Expert, integrated care for patients with trigeminal neuralgia, addressing both your physical and emotional needs

Advanced Treatment for Facial Pain

Our Facial Pain Program includes internationally recognized experts in the field who have advanced training in the very latest minimally invasive procedures used to treat TN.

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At Mayfield, our approach to facial pain is grounded in compassion and personalized care.

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

- Gamma Knife radiosurgery
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Mayfield’s Nationally Recognized Trigeminal Experts

Steven Bailey, MD  Vincent DiNapoli, MD, PhD  Yair Gozal, MD, PhD  George Mandybur, MD  Ronald Warnick, MD
It is wonderful to be able to depend on something or someone. It makes life so much easier.

In today’s world, it can feel like there are fewer and fewer things that are stable, dependable. Think of the number of times the word “unprecedented” is used these days. It is now commonly used to describe weather conditions, international relations, political divisions, supply chains, economic matters, pandemics, and so much more.

Fortunately, you can depend on the Facial Pain Association. Why are we an organization that you can depend on? The FPA has been continuously helping people in our community for more than 31 years. The FPA has full-time staff and over 100 trained volunteers standing ready to help you, including a world-class Medical Advisory Board. To provide you with the most accurate, up-to-date information, the FPA continues to build on the most comprehensive library of facial pain resources in the world, including studies, articles, webinars with medical experts, speeches by medical experts, and more to ensure that we provide the best information. In addition, the FPA hosts conferences - virtually in recent years - to help you learn what you need to know to best manage your condition. The FPA has approximately 30 Support Groups that meet either in person or virtually to provide information and support. The FPA has approximately 40 Peer Mentors ready to speak with you on a one-on-one basis. The FPA has many generous donors to ensure that we will be here for you for years to come if you need us. And more...

In other words, in a world of ever-accelerating changes, please take solace in knowing that you have a dependable, trusted partner standing ready to help with your facial pain challenge—undoubtedly a very important element of your life.

You should also know that, beyond everything mentioned that the FPA does to be a dependable partner to you, there are many other actions we are taking that may not be apparent to you at this time. Just two weeks ago, we added Dr. Beth Darnall, a Stanford University Pain Psychologist, to our Medical Advisory Board to help us deliver information about the mental health aspects related to chronic pain. This summer, the FPA will begin advertising directly to dentists to inform them of neuropathic facial pain conditions that do not benefit from dental procedures. Our goal for this effort is fewer people in our community being subjected to unnecessary tooth extractions and root canals. Later this year, the FPA plans to launch a patient registry so we can help collect vital information for those institutions conducting research to provide better medical solutions for our community. And more...

Almost every week, my wife and I say to each other, “Yep, the world’s crazy right now.” Maybe you’ve been thinking something similar. Please be comforted in knowing that when it comes to managing your facial pain condition, you have a solid, dependable, trusted partner in the FPA.

Sincerely,

David Meyers, Chairman of the Board
The Facial Pain Association
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Caren Hackman
A year ago, our Board of Directors sought to ‘reimagine’ the MAB to include clinicians whose focus was the treatment of chronic facial pain.

The organization, now called the Facial Pain Association, was born three decades ago at the kitchen table of an ambitious patient of Dr. Peter Jannetta, Claire Patterson. Dr. Jannetta had by then managed to overcome controversy and prove that tic douloureux was caused by vascular cross compression of the trigeminal nerve and that the optimal treatment was microvascular decompression.

Through their efforts and that of a small board of directors, patient support groups sprouted nationwide. Their goals were to educate patients with facial pain about this obscure entity and direct them to clinicians who were experts in its care. To that end, Dr. Jannetta formed a medical advisory board. It was composed of neurosurgeons that he identified as outstanding clinicians, teachers, and individuals who strove to advance the field with their peer-reviewed research.

At the first national conference, MAB members met in Cincinnati, Ohio, with the volunteer support group leaders to educate them on the status of the facial pain field and the nature of those procedures used to surgically treat TN. The leaders would then be better able to promulgate accurate and useful information at their regular local meetings.

At ensuing biannual national TNA conferences, patients were invited to attend. Many came to these conferences because they suffered from pain thought to be inoperable or a consequence of failures or complications of surgery.

Our evolution continued. Regional meetings were added to meet growing interest. To respond better to the diversity of patients in the facial pain community, the Trigeminal Neuralgia Association became the Facial Pain Association. This encouraged the inclusion of those whose pain could not be eliminated by surgery and straightforward medicine - patients with chronic, debilitating pain who increasingly benefitted from psychological concepts of pain control.

