

quarterly





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THE NEUROLOGICAL INSTITUTE AT COLUMBIA UNIVERSITY

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IS THAT I DIDN'T
SEE DR. SEKULA
SOONER**"
-PATIENT



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IMPROVED OUTCOMES
FASTER RECOVERY**



"Thankfully, many highly trained people are working together to make life better for people with facial pain. That's a good thing - because it will take all of us to get the job done."

From the Chairman of the Board

Helping those of us with trigeminal neuralgia (TN) and other forms of neuropathic facial pain is a big job. There are roughly 350,000 people living with TN in the U.S., and another 15,000 join this group each year. Offering support to just one person can take substantial time and effort. Like I said, it's a big job.

Thankfully, many highly trained people are working together to make life better for people with facial pain. That's a good thing - because it will take all of us to get the job done. In addition to our empathetic, energetic, and professional staff, we work with 18 professionals on our Medical Advisory Board (MAB). They represent expertise in multiple areas of pain management, from neurosurgery to mental health. Many of these medical and dental experts are leaders in their fields, working to develop new surgical procedures and medications designed to treat facial pain. This is all while also doing their day jobs as clinicians and advisors to the FPA!

Beyond our MAB, we have an incredible corps of volunteers focused on helping our community day-to-day. Among these are 74 trained Support Group Leaders and Peer Mentors. Many of you know first-hand how they are working to make life better for all of us. They help us find the right healthcare professionals, share important information needed to make the best decisions, lend support in group and one-on-one settings - and they are often there to lend an ear when we need to talk with someone who can truly relate to our situation.

In addition to our staff, MAB, and volunteer corps, there's the 11-person FPA Board of Directors working in the background to ensure that the FPA is properly

funded, stays on track strategically, has the best staff possible, and much more. Most of these board members serve on committees and manage projects to keep the organization moving forward. A great example is Anne Ciemnecki, who serves as our board secretary, is a support group leader, and co-edited the FPA's book *Facial Pain: A 21st Century Guide*, along with Dr. Jeffrey Brown, Chairman of our Medical Advisory Board. Anne is now embarking on a second FPA book while helping the organization in many other ways.

Our educational resources and programs would not be possible without the 1,300+ FPA donors who ensure that we have the resources to fulfill our mission. In the coming months, the FPA will launch a patient registry to collect and house information from people with facial pain. This information will be available to researchers who are developing new medications, devices, and procedures for our community. This is an incredible step toward innovations and new discoveries for the facial pain community.

As you can see, it will take all of us working together to solve the problem of neuropathic facial pain. Soon, you can take an active role in these efforts by participating in the patient registry, but there are ways to become active today if you want the opportunity. Remember, it takes all of us to face facial pain!

David Meyers, Chairman of the Board
The Facial Pain Association



Facial Pain
Association

Journal of The Facial Pain Association

Quarterly

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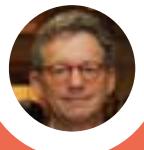
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A Message From the CEO

Happy New Year!

2022



Melissa Baumbick, CEO

As the FPA's new CEO, I have the benefit of seeing this incredible organization through a unique lens. While learning its history and gaining perspective on our mission to support, educate, and advocate for those living with facial pain, it has become clear to me that it takes all of us to face facial pain. In my brief time here, I have met experts in the field who genuinely care about this community. They work tirelessly, treating patients while researching new innovations in treatment methodologies and coping mechanisms. I am fortunate to work with a dedicated team of staff and volunteers whose commitment is unwavering and who go to great lengths to make sure the needs of the facial pain community are met. All of these people are critical to our mission.

As we face a new year, the FPA has several exciting initiatives designed to reach more people affected by facial pain earlier in their journey. Some of these initiatives include:

- Increasing awareness of facial pain among dentists and other medical professionals who don't specialize in this area
- Expanding our reach to inform even more people about available resources and educational opportunities
- Increasing our visibility in younger and more diverse communities
- Improving access to research

This last initiative speaks to a major step forward for the facial pain community. Later in 2023, the FPA will launch its Patient Registry, a repository of

information on facial pain. It will offer researchers a source for scientific, clinical, and anecdotal data to be used in research related to neuropathic facial pain and related healthcare conditions. The registry will also offer patients the opportunity to better understand their conditions. Reports from the registry will offer insights into others' experiences with facial pain, allowing them to see how their experiences compare. The registry will provide data that is vital to better understanding neuropathic facial pain and ultimately discovering more treatment options.

