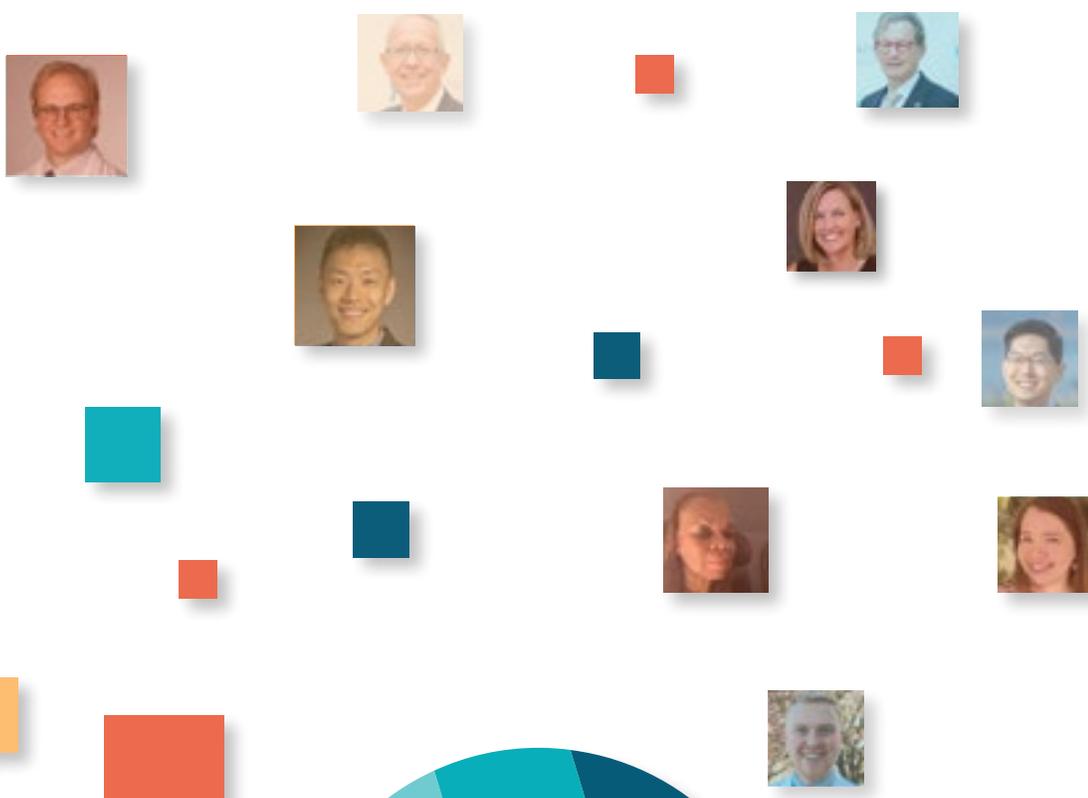


Journal of the Facial Pain Association

Spring 2023

# Quarterly



2023 FPA VIRTUAL  
CONFERENCE  
— APRIL 28-29 —

The Facial Pain Association  
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Raymond F. Sekula Jr., MD  
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## From the Chairman of the Board



Magic happened early last year: the Facial Pain Association (FPA) hosted a virtual conference that brought many of the leading medical professionals who focus on serving those with trigeminal neuralgia (TN) and other neuropathic facial pain to 1,300 of us from 26 countries around the world. It's doubtful that this much excellent information and advice has ever been presented to so many of us in one setting — magic! Given the overwhelming success of this conference, the FPA is doing it again on April 28 and 29, 2023. You won't want to miss it.

Trigeminal neuralgia and other neuropathic facial pain conditions are unlike other diseases for many reasons. An important one is that most healthcare professionals - even many specialists like neurologists and neurosurgeons - are not that familiar with TN because they have little to no experience treating patients like us. There are just too few of us. This means that you have to get smart to ensure you receive the proper care.

### **You're probably not a doctor, so what does "getting smart" mean? It means you should:**

- Get to know the basic approach to making the decisions that are ahead of you
- Have a rough understanding of some of the medicines you may be prescribed
- Understand the alternative surgical procedures that are available (and when they should be employed)
- Learn about complementary and alternative medicines (e.g., acupuncture, marijuana) that may help you mitigate pain
- Know about the mental health aspects of dealing with chronic pain.

It means all of this and even more.

The mission of the FPA is to provide information and support to help you with every aspect of your facial pain journey. And although we attempt to do this in many ways, the easiest and most efficient way for you to "get smart" is to join us at the 2023 FPA Conference and the future conferences we host. Nope — you won't learn absolutely everything that you need to know. That's why two years ago we published *Facial Pain – A 21st Century Guide: For People with Trigeminal Neuropathic Pain* (available on Amazon.com or FacePain.org) and a second book is currently underway. That's why we have our 18-person Medical Advisory Board full of real experts who help us get accurate information to you. That's why we have our wonderful staff and 92 trained volunteers here for you. That's why we have our website full of articles, studies, recorded webinars, and much more.

