Journal of the Facial Pain Association

Spring 2026

Quarterly

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

ON THE COVER

Living with trigeminal neuralgia or other neuropathic facial pain can be isolating, frightening, and overwhelming. You may feel alone, unsure of where to turn, or uncertain about what comes next. The Facial Pain Association (FPA) understands. For over 35 years, we have supported people like you, offering connection, understanding, and guidance when it is needed most.

The FPA provides a wide range of resources to help you navigate this journey. One-on-one Peer Mentors, virtual and in-person support groups, educational articles, conferences, and books all give you answers, reassurance, and practical tools. Our experienced staff is available to guide you toward the right support and information for your situation.

Our mission is to make sure you never feel alone, overwhelmed, or unheard. Whether newly diagnosed, struggling with treatments, or simply needing someone to listen, the FPA offers compassionate support, understanding, and community every step of the way. You are not alone — we are here for you. ■

From the Board Chair

The Facial Pain Association's (FPA) mission is to serve those with neuropathic facial pain including trigeminal neuralgia though Support, Education and Advocacy. This issue of the Quarterly is focused on what we do to provide Support.

When I first encountered the symptoms of trigeminal neuralgia (TN) 17 years ago, in addition to feeling excruciating pain, I felt scared, alone, bewildered, lost, frustrated and depressed. Everyone on our board and emeritus board has felt trigeminal pain and many of these other feelings, except for one whose daughter went through this and knows the impact of this disorder while also feeling the immense frustration of a mother who couldn't eliminate her 11-year-old daughter's pain. We all know firsthand how much we needed support. This first-hand experience coupled with our staff's deep understanding of the needed support from their day-to-day contact with people in our community, and our community research, guide our actions in this area.

The FPA has spent 35 years providing support to people like you and me. 35 years! We have articles, presentations, conferences, an expert staff, Peer Mentors, Support Groups, two outstanding books and much, much more to support you when you have these and many other questions.

- What condition do I have?
- What should I know about this condition?
- What is the right treatment plan? My healthcare providers don't seem to know.
- In addition to medications and surgical procedures, what else can I do?
- How do I find the right doctor? This is a rare condition and I can't find anyone.
- Can I talk to a staff member to steer me in the right direction?
- Can I talk to someone who has gone through this – such as a Peer Mentor?
- Can I just talk to someone? I'm down and frustrated.
- Is there a group in my area with TN, such as a Support Group?
- Is there a book focused on all aspects of trigeminal neuralgia?
- Is there a book focused on helping me live with facial neuropathic pain?
- Is there a conference so I can learn and talk to expert healthcare professionals

We at the FPA are not doctors, although we strongly rely on our Medical Advisory Board to help ensure we are providing accurate information. Healthcare providers, such as neurologists, neurosurgeons, orofacial pain specialists and others experienced in this area can help you address the pain. Meanwhile, the FPA is here to demonstrate that there are many of us with this condition and to provide accurate information so unlike me 17 years ago, you'll be less likely to feel scared, alone, bewildered, lost, frustrated and depressed...all while being in pain.

We believe that we have a deep understanding of the support you need and we've built an organization around meeting those needs. We are here for those with TN and other forms of neuropathic facial pain. We are here for you!

David J Meyers

David Meyers
Board Chair, The Facial Pain Association

A Message From the CEO

When the Trigeminal Neuralgia Association (now the Facial Pain Association) first came to be over 35 years ago, it was primarily because of the need for educational resources and support. One patient, looking for others who might understand her experience because of what they'd been through. Without the internet or social media, you can imagine how difficult it was to find that kind of community.

Fast forward to 2026 and we take for granted the ability to immediately connect with others. But when you are dealing with a rare condition, finding those other people becomes complicated once again. The Facial Pain Association is dedicated to helping people with facial pain make those connections.

Connection takes many forms, which is why our support network is intentionally broad. Our Support Groups, both virtual and in-person, offer safe spaces where individuals can share experiences, ask questions, and feel less alone. For many, this is the first time they have ever spoken with someone who truly "gets it."

Our Peer Mentor Program builds on that connection by offering one-on-one support. Trained volunteers who have walked this path themselves are matched with individuals who are newly diagnosed or navigating a particularly difficult chapter. These relationships often become lifelines and are grounded in empathy, honesty, and lived experience.

We also recognize that pain does not take holidays off. This season, when others are gathering and celebrating, can feel the loneliest for those who are not up to it because of pain. Our Holiday Help Line ensures that no one has to face moments of heightened isolation alone. During times when these feelings are often amplified, a compassionate voice on the other end of the line can make a meaningful difference. In an effort to meet people where they are, the Holiday Help Line now includes a chat feature for times when talking triggers pain and is simply too much.

Watching someone you care about in pain is incredibly difficult, and those who support their loved ones and friends living with facial pain need support too. The FPA offers resources and support for this incredible group of people as well. One of our topic-based support groups provides a place for caregivers to share experiences and offers reassurance to those who love and care for someone in pain — often quietly carrying their own burden.

Finally, we are deeply committed to supporting younger patients through our Young Patients Committee. Children, teens, and young adults face unique challenges in their medical journeys, their emotional health, and in their social lives and they need others who understand the unique challenges of going to college, being a young parent or trying to start a career with facial pain. This committee ensures their voices are heard, and their needs are addressed, helping them build resilience and community at a critical stage of life.

More than three decades after our founding, the heart of the Facial Pain Association remains the same: connection, compassion, and community. We are honored to walk alongside every person who turns to us and grateful to all who make this work possible.

Melissa Baumbick

Melissa Baumbick
Chief Executive Officer, The Facial Pain Association

Journal of The Facial Pain Association

Quarterly

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800-923-3608 • www.FacePain.org



Managing Editor & Circulation Manager
Natalie Merrithew

Medical Editor
Raymond F. Sekula, Jr. MD

Art and Design
Caren Hackman

Mark, E. Linskey, MD
Orange County FPA
Support Group Faculty Advisor
FPA Medical Advisory Board Member

MAB Corner

Why Support Groups Matter:

A Longstanding Model for Facial Pain Care

Support groups play a critical role for people living with trigeminal neuralgia (TN) and other facial pain conditions, even though their importance is not always clearly defined. Their benefits are real and long-lasting, providing education, connection, stability, and advocacy for patients and families.

