Journal of the Facial Pain Association Fall 2026

Quarterly

THE FACIAL PAIN ASSOCIATION
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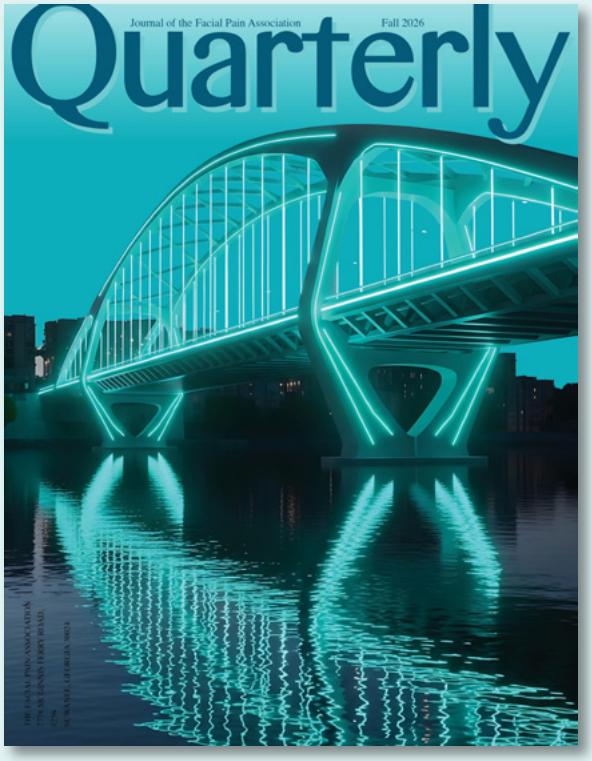
ON THE COVER



Awareness and advocacy are bridges — connecting people with the knowledge, care, and resources they need. Much of the FPA's advocacy work happens behind the scenes, strengthening bridges between our community and the healthcare professionals, organizations, and policymakers who can make a difference. Through outreach to dentists and neurologists, partnerships with organizations focused on headache, migraine, orofacial pain, and initiatives like Light It Up Teal, the FPA works to make facial pain more visible and better understood. Light It Up Teal brings communities together each October, turning landmarks, businesses, and structures teal to spark conversations about trigeminal neuralgia and related conditions. Every bridge we build creates another opportunity for someone to recognize their symptoms, avoid unnecessary procedures, find the right specialist, or discover the FPA's support and educational resources. Advocacy may not always be visible, but its impact is. Together, we are building bridges toward greater awareness, better care, and hope for everyone affected by facial pain.

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

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From the Board Chair

The FPA's mission is to provide Support, Education, & Advocacy for those connected to trigeminal neuralgia (TN) and related facial pain conditions. It is easy to see the opportunities for support and educational resources the FPA provides. However, Advocacy is less visible. It's like looking at an iceberg and not being able to see the ice below the waterline. Yet, it's a big part of what the FPA does, and it can be immensely helpful without you even knowing.

The analogy of bridges has been used to explain advocacy. Bridges to other organizations and groups that directly impact your life. The FPA builds, maintains, and invests in enhancing those bridges for your benefit.

You can see some of these bridges to other groups in your daily life. In recent years, the FPA has worked diligently to connect with the dental community. Many of us know firsthand that our symptoms present as dental problems and when we go to our dentist, they are usually unable to diagnose our condition. Instead, they do what they know how to do in an attempt to help us: root canals, tooth extractions, etc. This doesn't help and often inflicts even more pain and discomfort on us. So, the FPA develops and presents quarterly continuing education classes designed to educate dental professionals, advertises in dental periodicals, and presents at dental conferences to advocate for you and ensure that dentists are capable of properly diagnosing TN, or at least recognizing it's not a dental problem.

The FPA is building a neurologist outreach initiative that parallels our work with dentists, though the message differs. With neurologists, we focus on the standard of care for TN and related conditions, and on making sure these physicians know the FPA offers substantial resources for their patients. We reach them through neurology conferences, direct advertising, and ongoing professional outreach.

Less obvious, but possibly just as important, the FPA builds bridges with similar organizations to advocate on your behalf. The FPA is now a member of the Alliance for Headache Disorders Advocacy, which pursues policies and programming at the national level to secure more research funding and improve policies for the 40+ million Americans with migraine and headache disorders, including neuropathic facial pain.

In the future, when people with TN symptoms go to their dentist with pain that feels like a dental issue, and the dentist says, "This is not a dental problem; you need to see a neurologist," this advocacy work will be on full display. It will be visible when people go to their neurologists, fully aware of the standard-of-care for this uncommon condition and are encouraged to contact the FPA for education and support. And when more medical research is being done to create additional solutions for people with our condition, again, advocacy will be the driving force behind it.

The ice below an iceberg's water line is critical, just like FPA's advocacy work.

David Meyers
Board Chair, The Facial Pain Association

A Message From the CEO

Every October, our community comes together for Facial Pain Awareness Month. And every year I find myself thinking about how much weight that one word, awareness, must carry when your condition is rare.

Most of you know what "rare" really means. Trigeminal neuralgia affects so few people that your dentist, your family doctor, or the doctor in your emergency room may never have seen a case of it. That is why so many of our members tell the same story: years of appointments. Dental work that did not help. A growing feeling that no one believes what you are describing. Awareness is not a public relations exercise for us. It is the difference between a diagnosis in three weeks and a diagnosis in three years.

That is why the recent feature in The New York Times Magazine meant so much. One of our own volunteers shared her story with a national audience, and in doing so gave millions of readers, including clinicians, students, and people quietly living with undiagnosed facial pain, a clear picture of what this condition actually is. If you have not yet read it, I hope you will: [LINK]. I am deeply grateful to our volunteer for the courage it took, and I hope her example reminds all of us that a single story, told honestly, can travel further than a hundred brochures.

Attention like that does not come along often. So, we work to build it in other ways. We do that through advocacy and through partnerships.

Over the past year, the FPA has built strong relationships with groups whose members have far more in common with ours than most people realize. We work with headache organizations like the Coalition for Headache and Migraine Patients, the Alliance for Headache Disorders Advocacy and Miles for Migraine. Through them, we reach people whose facial pain has been called migraine as well as people with migraine whose facial pain turns out to be something else.

We also work with the American Academy of Orofacial Pain and The TMJ Association. They connect us with the dentists and specialists who often see facial pain first, and with patients who were given the wrong diagnosis before they found us.

These partnerships are not just a courtesy. Many people live with more than one of these conditions at the same time. The symptoms overlap. Even experienced doctors can find it hard to tell these conditions apart. So, every new audience we reach is a place where someone might finally recognize their own symptoms or those of a friend or family member.

This month, I hope you will help us extend that reach. Share the article. Share your story if you are able. Tell one doctor or dentist about the FPA who does not yet know we exist. For a condition like ours, awareness is built one conversation at a time.

