

Journal of the Facial Pain Association

Spring 2024

Quarterly



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

**2024 FPA VIRTUAL
CONFERENCE**

APRIL 27-28

Meeting You Where You Are: The Meaning Behind the Maze



The cover for this issue of the Quarterly journal features the 2024 FPA Virtual Conference logo, which symbolizes different journeys within the facial pain community. It portrays a maze inside the circle representing the faces of those living with facial pain. The idea is that the FPA is with you on your journey with facial pain, no matter where you are on your path. The maze represents the times when you feel like there is no way forward, when the pain is unbearable, and when no one seems to understand. However, it is also representative of the times when you find the right doctor, treatment option, or connect with others who understand your pain.

The 2024 FPA Conference logo was created by Natalie Merrithew, the FPA's Digital Marketing and Communications Coordinator. She has been a valuable and integral member of the FPA staff for three years and serves as the Editor/Circulation Manager of the Quarterly journal.

"Living with facial pain is unpredictable and ever-changing, adding many twists and turns to daily life. The Facial Pain Association is committed to being your source of personalized information and support no matter where you are on your journey. As the 2024 conference logo shows, the FPA is here to help you navigate the maze, walking with you every step of the way," Natalie says.

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Face Pain?

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hands.**

Ramesh P. Babu, MD
Board Certified,
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neurological surgeon
with 25 years of
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From the Board Chair



There are many excellent, well-trained, and extremely well-intentioned healthcare professionals who want to help those of us with trigeminal neuralgia (TN) and other neuropathic facial pain conditions. However, most of them don't see many patients like us. And without extensive experience, it's difficult for many of them to see the **big picture** — to develop an understanding of all the things that can be done to help mitigate and/or eliminate our pain, such as:

- Medications
- Surgical procedures
- Complementary & alternative medicine
- Mental health aspects of dealing with severe chronic pain

I'm convinced that the best way for you to consider all the relevant medical tools is for you to understand the **big picture**. No, you don't need to be trained like a doctor. You just need to know what questions to ask your healthcare team about important treatment options — “Doc, I understand that many people with my condition have found some pain relief from complementary and alternative medicines like medical marijuana and acupuncture. Can you help me in this area or is there someone you can refer me to who could advise me?” Or “Doc, this ongoing pain is really wearing on me. I understand that there is an important mental health aspect to what I'm going through. Do you have a mental health colleague who might have some ideas of how I can cope with this better?”

The FPA helps you develop an understanding of the **big picture** in many ways, such as at the upcoming 2024 FPA Virtual Conference on April 27 and 28, a new

section of the FPA Quarterly journal, changes to our website, and the launch of our second book this year. I'll expand on the April virtual conference and the FPA Quarterly in this letter today.

The upcoming 2024 FPA Virtual Conference (don't miss it — registration is open now!) is designed to help answer the question “Now what?” There will be presentations made by experts who diagnose and treat people affected by neuropathic facial pain on the full scope of relevant procedures, medications, etc. There will also be presentations discussing the many options you should be considering at your current stage with this condition. In other words, the theme of the conference is to help you garner the **big picture**.

This issue of the FPA Quarterly journal is adding a new section: **News You Can Use**. It will be a great source of information that you can take with you to appointments as a reference for yourself, as well as your healthcare providers. The first topic to be covered (in this issue) is written by one of the foremost authorities on neuropathic facial pain medications, Dr. Wolfgang Liedtke. He specifically covers rescue medications — the ones you should have available for when the pain gets really severe. Notice that this feature is removeable, so you have it when and where you need it.

What can you do to improve your situation? Develop a **big picture** perspective of all the things that could reduce or eliminate your pain and encourage your healthcare team to consider them.



David Meyers
Board Chair, The Facial Pain Association

A Message From the CEO



2024 FPA VIRTUAL
CONFERENCE
APRIL 27-28



In January, I traveled to Charlotte for an in-person Board of Directors meeting and invited members of our staff to attend. The weekend was inspiring and filled with people dedicated to the direction and improvement of the Facial Pain Association.

During this meeting, we discussed our plans for the year and our staff presented the initiatives they are working on to fuel our mission — it's an impressive list! This year, everything is focused on meeting you where you are on your facial pain journey and as David described in his letter, providing a **big picture** perspective on the information we present.

That is what this year's virtual conference is all about. Dr. Raymond Sekula, Chair of the FPA's Medical Advisory Board, and Dr. Joanna Zakrzewska, a consultant in oral medicine and leader in facial pain research, will discuss a pathway to treatment for those living with classical trigeminal neuralgia (TN). This is important because this talk will provide practical treatment options and how to use that information to make decisions about your medical care.

Dr. Wolfgang Liedtke will discuss medications used to treat facial pain. His presentation will discuss the breadth of medications available in the rescue, maintenance, and injectable categories, and he will talk about the order and ways each medication should be used. This guidance will help when a physician says there is only one medication approved to treat TN, or when they want to start with an older medication outside of the accepted protocol. Being informed and knowing what questions to ask provides you with the tools you need to get the right treatment the first time.