The value of support groups was recognized early by Claire Patterson, founder of the Trigeminal Neuralgia Association (TNA), after discussions with her surgeon, Dr. Peter Jannetta. In 1990, she founded the national TNA support group, which eventually grew into today's Facial Pain Association (FPA). While national groups provide vital resources, they cannot always meet the ongoing, local needs of patients.

The Orange County, California support group has been a longstanding example of how local support can be managed effectively. Founded independently by TN patient Claire Castle at Saddleback Hospital in Laguna Hills, the group quickly affiliated with the TNA when it formed. Today, it is the oldest support group affiliated with the FPA and the only one to have remained continuously active for more than 35 years.

When the Orange County group began, online resources were limited. Since then, internet-based support groups—especially on platforms like Facebook—have become essential, particularly for people in rural or sparsely populated areas. These groups help patients connect and share information, but they also have limitations. Discussions may be dominated by a few voices, information is not always accurate, and groups often lack experienced leadership or oversight.

Orange County's large population has made it possible to sustain a stable, in-person (and now virtual) support group. Even so, support groups are often fragile. They depend heavily on leadership, institutional backing, and volunteer energy. When founding leader Claire Castle stepped down, Linda Benson took over in 1998, securing sponsorship from Hoag Memorial Hospital Presbyterian and later the University of California, Irvine (UCI). She also launched the group's first newsletter and email communications and sought physician involvement.

In 2005, I joined the group as faculty advisor, a role I continue to serve more than 20 years later. In 2008, leadership transitioned again—this time to Deborah Kurilchyk, MPA, a TN patient with extensive nonprofit leadership experience. Her involvement marked a turning point.

Deborah modernized the group by moving communications fully online and co-directing a regional TNA/FPA conference at UCI. Most importantly, she introduced two major innovations. First, she created a leadership board, distributing responsibility across multiple people. This structure brought stability, ensured continuity, and created a pipeline for future leaders. Second, she expanded the group's mission beyond patient support to include professional and community education.

Under board leadership, the group developed a comprehensive new-member information packet. It included educational materials for primary care physicians, dentists, and emergency room providers—helping improve care, reduce fear around dental visits, and guide treatment during pain crises. These materials have since been widely shared and published through FPA channels.

The group also began broader outreach. Starting in 2008, it established an ongoing presence at the California Dental Association Annual Meeting, educating dental professionals about TN and facial pain.

In 2018, leadership passed smoothly to board member Andy Petitjean. He maintained the board structure and successfully guided the group through the COVID-19 pandemic by transitioning meetings to Zoom. This shift expanded the group's reach nationwide, allowing patients and leaders from across the U.S. to participate.

Today, the Orange County FPA support group meets quarterly via Zoom. Meetings include open discussion, peer connection, and expert presentations on topics such as surgery, medication, dental care, wellness, and complementary therapies. Educational outreach continues to grow, with recent efforts focused on emergency and urgent care providers across Southern California.

For those interested in starting or strengthening a support group, Deborah Kurilchyk's article in FPA Quarterly is highly recommended. The Orange County FPA support group can be reached at octnafpa@yahoo.com and is generous in sharing its experience and materials.

This year, Andy Petitjean received the FPA's first-ever Dr. Jeffrey Fogel Outstanding Volunteer Award, recognizing decades of collective leadership and service. It has been an honor to serve as faculty advisor to this remarkable group and to witness the lasting impact a well-run support group can have on an entire community. ■

Major Benefits of Support Groups

- **Realizing you are not alone**
- **Information and education regarding your condition**
- **Identifying treatments**
- **Identifying healthcare professionals**
- **Expressing feelings & reducing distress**
- **Learning coping strategies**
- **Gaining self understanding & insight**
- **Gaining hope**
- **Friendships and mutual support**
- **Emotional safety**
- **Helping others**
- **Affordability**

Facial Pain Registry

Data Speaks: The Power of Information

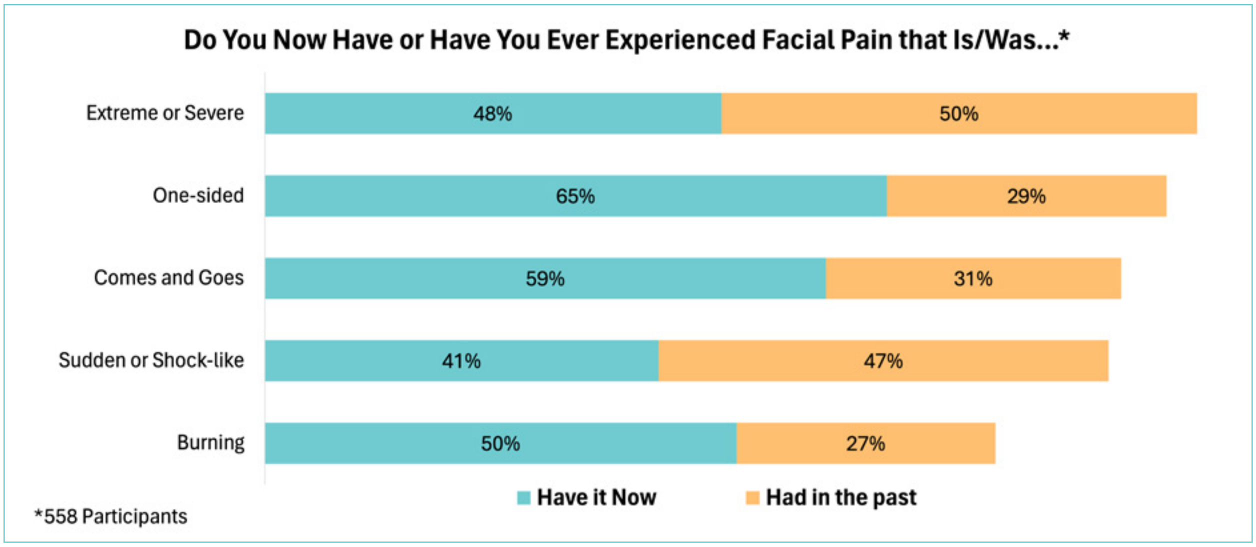
By Liam Winters, Tristan Olinger, and David Ciemnecki

Thank You to Everyone Who Has Participated in the Facial Pain Registry

In our Winter 2026 Quarterly, we reported that 409 individuals had completed at least one survey, and 377 had completed all three surveys. As of February 1, these figures increased to 608 participants with at least one survey completed and 558 who have completed all three. We are pleased to announce that we achieved our goal of 500 participants completing three surveys by the end of 2025 ahead of schedule. Our next objective is to reach 1,000 participants completing all three surveys by the end of June 2026.