Melissa Baumbick
Chief Executive Officer, The Facial Pain Association

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Quarterly

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MAB Corner

A Shared Mission, A Stronger Voice:

Joining Territories With an FPA-Ramsay Hunt Foundation Collaboration sets up a Win-Win

Wolfgang Liedtke, MD, PhD
Professor of Neurology, Duke University & Professor, New York University College of Dentistry

For our esteemed followers, and globally the millions living with neuropathic facial pain, the path to diagnosis, effective management to regain quality-of-life, and compassionate and empowering support is often fraught with delays, miscommunications, misdiagnoses, isolation and discrimination. The Facial Pain Association (FPA) has long aimed to function as a beacon for this community, often-times succeeding, always trying to be better. At the FPA, we have been providing our followers and essentially everybody approaching us with resources, education, and heartfelt, genuine and effective advocacy for those affected by conditions like trigeminal neuralgia. We also have set in motion a Facial Pain Patient Registry which has transformational power toward improved understanding of the condition. Now, a new opportunity for collaboration has emerged with the Ramsay Hunt Syndrome Foundation (RHSF), an organization founded in 2024 to elevate care for patients living with this condition. The prospect of aligning with the RHSF is appealing because a multiple win is likely. One shared feature between the medical conditions at the core of both organizations is life-altering facial pain — that should be a potent unifier. A closer partnership between the FPA and RHSF will facilitate addressing the profound, unresolved challenges of both conditions.

Ramsay Hunt Syndrome (RHS), caused by the reactivation of the varicella-zoster virus in nerve cells principally belonging to the facial nerve complex — the nerve operating the mimical musculature thus key for animals' facial non-verbal communication, perhaps richest in humans, is the second most common cause of facial nerve palsy. Yet, it is frequently misdiagnosed as Bell's palsy, leading to critical delays in antiviral treatment and increasing the risk of adverse long-term sequelae. This diagnostic challenge is compounded by the fact that up to 20% of patients never develop the characteristic otic rash (which one must look for), making clinical recognition difficult. Even when diagnosed, many RH patients are left with chronic, intractable postherpetic neuralgia (PHN). We know postherpetic trigeminal nerve pain well from our own territory. That's the key link.

While facing this reality, significant gaps remain in our understanding of RHS, similar to the obstacles we are battling with in the trigeminal pain arena. For example, the mechanisms that drive the transition from acute pain to chronic post-herpetic nerve pain are poorly understood. The role of neurovascular compression — now better understood in our own trigeminal territory — in RHS-related dizziness is only beginning to be explored. And while antivirals are the standard of care, we need more rigorous inquiries to truly define their efficacy and learn about optimal dosing. Is there an opening for the varicella-zoster vaccine beyond a reinvigorated urgent call for Shingrix vaccination starting age 50? What about molecular medicines targeting the reactivated varicella-zoster virus in the nerve cells of the facial nerve complex — in trigeminal sensory nerve cells? These are not just academic questions — they have an impact on the daily realities of patients who suffer in silence.

This is where the synergy between the FPA and RHSF becomes powerful. Both organizations face common obstacles: the lack of recognition of these conditions — we did make progress on this front, but there is more work to be done — limits research funding, and makes the critical clinical trials needed for new approaches to gain approval more difficult. We should also mention awareness by regulatory bodies like the US FDA so that guidelines for clinical trials and therapeutics' approvals can be revisited rationally. Both patient cohorts also have to live with a frustrating lack of awareness among healthcare providers, leading to hellscape medical odysseys. And both serve communities that experience profound social and emotional isolation.

A collaborative framework could move the needle on several fronts.

First, we can consider whether the FPA's established Facial Pain Registry, a landmark patient data initiative with an envisioned extension to become an empowering facial pain biobank (like UK Biobank), could be expanded to include a RHS module. This would provide the real-world evidence needed to better define disease natural history, identify prognostic factors, support research, both academic-translational, and, importantly, corporate to build therapeutics development pipelines.

Second, joint educational initiatives — such as co-branded patient guides and continuing medical education (CME) programs — could target emergency physicians, family physicians, neurologists, ENT doctors and dentists, the frontline doctors most likely to encounter RHS.

Third, the two organizations could partner on advocacy campaigns with all key stakeholders such as US Congress, US HHS (FDA and NIH under that roof) to effectively step up for our first amendment right "to lobby the Congress" so that our conditions will be appropriately prioritized.

Advocacy campaigns are a key element of this collaboration. By amplifying patient stories and leveraging the collective power of both communities, the FPA and RHSF can bring facial pain out of the haze of ignorance. The RHSF's first-ever in-person Patient Support Summit in September 2026 is a testament to the growing momentum — where I will certainly lend my ambassadorial voice. The FPA and RHSF share a fundamental mission: to ensure that no one faces facial pain alone. ***Let's do it together.*** ■