The FPA's Patient Registry has been years in the making, and we hope to start collecting information in the next few months – this is where you come in. We will need the people who are closest to this – those living with facial pain, past and present – to submit their information. The questions will be about your experiences, pain levels, and the effects on daily life. It shouldn't take longer than 20 minutes to complete, and there will be opportunities to update information already submitted and add new information as we develop additional modules. We are grateful to members of our Board of Directors, especially Anne Ciemnecki and her partners in the medical and research communities, who developed the modules designed to collect data. Once the modules are launched, we will depend on the participation of members of the facial pain community. This is your chance to truly impact research related to neuropathic facial pain.

I am excited about the future of the FPA and look forward to working with you this year and into the future. ■

A Multidisciplinary Team Effort to Treat Trigeminal Neuralgia with Percutaneous Balloon Compression



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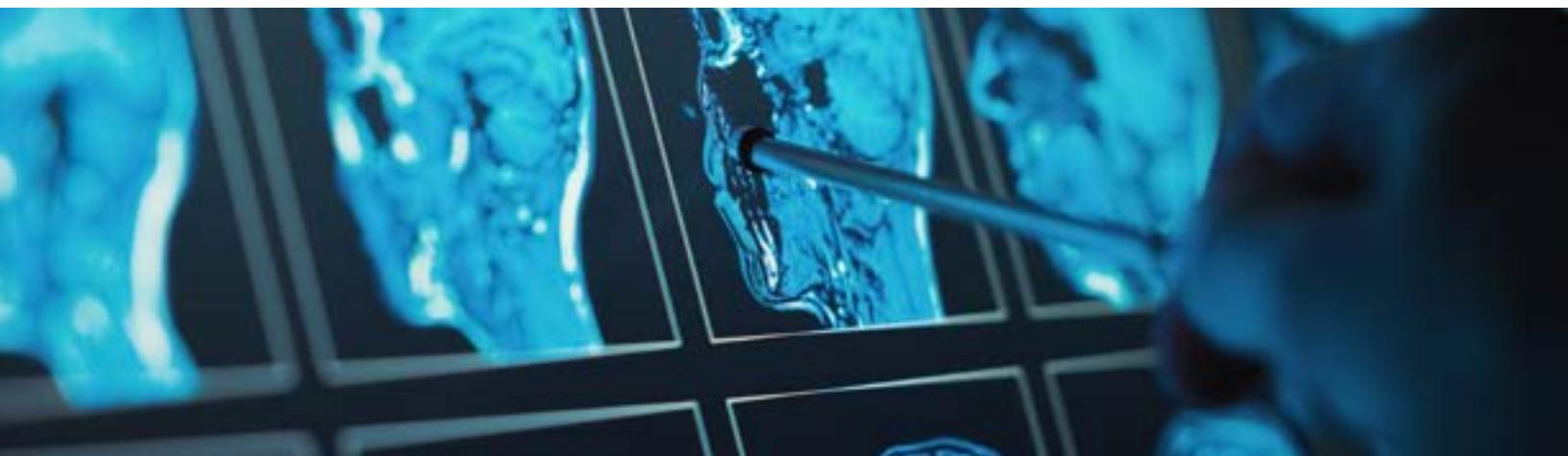
This article was written, and the research conducted by a team of physicians at Mayo Clinic Florida; Sanjeet S. Grewal, MD; William P. Cheshire, MD; Salim M. Ghazi, MD; Andres Ramos-Fresnedo, MD; Erik H. Middlebrooks, MD.

When medical management for trigeminal neuralgia (TN) fails to control the symptoms, we can explore the possibility of performing a surgical procedure. Some options include microvascular decompression of the nerve (MVD), stereotactic radiosurgery (SRS), or percutaneous procedures including balloon compression (PBC), glycerol rhizotomy (GR), or radiofrequency ablation. Similar clinical outcomes between these techniques have been reported in the literature, with between 20 and 65% reporting a recurrence among multiple studies. MVD is the one procedure designed to address the underlying cause of the pain when neurovascular compression is demonstrated. Percutaneous procedures have a lower complication rate and can be safely done in most patients that are unable, because of medical comorbidities, to tolerate a craniotomy under general anesthesia.