A year ago, our Board of Directors sought to “reimagine” the MAB to include clinicians whose focus was the treatment of chronic facial pain.

The addition of Beth Darnall, Ph.D., to our MAB begins this important transformation.

Dr. Darnall is a renowned psychologist and professor at Stanford University. She seeks to discover how harnessing the power of the mind to shape the demons of an injured nervous system can diminish pain. Her treatments empower those in pain to better control it and to limit their dependence on medications. The most innovative of her tools is the use of virtual reality. Mindful emphasis on pleasant experiences at times of pain exacerbation can be soothing. Virtual reality takes one a step beyond this. What if, by donning a 3D headset, you find yourself strolling on a virtual sun filled beach with a cooling breeze and the relaxing sounds of ocean waves splashing on the soft sand? When your pain is at its worst, you may no longer need to conjure such thoughts. Virtual reality transports you there.

Will that relieve your pain? Research suggests the possibility.

With Dr. Darnall’s appointment to our MAB, we hope to expand the ability of the Facial Pain Association to provide hope and healthfulness to the widest audience of patients who suffer from facial pain.
Leadership

Board of Directors

David Meyers, Chairman
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Melissa Anchan
Ramesh P. Babu, MD

Natalie Merrithew
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Regina Gore
Database & Volunteer Coordinator
Brandi Underwood
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Christina McCurdy
Bookkeeper

Young Patients Committee (YPC)

Kenzie Winslow
Co-chair
Lindsey Thacker
Co-chair
Rachel Triay
Member
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Case

A 46-year-old otherwise healthy man presented with new onset facial pain triggered by nose blowing. The pain started in the right nostril and radiated above the eye. He was diagnosed with trigeminal neuralgia and had symptom resolution with gabapentin which was eventually tapered and discontinued. However, 1.5 years later the patient developed the episodes again with a frequency of >100 attacks per day lasting up to 10 seconds in duration. This time they were associated with redness and drooping of the eye as well as tearing on the same side of the face and were triggered by talking, eating, brushing his teeth, touching his face, and again by nose blowing. The patient tried the following medications which were either ineffective or not tolerated: carbamazepine, baclofen, gabapentin, intravenous DHE, indomethacin, and melatonin. The following medications reduced pain or frequency of attacks: lidocaine, extracranial nerve blocks, SPG block, and intravenous fosphenytoin. He was maintained on lamotrigine, lacosamide, and prednisone for preventive treatment of pain attacks, as well as high flow oxygen and oxycodone/acetaminophen for acute treatment of attacks.

As part of his evaluation, the patient underwent an MRI of the brain with and without contrast which showed a vascular loop contacting the right trigeminal nerve (Figure 1). After consultation with neurosurgery, the patient underwent microvascular decompression of this vascular loop. During surgery, he was found to have a classic superior cerebellar artery compression as well as venous compression of the trigeminal nerve. Following decompression, the patient was able to taper off all his medications and has remained pain free.

Figure 1. Blue arrow: Vein Red arrow: Superior cerebellar artery Yellow arrow: Trigeminal nerve root entry

“Tic or Tac” continued on page 6
Diagnosis of Facial Pain

Definitions of headache syndromes, including facial pain, are set forth by the International Classification of Headache Disorders. Short-lasting unilateral neuralgiform headache attacks with conjunctival injection and tearing (SUNCT) and Short-lasting unilateral neuralgiform headache attacks with autonomic symptoms (SUNA) are part of the Trigeminal Autonomic Cephalgias whereas trigeminal neuralgia (TN) is classified under Painful Lesions of the Cranial Nerves.

SUNCT and TN share triggers that cause irritation of the trigeminal nerve such as chewing, touching the face, or brushing teeth. TN is typically distinguished from SUNCT by its lack of associated cranial autonomic features and presence of a refractory period between attacks, during which time another attack cannot be triggered. However, these clinical limits that set one apart from the other are not always entirely clear since patients can have overlapping features of both disorders. Examples of cranial autonomic symptoms as well as the defining features of SUNCT, SUNA, and TN are outlined below.

**SUNCT:**
Sharp, stabbing, burning, or shocks typically in the V1 distribution of the fifth cranial nerve lasting up to 600 seconds.
- Associated with cranial autonomic symptoms, specifically conjunctival injection and tearing.
- Can occur in a saw-tooth pattern in which the pain still occurs in paroxysms but never returns to baseline.
- Frequency up to 600 times daily.
- No refractory period preventing recurrence of attacks one after another which may cause a saw-tooth pattern of painful flares.