Facial Pain Registry

Data Speaks: Tracking the Natural History of Facial Pain

Why Your Follow-Up Survey Matters

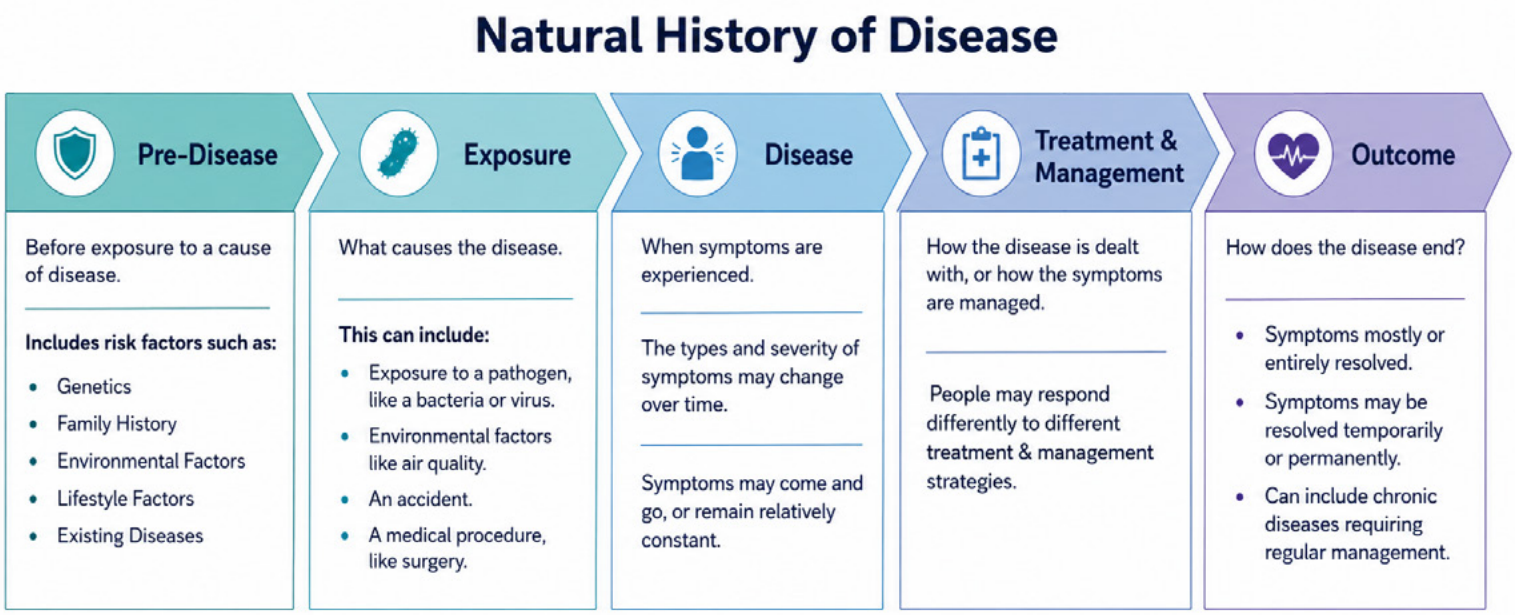
By Tristan Olinger and Liam Winters

In our Summer 2026 Quarterly, we looked at what registry participants told us about the causes of their pain. In this issue we turn to the "retake" surveys (which are simply annual updates). They ask how your facial pain condition has evolved over time, which is what researchers call the "natural history" of a disease. Two new surveys are being developed as well; one focused on medications and one focused on daily life and mental health.

The "retakes" are available on the Facial Pain Registry one year from when participants completed their first surveys. You will receive an email from NORD prompting you to complete the retake surveys, and you have about 180 days to do so. The new surveys will be available later this year

What Is the "Natural History of a Disease"?

Medical professionals and researchers use the phrase "natural history of disease" to describe how a condition unfolds over time, from before a person is affected to what happens after treatment. A disease's natural history is often divided into stages. We define these stages here as pre-disease, exposure, disease, treatment and management, and outcome. Comparing a common illness like flu with a facial pain condition like trigeminal neuralgia (TN) shows how the same stages apply to a short, familiar illness and to a rare, long-term one.



Pre-disease is the stage before anything happens. For flu, this is simply a person who has not encountered the virus. For TN, it is someone whose trigeminal nerve, the nerve that carries sensation from the face to the brain, is working normally and without pain. Risk factors are part of the pre-disease stage. These can include genetics, environmental and lifestyle influences, family history, and existing conditions. Someone with a condition that weakens the immune system, for example, may be at greater risk of contracting other illnesses.

Exposure is an event that sets a disease in motion. In infectious illness, this means contact with a pathogen, though in facial pain conditions the trigger is often structural or physical rather than infectious. For flu, exposure means contact with the influenza virus, such as sitting beside an infectious coworker. For TN, it might mean a blood vessel pressing against the trigeminal nerve, a car accident, a tumor, a dental procedure, or a condition such as multiple sclerosis that damages the nerve's protective coating. As we reported in the last issue, dental procedures were the event most often named by participants whose pain followed something specific, though facial pain is also frequently mistaken for a dental problem before the correct diagnosis is reached. We ask about these possible triggers because identifying them is central to understanding how the condition might have originated.

Disease is the stage where symptoms appear. Symptoms may change over time, come and go, or vary in how severe they are. For flu, symptoms often include fever, chills, and body aches, usually within a day or two of exposure. TN brings severe pain, often described as electric shocks or stabbing sensations on one side of the face, sometimes alongside numbness or tingling that began around the time of an accident, dental procedure, or other medical event.

Treatment and management are the steps taken to address the condition and manage its symptoms. Flu is usually managed with rest, fluids, and sometimes antiviral medication. TN is typically treated in stages, first with medications, and if those do not work or stop working, with procedures such as balloon compression, radiofrequency ablation, gamma knife radiation, or surgery to relieve pressure on the nerve.

Outcome is where and how a condition settles. Symptoms may resolve fully, resolve partly, or persist indefinitely. Most people recover from flu within a week or two, though some develop complications. Outcomes in TN and other facial pain conditions vary widely. Pain can resolve after treatment, return months or years later, or continue despite a variety of medical interventions. Some people go through long stretches with no pain at all, only to have it return when something new sets it off.

"Natural History" continued on page 8

"Natural History" continued from page 7

Why the Natural History of Facial Pain Matters

Knowing a facial pain condition's natural history allows healthcare providers to set realistic expectations, recognize a condition earlier, and choose treatments with a clearer sense of what tends to work and when. It is also how researchers tell conditions apart. This matters especially for rare conditions, which often lack data on patient experience. TN, persistent idiopathic facial pain, and painful trigeminal neuropathy can look similar at first glance but behave differently over months and years. Without tracking patients over time, that difference is hard to see. That's why your participation in our registry is so critical.

What the Registry Adds

The first three surveys captured a detailed picture of a single moment: what your pain felt like, where you felt it, and what you and your providers believed had caused it. But facial pain conditions rarely hold still. Symptoms shift and spread, new diagnoses arrive, and treatments that once worked sometimes stop working. A one-time snapshot cannot show any of that.

That is what the retake surveys are designed to record. They ask whether you have received any new diagnoses since you last completed a survey, whether a healthcare provider has identified a new cause for your pain, and whether your pain has changed, spread, or brought new sensations such as numbness or tingling. It also asks which medications you are taking and how well they are working, and it asks about mental health, because living with facial pain affects far more than the face.

Set against what your first three surveys captured and multiplied across the more than 850 people contributing to the registry, those answers form a pattern researchers can use to better map and treat facial pain conditions.

How to Help Us

Please participate in the Facial Pain Registry. Your unique experience is important in the data being collected. And please complete the retakes when prompted. It takes most people about ten minutes. Time is limited to provide updates to your original responses through these "retakes." All responses are confidential.

It is worth completing even if nothing about your condition has changed. "No change" is still an answer. Knowing that a person's pain has held steady since their earlier surveys, or that no new diagnosis or treatment occurred, is as valuable to researchers as knowing what has shifted. Stability is part of a condition's natural history, and the registry can only show it if people whose condition has stayed the same respond alongside those whose has not.

Not yet enrolled? The registry is always open. There is no deadline to join and no cutoff for starting the surveys, and people enroll every week. Enrollment is free and open to anyone living with neuropathic facial pain at facepain.iamrare.org. Most participants finish the first three surveys in 15 to 20 minutes, and all responses are confidential. ■

NSPC Brain & Spine Surgery

Michael H. Brisman MD, FACS
Attending Neurosurgeon,
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Could Epilepsy Provide a Model for the Treatment of Trigeminal Neuralgia?

20 Characteristics of Epilepsy Offer Evidence

The trigeminal nerve carries many different neurological signals or pathways. The trigeminal nerve supplies motor signals that help move and align the jaw. It also conveys many different sensory signals from the face. These include temperature, light touch, vibration, pressure, two-point discrimination, dull pain, and sharp pain. Trigeminal neuralgia (TN) is a disease of the trigeminal nerve sharp pain sensation pathways.

How we think of certain diseases influences how we study those diseases and try to manage them. The issue of the “philosophy” of the disease isn’t just a theoretical matter. It affects our practical management. Towards this end, one way we often think of diseases is through “models." In particular, we try to think about how similar diseases might give us insights into a disease we are focusing on.