Dr. Vivek Buch and Dr. Ashwin Ramayya will discuss pain management for anesthesia dolorosa, burning mouth syndrome, and the constant pain associated with atypical TN. Last year's conference was full of

patient questions about these conditions that are considered more rare than classical TN. Geniculate neuralgia is another "rarer" condition, and Dr. Mark Linskey will present his research on surgical approaches to treat it.

Complementary approaches are an important part of treatment for many living with facial pain. Dr. Jeffrey Fogel, a member of the FPA Board of Directors, will discuss medical marijuana and the landscape of options available to those who want to explore alternative methods of treatment.

We will also address issues associated with facial pain and dentistry, the importance of being treated by a multidisciplinary team of specialists, and the breadth of conditions that can mimic neuropathic facial pain, including migraine and dental pain.

We will not forget about the importance of mental health. Dr. Leesa Scott-Morrow will discuss the challenges associated with neuropathic facial pain and coping mechanisms that can help.

We hope you will join us for the 2024 FPA Virtual Conference. Topics and speakers are being added and this opportunity to hear from neuropathic facial pain experts is unmatched. Registration is open now. The tickets are \$35, but we are happy to offer complimentary admission to anyone who needs it – please email Natalie Merrithew at nmerrithew@facepain.org. Even if you cannot attend the live event, registration grants you access to the recorded presentations. Scan the QR code on page 12 to save your seat!

Melissa Baumbick

Chief Executive Officer, The Facial Pain Association

Table of Contents



4

**MAB Corner:
Medical Misinformation**



6

**Medical Marijuana
for Facial Pain**



14

**Facing Forward —
Advocacy in Action**



16

Chronic Pain and Anxiety



19

**Legacy Society &
Sustainer Circle**



20

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The MAB Corner

How to Identify and Combat Medical Misinformation

Have you heard that white potatoes are bad for you? Or that going out in the cold without a jacket will make you sick? Medical misinformation and health myths have been around for centuries. Now, with the help of social media and content sharing on the internet, these myths travel at lightning speed to all corners of the world.

Harmful health misinformation can have serious consequences. It can lead to medical misunderstandings, impact personal decisions related to health and treatment options, and cause harm, or even death.

When the world is in a state of panic and fear, like it was with the COVID-19 pandemic, people tend to hold onto misinformation a bit tighter. According to a study released by the Pew Internet & American Life Project, over 80% of internet users research

Kenneth F. Casey, MD
FPA Medical Advisory
Board Member



health-related issues. These internet search results can affect how people make decisions about their health and how they communicate with their healthcare providers, especially if they contain medical misinformation.

But what if it's not Dr. Google? What if it's your doctor advising mistaken remedies?

Experimental therapies or medicines can be good fodder for discussion, but misinformation and the improper use of medicines can hurt people. If not directly, the damage is done through incorrect diagnoses and therapies, wasted time and money, and potential impact to the patient's health and well-being.

On occasion, a doctor may fail to exercise the proper standards of care, including giving bad advice to a patient. In most cases, this isn't malpractice; bad advice can be a result of lack of knowledge or may simply be an oversight.

There are several ways misinformation in medicine can manifest:

False Claims: Misleading or false claims about certain treatments, supplements, or remedies can gain traction, leading individuals to believe in their efficacy despite a lack of scientific evidence.

Misinterpreted Studies: Sometimes, studies or research findings might be misinterpreted or taken out of context, leading to incorrect conclusions about the effectiveness or risks of certain medical interventions.

Formation: Platforms like social media can easily amplify misinformation in medicine. Rumors, unverified claims, and anecdotes spread quickly, often without proper scrutiny or fact-checking.

Conflicting Information: With the vast amount of health information available online, there can be conflicting advice, causing confusion and uncertainty among people seeking reliable guidance. The FPA and other reliable internet sites aim to work with and occasionally correct Dr. Google.

So how do we know what's real?

As a patient and consumer, recognizing medical misinformation involves education, skepticism toward unverified claims, and promoting a culture of evidence-based medicine to make informed decisions about health and wellness. **When verifying medical information, remember to:**

Educate yourself.

Get a second and third opinion.