Percutaneous balloon compression (PBC) for trigeminal neuralgia was first introduced by Mullan and Lichter in 1983. Briefly, the procedure consists of performing a rhizotomy (a technique to induce a partial injury to the nerve root) of the Gasserian ganglion. Using our intraoperative x-ray machines, a small needle is used to target the trigeminal nerve before it divides into its three main branches. Once the correct location has been confirmed, a balloon is inflated to compress the nerve root and interrupt the sensory signals from the face to the brain that trigger facial pain.

Some patients can achieve immediate pain relief; for others, it can take up to four weeks to attain relief. This is an outpatient procedure and patients can return home on the day of surgery. We recommend an ice pack to the area for the first day or two to help with any swelling. Patients can typically return to their normal activity within a week of completing the procedure.

At Mayo Clinic Florida, we have built a multidisciplinary team to manage trigeminal neuralgia and have shown good pain relief outcomes



over the years. In 2011, our group published our initial experience with PBC for trigeminal neuralgia (Correlation of clinical findings and results of percutaneous balloon compression for patients with trigeminal neuralgia, doi: 10.1016/j.clineuro.2010.08.005). For this study, we obtained data from 59 patients with facial pain syndromes that were difficult to treat with medications or had failed other procedures such as microvascular decompression or stereotactic radiosurgery. Our results showed that 83% of the patients were pain-free at the last follow-up. However, over 50% of patients eventually experienced a recurrence of pain. From these, 25 patients underwent a repeat procedure with the same efficacy rate as their first procedure. Patients experiencing atypical pain and patients with longer symptom duration were both predictors for higher rates of recurrence. In this study, only 3.4% of patients experienced surgical complications (typically facial numbness or unilateral masseter weakness), however, these were transient and resolved on their own within the first month postoperatively.

In 2018, our group at Mayo Clinic Florida published an updated study to evaluate the long-term outcomes of PBC for trigeminal neuralgia (Results of Percutaneous Balloon Compression in Trigeminal Pain Syndromes, doi: 10.1016/j.wneu.2018.03.111). We obtained data from 222 patients with trigeminal nerve pain who had failed medical therapy and who underwent PBC at our institution between 1998 and 2017. Our results showed that 89% of patients were pain-free after their initial procedure (with or without medication). Unfortunately, 31% of patients had to be re-intervened for recurrence of their facial pain and underwent a repeat procedure (93% were pain-free after their first procedure, and 90% of them were pain-free at their last follow-up). We typically wait for at least 12 weeks before attempting a repeat procedure. Our results from this study suggest that those patients with atypical pain were less likely to obtain excellent pain control than patients with typical pain. Other variables such as age, sex, symptom duration, or previous surgery were not associated with any specific differences in outcome. Lastly, our patients were most likely to have recurrence of symptoms if they had a history of previous surgery for TN.

There have been no randomized clinical trials comparing the results and long-term outcomes of multiple percutaneous procedures. The only studies available are retrospective in nature, similar to our own, and the results are controversial. Some of these studies have shown that GR provides superior pain relief compared to PBC, however, the risks of complications are significantly higher. On the contrary, other studies have seen a significant increase in complications with PBC but with similar pain relief outcomes vs. other techniques. In our experience, PBC has been associated with a lower rate of complications, which likely is due to a combination of the multidisciplinary team, as well as specific techniques such as monitoring the amount of pressure when applying compression to the nerve ganglion. Our multidisciplinary team treating complex facial pain includes neurologists, radiologists, pain medicine physicians, as well as neurosurgeons working together to develop a comprehensive treatment plan.

In conclusion, PBC for trigeminal neuralgia is a safe and effective method for pain control, even in those patients with atypical pain or who experience recurrence after their first procedure. A multidisciplinary team approach is essential to find the best treatment alternatives and maximize pain control.

