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.

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

Our treatments include:

- Gamma Knife radiosurgery
- Microvascular decompression surgery (MVD)
- Percutaneous stereotactic rhizotomy (PSR)

Mayfield’s Nationally Recognized Trigeminal Experts

Steven Bailey, MD
Vincent DiNapoli, MD, PhD
Yair Gozal, MD, PhD
Ronald Warnick, MD

For more information, visit mayfieldclinic.com/trigeminal or call 513-221-1100 to make an appointment.
“A great deal is being accomplished by the FPA to help improve the lives of those of us with facial pain. A couple of the things that I find most impressive include the Patient Registry and Dentist Initiative.”

From the Chairman of the Board

On behalf of the Board of Directors, Emeritus Board, Medical Advisory Board, and staff, I welcome Melissa Baumbick to the Facial Pain Association as our new CEO. Melissa has extensive direct experience in helping lead an organization very similar to the FPA, so we are very pleased to have someone who has hit the ground running. You’ll learn much about Melissa on pages 3 and 4 in this Quarterly.

A great deal is being accomplished by the FPA to help improve the lives of those of us with facial pain. A couple of the things that I find most impressive include:

**Patient Registry:** A patient registry is an invaluable tool to help organizations develop new medical solutions (e.g., medications, procedures, devices) more successfully. People provide information about their condition; researchers become much smarter, and when clinical tests are conducted, they can access those people who are willing to participate. An international consortium of leading healthcare experts who are working on finding better solutions for those of us with facial pain was formed to create a facial pain-specific registry to be launched early next year. The FPA and a couple of its Medical Advisory Board members are part of this effort. In fact, Anne Ciernnecki, a board member and co-author of FPA’s book, Facial Pain: A 21st Century Guide, is taking the lead in developing the materials. This tool will enable us to help those who are diligently working to create new solutions to relieve our pain - a big win.

**Dentist Initiative:** An advertising campaign targeting dentists is underway to inform them of trigeminal neuralgia and other facial pain that should not be confused with dental pain. This campaign delivers the message in leading dentist periodicals and then, via a QR code, directs them to the Dentist Initiative page on our website with more information. On top of this, Internet ads are being run, and articles are being placed in these periodicals. Imagine a day when a dentist says to himself, “Wait. This might not be a dental problem, and I shouldn’t do a root canal or extract that tooth. I need to refer this patient to a physician who can help!” Getting people in our community diagnosed faster and avoiding unnecessary dental procedures will be another big win.

Not surprisingly, the economic headwinds (e.g., inflation, economic uncertainty) that all of us are facing are also impacting the FPA. Our expenses are higher, and we’re concerned that we won’t have the same number of donors as we usually do. With that in mind, those of you who have donated in the past, please continue to do so, and at an even higher level if possible. For those of you who haven’t yet become a donor, now is the time to step up if you are able. FPA has terrific momentum that no one wants to see slowed. Thank you for your consideration.

David Meyers, Chairman of the Board
The Facial Pain Association
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In September 2022, Melissa Baumbick succeeded Allison Feldman as Chief Executive Officer of the Facial Pain Association. Melissa brings over 25 years of experience in marketing and communications, having worked in both corporate and small business environments. She has spent the last 11 years with the Acoustic Neuroma Association (ANA), a nonprofit organization dedicated to the support of people with a rare, benign brain tumor. She holds a bachelor’s degree in Journalism from Ohio University and is determined to use her varied background to lead the FPA and provide essential resources to people living with facial pain.

Melissa graciously accepted my invitation to introduce her to the facial pain community. During our conversation, she shared how her experience in the rare disease space helps inform her vision for the future.

**BU:** Melissa, we are thrilled to welcome you to the Facial Pain Association! Can you tell us more about yourself?

**MB:** I grew up in Maryland, in a suburb of Washington, DC, and moved to Atlanta in 1996 with my husband, Mark. We have three children; Emma is a senior at UGA, Sam is a freshman at GCSU, and Joey is still at home and in the 8th grade. I spent the first part of my career in the corporate world, working with companies like Georgia-Pacific and Coca-Cola. We moved to Ohio for a brief time after my daughter was born, and I started doing contract work so that I could be home with the kids. When we moved back to the Atlanta area in 2006, I did project work for smaller companies looking for marketing and communications assistance. That’s how I found the Acoustic Neuroma Association and fell in love with nonprofit work. I finally felt like what I was doing made a difference. I moved into a development role at the ANA, where I worked with sponsors and donors. I knew that at some point, I wanted to transition into a leadership role. When I’m not working, I love to spend time with my family and friends. I play tennis and work out, trying to stay as active as I can. I enjoy reading and love the water - my happy place is at the beach or the lake, surrounded by the people I love.

