

Quarterly

Special Edition Includes the 2022 Annual Report



The Facial Pain Association
7778 McGinnis Ferry Road, #256
Suwanee, Georgia 30024

It Takes All of Us



**Do you have trigeminal neuralgia?
Is your current treatment sub-optimal?**

If you answered yes to both, the **Libra Study®
may be an option for you!**

Who qualifies?

If you are an adult between the ages of 18-75 who suffers from primary or idiopathic trigeminal neuralgia and who is not fully benefitting from your current therapies, this study may be an option for you.

Study summary description

The study may last up to 20 weeks (about 4 and a half months) with visits occurring every week for 8 weeks (about 2 months) and then every two weeks after that through week 20. In addition, there is the possibility of a 12-month extension with visits occurring every 12 weeks (about 3 months).

If you qualify for the study, you will be expected to take the medication daily, by mouth, complete a pain diary, and attend study visits in clinic as well completing assessments remotely e.g., from home. You may be compensated for your time and travel.

Who is Noema Pharma?

Noema Pharma initiated the Libra Study® to evaluate the effect of basimglurant for the management of pain in patients with trigeminal neuralgia. A biotech company based in Switzerland, Noema Pharma is developing groundbreaking therapies to address the most debilitating symptoms in rare diseases of the brain and nervous system.



Need additional information?

More information on the study assessments and inclusion criteria is available on the ClinicalTrials.gov website (Study NCT05217628). A list of enrolling sites is also available on the website.

If you are interested in taking part in this trial, you can:

- For US residents, visit the following website panaceapatientrecruitment.com/trigeminal-neuralgia
- Or find the contact the closest center to you, using ClinicalTrials.gov (Study NCT05217628)
- Or connect with this center that is close to your location

See ClinicalTrials.gov
(Study NCT05217628)
for more information



**Check if
you qualify**





From the Board Chair

Enduring Benefits

I am happy to report that we have had a very successful year reaching our goals to strengthen how we support you and other community members.

Why should this be important to you? Each year we work to create an organization that is helpful and valuable to you now and in the future, or until you no longer need our support.

Accomplishing these goals has an enduring impact on the FPA – in a way, they create a legacy for years to come. Take a look at these FPA initiatives:

- **Dentist Initiative:** Over 100,000 dentists (around one half of all U.S. dentists) have been informed about trigeminal neuralgia (TN) multiple times this year. Their new knowledge will help ensure that those of us with TN and other forms of neuropathic facial pain will not have to endure unnecessary dental procedures.
- **2023 Virtual Conference:** The presentations by world-leading experts at April's virtual conference will serve our community members for years to come. In addition to the 800+ people who attended this conference, hundreds or even thousands more will benefit from the presentation recordings in the future.
- **Research Assistance:** Some of the eight research projects at major healthcare institutions and pharmaceutical companies that the FPA supported this past year by providing information and recruiting clinical trial participants will undoubtedly result in new medical solutions for us in coming years...hopefully, sooner than later.

- **Patient Registry:** We hope to launch in the coming year. The FPA is ready to enroll thousands of people in a patient registry that can be easily accessed and used by researchers developing new medications and other medical solutions to more effectively address neuropathic facial pain.
- **Enhanced Mobile Website:** We know that many people first access our website from a mobile device, and that other people only have access to a mobile device. So, we are completing an important effort to make this experience easier and more valuable.
- **Filling Information Gaps:** Each year, the FPA identifies existing information gaps and then works to fill those gaps by finding relevant research and/or talking with the relevant experts. Arguably, the most important asset the FPA has is information to help people like you, so we continue to expand and strengthen our educational resources which will be used for many years.

Many of you contribute your time and/or money to the FPA each year. I hope you can see that your contributions are turned into both immediate benefits for our community as well as benefits that will be realized by those who need them in the future. We work to leverage your generous contributions in ways that will have the greatest impact for people like us with neuropathic facial pain. You should take great satisfaction in knowing that your gifts “keep on giving.”



David Meyers
Board Chair
The Facial Pain Association

A Message From the CEO

It takes all of us

As we reflect on the past year and share the FPA's 2022 Annual Report, it seems appropriate to look back at the path we've traveled together and what we have achieved. As I write this, I am finalizing our 2023-2024 strategic plan, working with members of our Board of Directors and staff to determine our path forward. One thing is clear to me – **it truly takes all of us** to succeed in our mission.

The Facial Pain Association is the great connector. We connect people living with facial pain to resources – educational materials, lists of health care professionals who understand and treat facial pain, and other people living in similar situations. We also connect researchers with people interested in participating in their studies. We connect the facial pain community with the latest information available, becoming a trusted and reliable resource for those trying to manage pain and live their lives to the fullest. We couldn't do any of this without you: our volunteers, including our Board of Directors, who are the backbone of our organization; our medical advisors and partners, who provide reliable medical information and updates; our staff, who work behind the scenes making everything happen; members of the community who open their hearts and share their stories; and last, but certainly not least, our generous donors, who support all these efforts. **It takes all of us.**

In 2022, we reached over 100,000 dentists in our effort to educate these professionals about neuropathic facial pain. Over half of the facial pain population undergoes unnecessary dental procedures before getting the correct diagnosis. We are trying to reduce that number and equip dental professionals with the knowledge they need to identify facial pain and understand their next steps. This effort has included our Medical Advisory Board (MAB), the dental community, and partnerships with organizations focused on orofacial pain to make progress. **It takes all of us** and we will continue this work to ensure that patients are identified, and the unnecessary procedures stop.



Our patient registry is almost ready to launch and will provide the opportunity to leave a legacy through your participation – the opportunity to tell your story. **This effort will take all of us.** Members of our MAB and researchers from around the world worked together to create and evaluate effective questionnaires. Our Board Secretary, Anne Ciemnecki, also a retired survey methodologist and third generation woman with facial pain, is working with other researchers to determine what we need to know, how we gather the information and how it is analyzed so it is useful in studies and to the facial pain community. And you – we need your participation to feed the registry. You hold the key to our success and our ability to find trends, affect public policy, support research, and change the face of facial pain.

Looking forward, we will continue our efforts to reach EVERYONE living with facial pain. Our greatest resource is our connections – to reliable information and educational materials, to the research and medical communities, and to you – the facial pain community. We will use those connections to ensure our mission aligns with your needs. We are updating the mobile experience on our website, allowing for increased accessibility to younger populations and underserved communities. We are translating existing resources so we can reach non-English speakers. We are supporting research with the hope that new drugs and treatments will be discovered. We want to educate neurologists, using successful strategies from our Dentist Initiative. These are just a few things we have planned as we move through 2023 into 2024.

What do you want to see? What would you like to know? Please contact me – I am here for you, our staff is here for you, and this organization is here for you.

It takes all of us. ■

A handwritten signature in blue ink that reads "Melissa Baumbick".