The first FPA conference I attended was in Richmond, VA 16 years ago. I learned things at that conference that absolutely changed my life and helped me successfully manage my TN. I wish the same to happen for you during the 2023 FPA Conference.

On page 3, you will find an article from FPA's CEO, Melissa Baumbick, about the upcoming 2023 FPA Conference. I urge you to register and keep an eye out for our announcement of topics and presenters. I hope that you'll join us on April 28 and 29.



**David Meyers**  
Chairman of the Board  
The Facial Pain Association

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**Art and Design**  
Caren Hackman



## A Message From the CEO

As you read this, I hope you are well and enjoying a lovely spring day. It is still chilly here, and I am happily anticipating the warm, sunny days and blooming flowers that are surely on the way. I am also looking forward to the Facial Pain Association's upcoming virtual conference, which will take place on April 28 and 29, 2023.

The 2022 FPA Conference was an enormous success. Recently, I read the comments and suggestions from last year's follow-up survey and was struck by the immense appreciation expressed by those who attended. This conference means so much to the facial pain community and is one of the most important things we do every year. It is an opportunity for people all over the country and around the world to gather, connect with one another, and learn more about various aspects of neuropathic facial pain.

This year's focus, as we determine which topics to cover and how to organize them, is on what can help people really LIVE with their facial pain.

We will try to answer the questions we hear every day: What is this pain? How is it treated? What can I do to manage it?

We will look at the practical questions we hear: How do I choose a doctor and what should I ask them? Are there other people experiencing what I am?

We also want to address the difficult path that many face over time: How do I cope with the pain, the fear, the uncertainty? My pain is still here, what else can I do? I'm at a loss, can you help me?

The 2023 FPA Conference will be a little shorter than last year's event, kicking off on Friday with an evening of support, facial pain stories, and opportunities to connect with others. Saturday will offer a full day

of presentations featuring leading experts on the latest developments in diagnoses, treatments, and management of facial pain, with plenty of time for Q&A in each session.

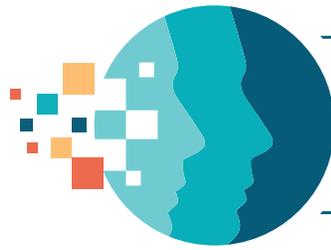
Our topics will cover everything from types of facial pain and how to treat them to alternative therapies and coping strategies. We'll discuss younger patients, research, and what's on the horizon. Look for the conference agenda, our list of presenters and how to register on FacePain.org. Tickets to attend the two-day event are \$25. Sales help defray the costs of this conference. However, if at this time you are not in a position to pay for a ticket, contact Natalie Merrithew at nmerrithew@facepain.org, and we will be happy to offer you complimentary admission.

We'll discuss the FPA's patient registry - an effort that has been YEARS in the making. When it launches, your participation will be critical to its success and we hope you'll participate. Learn more about why a registry is important and what it can do to further research.

This year's conference will remain virtual, allowing attendees to access experts dedicated to those living with facial pain in the comfort of their homes. In an effort to make the conference even more accessible, there will be live captions and translations available for those who need them.

I hope you'll join us on both Friday night and all day on Saturday for the full experience. See you there! ■

**Melissa Baumbick**  
Chief Executive Officer  
The Facial Pain Association



# 2023 FPA VIRTUAL CONFERENCE

— APRIL 28-29 —

## [Click to register for the 2023 FPA Virtual Conference!](#)

Tickets to attend the virtual event are \$25. Sales help defray the costs of this conference. However, if at this time you are not in a position to pay for a ticket, contact Natalie Merrithew at [nmerrithew@facepain.org](mailto:nmerrithew@facepain.org), and we will be happy to offer you complimentary admission.

### Friday, April 28, 2023

Welcome  
6:30pm EDT

Research | Patient Q&A  
7:00pm EDT

Dentistry | Patient Q&A  
8:00pm EDT

Topic-Based  
Support Groups  
7:00pm - 10:00pm EDT\*

\*Topics include: Glossopharyngeal Neuralgia, Young Patients, Medical Marijuana and more!