**SUNA:**
Same defining features as SUNCT except it must only have one out of any of the cranial autonomic symptoms.

**Cranial Autonomic symptoms:**
- Conjunctival injection
- Lacrimation
- Nasal congestion and/or rhinorrhea
- Eyelid edema
- Forehead and facial sweating
- Miosis
- Ptosis

Table 1. Comparison of SUNCT/SUNA and TN

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<tr>
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<th>SUNCT/SUNA</th>
<th>TN</th>
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<tr>
<td>Patient Population</td>
<td>SUNCT – Men; SUNA – Women</td>
<td>Women</td>
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<td>Ages</td>
<td>All Ages</td>
<td>Over middle age</td>
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<tr>
<td>Location</td>
<td>V₁</td>
<td>V₂, V₃</td>
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<tr>
<td>Frequency of attacks</td>
<td>Up to 600x/day</td>
<td>Variable</td>
</tr>
<tr>
<td>Duration of attack</td>
<td>Up to 600 seconds</td>
<td>Up to 120 seconds</td>
</tr>
<tr>
<td>Cranial autonomic symptoms</td>
<td>Present</td>
<td>Absent</td>
</tr>
<tr>
<td>Refractory period</td>
<td>Absent</td>
<td>Present</td>
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<tr>
<td>First line treatment</td>
<td>Lamotrigine, IV Lidocaine</td>
<td>Carbamazepine/Oxcarbazepine</td>
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</table>
Classical Trigeminal Neuralgia:

- Facial pain on the same side as compression of the trigeminal nerve, often by an artery or vein
- Previously termed ‘tic douloureux’ due to the excruciating pain that causes facial grimacing
- Typically a paroxysmal electric shock-like or burning pain, more often in the 2nd or 3rd divisions of the fifth cranial nerve, lasting up to two minutes.
- Has a refractory period in which after one attack another attack cannot be triggered for a given amount of time.

Please refer to Table 1 for a comparative approach to SUNCT/SUNA and TN. For ease of comparison, SUNCT and SUNA have been combined. Please note the difference between these two conditions per their definitions.

Pathophysiology

SUNCT/SUNA are generally primary headache disorders, meaning that the pain arises directly from dysfunctional neurons in the brain, but can have secondary mechanisms such as loops vascular (a blood vessel that contacts the nerve) or other structural lesions in the brainstem (tumors, demyelination) which should be screened for with brain MRI if the diagnosis is suspected.

In contrast, classical TN is considered a secondary headache disorder and is typically caused by a vascular loop contacting cranial nerve V. However, a structural cause of TN is not always found.

Symptom Overlap

The diagnosis of SUNCT versus TN can be difficult to determine due to the similarities in symptomology. The presence of autonomic features can aid in the diagnosis of SUNCT/SUNA but tearing and eye redness have also been noted in TN. Some speculate that TN and SUNCT have significant disease overlap. Up to two thirds of suspected trigeminal neuralgia patients have been reported to have at least one cranial autonomic symptom, some of those patients more appropriately fitting a diagnosis of SUNCT/SUNA. In the disease course patients can then revert back to symptoms characteristic exclusively of TN. However, unlike SUNCT and SUNA, TN has a refractory period during which time it is near impossible to generate another attack. The presence of a refractory period can be difficult to ascertain clinically.

The spectrum of SUNCT/SUNA and TN may cause misdiagnosis due to overlapping features.

If there is uncertainty between which diagnosis is most appropriate, then both should be applied.

Treatment

Treatment for TN and/or SUNCT/SUNA starts with the use of an oral medication that is taken daily, typically borrowed from the anticonvulsant class of medications. First-line treatment for trigeminal neuralgia includes oxcarbazepine or carbamazepine. These medications block sodium channels and reduce pain signals from neurons. Lamotrigine, first line treatment for SUNCT/SUNA also blocks sodium channels as well as the release of other neurotransmitters that can propagate pain. The goal of these medications is to reduce the frequency and severity of pain attacks. Intravenous lidocaine can also be used for acute flares of pain associated with SUNCT/SUNA though this requires careful monitoring in an inpatient setting.

If a brain MRI demonstrates compression of the trigeminal nerve by a blood vessel or disruption of the nerve by another structural lesion such as tumor, a neurosurgeon should be consulted to determine if there are surgical options for pain relief.
Abbreviations:

SUNCT – Short lasting unilateral neuralgiform headache attacks with conjunctival injection and tearing.

SUNA – Short lasting unilateral neuralgiform headache attacks with cranial autonomic symptoms.