As such, it is reasonable to consider what other diseases might give us the most insight into a disease like TN. Probably the closest disease model is “epilepsy.” While many people are aware of at least a few of the similarities between epilepsy and TN, the extensive similarities between these two diseases are often not appreciated. Epilepsy can cause a patient to have uncontrollable shaking of an arm or leg without loss of consciousness (a “focal” seizure), and can also cause diffuse body shaking with loss of consciousness (a “generalized” seizure).

"NSPC" continued on page 10

"NSPC" continued from page 9

1. Epilepsy is a result of abnormal and overactive electrical activity in the brain, usually in the upper part of the brain, the cerebrum, but sometimes involving the brainstem. TN is also a result of abnormal and overactive electrical activity in the brain, specifically in the trigeminal nerve pathways near where the trigeminal nerve enters the brainstem.

2. There are many different causes of epilepsy (for example, bleeding in the brain, infection in the brain, injury to the brain, tumors in the brain, inflammation in the brain, etc). There are many different causes of TN (for example, brain tumors, blood vessel compression of the nerve, multiple sclerosis , etc).

3. Despite the fact that there are many different causes of epilepsy, all causes can be broken down into the two categories of (a) compressive causes that affect the brain by pressure and (b) non-compressive causes of intrinsic disease in the brain itself. Despite the fact that there are many different causes of TN, all causes can be broken down into the two categories of (a) compressive causes that affect the trigeminal nerve root by pressure and (b) non-compressive causes of intrinsic disease in the trigeminal pathways themselves.

4. Regardless of the cause of disease, epilepsy can present clinically in very similar ways, such as a generalized seizure. A seizure from one cause may look the same as a seizure from another cause. A seizure is a "final common pathway" of certain types of disease in the brain, with a common "phenotype" or clinical presentation. Likewise, TN from different causes can present clinically in very similar ways. That is, regardless of why a person has TN, TN pains from one cause may feel the same as a TN pains from another cause. TN is a "final common pathway" of certain types of disease in the trigeminal nerve pathways, with a common "phenotype" or clinical presentation.

5. Seizures can come on all of a sudden. TN pain episodes can come on all of a sudden.

6. Seizures can come to a sudden end. TN pain episodes can come to a sudden end.

7. Seizures can come on without any clear warning. TN pain episodes can come on without any clear warning.

8. Seizures can be triggered suddenly by certain sensory stimuli, such as bright flickering lights or certain visual patterns. TN pain episodes can be triggered suddenly by certain sensory stimuli, such as light touch of the face.

9. An epilepsy patient can, for unclear reasons, have one or more seizures, and then have spontaneous remissions, and not have another seizure for months or years. A TN patient can, for unclear reasons, have one or more TN episodes, and then have spontaneous remissions, and not have another TN episode for months or years.

10. Seizures often cause sudden, unpredictable, brief neurological "attacks" that last seconds or minutes. TN often causes sudden, unpredictable, brief neurological pain "attacks" that last seconds or minutes.

11. After the seizure, the area affected by the overactive neurological activity can, for a period of time, demonstrate underactive activity. For example, a seizure that causes the right arm and leg to shake and move excessively, could, afterwards, lead to a period in which the right arm and leg were very weak or unable to move at all (a "Todd's paralysis). After the TN pain episode, the area affected by the overactive neurological activity can, for a period of time, demonstrate underactive activity. For example, a TN episode that causes excessive painful sensation, could, afterwards, lead to a period in which the face felt somewhat numb, with a reduced sense of sensation).

12. About 2-5% of patients with multiple sclerosis develop epilepsy due to the demyelination of some of the brain pathways. About 3-4 % of patients with multiple sclerosis develop TN due to the demyelination of some of the trigeminal pathways.

13. Epilepsy is sometimes inherited. TN is sometimes inherited.

14. Epilepsy will usually respond to a certain category of medicines, “anti-epileptics” or “anti-convulsants”, that reduce electrical activity. TN will usually respond to a certain category of medicines, “anti-epileptics” or “anti-convulsants”, that reduce electrical activity.

15. Some seizure medicines are more effective for certain types of seizures than others. Some seizure medicines (such as carbamazepine and gabapentin) are more effective for TN than other seizure medicines.

16. Siezures can be related to abnormalities in the brain’s ion channels, particularly in cases of familial epilepsy. TN can be related to abnormalities in the brain’s ion channels, particularly in cases of familial TN.

17. Epilepsy patients can experience “refractory periods”, time intervals after a seizure episode when another seizure cannot occur. TN patients can experience “refractory periods”, time intervals after a TN pain episode when another pain episode cannot occur and cannot be triggered by facial stimulation.

18. If the cause of epilepsy is compression of the brain, decompression may be able to successfully treat the epilepsy and stop/cure the seizures. If the cause of TN is compression of the trigeminal nerve root, decompression may be able to successfully treat the TN and stop/cure the episodes of pain.

19. If the cause of epilepsy is compression of the brain, decompression sometimes will not stop the seizures, presumably because certain irreversible intrinsic damage has already occurred. If the cause of TN is compression of the trigeminal nerve root, decompression sometimes will not stop the pain episodes, presumably because certain irreversible intrinsic damage (such as demyelination) has already occurred).

"NSPC" continued on page 12

"NSPC" continued from page 11

20. There exist certain surgical procedures that can cure or limit seizures regardless of whether the cause of the seizures was due to compression or not. Such surgical procedures all focus on injuring or reducing function of the overactive seizure cells. These procedures include injuring the seizure cells with a heating laser (Laser interstitial thermal therapy/LITT), removing the seizure cells, injuring nerve fibers needed for propagation of a seizure (like corpus callosum fibers that connect the two hemispheres of the brain), deep brain stimulation (DBS), vagus nerve stimulation (VNS), and responsive neuro-stimulation (RNS).

There also exist certain surgical procedures that can cure or limit TN pain regardless of whether the cause of the TN was due to compression or not, and these procedures also focus on injuring or reducing function of the trigeminal nerve pathway cells. Such procedures include injuring the trigeminal pathway cells with a heating radiofrequency needle, with a glycerol injection, with balloon compression, with super-focused radiation, with direct injury of the nerve during a craniotomy, and with neuro-stimulation.

The point of this extensive comparison is to show that TN is a very similar disease in many, many ways to epilepsy. The abnormal electrical transmissions in TN seem to mostly occur in or around the Trigeminal Root Entry Zone (TREZ), the area where the trigeminal nerve enters the brainstem. As such, they are more like "focal" seizures which cannot cause loss of consciousness, because the abnormal electrical activity does not occur in the cerebrum or other areas related to consciousness. TN can in many ways be thought of like focal epilepsy of the trigeminal sharp pain sensory pathways. Better understanding of TN, possibly using an epilepsy model, may help us better treat this debilitating disease and better help the people who suffer from it. ■

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Turning Pain into Purpose

An Interview with Marsha Garcia, a recipient of the Dr. Jeffrey Fogel Outstanding Volunteer Award
By Danielle Clements, Special Correspondent

For many people living with trigeminal neuralgia, the diagnosis can feel isolating. Marsha Garcia understands that feeling firsthand. A lifelong racer, advocate, and the July 2026 recipient of the Dr. Jeffrey Fogel Outstanding Volunteer Award, she has transformed her own experience with chronic facial pain into a mission to connect, educate, encourage and advocate for others. Through awareness campaigns, creative outreach, and countless conversations with newly diagnosed patients, Marsha reminds people that even in the darkest moments, they are never alone.