Descriptions of Pain Vary from Person-to-Person

Registry participants reported whether they currently have, previously had, or never had pain. The charts below show the percentage of respondents who experienced different pain types. Most reported extreme, severe, or one-sided pain, and for 90% the pain was episodic, meaning it came and went.


Do You Now Have or Have You Ever Experienced Facial Pain that Is/Was...*

*558 Participants

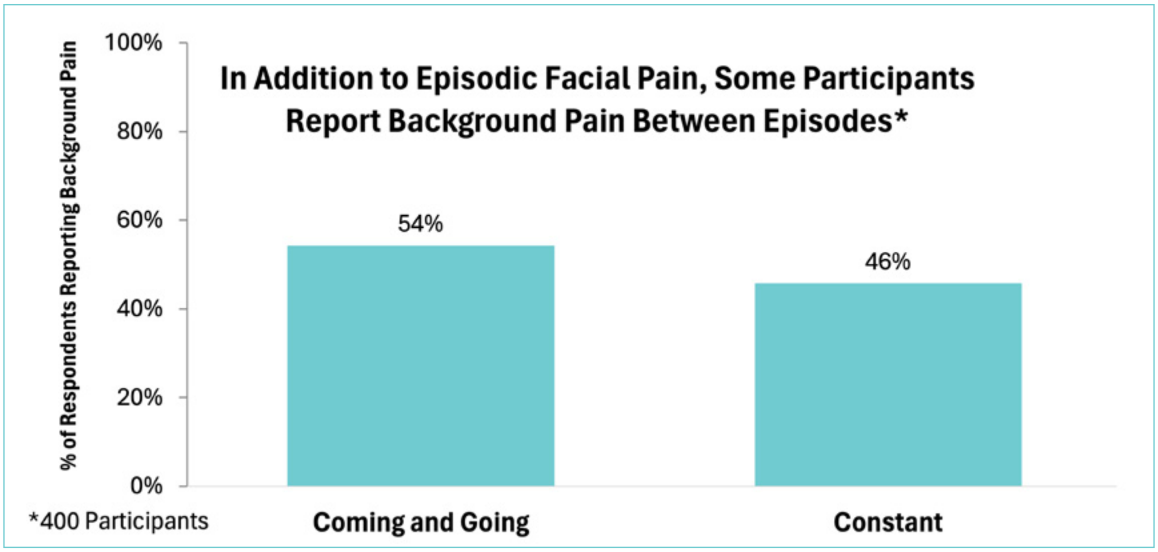
Join the Facial Pain Registry!

The three initial surveys focused on participant backgrounds and pain description. Upcoming surveys will address topics such as medications and mental health. We anticipate launching these new surveys during the summer.

If you have yet to complete the registry surveys, we encourage you to log in by scanning the QR Code so your experiences are represented. It will take just 15-20 minutes for most participants.

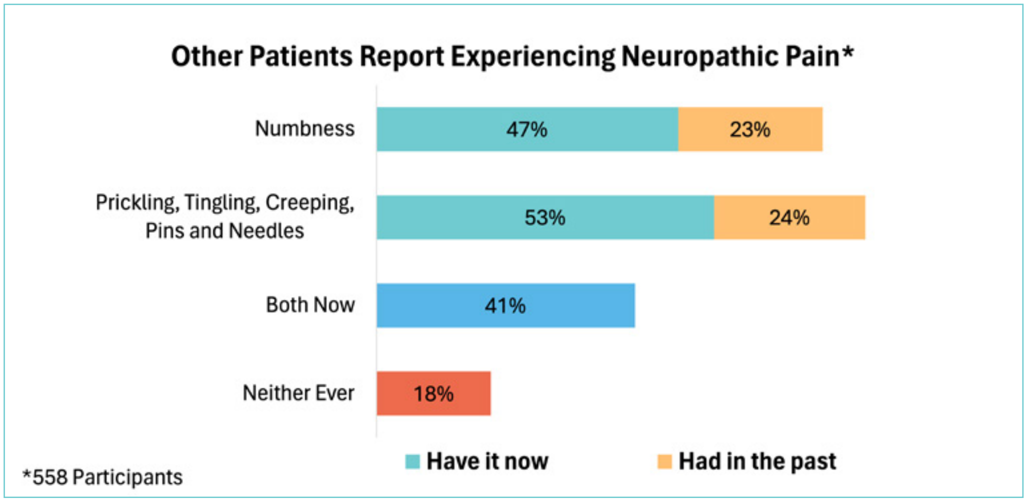
Nearly Half Describe Concomitant Continuous Pain

We also asked participants if they experienced mild background pain between pain episodes. Seventy-two percent (400 participants) reported having such pain. Of these, just over half (54 percent) said their pain between episodes was intermittent, while slightly less than half (46 percent) described it as continuous. The term for continuous pain between episodes is "concomitant continuous pain." According to an Italian study,[1] concomitant continuous pain can occur in up to half of people who experience intermittent shock-like pain. At the FPA, we are encouraged to see our registry data align with findings from other researchers globally, confirming its validity and usefulness for further research. The more individuals who participate in the registry, the more valuable the data becomes.



Nearly Half of Participants Report Being Affected by BOTH Numbness AND Prickling, Tingling, or Pins and Needles

We described types of neuropathic pain related to the trigeminal nerve. While many refer to all such pain as trigeminal neuralgia, symptoms like numbness, tingling, or pins and needles indicate trigeminal neuropathy. Trigeminal neuralgia is marked by sudden, shock-like facial pain often triggered by light touch and commonly caused by blood vessel compression, but tumors or multiple sclerosis are also possible causes. In contrast, trigeminal neuropathy involves constant burning or aching due to nerve damage, typically resulting from injury, dental work, shingles, or autoimmune disease. Since each condition has different causes and treatments, our upcoming medication survey will help assess whether trigeminal neuropathy is managed correctly.



Seventy percent of registry participants reported numbness, with 47% currently experiencing it. Pricking, tingling, or pins-and-needles sensations were noted by 77%, and 53% still have these symptoms. Currently, 41% report both numbness and tingling, while only 18% have never experienced either symptom.