### Saturday, April 29, 2023

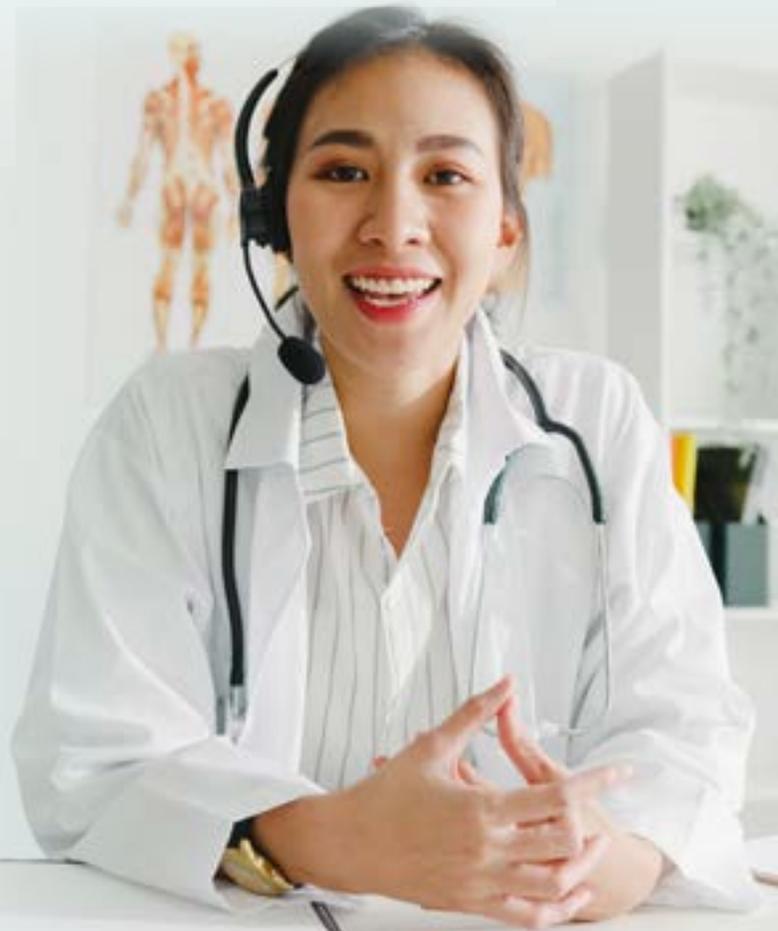
Welcome  
11:00am EDT

Educational Presentations  
11:30am - 6:30pm EDT

Conclusion:  
Looking Ahead  
6:30pm EDT

## PRESENTATIONS

- Auricular Acupuncture in Facial Pain
- The Autonomic Effects of Trigeminal Nerve Injury
- Decision Making Surrounding Surgical and Ablative Procedures
- Empowered Relief: A One-Session Pain Relief Skills Intervention
- Repeat MVDs
- Surgical Q&A - A Physician Panel
- Types of Facial Pain
- Update on Medical Treatment of Craniofacial Pain Disorders
- What's on the Horizon: Pain Management, Neuromodulation, and New Drugs for TN



## FPA VIRTUAL CONFERENCE PRESENTERS



Michael H. Brisman, MD, FACS



Jeffrey A. Brown, MD, FACS, FAANS



Beth Darnall, PhD



Wolfgang Liedtke, MD, PhD



Michael Lim, MD



Mark E. Linskey, MD



Julie Pilitsis, MD, PhD



Raymond F. Sekula, Jr., MD



Gary L. Stanton, MD



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Richard S. Zimmerman, MD

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Office: 212-686-6799 • Fax: 646-454-9148 • Email: rameshpitti@yahoo.com

## The MAB Corner

Each year, thousands of individuals experience facial pain for the first time, and many more continue to cope with this debilitating, poorly understood, and often inadequately treated condition. Recently, I was elected as Chair of the Facial Pain Association's Medical Advisory Board (MAB), and I realize that the responsibility is an awesome one. As I write this piece, I'm thinking of a woman of advanced age with facial pain, who was seated next to me at an annual meeting probably ten years ago. During lunch, she turned to me and explained that her facial pain had become unbearable during the morning session, and she had taken some medication to help with the pain. Now, she was feeling lethargic and "not myself...doctor, would you be offended if I excuse myself for a few minutes?" She did not return to lunch. I've thought of her often. Is she alive today? Did she ever find pain relief? Did she die in pain?

As advisors to the FPA's Board of Directors and staff, all members of the MAB have been carefully selected to provide expert opinions and guidance for the variety of conditions experienced by those living with neuropathic facial pain. In the coming months, you will witness continued efforts from the MAB to serve you. After admirably serving as MAB Chair for the past 6 years, Dr. Jeffrey Brown, MD, FACS, FAANS will continue to serve patients in his New York office and in a variety of capacities with the MAB. In fact, he has graciously accepted the responsibility of editing this issue of the Quarterly. Dr. Brown, we are deeply indebted to you for past and expected future service to the facial pain community.

### Introducing the Facial Pain Association's New Medical Advisory Board Chair

Raymond F. Sekula, Jr., MD  
Columbia Neurosurgery  
Director, Trigeminal Neuralgia  
and Facial Pain Program



When I was a much younger man, I had the pleasure of meeting Claire Patterson, founder of the Trigeminal Neuralgia Association. In those days, she was a constant at the regional and annual meetings. She knew many of the members by name, and she was, as I recall, intensely focused on providing support for the facial pain community and the need for more research monies directed to this "rare" (as designated by the National Institutes of Health) neurological condition. While the organization has evolved considerably over the past two decades, Ms. Patterson's passion for serving the individual and finding new treatments for facial pain persists within the organization.