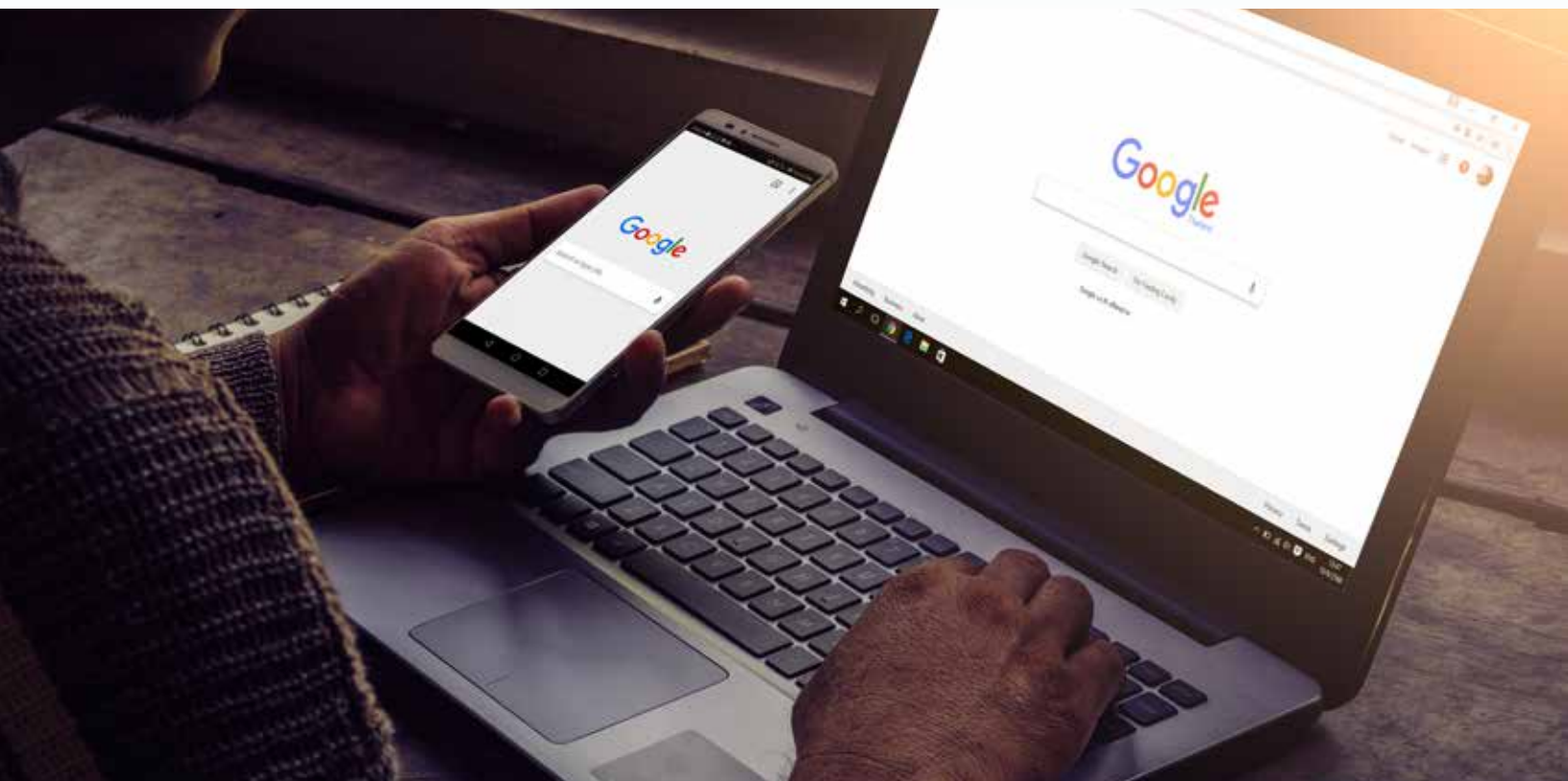
Consider the source — is it reputable?

Search for evidence-based supporting facts.

Ask yourself — is it biased?

Communicate with your doctors directly and often.

Doctors combat misinformation in medicine by using critical thinking, promoting health literacy, and relying on reputable sources of information such as peer-reviewed studies, expert opinions, and trusted medical institutions. Your FPA, with the input from its expert Medical Advisory Board, stands ready to guide you and your healthcare providers. ■



What You Need to Know About Using Medical Marijuana for Facial Pain



Jeffrey Fogel, MD
Member, FPA Board of Directors

Dr. Jeffrey Fogel is an FPA Board Member and pediatrician who was diagnosed with trigeminal neuralgia (TN) in 2008 and geniculate neuralgia (GN) in 2013. He is the FPA Support Group Leader for the Geniculate Neuralgia Support Group and Co-leader of the Philadelphia Support Group. After 30 years in private pediatric practice in the Philadelphia suburbs, he had to stop practicing medicine in 2013 due to TN. He was active in the passage of Act 16 (2016), which legalized medical marijuana in the Commonwealth of Pennsylvania. He has spoken about medical marijuana at FPA conferences and hosted webinars on the topic.

It's been nearly five years since the Facial Pain Association (FPA) published a Special Edition Quarterly journal (Summer 2019) that was devoted solely to medical marijuana. In that issue, we discussed the history and pharmacology of marijuana, the status of medical marijuana in the United States, travel restrictions, and three patients shared their experiences using marijuana for their neuropathic facial pain. You can read the Special Edition Quarterly by visiting www.FacePain.org/Quarterly-journal/Summer-2019/.

Since that Special Edition Quarterly was published, the number of states that have initiated medical marijuana programs, as well as those approving recreational marijuana use, has increased significantly. 40 states and the District of Columbia now have some type of medical marijuana program. However, marijuana is still not approved for medical use in ten states: Idaho, Indiana, Kansas, Nebraska, North Carolina, South Carolina, Tennessee, Texas, Wisconsin, and Wyoming.

The rules within the 40 states that permit medical marijuana vary greatly, including dosage of tetrahydrocannabinol (THC) permitted and medical

indications for acceptance into a program. It is important to check with your individual state for more information about their particular program's rules and regulations.

As someone who regularly receives questions on medical marijuana from fellow facial pain community members, I thought it might be helpful to answer the top three questions I get asked most often from others living with neuropathic facial pain.

What is the best form of marijuana to use?

To answer this question, one must consider three factors: onset, duration, and form. First, how quickly would you like the onset of pain relief to begin? Second, how long do you need the effect to last? Third, what form are you most comfortable taking and which one best suits your needs?

