Journal of the Facial Pain Association Summer 2025

Quarterly

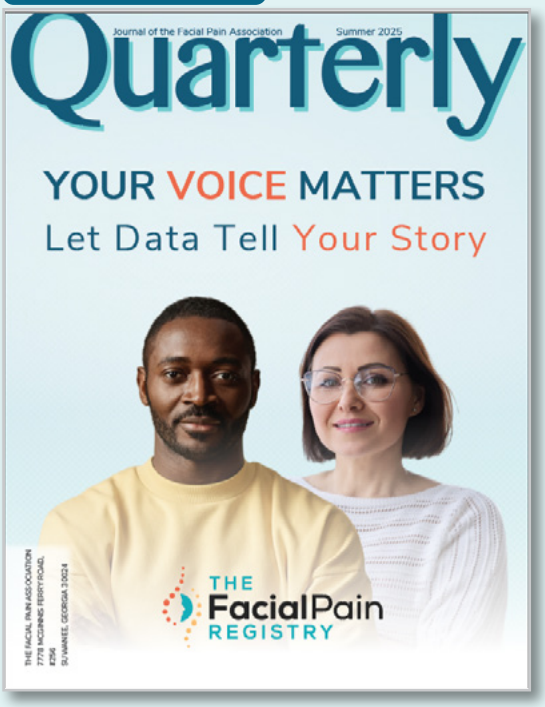
YOUR VOICE MATTERS

Let Data Tell Your Story

THE Facial Pain REGISTRY

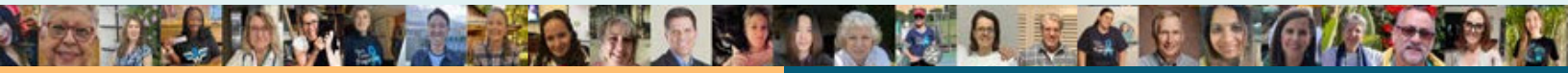
THE FACIAL PAIN ASSOCIATION
7778 MCGINNIS FERRY ROAD,
#256
SUWANEE, GEORGIA 30024

ON THE COVER



The Facial Pain Registry is now live as of June 11, 2025—a major step forward in advancing research and care – and our cover was designed to highlight this incredible accomplishment. This platform allows patients worldwide to amplify their voices and share information about their experience with neuropathic facial pain. Being a part of the registry helps support the facial pain community by providing researchers and healthcare providers with data to improve treatment options and care.

In this issue, our News You Can Use has an FAQ about the Registry, which covers basic questions one may have about participating. To participate in the registry or for more information about the Facial Pain Registry, please click button at left. ■



35 YEARS FacialPain Association

35k *in 35 days*

Thirty-five years ago, a handful of determined voices gathered around a kitchen table with one shared mission: to ensure no one facing facial pain would ever feel alone. That table ***sparked a movement***.

Today, the ***Facial Pain Association*** stands as a lifeline for thousands — offering answers when there are few, community in times of isolation, and a platform to push for better care, research, and understanding.

Now, ***we're inviting you*** to shape what comes next. As we celebrate our 35th anniversary, we're launching a challenge – to raise $35,000 in 35 days.

Your gift will fuel progress for the next 35 years, providing

Knowledge – expanding trusted, expert led education for patients and medical professionals.

Connection – Growing a national network of support that reminds everyone facing facial pain that you are not alone.

Change – Powering advocacy efforts to bring facial pain out of the shadows and onto the national stage.

We've come a long way from that kitchen table. But we're not done. The next chapter depends on you.

Help us build the future one day, one story, and one gift at a time. Give today.

Make a Gift

FPA 35th Anniversary Timeline

From the Board Chair

After years of hard work, the Facial Pain Registry is now live! On June 11, the Facial Pain Association (FPA) launched the registry in partnership with the National Organization for Rare Disorders (NORD®). The IAMRARE® platform allows patients from around the world to share their experiences and information about neuropathic facial pain.

A big thank you to the members of the Patient Registry Advisory Board: Dr. Raymond Sekula, Dr. Wolfgang Liedtke, Dr. Joanna Zakrzewska, Anne Ciemnecki, Melissa Baumbick, and the rest of the dedicated staff at the FPA.