Melissa Baumbick

Chief Executive Officer, The Facial Pain Association

Table of Contents



4

Leadership



5

The MAB Corner



8

Autonomic Effects of
Trigeminal Nerve Injury



10

2022 Annual Report
It Takes All of Us

11

Giving our Time

20

Raising Awareness

22

Learning Together

27

Investing in the Facial
Pain Community

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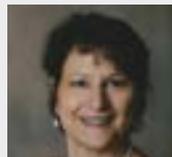


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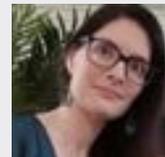
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The MAB Corner



Kenneth F. Casey, MD
Neurosurgeon

So, your face hurts. and it has happened a couple of times.

You consult Dr. Google and their colleagues to see what is going on, but you are not sure.

You go to see your family doctor. After careful history taking and a brief exam, your family doctor sends you to see an ear, nose, and throat (ENT) doctor, or maybe a dental professional. Each one of these professionals gives you a partial diagnosis and some treatments to follow, but the pain is still there. You return to your family doctor, and because there were no structural problems seen in the sinuses or in the jaw or teeth, they decide to send you to a neurology pain specialist, who gives you another diagnosis. Sometimes it is a variation on the different face pain diagnoses. Medicines are prescribed. Sometimes even injections. But the pain persists. Now you are sent to a surgical pain specialist with a scalpel – the neurosurgeon. Scary, right? And now, another diagnosis and sometimes a recommendation for surgery – but what surgery? Dr. Google and their colleagues do not seem to agree with your specialist. ***What to do now?***

Patients often ask me about second opinions. When you go from your family doctor to a different specialist, and finally to a neurosurgeon, those are all second opinions. Unfortunately, people think of a second opinion as questioning the first doctor or specialist. Often in neurological issues, the diagnosis is not clear, or it is not fully recognized. It can take time for all the symptoms to evolve to produce a clear answer. So, you have already had several “second opinions.” Patients and families often would ask me at meetings – should they get a second

opinion? Most well-trained neurosurgeons welcome the question, and the answer is ***YES. Why?***

An accurate diagnosis is the cornerstone of any treatment plan. A patient who receives treatment for an illness they do not have will not likely get better; in fact, they might get worse, either as a result of their disease or from side effects of their medical treatment. That is why confirmation of a diagnosis is crucial.

Yet, such confirmation is not commonplace. About 1 in 20 American adult patients seeking outpatient care are misdiagnosed, according to a 2014 study published in *BMJ Quality and Safety*. 70-80% of Americans “feel confident in the accuracy of their doctor’s advice, and do not feel the need to check for a second opinion or do additional research” (2010, 2015).

One reason for poor treatment response is an incorrect diagnosis. Neuropathic facial pain is not “one size fits all.” Getting a correct diagnosis can save you from unnecessary treatments that do not help your pain. One step is to use the self-diagnostic site “TGN: A Public Platform” to solidify your story. The incidence of trigeminal neuralgia, or how many people are newly diagnosed each year, is thought to be 4.3 people per 100,000. Other neuropathic facial pain conditions are also rare. Some people have more than one type of pain, either concurrently (at the same time) or subsequently (one follows the other).

One reason for a poor treatment response is that the causative diagnosis was incorrect. ENT surgeons

“The MAB Corner” continued on page 6

may diagnose a sinus condition when it is not present. Dentists may consider trigeminal neuropathic pain to be treatable by invasive dental surgery when it should not be. Differentiating between the various types of facial pains and mechanisms associated with neuropathies can sometimes be confusing, especially if the symptoms are complex and do not fall into any one specific category. Over the years, the terms used for trigeminal neuralgia have changed, and one doctor will apply these terms differently than another. The cause of classical TN is typically nerve compression by a vessel, usually the superior cerebellar artery, on the trigeminal nerve root as it leaves the brain stem. However, in some cases, compressions may not be found. Your description of your pain may not match your diagnosis. You may have an underlying disease causing your pain. A large portion of patients have

continuous pain between attacks. Most facial pain is not neuropathic, so a systematic approach to its diagnosis is essential. Non-neuropathic conditions that should be considered in the differential diagnosis include myofascial pain, temporomandibular joint disorder (TMD), dental disease (cavities or gum disease), cracked teeth (with exposed nerve roots), infections including sinusitis, and migraine headache.

Surgical second opinions are consultations sought by patients when they want another expert's evaluation of their medical condition and treatment plan before undergoing surgery. These opinions can provide patients with valuable insights, reassurance, and potential alternative options. Since your primary doctor has already used this path, there should be no hesitation for you to continue to follow it.

The Second Opinion

You can get a second (or third, or more) opinion for any reason. Some reasons people have given are:

- You want to know every possible choice for treatment.
- Your doctor is not sure what is causing your pain.
- You have a rare or unusual diagnosis.



Here are some key points to consider regarding surgical second opinions:

1. **Expertise and perspective:** Obtaining a second opinion allows you to benefit from the expertise and experience of another qualified surgeon. Different surgeons may have varying approaches, techniques, and opinions on the best course of treatment, providing you with a broader perspective.
2. **Confirmation of diagnosis:** A second opinion can help confirm the accuracy of your initial diagnosis. Misdiagnoses can occur, and it's important to ensure that your condition has been correctly identified before proceeding with surgery.
3. **Treatment alternatives:** A second opinion may present alternative treatment options that you were not previously aware of. These can include less invasive procedures, different surgical techniques, or even non-surgical alternatives. Exploring all available options can help you make a more informed decision about your treatment.
4. **Reassurance and peace of mind:** Surgery is a significant decision, and seeking a second opinion can provide reassurance that you are making the right choice. It can help alleviate doubts, provide additional information, and increase your confidence in the recommended treatment plan.
5. **Complex or high-risk cases:** Second opinions are particularly beneficial in complex or high-risk surgical cases. These cases often require specialized expertise or a multidisciplinary approach. Consulting multiple experts can help you understand the risks involved, potential outcomes, and whether there are any additional precautions or considerations to be taken.
6. **Communication and collaboration:** Second opinions can promote communication and collaboration between healthcare providers. With your consent, the second opinion surgeon can review your medical records and consult with your primary surgeon, leading to a more comprehensive and coordinated approach to your care.

To seek a surgical second opinion, you can start by discussing it with your primary healthcare provider or surgeon. They can provide referrals to other specialists or institutions known for their expertise in the specific area of surgery you require. Additionally, some insurance plans may cover the cost of a second opinion, but it is essential to check with your provider beforehand.

Remember, obtaining a second opinion does not necessarily mean you have to switch surgeons. It is meant to enhance your understanding and confidence in your treatment plan, ultimately empowering you to make the most informed decision about your healthcare.

Now you have different options, from different doctors, some in the same specialty – what do you do?

That is not an easy answer. In the arena of facial pain, you can rely on the reputation of the specialists. You can also rely on the word of mouth from other patients. That is the benefit of support groups.