Figure 1: Lateral X-ray revealing ideal shape of inflated balloon





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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My Journey with a Rhizotomy

Stephanie Blough



Hello, my name is Stephanie Blough, and I am honored to share my experience with trigeminal neuralgia (TN) and the successful surgery I had that has left me pain and medication free since 2013. I will begin with what led me to this decision...



It wasn't until after my surgery that I learned I have had TN as far back as I can remember. What I would call my "first memory" of TN was standing at the bus stop in elementary school, and I got a sharp stabbing pain in my left ear. It was a fast episode and stopped just as quickly as it came on. I never said anything because I thought this was just something that happened to everyone. These sharp pains would come and go from that day forward until I was in my mid-twenties. It was then that the episodes would happen as the cold air hit my face getting out of the shower or when the wind blew outside, and it literally dropped me to my knees.

At that point, I began discussing these episodes with my family doctor, who diagnosed me with chronic sinusitis due to allergies (my main trigger point was beside my nose, in the sinus area of my left cheek). For five long years, I was on and off antibiotics, still in pain, until I decided to see an otolaryngologist,

more commonly referred to as an ear, nose, and throat (ENT) doctor. Not even five minutes into my appointment, he told me he was certain of my diagnosis and was referring me to a neurologist for trigeminal neuralgia. Thankfully, a local neurologist was knowledgeable about TN, and he started me on antiseizure and nerve pain medication.

At that time, I was a full-time employee in a finance role and continuing my education at night. The medications often left me with immense brain fog, making it difficult to concentrate and retain information. I brought this up to my neurologist, and he proposed I see a pain management specialist, who suggested I try nerve blocks. This was my first real exposure to being pain-free. I had eight successful nerve blocks, anywhere from 6-8 weeks apart, until I had a minor issue with my ninth block pushing me to seek a more permanent solution.

"Rhizotomy" continued on page 8

When I discussed my struggles with my neurologist, he referred me to a neurosurgeon in Cleveland, Ohio. I was scared to death - I did not want a microvascular decompression (MVD), and I was unaware there were other surgical options that could help. When I met with my neurosurgeon, I was surprised to learn that, in fact, he did not recommend an MVD for me because I did not have any compressions visible on my nerves. His suggestion was a percutaneous radiofrequency rhizotomy. He explained that he would make a small incision in my cheek, add a dose of high heat to the needle, and put small lesions as far out as he could on the nerves causing my pain, which would stop the signals from telling my brain that there was pain in those areas. He shared that the biggest side effect I would have is numbness, which is an expected outcome of this procedure. I'm going to say that again because this is what I have found to be the most misunderstood part of this surgery for others to grasp: the expected outcome of this procedure is numbness. For me, this was a comfortable and promising tradeoff for pain and medications. I made the appointment right then to come back for the surgery.

My rhizotomy was a same-day procedure done in the operating room (OR) at the hospital. I was in the waiting room at 6am and on my way home by 1pm that afternoon. An anesthesiologist put me under as I went into the OR. I'm told I was brought into a twilight state when the surgeon needed me to confirm where my pain was with his assistance in recreating a flare (I do not remember this at all), and then I was put back

to sleep to complete the procedure. When I awoke, they used a safety pin to poke my face where my pain had been, and I could not feel it. Then, they poked an area that was not touched during the procedure, and it hurt. We had achieved what we wanted to do, and I was sent to recovery. Leaving the hospital that day I was sore, feeling like someone hit me upside the head with a baseball bat - but I did not have any TN pain. I spent the weekend resting and was back to work and school that following Monday.

What is the outcome of my surgery, you ask? With the guidance of my neurologist, I weaned off the medications, I am numb in many parts of the left side of my face, and most importantly, I am TN-pain-free. I was advised this procedure is usually a fix for about five years and that if the pain should come back, I am able to call my neurosurgeon and they will get me in to perform the procedure again. Thankfully, it has been a blessed nine years for me, and I have not had to make that call. Would I do it again? You betcha! For me, this was the way I got my life back. No one knows I am numb unless I share my story and that numbness is what has allowed me to become me again. I'd take the numbness over pain any day.