TN – Trigeminal neuralgia.

DHE – Dihydroergotamine.

SPG – Sphenopalatine ganglion.

References


5. Cohen AS, Matharu MS, Goadsby PJ. Short-lasting unilateral neuralgiform headache attacks with conjunctival injection and tearing (SUNCT) or cranial autonomic features (SUNA)— a prospective clinical study of SUNCT and SUNA. Brain : a journal of neurology. 2006;129(Pt 10):2746-60.


Disclaimer:
The FPA does not endorse any product, doctor, procedure, medical institution, or its staff.

Note from Medical Editor, Dr. Jeffrey Brown
When I injure the trigeminal nerve by the procedure of balloon compression rhizotomy, it is routine for me to check the eye ground on the side of surgery for a flushed red appearance. It is well known that there are autonomic effects from trigeminal nerve injury. Compressing the trigeminal nerve causes slowing or speeding of the heart rate and dropping or raising of the blood pressure depending on the site and severity of injury. The trigeminal nerve is intimately associated with the autonomic nervous system, though the precise neural pathway is not well defined.
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, FPA supports patients, their loved ones and caregivers, and healthcare professionals who diagnose and treat people affected by facial pain.

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 group forum for those in the facial pain community to experience an encouraging, sympathetic group in person, virtually, or in a combination of both.
- 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 social media 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, event planning, grant writing, patient advocacy, patient research advisory panels, and social media moderation.

We provide education:

FacePain.org includes the latest information about 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 top medical professionals, event notifications, research updates, and more.

We promote patient advocacy:

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

Social Media - FPA maintains an active Facebook Page, Facebook Group, and accounts on Twitter, Instagram, YouTube, and LinkedIn.

The FPA Young Patients Committee (YPC) recognizes the unique issues faced by people under age 40. YPC gives a voice to younger patients and raises awareness that neuropathic facial pain does not only affect older adults. YPC also has a Facebook Page and Instagram account.

Together, We Made a Difference

The 2021 Annual Report shares the story of how we made a difference through volunteering, learning, raising awareness, and investing in the facial pain community— together.
Small Acts of Kindness
Make Big Things Happen
By Regina Gore, FPA Volunteer Coordinator

Facial Pain Association volunteers regularly perform small acts of kindness that make big things happen. They are on the front lines of connecting those in need with support, education, and advocacy. Our volunteers make the mission of FPA happen. They make a larger community happen. Their acts of kindness allow the FPA to support and build community. In fact, it was Claire Patterson whose acts of kindness started the FPA 32 years ago. Claire has said her inspiration came from Dr. Peter Janetta, who was her surgeon and the pioneer of microvascular decompression surgery. Claire has, in turn, inspired hundreds of others to continue her work of supporting facial pain sufferers, their families, and loved ones.

Each act of kindness is a shining, precious gem dropped into a funnel adding to a mountain of kindness on the other end. Rubies. Sapphires. Emeralds. Diamonds. Each one perfect in itself and each one adding to a larger good.

If you listen closely, you can almost hear the plink of another gem drop when a volunteer answers the phone. The plink when a volunteer shares their story. Leads a group discussion. Plink. Posts a positive message on Facebook. Plink. Plink. Starts a new Support Group. Plink. Plink. Lends a sympathetic ear as someone cries. Plink. Plink. Plink. Each gem piling up until there is a mountain of kindness. Not to be secreted away and admired from time to time but to be shared so that each act of kindness may inspire another.

FPA volunteers are gems themselves just as much as their acts of kindness. Without their efforts, there would be no FPA. We are so very grateful to them for creating a community and furthering an organization dedicated to its support.

If you are interested in joining our wonderful corps of volunteers, please contact Regina Gore, Volunteer Coordinator, at rgore@facepain.org.

Read more about volunteering with the FPA at www.facepain.org.
Join us in thanking all FPA Volunteers for their dedicated service to the facial pain community.

Jeanne Tarullo Hays
Oxford, MS, Peer Mentor

When I was diagnosed with trigeminal neuralgia over twenty years ago, I felt like an alien. I had never heard of the condition, and nobody I knew had ever heard of it. Fortunately, my husband began furiously researching TN and came across the Trigeminal Neuralgia Association, now the Facial Pain Association, and I was thrown a lifeline in the form of information and reassurances. However, a peer mentor program did not exist at the time, so I was still isolated. How comforting it would have been to talk to someone who knew what I was going through, who had actually felt the invisible pain that I attempted to describe to family and friends. After a number of years on medications to control the pain albeit with their unique side effects, I discovered acupuncture which gave me back my life – no more drugs; no more pain.