But in the end, it comes down to what you feel and think about that last specialist. Your sense of trust and the way that specialist treated your story is ultimately how we all decide to move ahead with care. It is not a perfect system, but it is the best we have right now. ***Always questioning and seeking more information from specialists is absolutely the right path. ■***

What are the **Autonomic** Effects of Trigeminal Nerve Injury?



Jeffrey A. Brown, MD
NYU Langone Long Island

In 1908, a physiologist first described something called the “oculocardiac reflex” – push on your eyeball and your heart rate drops. As it turns out, this was the first understanding of the role that the trigeminal system plays in the involuntary functions of body elements that we cannot consciously control. The eyeball is innervated by the trigeminal nerve. Irritate it, and things happen in your body, not just in your face. Irritate it enough, and your heart can even (briefly) stop beating.

This is an “autonomic” function.

First, let us define the term “autonomic”:

Autonomic refers to the involuntary functions of the nervous system – the things we cannot consciously control. It relates to the working elements of the internal organs of our body – the muscles of the heart, blood vessels, stomach, intestines, functions of the lungs, sweat and salivary glands. The autonomic nervous system also aids in digestion, relaxation, and even “instinctual” emergency responses to injury or potential injury.

Any form of injury, even minor irritation, to the trigeminal peripheral branches in the face will have some autonomic consequence, because the wiring of the trigeminal nerve is intimately intertwined with the autonomic nervous system within the brainstem.

It is the brainstem that runs the unconscious activity of the body. Think of it as our body’s “operating system,” like that of your iPhone or computer. If it gets reprogrammed, your phone can work better, but if it is damaged, things can go literally “haywire” (Haywire—the thin, too flexible wire used to hold bales of hay in the fields. Left alone, the wires tend to get intolerably tangled).

One principle: The more intense the injury to the trigeminal system, the more widespread the effects—even down to the control of your digestive system.

Why?

The trigeminal nerve nucleus in the brainstem has connections to other nuclei that connect to the vagus nerve. The vagus nerve is appropriately named “vagus” because it has “vague” or diffuse (autonomic) effects throughout the body. These interconnections go through another nucleus called nucleus solitarius. A nucleus is the energy center of each nerve and the cable that emerges and enters into it. The output of the vagus nerve can be parasympathetic or sympathetic. One excellent way of understanding the difference is to use the rhyming phrases “rest and digest” and “feed and breed” to describe the parasympathetic plethora of functions. Some examples of parasympathetic functions: the heart rate is slowed and airway muscles in the lungs

are tightened reducing the amount of work the lungs must do. The problem is that with trigeminal nerve injury the response in the body then depends on the unpredictable mix of stimulating and inhibiting nerve channels that are turned on.

Disease can do this as well. One way is by causing inflammation.

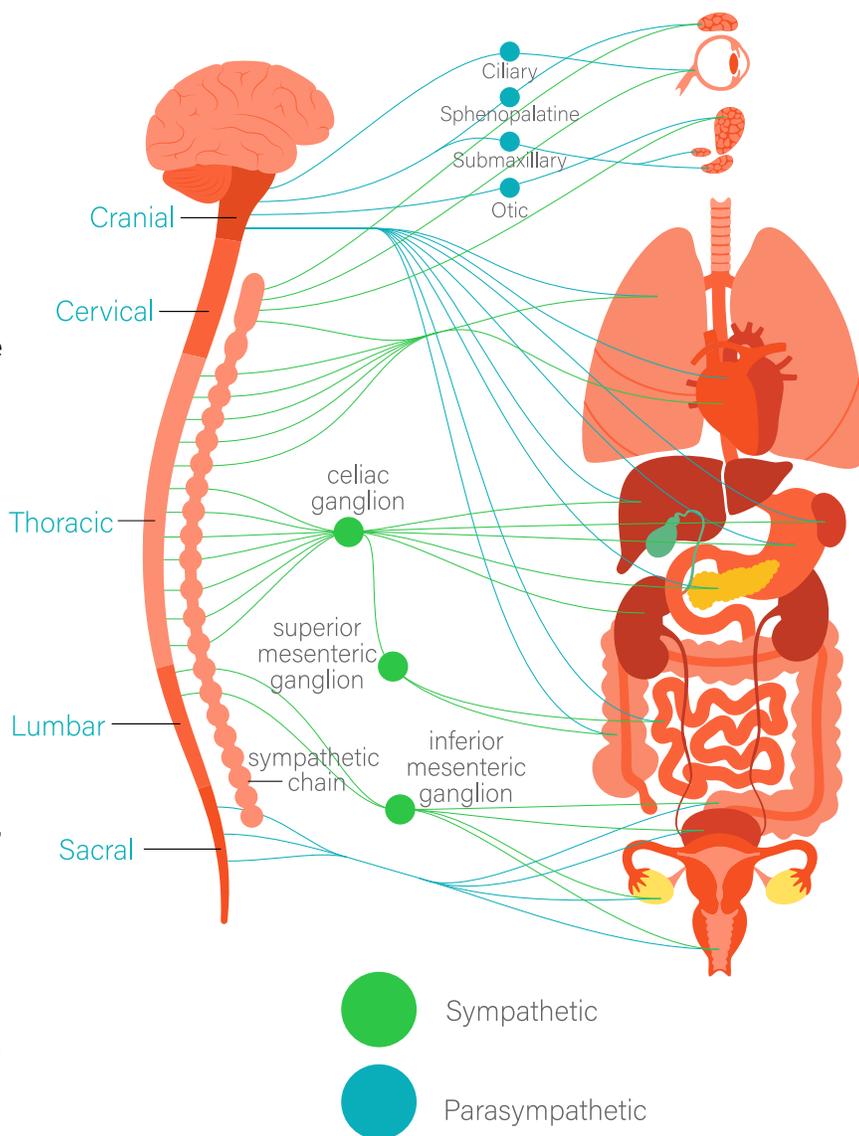
Is this really a different entity or is it another in the confusing plethora of manifestations of trigeminal nerve injury? From the discussion above one could understand it to be the latter.

Trigeminal neuralgia is that, too.

Trigeminal neuralgia is better understood, in my opinion, as a single form of **“trigeminal neuropathic pain,”** meaning trigeminal nerve injury. It can manifest itself with short bursts of short circuits – stabbing pain; or it can be felt by constant pain – often burning; or a mixture of the two. Usually intermixed with the neuropathic (electrical, nerve injury pain), there can be a residual aching pain. Aching pain is not nerve pain. It is what is called “nociceptive” pain. This is the type of pain transmitted to the brain by nerve endings in response to injury of the body. The pain felt in the face from the neuralgia attacks, through another pathway in the that nucleus solitarius, can evoke this different form of pain as a secondary response.