We are listening to you, and we need your continued input. Melissa Baumbick (The FPA's CEO) and I recently reviewed post-attendee comments from the 2022 FPA Conference. We are designing this year's event (April 28-29, 2023!) in direct response to these comments to best serve your needs and concerns. The FPA is launching a new patient registry to better understand facial pain of all types, which is the result of a great deal of work from international experts. In the next year, you will notice new additions to the MAB team and the implementation of new ideas. We welcome your suggestions and feedback. Finally, I'm humbled to serve in this capacity, and I look forward to a brighter future for facial pain patients.

Very truly,

A handwritten signature in blue ink that reads "Raymond F. Sekula, Jr." The signature is written in a cursive, flowing style.

**Raymond F. Sekula, Jr.**  
Medical Advisory Board Chair  
The Facial Pain Association

# The Faces Behind the Quarterly



## Managing Editor — Brandi Underwood

Brandi is the FPA's Marketing and Communications Manager. She is a communications professional with a diverse background in corporate, small business, and non-profit marketing. She holds a Bachelor's Degree in Political Science with a Minor in Communication Studies from West Virginia University. As a member of the facial pain community, Brandi strives to support, educate, and advocate for all people living with neuropathic facial pain.



## Editor/Circulation Manager — Natalie Merrithew

Natalie is the FPA's Digital Media Coordinator. She is a communications professional with a background in non-profit media and a graduate of Clemson University. She studied English with an emphasis in Writing and Publication Studies and a minor in Writing for News Media. As our digital media coordinator, Natalie aims to make our content accessible and engaging for all who desire support in living with facial pain.



## Art and Design — Caren Hackman

Caren is the FPA's Artist and Designer for the Quarterly journal. She holds a Bachelor's Degree in Industrial Design from Syracuse University and has a diverse client list of corporations, businesses, governmental entities, non-profit organizations, and individuals. In addition to her training in industrial and graphic design, she is a respected illustrator and fine artist, providing her clients a unique combination of talents. Her marrying of graphic design and fine art provides a one-of-a-kind opportunity for clients who are looking for a comprehensive approach to establishing their distinct visual identity and brand.



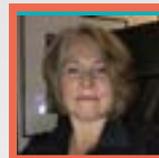
## Medical Editor — FPA Medical Advisory Board Members

Spring 2023 -

**Jeffrey A. Brown, MD, FACS, FAANS**

Dr. Brown attended The University of Chicago Pritzker School of Medicine and completed his residency training in neurosurgery at The University of Chicago Hospitals and Clinics. He has published more than 50 peer-reviewed articles on such topics as chronic pain, especially facial pain, spinal vascular, tumor and trauma neurosurgery and is the co-editor of *Facial Pain – A 21st Century Guide: For People with Trigeminal Neuropathic Pain* as well as other textbooks and patient guidebooks. He is immediate past Chairman of the FPA Medical Advisory Board (MAB) and has served as the Quarterly journal's Medical Editor for six years.

The FPA would like to thank Dr. Brown for his years of hard work and dedication to the role of Medical Editor. We are grateful for his knowledge and insight and look forward to his continued expertise as he serves on the MAB. In January 2023, the FPA Board of Directors elected Dr. Raymond Sekula as the new Medical Advisory Board Chair. Dr. Sekula has decided to rotate the Medical Editor role amongst the members of the Medical Advisory Board based on their areas of expertise.



## In Memorium Editor/Circulation Manager — Nancy Oscarson

It is with deep sadness and heavy hearts that we inform you of the death of our colleague and friend, Nancy Oscarson, who passed away on February 7, 2023. Nancy was dedicated to the facial pain community and fulfilled by her work with the Facial Pain Association for 12 years, until her retirement in January 2022. For many years, she was the engine that made this organization run, managing the Quarterly, planning events, and being the primary and everyday contact for people living with facial pain. We are grateful for everything she did to support this community, and we are saddened by her loss. Our thoughts are with her family and friends. ■

# 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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Ronald Warnick, MD

For more information, visit [mayfieldclinic.com/trigeminal](http://mayfieldclinic.com/trigeminal) or call **513-221-1100** to make an appointment.



## Mindfulness and Meditation

---



There is something particularly difficult about living with facial pain in the colder months. We encourage mindfulness and meditation as a practice throughout the year but know that it can be especially helpful during the days that seem colder and darker than the rest.

This time of year can also be rejuvenating. It's a chance to reset, recharge, and focus on yourself. Meditation allows you the opportunity to look inward rather than backward. If you practice often enough, it can help with the healing process as well. It isn't uncommon to experience a denial or grieving period when you are diagnosed with facial pain. Looking inward and focusing on yourself gives you a chance to learn acceptance and promote healing.

Meditation allows you the opportunity to thank your body for all it has experienced and done to help you overcome and endure throughout the year.

There are many options online that can help with guided mindfulness and meditation. You can find these on platforms such as YouTube, Spotify, and apps designed for these exercises. You can also give it a go with just these simple tips below.

First, it's good to keep in mind that meditation and mindfulness don't always look the same for everyone. You don't have to get it perfect to practice these helpful exercises. Don't be afraid to switch things up and make mindfulness and meditation work for you!

