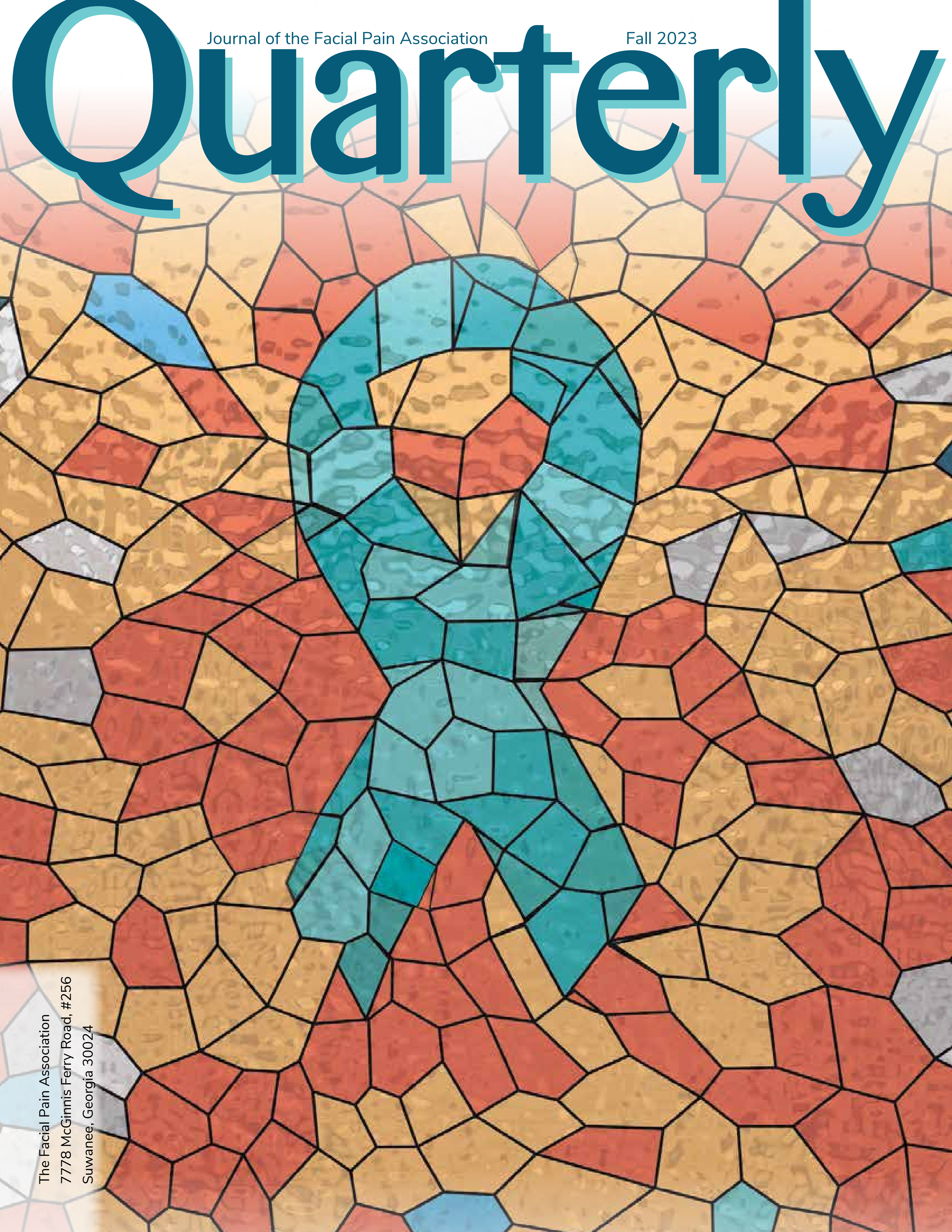
Quarterly

Journal of the Facial Pain Association

Fall 2023



The Facial Pain Association
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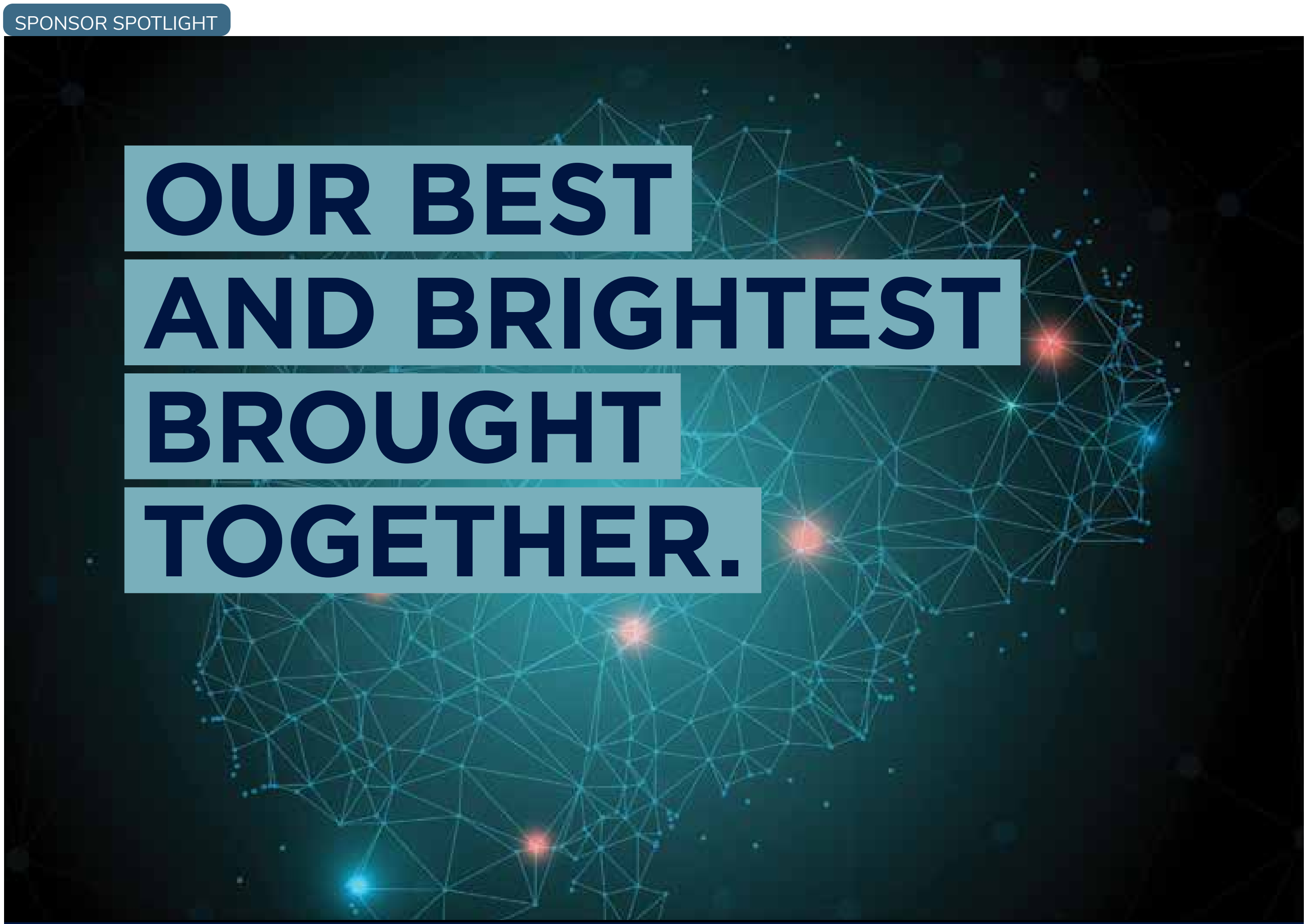