This was no easy feat! Data from the Facial Pain Registry has the potential to help drive research forward, improve treatment, and advocate for better care. But we are nowhere near done. We need you. Your story and your data are key to fulfilling the registry's potential.

The Facial Pain Registry is designed to address the following objectives:

- Create an easy-to-use online platform for participants or caregivers to report their experiences with neuropathic facial pain.
- Build a contact list to notify eligible participants about research studies and clinical trials.
- Understand and describe the overall population affected by neuropathic facial pain.
- Support the neuropathic facial pain community in developing care recommendations and standards.
- Act as a resource for researchers working on retrospective, interventional, or prospective studies.
- Determine how neuropathic facial pain affects daily activities and mental health over time using reliable measures.
- Allow personalized healthcare through shared data that improves communication between participants and healthcare professionals.

Your participation is the key to fulfilling these objectives. Your data is key to our proactive advancement towards better treatment and healthcare.

We are rare. Neuropathic facial pain is rare. By participating in the registry and sharing your unique experiences through data, you play an important role in helping researchers, doctors, and policymakers gain a deeper understanding of the true impact of facial pain. This, in turn, paves the way for better outcomes.

We, those of us living with neuropathic facial pain, are the experts. Together, we can support one another and use the registry to make a significant difference in our lives. Your voice matters. Let data tell your story.

David Meyers
Board Chair, The Facial Pain Association

A Message From the CEO

What a busy and exciting few months the FPA has had! We've just returned from our first in-person conference in six years — it was an amazing event full of support, information, and the opportunity to connect with the facial pain community face-to-face. That was a first for me, and it was an unforgettable and incredible experience. We were joined by experts from our Medical Advisory Board and from the University of Minnesota, in addition to doctors from around the country – Mayo Clinic, University of Alabama at Birmingham, UNC Chapel Hill, University Hospitals in Cleveland, and Emory in Atlanta. The topics covered included everything from medications and surgical treatment to neuromodulation and mental health; geniculate and glossopharyngeal neuralgias to dentistry. It was an inspiring two days, and I hope you will consider joining us as we continue to think about future in-person events. We certainly understand the costs are just not tenable for some, so we plan to make the conference presentations available to everyone in the coming months. The online version will soon be available for purchase later this summer.

We also just launched our patient registry, an effort that has been in the works since I arrived at the FPA almost three years ago — and I understand that it was being worked on long before that! Participation in the Facial Pain Registry is an opportunity to tell your story through the data we collect. It is an opportunity to have your voice heard by answering questions in the surveys presented on the platform. We will continue to develop surveys on different aspects of living with facial pain — types of pain, treatment mechanisms, mental health and more, in an effort to capture your entire experience. We do hope you'll participate. We have partnered with the National Organization for Rare Diseases (NORD®), using their proven IAMRARE® platform, which offers a safe and protected repository for your health information. Please reach out to me directly if you have questions or concerns about participating in the registry.

As we collect important data from members of the facial pain community, we are already looking forward to the next step in the Facial Pain Registry, which is to analyze and distribute the information we collect. We want to inform the community about trends and new information that is discovered as well as provide a resource for scientists and medical professionals looking to do research in this area. Our hope is that we can publish articles and reports in future Quarterly journals that highlight trends based on the information being collected. We have a Registry Advisory Board in place to determine if and how the data is used by outside entities looking to do research.

We are also coming to the end of our fiscal year, which means that we are working on our annual strategic plan to determine the direction of the organization. We are reviewing current objectives and looking forward, figuring out how to best serve those in our community. In past years, we have published our annual report in the summer issue of the Quarterly journal. This year, in an effort to make sure funds are being used most effectively and benefiting the community directly, we have moved our annual reports online. You can find this year's annual report here: https://www.facepain.org/annual-reports/

With that said, our donors are critical to the work we do. Your generosity drives our ability to deliver programs like the in-person conference and the Facial Pain Registry to the community. We have educational resources, a strong volunteer program, the ability to support researchers in their work, the opportunity to influence policy through advocacy, a robust website, and programs to educate medical professionals about facial pain — all because of our donors. We are grateful for your generosity. You will still see all of our donors highlighted in the summer issue of the Quarterly, as we have always done. It is important that we recognize everyone who supports our mission and those who make everything we do possible. Those lists are still included in this issue.