**Find somewhere that feels peaceful, calm and free from distractions.**

**Add some music that is soothing in the background.** Having sounds of nature can be helpful, especially in colder months. It can transport you to the outdoors when that might not be possible due to cold weather and facial pain.

**Light some candles with scents like lavender or mint.** These scents are known to lessen stress levels and increase soothing feelings!

“Mediation allows you the opportunity to thank your body for all it has experienced and done to help you overcome and endure throughout the year.”



**Get comfortable.** Many think that meditation and mindfulness must be uncomfortable, but that isn't the case. If you are comfortable sitting in the classic meditation pose, the lotus position, then go for it! But if not, then choose another way to sit, lie, or stand. You can decide what works best for you. You are in control!

Focus on your breathing. Breath work is an amazing tool that can be accessed and harvested anytime. It is

also a great technique to use for chronic pain. You can learn to breathe through the pain, relax the muscles in the body, and reduce tension. Breathe in deeply through the nose. Hold your breath and count to four. Then release the breath through your mouth while counting to seven. Take a few seconds to relax. Repeat this process.

**Focus on your breath for a little while.** If a thought or sudden surge of pain occurs, acknowledge it, and then if you're able, return your focus to your breathing.

**Be mindful of your self-talk.** We all have our own self-talk, and it may change from day to day. How we talk to ourselves is very important. Using compassion and love to talk to ourselves, especially to our mind and body, can help in how we face each day with facial pain. If our self-talk looks like telling ourselves that we are a burden to others because of our facial pain, then we will start believing it, and our ability to work through the pain that day may be harder than if our self-talk was gentle and compassionate. Adding some personal mantras can help and be empowering to our self-talk.

Often, having facial pain can make us feel like we have no control. Mindfulness and meditation can give us that sense of control and can be a gift we give ourselves now and into the warmer seasons. ■



@youngpatients



@youngpatients



@youngpatients



@tealribboncrafts



Happy Mail

### Connect with the FPA Young Patients Committee!

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

# The NRF2 Network: A potential therapeutic target for trigeminal neuralgia



**Risheng Xu, MD, PhD**  
Department of Neurosurgery,  
Johns Hopkins University School  
of Medicine, Baltimore, MD, USA



**Collin B. Kilgore, BS**  
Department of Neurosurgery,  
Johns Hopkins University School  
of Medicine, Baltimore, MD, USA



**Michael Lim, MD**  
Department of Neurosurgery,  
Stanford University School of  
Medicine, Palo Alto, CA, USA

Typical trigeminal neuralgia (TN) is thought to result from vascular compression of the trigeminal nerve, the principal sensory nerve of the face. This compression can injure the nerve, rendering it more prone to sending painful signals back to the brain. The only U.S. Food and Drug Administration (FDA)-approved drug for managing TN is carbamazepine, an anti-convulsant, which broadly reduces brain signaling. Patients who do not find relief from medication may resort to surgery, in which microsurgical dissection frees the nerve from the offending blood vessel. Microvascular decompression (MVD) is often effective, with most patients reporting sustained pain relief years after surgery. However, this procedure still leaves some patients with persistent or recurrent pain.

To date, we still have an incomplete understanding of the molecular mechanisms behind TN. Not all patients with TN have an identifiable vascular etiology causing the short circuits felt as stabbing pain. Multiple sclerosis patients, for example, most often do not have one because the disease can cause sclerotic plaques in the trigeminal white matter that jumble normal neural transmission.\* Regardless, all these potential causes for TN converge upon orofacial pain. A common consequence of nerve injury and inflammation is the generation of reactive oxygen species (ROS). ROS are unstable molecules and when uncontrolled, can wreak havoc in our body's cells by damaging signaling proteins through a process called

oxidative stress. Several studies have found that ROS may contribute to neuropathic pain signaling. In animal models of sciatica, blocking ROS using antioxidants offered some pain relief. However, the sciatic and trigeminal nerves are very different, and we needed to do more work to investigate what these results could mean for TN.

To start, we collected cerebrospinal fluid (CSF) from patients with TN during their MVD procedure. We found that most of these patients had elevated markers of oxidative stress in their CSF. To validate these findings, we turned to an animal model for TN, and found the same elevated markers for oxidative stress that we saw in patients.

After establishing that oxidative stress is occurring in trigeminal neuralgia, we wanted to know which pain pathway was activated. We hypothesized that TRPA1 – a well-known pain producing channel located in both pain - and itch-encoding sensory neurons – was being activated in TN (by building on the works of others). To confirm our hypothesis that the channel was activated by ROS seen in our TN patients, we first created a line of cells containing TRPA1. We then introduced patient CSF samples from our TN patients to the TRPA1 cell line. To our surprise, we found that TRPA1 was activated by our patients' CSF! Furthering this hypothesis, we treated our TN mice with compounds blocking TRPA1, and found that we could improve their pain.

