD, PhD
Stanford Medicine Endowed Director
Clinical Professor, Anesthesiology,
Perioperative and Pain Medicine Clinical
Professor (By courtesy), Neurosurgery

Facial pain conditions, including trigeminal neuralgia, painful trigeminal neuropathy, post-traumatic facial pain, burning mouth syndrome, glossopharyngeal neuralgia, migraine-related facial pain, and other complex craniofacial pain syndromes, can be among the most disabling conditions in medicine. For many patients, the pain is severe, unpredictable, frightening, and difficult to explain. Some experience electric shock-like attacks triggered by brushing teeth, chewing, talking, touching the face, or even a light breeze. Others live with constant burning, stabbing, aching, pressure, or numbness. Some patients have pain after dental procedures, facial trauma, jaw surgery, shingles, or other injuries. Others have symptoms that overlap across neurology, neurosurgery, dentistry, pain medicine, ENT, and primary care.

One of the greatest challenges in facial pain care is getting the right diagnosis. Trigeminal neuralgia is a well-recognized condition, but not every facial pain patient has classic trigeminal neuralgia. Some patients have painful trigeminal neuropathy, post-traumatic trigeminal pain, persistent idiopathic facial pain, temporomandibular disorders, migraine biology presenting in the face, or mixed pain syndromes. A small difference in symptom pattern can completely change the diagnosis and treatment pathway. For example, brief electric shock-like pain with clear tactile triggers may suggest classic trigeminal neuralgia, while persistent burning pain after dental trauma may suggest painful post-traumatic trigeminal neuropathy. Facial pain associated with light sensitivity, nausea, and episodic attacks may reflect migraine-related mechanisms. These distinctions matter because the best treatment depends on the correct diagnosis.

Unfortunately, many patients travel a long and frustrating road before they reach the right specialist. They may see multiple clinicians, undergo repeated dental or surgical procedures, try many medications, and still feel that no one has fully understood their pain. This is not because physicians do not care. Rather, facial pain is genuinely complex, and the current healthcare system often does not give patients or doctors enough time to reconstruct the full story.

That is why patient education and careful history-taking are so important. A facial pain diagnosis often depends heavily on the details of the patient's story: where the pain is located, how it feels, how long it lasts, what triggers it, whether there is numbness, what treatments have helped or failed, what procedures have been done, and how the pain affects daily life. The more clearly a patient can tell this story, the better the clinician can understand the pattern and make a thoughtful plan.

This is where artificial intelligence may help. At Stanford and through our broader work in facial pain and headache medicine, we have been developing an AI-based clinical tool called **AlphaDX AI.** The mission of AlphaDX is simple: to help patients tell their story more completely, and to help physicians receive a clearer and more organized summary before the visit even begins.

AlphaDX is designed as a conversational AI doctor assistant. Before seeing the physician, a patient can speak with the system in a structured but natural conversation. The tool asks about pain location, quality, timing, triggers, prior diagnoses, medications, procedures, imaging, functional impact, and other relevant history. It then generates a structured report and a differential diagnosis for physician review.

The goal is not to replace doctors. The physician remains responsible for diagnosis and treatment decisions. Instead, the AI acts as a preparation tool. It helps organize the patient's history, highlights important patterns, and gives the clinician a more complete starting point. In this way, the visit can focus more on clarification, education, shared decision-making, and care planning.

AlphaDX was built specifically with complex headache and facial pain conditions in mind. These are not simple checklist diagnoses. A useful AI tool must know what questions to ask, when to ask follow-up questions, and how to organize the answer in a way that is meaningful to a specialist. For example, a good facial pain intake should distinguish pain attacks lasting seconds from pain lasting hours, pain triggered by light touch from pain triggered by chewing, pain with numbness from pain without sensory change, and pain that began after a procedure from pain that started spontaneously. These details may seem small, but they can be decisive.