A decade later, when given the opportunity to become a peer mentor, I gladly volunteered. Whenever I correspond with people desperate in their pain, I am so grateful that I can offer them hope and reassurance. I offer hope that life can improve and reassurance that they are not alone in their journey. Recently, I was able to correspond with a French speaker, using my skills as a retired French teacher. The confluence of my own experience with TN and my knowledge of a foreign language merged as a blessing. Connections are crucial for humans, particularly when they are vulnerable, and I am honored to be able to be an instrument of connectivity.

FPA welcomes volunteers from varied backgrounds, life experiences, and medical histories. No specific skills, educational background, or experiences are required. Potential volunteers are asked to complete an application and screening process. FPA provides training, educational opportunities, and ongoing support. If you are interested in volunteering please contact Regina Gore, Volunteer Coordinator, rgore@facepain.org.
An awkward silence eleven years ago prompted me to volunteer to co-lead the FPA St. Louis Support Group. Three months after joining the support group, the leader announced he was stepping down, and it looked as if no one was stepping forward. Finally, I decided to take the plunge, but only if someone would co-lead. Sharon Whitener raised her hand, and together we have been leading the group ever since.

I was recently asked to lead a special topic support group session at the 2022 FPA Conference. I chose the topic of tumors and facial pain due to my personal experience of having a meningioma as the cause of my facial pain. During the session, someone asked why there couldn’t be an ongoing support group for people with tumors affecting or causing their facial pain. As a result of that session, a new support group was born. I agreed to get things started as the leader, and we began meeting every two months. It is a small but important group that we hope to grow as the word gets out.

“Our conditions are rare, and it’s important that we stick together, support each other, and reach others with similar experiences.”

Vince Holtmann
St. Louis, MO, Support Group Co-leader

Support Group Leaders (SGL) & Peer Mentors (PM) by US State

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Support Group Leaders (SGL) & Peer Mentors (PM) by Country

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Photo top left: Fishing is my passion – find me in my boat and on the water with a beautiful fish.

Photo bottom right: My wife Ann and me at the wedding reception we had for my daughter three years ago.
My name is Christine Cohen, and I have trigeminal neuralgia, occipital neuralgia, Eagle’s Syndrome, and Arnold Chiari malformation. Each one of these medical conditions is considered rare. During my search for answers and treatment, I often felt alone, frustrated, and inadequate.

The responses I received to questions posted on social media came from complete strangers, but they still took the time to offer suggestions, advice, or even just words of support. These were such small gestures, but knowing that I was not alone and having a community to turn to meant quite a lot to me. I was able to use the advice given to me to research my symptoms and better educate myself as a patient. I know firsthand that any small gesture like this can make a large impact, but none have stuck with me more than the connection I made with a fellow patient through an online support group.

In 2011, I was struggling with new, unexplained symptoms when I read about TN. One woman took the time to reach out to me privately. She told me about her experience with TN and described her path to a diagnosis as well as her treatment. After that, we began communicating regularly. She was always available to answer my questions and offer suggestions regarding communication with my doctors. As she had already undergone a successful MVD procedure, she was able to provide me with important information regarding this surgery.

Her perspective as a patient who had a successful MVD made me feel more confident in my decision to undergo the same procedure. Her support during my recovery was invaluable. Being able to converse with someone who knew exactly what I was going through and exactly how I would feel after surgery made all the difference in the world.

In all our conversations, I tried to impress upon her how grateful I was that she took the time to talk to me. Every time, she insisted she was happy to do what she considered a small thing and that no thanks were necessary. While she may not have thought she was doing very much, her advice and support really changed my life.

I now have the opportunity to make those small gestures, like taking a phone call from a patient or hosting the Support Group Meetings, that can hopefully make a big impact.

“Throughout the years, I found some of the best information and advice not from the medical community but from people who have the same conditions as I do.”

“Her efforts inspired me to become a Peer Mentor and Support Group Leader with the Facial Pain Association so that I have the chance to do for someone else what she did for me.”

Christine Cohen
Atlanta, GA, Peer Mentor and Support Group Leader
Stephanie Blough joined the FPA Young Patients Committee in October of 2014 and became chair in 2017.