*"NRF2 Network" continued on page 12*

\* Vasavda C, Xu R, Liew J et al. Identification of the NRF2 transcriptional network as a therapeutic target for trigeminal neuropathic pain. *Sci Adv.* 2022 Aug 5;8(31)

"NRF2 Network" continued from page 11

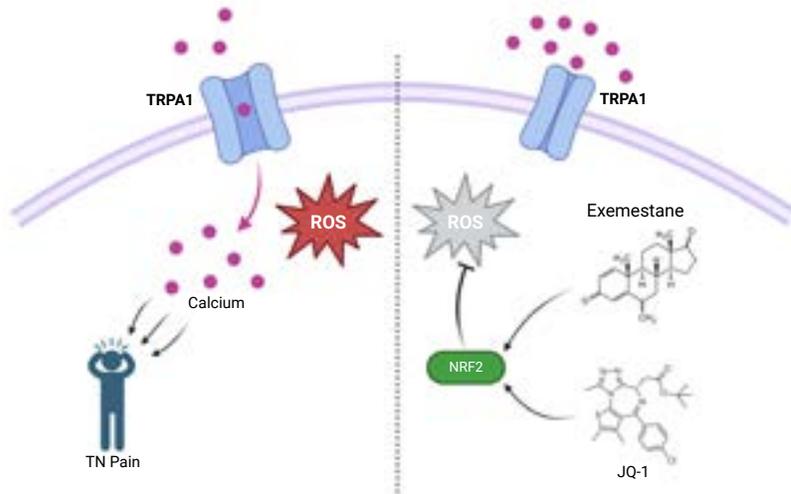
Now that we knew that blocking TRPA1 had pain-reducing effects, we believed it could be a promising therapeutic strategy in managing TN. However, current approaches to block TRPA1 in diabetic neuropathy and postoperative pain were disappointing. This pushed us to try a new approach – to go back to the cause of the pain, which was to try and reduce the oxidative stress. For this, we turned to NRF2 – a known factor that the body uses to create natural antioxidants. As TRPA1 seems central to pain in the mouse model of TN, we hypothesized that activating the NRF2 antioxidant network may lessen pain by reducing ROS.

We now had a goal. If we could somehow find a drug that could turn on the NRF2 antioxidant network, perhaps we could have a new treatment for TN. Using complex state of the art drug screening tools (that

**We now had a goal. If we could somehow find a drug that could turn on the NRF2 antioxidant network, perhaps we could have a new treatment for TN.**

are being used in cancer, diabetes, and inflammatory bowel disease), we identified and focused our efforts on two compounds with a high likelihood of activating the NRF2 antioxidant network – exemestane and JQ-1. When we applied both drugs to our TN cells, we observed that exemestane elevated NRF2 activity better than JQ-1, but both still reduced oxidative stress. When we applied either exemestane or JQ-1 to our TN mice, we were excited to see that the

mice experienced much less pain, suggesting these drugs have promising potential. We even found that applying exemestane directly to branches of the trigeminal nerve lessened pain – a technique that could potentially be harnessed by surgeons as a more targeted form of therapy.



By leveraging a combined clinical, molecular, and computational approach, our study identified the NRF2 antioxidant network as a potential therapeutic target for TN pain. Using a transcriptome-guided drug discovery approach, we identified exemestane and JQ-1 as two candidate NRF2 network modulators for treating TN pain. In contrast to current pharmacologic agents that mask pain by blunting nerve firing, increasing the NRF2 transcriptional network may be a therapeutic approach that seeks to improve pain through oxidative control. These drugs are still in the very early stages of investigation, but we hope that they represent a promising new direction for TN therapy. Should they succeed in future clinical trials, the compounds we found could represent a new line of medications that patients and providers could use in TN management. ■

#### Disclaimer:

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

#### Note From Medical Editor, Dr. Jeffrey Brown

In 1756 Nicolaus Andre, a French physician, in his book on maladies of the urethra coined the term tic douloureux when commenting on other convulsive movements he observed in the body. His proposed treatment for this "Maladie cruelle and obscure" was to gradually drip mercury water and apply cauterizing stones over the face at the site of pain. It was an innovative form of nerve ablation. The cauterizing stones were added to assure that no blood clots formed that might put pressure on the offending nerve—an hypothesized cause of nerve injury. It was not until 1962, two centuries later, that an oral anticonvulsant medication, carbamazepine (Tegreto) was discovered to be an effective therapy for trigeminal pain. The drug was approved by the FDA. Since then, no further drugs have been approved because so little effort has been made to investigate any. This study summarized so well by Risheng, Kilgore and Lim is remarkable because it represents the first modern laboratory investigative leap into the medical treatment of trigeminal neuropathic pain. Bravo to the authors for this work and cross our fingers that it will lead to an effective alternative to the seizure medications that compose our mainstay medical therapy.

# My Experience Participating in a Clinical Trial

**Anne-Marie Clarke is a retired Family Court Judge.** She loves to travel. She is grateful for the help she has found for dealing with trigeminal neuralgia (TN) through Facebook and support groups. She is most thankful for her dentist who didn't treat the pain as a dental problem, for the endodontist who realized the pain didn't require a root canal, for her primary care physician who was familiar with TN and made the referral to the neurologist, and to the neurologist who has listened patiently throughout this journey and made the referral to the clinical trial.