To evaluate the system, we trained and validated AlphaDX using representative headache and facial pain conditions. The model was tested in a four leading medical center clinical study across the United States and Canada comparing its diagnostic performance with board-certified headache and facial pain specialists. The system was evaluated on clinically realistic cases, and its differential diagnoses were reviewed for accuracy, comprehensiveness, and appropriateness. A manuscript describing this work has been submitted for peer review.

AlphaDX is already being used by facial pain specialists and neurosurgeons, including Dr. Michael Lim at Stanford and colleagues in the nation, to support pre-visit preparation and physician review. In these early clinical workflows, the goal is not for AI to make final medical decisions, but to help patients organize their history before the visit and help doctors begin the encounter with a clearer, more complete understanding of the patient's symptoms, prior treatments, imaging, and concerns.

The tool is also being implemented in multiple clinics nationally to help physicians expand access and prepare more effectively for complex visits. For patients with facial pain, this may be especially valuable because the diagnostic journey is often long, confusing, and fragmented across dentistry, neurology, neurosurgery, pain medicine, and primary care.

"Helping Facial Pain Patients Tell Their Story" continued on page 16

"Helping Facial Pain Patients Tell Their Story" continued from page 15

For the Facial Pain Association (FPA), this mission is deeply aligned with the work the FPA has already done for many years: helping patients learn, connect, advocate, and find their way through complex facial pain conditions. The FPA provides something that is difficult to replace: a trusted, patient-centered community. AlphaDX may be able to add another layer of support by helping patients organize their own story before they meet with a clinician.

One possible future direction is to make this type of tool available through the FPA in a responsible and educational way. Patients could use an AI-guided intake to prepare for a visit with their own physician, organize their symptom history, and better understand what information may be important to share. The output could help patients ask more informed questions and communicate more effectively with their healthcare team. This would not be a substitute for medical care, but rather a way to support preparation, education, and access.

Patient-centered AI must be developed carefully. Accuracy, privacy, transparency, and physician oversight are essential. Patients should always know when they are interacting with AI. They should know that AI is not making final medical decisions. **Their physician must review the information, interpret it in context, and guide treatment.** AI tools must also protect patient data and avoid overpromising what technology can do.

But if developed responsibly, AI can become a powerful educational partner. It can help patients prepare for visits. It can help physicians see patterns more clearly. It can help reduce the burden of repeating the same history over and over again. It can also help patients who live far from specialty centers begin to organize their symptoms before they are able to see an expert.

The future of facial pain care will not be AI replacing physicians. It will be patients, physicians, and carefully designed AI tools working together. Patients bring their lived experience. Physicians bring clinical judgment, compassion, and expertise. AI can help organize information, identify patterns, and make the patient's story easier to hear.

For the facial pain community, that may be one of the most important contributions of all: helping every patient tell their story clearly, completely, and in a way that leads to better understanding and better care. ■

YPC Facial Pain Association
Young Patients Committee

Spring 2026 Facial Pain Resiliency Academic Scholarship Recipient

Julie D'Onofrio

Trigeminal neuralgia is often described as one of the most painful conditions a person can experience. For me, it was not only a medical diagnosis but also a defining obstacle that reshaped the way I approached education, work, and life itself. As a student majoring in horticulture at Bronx Community College, I was confronted with severe facial pain that disrupted nearly every aspect of my daily routine. Yet despite the physical and emotional challenges it created, the experience ultimately strengthened my determination to pursue higher education and deepened my understanding of resilience, purpose, and healing.

At the same time, managing trigeminal neuralgia while attending college remained extremely difficult. Chronic pain does not operate on a predictable schedule. There were days when concentrating on lectures or completing assignments felt nearly impossible. Balancing coursework, fieldwork, and medical care required constant adaptation and persistence. Eventually, the progression of my condition required neurosurgery, forcing me to temporarily step away from work and focus on recovery. Although this period was frightening and uncertain, it also reaffirmed how deeply I cared about my academic path. Even during recovery, my interest in plant science remained a source of motivation and hope.