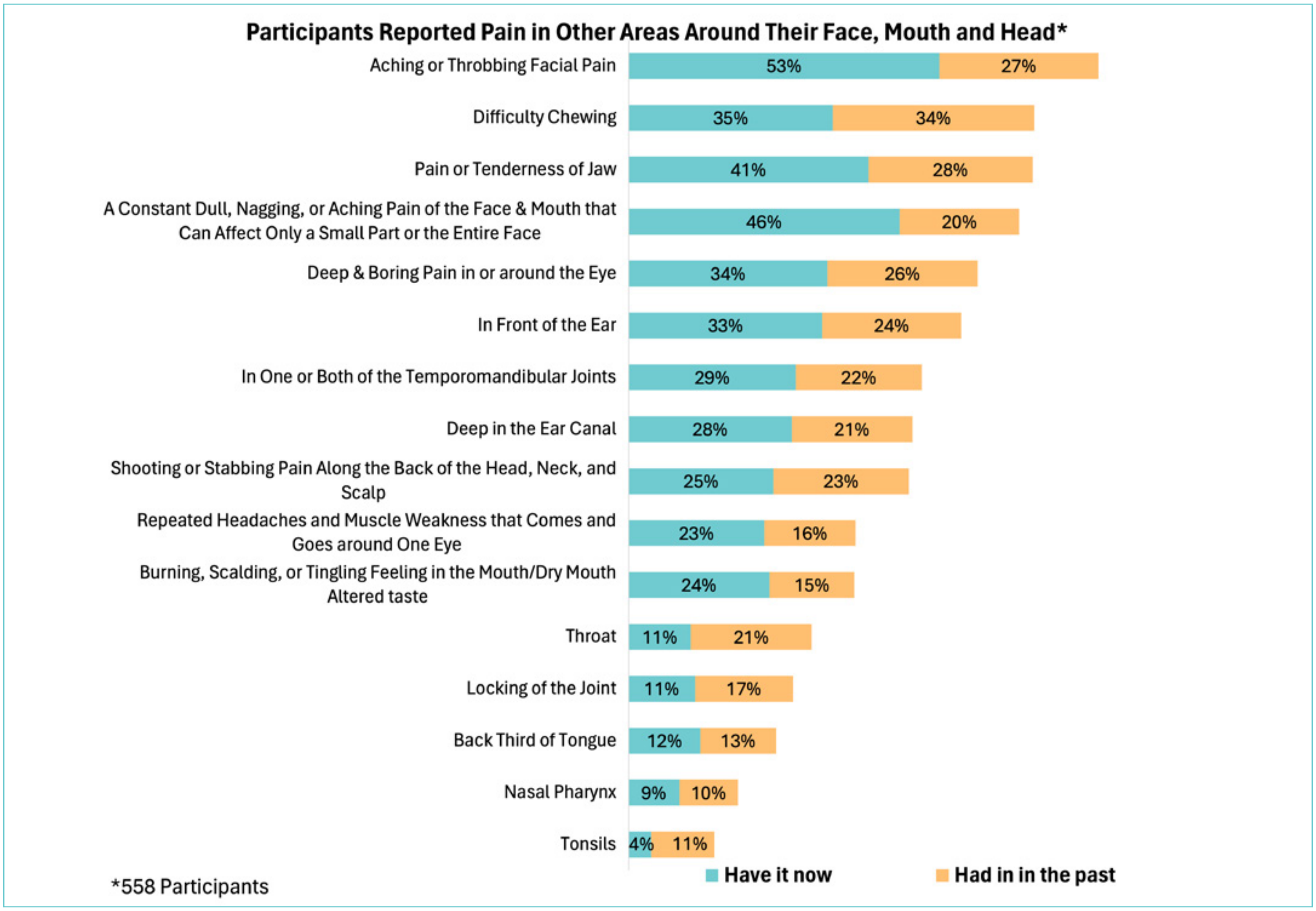
Most Registry Participants Experience Pain Along the Distributions of the Trigeminal Nerve

To better understand participant pain, we asked about location and characteristics. Pain most often occurs along the distributions of the trigeminal nerve, with one-third currently reporting pain near the eye or ear, and 41% near the jaw. About one-quarter currently experience burning mouth or dry mouth and another quarter have pain along the back of the head, neck, and scalp, suggesting that they have occipital neuralgia. About one-half *currently notice aching or throbbing sensations.

You tell us . . .

Email us!

Do these pain descriptions resonate with you? Can you see yourself in these data? Do these results make you feel less alone? Drop us a note using this QR code and let us know.



Participants Reported Pain in Other Areas Around Their Face, Mouth and Head*

*558 Participants

References:

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The Power of Integration

Psychological Support as a Pillar of Facial Pain Wellness

Kathryn Min, PsyD

Support is one of the three central pillars of the Facial Pain Association's mission, and psychological support is essential to that foundation. Facial pain is more than a physical condition. People living with facial pain consistently share that their symptoms disrupt emotional well-being, relationships, daily functioning, identity, and overall quality of life in profound ways [1, 2].

Even with remarkable resilience, the daily demands of facial pain can take a cumulative toll. This is why access to psychological support matters so deeply. Support is not one-size-fits-all and may change over time as symptoms and life circumstances evolve. Some phases of the pain journey call for formal therapeutic support to process the emotional weight of pain, uncertainty, and stigma, while other phases may be supported informally through peer connection, self-guided mindfulness or gentle movement, or mental health–focused podcasts.

Asking "What do I need right now?" can be a powerful starting point. When lived experience guides care, support becomes more responsive and meaningful [1, 2].

Living With Facial Pain: Daily Life and Care Realities

Facial pain carries a substantial emotional burden, often shaping a person's sense of safety in their own body. At the same time, many individuals are required to navigate complex healthcare systems that demand persistence, coordination, and self-advocacy — often while pain remains unpredictable and poorly understood. For many, the burden of care becomes part of the pain experience itself [1, 2].

Common realities include:

- Grief related to changes in identity
- Social withdrawal
- Sleep disruption/Exhaustion
- Fragmented care across multiple providers
- Fatigue from repeated pain story retelling
- Invisible illness stigma and self-doubt
- Barriers to accessing specialized care

These experiences are not signs of weakness. They reflect how chronic pain is shaped by the nervous system, stress, and lived experience. Highlighting the importance of care that supports the whole person — not just symptoms [2, 4, 6].