**BU:** You bring more than 25 years of experience in marketing and communications, 11 of those years with a nonprofit organization. How has this experience prepared you to lead FPA?

**MB:** I think my experience working with patients and specialists dealing with a rare disease will be the most helpful as I transition to the FPA. At the ANA, I gained an understanding of patients’ perspectives and how difficult it can be to find information and support. I empathized with the loneliness that comes from not knowing others dealing with similar issues. Being able to offer resources and support for that community showed me how critical this work is. It is also helpful that many of the physicians and medical centers that treat acoustic neuroma patients also specialize in facial pain, and I already have relationships with some of them. I am thrilled to be FPA’s new CEO and work with a fantastic team dedicated to serving our mission. I look forward to working with these experts to learn more about facial pain and developing materials and programs that offer needed education and support to this community.
BU: You bring a fresh perspective. What is your initial impression of FPA?

MB: The FPA puts people first, which is my priority as well. Whether I was doing research on our website, exploring our social media, or reading the most recent book on facial pain, FPA does an exceptional job of placing the primary focus of our organization first – people living with facial pain. I hope to keep that mission at the forefront no matter what initiatives we take on moving forward. As I have had the chance to work with our board of directors, staff, and volunteers, I find that everyone cares deeply about this organization and helping people who need it. To me, that is such an important part of success and of achieving the goals we set. I think we’re on excellent ground here.

BU: What are your highest priorities in your first 100 days as CEO?

MB: I want to get to know our staff and Board of Directors. These are the people who best understand the FPA and the ones who have been holding the reins for the last couple of months. I want to understand the active projects and upcoming strategic priorities. That will provide insight into where the organization is currently, so I can help to create a path forward. I also want to begin building relationships with volunteers, donors, medical professionals, and sponsors – the groups who engage with us in different ways. And last, but most certainly not least, I want to learn everything I can about facial pain and the people and families who deal with it every day.

BU: How do you define success, and what is your vision for FPA’s future?

MB: If we continue to serve people affected by neuropathic facial pain in the way that they need it, we will be successful. I have a broad vision for FPA’s future that involves pushing the organization forward in all our areas of focus – education, awareness, support, and advocacy. In our efforts to provide education and increase awareness, I hope we can attack the issue of misdiagnosis, decreasing its incidence and shortening the journey to successful treatment. I want to continue developing and maintaining relationships with the medical community, so they understand the resources we can offer their patients. Our partnerships should lead to the most up-to-date educational resources, providing vital knowledge to those dealing with facial pain so they can cope with and understand this condition. And finally, I hope we continue to meet people where they are, offering the help they need to support their journeys in the way that is most helpful. As we have recently witnessed through the pandemic, those needs for support can change, and we need to be proactive to offer it in the most productive and relevant ways.

BU: What is the best advice you have ever received, and what wisdom do you have to pass along?

MB: The best piece of advice I have ever received came from my mother. She always told me to believe in myself, and that advice has carried me through some difficult situations and encouraged me to do things I thought I couldn’t. She was right, and now I give my kids this same advice. The wisdom I have to pass along comes from patients. Give yourself grace - the grace to...
enjoy life when you can and the grace to rest when you need to. Take care of yourself. As a mom, I learned that you can’t be helpful to anyone else if you don’t take care of yourself first. I think that applies to everyone.

BU: Leading the Facial Pain Association is an incredible opportunity and equally challenging. What do you like to do to relax and unwind?

MB: I love to travel. My younger sister recently moved to Berlin, so that will definitely be my next trip overseas, but there are so many places I want to go – Greece and Italy are at the top of the list. I also love sports and have fully jumped on the SEC football bandwagon since my daughter started at UGA (Go Dawgs!). Day to day, I enjoy reading and spending time with my family. With two of my three children in college now, the times when all of us can be together are really special, and they mean the world to me.

Thank you, Melissa, and welcome to FPA!
The mission statement of the Facial Pain Association (FPA) stipulates the purpose of this patient organization is to serve those with neuropathic facial pain (NFP). Since dentistry is intimately involved with the face, both from an extraoral and intraoral perspective, it is a profession, due to its practices, that perfectly intersects with the goals and objectives of the FPA. Many patients who are experiencing NFP seek guidance and assistance from their oral healthcare provider due to the signs and symptoms associated with this perplexing and often debilitating condition. The characteristics of NFP are rather complex, and our understanding of its process is still somewhat rudimentary. Therefore, it is easy to understand why the presentation of this pain condition may pose significant difficulties for the oral healthcare provider since the structures the patient reports as painful often appear clinically normal. Unfortunately, this can often lead to misdiagnosis or incomplete diagnosis and result in misdirected or incomplete treatment by well-intentioned and caring oral healthcare providers.