In summary, the trigeminal nerve is intimately intertwined with the autonomic system of the body, and as such, any disease or injury to the nerve will cause an autonomic response that can be something so seemingly innocuous as a “red face,” or possibly full cardiac arrest. The difference is in the severity. ■

AUTONOMIC NERVOUS SYSTEM



We Are the Facial Pain Association

2022 Annual Report



Mission

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

Who We Are

The Facial Pain Association is the largest patient organization supporting all people affected by neuropathic facial pain, leading the world in resources for information and healthcare guidance. Through programs of education, personal support, and advocacy efforts, the FPA supports patients, their loved ones and caregivers, and healthcare professionals who diagnose and treat people affected by facial pain.

The FPA is volunteer-led and community-focused. Guiding the FPA is a volunteer Board of Directors and a Medical Advisory Board which is composed of experts in neurosurgery, neuroscience, pain management, dentistry, and mental health.

What We Do

We provide personalized support:

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

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

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

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

We provide education:

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

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

We promote patient advocacy:

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

The FPA Young Patients Committee (YPC) recognizes the unique issues faced by people under age 40. The YPC gives a voice to younger patients and raises awareness that neuropathic facial pain does not only affect older adults. The YPC maintains an active Facebook Page, Facebook Group, and accounts on Twitter, Instagram, YouTube, and LinkedIn.

It Takes All of Us to Make a Difference

The 2022 Annual Report is a reflection of you, our incredible community, and how you made a difference through giving your time, raising awareness, learning together, working together, and investing in the facial pain community. It Takes All of Us—including YOU!

It Takes All of Us Giving Our Time

FPA Volunteers



The Facial Pain Association could not do what we do without the dedicated group of volunteers who serve as Support Group Leaders, Peer Mentors, Young Patients Committee members, and on a variety of ongoing and short-term projects,

including conference support, the holiday helpline, and literature review. FPA Volunteers either live with facial pain themselves or are caregivers or family members. They are from 31 US States, Canada, the UK, and Brazil. Volunteers provide support by drawing on their own experiences, as well as training provided by the FPA.

We welcome volunteers from varied backgrounds, life experiences, and medical histories.

No specific skills, educational background, or experience is required to serve as an FPA Volunteer.

FPA Volunteers:

- Help others feel less alone.
- Help the organization reach as many people living with facial pain as possible.
- Build a support network.
- Find a sense of accomplishment.

If you are interested in volunteering with the FPA, contact Regina Gore, Volunteer Coordinator at rgore@facepain.org or call us at 800-923-3608 for more information. ■



Scan this QR code or click here for a special message about volunteering with the FPA.

FPA Volunteer Roles Key

C	Counselor
PM	Peer Mentor
P	Special Project
SGL	Support Group Leader
YPC	Young Patients Committee Board

Alia Aboulhosn	SGL		P (2)
Claude Aldridge		PM	
Jean Aldridge		PM	P
Sarah Ancell	SGL	PM	
Sylvia Arroyo	SGL		
Larry Bailes			P(2)
Shannon Bailey			P (2)
Amy Barris		PM	P
Anna Beard	SGL		
Carol Bloom		PM	
Chyrl Bowers		PM	P
Diane Boyd	SGL		
Terry Brown		PM	P
Jennifer Byram	SGL		
Joan Cannelli		PM	
Nora Casas	SGL		P (2)
Anne Ciemnecki	SGL	PM	P
Cathleen Clay			P
Christine Cohen	SGL	PM	
Michael Cohen	SGL		P
Michele Cohen	SGL		P
Tatiana Colledan	SGL		P
Mabel Contreras			P
Lauren Corson	SGL		
Diana Crites	SGL		
A. Marie Davis	SGL		
Jill Della Ratta	SGL		
Hosanna Derderian		PM	
Lisa East	SGL		
Ellie Eichenlaub	YPC		
Allan Enis	SGL	PM	
Shelby Ennis	SGL		
Thomas Fenstermacher		PM	
Kim Fields	SGL		P
Jeffrey Fogel	SGL	PM	P
Darrell Fryer		PM	
Rose Gaffney			P
Stuart Gause	SGL	PM	
Jimena Giudice			P
Deirdre Glascott	SGL		
Bob Golub		PM	
Kurt Goodman	SGL		
Supriya Goyal	SGL		P
Thomas Guith	SGL		
Neave Halvorson		PM	
Megan Hamilton	SGL		
Sarah Hawbecker		PM	P

Kathleen Hays	SGL		
Katrina Holliday		PM	P
Vince Holtmann	SGL	PM	P
Sara Illsley	SGL		
Elaina Jackson	YPC		
Susan James			P
Rosa Jimenez		PM	
Tamar Krivosha		PM	P
Tom Kruse	SGL		P
Ally Kubik	SGL	PM	
Laura Launderville			P
Gwen Lias-Baskett	SGL		
Liz Long		PM	
Judy Love-Eastham		PM	
Emmy Macnicol		PM	
Amy Marshall	SGL		
Alexis Mayle		PM	
Mike Mercurio		PM	P (2)
Susan Mills	SGL	PM	P
Jessica Mortensen		PM	
Yvonne Omer	SGL		
Julie Parks			P
Andy Petitjean	SGL		
Mary Pingel	SGL		
Ruth Purchase		PM	
Robert Ramsey	SGL		
Mary Rice	SGL		
Tammy Roberts	SGL		
Lynn Ruppe	SGL		
Rachel Scherer	SGL		P
Abby Scherr			P
Brittany Shaffer		PM	P
Christine Spor		PM	P
Maureen Stone			P
Jeanne Tarullo Hays		PM	
Miorky Torres			P
Rachel Triay	SGL	YPC	
Barbara Turczyn	SGL	PM	
Ann Voynow		PM	
Lindsey Wallace	YPC		P
Dan Wegner		C & PM	P
Gail Wells	SGL		
Sharon Whitener	SGL		P
Alice Whynaught	SGL		
Mackenzie Winslow	YPC	PM	P
Heidi Wittgren	SGL	PM	P
George Zack		PM	

Three Long-Time Volunteers Stepping Back

The Facial Pain Association wishes to thank three long-time volunteers, Thomas Guith, Lynn Ruppe, and Tom Kruse for their selfless service to those living with facial pain, their families, and loved ones. Your outstanding dedication is an inspiration to all.

Tim and Lynn led the Suburban Detroit Support Group starting in 1998. Lynn's husband, Pete, lent invaluable technical assistance with video conferencing.

Tom started his volunteer service by helping the Tucson, AZ group in the early 2000s. He then continued as the Support Group Leader, expanding the group to all of Arizona, then to the entire Southwest with the use of video conferencing.



Thomas "Tim" Guith

Support Group Leader, Suburban Detroit, MI

Tim was an executive with General Motors for over 30 years who retired on disability at the age of 52 due to facial pain. He credits his wife,

Donna, with helping him get through those early months before being diagnosed by packing his face with ice packs. "It has been a pleasure to help those suffering as we did," he says.



Lynn Ruppe

Support Group Leader, Suburban Detroit, MI

Lynn's professional background as a nurse, along with her calm, warm-hearted personality, made her the perfect Support Group Leader. For the

first 20 years, the group met at a local medical center that was a 45-minute drive for Lynn, who made the trip every month no matter the weather.