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"The Power of Integration" continued from page 9

Psychological Support as Best Practice in Facial Pain Care

In pain medicine, integrating emotional and behavioral support from the earliest stages of treatment is considered best practice because:

- Pain and emotion are deeply interconnected, sharing overlapping neural pathways [6]
- Chronic pain affects the whole person, including emotional, behavioral, and nervous-system responses [6]
- Integrated, interdisciplinary care improves outcomes and quality of life [3]

Pain psychologists and other mental health clinicians trained in pain care help people to reduce fear and confusion around symptoms, support nervous-system regulation, heal from trauma and medical invalidation, and build practical tools for daily life [3, 5]. Rather than "thinking pain away," psychological support helps to restore a sense of safety, agency, and connection so that people can live more fully, even when pain persists.

Psychological support is most often used alongside medical treatments, including medication, as part of a coordinated approach to facial pain care within interdisciplinary care (e.g., neurology, orofacial/dentistry, pain medicine/anesthesiology, otolaryngology, physical therapy, physiatry, psychiatry).

Evidence-Based Psychological Supports: An Overview

Both longer-standing and emerging approaches can play an important role in supporting those with facial pain, depending on their needs, preferences, and stage of the pain journey [4–10]. Support may also be offered in different formats (e.g., in person, virtual, hybrid). What matters most is how an approach resonates with an individual because, as we know, meaning is a deeply personal experience.

Approach	Primary Focus	How It May Help
Cognitive Behavioral Therapy for Chronic Pain	Thought–behavior patterns	Offers tools to reduce distress and support daily life
Acceptance & Commitment Therapy	Values and meaning	Supports engagement in what matters, even with pain
Mindfulness-Based Stress Reduction	Nervous-system calming	Eases stress and reduces reactivity during flare-ups
Self-Compassion–Focused Therapies	Kindness toward self	Helps soften self-criticism and emotional exhaustion
Pain Reprocessing Therapy	Learned pain responses	Supports relearning safety when pain is not signaling harm
Emotional Awareness & Expression Therapy	Stress and emotions	Creates space to safely process emotions that influence pain

What These Approaches Can Look Like in Real Life

Cognitive Behavioral Therapy for Chronic Pain (CBT-CP)

CBT-CP helps people notice patterns between thoughts, emotions, and behaviors that can unintentionally intensify suffering. For example, noticing jaw tightness may trigger the lingering thought, “This is going to spiral and ruin my day,” leading to worry, muscle tension, or pulling back from daily activities. CBT supports learning new, more supportive ways of responding to these moments to stay engaged in daily life, even when symptoms persist [5].

Acceptance and Commitment Therapy (ACT)

(ACT) is based on the idea that struggling against pain can increase suffering. ACT helps people make room for pain while reconnecting with what matters most to them — such as relationships, meaningful activities, creativity, faith, work, or being present for everyday moments — so life is not put on hold while working toward wellness [7].

Mindfulness-Based Stress Reduction (MBSR)

MBSR focuses on gently bringing attention to the present moment without judgment. Many people with facial pain notice constant monitoring of symptoms that can feel overwhelming, leaving the nervous system on high alert. MBSR teaches skills that help the body settle and the mind soften, making pain and stress feel more manageable over time [8].

Self-Compassion–Focused Therapy (SCFT)

Living with chronic pain often brings harsh self-criticism, such as “Why can’t I handle this better?” SCFT supports a kinder inner response to pain, reducing self-criticism, shame, and emotional exhaustion [9]. Think of it like treating yourself with the same kindness that you would a friend.

Pain Reprocessing Therapy (PRT)

PRT is a newer approach that may help some people whose pain is driven by ongoing nervous system sensitivity rather than injury. While research is still emerging, PRT supports responding to pain with less fear and more reassurance, gently helping the nervous system relearn safety so pain signals can soften over time [10].

Emotional Awareness and Expression Therapy (EAET)

EAET is also a newer approach that creates a safe, supportive space to explore how stress, and unresolved emotions and trauma influence pain. EAET helps reduce pain by addressing how stress and unprocessed emotions can keep the nervous system in a state of high alert, which can intensify or prolong pain [4].

How to Access Psychological Support

Psychological support may be accessed through referrals from your pain providers or integrated pain clinics, as well as through insurance provider websites, where you can search for in-network mental health clinicians with pain specialization. Widely used therapist directories such as Psychology Today allow you to search for licensed mental health professionals, including pain psychologists, marriage and family therapists, counselors, social workers, psychiatrists, and psychiatric nurse practitioners who list experience working with chronic pain or health-related conditions. Finding the right support can take time, and it is appropriate to ask clinicians directly about their experience working with chronic pain and related conditions.

Returning to the Whole Person

Facial pain already asks much of those who live with it. I have come to understand this truth as a clinician and researcher working with women Veterans navigating invisible chronic pain and trauma, as a former caregiver to a teenager with a post–dural puncture headache, and as someone with lived experience of migraine, temporomandibular joint disorder, and occipital myalgia. Seeking emotional support is not simply a coping strategy — it is a resilience strategy. Nervous systems heal best when they are not asked to carry pain alone.

"The Power of Integration" continued on page 12

"The Power of Integration" continued from page 11

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An Outstanding Award for an Outstanding Volunteer

An Interview with Andrew Petitjean, the inaugural recipient of the Dr. Jeffrey Fogel Outstanding Volunteer Award

By **Danielle Clements**
Special Correspondent

Recently, the FPA announced a new prestigious accolade honoring an exceptional volunteer. The Dr. Jeffrey Fogel Outstanding Volunteer Award—the first of its kind—celebrates the incredible dedication of FPA volunteers and the profound impact they have on the facial pain community by recognizing those who go above and beyond in service.

Dr. Fogel, a retired pediatrician, is an FPA board member, a trigeminal neuralgia and geniculate neuralgia patient and a longtime volunteer himself. Having led support groups for many years, he understands firsthand the importance of these programs and the difference they make in the lives of people living with facial pain.

The inaugural recipient of the award is Andrew Petitjean, who has been part of the FPA family for nearly 17 years. What began as participation in a patient support group has grown into leadership—today, Andy leads that very group. The FPA recently sat down with Andy to talk about why the organization and his volunteer work mean so much to him.

During the nomination process, one supporter shared: "Andy's passion for helping the facial pain community is unending. Aside from running the Orange County Support Group, he is a lifelong learner—constantly reading new articles about studies, drug developments, and more. He is also incredibly generous with his time, spending countless hours on the phone providing one-on-one support to new patients seeking information and hope."