Looking back, living with trigeminal neuralgia while pursuing my education taught me several important lessons. First, resilience is rarely a dramatic moment of triumph, more often it is the quiet decision to keep moving forward despite uncertainty. Many days required small but meaningful victories, attending a class, completing an assignment, or spending time outdoors observing plants. Over time, these small steps accumulated into significant progress.

For young patients who are facing trigeminal neuralgia or other chronic conditions while pursuing education, my advice is simple but sincere. First, be patient with yourself. Chronic pain can make progress feel slow or uneven, but persistence matters far more than speed. Second, find something that genuinely inspires you, whether it is a field of study, a creative pursuit, or time spent in nature. Having a meaningful focus can provide necessary strength during difficult moments. Third, seek out supportive mentors, professors, and peers. You do not need to face these challenges alone, and many people are willing to help when they understand your situation.

Most importantly, remember that a diagnosis does not define your potential. Trigeminal neuralgia introduced obstacles I never expected, but it also reshaped my perspective in ways that ultimately strengthened my commitment to learning, discovery, and empathy. Though neurosurgery did not provide me the relief I hoped for, through perseverance, curiosity, and the healing influence of the natural world, I was able to continue my education and pursue the field that inspires me most. In many ways, the journey through pain has made my academic path more meaningful, reminding me that growth, both in nature and in life, often emerges from adversity. ■

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Stefanie Rene Salyer

Living Through the Shock

I can still remember the first moment that the pain struck my face. I was a special education teacher standing in front of my classroom. As a full-time educator who was trying to balance the demands of graduate studies, I never felt like I had a moment to slow down. That day, everything changed. The day was ordinary in nature. I was grading papers, preparing to teach our new unit, and developing my schedule for completing class assignments late into the evening. Then, as I stood in front of my students, an electrical shock pain ripped across the right side of my face. It had felt like lightning. I froze, struggled to move, and couldn't speak. Taking a breath in that moment felt dangerous. I was afraid to move and trigger another shock.

At this point in my life, if I could give advice to another youth patient with trigeminal neuralgia or another facial pain condition, I would offer this: trust yourself. You are the only expert of yourself and your experience. Pain that disrupts your life deserves true care and attention. Pain is not always visible, but it doesn't make it less real. Your life is not over with this pain or diagnosis. There are difficult days, I won't lie to you. There will be days when you don't know how to try again. Moments where the pain is so loud that you can't take another step. But you can show up again. You can pursue the education, career, relationship, or dreams that you have. Now, please know that the path might be a little different from what you initially expected, but you can find a path to walk that is still beautifully yours.

Trigeminal neuralgia has been the hardest medical condition I have ever had to face. It reshaped how I view and understand resilience as a whole. From that first electrical shock in the front of my classroom to sitting in my doctoral program crying through an exam, it has defined so much of my journey. But most importantly, it did not end my journey. I am still teaching, studying, and building a career that I love. Getting to be a Ph.D. candidate in Special Education and an M.Ed. student in Clinical Mental Health Counseling is something that I never take for granted. My experiences of being dismissed and misunderstood due to my TN built a passion for understanding how disability, resilience, and support must co-exist. My research and professional goals are not just academic curiosity, but are grounded in the lived experiences I have.

Experiencing TN has strengthened my empathy for students and clients navigating physical pain, emotional distress, and systems that do not always recognize their needs. It has reminded me that validation, advocacy, and compassionate support can change the trajectory of someone's life.

The same validation that helped me find my way forward is the kind of support I now hope to provide for others through my work in education and mental health. ■

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The Facial Pain Association is grateful to our generous donors whose gifts serve to honor special people in their lives, commemorate milestone events, or memorialize the legacy of those who have passed. The following donors made tribute gifts between January 1, 2025 and March 31, 2026.