Let's address the onset question first. There are three main delivery methods: **inhalation, tincture, and edibles**. Each has advantages and disadvantages.

Which form you should take depends on your need for immediate versus long-lasting relief. At one end

- 1. INHALATION:** This includes inhalation either by cigarette, pipe, or vaping. By going directly into the lungs, absorption into the body occurs very rapidly, with the onset of relief occurring in as little as five minutes. However, the quick relief is accompanied by a shorter duration, often lasting only two to four hours.
- 2. TINCTURE:** A tincture is a liquid that comes in a dropper bottle and is held under your tongue or between your gum and cheek for several minutes. The onset of action is slower — usually 20-40 minutes — but the effect lasts for four to six hours.
- 3. EDIBLES:** Edibles encompass anything where absorption occurs through the stomach. Included in this category are gummies, brownies, or any other cooked variety. The absorption time for this method is longer (an hour or so before relief), but the effect can last up to eight hours. Since the peak effect is so gradual, it can be difficult to determine the true time of relief onset.

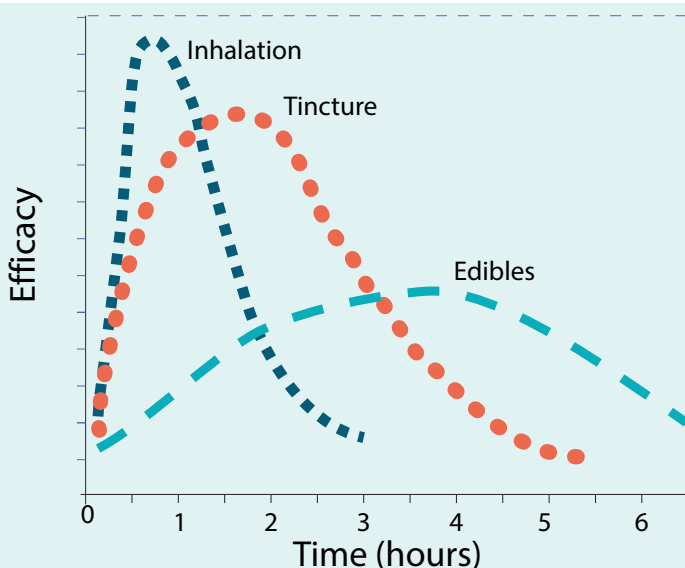
of the spectrum, inhalation would be the best option for immediate relief, but you must first consider if you have any preexisting lung conditions, are in an environment where smoking is not permitted or appropriate, or simply just do not feel comfortable inhaling marijuana.

On the other end of the spectrum are edibles. They are best for those who have more chronic pain and are unable to dose medical marijuana throughout the day. However, because of the long latency and lack of a true peak-effectiveness, edibles are not considered a good choice for acute pain attacks.

Tincture products fall in the middle. They don't provide the instantaneous relief that inhalation does, nor do they last as long as edibles. But they do provide an onset of pain relief much quicker than edibles and provide a nice peak, making them a good choice for acute pain episodes for those patients who are unwilling or unable to use the inhalation method.

I tried marijuana for facial pain and it didn't work. Why?

The most common reason it didn't work is because the product or dose was not correct for the individual. To better understand this, we need to recognize that marijuana is complex and not a uniform product.



Times are not exact and are for illustration purposes only.

Illustrative Demonstration of the Typical Time Course Based on Mode of Administration

This graph demonstrates how inhalation peaks highest and quickest, while tincture peaks a little lower and slower but lasts longer, and edibles have an even lower and more gradual peak but last the longest.

"Medical Marijuana for Facial Pain" continued on page 8

To begin with, marijuana is composed of two main cannabinoids: tetrahydrocannabinol (THC) and Cannabidiol (CBD). THC is psychoactive and is composed of two different strains — Sativa or Indica. The Sativa strain makes you feel “high” or energetic. The Indica strain makes you feel mellow. A particular marijuana product can have one strain or the other. There is also a third option which is a hybrid of the two strains.

Then, there is the CBD component. CBD is not psychoactive, and while it has been shown to be helpful for conditions such as insomnia and anxiety, CBD alone has never been demonstrated to be an effective treatment for central neuropathic pain conditions, such as trigeminal neuralgia (TN). To treat a central neuropathic pain condition like TN, both THC and CBD are required. THC and CBD work in a synergistic manner, meaning they work better together.

Next, we must look at both the ratio and concentration of THC:CBD in the product. Taken together, these factors will impact both the efficacy as well as the side effects. To understand the difference between the ratio and concentration, think of a peanut butter and jelly sandwich. The ratio would be the amount of peanut butter there is compared to the amount of jelly. Is there the same amount (1:1) of each, or twice as much peanut butter as jelly (2:1)? Or five times as much (5:1)? A product with a lower THC:CBD ratio (such as 1:1) will have fewer side effects, but also may be less likely to provide pain relief than a product with a higher THC:CBD ratio (such as 5:1).

Lastly, we need to consider the concentration, which is the absolute amount of each component. Back to the PB&J sandwich analogy, did we make the sandwich with two tablespoons of peanut butter, or five, or ten? Obviously, the higher the dose, the greater the effect will be, but there is also the potential for increased side effects.