Stephanie reflects on her time as YPC Chair, saying that “as a group under my leadership, we all worked on things together, but I am proud that we have worked/been a part of every conference the FPA has held since New York in 2014, making sure we sponsored young patients to attend these events too. We have represented the FPA at several community events across the US, created the YPC Academic Scholarship, written articles for the FPA Quarterly Journal, created multiple fundraising efforts, especially with our Etsy store, made over 600 masks through the pandemic, and have an official YPC support group for those under 40 now.”

FPA is very thankful to Stephanie for her impact and is excited to welcome Lindsey Thacker and Kenzie Winslow as new co-chairs!

On the following pages are ten books (listed in no particular order!) that have helped us through our experience with trigeminal neuralgia and chronic illness. Each of these books has helped us improve our outlook on life and also in choosing friends who uplift and support us. We hope that you find answers and joy in one of these books. Happy reading!

FPA YPC announces new co-chairs and extends gratitude to Stephanie Blough for her years of service

Stephanie Blough  Lindsey Thacker  Kenzie Winslow

4,800+ Followers across social media

50+ FPA YPC members sharing happy notes via mail

Happy Mail

@youngpatients  @youngpatients  @youngpatients  @tealribboncrafts
The Book of Joy by Dalai Lama, Desmond Tutu and Douglas Carlton Abrams

The Book of Joy focuses on how to find joy amidst times of suffering. As those who live with chronic pain, this can be a question we thought we might never find the answer. Though we understand real suffering because of our chronic pain, this book also shows you to relate to those around you who are going through different forms of suffering. Find friends who are willing to listen and understand what you are experiencing, then find ways together to look for joy.

Striking Back by George Weigel and Kenneth F. Casey, M.D.

Striking Back provides a comprehensive look at trigeminal neuralgia and tips from other chronic pain patients on how to cope with chronic pain. Though this book is more of a handbook for life with trigeminal neuralgia, it provides valuable insight on how to live life with chronic pain, rather than letting chronic pain rule your life. If your friends are struggling to understand your experience with chronic pain, choose a chapter or two from this book to begin to understand. Choosing friends who want to understand is an integral part of life with chronic illness - you want to surround yourself with people who will support you and who are willing to learn.

Guts by Raina Telgemeier

This book is a graphic novel that dramatizes the author’s fears and anxieties about her chronic illness, but it also focuses on her triumph over those fears. This book also destigmatizes the use of therapy to understand your personal experience with chronic illness. Guts is an excellent read for children with chronic diseases. It primarily focuses on the use of healthy childhood friendships to overcome fears and anxieties. Telgemeier uses imagery to emphasize the importance of friendship throughout a chronic pain experience.

Tales of a Spoonie Warrior by Saidee Wynn

Wynn uses a collection of short essays to describe the highs and lows that come with living with chronic illness. She uses humor and honesty to portray what life is like accurately. When choosing friends to have in your inner circle of confidants, you want someone willing to hear about the highs and the lows of your life. This book shows one way in which you can share your own experience with those closest to you. Allow your friends to see the lower side of life with trigeminal neuralgia and allow them to help you. It can be scary to share those intimate snapshots of living with chronic illness, but a true friend will help you.
The Courage to be Disliked
by Ichiro Kishimi and Fumitake Koga
One of the hardest parts of living with a chronic illness is the societal expectation of being always “okay.” This book challenges that ideal and encourages you to live life authentically - to do what makes you happy. You can never please everyone in life, so you need to live for yourself. Life with a chronic illness means you may have to do things differently from others, but it doesn’t make you do things any less relevant or meaningful. Find friends who push you to live authentically and are excited to try new ways of doing things!

Girl, Wash Your Face
by Rachel Hollis
A self-help book full of real-life insight and Hollis’s self-deprecating humor means you feel like you’re talking to a friend. Hollis wants to show you how to become who you are meant to be rather than focusing on the lies you believe about yourself. This book teaches you how to count the positives in life, even the small ones, and start to see how they can add up to make significant changes in your life. Girl, Wash Your Face would be an excellent book to read with a friend to help each other focus on all of the positives in life.

Surviving and Thriving with an Invisible Chronic Illness
by Ilana Jacqueline
We all know living with a chronic illness is challenging enough, but when our pain is invisible, we can be left isolated and alone. Jacqueline writes about real-world examples of people who face invisible illnesses daily. With so many real-world cases, this book can begin to help you feel less isolated in your experience. Because our friends and family cannot always see the pain we are in, they may not still understand the severity of what we are feeling. The friends you surround yourself with should be willing to learn about the invisible aspect of trigeminal neuralgia, and this book can help you shape your experience into words.