FacialPain
Association

From the Board Chair

In this issue of the Quarterly, you'll read about Trigeminal Neuralgia (TN) Awareness Day. We try to get the word out about our condition; however, please don't think that we concentrate on this for just one day each year. Increasing awareness about trigeminal neuralgia is a particularly important ongoing activity of the Facial Pain Association (FPA). This is because TN is an "orphan condition" in the medical community, meaning it occurs very infrequently in the general population. The extraordinary importance of the fact that TN is an "orphan condition" is that many people – and yes, many people in the healthcare profession – don't know much about it. That's not good for us!

By now, you should know that last year the FPA began a major, multi-year effort to make dentists aware of this condition. As most of you know from first-hand experience, TN symptoms often present themselves as a severe dental problem, which results in many of us undergoing unnecessary root canals, tooth extractions, and delayed proper care because many dentists don't know about TN. Last year's two-prong strategy of advertising to dentists and providing a Continuing Dental Education course appears to have been remarkably successful, reaching half of the 200,000 dentists in the U.S. In the coming year, the advertising will continue, and dentists will be offered Continuing Dental Education courses every quarter – four classes in all. The FPA is fully committed to helping dentists accurately diagnose TN and refer their patients to a medical professional who can help. For all of you, like me, who underwent unnecessary dental procedures, you can easily appreciate how valuable this effort is.

This year, the FPA will also pursue making neurologists in the U.S. better equipped to help those of us with TN. Although most neurologists should be able to diagnose TN, the FPA's research indicates that they are often unaware of all the procedures and medications available to help their patients. This situation should not be a surprise. Expertise is usually acquired through experience, and if the neurologist has never had a patient with TN, or has only had a few, it's unlikely that they have built an expertise in treating people like us. When I began to learn about the procedures and medications that might be helpful for my TN, I realized that I knew much more about this area than my neurologist, and that was a frightening revelation. To be clear, most neurologists are well trained and do their best. But, if you spent most of your day treating patients with dementia and other common neurological problems, you wouldn't be an expert in TN either. The FPA is going to make neurologists much more aware of the procedures and medications available for our condition, so your care is improved.

What can you do to get the word out about TN, especially to your healthcare professionals? The FPA website is loaded with articles and webinars about TN by some of the leading medical experts in the world. You may want to point them toward www.FacePain.org.

David J Meyers

David Meyers
Board Chair
The Facial Pain Association

A Message From the CEO

Awareness Month

As most of you know, October is Facial Pain Awareness Month. I think it is important to take a step back and think about why awareness is necessary and who needs to be aware of facial pain.

For people living with facial pain, finding an accurate diagnosis is key. With that knowledge, options that might help mitigate the pain can be explored. Hearing that diagnosis was probably the first exposure to the words trigeminal neuralgia (TN) or geniculate, glossopharyngeal, or occipital neuralgia. As a newly diagnosed patient who has never heard of this condition, what do you do? Who do you ask for advice? Where do you turn?

The FPA's goal is for more people to know about TN and all other forms of neuropathic facial pain. We hope that people receiving these diagnoses in the future understand that there ARE options available. We want family and friends to be familiar, so they can add to the conversation with hopeful options. Most importantly, we want doctors to be aware –

- ER doctors so no one has to explain what they are experiencing and defend their need for pain relief.
- Ear, Nose, and Throat (ENT) doctors so you don't spend time and money on cures for sinus infections.
- Dentists, so you don't continue to undergo unnecessary procedures that don't help.
- Neurologists, who generally know about trigeminal neuralgia, but see so few cases that they may not be familiar with all of the available options to treat.

That last group of doctors might be a bit unbelievable. They are a primary group of treatment providers for TN. We have heard from patient after patient, that their neurologist was not an EXPERT in TN. And how could they be? Remember, this is a rare condition!

July 1 marked the beginning of the FPA's fiscal year. We have finalized our strategic plan and set new priorities for 2023-2024. One primary objective is our neurologist initiative — an effort that will focus on equipping neurologists with the resources they need to treat facial pain effectively. We aim to provide information to a significant number of the nation's neurologists, so they know how to best treat their patients medicinally, when to transition them from medicinal to surgical options, what to do if the pain returns, and more.

This effort will also help us to expand our engagement with neurology specialists and allow them to pass their knowledge on to you in the form of webinars, articles in the Quarterly journal, and blog posts. We also hope to help neurologists understand that there is a population of young patients, some elementary school-aged or younger, who also need help; who are experiencing this pain and need someone to understand that it isn't a migraine, tooth pain, or a sinus infection. We hear from many young people that they have trouble getting adults – not just doctors, but many adults in their lives – to believe them and their pain.

This is why awareness month is so important: we need everyone to understand the depth of the pain people experience and its effects on their everyday lives - on their jobs, on their lives at school, on their ability to take care of their families. We are going to focus on neurologists during this specific effort, just like we focus on dental professionals in our dentist initiative, but October is bigger than all of that. It is about making everyone aware of what it's like to have facial pain. It is important work, and we hope that you will all participate. As always, it takes all of us! ■

Melissa Baumbick

Melissa Baumbick
Chief Executive Officer, The Facial Pain Association

FacialPain Association

Journal of The Facial Pain Association
Quarterly

Table of Contents






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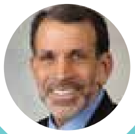


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The MAB Corner

Wolfgang Liedtke, MD, PhD
Neurologist

Dear members of the Facial Pain Association,

I'd like to give you my take on the FPA patient registry, which is in the pipeline.

I wholeheartedly endorse it and enthusiastically encourage you to join to help the entire community and make your own contribution toward our fight against trigeminal nerve pain/oro-cranio-facial pain.

The initial setup of the registry is currently being finalized and will house de-identified data on clinical phenotype (characteristics) of patients with trigeminal nerve pain/oro-cranio-facial pain.

Needless to say, it will only work if you participate and if you answer the questions as completely and authentically as possible.

I remain very enthusiastic about the registry because it is a highly constructive asset that we can bring to the table as a community. I hope that some of my explanations below help you come to a decision about your future participation.