My advice to my fellow facial pain community members is to be your own advocate, and don't limit yourself to the first solution you come across. Be open and honest with your medical team and if you are not getting to the place you want to be, get another opinion. What works for one doesn't always work for or isn't the best choice for another, but there are procedures that can help - do what is best for you! ■



The Reality We Live With:

Understanding the Challenges Confronted by People Living with Chronic Orofacial Pain



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Broadening Our Lens on Chronic Orofacial Pain

Treatment of chronic orofacial pain is typically biomedical (e.g., focuses primarily on physiological factors) (1–3). However, growing evidence suggests a connection between psychological factors like stress, social considerations, and chronic orofacial pain symptoms and outcomes.

The bio-psycho-social model provides a useful framework for a more integrative assessment of these individuals' experiences, concerns, and priorities (4,5). As implied in its name, the bio-psycho-social model takes into consideration not just the biomedical aspects of living with a condition, (i.e., challenges relating to physical function and physiological aspects

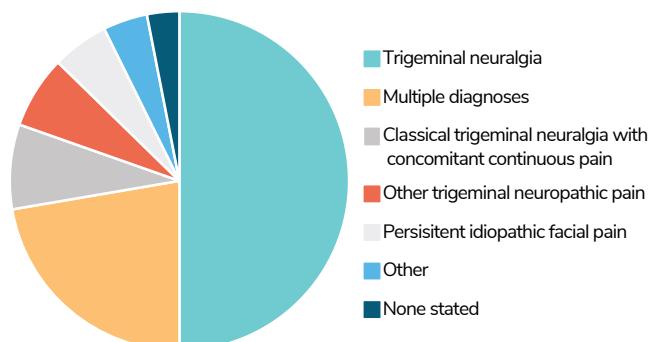


of injury), but also the psychological aspects (i.e., challenges relating to cognition, coping, emotion, and mental health or well-being) and social aspects (i.e., challenges relating to interpersonal, socioeconomic, community and life participation factors) (6,7). Identifying specific biomedical, psychological, and social challenges for individuals with orofacial pain is critical for improving care and working towards meeting their needs.

Listening to the Voices of People with Chronic Orofacial Pain

What better way to learn about the challenges associated with chronic orofacial pain than by asking individuals to share their lived experiences? Qualitative research methods (i.e., collecting

Figure 1: Orofacial Pain Diagnoses In This Study



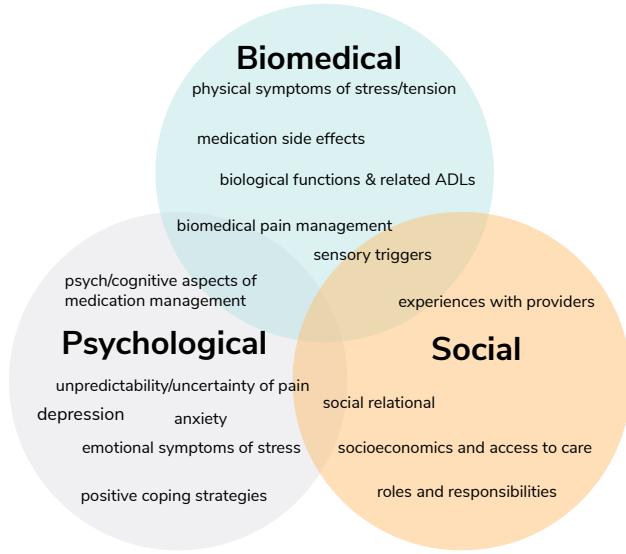
"Reality" continued on page 10

and analyzing participants' experiences in their own words) can help shed light on people's own perspectives of living with chronic orofacial pain.

For our study, we recruited 260 participants with chronic orofacial pain (e.g., trigeminal neuralgia, trigeminal neuropathic pain, persistent idiopathic facial pain, multiple co-occurring pain diagnoses, and others). See figure 1 for a graphic depiction of diagnoses represented in the study.

Participants were members of the Facial Pain Association. They responded to the question "What is the biggest challenge you face in managing your condition?" by typing their answer into a text box as part of an online survey. We compiled these responses and mapped them onto biomedical, psychological, and social themes. Figure 2 depicts the distinct and overlapping subthemes of participants' reported challenges across the bio-psycho-social model.