Tom Kruse

Support Group Leader, Southwest

Tom describes himself as a "happy caregiver" to his wife who was diagnosed with trigeminal neuralgia in 2003. He says: "As a caregiver, I have

always felt like an outsider, but your organization realizes that caregivers need support, too. I wish to give you all a BIG THANK YOU for your time helping all in this community."

Counselor (C),
Peer Mentor (PM),
Special Project (P),
Support Group
Leader (SGL),
YPC Board (YPC)
by US State

▼ C ● PM ◆ P
■ SGL * YPC

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FPA Volunteers



“One attendee turned off her camera so she could cry because she felt so validated to hear others’ stories. This group is powerful.”

—Anne Ciemnecki, Support Group Leader

“I am always excited for the next Support Group Meeting! It has become a special and precious part of my life! And I am so grateful because you [FPA] gave me this opportunity!”

—Tatiana Colledan, Support Group Leader

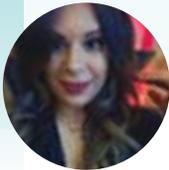


“...there is nothing like working with passionate people who care about their mission, especially one as noble as the FPA. Collaborating with dedicated, passionate people makes my work very easy to do.”

—Rose Gaffney, Project Volunteer for Video Productions

“This has been so rewarding for me. I remain pain free and being able to support others is something I truly want to continue doing, especially during my healing process. I believe we heal when we help others heal.”

—Miorky Torres, Project Volunteer for Holiday Helpline and Conference Support



“I can’t describe how it felt to be helping someone. Almost like I was the one benefitting from it.”

—Larry Bailes, Project Volunteer for Holiday Help Line and Conference Support

“I really feel this is a good thing and the more people we spread the information to through the year will help next season. Thanks for the opportunity to be here. It helps us all.”

—Julie Parks, Project Volunteer for Holiday Helpline



“All I can say is “WOW” We are getting the word out and people [are] connecting with us! So awesome! If there’s anything else I can help with, let me know!”

—Christine Spor, Peer Mentor, Project Volunteer for Holiday Helpline and Conference Support



Counselor (C), Peer Mentor (PM), Special Project (P), Support Group Leader (SGL), YPC Board (YPC) by Country

BRAZIL■
CANADA●
UK.....●



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AND BRIGHTEST
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INSTITUTE**

To learn more, visit h.uconn.edu/bsi

FPA Young Patients Committee

We have had such an amazing time as Co-Chairs of the YPC!



Lindsey Wallace

We've both been part of the YPC for years and taking on a larger role within the committee has been an exciting challenge.

Our goal has always been to advocate for people for facial pain and with these new roles we've had the chance to really increase our impact. Over the last year, we've had the chance to get to know more patients on a deeper level. We've taken those conversations to heart and tried to implement more impactful projects within the YPC. The FPA as a whole has always supported the YPC's mission, but



Kenzie Winslow

we've both loved the opportunity to take part in the broader facial pain discussions and speaking up for young patients. We hope to continue to be a voice for everyone over the next year! We have so many exciting projects in the works, so keep an eye out. We're so thankful for this community and all of the love and support we receive from you all!

— Kenzie and Lindsey ■



@youngpatients



@youngpatients



@youngpatients



@tealribboncrafts



Newsletters



4,600

Followers across social media



135

Members receiving email newsletters from the YPC

Connect with the FPA Young Patients Committee!

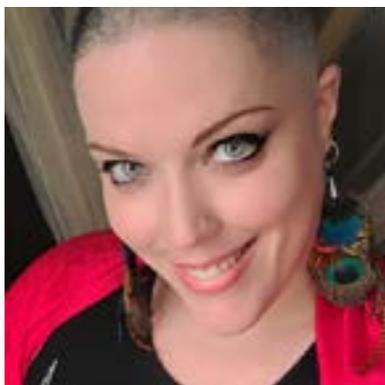
The YPC is a wonderful group of people under 40 who, like you, also deal with facial pain. They may be able to provide you with some guidance and support as you adjust to life with facial pain.

Congratulations Hannah and Colette,
the FPA Young Patients Committee Facial Pain Resiliency Scholarship recipients for Fall 2022!
We invite you to read a portion of their winning essays on the following page.



Young Patients Committee

Facial Pain Resiliency Scholarship 2022



Scan QR code or click HERE to read Hannah's essay in its entirety.

Hannah Crazyhawk

I needed help and realizing that it is okay to ask for that help when I need it has been one of the biggest challenges in my college career and life. Through this journey, I have learned that I am more resilient, intelligent, proactive, and resourceful than I ever could have imagined. If you battle chronic illnesses and endless pain, asking for help is frightening. Our medical system is not designed to help patients like us. We are seen as too young to be in pain and too healthy looking. That is ableism; chronic pain and illnesses do not discriminate. We are complicated, and it is not our fault. We are fighting enormous, invisible battles every single day. Facial pain can rip your life away. I know that people like me are strong enough to succeed in our educational goals because we are fighters. We fight the most excruciating pain and are still here with hopes and dreams. College is difficult, but it is no match for us. ■



Scan QR code or click HERE to read Colette's essay in its entirety.

Colette Miller

My goal is to become a pediatric nurse. I am not sure what specialty, but maybe the Intensive Care Unit (ICU), Emergency Room (ER), or maybe helping kiddos who have the same conditions I have. I would be able to give them a personal and compassionate perspective and so much other knowledge that comes over time from living with these conditions. It has personally affected me, making me learn to be strong and to have perspective through medical challenges. I taught myself that it may seem hard now, but that it will get better later. These opportunities have also given me so much knowledge about my medical conditions and treatment options, ways to make it better, and so much other information I would have never learned in nursing school or life. ■

The Young Patients Committee Facial Pain Resiliency Academic Scholarship is available to students in the US between the ages of 18-40 attending school, college, or university that have facial pain. An exception to age will be made if you are 17 and entering college in the semester following the application. Applicants must complete this application in full, including upload requests, to be deemed eligible for award consideration. Be on the lookout for the next application round!

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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MAYFIELD Brain & Spine

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

Our treatments include:

Gamma Knife radiosurgery



Microvascular decompression surgery (MVD)



Percutaneous stereotactic rhizotomy (PSR)



Mayfield's Nationally Recognized Trigeminal Experts



Steven Bailey, MD



Vincent DiNapoli, MD, PhD



Yair Gozal, MD, PhD



Ronald Warnick, MD

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

Changing the Face of Facial Pain — The FPA’s Patient Registry



Anne Ciemnecki

FPA Board of Directors Secretary, Peer Mentor, Support Group Leader,
and co-editor of Facial Pain: A 21st Century Guide



About eighty years ago, my grandmother heard the words trigeminal neuralgia for the first time. As a third-generation woman with facial pain, I intimately understand the daily struggle and long-term impact of this condition. My name is Anne Ciemnecki and I am honored to serve on the Facial Pain Association’s Board of Directors, where my experience propels my passion.