What, why, how, and caveats:

- **De-identified patient data** means that the initial entry into the database will be conducted so that the entry cannot be traced to the individual submitter. Completely separate and uncoupled from the de-identified entry into the registry, we will set up a file that will allow de-identified entries to be reconnected with the person who is behind the entry. This will serve the purpose of requesting additional information, accessing additional medical data/information that might be available, or laying out opportunities to participate in specific studies if the need ever arises. The link to re-associate the de-identified data with the real person will be kept as safe as can be, not only leveraging encryption, but an extended armamentarium of tech-tools against illicit access to this sensitive information. People who provide their entries into the de-identified data set will also be given the option to be excluded from the re-identifying mechanism.
- **Clinical phenotype** refers to everything relevant to the pain that you suffer and to your medical history: life habits as they pertain to your pain, possible sources of inflammation, and general sensitivity of your nervous system, to pain stimuli and your family history of pathologic pain, as well as other hereditary traits that might be relevant for understanding your pain.
- **All of these health-related issues** will be queried in a standardized manner that will transform your answers into metrics (quantitative where possible). That's the pain phenotype that we want to establish from each entrant. This will allow us to derive powerful metric outcomes, then meaningfully combine single parameters into composite indices of pain in multiple contexts, e.g. in the context of other diseases that you also have (co-morbidities), in the context of family liability to pathologic pain, inflammatory and other relevant disorders (e.g.) Ehlers Danlos Syndrome, Lupus). There is power in numbers, and that is where the unique opportunity lies here.
- **Your data will be captured** via the FPA website with secure interface, and possibly an app for mobile device enabling.

There should be no caveats if we execute this correctly, leveraging the technology to our advantage.

Outlook

Existing general health patient repositories have been coupled with medical records and exploration of specific biospecimens, e.g. British Biobank or FinnGen. This will be a future option and will benefit from generating even deeper experiences beyond the astounding success that has already been accomplished. Both biobanks essentially couple clinical phenotypes with biological metrics that have already been conducted, e.g. brain MRI scans and measurements in blood. Undoubtedly the most powerful and promising method is DNA genomic sequencing. Sequencing a patient's exome, essentially the part of their genome that codes for proteins, will be a powerful, practical, and fiscally feasible way forward. In addition, blood proteomics data now can be derived on less than 1 milliliter of serum, currently allowing measurements of several hundreds of proteins (very soon several thousand) that can be detected and quantified. Costs for these measurements have come down drastically (not to be carried by the patient, in any case, to be clear). Of course, this will only work by adhering to the informed consent principle, and to the deidentification principle that already guides the data entry.

What could come out of this?

A previously considered unthinkable analysis of clinical phenotypic data can provide clues about disease biology that we currently have no idea and/or certain misconceptions about, and where we are in dire need of reality-based corrections. Starting from there, numerous call-back studies can be envisioned, such as requesting relevant details of the pain phenotype that have not been asked, obtaining and digitally archiving associated existing MRI scans in selected cases. We are excited to clearly see a beacon on this hill in the not too distant future: assessment of systemic proteome and protein-encoding genome of a large cohort of trigeminal nerve pain/oro-cranio-facial pain patients. I am saying "beacon on the hill" because this approach has transformative power for getting things done in the pain arena that were unthinkable not that long ago.

This is from my perch as a corporate executive in biotech-pharma (with my employer Regeneron having a dedicated interest in pain), previously having enjoyed decades of working together with my patients as academic health center physician, and in my laboratory as basic science researcher (at Duke University), with my focus on trigeminal nerve pain/oro-cranio-facial pain.

Finally, we believe there is no other stakeholder more suitable than us at the FPA to get a patient registry off the ground, to own it responsibly and ethically, to be independent of vested interests (including commercial, academic, governmental), and to maintain and run it successfully.

Please share your thoughts with the FPA at info@facepain.org as we put the finishing touches on our patient registry.

My best,

Wolfgang Liedtke

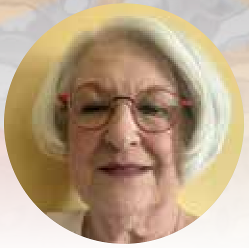
Dr. Wolfgang Liedtke, MD, PhD

Dr. Liedtke is a member of the Facial Pain Association Medical Advisory Board. At Regeneron Pharmaceuticals, he is Chair of Neurology, Psychiatry, Pain Medicine, and Sensory Systems, and a member of the Global Development Scientific Council.

(Opinions expressed here do not represent the view of Dr. Liedtke's employer, Regeneron Pharmaceuticalsnor of his academic affiliates, Duke University and New York University College of Dentistry.)

My Life with
Trigeminal Neuralgia

Carol Bloom
FPA Peer Mentor and
Former Support Group Leader



My name is Carol Bloom, and I am a peer mentor with the Facial Pain Association. I had my first episode of trigeminal neuralgia (TN) when I was 26 years old. I am now 73 years old, and TN has finally become a smaller part of my life. At times I felt it was the devil that lives within me, but I have learned over the years to make peace with it. When I had my first episode, I was out shopping, and I thought I had been struck by lightning. The pain was intense and frightening but it left as quickly as it started. Then began my long and arduous search for answers.

> At that time in 1976, TN was considered an "old woman's disease" by the medical community. Not much was understood about how debilitating and life changing it could be. There were few options for treatment and even fewer physicians who understood the cause.

For the next 15 years, the frequency of the episodes grew, and the intensity of the pain became worse. I never knew when it would happen or how long it would last. During those years, I saw several neurologists who all said I was too young to have TN and told me to learn to live with the pain. Finally, the anesthesiologists I worked for noticed what was happening and recommended I see a new doctor. Fortunately, my new physician recognized my symptoms and recommended a short course of Tegretol (carbamazepine) to see if it would help. For the first time in years, I was pain free.

I continued taking Tegretol for 3 years with success, and I was now looking for a neurologist in case the medicine stopped working. It took time, but I was put in touch with a neurologist who was very interested in TN and wanted to see me.

For the next 5 years, I stayed on Tegretol, but began to have problems with my white blood cell count dropping, so I stopped taking Tegretol and tried baclofen, Elavil (amitriptyline), and gabapentin. They helped a little, but TN was starting to take control of my life again. Since we were running out of options, it was recommended that I see a neurosurgeon. An MRI revealed that a major artery was wrapped around my trigeminal nerve three times and an MVD was recommended. I had the surgery, and for 6 months, I was pain free.

Unfortunately, I had suffered for so many years that permanent damage had been done to the nerve. The pain returned, although not as severe as before. Around that time in 2005, Trileptal (oxcarbazepine) was being recommended to treat TN. I began to take it, and after a short time and the right dose, my pain began to lessen. I have taken Trileptal ever since. I still work with my neurologist to adjust the dose if I have an episode, and then return to my regular dose of 600 mg twice a day.