To avoid these pitfalls, diagnosis must begin with a comprehensive history and clinical/imaging examination. Once the diagnosis of NFP is established, the oral healthcare provider must decide whether to treat these individuals or provide a referral to a healthcare professional who understands these neuropathic conditions. Another consideration that may confront the oral healthcare provider is that the patient with NFP may require dental treatment for an existing dental problem or for routine maintenance of their dental health. Hence, there is a great need to educate those students who are enrolled in dental schools as well as those who have graduated on these most concerning issues they may encounter during their careers.

Dentistry, like its medical counterparts, has specialties (twelve dental specialties in total) which are recognized and accredited by respective governing national organizations. Simply put, a specialist is an individual who devotes themselves to one subject or to one particular branch of a subject or pursuit. An example of a recognized specialist in dentistry would be an orthodontist, who is a dentist that has undergone training to specialize in the diagnosis, prevention, and treatment of irregularities in the jaw and teeth. Commonly, the orthodontist provides the patient with “braces.” In March 2020, the American Association of Orofacial Pain’s request to recognize orofacial pain as a dental specialty was granted by the National Commission on Recognition of Dental Specialties and Certifying Boards (NCRDSCB) based on compliance with the Requirements for Recognition of Dental Specialties as determined by the American Dental Association (ADA). The ADA states that “Dental specialties are recognized by the NCRDSCB to protect the public, nurture the art and science of dentistry, and improve the quality of care. Specialties are recognized in those areas where advanced knowledge and skills are essential to maintain or restore oral health.” As of March 2022, the NCRDSCB recognized the American Board of Orofacial Pain (ABOP) as the national certifying board for orofacial pain. Thus, ABOP represents the examining and certifying organization for qualified providers to be considered for specialty status when standards for providing appropriate orofacial pain care are met.
These events have resulted in legitimizing the field of orofacial pain, which is now considered a specialty of dentistry that encompasses the diagnosis, management, and treatment of pain disorders of the jaw, mouth, face, and associated regions. Orofacial pain disorders include but are not limited to temporomandibular muscle and joint (TMJ) disorders, jaw movement disorders, neuropathic and neurovascular pain disorders, headache, and sleep disorders. The orofacial pain specialist is dedicated to the evidenced-based understanding of the underlying pathophysiology, etiology, prevention, and treatment of these disorders and improving access to interdisciplinary patient care. Due to these events, patients who are experiencing NFP now have a legitimate dental resource who has the recognized specialized training to assist in the management of their condition.

The FPA, recognizing that dentistry is integral for complete patient management and more specifically for those with neuropathic pain, is making great strides in implementing various initiatives to enhance their engagement with this profession. The FPA clearly understands and acknowledges that these conditions are multi-etiological and require a multi-disciplinary team approach, thus recognizing that the partnering and involvement of dentistry is essential in providing patients with the ultimate care.

Can you diagnose trigeminal neuralgia?

The Facial Pain Association’s Dentist Initiative communicates a vital message — it takes Exactly Zero tooth extractions to diagnose neuropathic facial pain. As part of our effort to educate the dental community, we invite dentists to take the following quiz on our website.

Fill out the quiz below and check your answers in the key below.

1. Are dental pain and facial pain treated the same way?
   - Yes
   - No

2. Who do the majority of patients with trigeminal neuralgia visit first?
   - Primary Doctor
   - Neurologist
   - Dentist
   - Ear, Nose, and Throat Doctor

3. The majority of medical malpractice lawsuits on trigeminal neuralgia involve dentists.
   - True
   - False

4. What’s the first thing you should do if a patient presents with shooting, sharp pain in their face and jaw?
   - Ask the patient a few questions
   - Start pulling teeth
   - Get full X-rays

5. Early diagnosis is the best way to help a patient suffering from trigeminal neuralgia.
   - True
   - False

Answer Key

Scan to take the quiz on our website

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Hi, I'm Amy Barris. Many friends call me Murphy - if something can go wrong, it will for me.

I am just shy of turning 64, a mom to four grown kids and a grandma to eight. I married my best friend 42 years ago, and he has always been my rock.