Trigeminal neuralgia and other neuropathic facial pain conditions are rare, with little dedicated research and even less funding. Last year, our board decided to create a forum where your voice can be heard, where everyone’s voice can be heard. **The Facial Pain Association’s Patient Registry** will be a platform where we can securely and confidentially gather data about your experience.

The registry must be designed so that the data you submit can be extracted and analyzed. For more than 30 years, I served as a survey methodologist working for foundations and the federal government. In the decade before I retired, 80% of my work focused on collecting data from people with disabilities to inform the Social Security Administration (SSA) of their needs. The combination of my personal and professional experience makes me uniquely qualified to spearhead this project.

As part of the rare community, we must combine our individual experiences into a symphony of voices. This is your opportunity to affect change!

Using questionnaires designed by researchers and survey professionals, we can collect data over time to help inform clinical trials and affect public policy to better help the facial pain community. We hope to launch the registry in the coming year to start making progress in these impactful areas and we need your support.

When you participate in the registry, the questionnaires will:

- Ask about YOUR experience. There are no right or wrong answers.
- Take approximately 15 minutes with a new questionnaire every 4-6 months.
- Include questions about your pain, medications, treatments you have tried, side effects, and family history.
- Inquire about your daily function. For example, can you exercise, carry a bag of groceries, participate socially, or talk on the phone?



This registry will help transform anecdotal data into evidence, which is vital in the rare community. Information from the registry could help connect people with appropriate clinical trials and assist Social Security Disability determination.

Photos from top right: Anne Ciemnecki today (photo by David Ciemnecki), top left: Anne’s grandmother and mother, bottom left: Anne with her grandmother, next page: Anne with her mother.



Unfortunately, it is not free. There are significant costs associated with launching and maintaining a patient registry, and just like we can combine our voices, we can combine our resources to make this happen. If we invest in this today, we can make life better tomorrow and leave a legacy for the future.

Warm regards,

Anne B. Cierniecki

We want to hear from you!

What is one question you would like to see included in the FPA's Patient Registry?



Please use the enclosed envelope, click [HERE](#), or scan the QR code to make a contribution. When you send in your gift, please tell us what information you would like to see included in the patient registry.

You can also email your suggestions to info@facepain.org.

Give to FPA with Confidence

The Facial Pain Association (FPA), formerly known as the Trigeminal Neuralgia Association (TNA), is a registered non-profit, 501(c)(3) volunteer organization founded in 1990.

GuideStar

Platinum
Transparency
2023

Candid.

The Facial Pain Association earned GuideStar's highest level of recognition, the Platinum Seal of Transparency

GuideStar is the world's largest source of information on nonprofit organizations. It gathers and provides access to the most comprehensive, up-to-date, and accurate nonprofit information available. GuideStar's mission is to revolutionize philanthropy by providing information that advances transparency, enables users to make better decisions, and encourages charitable giving. GuideStar is a 501(c)(3) public charity.

It Takes All of Us Raising Awareness



Facial pain can be a silent but debilitating condition, often misunderstood and misdiagnosed. **It takes all of us** to increase public knowledge about neuropathic facial pain, including trigeminal neuralgia, and emphasize the urgent need for early diagnosis and effective treatment options.

Facial Pain Awareness Month and Rare Disease Day serve as beacons, rallying communities, healthcare professionals, and advocacy groups to shed light on

trigeminal neuralgia. Increasing awareness also plays a vital role in providing support and solidarity.

Together we can unmask the challenges faced by those living with this condition by amplifying the voices and sharing the experiences of people with facial pain. Through this collective support, we can help break the isolation often felt by those affected by facial pain during awareness month and throughout the year.



Scan this QR code or click [HERE](#) for a special message from Brandi Underwood, the FPA's Marketing and Communications Manager.



@facialpainassociation



@facialpainassoc



@facialpainassoc



Facial Pain Association



Facial Pain Association



795,000+

Reach/Impressions

Reach/Impressions measures the people who see FPA's content.



18,600+

Likes/Follows

Likes/follows measures the people who support FPA on social media.



18,600+

Reactions

Reactions measures engagement with FPA's content.



4,200+

Shares/Retweets

Shares/Retweets measures the amplification of FPA's content.



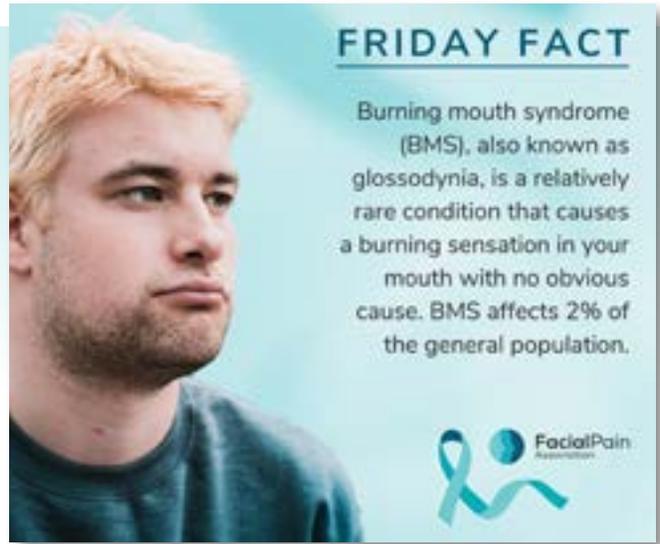
1,100

Comments/Mentions

Comments/Mentions measures interactions with FPA content.

You Educated Your Community

Throughout October, you shared facts about facial pain and promoted grassroots awareness events.



You Shared Your Story

“My #TNStory has not been a walk in the park by any means. As many of you know, one year ago this month I underwent brain surgery in hopes of parting ways with this pesky affliction. Unfortunately, things don't always go to plan...”

– @ayaleslie2

You Turned Social Media Teal

You shared others' stories, awareness day posts, fundraising efforts, and more over 1,200 times in October, reaching more than 75,000 people.



#FaceTodayTogether

It Takes All of Us Learning Together

More than 800 people from 6 continents and 23 countries participated in the 2023 FPA Conference.



2023 FPA Conference

Your generosity not only allowed us to keep the cost of admission low, but also provided complimentary admission to 112 attendees who reached out to us for support.

“Essential information delivered with clarity and heart. Thank you!”
— Katie



80,000+

Website users



530,000+

Bulletins emailed



17,500+

Facebook Group Members



10,000+

Quarterly journals mailed



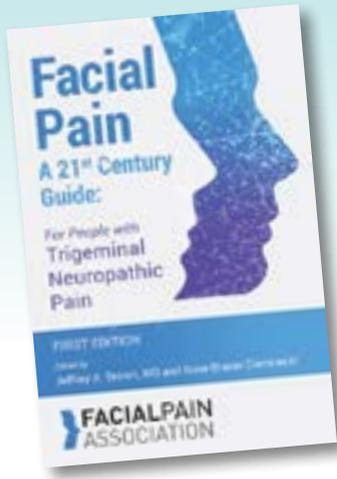
8,000+

2022 FPA Video Series views



2,500+

Calls for information



Facial Pain: A 21st Century Guide

Thanks to the tremendous generosity of our donors, we have provided a complimentary copy of Facial Pain: A 21st Century Guide to more than 130 people who reached out to us in need.