> My TN is not completely gone but it is controlled. I am thankful for my coworkers realizing the kind of pain I was in, and for my neurologist being knowledgeable about TN, listening to me, and working with me to find a way to mitigate and manage my pain. ■

October is Facial Pain Awareness Month

Share Your Story

If you are ready, we encourage you to share your story to help others on their journey with facial pain. When you share your story on social media, please tag the Facial Pain Association, and use the following hashtags:

- **#FaceTodayTogether**
- **#MyTNStory**
- **#MyGNStory**
- **#MyGPNStory**
- **#MyONStory**

Raise Funds and Awareness

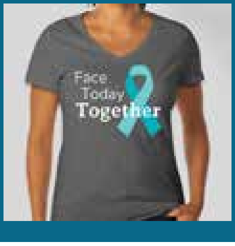
Stream for Charity — You can raise funds and awareness while live streaming your favorite activity! Select the Facial Pain Association as your intended charity on Tiltify.

Fundraise Your Way — YOU can raise funds and awareness for facial pain by fundraising YOUR way! Run a race, host an event, share your story, and more – you can show support and raise awareness any way you choose!

If you are planning an awareness event, please share it with us by visiting facepain.org/face-today-together. When sharing your event on social media, please tag the Facial Pain Association.

"Great conversation starter, so many are unfamiliar with the conditions that cause face pain. We may look fine, but are struggling just to get to the next minute."— KI

"I have Trigeminal Neuralgia so any way I can help raise awareness and funds towards finding a cure for atypical facial pain, I will always support!"— Anonymous



"Thank you for all of the help you've offered. You have my full support!!"— AH

"I live with neuropathic pain and want to help make others aware of this debilitating disease. Also, if there are others in my community living with this, it is a good way of connecting with them so that they know they are not alone."— MV

Thank You for Raising Funds and Awareness!

Wearing a shirt with a teal ribbon is a great way to start the conversation about facial pain – it can lead to opportunities to educate others, advocate for yourself, and show your support for the facial pain community.

This year for Facial Pain Awareness Month, the FPA hosted an apparel fundraiser to support our mission to serve all people living with neuropathic facial pain.

You can help raise awareness when you share a photo wearing your shirt on social media with the hashtag **#FaceTodayTogether** and tag the Facial Pain Association. Let's face facial pain together!

Along with supporting our fundraiser, many community members shared why they support Facial Pain Awareness Month. We invite you to CLICK HERE or use the QR code below to watch a video with more statements of support.

Kicking off Facial Pain Awareness Month with Education

The FPA is kicking off Facial Pain Awareness Month in October with a live webinar, followed by the launch of the 2023 FPA Video Series, featuring two presentations with patient Q&A sessions from April's Conference. Learn more by visiting www.FacePain.org/Tag/Webinars/.


Libra Study Design Focused on Participant Needs

Wednesday, October 11: The Future of Facial Pain Research with Raymond F. Sekula, Jr., MD, Director of the Trigeminal Neuralgia and Facial Pain Program and Professor of Neurological Surgery at The Neurological Institute at Columbia University and FPA Medical Advisory Board Chair; and Amine Tahiri, Vice President of Clinical Development for Adult Programs at Noema Pharma.

Wednesday, October 25: The Multidisciplinary Approach to Treating Facial Pain with Meredith Barad, MD, Clinical Associate Professor in Anesthesiology, Perioperative and Pain Medicine, and Neurology & Neurological Sciences at Stanford University School of Medicine and Steven D. Chang, MD, Professor and Vice Chairman of Strategic Development and Innovation in the Stanford University School of Medicine Department of Neurosurgery, and an FPA Medical Advisory Board Member.

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.

What is Burnout and How Does It Impact Your Facial Pain?

YPC Facial Pain Association
Young Patients Committee

When you are chronically ill and have something as painful and unique as facial pain, it is very easy to get overwhelmed and experience burnout. More often than not, when you hear the term "burnout," it is used in reference to working a very taxing job and being overwhelmed to the point that you lose all passion for the work you do, along with the drive to even follow your dreams.

Chronic illness, in and of itself, is more than a full-time job. It can be 24/7. And because of that, chronic illness can also cause burnout.

Trying to maintain your overall health, seeing multiple specialists and doctors, and frequent appointments can oftentimes become overwhelming. On top of that, the medications you take can cause side effects like fatigue, depression, anxiety, and other symptoms often experienced during burnout. The stress of living with pain and its effects on your everyday life can be daunting. It can take a huge toll on your physical, emotional, and mental health. That's why it is so important to not only know the signs of burnout, but to be able to recognize when you may be drifting into it. It's also imperative that you learn strategies to prevent it from the start. Here is a look at what burnout is, how to recognize it, and how to prevent it.

What is burnout?

Burnout is something that can affect anyone emotionally, mentally, and physically. It comes from a prolonged state of stress. Facial pain is very stressful to experience on its own – it is felt not only in the face and head, but also impacts your whole body.

How do I know if I am experiencing burnout from chronic illness/facial pain?

Stress and Overwhelm

Illness is stressful. Chronic illness and facial pain go hand in hand with continuous stress. It can influence everything about your everyday life. Things such as school, work, parenting, etc., may be impacted along with relationships and friendships.

Irritability, Anger and Frustration

Feeling these emotions can be quite normal for many, but if it has progressed to the point where you don't feel like yourself, you may be experiencing these emotions due to burnout.

"Burnout" continued on page 10

"Burnout" continued from page 9

Depression

Some chronic illness patients have depression outside of their physical health; others may have developed depression after their illness showed up. Depression can be a condition as a byproduct of illness. It can also be a sign of burnout.

Trouble Sleeping

Chronic pain can cause quality sleep to become incredibly difficult and even impossible at times. Lack of sleep makes it harder to work through the challenges of facial pain and affects your emotional and mental health. Did you know that struggling to sleep and experiencing insomnia can indicate burnout?

Dread

Feeling a sense of dread about approaching doctor's appointments and having to go to those appointments are often clear signs that burnout is present. The dread of managing your health, even though you know it to be beneficial, can be due to being overwhelmed by a chronic illness.

Avoidance

Avoidance can go hand in hand with dread. The dread may lead to avoidance when trying to look after your health. Avoiding scheduling doctor's appointments, avoiding going to scheduled doctor's appointments, putting off refilling medications on time, or not picking up those medications from the pharmacy because it feels so overwhelming to do so are telltale signs of burnout in managing your health.

If these and more symptoms are possible signs of burnout, how can you counter or prevent burnout when you have conditions that are ever-present and won't go away? That's a great question!

Countering and preventing burnout also go hand-in-hand. Once you work on countering burnout, you will find ways that help you. And you can use those ideas to help prevent burnout in the future.

Here are some tips to counter and prevent burnout:

Self-Compassion

First, try not to shame yourself for feeling burnout due to your chronic illness. Experiencing the symptoms of burnout does not mean that you do not care about your health. Be gentle with yourself. You are doing your best.

Being Mindful of Our Self-Talk

This is such an important piece to the puzzle. It's easy to tear yourself down when you feel like you should be getting those calls to the insurance company done, scheduling appointments and tests, and all the things that can take up your day due to having chronic illness. You may not be able to get everything done in one day. That is okay. It does not mean you are failing. You can only take things one day, one hour, and one minute at a time. You are amazing!