At 41, I was diagnosed with breast cancer. But there was a light at the end of the tunnel: I finished my treatments, and they saved my life. I was blessed to watch my children grow up and our family expand. My facial pain is different, because I know I will have it for the rest of my life.

The pain began 11 years ago with a toothache on my bottom right second molar. I was seen by a very trusted endodontist and had a root canal, but my toothache never went away. I dealt with that pain for five months until I finally had the tooth extracted by an oral surgeon. I was thrilled that my pain was finally gone, but it only lasted for three months.

After my pain returned, I went back to my oral surgeon. I was told the bone graft from the root canal was gone, and the pain I felt was coming from the neighboring tooth. I was sent back to my endodontist and wasn’t thrilled about another root canal (or the cost). This time, I was very scared because I didn’t know what was happening to my mouth. But I got the root canal, and it went well. My pain was gone again - or so I thought.

One month after the second root canal, I went to the dentist to get my permanent filling and care for a cavity on the opposite lower side of my mouth. My dentist numbed only the lower left side of my mouth and repaired the cavity. He said he didn’t need to numb my right side to put in the permanent filling since the roots were gone; I agreed. While cleaning out the temporary filling, his drill hit a nerve, and I almost flew out of the chair. He put his hand on my shoulder and said, “you need to sit still.” I will never forget those words. My life had just changed in that instant. He finished his work, and I was out the door.

I started seeking help, from dentists to orthodontists to neurologists, periodontists, and any specialist I could find. No answers, just many tears from the frustration of no one being able to help me – and the pain. The pain of a throbbing tooth that feels like it’s being stabbed and squeezed by pliers.
I went back to the oral surgeon and had that tooth extracted. I was never told it wasn’t my teeth causing the pain. I was so petrified that I needed double the medication to sedate me. I thought this extraction would be the end of my pain... remember when I said my nickname is Murphy? Well, the pain moved over to my lower canine tooth. I couldn’t stop wondering - how can this be, and how come no one can help me?

After that, I found out about the Facial Pain Association (FPA), and a Support Group Leader in Michigan reached out to me and was very helpful. Hearing his story made me feel that I wasn’t making this up and my pain was real. Thank you, Tim G.

Then, a year after my first root canal, I saw Dr. Larry Ashman at the University of Michigan. He sent me to a neurologist, hoping they would understand what I had. We tried so many medications and two nerve blocks to no avail. None of the drugs were tolerated except Klonopin, which I still take today.

The day I saw Dr. Kenneth Casey was the day I was officially diagnosed with neuropathic tooth pain. I could have removed all my teeth and still been in pain. I was thankful for Dr. Casey and this new knowledge, but I was still curious about another condition called atypical odontalgia (AO). I could have written the definition - it described my pain. I wasn’t crazy.

After reading about AO, I decided to create a private Facebook group called Surviving Atypical Odontalgia and Neuropathic Pain. I knew I couldn’t be the only one with this, and I wanted to help others so no one would ever feel alone. Today, there are almost 400 members in the group from all over the world. We help each other no longer feel alone and lean on each other on our good and bad days. We share ways to cope, new medications that help, strategies for living despite the pain, and more. We understand each other, and that in itself is a true gift.

Today, I love life, and I’m thankful I have come to terms with this cruel condition. It has taught me many things, including that when you find a caring and compassionate doctor, you should hold on to them. Dr. Ashman is now retired, and I am grateful he was part of my journey. Another great part of my journey is the FPA. Last year, I jumped at the opportunity to become a Peer Mentor and have connected with even more facial pain sufferers like me. Whenever I see a new doctor, I take the FPA patient guide with me and let them read it. Their latest book, Facial Pain: A 21st Century Guide, is another great source of information for doctors and patients alike. ■

“I want to thank the FPA for all they do and for giving me the chance to share my journey with you. Because of their support, I now know I will survive this.

Has it been an easy road? Absolutely not. Am I alone? Never again.”
Patients have spoken. Thousands of people living with pain responded to requests for information from the Centers for Medicare and Medicaid (CMS) and the Centers for Disease Control and Prevention (CDC) to understand issues around access to covered pain treatments. For the latter, the CDC solicited information and conducted interviews with patients and other stakeholders to integrate their perspectives into a forthcoming update to the 2016 CDC Guideline for Prescribing Opioids for Chronic Pain.\(^1\) One output of these efforts was the 2022 CMS Chronic Pain Experience Journey\(^2\) which illustrates thematic content voiced by patients.