Marsha's advocacy has been recognized well beyond the Facial Pain Association. Her story was included in Dr. Sanjay Gupta's 2025 book It Doesn't Have to Hurt, detailing the triumph of the human spirit. She was also featured in the November 2025 issue of AARP The Magazine in a profile titled, "The Unstoppable Marsha Garcia."

One sentence from Marsha's award nomination captured her impact perfectly: "Marsha Garcia is a one-woman force for awareness of trigeminal neuralgia, neuropathic facial pain, and the Facial Pain Association." We were honored to sit down with Marsha to talk about her advocacy, her resilience, and her experience living with trigeminal neuralgia.

Before people knew you as an advocate, who was Marsha?

I was just racing and trying to find something to do with my life. Living in Arizona, it can be really depressing during the summertime. I'm sure it's the same in places where there's snow. You're kind of secluded because you can't really go outside. I'm an outdoor person. I like hiking, I like racing, I like being outside. During the summer, I mostly stayed inside and waited for racing season to start again. When I got diagnosed [with trigeminal neuralgia], though, it lit a fire under me. I didn't want anybody to go through what I went through—going to the emergency room looking for help and feeling like people thought I was seeking drugs... I wanted people to know about trigeminal neuralgia.

With racing, I'm really the only African American woman out there. There's one other African American racer who's a man - it's a very male-dominated sport. I ended up putting the two together. One thing I love. One thing I hate. And it blossomed into what it is today. Before that, I was just Nana...and racing.

"Pain into Purpose" continued on page 14

"Pain into Purpose" continued from page 13

Why do you think it's so important to talk openly about the mental health side of living with facial pain?

When I was first diagnosed, I didn't have the Facial Pain Association to turn to. Like a lot of us, I went to Facebook. I started reading through what people were posting, and honestly, it depressed me. It almost made me feel worse. I remember one military veteran writing that he would have been okay not coming back from his tour of duty because of trigeminal neuralgia.

That just broke my heart. At that point I wasn't an advocate yet. I didn't know enough about the condition, and looking back, I wish I had reached out to him. I just felt like there wasn't enough information out there. People weren't being directed to the Facial Pain Association. Not even at the doctor's office. When I left my appointment, it was basically, "Here's your prescription. Good luck. Come back in four to six weeks and we'll see where you're at." There was nothing. So, I started reading everything I could. People talked about medications, vitamins, magnesium, different sprays—anything that might help. I started writing everything down. If someone mentioned something, I'd research it or ask my doctor about it.

I have a very low tolerance for medications. My body doesn't break them down well. Gabapentin was horrible for me. One medication I was taking after my Gamma Knife procedure actually made my anesthesia dolorosa worse. So, I started trying other things. If something worked, I'd share it with the support group. Helping other people kept my mind busy. Instead of sitting there thinking about my pain, or the amount of time I was spending on the couch, or the fact that I couldn't even get up and do laundry, I focused on learning what worked for me. I realized I was fortunate. My pain wasn't as severe as what so many other people were experiencing. I always wanted to be the voice for the people who couldn't speak. The people who had taken their lives. The people who weren't comfortable standing up and talking about what they were going through. I wanted to be that person.

How has your understanding of resilience changed over the years?

After I had my Gamma Knife procedure, I was pain-free for an entire year. I raced 500 miles on my ATV. I was living my best life. I honestly felt like a young adult all over again. I left all of it behind. Then, almost exactly one year later, the pain came back. I remember thinking, "I never should have left." I felt like I had abandoned that journey. I wasn't advocating anymore. I wasn't talking about trigeminal neuralgia. I was just living my life because I thought I was cured. Looking back now, I wish I had stayed involved. But when the pain came back, it gave me even more motivation to get out there and do more.

I've always thought of myself as a bit of a tomboy. I've never really been into getting my nails done or all of that. I've always been active. I've broken just about everything on my left side. I recently broke my right arm. A lot of the things I've chosen to do require resilience because you're going to get hurt. I've always believed that if I set my mind to something, I'm going to do it. Living with trigeminal neuralgia takes that resilience to another level. You don't really have another choice. You may not push yourself the way I do, but every single day you're going to have to deal with it. Whether your pain is a two or a ten, you get through that day and then wake up the next morning and do it again. When I'd wake up already feeling a flare starting, I'd ask myself, "How can I manage this today?" I'd try meditation. I'd practice box breathing. After a race I'd use heat. Sometimes I'd use an ice pack. Over time I developed my own routines. Living with this condition forces you to become resilient. I really feel like if I can deal with this every day, I can do anything I put my mind to.

My parents were both military. There wasn't a lot of crying in our house (laughing). They always taught me that I could do whatever I wanted if I was willing to work for it. I still believe that.

How did your advocacy grow from volunteering into creating awareness initiatives like Keep It Rolling and Where's Sparky? —the project where your traveling mascot visits people living with facial pain across the country?

It happened gradually. Once I found the Facial Pain Association, I started looking through the website. I saw they were looking for volunteers, and I thought, “I think I can do that.” So, I reached out, and it just snowballed from there. I realized that a lot of people still didn't know about trigeminal neuralgia. One of the first awareness projects I created was called **Keep It Rolling**. I took a train trip from Flagstaff, Arizona, to North Carolina. I had all these little toy cars, and at every stop along the trip I left one behind with a tag explaining trigeminal neuralgia and directing people to the Facial Pain Association website. I wasn't trying to make people remember the name. I just wanted people talking about it. Maybe someday someone they know would say, “I'm having these stabbing, lightning-bolt pains in my face,” and hopefully they'd remember that conversation. Maybe they wouldn't remember the name trigeminal neuralgia, but they'd remember that there was a name for it. If they Googled “stabbing lightning pain in the face,” hopefully trigeminal neuralgia would come up. That was really the whole purpose behind it. I even sent some of the cars to Hawaii. One of the women there placed them around the island. We had so many people clicking through to the website and reading about trigeminal neuralgia. When that project finished, I started thinking about how isolated everyone kept saying they felt. That became the inspiration for **Where's Sparky?** I sent Sparky to New Jersey first. Since then, he's been traveling to one person living with facial pain in every state. Each person writes in his journal. They include a small gift or memento before sending him on to the next person. I wanted Sparky to become a mascot that reminds people how strong we are and how connected we are. He's keeping us together.

How has helping other people changed your own journey with facial pain?