Self-Care

We hear a lot about self-care these days, we know. But it does make a difference and can help counter and prevent burnout. The awesome thing about self-care is that you get to decide how that looks for you! It's an individual thing. Some may find that meditation is what works for them while another may find journaling to be the key, or another person takes walks in nature. Finding that one thing, or even a combination of things for your self-care can be a huge help! If you want to read more about mindfulness, meditation and deep breathing, check out the article that the YPC wrote for the Spring 2023 Quarterly on FacePain.org in the Quarterly journal section!

Take Time for Your Hobbies

It's extremely easy to get caught up in the pain and overwhelm of your health that you lose sight of things that give you joy. We understand. Sometimes, you don't have the energy to engage in the hobbies you love. If one of your hobbies is something you can no longer experience due to your health, try to look for other things that bring you joy. We have facial pain; that doesn't mean we shouldn't feel excitement and happiness from something we enjoy.

Talk About Your Burnout with Someone You Trust

Bottling up what is overwhelming you only adds to your negative feelings. You are not a burden; you don't need to carry a burden all on your own to be strong. You are always strong, even when you don't feel like you are. You are no less strong for talking about what is overwhelming you. You don't have to go through burnout alone. There are people who care. Talking to a friend, loved one, or therapist can help. Checking out a YPC support group meeting might also be a good option! Not only can you talk in a safe space, but you can be amongst others who "get it."

Sleep

Getting a good night's sleep can make a huge difference. It can help to prevent burnout; and of course, it's also good for our overall health. Trying out some sleep meditations and relaxation techniques might help. You can also talk to your doctor to see if they can help you get some relief from sleep difficulties.

Eliminating Unnecessary Stress

This can be a hard one. Saying "no" more often to honor your emotional and mental health can help prevent burnout. Not taking on more tasks when you are currently burnt out can also be incredibly important. Saying "no" to others can be hard at times, but it is vital. If you find it difficult to say no even when you know you need to, reframe the narrative! You are not saying no, you are saying yes to yourself and your mental health.

You've got this!

Free Time

You need to prioritize time for yourself. It seems that not doing this is also one thing that leads to burnout. Try scheduling free time for yourself to be able to relax by filling that time with whatever brings you peace and joy. When others are asking too much from you, let them know you have something on the calendar. And you do – it's called free time!

Pace Yourself

Managing chronic health is very demanding on your mind and body. The many doctor's appointments, paperwork, pharmacy runs, etc., can wear you out. We know you get it. Pacing yourself helps with overwhelm. If possible, schedule appointments with time in between. Try adding in a fun activity while out for your appointment, whether it's bringing a book to read on a park bench or taking a stroll and soaking up that sunshine. Sometimes, sitting in the grass and grounding yourself in nature can also do the trick. You can plan something to look forward to after your completed appointment, like cuddling with your fur baby as you watch a favorite movie. The goal is to take breaks from stress and stay connected to the things that bring you joy.

Burnout is tough. If you are experiencing burnout, please know that many people have experienced the exact same emotions and understand what you are going through. You do not have to go through burnout alone – you are never alone. Reach out to the YPC via email (youngpatientscommittee@gmail.com) or social media at any time. We are always here for you! ■

When the Doctor is on the **Other Side** of the Sheet

Kenneth F. Casey, MD
Neurosurgeon

We doctors spend our days running around, seeing patients, looking things up (really, we do – all the time!) and filling out seemingly endless insurance forms, and patients and their families still have to fight the system with us. It has always been an eye-opener to "switch roles" for a bit, but not wishing for anyone to have to fight for their health or with the system.

Since finishing medical school, I have had the opportunity to be on the patient side of the sheet a few times for some pretty major reasons: a liver transplant, gunshot wound care, and kidney stone treatment. It is a sobering journey for anyone, but I have experienced a change over the years.

Here I was, a starting tackle on our college football team. We made it to a bowl game. Sadly, I cannot remember anything past the first quarter. The story, as related to me two days later, is that in the third quarter, while blocking an opposing player, I had my "clock cleaned" (to use the vernacular of the time). It took two weeks of recovery before my brain was feeling okay.

No one looks to get shot, but it happens. In my case, I thought I had a bruise under my vest. But no – it was a gunshot wound! This time around, the care was fragmented between an overseas healthcare system and the US healthcare system. Interestingly for that time (1973), the caring nature of the doctors overseas was more evident than in the US, where it seemed to me that our healthcare system was a bit stressed.

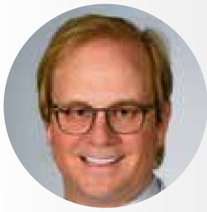
Fifty years later, in 2022, I developed liver failure from Hepatitis C. A side note here: very few people are screened for Hepatitis B or C, as routine blood testing does not look at either. With 17,000 new cases yearly, and over 75% with no symptoms in the early and middle stages, both are a risk. Well, I met that risk. After severe Covid-19, (at least I couldn't taste my bad cooking), I just didn't turn the corner. After a month or so, I had to cut down on my patient commitments, even starting to move some surgeries. Somewhere in that timeframe, my accurate account of the days and weeks was lost due to "liver brain," better known as hepatic encephalopathy – I couldn't spell that in my state, so don't quail when terms are thrown at you. In my case, my wife-caregiver-friend, truly my savior, would force doctors to speak to her in layman's terms. In fact, she related that on one ambulance run, she was telling the EMTs what I had and why.

In the following months, after sneaking onto the transplant list (again a blur), she tells me of several more hospitalizations, four in part with my status worsening, with no donor, dead or alive, on the horizon. At the four-month mark, she told me that an early morning call to our Detroit abode spoke of a possible donor, who was brain dead. We rushed to Pittsburgh, where I was admitted, underwent lab testing, and began to wait. At the twelve-hour mark, the transplant surgeon told my wife that the nearly deceased donor's liver was not in condition to go ahead. A bit of a blow, more so for her, as she understood that my time was running out. After one more near death experience in the hospital, a miracle happened – a living donor match was found!

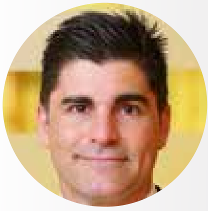
This hero gave me a piece of his liver, and gave me, my wife, and children a new outlook on life. I intend to make the best of it and keep in touch with all of you.