An engineer by trade, Andy's warmth and compassion for fellow patients are undeniable. His tireless efforts to raise awareness, share knowledge, and offer hope are nothing short of extraordinary.

You've had your own journey with trigeminal neuralgia (TN), which in and of itself is so challenging. Tell us what it was that led you to the FPA.

I had a long journey and had a pretty good outcome and I feel blessed, so I thought I'd pay forward and give it back. For 2.5 years, I kind of wandered around in the darkness. I went through 4 different neurologists, had 2 different MRIs. One MRI radiologist literally told me I didn't have TN.

It took two and half years to get to a doctor who could give me proper medication. They had me on gabapentin for two and half years. The whole time, the TN was coming and going, going up and down and I had no idea if it was providing me any relief.

I don't remember how I found out about the support group, but I did – and it was here in Orange County (California) where I live. I called them up and they said, "hey, we just had this neurologist speak to our group. Why don't you give him a call?" And he ended up becoming my 4th neurologist (Dr. Neal Hermanowicz at UC-Irvine medical, who suggested Dr. Mark Linskey, neurosurgeon, if I wanted surgical treatment).

From that point on, I kind of slowly started to become a support group member. So I've been a member since around 2009.

"Volunteer" continued on page 14

"Volunteer" continued from page 13

How long have you been a leader of the group? What was the genesis that led to your role?

I want to say since about 2018, 2019. I found Dr. Linskey. I got a really good MVD – the excellent outcome meaning no pain and no medications. I just stumbled upon this support group and have benefited from a support group that has been stable over the years. The FPA started out as the TN Association in 1990 with Claire Paterson. Our support group started that same year, 1990. I don't know the exact origins on how it started, but ever since then, there's been stability with this organization. I inherited that stability, so that was a blessing. The other great thing that I inherited, and this is something that I would advocate every support group do, is [to find] a doctor local to the group to be the advisor.

Dr. Mark Linskey lives in and works locally in Orange County, California. He's our advisor. And has been the advisor for this support group for a long time.

My predecessor [Deborah Kurilchyk] was very disciplined. She brought a lot of discipline to the support group; she was very organized. Toward the last years of her tenure as the leader, she created what she referred to as a board. We have this 5-member board that manages the support group. It was very helpful because now you had 5 people willing to do some volunteer work, and then you had Dr. Linskey advising, “We should consider this. We should consider that.”

He’s sort of driving the bus and then you have all of us volunteers doing work. For example, we created all kinds of pamphlets and flyers. We created a dental flyer. We recently helped Dr. Linskey prepare an ER protocol letter. A lot of these have been so helpful. And, the FPA has since added some of this information to the website and quarterly journals and handouts.

But, I'm blessed to have inherited this situation. I was on that board for a while. Deb was saying that her health was starting to deteriorate a little bit, so she needed to step down and I thought, “well, I'm an engineer...Am I going to be any good as a support group leader?” But you know, having all that stability and that support and the other members of the board and Dr. Linskey's support? I mean, that was all I needed.

What kind of events does the Orange County support group run? Are they in person? Are they virtual? Is it both?

It used to be all in-person, and then COVID hit. Since then, it's been all virtual. There are pros and cons to each. At the end of the day, I think the virtual kind outweighs the in- person. There's quality and then there's a quantity. The way I look at it, you're trying to reach as many people as you can, but you also want to provide quality - and you're a volunteer and you only have so many hours in a day.

The nice thing about meeting in person is you can get more personal with people, and especially people with chronic pain. That's definitely the reason to meet in person. But virtually you can help a lot more people who are just starting their journey and help them get to whatever resource they need quicker. So they don't have to walk around in the wilderness like I did for two and half years.

What do you think is so special about the FPA’s work?

When I first started, we had a lot of repeat participants. They would just keep coming. Then you get the occasional new person. Most people want a quick solution, and then they want to put it all behind them. Most people don't want to be volunteers. And I can understand why. Who wants to remember that excruciating pain. I've been doing it long enough that I've noticed a shift. This is where I think TNA, and now FPA is really getting the word out, the outreach. People just come and go quicker.

You don't hear the “I walked around for 4 years without answers” stories much anymore. It's more like, “this happened to me 6 months ago and I didn't do much, but now I need to do this…” They're finding and getting to the doctors quicker. I mean, some people. I'm amazed, but I've met a dozen people who've had TN for 20, 30 years and all they've done is a little bit of medication now and then. It's a little scary to me. I look back in hindsight and wish I had done it [the MVD] sooner.

If you have a rare disorder, rare condition, you definitely need support groups. Because they know who the good doctors are and who the bad doctors are. I think the FPA is doing a great job of getting the word out. It seems like dentists are becoming more and more aware. Years back, most of them didn’t even know what it was, but now most of them now do. They've heard of it.

So I think the FPA is doing a great job of getting the word out. I think they're getting there over time. They went from focusing on just the one disorder to all facial pains. They're getting more refined. They're getting more prescriptive. They have maybe 30 or 40 general support groups across the country, but then they also have individual people who focus in on one thing on a national level, like Susan Mills and dental injuries leading to facial pain.

By the way, our support group has what we refer to as a new member packet. We’re able to give about 30 pages of information [to new members]. There are individual flyers, and a combination of some of the stuff we and the FPA have done over the years. We've saved a few articles that we include. We can give you a paper copy or we can give you an electronic copy on a flash drive.

Is there anything you see that you would like to see the FPA do in the next few years?

I mean, continue the outreach, continue the conferences, maybe a combination of virtual and in-person conferences. Maybe they do a national virtual and then a regional in person. There was a while there they were doing that. They were having one national and multiple regional conferences in any given year.

They're [the FPA] on the right track. There's stability at the board level with the FPA. They’ve got a great staff of people managing things. I suppose just continued refinements. The patient registry is a major refinement in the right direction.

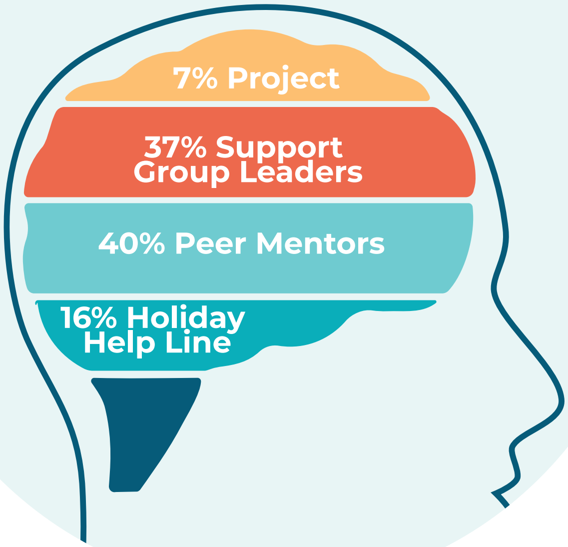
Is there anything else that is near and dear to your heart about your role with FPA?