Helping other people helps me focus on something other than my own pain. There are still so many things I want to do. I'd like to go back to work. I'd like to have the new procedure that's being done in Ohio. Hopefully my insurance will approve it. If it works, maybe I can go back to work. Not necessarily because I need a paycheck. I'd just like to do something again. Maybe go back to school. Maybe return to acting. Those are still goals I have.

Helping other people takes my mind off what I'm dealing with and lets me focus on someone whose pain might be even more severe than mine.

"Pain into Purpose" *continued on page 16*

"Pain into Purpose" *continued from page 15*

When someone who's newly diagnosed reaches out to you, what do you hope they take away from that very first conversation?

I want them to know they can call me anytime. They can text me. They can email me. They can visit my website. They can go to the Facial Pain Association website. I always tell them there may not be a cure yet, but you have to look for the bright side. If you stay in the mindset of, "Woe is me," you're going to fall into that black hole. Once you fall in, it's really hard to climb back out. You have to stay strong.

Has there ever been a time when someone you've supported ended up helping you?

Yes.

I've become very close with another woman who's living with trigeminal neuralgia. She's also had a double mastectomy, multiple sclerosis, and it seems like just about everything that could happen has happened to her. But she has such a positive attitude. Whenever I'm feeling down, I can call her, and she always seems to know exactly what to say. I lost my mom two years ago. My mom used to call me "Sugar." I told this woman about that once, and now every time we talk, she calls me "Sugar." That may seem like a little thing, but it has meant so much to me. My family knows what I go through, but they can't really imagine the pain. She understands because she's living it too. She knows exactly what I'm going through, and I know exactly what she's going through. She's helped me tremendously.

What would you say to someone who feels like nobody understands what they're going through?

I tell them, "I get it." A lot of people don't realize this, but when I post on Facebook or Instagram, those posts are usually about what I'm personally going through. The people who connect with those posts are often experiencing the very same things. Some days I'm dealing with brain fog, doom scrolling, pain, or exhaustion. Other days I feel good. One of my biggest challenges is that when I start feeling better, I immediately switch into go mode. I do too much. I wear myself down. Then I'm right back where I started. I've learned so much from other people living with trigeminal neuralgia, and they've learned from me. We share ideas. We ask each other, "Have you tried this?" or "Have you done that?"

Most importantly, we give each other hope. You have to have hope with trigeminal neuralgia. If you don't have hope, that's when people start thinking about giving up. Giving up isn't an option. It just isn't.

If your advocacy changes just one thing for the next generation of people living with facial pain, what do you hope it changes?

I hope more people become advocates. The more voices we have, the louder we become. The louder we become, the more awareness we create. More awareness brings more funding. More funding leads us closer to a cure. I honestly believe our cure is going to come from somebody looking at this disease with fresh eyes. Maybe not a neurologist. Maybe not a pain specialist. Maybe someone from outside the field who hears all of these different stories and asks, "Has anyone looked at this?" or "Has anyone studied that?" That's what's going to move us forward.

For a condition that's often called the suicide disease, it simply doesn't receive enough attention. The level of pain people experience doesn't match the level of awareness. That has to change. I just try to do my part by putting it out there. ■

Learn more about Marsha's advocacy efforts by visiting her website.

Pain and Sleep:
A Bi-Directional Relationship

Dennis R. Bailey, DDS

With respect to orofacial pain, as well as pain in general, sleep is related in a variety of ways. Good sleep can help in managing one's pain and poor sleep may result in higher levels of pain. Therefore, addressing sleep when pain is the major concern needs to be a consideration. Recognition and addressment of a sleep issue can result in better management of facial pain.

First of all, it must be understood that sleep is not an altered form of consciousness. It is in fact a separate state of being. Much of our understanding about sleep only scratches the surface as to what sleep actually does. It is well recognized that sleep is an essential aspect of life and is necessary to sustain our quality of life. Good sleep restores our bodies and organs to maintain our health and well-being.

The relationship between pain and sleep, despite being bidirectional, is not equally impactful. It has been shown that poor sleep has a greater impact on pain than pain does on sleep. This requires attention to the various aspects of poor sleep that may impact pain levels. The more common sleep conditions that may impact pain are:

Insomnia: The inability to fall asleep or stay asleep. Normally, one should be able to fall asleep in 15 to 20 minutes. It is not uncommon to wake up once during the night. The key is to be able to get back to sleep quickly.

Sleep Fragmentation: This refers to frequent periods of broken or disrupted sleep that may or may not always be evident. People may wake up and not feel well rested or feel tired.

Sleep Quality: This is based on one's subjective view of their sleep.

Sleep Duration: Less than 7 hours of sleep and especially less than 6 hours is associated with increased pain perception and over time impacts quality of life.

Non-Restorative sleep: This is the feeling of poor sleep and not feeling rested. This may be related to a sleep disorder (insomnia or sleep apnea) that is not recognized or diagnosed.

Sleep Efficiency: This basically relates to being asleep 85% of the time or more when in bed.

Sleep is made up of two major forms: REM (Rapid Eye Movement) sleep and NREM (non-REM) sleep. NREM sleep is further broken down into three stages: stage 1 or N1, stage 2 or N2, and stage 3-4 or N3. The chart below describes these and the approximate amount ideally people should have each night. A reduced amount of REM sleep may result in increased pain levels. Stage N2 is important because this is a lighter plane of sleep and is where bruxism (teeth grinding) is most likely to occur. More N2 sleep may also be associated with reduced N3 sleep, which is also known as deep sleep or restorative sleep. Hence, reduced N3 sleep often results in one feeling tired and less well rested.

"Pain and Sleep" continued on page 18

"Pain and Sleep" continued from page 17

Sleep Type	% of sleep	Characteristics
REM	**20-25%**	**Dream sleep – for memory consolidation**
NREM:		
Stage N1	5%	Transitional sleep stage between REM into NREM stages
Stage N2	50%	Lighter stage of sleep
Stage N3	20-25%	Deepest stage of sleep – also known as restorative sleep

These stages of sleep fluctuate during the night as shown below. These stages as well as their length may differ with age as well as health issues, medication usage, and of course painful conditions.

Ideally, based on research and consensus, the amount of sleep each night should be between 7 and 8 hours. Seven hours has been found to be optimum. It is not true that as we age, especially for those over the age of 70, we do not require less sleep.