Everything I Need to Know I Learned from Mister Rogers’ Neighborhood
by Melissa Wagner
Everyone knows Mister Rogers, and this book compiles all of the wisdom he shared over the years. From seeing the good in ourselves to seeing the good in the world, this book reminds us that there is much to celebrate in life. Remember: you are special, and all kinds of feelings are okay.

The Boy, The Mole, The Fox, and the Horse
by Charlie Mackesy
A story of four unlikely friends who share one unbreakable bond, this book reminds us that though we may all look different, we are all the same inside. Mackesy uses universal truths and wisdom to celebrate our differences. Our friends might not always experience life the same way that we do, but they can still be there to share in our successes. Full of short, but profound conversations between friends, this book provides hope.

Happy
by Fearne Cotton
We often live in a state of confusion and pain, but Cotton wants her readers to know that they are not alone. She uses her personal experiences with feelings of isolation and sadness to relate to her readers. Her stories, when paired with expert advice, offer practical ways to find happiness in the mundane moments of life. Just like Cotton’s book reminds us, many people experience feelings of sadness too often, which is vital for us to remember. As much as we need our friends to be there for us, we must also be there for them. Friendship such as this will create lasting feelings of happiness and companionship.

“With the help of FPA, I am on the right path to the way of freedom and understanding...a sweet path at that.”
— Janet
More than 1,300 people from 6 continents and 26 countries participated in the 2022 FPA Conference—the largest educational event in FPA’s history.

“…thanks a lot. I look forward to next year.” — Vanessa

2022 FPA Conference

Your generosity not only allowed us to keep the cost of admission low, but also provided complimentary admission to 144 attendees who reached out to us for support.
Find a Doctor

The Facial Pain Association is privileged 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 that 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 this site does not constitute an FPA endorsement of any physician, surgeon, medical procedure, medical institution, or its staff.

FPA’s New Website

In 2021, we launched our new website, www.FacePain.org, which houses all of our webinars, Quarterly journals, upcoming support groups, and more. As we envisioned, the website is faster, easier to navigate, and more accessible, with up-to-the-minute information available at your fingertips.

“What an absolutely wonderful website you have...I am so grateful I found your group.”
— Michelle

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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 100 people 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.

“This year I had the opportunity to help provide education to people who would otherwise not be able to purchase FPA’s book. My gift continues to enlighten the path for people living with facial pain, and you too can make an impact.”
— David Meyers

2021 FPA Webinars

The 2021 FPA webinar series, based on topics from our book Facial Pain: A 21st Century Guide, had more than 1,700 registrants and has been viewed more than 3,000 times.

All FPA webinars are free and available in our library at www.facepain.org/tag/webinars

2021 FPA Bulletins

More than 500,000 FPA Bulletins were received by the facial pain community in 2021.

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/
The Facial Pain Association is committed to providing access to everyone suffering from neuropathic facial pain regardless of diagnosis, age, or needs. In 2021 we chose a new logo that honors our legacy while communicating our ongoing commitment to inclusion. To further align with this goal, we expanded Trigeminal Neuralgia Awareness Day to Facial Pain Awareness Month, kicking off on October 1, 2021.

Anne Ciemnecki has been committed to facial pain awareness for over 20 years. She is a third-generation woman with trigeminal neuralgia, preceded by her mother and grandmother who both had TN. In 2021, she took her facial pain awareness to the next level - turning Facebook teal by using a trigeminal neuralgia profile picture, adding teal highlights to her hair, and getting a teal ribbon tattoo behind her right ear. The inspiration for the tattoo came from Anne’s friend Susie, a fellow member of the facial pain community and one of Anne’s many connections she’s made through spreading awareness.

Anne has a true passion for raising awareness and supporting others on their facial pain journeys. She says: “I always find someone who knows someone with TN, and I can educate them about the condition. The best scenario is when I meet someone with undiagnosed facial pain, and I can direct them to resources. My overarching message is that TN is not easy to live with, but living a complete, productive life of your own definition is possible.”
You Educated Your Community

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

You Shared Your Story

“For those who may not know, I suffer from a rare condition called trigeminal neuralgia and the FPA helps patients like myself…”

@caitdevon

You Turned Facebook Teal

You raised awareness, sharing FPA’s announcement of Facial Pain Awareness Month more than 300 times, and reaching more than 35,000 people.