Issues displayed in the infographic illustrate the multitude of challenges patients face. The net result is that many patients are left to navigate their daily life circumstances while coordinating what care they can receive and managing a variety of care gaps with little or no support.

Persistent barriers to pain care can greatly compound pain and suffering. Proximity to healthcare centers, insurance issues, too few trained providers, and costs are just some of the issues that impede patients’ access to needed pain treatment. These issues are not new,\(^3-4\) and solutions are needed to address them. Issues connect patients to effective pain care.

- **Scalable and home-based treatments.** The 2016 Federal Pain Research Strategy and the 2019 HHS Pain Management Interagency Best Practices Task Force\(^5\) identified the need for scalable and accessible pain treatment options. Home-based, automated, online, and telehealth options offer treatment avenues that may support patients where they are, and thus better equalize access to pain treatment.

- **Reimbursement.** Improved reimbursement models are needed for telehealth and evidence-based automated treatments.

- **Prior authorization red tape.** Extensive prior authorization and repeated denials from insurance leave clinicians and patients with few feasible treatment options. Payors should be incentivized to support patient-centered pain care with early access to conservative treatments and a stepped-care approach that tracks with costs and treatment intensity.

- **Addressing the unintended consequences of the CDC opioid guideline.** The CDC documented the unintended consequences of the 2016 Opioid Prescribing Guideline: misapplication that included a regulatory climate of “legislated medicine” that punished clinicians who prescribed opioids and led to many patients losing access to medication they may have benefitted from. The CDC is soon to publish its update to the 2016 opioid prescribing guideline with language stating that the opioid doses discussed are meant to be a guide and not hard thresholds that would replace clinician decision-making around individual considerations. As history has shown that such clarifications are insufficient for curbing inappropriate state and federal legislative and regulatory behaviors, stronger actions are needed to protect patient-centered prescribing and thus the fraction of patients who require opioid analgesia. Such actions could include a CDC registry for public documentation of misapplications and a task force dedicated to addressing large-scale misapplications (e.g., state based prescribing laws, state medical board regulations, and policies and practices of the Drug
Enforcement Agency). Specific to care gaps and the problems outlined in the CMS infographic, the CDC may anticipate misapplications of the forthcoming update to the opioid prescribing guideline. Out of an abundance of caution, the CDC could consider creating a system for public reporting to allow rapid corrections and impactful public and professional communications to ensure patient safety and minimize harm.

- **Addressing stigma.** The infographic included provider fear and providers opting out of caring for the person with pain. With repeated insurance denials and other issues, the increased provider burden of caring for people with pain may be actual or perceptual; in either case, it can contribute to stigma and further erode patient access to pain treatment. Stigma experienced by patients within a healthcare system can fracture their connection to their care and may impede them from even seeking care. Enhanced medical and provider education may address aspects of stigma and support good communication and functional patient-clinician relationships. Patient-level interventions may support coping with stigma. Finally, systems operations improvements that reduce provider burdens may enhance engagement and ultimately patient receipt of care.

**Federal Actions to Pave the Way**

How can we better support patients with pain and the clinicians who treat them? A roadmap is needed, and the 2016 National Pain Strategy provided a blueprint for improving pain care systems nationally. The 2020 Best Practices Interagency Pain Management Task Force provided additional actionable recommendations.

- **Congress.** Congressional appropriations supported the HEAL initiative, which in part has led to funding for pain research. However, a gap analysis is needed in terms of the National Pain Strategy and the Best Practices Interagency Pain Management Task Force and required appropriations to urgently shore pain care gaps.

- **CMS.** CMS has several efforts underway, including improving fee schedules for pain management billing codes (see Federal Register here: https://public-inspection.federalregister.gov/2022-14562.pdf) and improved utilization of codes to increase access to non-pharmacologic pain treatments. CMS also notes that they are actively seeking collaboration with federal partners and are exploring opportunities to address issues identified and illustrated in the Chronic Pain Experience Journey Map.

Opioid litigation settlements are in excess of $26 billion. State allocations represent an opportunity to direct funds in needed ways to ensure patients have access to evidence-based, coordinated, and effective pain care for each individual.

Finally, only by keeping patients at the center of the conversation will problems be addressed effectively. Inclusion of patients on policy boards, state medical board committees, and meetings is needed to fully appreciate the patient perspective and to develop patient-centered policies and practices that meet their needs.

*Improving Pain Care* continued on page 12
“Improving Pain Care” continued from page 11

References


2. Chronic Pain Experience Visual (cms.gov)


Chronic Pain Experience

Understand access to covered treatment and services for people with chronic pain.