Melissa Baumbick
Chief Executive Officer, The Facial Pain Association

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Quarterly

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The MAB Corner
Facial Pain Registry

Wolfgang Liedtke, MD, PhD

Dear members and supporters of the Facial Pain Association,

I'd like to give you my updated take on the Facial Pain Registry, which is coming along and out of the pipeline.

As stated previously, 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.

We made it through the initial launch of the registry. This platform will securely house deidentified 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. We will keep the link that connects the de-identified data to real people as safe as possible. We will use encryption and other tools to protect your sensitive information from unauthorized access. People who share their information can choose to opt out of the re-identification process. **Clinical phenotype** refers to the entire spectrum of clinical history relevant to the pain that you suffer. For example, 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 measurable data. 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, history of COVID, etc. There is power in numbers, and that is where the unique opportunity lies here.

Your data will be captured securely via the FPA website and mobile device app interface.

We have worked hard on this, and there should be no caveats if we continue to execute this correctly, leveraging the technology to all our advantage.

Outlook:

Existing general health patient repositories have been coupled with medical records and exploration of specific biospecimen, e.g. UK Biobank. This will be a future option and will benefit from generating even deeper experiences beyond the astounding success that has already been accomplished. Such 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 quantitative measurements of hundreds of proteins, with price tags going down with time (costs 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 de-identification principle that already guides the data entry.

What could come out of this?

Analyzing clinical phenotypic data, which we previously thought was impossible, can give us new insights into disease biology. This analysis can help correct misunderstandings we currently have and help plan follow-up studies. For example, we can ask for more details about the pain phenotype that we haven't explored yet, and we can gather and archive related MRI scans for certain cases.

We are excited to clearly see a beacon on this hill in the not-too-distant future: genome and serum proteome of a large cohort of trigeminal nerve pain/oro-cranio-facial pain patients. I keep saying "beacon on the hill" because this approach has truly transformative power for getting things done in the pain arena that were unthinkable not that long ago.

This is from my perch as an industrial therapeutics developer, previously having enjoyed decades of working together with my patients as academic medicine physician and clinical developer, 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 continue to share your thoughts with the FPA at info@facepain.org as we put the finishing touches on the Facial Pain Registry. ■

My very best to all of you,

Wolfgang Liedtke, MD, PhD
Neurologist
Facial Pain Association Medical Advisory Board

Facial Pain Registry

Read the FPA's June 11 press release to learn more

Opinions expressed here do not represent the view of Anavex, nor of his academic affiliates, Duke University and New York University College of Dentistry.