Now, with all these variables, it may be easier to understand that if one product didn't work, you may need to adjust the strain of THC, the ratio of THC:CBD, or the concentration of the THC dose. Similar to the use of antibiotics for infections — just because one didn't work doesn't mean we avoid antibiotics altogether. Instead, a doctor will need to try something different to find the one that works for your particular situation.

The real advantage of having so many different dosing and delivery options is that it offers you the opportunity to tailor the product and dosing to meet your needs and lifestyle. For example, you could take one product during the day for acute pain episodes which allows you to work (e.g. tincture with Sativa), and a different one at night that lasts longer and helps you sleep (e.g. gummy with Indica). A gummy during the day could be ideal for chronic relief without the peaks and valleys that would be seen with the shorter acting products.

If I live in a state with recreational marijuana, why should I spend extra money for a marijuana card?

While on the surface it may seem unnecessary to spend extra money, there may be good reason to do so. If your state has a medical as well as a recreational marijuana component, check to see if they have kept the medical dispensaries separate from the recreational. As can be seen from the answers above, getting a product that works well for your particular type of facial pain can require dosing adjustments that may be beyond the ability of the typical recreational “budtenders” — dispensary staff members who can offer suggestions, answer customer questions, and handle and showcase marijuana products. There is a vast difference between using marijuana for its psychoactive effects versus using it to relieve intense pain while still allowing you to function and maintain your lifestyle. Medical marijuana programs are set up to provide you with the optimal product tailored for your condition and needs. In addition, some states permit those with medical marijuana cards to purchase and carry more product than recreational users. ■

Neuropathic facial pain is as complex as the options currently available to treat it, and medical marijuana is an option that has provided real relief for many people with facial pain. The FPA encourages you to be informed and armed with the tools needed to achieve pain-free days.

Visit our library of medical marijuana resources.
www.FacePain.org/Medical-Marijuana-Facial-Pain/



News You Can Use

Wolfgang Liedtke, MD, PhD



Dr. Wolfgang Liedtke is an Executive with Regeneron Pharmaceuticals in Genetic Medicines in their Global Clinical Development Unit, and member of their Scientific Council where he is Chair of Neurology, Psychiatry, Pain Medicine and Sensory Systems. Prior to joining Regeneron in 2021, he was a tenured professor at Duke University for 17 years. He conducted basic neuroscience pain research and co-founded the Duke University pain research group. He also founded two Duke clinics dedicated to pain medicine, one in neurology, one in anesthesiology, providing science-based yet empathetic clinical care to patients suffering from head face pain, generally refractory pain and pain in the context of complex comorbidities.

He was clinically trained in neurology and psychiatry in his native Germany and in neuropathology in New York City, where he conducted neuropathology and molecular genetics research (Albert Einstein College of Medicine; The Rockefeller University), after coming to the US in 1994. Dr. Liedtke is a member of the

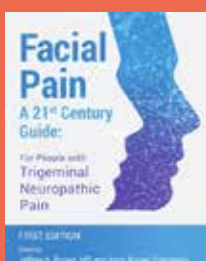
FPA Medical Advisory Board, an elected member of the American Clinical and Climatological Association, a faculty member of the New York University Pain Research Center, Adjunct Professor of Neurology at Duke, and Adjunct Professor of Dentistry at New York University.

Dr. Liedtke has contributed a chapter on facial pain medications in our forthcoming book titled *Facial Pain: A 21st Century Guide, Book II*. In this chapter, he discusses various medications that can be used to manage chronic facial pain under the guidance of a physician, depending on the severity of the pain.

Dr. Liedtke categorizes these medications into three types:

- **As needed/rescue medications**
- **Baseline medications for continuous management**
- **Injectables for maintenance management**

The first **News You Can Use** section of the Quarterly journal includes a tear-out chart, following this article, that lists the as-needed/rescue medications. These medications address the question — **what can you do when the pain becomes intolerable?** and are great to keep on hand in case of sudden pain flares. This information is also available at www.FacePain.org/Blog/Rapid-Acting-Medications.



Facial Pain: A 21st Century Guide, Book II will be published later this year. To purchase the first edition of the book, visit our website, www.FacePain.org/Understanding-Facial-Pain/Buy-The-Book.