It has been a struggle at times, dealing with the hands I've been dealt by fate. But I have found that by surrounding myself with excellent healthcare providers, a strong care network, and information and support from the FPA and the facial pain community, it's a little easier to endure the pitfalls of our healthcare system. ■

Columbia Neurosurgery's
Reflections on the Facial Pain Patient Journey and Treatment Options



Raymond F. Sekula, Jr., MD, MBA, Director of the Trigeminal Neuralgia and Facial Pain Program and Professor of Neurological Surgery, The Neurological Institute at Columbia University; FPA Medical Advisory Board Chair



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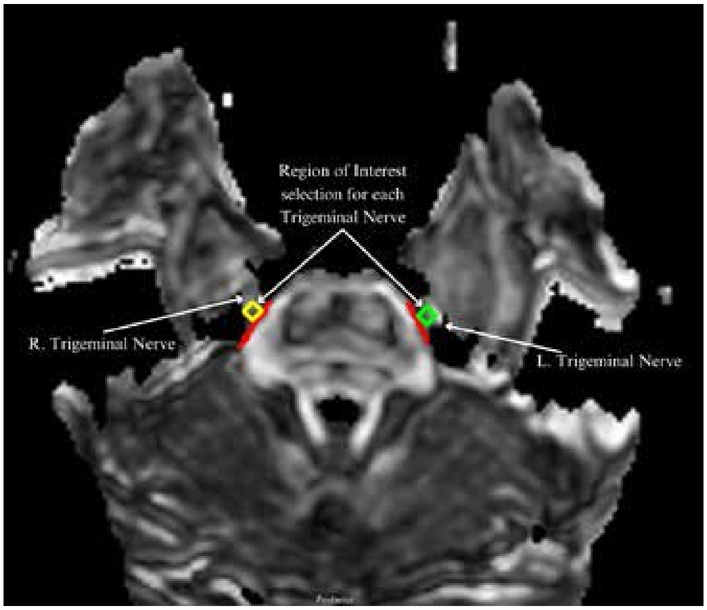


Figure 1

When Lightning Strikes

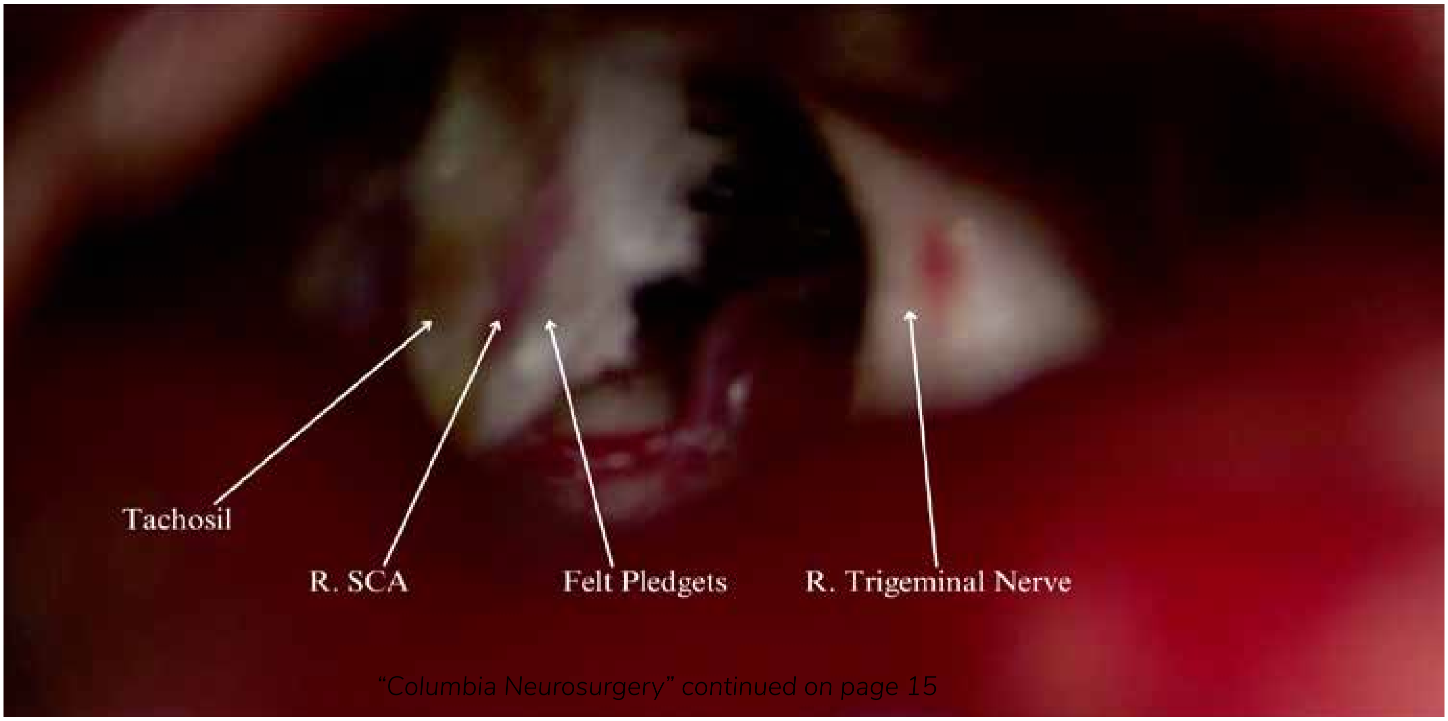
Most patients remember the day their pain began – it's that bad. Many patients report that "it's the worst pain you've ever imagined." That statement is sobering and drives our intentions to help as many patients with facial pain as possible. At Columbia University's Center for Brainstem and Cranial Nerve Disorders, we have joined experts in neurosurgery, neurology, radiology, anesthesia, oromaxillofacial surgery, pain management, and a variety of other distinguished researchers to develop a true center of excellence for facial pain sufferers.

Our research begins with our patients. We actively follow over 1,500 patients undergoing one or more surgical treatments for trigeminal neuralgia (TN). We also have an active preclinical (i.e., research conducted typically on laboratory animals) research program funded through the National Institutes of Health. Currently, we are investigating areas ranging from dysfunction of specific ion channels to abnormal electrical currents within cells of small animals and humans with trigeminal neuralgia. This work is fundamentally directed toward discovering new drugs for various facial pain syndromes. In the clinic, we are working to better understand which patients with trigeminal neuralgia can benefit from surgical intervention. We know that patients with classical trigeminal neuralgia (CTN) fare better with most of the available surgical treatments than those with other types of TN. Information gleaned from a detailed history (i.e., a conversation between patient and physician) allows the physician to diagnose classical trigeminal neuralgia. Patients with CTN describe sharp, intermittent facial pain usually lasting seconds or less and never longer than a minute. This pain does not encompass the posterior third of the scalp or the ear. Triggers include innocuous stimuli such as light touch, wind, or chewing. Attacks may occur numerous times daily with periods (i.e., days to months) of remission. Sensory deficit (i.e., orofacial numbness) is not a related symptom.

Most patients with CTN will wince (i.e., the so-called "tic doloreux" or painful spasm) with pain. All patients with CTN will benefit from a neurosurgical consultation. Approximately 85% of patients with CTN will have evidence of vascular compression of the trigeminal nerve by high-resolution magnetic resonance imaging (MRI) T2 (transverse relaxation time) images. In our Center, we perform high-resolution imaging (Fig. 1) on a higher MRI magnet

"Treatment Options" continued on page 14

"Treatment Options" continued from page 13



"Columbia Neurosurgery" continued on page 15

Figure 2

(i.e., 3T or 3 Tesla, which is a unit of measurement quantifying the strength of the magnet) than found in community hospital MRI machines. Perhaps more important than magnet strength is the "recipe" used to visualize the trigeminal nerve and adjacent vasculature. Too often, we review scans that have not been performed so that the clinician can determine vascular compression of the trigeminal nerve.