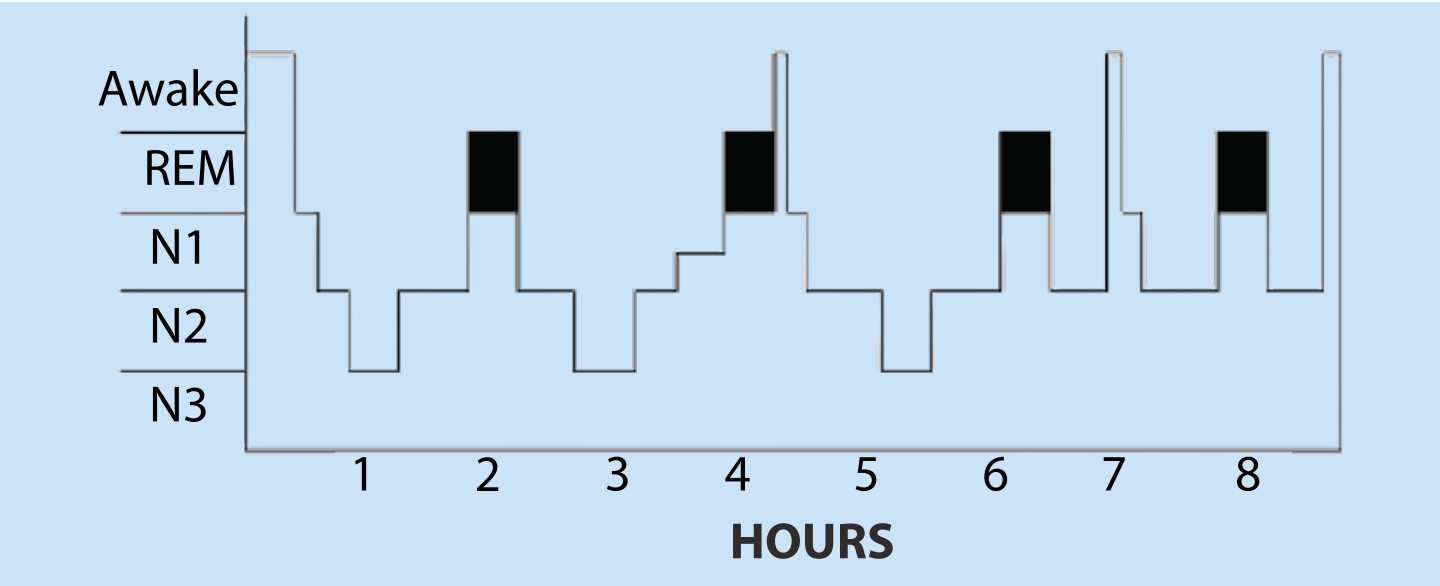
There are six major categories of sleep disorders. Three of these are more likely to be associated with orofacial pain and are:

Insomnia: This is the most common sleep disorder.

Sleep Apnea: Also referred to as a sleep-related breathing disorder. This is the most recognized disorder, is often associated with snoring, and gets attention due to the relationship to so many health issues such as hypertension, cardiovascular disease (especially A-fib), Diabetes type 2 and its impact on quality of life. Another aspect is hypoxemia, or lower blood oxygen levels.

Movement disorders: These include restless leg syndrome (RLS) and periodic limb movement disorder (PLMD), both of which impact sleep quality. This also includes sleep bruxism that may have a relationship with facial pain and headache pain.

A fourth condition termed **COMISA (Comorbid Insomnia and Sleep Apnea):** This is often not well



recognized. These two disorders often co-exist and may need to be managed in concert with one another, especially in the presence of pain.

As mentioned, hypoxemia is also a concern. It has been shown that this is associated with the potential for increased pain, especially headache. Lower blood oxygen levels are associated with sleep apnea, especially a condition termed intermittent hypoxia, where blood oxygen levels fluctuate over the night. This is related to cardiovascular disease and hypertension. Hypoxemia is also related to increased levels of inflammation, a major finding associated with pain.

In addition, the way we breathe is important, both during the day and at night. Often these are not the same. Increased mouth breathing is often more likely during the night as opposed to the daytime. The preferred route of respiration is through the nose. The nose is often referred to as the carburetor of the body. This is usually not emphasized as it should be. Nose breathing is critical to improved oxygen levels for the body and especially the brain. It assists with oxygen levels by warming and humidifying the air we breathe so that the inspired air (oxygen) is better absorbed by the lungs. This is further improved because the sinuses around the the nose release nitrous oxide into the air and this assists with the absorption of oxygen by the lungs. Helping people with their breathing has a major impact on their pain levels along with the ability to relax and reduce stress.

If a sleep disorder is suspected, there are several screening methods that can be utilized to determine if a person is at risk for a specific sleep disorder. Most practitioners are aware of these and should be able to assist with their use of them. Some are specific to sleep apnea or to insomnia. All of these are available online. Also, the use of a sleep dairy can be helpful to determine if one's sleep is fragmented or if an adequate number of hours of sleep are accomplished each night.

Medications that may be used to manage orofacial pain or are used for a medical condition may also impact your sleep. It is important to be aware of the impact the medication may have on sleep. Discussing this with the person who prescribes the medication is an important first step. This then can lead to ways to address your sleep and thus improve the impact of the medication on the painful condition.

- Improving sleep in conjunction with pain management can be accomplished with some very basic techniques.
- Improved breathing with emphasis on nose breathing and reduction of mouth breathing.
- Cognitive Behavioral Therapy (CBT) is helpful for sleep, especially insomnia, and with pain management.
- Mindfulness training focuses on relaxation and breathing.
- Improve sleep hygiene and conditions – keep bedroom cool and dark with noise reduction. Do not watch the clock.

The management of pain should be viewed as a multidimensional approach with good sleep being a major aspect of the plan. Being aware of the presence of a sleep disorder or just poor sleep is the first step. Once recognized and then addressed with your doctor(s) can help facilitate a reasonable plan to improve your sleep with the ultimate goal of improved pain management. ■

YPC Facial Pain Association
Young Patients Committee

As both neurologist and facial pain patient, Rachel Glasser, MD, brings a unique perspective to every patient encounter.

An interview with Rachel Glasser, MD by Danielle Clements, Special Correspondent

A View From Both Sides

When patients walk into Dr. Rachel Glasser's office, they're looking for answers. But they're also looking for hope. They want to feel seen, heard and understood. What many don't realize is that long before Rachel became a neurologist specializing in headache medicine, she once sat where they now sit, yearning for those very same things.

Rachel was just 15 years old when a persistent pain in her ear first appeared. What followed was a long and frustrating search for answers—countless physician visits, imaging studies and tests—before she was finally diagnosed with trigeminal neuralgia. Over the years, she underwent multiple microvascular decompression surgeries, nerve blocks, Gamma Knife procedures, and other treatments. In an especially rare circumstance, the condition affected both sides of her face. While treatment ultimately brought her trigeminal neuralgia under better control, it also ushered in a new challenge: chronic migraine.

Living with relentless facial pain is difficult at any age. Rachel faced it while navigating adolescence and early adulthood, trying to build a future even as she struggled to understand what was happening to her own body. That experience would ultimately shape not only the course of her life, but the kind of physician she would become.

The correlation between Rachel's own experience with facial pain and her decision to pursue medicine may seem obvious, but for Rachel, the path wasn't defined by a single moment of clarity. “I think it was a very natural progression for me,” she said. “There wasn't one day I can remember that I knew I wanted to be a doctor because I've always been interested in science and the human body. Then this”—her diagnosis and the journey that followed—"just got me more interested because I did a lot of self-research on different things when I was looking for a diagnosis.”