Rapid-Acting, As-Needed Medications for Trigeminally-Mediated Pain

| Drug Type | Compound | Formulation and Dose | Comments and Links to Rxlist.com and Wikipedia or Journal Article |
|------------------------|-------------------------|--|---|
| Sodium channel blocker | Carbamazepine | Chewable ¹ 50-200 mg (100 mg tablet Rx) | Can be repeated 5-10 min later, up to 400 mg/attack total. Longstanding first line experience. Tegretol (Carbamazepine): Uses, Dosage, Side Effects, Interactions, Warning (rxlist.com) Carbamazepine - Wikipedia |
| Sodium channel blocker | Oxcarbazepine | Liquid 50-200 mg (variable doses possible with liquid) | See chewable carbamazepine. Can also be used as "swish and spit," exclusively intra-oral effect with minimal systemic absorption, chewable carbamazepine alternative. Trileptal (Oxcarbazepine): Uses, Dosage, Side Effects, Interactions, Warning (rxlist.com) Oxcarbazepine - Wikipedia |
| Benzodiazepine | Clonazepam ² | Orally dissolving tablet 0.125 mg -0.25 mg | Can be repeated up to 1 mg total (soft limit). Balance with mild sedation (which will not kick in at lower dose because of the trigeminal pain attack). Other benzodiazepines are not analgesic. Longstanding first line experience. Synergistic combination with carbamazepine. Klonopin (Clonazepam): Uses, Dosage, Side Effects, Interactions, Warning (rxlist.com) Clonazepam - Wikipedia |
| Gabapentinoids | Gabapentin | Liquid 100-300 mg | Alternative if carbamazepine/oxcarbazepine works poorly or if patient has known gabapentin/pregabalin response to maintenance medication Neurontin (gabapentin) for Seizures and Nerve Pain: Uses, Dosage, Side Effects, Interactions, Warnings (rxlist.com). Gabapentin - Wikipedia |
| NMDA-receptor blocker | Ketamine ² | Nasal spray 10-15 mg/puff (100-150 mg /mL) | 2-4 puffs per nostril; can be used bilaterally (on both sides) depending on laterality of the pain and on laterality of effect. Soft limit 100-200 mg/ attack and 200-400 mg/day. Dose limiting effects are psychotropic effects (feeling weird; higher doses can be hallucinogenic (which many patients have tolerated when facing trigeminal pain attacks.) Some patients are very responsive to lower doses. Most need higher doses. Nasal irritation can be overcome by pretreatment with 1% lidocaine liquid or jelly. One of the most rapid onset medications against trigeminal pain. Newer approach, possibly promising. Ketamine Hydrochloride (Ketamine HCl): Uses, Dosage, Side Effects, Interactions, Warning (rxlist.com) Ketamine - Wikipedia |

| | | | |
|-------------------------------------|---|--------------------------------------|--|
| NMDA-receptor blocker | S-ketamine ^{2,3} ES-ketamine ^{2,3} | nasal spray 28 mg/ puff | Spravato Rx-medicine (controlled substance, high insurance hurdle). If patients use this, medication for mood disorder is recommended. Spravato (Esketamine Nasal Spray): Uses, Dosage, Side Effects, Interactions, Warning (rxlist.com) Esketamine - Wikipedia |
| - gepant (CGRP receptor blocker) | Rimegepant ³ | 75 mg orally- dissolving | 1 tablet - can repeat with sufficient supply. Patients need to have a sufficient supply of tablets to engage in repeat applications as-needed. Since it is officially covered over the migraine indication, there will be limits of monthly supply, such as 4 or max 8 tablets that patients can have per month. Patients need to “budget” with what they have so they have enough until the next refill. This is an important practical consideration that can cause stress. Newer approach, with limited experience: some patients experienced a high-impact beneficial response, for most it is a suitable combination to carbamazepine and/or clonazepam. Nurtec ODT (Rimegepant Orally Disintegrating Tablets, for Sublingual or Oral Use): Uses, Dosage, Side Effects, Interactions, Warning (rxlist.com) Rimegepant - Wikipedia |
| -Gepant (CGRP receptor blocker) | Zavegepant ³ | 10 mg nasal spray | 1 puff; can have second. Very recent approach, possible equi-effective to Rimegepant No practical experience. Possibly use Rimegepant for 3rd branch pain, Zavegepant for 2nd and 1st branch pain. Both -gepants suitable for trigeminal pain that facilitates migraine (or cluster headache.) Zavzpret (Zavegepant Nasal Spray): Uses, Dosage, Side Effects, Interactions, Warning (rxlist.com) Zavegepant - Wikipedia |
| Sodium channel blocker | Lidocaine | 1-2% jelly, spray | Intra-oral use for 3rd branch triggered trigeminal pain. Nasal spray for 2nd branch triggered pain. Add-on to carbamazepine/clonazepam Pre-medication for nasal ketamine in case ketamine has nasally irritant properties which would defeat its powerful action on the trigeminal system. https://www.webmd.com/drugs/2/drug-10414-252/lidocaine-hcl-mucous-membrane/lidocaine-jelly-mucous-membrane/details Lidocaine - Wikipedia |
| Oxytocin | Oxytocin ¹ | nasal spray 24IU/ puff (240IU/mL) | 2 puffs per nostril, bilateral (both sides.) Limited experience; however: great safety, adjunct to any partially effective as-needed rapid-onset medication. Pitocin (Oxytocin Injection): Uses, Dosage, Side Effects, Interactions, Warning (rxlist.com) Oxytocin (medication) - Wikipedia |

¹ Requires formulation by a compounding pharmacy

² Controlled substance

³ Insurance approval hurdles/expensive

Disclaimer: The information contained in this list is not intended to be individual medical advice, diagnosis, or treatment or to induce the reader to seek care with any specific physician. Always seek the advice of your physician or other qualified health care provider with any questions you may have regarding a medical condition or treatment, before undertaking a new health care treatment, and never disregard professional medical advice or delay in seeking it because of something you have read in this list.