*Hello everyone. My name is Anne-Marie Clarke, from St. Louis, Missouri, and I have trigeminal neuralgia.*

On December 5, 2018, my husband and I were getting ready for a trip to Jamaica, one of our favorite vacation spots. I was brushing my teeth when I brushed a tooth on the upper left side of my mouth, causing the most searing pain to shoot through my face. It felt like an electric shock that went up my face and into my head, stabbing and throbbing but eventually stopping. I immediately thought, "I'll have to call my dentist about a toothache when I come back from the trip." I had some naproxen from a previous dental visit and took some. The pain came back intermittently during the flight and the trip even as I continued to take the naproxen.

I visited my dentist on December 10, 2018, who thought it might be a dead nerve and referred me to an endodontist for a root canal. I saw the endodontist on December 19, 2018, who said there was good news and bad news; the good news was I didn't need a root canal, and the bad news was I didn't need a root canal. He said this wasn't an endodontic problem and referred me to a neurologist. That appointment was scheduled for April 2019. I was still in near constant pain and taking naproxen. I saw my primary care physician (PCP) on December 27, 2018, who referred me for an MRI which was completed on January 7, 2019. My PCP then referred me to a neurologist who I saw on January 28, 2019. When he gave me my diagnosis of trigeminal neuralgia, I told

*"Clinical Trials" continued on page 14*



Anne-Marie was presented with a Resolution acknowledging her service as Family Court Judge by the St. Louis City Board of Aldermen on January 11, 2019.

Anne-Marie went to Iceland twice in 6 weeks (January then February 2019) because she was on a mission to see the Northern Lights! She was able to see them on her second trip. It is very cold in Iceland!





Receiving the Saint Louis University Law School Order of the Fleur de Lis Hall of Fame Award January 25, 2019. This is the law school's highest award.

him that my misery now had a name. I was fortunate that I didn't have unnecessary dental procedures and that I got a quick diagnosis.

He prescribed oxcarbazepine and the dose kept getting adjusted. I was still having pain, which was triggered by talking. As a family court judge, I was required to talk a lot. When the pain became unbearable, I would pause and clench my jaw. It was usually brief, and everyone thought it was just the judge being thoughtful.

I retired after 33 years on the Bench in March 2019. If my TN is aggravated by stress, at least the stress from my professional work was over. I began Botox injections on August 20, 2019. I continue to receive more than 30 injections in my shoulders, the back of my neck, my skull, my temples, my face, my forehead, and my jaws every 12 weeks. There was improvement from the treatment. I was able to go for dental teeth cleanings and cosmetic facials, chewing wasn't a problem, and I was able to give speeches. At my Botox appointment in February 2021, the neurologist mentioned a clinical trial he thought I might be a candidate for.

I was screened for the study on March 9, 2021. It was a double-blind study where participants would receive a daily dose of medication or a placebo for two weeks and, after a pause, a daily dose of medication or a placebo for two weeks. There was compensation for each office visit. I completed my visits on May 18, 2021. I believe I received the medication first, as my pain levels declined significantly, and increased when taking the second round of tablets. I am uncertain, though, since it was a double-blind study.

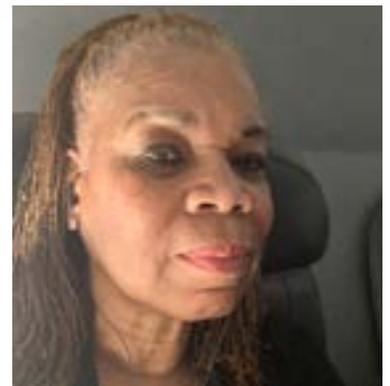
In August 2022, I was advised that phase two of the study was beginning and patients would receive a daily medication dose for two and a half months! Over the course of the trial, my pain level dropped to zero. Since ending the study in November 2022, my neurologist has continued to prescribe the medication.

Participating in the clinical trial allowed me to receive a medication that was truly beneficial for me. I was grateful for not only the opportunity to be a part of the study, but to find relief for this disease. I urge everyone who is seeking something to help with facial pain to consider participating in a clinical trial. ■



With the Stanley Cup won by the St. Louis Blues. October 14, 2019.

December 5, 2018 was the onset of Anne-Marie's trigeminal neuralgia. Flying to Jamaica, the left side of her face hurt and her left eye was closing.





## The FPA's Research Initiative

Our goals for this initiative are to empower patients and caregivers with knowledge that helps you be educated partners in your healthcare, and to encourage more research on facial pain and relevant issues faced by those with facial pain.

To reach these goals, the FPA provides four resources:

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

The Facial Pain Association shares information about relevant medical studies and trials which may be of interest to people affected with neuropathic facial pain. These listings are provided as a convenience only and are not to be considered an endorsement or recommendation by FPA. The safety and scientific validity of a study listed on our website is the responsibility of the study sponsor and investigators.