If you know someone in need, please call the FPA office at 800-923-3608 or email info@facepain.org to request a copy.

"I've been battling TN for 6 years. Thanks so much for this very valuable resource."

— DeeAnn

2022 FPA Video Series

The FPA's Video Series, based on presentations from the 2022 Virtual Conference, has been viewed more than 8,000 times. All FPA webinars are free and available in our library at www.facepain.org/tag/webinars.



2022 FPA Bulletins

More than 530,000 FPA Bulletins were received by the facial pain community in 2022.

You can receive the latest facial pain news, upcoming events, and information in your inbox when you sign up at www.facepain.org/sign-up/.

Find a Doctor

The Facial Pain Association is fortunate to have the guidance of the Medical Advisory Board composed of experts in neurosurgery, neuroscience, pain management, dentistry, and mental health.

If you have facial pain, it is important to find the best doctor for you who knows about your condition. Although we do not recommend specific doctors, you may start your search with the facial pain experts on our Medical Advisory Board and the Find a Doctor list on our website at www.facepain.org/find-support/find-a-doctor

Please Note: The doctors on our Find a Doctor list pay a fee to be listed on our website; FPA does no independent examination of the professional qualifications, education, experience or other credentials of those with whom we have linked, the validity or suitability of the services or products



they offer, or of the accuracy of the content of the linked sites.

Listing on our site does not constitute an FPA endorsement of any physician, surgeon, medical procedure, medical institution, or its staff.

The Research Initiative

We aim to empower patients and caregivers with the knowledge that helps you be educated partners in your healthcare and to encourage more research on facial pain and relevant issues faced by those with facial pain.

As part of FPA's research initiative, we are committed to keeping you informed of efforts that may result in better treatment options for trigeminal neuralgia and other neuropathic facial pain.



To reach these goals, FPA will provide four resources:

1. Information about clinical trials and studies
2. Opportunities to get involved with research
3. Articles on published studies
4. Non-financial support for researchers

Visit <https://www.facepain.org/research/> to learn about clinical trials and studies, opportunities to get involved with research, articles on published studies, and more.

Please Note: The FPA is enthusiastic about medical research for facial pain patients, and encourages those with TN to consider participation. It is important to note, however, that the FPA is not offering, nor is it qualified to offer, a scientific or medical endorsement of any Institutional Review Board (IRB) approved patient study. An IRB is a committee established to review and approve research involving human subjects. The purpose of the IRB is to ensure that all human subject research be conducted in accordance with all federal, institutional, and ethical guidelines. All studies and trials

listed have IRB or Ethics Committee approval where relevant. The safety and scientific validity of the study is the sole responsibility of the study sponsors and investigators. Patients should use the contact information provided to contact the research organization for more information.

Choosing to participate in a study is an important personal decision. Before you participate in a study, discuss all options with your health care provider. Although study sponsors may donate to the FPA, such donations do not influence or guide our decision about the studies we identify.

It Takes All of Us Working Together

In 2022, Melissa Baumbick and Brandi Underwood applied, interviewed, and were selected to participate in Headache on the Hill, an annual advocacy event organized by the Alliance for Headache Disorders Advocacy (ADHA).

On February 14, 2023, Melissa and Brandi joined 300 other ADHA advocates from 48 states, meeting with the offices of US Senators and Representatives from Georgia.

Neuropathic facial pain, including trigeminal neuralgia, is diagnostically classified by the International Headache Society in The International Classification of Headache Disorders. Headache on the Hill brings together health professionals, advocates, patients, caregivers, and researchers in support of the common goal to make life better for all those living with or otherwise impacted by headache disorders in the United States.

Our primary goal and reason for participating in this event is to raise awareness about neuropathic facial pain in the larger headache space.



“As CEO of the Facial Pain Association, the largest patient organization supporting all people affected by neuropathic facial pain, I am here to be a voice for those in our community, some of whom literally cannot speak because of their relentless pain.”

— Melissa Baumbick, CEO



“I hope to work together in pursuit of equitable policies, research, and funding for people living with headache conditions, including neuropathic facial pain. Through sharing our stories, we can help reduce barriers and stigma, especially in rural and underserved communities.”

— Brandi Underwood, Marketing and Communications Manager

We are grateful for all centers, organizations, companies, researchers, and individuals who collaborate and partner with the FPA to spread awareness about neuropathic facial pain.

Community of Collaboration

Alliance for Headache Disorders Advocacy

American Academy of Orofacial Pain

Association of Migraine Disorders

Biohaven Pharmaceuticals

Brotman Facial Pain Clinic

Cleveland Clinic

Coalition for Headache and Migraine Patients

Columbia University

Facial Pain Research Foundation

Juan M. Hincapie-Castillo, PharmD, MS, PhD

Jonathan Greenberg, PhD

KORTX

Mayfield Brain & Spine

Mayo Clinic

Migraine World Summit

North American Neuromodulation Society

Noema Pharma

NSPC Brain and Spine Surgery

Rare Disease Day

Stanford Medicine

TMJ Association

U.S. Pain Foundation

If you are interested in partnering with the FPA, please contact Brandi Underwood at bunderwood@facepain.org.

NANS and the FPA: Women Leading the Way



Julie Pilitsis, MD, PhD

Dr. Julie Pilitsis, Vice President of Health Affairs and FAU Health Network and Dean of Charles E. Schmidt College of Medicine at Florida Atlantic University, is the North American Neuromodulation Society's (NANS) new president!



In addition to becoming the first woman neurosurgeon to serve as a Dean of a US Medical School, she is the first woman president of NANS in its 30-year history.

In 2014, Dr. Pilitsis began her involvement with NANS leading the Women in Neuromodulation Section, where she was the first chair. She then served as scientific program chair, where she ensured that 25% of speakers were of diverse backgrounds and ultimately joined the Executive Committee of NANS as Treasurer. Dr. Pilitsis became involved with the Facial Pain Association (FPA) in 2019 as a member of the Medical Advisory Board.

Dr. Pilitsis believes in the principle of “We rise by lifting others.” Her visionary leadership and keen sense for the needs of others guide her in empowering fellow physicians and scientists toward reaching their goals and patients toward holistic care. Notably, some of the people that lifted her during her training – Jeffrey Brown, MD and Kenneth Casey, MD – are long-standing members of the FPA Medical Advisory Board and she was eager to join them in supporting patients with facial pain.