This visual is derived from stakeholder interviews focusing on the experiences of those living with and treating chronic pain. Its intent is to highlight the most prominent barriers experienced by people accessing care and the influencers acting on providers, ultimately affecting the person with chronic pain, their quality of care, and their quality of life. These sentiments were derived from requests for information (RFIs) conducted by CMS and CDC, including as part of CDC’s efforts to understand and integrate the lived experiences of patients and providers into their update to the 2016 opioid prescribing guideline.

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

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Facial Pain Awareness Month 2022

Let’s Face Today Together

October is Facial Pain Awareness Month, an annual grassroots campaign to raise awareness about neuropathic facial pain.

Throughout October, FPA will share facts about facial pain and lift the voices of our community by sharing stories and promoting grassroots awareness events.

- **Oct. 7:** Trigeminal Neuralgia Awareness Day
- **Oct. 10:** Geniculate Neuralgia Awareness Day
- **Oct. 14:** Glossopharyngeal Neuralgia Awareness Day
- **Oct. 25:** Occipital Neuralgia Awareness Day

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

Awareness Events

If you are planning an awareness event, please share it with us by visiting facepain.org/face-today-together and we will share your event with the facial pain community. When posting about your event on social media, please tag the Facial Pain Association.

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.
- **Facebook and Instagram Fundraisers** — Share your story and raise awareness and funds to support the facial pain community.
- **Fundraise Your Way** — Visit FacePain.org/Face-Today-Together to learn more.
I am Rachel Scherer, living on Heritage Fields Farm in Orange, Massachusetts. We raise LaMancha dairy goats and have a small farm store where we sell milk, cheese, eggs, and meat. We have the indescribable pleasures of having our children and grandchildren close by and a truly wonderful community of friends and neighbors. I also have a “very, very rare” side effect of interventions for trigeminal neuralgia (TN), usually called anesthesia dolorosa (AD). I was diagnosed with TN in 2013, had microvascular decompression (MVD) surgery in 2014, and then stereotactic radiosurgery (SRS) in 2018. I enjoyed low pain/low medication periods after each of these – especially after the SRS. But 18 months after the SRS, I noticed a cold numbness in my nose that spread to my cheek and then across my entire face. I now had intractable pain in all three branches of the trigeminal nerve, instead of just middle branch TN.

I am fortunate to have a truly wonderful neurologist who has always been on my side. He had been very cautionary about me having the SRS, but I must stress that it is only now that I understand why. I did not realize what lurked in the descriptor of “numbness” as a potential side effect. I couldn’t believe there was something worse than TN, but there is. This is very rare, but now I am part of a community of people with facial numbness and deafferentation pain resulting from procedures undergone to provide relief from TN. As a community, we find so much in common in our stories that it becomes difficult to relate to the word “rare.”

At the 2022 FPA Virtual Conference, I asked questions relevant to our community at every session. I met several new companions along the way. We began to talk about making ourselves more present in the FPA. We wondered why there was not an AD support group among the FPA groups, so I volunteered to become an FPA Volunteer support group leader. The Volunteer Coordinator, Regina Gore, is a great resource in

**Volunteer Spotlight**

I am Rachel Scherer, living on Heritage Fields Farm in Orange, Massachusetts. We raise LaMancha dairy goats and have a small farm store where we sell milk, cheese, eggs, and meat. We have the indescribable pleasures of having our children and grandchildren close by and a truly wonderful community of friends and neighbors. I also have a “very, very rare” side effect of interventions for trigeminal neuralgia (TN), usually called anesthesia dolorosa (AD). I was diagnosed with TN in 2013, had microvascular decompression (MVD) surgery in 2014, and then stereotactic radiosurgery (SRS) in 2018. I enjoyed low pain/low medication periods after each of these – especially after the SRS. But 18 months after the SRS, I noticed a cold numbness in my nose that spread to my cheek and then across my entire face. I now had intractable pain in all three branches of the trigeminal nerve, instead of just middle branch TN.

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**About AD**

Anesthesia dolorosa (AD) is a feeling of pain in an area that is completely numb to the touch. “Anesthesia dolorosa” literally means “painful numbness.” Numbness describes a loss of sensation or feeling in a part of your body, but it is often accompanied by or combined with other changes in sensation.
preparing and helping me figure out how a group that feels like outsiders can become more at home with the FPA – and vice versa. When I announced the formation of the support group in an online AD discussion group, over 40 people in 7 time zones requested to be kept informed. I hope that we as a group can provide valuable input to FPA as well as benefit from FPA’s resources. I also hope we can share the ways we manage day by day and learn from others all the little things that help us feel just a few percent better a few minutes at a time. I’m scheduling informational sessions with a pharmacologist, a neuromodulation specialist, and a mindfulness meditation instructor, too.