All studies and trials listed on the FPA's website have IRB or Ethics Committee approval where relevant. An Institutional Review Board (IRB) is a committee established to review and approve research involving human

subjects. The purpose of the IRB is to ensure that all human subject research be conducted in accordance with all federal, institutional, and ethical guidelines. The FPA website provides a brief introduction to studies and trials, with links to the study and contact information. All information is provided by the research organization. Patients should contact the research organization for more information using the contact information provided.

Members of the FPA Medical Advisory Board (MAB) will provide ongoing guidance and information about relevant research studies.



**Are you interested in finding a facial pain clinical trial?**

Scan the QR Code on the left to visit [www.FacePain.org/Research](http://www.FacePain.org/Research) and learn more about the FPA's Research Initiative and facial pain clinical trials.

Disclaimer: Choosing to participate in a study is an important personal decision. Before you participate in a study, discuss all options with your healthcare provider. The FPA does not endorse any product, doctor, procedure, medical institution or its staff.



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

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

### Who qualifies?

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

### Study summary description

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

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

### Who is Noema Pharma?

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



### Need additional information?

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

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

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

**See ClinicalTrials.gov**  
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Libra Study (NOE-TGN-201) - Document: Libra Webpost US draft v1 09/19/2022

# What is Glossopharyngeal Neuralgia?



Jeffrey A. Brown, MD, FACS, FAANS

Glossopharyngeal Neuralgia (GPN) was first described by the one of the first modern neurosurgeons, Walter Dandy, as “paroxysmal pain frequently brought on by eating and swallowing with involvement of the root of the tongue and pharynx, with radiation to the throat and/or the deep ear structures.”

*The description is still accurate.*

## What is the glossopharyngeal nerve?

This is the ninth of twelve cranial nerves, meaning nerves that directly enter or exit the brain not the spinal cord, and is anatomically closely related to the tenth cranial nerve, the vagus nerve. As the above definition notes, the glossopharyngeal nerve provides sensation to the throat and base of the tongue, the deep middle ear, but also the parotid gland. The parotid gland is at the base of the jaw. Injury to it will cause a dry mouth. The ninth nerve provides taste sensation to the base of the tongue and some motor function to a swallowing muscle of the throat.

Dandy’s definition was used by Peter Jannetta to select patients in which he first performed vascular decompression of the vago-glossopharyngeal complex as the most appropriate treatment for this entity.<sup>1</sup> Note- He spoke of decompressing two nerves-the vagus and the glossopharyngeal.

## Why?

The glossopharyngeal and vagus nerves, compose a web of fascicles such that a vessel in contact with the ninth nerve will also be in contact with the lower fibers of the tenth nerve. These also are sensory to the throat.

Distinguished trigeminal and glossopharyngeal neurosurgeons believe that glossopharyngeal neuralgia is an inaccurate description of this entity leading to neuropathic (stabbing) ear and throat pain.<sup>5,6</sup> Glossopharyngeal neuralgia is more appropriately categorized as vago-glossopharyngeal neuralgia when caused by a vascular compression because of the close relationship of the fibrous web that enters the jugular foramen at the skull base. This is the opening in the skull that also allows exit from the brain of the large jugular vein, which drains blood from one side of the brain. For this reason, efforts to treat GPN by a rhizotomy, a heat injury to the nerve done with a special needle, is a concern. The vein can be punctured. Surgeons who choose to section the GPN rather than decompress it have learned that they must also section these vagus fibers to achieve adequate pain relief. Of course, this leads to permanent, and sometimes uncomfortable, numbness in the throat. There thus remains controversy if GPN is better treated by sectioning the GPN and adjacent sensory fibers of vagus nerve or by attempting to decompress.<sup>3</sup>

“GPN” continued on page 18

## What happens to the body with injury to the vagus nerve near the base of the skull?

If the motor fibers of the nerve are injured there can be weakness of the palate, giving the voice a nasal element. Trouble with swallowing follows weakness of the pharyngeal (throat) muscles. There may be weakness or even paralysis of the vocal cord causing hoarseness.

One of the lesser-known issues with vago-glossopharyngeal neuralgia is that when the vagus nerve is involved there can be speech difficulty-lowered volume of speech or hoarseness with ongoing effort, perhaps a chronic cough.

## The good news is that GPN is surgically treatable.

In Jannetta's series, 79% of 39 patients treated over the course of 24 years had immediate pain relief and 76% had continuing complete relief with follow-up of 6 months to 14 years with a mean of 4 years. Many more series of patients by other centers have confirmed the benefits of glossopharyngeal nerve decompression for glossopharyngeal neuralgia.<sup>2-4</sup> There has also been a small study of decompression surgery of the "lower cranial nerves" specific for "dysphonia-" speech quality issues including chronic cough, breathing irregularity and hoarseness.

Finally, it may be possible for one to have both trigeminal and glossopharyngeal neuralgia. It may not be clear when there is ear pain whether it is from trigeminal or from glossopharyngeal neuralgia.

Choose your physician with care to find one that understands the nuances of your care and you should do well. ■

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



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