Why is this important? If a scan is interpreted as negative for vascular compression by the radiologist, the treating neurologist is led to believe that a referral to neurosurgery is unwarranted. We also know that the degree of vascular compression of the trigeminal nerve is essential. Patients with more compression of the nerve do better with surgery. In some patients (as many as 15%) with classical trigeminal neuralgia, there is no neurovascular compression. These patients do poorly with microvascular decompression surgery (MVD). This is similar to someone with tooth pain but no structural problem of the tooth who undergoes a root canal. It doesn't work and often worsens the pain. Those patients with CTN without evidence of neurovascular conflict, or an inability to tolerate a general anesthetic, are referred for ablative procedures to the trigeminal nerve.

A patient's response to the antiseizure drug carbamazepine or oxcarbazepine also provides helpful information for the clinician. Many patients report rapid facial pain relief within minutes of taking the first tablet or two. While we do not fully understand why the response to the drugs is a significant predictor of response to neurosurgical intervention, we do know that it is crucial. For the past ten years, we have been performing diffusor tensor imaging (DTI) (Fig. 2) on all patients with various types of TN. Until recently, however, we have struggled to understand the significance of the powerful MRI sequence. This year, we will publish our first analysis of TN patients who have undergone DTI, and we hope this tool will further our understanding of the condition. A few years ago, we developed a readily applicable, quantitative grading (or scoring) system to aid patients and referring clinicians in understanding if microvascular decompression is the optimal choice. For some patients, an ablative procedure (i.e., one that purposefully injures the trigeminal nerve) may be warranted and valuable. These procedures include injury (i.e., using blunt trauma, chemicals, or radiation) to the nerve. We also have some very good surgical treatments for patients with TN due to multiple sclerosis (5% of MS patients have TN).

When It Is Not Classical TN

Although many effective pharmacologic, interventional, and surgical strategies are available to treat classic trigeminal neuralgia, many patients have facial pain that does not so readily respond to these treatments. Many types of facial pain syndromes are quite different from classical trigeminal neuralgia. Because of this, they have different treatments than trigeminal neuralgia.

Some patients have constant facial pain. These patients can have pain that is always present, perhaps burning or numbing in nature. Sometimes patients with classical trigeminal neuralgia develop a continuous burning pain after destructive procedures are used to treat the lancinating pain. In many cases, the lancinating pain disappears, but is unfortunately replaced by a different, constant pain syndrome. This type of pain is called trigeminal deafferentation pain. Some patients describe this pain as worse than the original trigeminal neuralgia lancinating pain, since the pain is relentless and never goes away.

Some patients have facial pain that persists after a zoster outbreak in the face. This pain is often associated with severe itching, numbness, and burning. Although the pain usually fluctuates in severity, it is almost always present to some degree. This type of pain is known as trigeminal postherpetic neuralgia.

Some patients develop severe neuropathic facial pain following injuries to the trigeminal nerve or one of its branches. These nerve injuries can occur with trauma to the face, surgery to the face, or dental procedures. The patients often describe numbness in part of the face following the procedure or injury. Patients often report burning pain that develops in the numb area several weeks after the injury. This pain syndrome is called trigeminal neuropathic pain (TNP).

Patients with these constant facial pain syndromes may benefit from some combination of anticonvulsants, antidepressants, baclofen, medical marijuana, and topical medications. Sometimes nerve blocks and Botox injections can be helpful. Patients who do not obtain sufficient pain relief with these strategies are often referred to a neurosurgeon for more definitive management of their pain syndrome.

It is essential to remember that the constant neuropathic facial pain associated with these syndromes does not typically respond well to the traditional surgical treatment for classical trigeminal neuralgia. Microvascular decompression is usually ineffective and destructive procedures may make the pain worse. You and your physician must be aware of the different treatments available to treat these constant pain syndromes and avoid unhelpful surgical treatments that may worsen the pain.

Neuromodulation, which is the application of electricity or medication to the nervous system to alter its activity, may be an effective option for patients with these constant facial pain syndromes. Peripheral nerve stimulation is a type of neuromodulation where one or more electrodes are placed next to the nerve, innervating the painful area. Commonly, a needle is used to insert each wire into position with a local anesthetic, without requiring an incision or any surgical dissection. Once in place, the electrode administers a weak electrical current to the nerve to block the pain signals. When the electrode is activated, the patient may feel a tingling sensation, depending on the exact type of stimulation used. Sometimes the simulation is not felt by the patient. The electrode is left in place for one week, during which time the patient determines whether the stimulation helps relieve the pain. At the end of the week, the electrode is removed. If the patient has sufficient pain relief, then the patient may undergo permanent implantation of one or more electrodes connected to an implantable battery pack that is also placed under the skin. This therapy, also called trigeminal branch stimulation, is typically used to treat pain within the supraorbital and infraorbital nerve distributions.

Sometimes, electrical stimulation of nerves does not provide sufficient pain relief for the patient. In these cases, the distribution of pain is not amenable to treatment with peripheral nerve stimulation,

"Treatment Options" continued on page 16

"Treatment Options" continued from page 15

AP view - peripheral nerve stimulator

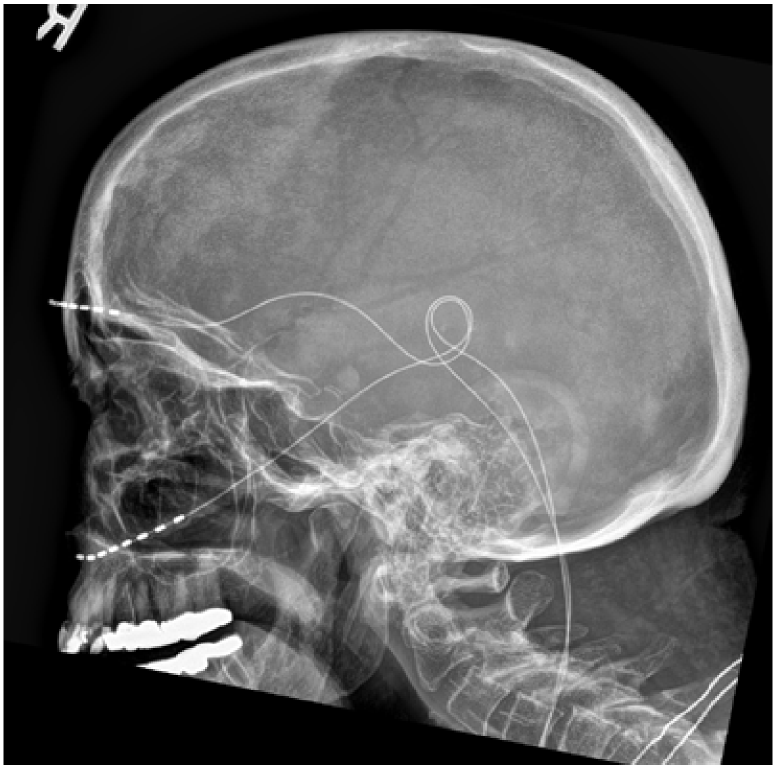


Figure 3: Lateral view - peripheral nerve stimulator

sometimes due to the pain being too deep or out of reach of the stimulation. In some cases, the pain is too extensive for the array of electrodes to treat. In these instances, patients may respond better to a type of neuromodulation that uses medication administered along the spinal cord. This treatment is called a spinal infusion pump.