I wish you all could be here with me, listening to the wind in the pines, the happy clucking of the hens, and seeing the goats out on their morning pasture walkabout. By practicing staying open to all these opportunities to cultivate a sense of happiness, my pain is reduced bit by bit, moment by moment. I wish you all many of these moments.

**SPONSOR SPOTLIGHT**

**Face Pain?**

You’re in good hands.

Ramesh P. Babu, MD
Board Certified, Fellowship trained neurological surgeon with 25 years of clinical practice

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The dating world, in general, can be a bit daunting for anyone. Putting yourself out there can be a vulnerable step and can even be a bit intimidating for some. When you have chronic illness, specifically facial pain, the challenges may seem more complex, and a young patient who wants to date may feel more reluctant to venture into the dating world for fear of these challenges. But everyone that wants to experience the dating world should feel that they can. Facial pain does not have to be the deciding factor on whether you date or not.

Dating can bring up feelings of vulnerability for many with facial pain and finding answers for some of the questions that are more unique to those with facial pain may be difficult. While there is information out there about facial pain, we found that there wasn’t a lot on how to navigate the dating world as a facial pain patient.

The following questions and answers are things we learned as facial pain patients in the dating world:

**Dating is Possible with Facial Pain**

First off, regardless of facial pain, you are no less of a human, no less worthy of experiencing joy, fun, love, and adventure while dating. You deserve wonderful things. Facial pain doesn’t change that.

**When Do I Tell Someone About My Facial Pain?**

One of the biggest questions many patients with facial pain face is when to share about their condition. Our answer to this: there is no wrong time to share about your pain. Each person with facial pain is their own individual, and it comes down to what makes you feel comfortable and is the right decision for you. Some may feel comfortable with disclosing up front that they have a health condition; some may feel they want to wait until further down the line. Others may be comfortable telling someone that they have a health condition but not disclose the exact nature of their condition. And those are ALL more than all right. What might be comfortable for one patient with facial pain may not be for another, and that is completely okay. You have autonomy over your own self and that includes when and whether you tell a potential date about your health condition and medical history.

If you do decide to tell your date about your condition, having information about your condition on hand can be helpful for someone who is not familiar with your diagnosis. The Facial Pain Association (FPA) is a great place to start with that information! We also advocate for letting each person know that face pain is not always textbook. No one knows about your face pain more than you. So, while sharing resources is incredibly helpful for future partners, sharing your unique experiences will enlighten a person who does not understand exactly what the journey of facial pain looks like.
What If a Potential Date Suggests an Outing that Triggers My Facial Pain?

When it comes to facial pain, each patient has their own triggers. As mentioned before, facial pain isn’t always textbook. So, what might trigger one’s pain may not trigger another’s pain. If you are able to know your triggers, then we suggest this rule of thumb: What do you want to get out of your date? If you experience pain (or an increase in pain), can you come back from that pain? It’s about trying to be in the moment. If your triggers are, for example, the wind, choosing an indoor activity would most likely be a better date option than an outdoor outing. Or, if eating is a trigger, skipping a dinner date might be a better idea. It’s also okay for you to offer an alternative type of date! This can reduce the unneeded nervousness of worrying about a particular trigger occurring (or increasing your pain), and you can enjoy the date!

What If I Suddenly Need to End the Date Sooner than Planned Due to Pain? Can I Do That?

You can absolutely end a date, any time, for whatever reason, including your health! Having a plan tends to make those of us with facial pain feel more comfortable. In general, when going on a date, it is helpful to have a safety plan in place. For example, we let a trusted friend or family member know where we are going, when we will be at our date location, and transportation plans for getting to and returning from the date. That plan can also help when it comes to our health.

If you need to end the date sooner rather than later, having that option prepared in advance will help. If you are unable to drive, have a plan in place for getting home, whether that be a trusted individual on standby to pick you up or using a transportation app. Have your “In Case of an Emergency” contact information handy, including lists of medications, allergies, and health conditions. Have on hand anything that you normally would have on you when venturing out in public that helps your face pain and allows you to be more comfortable. If this includes emergency medication, keep in mind for those of legal age, if you have consumed alcohol on your date, some
medications can’t be taken safely. Also, remember some medications’ side effects may impair you.