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2024 FPA VIRTUAL CONFERENCE

— APRIL 27-28 —

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SPEAKERS



Vivek Buch, MD



Jeffrey Fogel, MD



Laine Green, MD



Lauren Levi, DMD, MS



Wolfgang Liedtke, MD, PhD



Michael Lim, MD



Mark Linskey, MD



Asher Mansdorf, DDS, MS



Ashwin Ramayya, MD, PhD



Jonathon Parker MD, PhD



Ameet Patel, MD



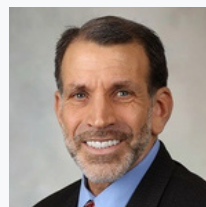
Leesa Scott-Morrow, JD, LP, PhD



Raymond F. Sekula, Jr., MD



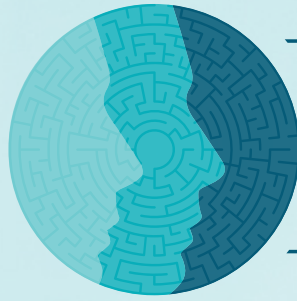
Joanna Zakrzewska, MD



Richard S. Zimmerman, MD



John Zuniga, DMD



2024 FPA VIRTUAL CONFERENCE

— APRIL 27-28 —

The information listed is subject to change and may include additional presentations. Visit www.FacePain.org/2024-FPA-Conference/ and @facialpainassoc on social media for more details.

TOPICS

- Facial Pain Medications
- Facial Pain and Mental Health
- Medical Cannabis
- Nerve Repair after Dental Injury
- Neuromodulation Techniques to Treat Atypical Facial Pain
- Surgical Treatment of Genuiculate Neuralgia
- The Spectrum of Orofacial Pain
- Treatment Protocol for Classical Trigeminal Neuralgia

CONFERENCE REGISTRATION INSTRUCTIONS

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Enter your information (fields with * are required). For each ticket, you will need to provide the attendee's name and email.

If you choose, you can also personalize your registration by uploading your photo, social media handle, and information about yourself. This information will be seen by others during the conference and help you connect.

Click 'Continue.'

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Review your Order Summary and click 'Place Order.'

Step 3: Confirmation

You will receive a confirmation message and email.

**Please note that you will need to use the email you used to register to login to the event.*

If you need assistance with registration, please call us: 800-923-3608.

Facing Forward – Advocacy in Action



We are focused and facing forward, putting advocacy into action. This year, we have hit the ground running, adding our voices to the halls of Congress and our words in letters to the White House. We are taking our seat at the table with the organizations in charge of funding what will move research forward.

Advocacy lies at the core of our mission. Through educational resources and volunteer support, the FPA empowers the facial pain community to advocate for themselves and one another. From using our voices during Facial Pain Awareness Month and Rare Disease Day to sharing our lived experience with researchers seeking to understand facial pain and find better treatments — we have made tremendous progress, but there is more that we can do.

Our goal is to build on the success of our individual efforts and expand advocacy to a national level. By partnering with organizations committed to advocating for legislative changes, funding allocations, and policy reforms, we can amplify our collective voice and have a greater impact. As part of our commitment to fostering systemic change, it is my pleasure to announce that the FPA has joined the Alliance for Headache Disorders Advocacy (AHDA) as a member organization where we have the honor of serving on their board.

For nearly two decades, the AHDA has been the leading voice in federal headache advocacy. In March, the FPA participated in Headache on the Hill, an annual advocacy event with the AHDA bringing together healthcare 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, including neuropathic facial pain,* in the United States.

As the FPA continues to meet you where you are today, we press forward for progress. We are focused and facing forward, putting advocacy into action.

This year, we have hit the ground running, adding our voices to the halls of Congress and our words in letters to the White House. We are taking our seat at the table with the organizations in charge of funding what will move research forward. As we continue to expand our efforts, we are adding a new section on our website dedicated to advocacy where you can read updates and learn more about how you can get involved.

With gratitude and deepest appreciation for your support,

Brandi Underwood

Manager of Development, Research, and Advocacy,
The Facial Pain Association

* Neuropathic facial pain, including trigeminal neuralgia, is diagnostically classified by the International Headache Society in The International Classification of Headache Disorders.

Updates On The FPA's Research Initiative

Dedicated to advancing the understanding and treatment of neuropathic facial pain, the Facial Pain Association (FPA) provides non-financial support of research efforts, including letters of support, community survey data, patient and caregiver advisory groups, focus groups, and survey/questionnaire distribution. The FPA will also launch a patient registry through NORD's IAMRARE® program this year to gather invaluable data to help move research forward.

Since launching our Research Initiative in 2021, we have made tremendous progress.

- FPA Volunteers have shared their stories with scientists and researchers and served on patient advisory boards.
- Members of the community have participated in clinical trials, completed surveys, and provided research reviews.
- We have signed letters of support for physicians and researchers requesting grants from the

National Institutes of Health (NIH), the NIH's National Institute of Dental and Craniofacial Research (NIDCR), and the NIH's National Institute of Neurological Disorders and Stroke (NINDS) to better understand facial pain and develop new treatment options.

- We have partnered with organizations to advocate for policy changes and signed letters of support for increased research funding to benefit the facial pain community.

If you are applying for a grant to research neuropathic facial pain, investigating a new treatment option for a clinical trial, or conducting a study to better understand current treatment options, we are here to support your efforts.