Figure 2: Bio-psycho-social Model: Map of Subthemes



Outlining the Challenges of Chronic Orofacial Pain and Offering Suggestions to Tackle Them

Participants identified several biomedical challenges including pain management, medication side effects, biological functions and related activities of daily living (e.g., sleep, eating, exercise), sensory triggers, and physical symptoms of stress and tension. Our findings illustrated how these biomedical elements impacted

participants' overall health, wellness, and quality of life. We

"The more effective medications affect my thinking and motor skills too much to use them."

identified several recommendations to address these issues. For example, providers could discuss common medication side effects to empower individuals to make conscious choices about the cost benefit of their medications. To address challenges with activities of daily living, providers should assess and treat sleep, communication, nutrition, and other aspects of self-care to boost people's health and function despite their pain (8). People with chronic orofacial pain may benefit from referrals including occupational therapy for modifications to activities of daily living (9), speech-language pathology for treatment of communication and swallowing function, dietetics to address nutrition, counseling to develop strategies to help manage sensory triggers, and pain-informed mind-body interventions to develop skills around stress and pain management (10).

Psychological challenges described by our participants included anxiety, depression, emotional symptoms of stress, unpredictability/uncertainty of pain, psychological and cognitive aspects of medication management, and positive coping strategies (resilience/mindfulness). Participants'

"Endless loop: Working long hours distracts from the pain but deepens the stress, which aggravates the pain."

psychological and emotional challenges were further reflected by the fact that 67% of them exhibited clinically meaningful symptoms of depression and 56% exhibited clinically meaningful symptoms of anxiety based on validated measures.

Participants described the interplay of depression, anxiety, and general mental suffering with the severity of their pain condition. They additionally mentioned the unpredictability of their pain as a source of anxiety which impacted their ability or willingness to participate in social activities and work. Our results



show the need for accessible and effective psychological programs to target these challenges. Such programs may include Cognitive Behavioral Therapy, mindfulness-based and relaxation interventions, and biofeedback (11–15).

Social challenges described by participants included changes to relationships, roles and responsibilities, experiences with providers, and socioeconomic and access to care. Some described withdrawing from their communities and limiting their engagement in meaningful activities which increased their sense of isolation and hopelessness. To address these

social challenges, people with orofacial pain may benefit from treatment which involves spouses and family members. Clinicians may additionally provide people with chronic orofacial pain with resources such as

"I feel isolated and unsupported by some people around me. It's hard to understand pain when you don't experience it."

orofacial pain support groups, online forums, and advocacy organizations (e.g., the Facial Pain Association).

Participants described difficult experiences with medical providers and navigating care (e.g., distress around not being "believed" by their providers, difficulty obtaining a definitive diagnosis, and a sense that their providers aren't knowledgeable enough).

"Finding doctors that have knowledge and can help."

These findings suggest a need for more training and resources for providers who manage these cases and raising awareness of the prevalence of orofacial

pain that does not have a known cause. Some participants described difficulty accessing care due to the cost of treatment and insurance coverage issues. This challenge may be particularly prominent for those who are uninsured, experiencing financial insecurity, or who have fewer financial resources (16). To help with this, people with orofacial pain could benefit from the help of social workers to assist in navigating financial and social resources and work accommodations. Our findings also suggest a need for change in policy such as reduced cost for effective pharmaceuticals, and expansion of coverage to evidence-based complimentary therapies.

Facing Forward

One unique aspect of this project was the inclusion of individuals with a variety of orofacial pain diagnoses. While most previous research on orofacial pain "silos" participants based on their different diagnoses, the current findings show more similarities than differences in challenges experienced among diagnoses in our sample.

These findings illustrate the wide range of challenges that individuals with chronic orofacial pain face across the bio-psycho-social continuum and suggest important areas for consideration to improve future care. ■

FPA Volunteers

Regina Gore, Database and Volunteer Coordinator



Sometimes, it's hard to wrap my mind around how many people living with facial pain, their families, and loved ones our volunteers already reach.

Our dedicated volunteers are spread over seven time zones, from Hawaii to California, from Colorado to Minnesota, from New York to Brazil, and across the pond to Scotland. The FPA is grateful to work with sister organizations and international contacts as close as Canada and as far away as Australia, New Zealand, and Israel.