Well, like I said, I feel blessed. I am grateful for the honor. I'm blessed because I have all this support around me. I worry about the person who, for example, if there's a support group leader in the middle of Nebraska or in the middle of Indiana or somewhere who's doing this as an individual without any help whatsoever. That’s the kind of person that I worry about because that's the person that needs resources. ■

On behalf of the Orange County California FPA support group, I thank Dr. Fogel for the honor, recognition, and award. I thank him for his FPA service as well. And I accept on behalf of myself, my predecessor, Deb Kurilchyk, and the two OC support group leaders before her. I have written a research paper about my TN. You will probably not be surprised to know that I kept a log and a chart of all TN attacks. The data will help researchers unlock a better understanding of TN. In the meantime, I am trying to find a research journal to publish my paper. Since I do not have a research university behind me, I have to pay the publishing fee. This award will go towards that fee.

FPA Volunteers

153 Roles Filled
118 Total Volunteers



Volunteer Numbers

35 support groups

50 support group leaders

54 peer mentors

1050 hours of Holiday Help Line support since 2022

Number of Support Group Meetings By Year

2025 • 309

2024 • 241

2023 • 221

2022 • 181

2021 • 145

2020 • 75

> *“Just having someone stay on the line, listen, and care—it softens the edges of something so unbearable.”*
> — J.C.

When You Are Feeling Alone and Forgotten in Your Pain

Part of having a chronic condition like facial pain is that it can be a constant. Some may experience its horrendous pain daily, while others may go in and out of flares; regardless, for some extended amount of time, the sufferer often feels at the mercy of their facial pain.

Having had facial pain for as long as I have (a little more than fifteen years), it has become normal for family and friends to know that I suffer from this condition, and often they expect me to be in some amount of pain. Pain becomes the norm for me and seeing me in pain becomes the norm for them. It makes sense.

But what about when the pain is extra bad, the episodes extra excruciating, and the battle every single day is wreaking havoc on you, because it is common for you to have this condition, you feel people forget about how bad it can be for you.

Feeling forgotten is awful for anyone, even if it's just the perception of being forgotten; regardless, it can be one of the loneliest moments for chronic illness patients. On the one hand, you understand that others have their own lives, and well, it's normal for you to be sick, and you get that, but on the other hand, you just want someone to acknowledge how intense and painful life is for you right now.

One of the struggles I (and I imagine many with facial pain) have struggled with is knowing whether to be honest about my pain or to toughen up about it. I tend to underplay how much pain I am in and how dark life feels because of the pain. Good moments can feel interrupted or stolen completely from me because of the intrusion of an episode of facial pain. I withdraw to lessen the pain, which can look like me withdrawing from the touch of a loved one or not wanting to engage with life if it could be potentially painful. Sometimes I feel loved ones and friends don't fully know how much I'm suffering physically, emotionally, and mentally. Maybe you are feeling the same or have felt the same in the past.

Dealing with chronic pain, such as facial pain, is overwhelming. We can easily feel defeated or slip into a depressed and anxious state. Our friends and loved ones can be a huge help, but sometimes we must remember to let them know that although pain is common for us, it doesn't always mean we feel strong enough to face it every day, and we need help. We need validation. We need them.

Sometimes we must take the initiative and be blunt and admit to those we love and who love us (or to a therapist) that we aren't okay, and we need support. Sometimes that looks like saying, "I know I am used to the pain, and I'm strong, but this is bad, I'm scared, I feel forgotten and alone.

"You are not forgotten" continued on page 18

"You are not forgotten" continued from page 17

And although the sun is shining brightly, my world feels gray and cloudy because of this awful pain. I need support."

Often, as chronic pain patients, we feel the need to hide our pain and how bad it is, maybe to protect our loved ones, because we feel like our pain (and ultimately, we) are a burden, or perhaps we just don't have the energy to communicate.

But allowing and accepting support can truly help. One of the things that can help most with chronic illness is being validated and heard. I think it is often the life preserver that is thrown to us into the crashing waves of pain.

Sometimes we just need someone to ask us genuinely how we are. And for us not to feel like we have to mask the truth. Because often for us the truth is ugly, it's painful, and even scary at times. We need someone to have big enough shoulders and sit amidst the pain. Sometimes we need to ask someone to hold space for us, authentically.

We need to feel not forgotten.

If you need support and need to be reminded that you are not alone, the Young Patients Committee is here for you. We understand and will hold space for you. Email us at youngpatientscommittee@gmail.com to check out the ways we can support you! ***You are not forgotten.*** ■

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

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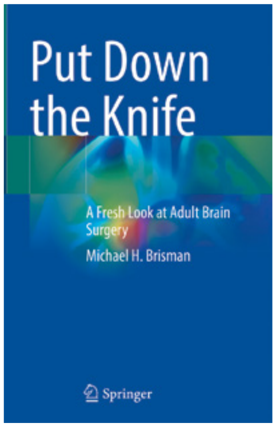
Michael Brisman, M.D.

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

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.*



Put Down the Knife

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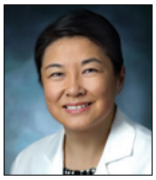
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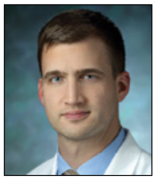
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This book is a companion to the FPA's first book, ***Facial Pain, A 21st Century Guide: For People with Trigeminal Neuropathic Pain***, which provides essential information across a broad set of subjects to serve as an introduction to this condition.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

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FacialPain Association

Connect with 1:1 Support

Peer Mentors offer one-on-one support to others, like themselves, who are affected by facial pain. They are trained volunteers who can be empathetic listeners, share their experiences, connect you to resources, and share tips for coping with facial pain.