Contact Brandi Underwood, Manager of Development, Research, and Advocacy at bunderwood@facepain.org, visit www.FacePain.org/Research, or call 800-923-3608.



Juan M. Hincapie-Castillo, PharmD, MS, PhD, an Assistant Professor of Epidemiology at the Gillings School of Global Public Health at the University of North Carolina Chapel Hill, received a 5-year career development (K01) award from the National Institute of Dental & Craniofacial Research (NIDCR) focused on trigeminal neuralgia (TN) in older adults.



Disclaimer: The Facial Pain Association (FPA) is enthusiastic about medical research and encourages those with neuropathic facial pain, including trigeminal neuralgia, and related healthcare conditions 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 is conducted in accordance with all federal, institutional, and ethical guidelines. All studies and trials listed have IRB or Ethics Committee approval where relevant. The study's safety and scientific validity 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 healthcare provider. Although study sponsors may donate to the FPA, or support the FPA through advertising or corporate sponsorship, such support does not influence or guide our decision about the studies we identify.



Chronic Pain and Anxiety

Young Patients Committee

Worrying about your next pain flare and how people may perceive you when experiencing facial pain is common in the facial pain community. Due to their nature, facial pain episodes and flares may happen at any moment, with or without warning. This can leave you in a constant state of anxiety and worry, taking you out of the present moment.

Often, we try to prevent pain before it happens, and attempt to take control to either stop or lessen the amount of pain we will experience. This is a natural response — trying to avoid or fight the pain. Unfortunately, it is not healthy for our emotional, mental or physical health. It can actually increase our pain.

The pain becomes an all-consuming thought; a difficult cycle of anxiety and fear that the pain will return. It becomes our focus.

To combat this, we find that developing a robust self-care toolkit containing ways to center our thoughts, move toward a positive mindset, and prioritize mental and physical well-being, are powerful ways to take control of these feelings of anxiety.

Yoga, Breathwork, and Meditation

One of the best ways our community has been able to reduce anxiety is through yoga, breathwork, and meditation. These practices allow you to pull focus back and reach a state of calm. We have found that through yoga, breathwork, and meditation, you can center yourself, be in the present moment, and focus

on the things in life that make you happy. Breathwork can assist in shifting your energy, focus, and even lift your mood. Studies show that breathwork helps relax the parasympathetic nervous system, reducing fight or flight tendencies and thus reducing stress and anxiety. Anxiety is likely inevitable when living with chronic pain, but taking a deep breath, and reminding yourself of all of life's joy in a calming environment is a good step to combat that anxiety.

Drawing and Art

Similar to yoga, our goal when combating anxiety is to center ourselves around calming activities and thoughts. You don't have to be the best artist in the world to use art to find a sense of calm and joy. Art therapy has been found to connect people to their emotions, which is important when trying to reduce anxiety. Our community recommends crocheting, knitting, coloring books, or scrapbook journaling to help with anxiety.

Journaling

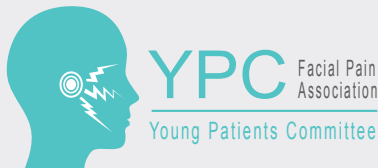
When dealing with emotions, identifying what you're feeling is a good step towards combating any negative emotion you are experiencing. Identifying how you're feeling and acknowledging your own experience is a powerful way to take control of those negative feelings. One thing we have found to help our anxiety is to take power away from the feeling. If you can identify it, write about it, and take steps to combat it, then you are well on your way to being in control of it!

Identifying a Self-Care Routine

Finding what works best for you is so important when living with chronic pain. We’ve identified that yoga, art, and journaling help much of our community but how we individually practice these mechanisms can look different. Everyone’s chronic pain is different, and we all use different practices to live with facial pain. In the same way, anxiety looks different for everyone. Finding what works best for you will always be the best way to live with the cyclical nature of anxiety. After you find what works best for you, find time every day to practice self-care through your routine.

Always remember that your mental health is most important and should be a priority in your daily life. Routines will give you the space and permission to prioritize yourself.

As always, we are here for you through your chronic pain journey. If you have found something that has helped you, we’d love to hear from you and share your advice with our community! You can connect with us through our monthly support group, our social media accounts, and via email at YoungPatientsCommittee@gmail.com. ■



Connect with the FPA Young Patients Committee!



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Newsletters

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)



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





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.

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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.

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We strive to be the most reliable and comprehensive resource on facial pain conditions for patients, their families, and healthcare professionals. If you would like to be recognized among the 150+ doctors and medical centers participating in the FPA's Professional Membership program, please contact Brandi Underwood at bunderwood@facepain.org or call (800) 923-3608.

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Michael Brisman M.D.

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

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



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Trigeminal Neuralgia

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The study is enrolling patients 18 to 75 years old, with classical or idiopathic Trigeminal Neuralgia.

See ClinicalTrials.gov
(Study NCT05217628)
for more information



Check if
you qualify



Noema Pharma A.G. For distribution in US Only
Libra Study (NOE-TGN-201) - Document: Libra Webpost US draft v1 09/19/2022

Please note that the sites currently enrolling subjects include Kaizen Brain Center - La Jolla, California; University of South Florida - Tampa, Florida; University of Cincinnati - Cincinnati, Ohio; and Columbia University Irving Medical Center - New York, NY.