Our volunteers serve in rural areas, big cities, and everywhere in between. Beyond geographic reach, our volunteers provide resources for those with numerous facial pain diagnoses, from trigeminal neuralgia to anesthesia dolorosa, from post-herpetic neuralgia to atypical odontalgia, as well as those with nerve damage caused by an accident or dental procedure.

FPA volunteers help in a myriad of ways. They provide group support, both in person and virtually, and one-on-one support, where they lend a sympathetic ear and a positive voice. Volunteers share their stories in the Quarterly journal and on social media. They lend their artistic talents to increase awareness, and they search for scholarly publications to add to our resources. Still, others serve as mentors to new volunteers and provide valuable insights to develop future projects.

We are so very grateful for the time and talent of our volunteers. We simply cannot do what we do without their help.

As much as we are doing, it is both enough and not enough. To paraphrase the poet Robert Browning, "Let your reach exceed your grasp. Or else what is heaven for?" His words suggest that to achieve anything worthwhile – to achieve the perfection of heaven – we should attempt even those things that may be impossible.

**"Let your reach exceed
your grasp. Or else what is
heaven for?"**

— Robert Browning

The FPA, driven by our amazing volunteers, is attempting to achieve no less a goal than providing support, education, and advocacy for every person affected by facial pain. We strive to include spouses,

siblings, children, caregivers, employers, and co-workers, along with neurosurgeons, neurologists, researchers, dentists, therapists, chiropractors, and healthcare providers in all disciplines. Sometimes we don't know what we don't know, especially when it comes to identifying and reaching out to underserved communities. And yet, we all continue to reach.

We have come a long way, but we have further to go. It's tempting to plant a flag and pitch a tent halfway up the mountain. Halfway is good, considering how many of us struggle daily, living with pain. We have a right to be proud of how far we've come. But I encourage you to look up, set your sights on the summit, and strike out for it. FPA volunteers will be right beside you.

If you are interested in joining the Facial Pain Association's team of volunteers, contact Regina Gore, Volunteer Coordinator, at rgore@facepain.org or visit the website www.FacePain.org. ■

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Face Pain?



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**Facial pain can
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Fall 2022 YPC Scholarship Recipients



We invite you to read the following excerpts from Kaitlyn and Taylor's winning essays. Please scan the QR code on the following page to read the essays in their entirety on the FPA's website.

The Young Patients Committee (YPC) assists in fulfilling the mission of the FPA by representing the interests of neuropathic facial pain patients under the age of 40. In 2021, the YPC launched the Facial Pain Resiliency Academic Scholarship, available to students in the US between the ages of 18-40, attending college or university, who have facial pain. Students who struggle with or succeed in their fight against facial pain deserve assistance in their pursuit of post-secondary education. Ambitious students who attend college despite their facial pain setbacks display impressive resolve, and the Young Patients Committee of the Facial Pain Association wants to recognize and reward these determined individuals.

The FPA YPC is pleased to announce two recipients who each received a \$500 scholarship. This scholarship is made available through donations and the generosity of people like you.

Congratulations, Kaitlyn Ready and Taylor Maynard!



Kaitlyn Ready

Kaitlyn Ready is an undergraduate student at Purdue University, pursuing a Bachelor of Science degree in biology with a minor in psychology and a certificate in entrepreneurship.

Read an excerpt from Kaitlyn's Essay on the following page.

Taylor Maynard

Taylor Maynard is a graduate student researcher at the Mesulam Center for Cognitive Neurology and Alzheimer's Disease at the Northwestern University Feinberg School of Medicine.

Read an excerpt from Taylor's Essay on page 16.

Excerpt from Kaitlyn's Essay

I was in my Intro to Kinesiology course talking about nerve disorders. I sat through the entire lecture, until, near the end, the professor brought up a slide on trigeminal neuralgia. The professor gave some basic facts, then had us watch a short video following several older TN patients. They were completely debilitated by the pain.

I saw videos similar to this after I received my diagnosis. They all followed the same story: an elderly person gets TN from an obscure facial injury, the pain is so debilitating they can't leave the house, and no treatment seems to work.