Once a patient and their physician decide to proceed with a spinal infusion pump, the patient can undergo a trial to assess whether spinal medication is helpful before surgery to implant the pump system. The trial consists of a single injection of medication into the spine with a needle. The medication is usually a synthetic, non-opioid medication that can be highly effective in treating neuropathic facial pain. If the patient has significant pain relief with the trial medication, then they may elect to undergo surgical implantation of a permanent spinal catheter and pump system. This implantable device consists of a catheter inserted into the spinal canal connected to a programmable reservoir that continually administers low doses of the medication directly into the spinal canal.

Patients who have spent years on their facial pain journey trying to find relief from their pain without success may eventually discover that spinal medication can be an effective treatment option for their facial pain, even when every other treatment has failed. ■

There is Hope

Even with the various surgical and medication options currently available, for some people, the pain persists. Through research, we continue to expand our understanding of facial pain, hoping to develop more options to treat neuropathic facial pain. Whether you have classical trigeminal neuralgia, trigeminal neuropathic pain, post-herpetic neuralgia, or facial pain caused by an underlying condition such as MS – **there is hope.**

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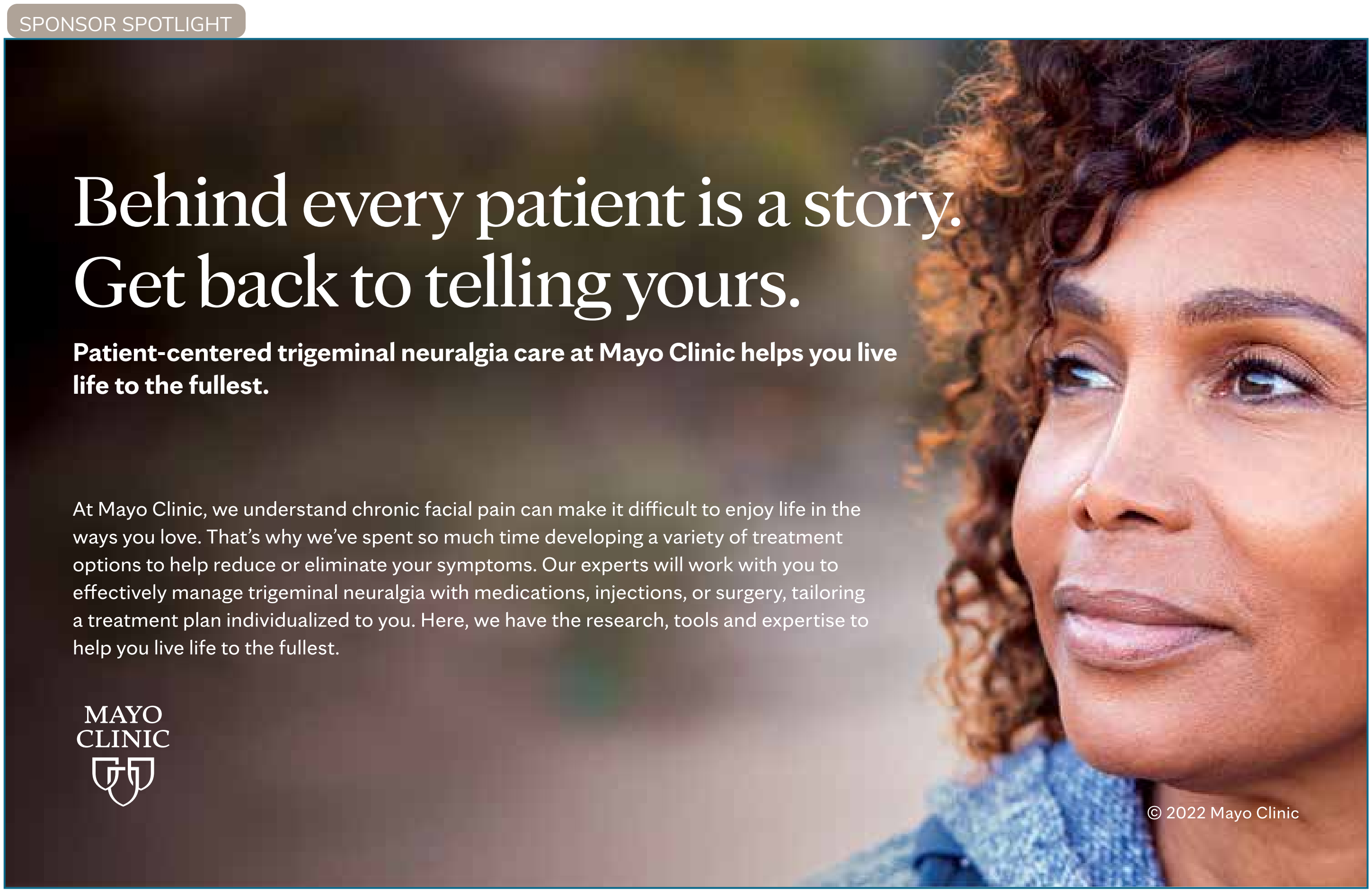

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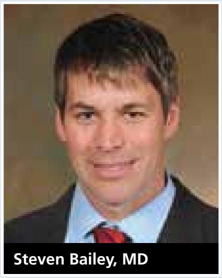

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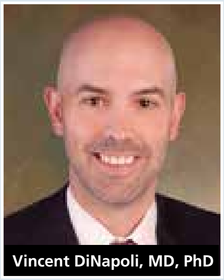

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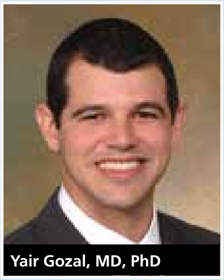

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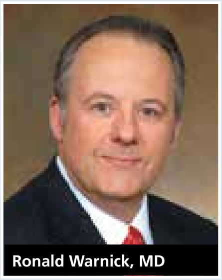

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For more information, visit **mayfieldclinic.com/trigeminal** or call **513-221-1100** to make an appointment.

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Please note: the site in New York, NY at Columbia University Irving Medical Center and the site in Boston, MA at Beth Israel Deaconess Medical Center are not accepting subjects at this time.

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