That curiosity eventually carried Rachel through medical school, a neurology residency at University Hospitals in Cleveland and, today, a headache and facial pain fellowship at Cleveland Clinic. Next year, she plans to return to University Hospitals, where she hopes to treat both adult and pediatric patients while continuing to practice general neurology. For Rachel, choosing a specialty wasn't driven solely by her diagnosis. She approached medical school and residency with an open mind, giving every specialty “a fair shot.” Still, neurology always felt like home. “I really enjoyed a lot of my other rotations,” she said, “but neurology was always just my favorite. It just felt like the natural place to go.”

Along the way, Rachel found physicians who did far more than diagnose her. They listened. They believed her. They encouraged her dream of becoming a physician herself, becoming the kind of mentor—and ultimately the kind of doctor—she hoped to be for others.

Anyone who has watched a medical drama on television has some appreciation for the demanding and grueling pace of residency. Now imagine navigating those long hours while carrying your own migraine medication in your pocket. For Rachel, the practice of medicine itself often became a welcome distraction from the pain.

Living with chronic illness has also given her an unexpected appreciation for time. “It has helped me prioritize my time,” she said. “I know when I'm feeling well that I can do all these great things. But you never know if the next day, you’re going to be feeling well or not.” That uncertainty has

taught her to embrace the good days. “You really have to take advantage of every second that you are feeling well… and enjoy your life.” It's a lesson she learned as a patient, and one she now carries with her as a physician.

Rachel understands something many physicians never have the opportunity to experience: what it feels like to sit on the other side of the exam table. Having been both patient and provider, she approaches every encounter with a perspective shaped as much by lived experience as medical training. She asks the questions she once wished someone had asked her. That said, she is careful to ensure each patient conversation is focused and purposeful. “The time that I have with patients is about them and for them. While I might use my own personal experience to express more compassion and empathy, I never want to turn the conversation on me [and my experience],” she said. “You only get so many face-to-face moments with patients and their time is valuable. They may have waited six months [for an appointment] to see me,” she continued.

Drawing from her own experiences, Rachel begins each visit by understanding what success looks like to the patient. She has learned that physicians and patients don't always arrive with the same definition of success. A physician may be focused on treating the disease. A patient may simply want to enjoy dinner with their family without pain. Recognizing that distinction is foundational to building trust.

Rachel’s commitment to facial pain advocacy extends well beyond the doors of her practice. As an integral part of the Young Patients Committee (YPC) with the FPA, Rachel was key in establishing the YPC Resiliency Scholarship – a scholarship for any young patient pursuing higher education, something near and dear to Rachel’s heart. Additionally, her efforts to help develop and lead the Young Patients Support Group is clearly something she is proud of. The monthly support group reminds young people living with facial pain that theirs is not a road they need travel alone.

Looking back, she knows exactly what she would tell the frightened 15-year-old girl who was overwhelmed by pain and terrified that life as she imagined it had slipped away. “It’s all going to work out. It’s all going to be ok. The world is not over. This isn't the end,” she stated. She pauses before admitting something else, “I don't know if I would have believed it at the time, but I would have appreciated the reassurance.” Living with facial pain can make it feel as though every dream is suddenly out of reach, but Rachel knows differently. “Just because you get diagnosed with this does not mean it's all over, you can still do all the things you want to do.”

For Rachel, those aren't simply words of encouragement—they're a life she's already living. ■

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#MyTNStory

#MyGNStory

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#MyONStory

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Visit www.FacePain.org/Face-Today-Together for more information.

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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

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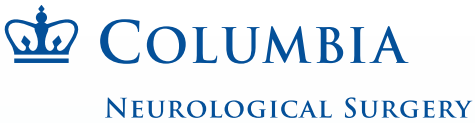

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MAYFIELD
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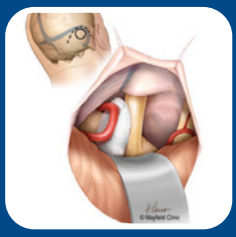
Mayfield offers several treatment options for patients with trigeminal neuralgia, glossopharyngeal neuralgia, hemifacial spasm, and other types of facial pain.

Our treatments include:

Gamma Knife radiosurgery

Microvascular decompression surgery (MVD)



Percutaneous stereotactic rhizotomy (PSR)

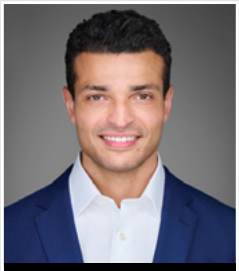
Balloon compression rhizotomy

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.

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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$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!

How to Talk to Your Loved Ones about Your Facial Pain

Facial pain can be incredibly isolating. When pain forces you to cancel plans, miss important events, or step back from the people you care about, it's easy to feel like you're letting others down — as a friend, parent, spouse, or partner. But living with facial pain is not a reflection of your commitment to the people you love. No one should have to face that journey alone.

Think about Alternative Ways to Communicate

If talking hurts, there are many non-verbal communication styles you can try. Just because you can't speak doesn't mean you don't have a voice — you just need to find new ways to communicate. Try writing on paper or in your phone, or encourage your loved ones to learn sign language with you.

Think About Your Loved Ones

This can be difficult to hear, because it might feel like it is de-centering your experience with facial pain, or that you always have to think of others before yourself — but this is not the case.

When you understand how your facial pain affects your loved ones, communication, collaboration and boundaries become easier. Your facial pain is something your whole family and social circle experiences.

When talking to your loved ones, validate their feelings. Validating does not mean agreeing — it simply means you recognize their emotions and understand what they are saying.

Place emphasis on saying how you feel, recognizing the other person's emotions, creating collaborative plans, working within the limits of your facial pain, and setting flexible boundaries where everyone feels they have the right to say "no" without fear of an argument.

What Not to Do When Talking to Your Loved Ones

Don't lash out in anger and frustration. It is understandable that you are in pain and feel isolated — but anger and harsh words won't help the people who care about you, and can cause conversations to spiral into accusations on both sides.

Don't assume that your loved ones don't care about you just because they are upset, or don't understand your pain. We are all human, and it's natural to make mistakes and feel strong emotions, facial pain or not.

Discuss Caregiver Roles

No facial pain patient wants to have a conversation with a loved one about that person becoming the primary caregiver if facial pain becomes severe enough.

It can feel like a loss of autonomy for the patient and creates anxiety around the response from the loved one about taking on a large responsibility.

However, it is better to have these conversations before facial pain becomes severe and it leaves both parties in a state of panic and disorganization.

Only you can decide when and where you need to have this conversation with your loved one. As with all conversations, make sure to leave room to listen and talk in a calm environment where both of you feel comfortable setting boundaries and communicating expectations. Make sure to end on a positive note about your appreciation for your loved one's help.

Make Room for Quality Time

Making room for quality time with your loved ones when you have facial pain can be difficult.

You might want to do activities to bond with your loved ones and find that they are complicated by your facial pain. Facial pain is not something you can turn off when you want to have a good time. This can lead to feeling demoralized and unmotivated to connect with others.

You are worthy of love and connection, even when you have facial pain. Make sure you continue to make room for quality time with others — it will benefit your mental health, build trust and connection with others and help you remember:

You are more than your facial pain.