It was always a sad story, but never one I could relate to. None of the videos ever showed someone my age going to college, while still dealing with the stress and pain that comes with a chronic illness like TN.

When the video ended, the professor asked the class, "Do you know anyone with TN?" I raised my hand along with two other students. The professor asked who it was that had TN. The other students' answers were "my great aunt" and "an older cousin."

Then the professor pointed to me.

"I have it," I confidently answered.

She looked puzzled, like she had misheard me.

She asked again, "No, who do you know that has trigeminal neuralgia?"

I paused, before again saying "It's me. I have trigeminal neuralgia."

There was an awkward silence in the room. The professor looked away and moved on with class announcements.

I was left frustrated and confused. Why wouldn't my professor listen to my story? I thought to myself, "Maybe this is something I should be ashamed of after all."

I told my mom that I just wished someone my age could understand. I felt alone in my pain, which only worsened my depression and anxiety.

One day, my mom called and told me she had found something that might be helpful for me. She sent me a link to the Young Patients Committee Instagram page. I was so surprised to see people my own age sharing their stories about facial pain. It was the first time since I woke up from surgery that I felt somewhat understood, even though I was just scrolling through an Instagram account, laughing at the memes.

I immediately signed up for the next support group meeting the following week. ■



Excerpt from Taylor's Essay

It's been five and a half years since I graduated college. Since then, I have worked in both clinical and research settings, seeing patients living with disorders ranging from Autism to Alzheimer's, and publishing several research studies in peer-reviewed journals. It was during that time that I was also diagnosed with TN type 1.

My diagnosis came during the beginning of the pandemic when the whole world was confused about its future and safety. I'll never forget those initial, debilitating electrical zaps of pain in the left side of my mouth and face when I would bend over, walk outside in the cold winter wind, and eventually when I would attempt to eat, speak, and, on my worst days, simply sit up in bed. Or the numerous emergency trips to the dentist and then the endodontist for a root canal consultation. Without that consultation, however, perhaps it would have taken much longer to find a doctor who would listen to my concerns about a possible neurological disorder.

I remain endlessly grateful to that endodontist for confirming that indeed, I was suffering from nerve pain and that I should see a specialist immediately.

Thanks to him, my TN type 1 was confirmed via MRI, and I have since found a medication that is mostly effective and allows me fairly long periods of remission, briefer periods of severe flares, and overall better quality of life.

Despite this, coming to terms with the strong possibility that my condition would progressively worsen as I got older made me realize how life-changing this diagnosis really was. It made me second-guess my ability to pursue higher education and a career in such a challenging field of science and patient care. How would I be able to provide excellent patient care if/when the monster that is TN returns with a vengeance (because I knew it would)? It was one of the most challenging questions I had asked myself in a long time. It wasn't long before I realized that I would not let TN define me or my career goals and dreams, so I pressed on.

Though TN is a treacherous diagnosis that I would not wish upon anyone, I can't help but think that it has shaped me into the resilient woman I am today. Being diagnosed and coping with TN kind of makes you feel like you can handle anything—whether it's applying to graduate school, dealing with grief and loss, and even coping with someone else's diagnosis. While this feeling isn't always static, it is persistent enough to make you feel like a true warrior on most days, and that's all we can really ask for, right? We all just want the strength to get up in the morning, fight, make the right decisions, and hopefully make someone else's day easier or brighter. ■

Scan the QR code on the previous page to read Kaitlyn and Taylor's essays in full on FacePain.org.



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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.



**Do you have trigeminal neuralgia?
Is your current treatment sub-optimal?
If you answered yes to both, the Libra Study[®]
may be an option for you!**

Who qualifies?

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

Study summary description

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

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

Who is Noema Pharma?

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



Need additional information?

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

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

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

See ClinicalTrials.gov
(Study NCT05217628)
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Check if
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The Sustainer Circle is an incredible community of monthly givers who
help ensure that FPA meets our mission of support, education, and
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Michael Brisman, M.D.

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



Jeffrey Brown, M.D.

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.



Brian Snyder, M.D.

Dr. Snyder is a fellowship-trained, functional neurosurgeon who specializes in the use of neuromodulation to treat complex crano-facial pain conditions.



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