Both organizations have continued to grow since their advent, and with the increasing popularity of neuromodulation as a treatment option for chronic pain, it is no surprise that Dr. Pilitsis sees an opportunity for the FPA and NANS to have intertwining goals. Neuromodulation is a favorable option for medication-refractory facial pain. Peripheral nerve stimulation (PNS) is typically the starting point, as it is the least invasive and has shown promising results in patients with trigeminal neuralgia and craniofacial neuropathic pain. If PNS is unsuccessful, high cervical spinal cord stimulation (SCS) may be offered, followed by motor cortex stimulation (MCS), and deep brain stimulation (DBS). Collaboration among the two societies would allow for like-minded physicians and scientists to continue exploring neuromodulation for all its indications in

advancing patient care. Both societies share similar approaches to their mission by hosting conferences, webinars, and seminars throughout the year to raise awareness among their target communities.

Dr. Pilitsis aims to focus on the patient at the 2024 NANS Annual Meeting by promoting **#PatientFirst** as the conference's theme.

Dr. Pilitsis leads a prolific team which has published more than 230 journal articles, four books, and numerous chapters. She values the wealth of thought-leadership that research brings for both organizations. Both NANS and the FPA are avid promoters of research, with NANS hosting the largest annual neuromodulation meeting each year. The FPA provides information about relevant medical studies and clinical trials which may be of interest to people affected by neuropathic facial pain. Primary goals include empowering patients and caregivers with knowledge that helps them be educated partners in their healthcare and encouraging more research on facial pain and other issues relevant to the facial pain community.

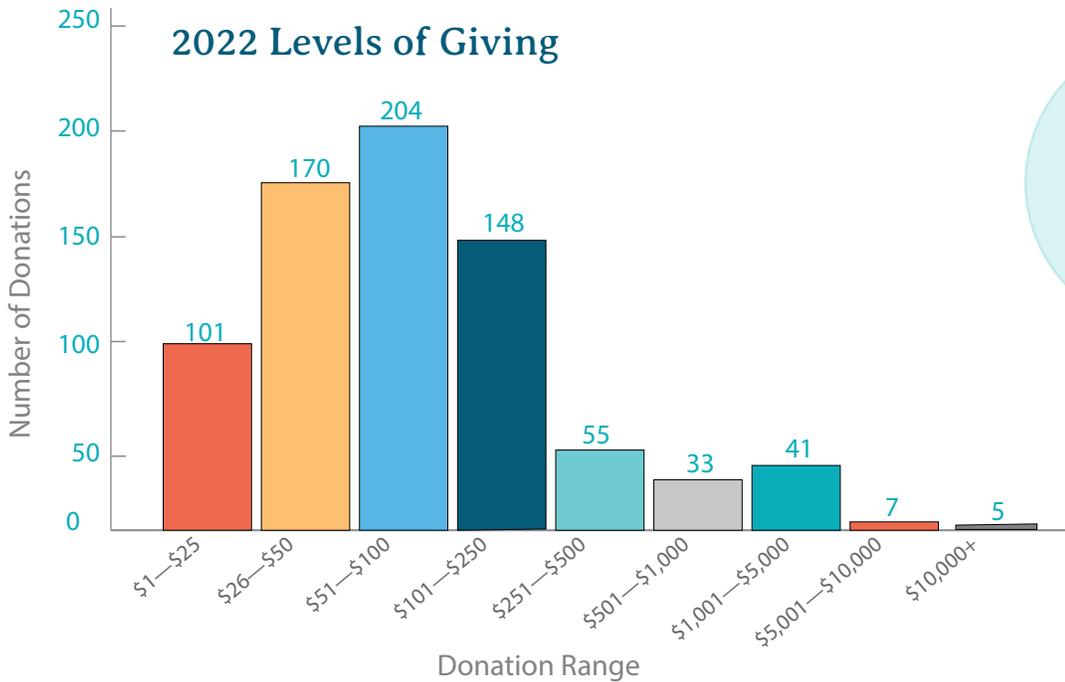
Being a transformational leader, Dr. Pilitsis sees the endless possibilities between NANS and the FPA, with opportunities to improve her lifelong dedication to helping patients with chronic pain.

Together NANS and the FPA create alignment for the perfect conduits between patients and providers to improve pain management and change lives. By tapping into the power of patient advocacy groups through #PatientFirst to feature patient testimonials and share their success stories, the organizations' stewardship will transform the experience for patient centric care.

Physicians involved with NANS can provide accurate and updated information about neuromodulatory therapies to patients with neuropathic pain, utilizing the vast network of chronic facial pain patients managed by the FPA. This channel will match patients interested in neuromodulatory therapy options with physicians.

This is just the tip of the iceberg – there are endless possibilities under the outstanding leadership of the group that inspires us to redefine and move forward the future of pain management. ■

It Takes All of Us Investing in the Facial Pain Community



Every support group, every webinar, every phone call, and email of support is made available through the generosity of people like you.





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

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

 Pledged

 Claude and Jean Aldridge
 Anne & John Ciemnecki
 Kaarina Ederma
 Susan H. Gay

Doris Gibson
 Regina Gore
 Ronald David Greenberg
 Carlin Lagrutta

Miriam Leinen
 Mary Ann McCann
 David & Jody Meyers
 Charles Muchnick

Mary-Ann Neri
 Arlene & Bernard Richards
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 Arthur & Ann Schwartz

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



FacialPain Association | **Sustainer Circle**

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

Jerry Adkins
 William Albert
 Heidi Battistini
 Melissa Baumbick
 Joan Beelen
 Carol Bender
 Cynthia Bennett
 Carol Berardi
 Susan Blowers
 Erika Blumberg

Jennifer Byram
 Joey Callahan
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 Irene Fulk
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 Treana Hansen
 Warren Huss
 Jeri Klein
 Ally & Danny Kubik
 Lisa LaGrego
 Andrew & Amy Louie

Audrey Martinuzzi
 Arthur Matson
 Laura Ortiz
 Jeanne Tarullo Hays
 Brandi Underwood
 Candace Walkup
 Kathleen Warren
 Linda Wilson
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If you would like more information on joining the FPA Sustainer Circle, please call 800-923-3608 or email Brandi at bunderwood@facepain.org.

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Carrie Turco
Dorothy Wehunt
Glenn & Christy West
WHA International, Inc.
Cynthia Woods

"I would say that the support group is almost as important as taking the right medication. I'm so appreciative of you organizing this..."

—Robert

Chair's Club
(\$15,000+)

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(\$5,000 to \$14,999)

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(\$2,000 to \$4,999)

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“The information that you have sent us will greatly help us in our decision making. It helped me tremendously to begin the journey of providing relief for my wife, who has been dealing with trigeminal neuralgia. Additionally, I had a very nice conversation with [volunteer] Tom Kruse who also provided valuable information.”

—Dan

“Donors” continued on page 31

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“Your lovely emails have really helped me. I am really struggling to come to terms with this being something that isn’t going to go away. Thank you again, you really have made a huge difference to me already.”

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Dr. Brown is the Facial Pain Association Medical Advisory Board National Chairman. He serves as the Neurosurgery Director of the NYU Langone Long Island CyberKnife® Program in Mineola, NY.



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