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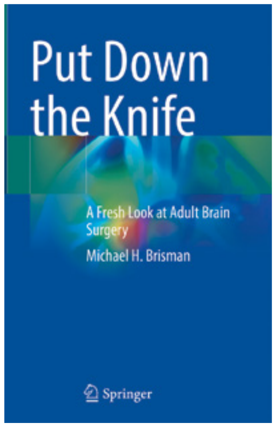
Dr. Brisman has served as Chief of Neurosurgery at NYU Winthrop Hospital, Mineola, NY, and is Co-Medical Director of the Long Island Gamma Knife® Center at Mount Sinai South Nassau in Oceanside, NY.

Dr. Brisman is the author of Put Down the Knife *(Springer Publishing), a textbook on adult brain surgery which promotes the importance of minimally invasive surgical procedures and conservative treatment options.*



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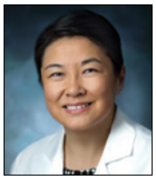
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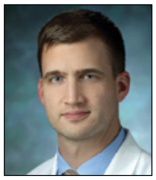
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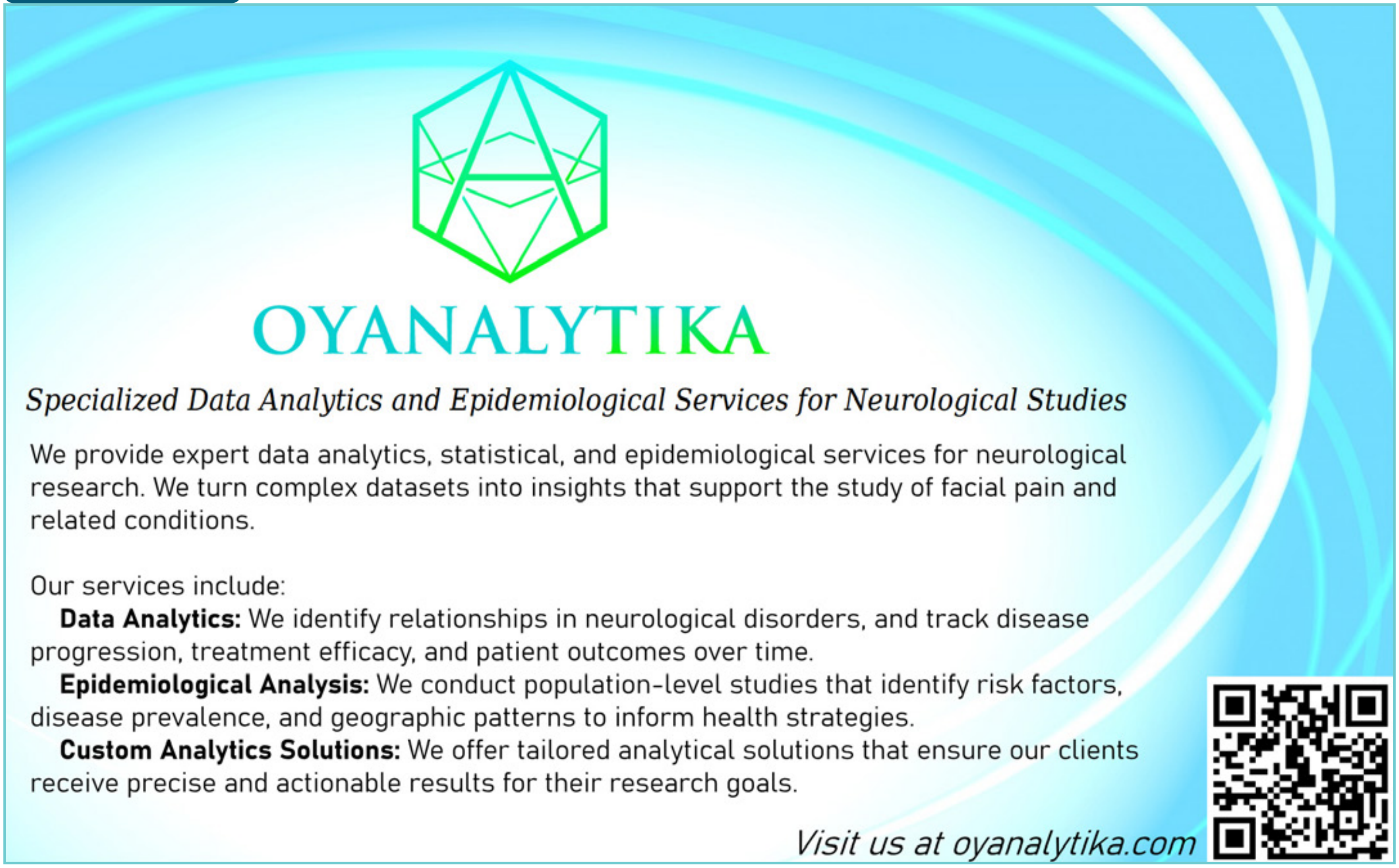