Going on a date should be a fun experience, so having a plan for your facial pain can give you the chance to lean into the fun! We know that chronic pain can be difficult to predict, so open communication with those you trust (your “In Case of Emergency” go-to people) is always important. Let those around you help you plan so you can focus on living your life!

**What If Someone is No Longer Interested When Finding Out About My Health Condition?**

For some, hearing that someone has a health condition may be unexpected, and they may not be sure how to correctly or properly respond. Unfortunately, some may also respond unkindly. Knowing that this may occur can help better prepare you. Something to try and keep in mind, regardless of someone’s response to your condition, is that you deserve love and happiness. Their response does not reflect your value as a person, a partner, or a potential date. If someone can’t see the beautiful person you are on the inside and out, they are missing out.

**What About Kissing with Facial Pain?**

This may also be a common concern amongst those with face pain. Many forms of facial pain can be triggered by touching the face, including kissing. This may be hard to navigate and even cause some anxiety. The key is communication. When you feel it is the best time to have a conversation about your worries, concerns, and boundaries, communicating to your date/partner that this is something you worry about and may cause you to experience pain may help. Also, practicing consent and communicating to your partner to practice asking if you want your face touched, or if you want to share a kiss beforehand leaves the decision up to you. It gives you more control of your health.

A beautiful thing is that intimacy can look like many different things. Kissing may be a common demonstration of attraction or love, but intimacy can be expressed in many other ways, such as holding hands or gazing into your date/partner’s eyes. Intimacy doesn’t always have to look the same way for everyone. Find ways that work for you!

The reality is having face pain is tough. Having face pain as a young patient is its own type of tough. We know. When we thought about trying to date, we scoured the internet, looking for anything we could find on how to date while having facial pain, and really couldn’t find answers. If you, too, are wanting to experience dating, hopefully, these tips help make you feel more comfortable and confident navigating the dating world while having facial pain. Remember, you are a wonderful, beautiful human! Facial pain doesn’t change that. You got this! Happy dating!
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The Sustainer Circle is an incredible community for monthly givers who help ensure that FPA meets our mission of support, education, and advocacy of the facial pain community. Your donations provide a reliable source of funding that allows us to sustain the initiatives of the Facial Pain Association while spending fewer resources on fundraising.

Legacy Society
The Facial Pain Association exists to serve all those affected by neuropathic facial pain. Our Legacy Society members are an instrumental group of supporters who have included a gift to FPA in their estate planning. Planned gifts ensure FPA continues to remain the premier resource for education, support, and advocacy for years to come. Extend your caring for the facial pain community beyond your lifetime by choosing to include the Facial Pain Association in your estate plan.

For more information, call or email Brandi at 800-923-3608 or bunderwood@facepain.org.

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There are special people in our lives we treasure. Increasingly, FPA supporters are making gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support FPA’s growing initiatives on behalf of people with neuropathic facial pain and their families.
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When you buy games or eBooks through the Humble Bundle digital platform, you can choose to support the Facial Pain Association with every order.

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Are you planning a walk for Facial Pain Awareness Month? Do you want to share your story and fundraise to support others living with facial pain? Visit FacePain.org/Face-Today-Together and select “Fundraise Your Way” to create a personalized fundraiser.

Raise Awareness and Funds

Fundraise on Facebook
Did you know that you can raise awareness of facial pain among your friends and family while raising money to support the facial pain community? Host a Facebook Fundraiser, share it on your Facebook page, and ask your friends and family for support. Start by visiting https://www.facebook.com/fund/facialpainassociation

Stream on Tiltify
You can raise funds and awareness while live streaming your favorite activity! Play a video game, share a special talent, and more. If you are interested in raising awareness and supporting people suffering from facial pain, select the Facial Pain Association as your intended charity on Tiltify.

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Workplace Giving Campaigns give employees, their spouses, and retirees a convenient way to give to FPA through automatic payroll deduction. Check with your employer to find out how you can designate the FPA through your Workplace Giving Campaign. (FPA EIN#: 22-3071645)
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Dr. Brisman has served as Chief of Neurosurgery at NYU Winthrop Hospital, Mineola, NY, and is Co-Medical Director of the Long Island Gamma Knife® Center at Mount Sinai South Nassau in Oceanside, NY.

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

Dr. Mechanic served as Chief of Neurosurgery at Huntington Hospital, in Huntington, NY, from 1996 to 2014. He has served as Chairman of the Nassau Surgical Society Section of Neurosurgery.

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