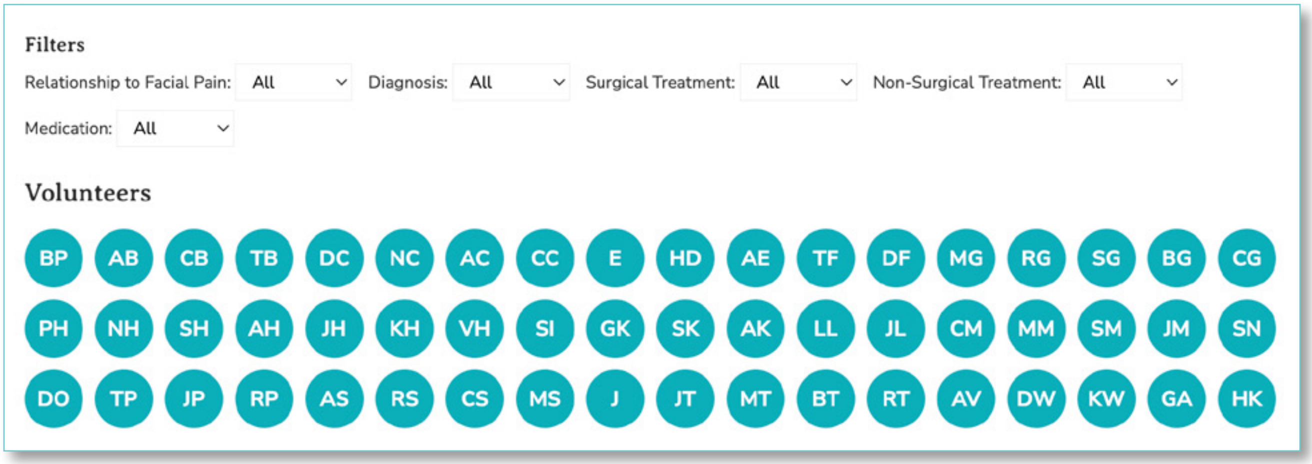
The goal is to provide support customized to your needs so you can connect with someone who knows what you're going through. It's up to you to make the first contact. However, once you reach out, volunteers will respond in a timely manner.

There are two ways to connect with one-on-one support:

Choose your own Peer Mentor

Set the filters on our website at *www.FacePain.org/Connect-with-11-Support* to find a connection. The more general your selections the more volunteers will be suggested. The more specific your selections the fewer volunteers will be suggested.

- Roll over each circle to see the volunteer's name.
- Click on a circle to see more information.
- Email your connection by clicking the email address linked in their information. An email with a pre-filled subject will pop up. Add your message and send.



Filters

Relationship to Facial Pain: All

Diagnosis: All

Surgical Treatment: All

Non-Surgical Treatment: All

Medication: All

Volunteers

BP AB CB TB DC NC AC CC E HD AE TF DF MG RG SG BG CG

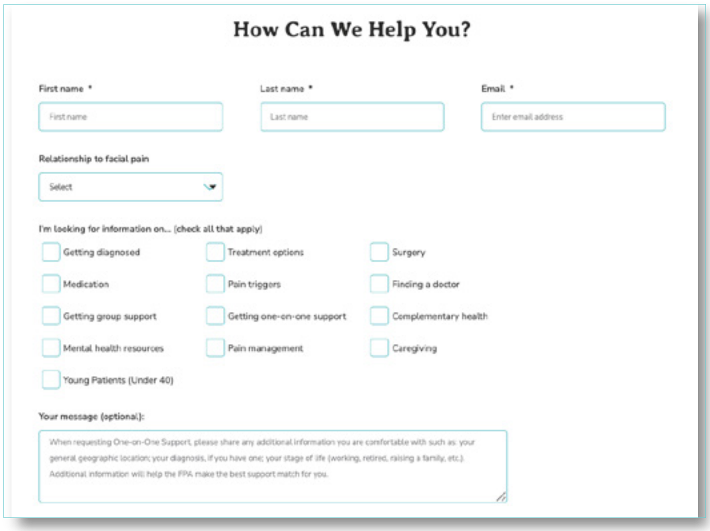
PH NH SH AH JH KH VH SI GK SK AK LL JL CM MM SM JM SN

DO TP JP RP AS RS CS MS J JT MT BT RT AV DW KW GA HK

Custom Help Form

Get a personalized recommendation by completing the Custom Help form. An FPA staff member, or trained volunteer, will respond by email with recommendations based on the information you provide.

Connect with
1:1 Support



How Can We Help You?

First name * First name

Last name * Last name

Email * Enter email address

Relationship to facial pain: Select

I'm looking for information on... (check all that apply)

☐ Getting diagnosed
☐ Medication
☐ Getting group support
☐ Mental health resources
☐ Young Patients (Under 40)
☐ Treatment options
☐ Pain triggers
☐ Getting one-on-one support
☐ Pain management
☐ Surgery
☐ Finding a doctor
☐ Complementary health
☐ Caregiving

Your message (optional):

When requesting One-on-One Support, please share any additional information you are comfortable with such as: your general geographic location; your diagnosis, if you have one; your stage of life (working, retired, raising a family, etc.). Additional information will help the FPA make the best support match for you.

FacialPain
Association

Connect with Group Support

The FPA provides support group meetings where you can connect with others who know what you are going through. Support Groups are led by trained volunteers and are offered free of charge to anyone living with facial pain, their family members or loved ones.

Common Ground Support Groups

- Anesthesia Dolorosa
- Dental Injury and Facial Pain
- Diagnosis After 60
- Friends and Family
- Geniculate Neuralgia
- Jaw Disorders and Facial Pain
- Multiple Sclerosis and Facial Pain
- Tumors and Facial Pain
- Women’s Group
- Weekly Group
- Young Patients

United States Support Groups

- **California**
  - Los Angeles
  - Northern California
  - Orange County
  - Palo Alto
  - San Diego
- **Florida**
  - Tampa Bay
- **Georgia**
  - Central Savannah River Area
  - Columbus
  - Metro Atlanta
- **Indiana**
  - Indianapolis
  - Central Indiana
- **Kentucky**
  - Louisville
- **Massachusetts**
  - Boston
- **Michigan**
  - Detroit
- **Midwest USA**
- **Missouri**
  - St. Louis
- **New England**
- **New Jersey**
- **New York**
  - Long Island
  - New York
  - Utica
  - Westchester
- **Pacific Northwest**
- **Pennsylvania**
  - Philadelphia
  - Pittsburgh
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- **The Carolinas**
- **Texas**
  - North Texas/Dallas-Fort Worth
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Connect with a Support Group