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Facial Pain Book Bundle

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

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Join the
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FacialPain
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How to Talk to Your Doctors About the Facial Pain Association

The Facial Pain Association is the largest patient organization serving people with neuropathic facial pain. Healthcare professionals can benefit from the FPA's resources to further their understanding and treatment of facial pain, connect their patients with knowledgable support, and better serve your health goals with your facial pain in mind.

What kind of doctors can benefit from knowing about the FPA?

In short, any doctor that helps you to manage your facial pain! This might include:

- Primary Care Physicians
- Dentists
- Oral Surgeons
- Neurologists
- Orofacial Pain Specialists
- Neurosurgeons
- Pain Management Specialists

Even doctors who misdiagnosed your facial pain can become valuable allies to future patients once they are educated.

You can mail the brochure to doctors who are no longer treating you, along with a personalized note describing how your life has changed since being correctly diagnosed and what tests or considerations made your diagnosis possible.

You are doing important work for the future of facial pain by talking to your doctors about the Facial Pain Association. Educating doctors can be an empowering form of advocacy that can inspire change in how neuropathic facial pain is treated and diagnosed on a grassroots level.

Healthcare professionals are eager to learn more about their patients — they just need to know what resources are available to them. Email **info@facepain.org** for resources to share.

It all starts with a conversation.

In case your doctor is ready to connect with the FPA:

The FPA's Professional Membership Program connects the facial pain community with specialists diagnosing and treating neuropathic facial pain and related health care conditions. Your doctors can connect with the worldwide facial pain community through an annual individual or center FPA professional membership by emailing **development@facepain.org**.

Here's How You Can Help

Be vulnerable about your experience with facial pain — it's important they know how much it affects you.

I experience such intense pain everyday, it keeps me from living my life

Having facial pain affects my ability to reach my physical and mental health goals

I'm always scared of when my next pain flare will happen

Highlight the difficulties you faced in getting diagnosed — once they understand the gaps in healthcare, they can become a part of the change.

I spent 7 years with a diagnosis of anxiety and it prevented me from getting proper help

I had 4 teeth pulled before my dentist realized it wasn't a toothache

None of the specialists I saw knew what neuropathic facial pain was, so it was never considered

Tell them how much the FPA has positively impacted you and the patient resources you use.

They have monthly webinars that keep me informed of new treatment options

The FPA's Patient Guide helped me to create my current care plan

I go to support group meetings — it helps me feel less alone

Talk about the valuable resources the FPA has for healthcare professionals.

You can get free continuing education credits by attending their webinars

The Facial Pain Registry is a great way for doctors and researchers to learn more about facial pain

They have a list of doctors on their website — I think you should join it

Leave any literature with them along with information about local FPA support groups and any other local resources. Encourage them to share the literature and resources with future patients. Tell them to contact the Facial Pain Association to get the Quarterly journal in their waiting room by emailing **info@facepain.org**.