Community of Collaboration

Association of Migraine Disorders
Biohaven Pharmaceuticals
Cleveland Clinic
Coalition for Headache & Migraine Patients
Mayo Clinic
Migraine World Summit
Noema Pharma
NSPC Brain & Spine Surgery
Rare Disease Day
Stanford Medicine
TMJ Association
U.S. Pain Foundation

Reach/Impressions: 904,000+
Likes/Follows: 15,000+
Reactions: 18,000+
Shares/Retweets: 3,900+
Comments/Mentions: 2,000

Reach/Impressions measures the people who see FPA’s content.
Likes/follows measures the people who support FPA on social media.
Reactions measures engagement with FPA’s content.
Shares/Retweets measures the amplification of FPA’s content.
Comments/Mentions measures interactions with FPA content.
A few months ago, I visited my dentist, who is familiar with neuropathic facial pain. Near the beginning of the appointment, she introduced a student who would be assisting. As they began, I could feel my heart beating faster and my shoulders tensing as I anticipated the strike of pain from the jet of cool water. But then I heard my dentist ask the student if she was familiar with trigeminal neuralgia. Immediately, I felt a wave of reassurance wash over me. My dentist began to teach her about the symptoms and how to minimize discomfort during dental care. In that moment, I realized that this is where change takes place. It is during these moments when medical professionals are educated.

As I left my appointment with gratitude, my heart was also heavy, knowing many have not had a similar experience. I joined the FPA staff in 2020 because of my passion to reduce the suffering of others living with facial pain. One theme that jumped out at me time and time again during the 2022 FPA conference was participants asking questions such as, “How can I get my doctor to connect with FPA?” or “How can my doctor become more educated about the information being discussed?” After the conference, the FPA staff and Board of Directors discussed lessons learned and committed to increasing our efforts around educating the medical and dental communities. As I reflected on the conference and my personal experience from a month earlier, it became clear that to do so, we need to reach one by one, doctor by doctor, until everyone with facial pain is surrounded and supported by better educated healthcare professionals.

As patients, we discover early in this journey that we must become our own self advocate. This requires searching for the correct diagnosis, and finding a doctor who will partner with us to find the right balance to reduce pain and minimize side effects. Having facial pain can feel very lonely. Individually, there is only so much we can accomplish, but we are not alone.
Brandi Underwood, diagnosed in 2018 with trigeminal neuralgia, is pictured with her family.

The Facial Pain Association enables us to combine our individual efforts into a collective voice. As we strive for a greater quality of life for all people with facial pain, we will accomplish more together than we ever can alone.

Whether you suffer from facial pain or love someone who does, you can make a difference by helping us reach the medical community. FPA is committed to this work, and we invite you to share your doctor’s contact information so that we can reach out and invite them to connect with us. Please email info@facepain.org and include your name and your doctor’s information.

Thank you for joining me in this mission,

Brandi Underwood
FPA Marketing and Communications Manager

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.
www.FacePain.org

The Facial Pain Association received a “Give with Confidence” Encompass rating from Charity Navigator
Charity Navigator is America’s largest charity evaluator, rating nearly 200,000 nonprofits and equipping donors with tools to make informed, impactful donations.

The Encompass Rating System is a comprehensive evaluation tool that analyzes nonprofit performance based on four key indicators.
- Finance & Accountability
- Impact & Results
- Leadership & Adaptability
- Culture & Community

The Facial Pain Association earned GuideStar’s 2021 Gold 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.
Together, We Invested in the Facial Pain Community

2021 Sources of Revenue

- Donations 80.9%
- Investment Income 1.1%
- Conference 1.9%
- Sale of Material 1.6%
- Advertisement 1.5%
- YPC 0.5%
- PPP Loan Forgiveness 6.2%
- Professional Membership 6.3%

2021 Expenses

- Programs 70%
- Support Services 7%
- Fundraising 23%

2021 Levels of Giving

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

Scan to give at facepain.org
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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Linda Wilson
Cynthia Woods

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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“This organization has led me to many outstanding options to help with my years of facial pain struggles, I am so grateful.”
—Beth

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— Sara
“I am only sorry I didn’t find FPA many years ago. I truly feel cared about.”
— Dianne
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“You may not have eliminated all my pain, but you have made a big difference in my life.”
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— Michele

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“The FPA has been my information center for half of my life. Thank you FPA for being here for me, all of these years.”

— Abby
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“...I can’t begin to tell you how happy I am to have this support. This is incredible and it gives me hope that I will be able to have a normal, or close to normal, life again. This is a wealth of information and has already lifted my spirits!”
— Maureen

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

Dr. 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.

Dr. Mechanic served as Chief of Neurosurgery at Huntington Hospital, in Huntington, NY, from 1995 to 2014. He has served as Chairman of the Nassau Surgical Society Section of Neurosurgery.

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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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