Geniculate Neuralgia — Shooting Pain in the Ear

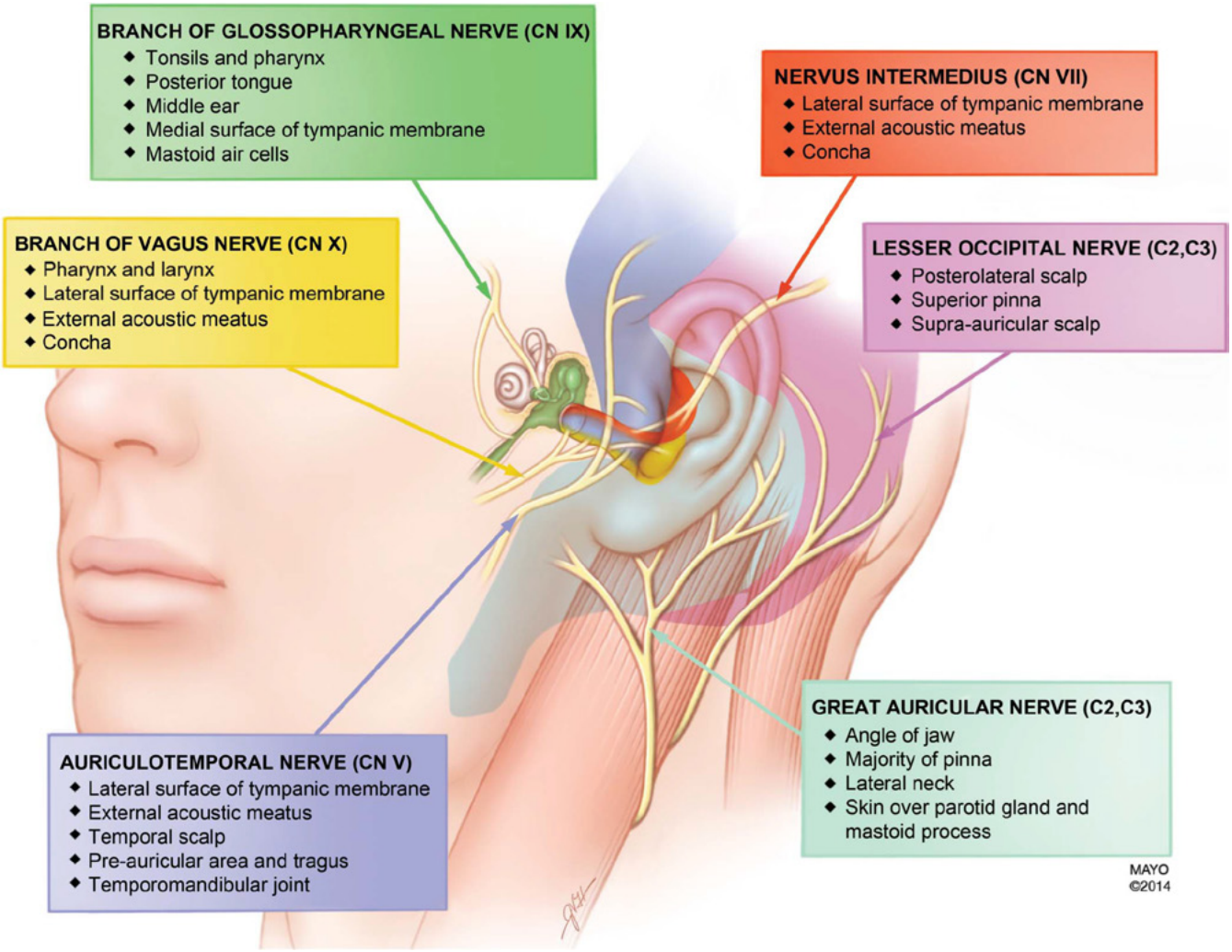
Konstantin Slavin, MD, FAANS
Department Of Neurosurgery,
University Of Illinois At Chicago

One of the most important elements in making the correct diagnosis in patients with facial pain is the precise determination of the pain's location. Facial sensation comes from multiple nerves that overlap in their areas. However, some specific areas are primarily linked to specific nerves and branches. And just as the upper lip location of the trigger points suggest involvement of the maxillary nerve and the pain in the region of the root of the tongue and the tonsil – of the glossopharyngeal nerve, the pain that focuses inside the ear canal tends to point toward the intermediate nerve (nervus intermedius) that is the culprit of so called geniculate neuralgia, also known as the nervus intermedius neuralgia.

The nervus intermedius, sometimes called the 13th cranial nerve, is a very small structure that travels along the seventh (facial) and eighth (vestibulocochlear) nerves from the brainstem toward an opening in the petrous bone, the porus acousticus. The facial nerve is a predominantly motor nerve; its main function is the control of facial muscles on one side of the person's face. As opposed to the motor portion of the trigeminal nerve that controls the muscles of mastication (chewing), the facial nerve is in charge of the muscles that move the face, close the eye, make person smile, etc.; when the nerve is damaged, the patient exhibits facial palsy (as in Bell's palsy), and when it is irritated, one side of the face twitches (hemifacial spasm).

The vestibulocochlear nerve carries information from the inner ear; the cochlear part is responsible for hearing (acoustic sensation) and the vestibular part is balance. Injury to the cochlear portion of the eighth nerve would produce loss of hearing / one-sided deafness; its irritation may result in tinnitus (ringing in the ear). Vestibular nerve damage may not be very noticeable if only one side is involved, but the nerve irritation may cause vertigo and dizziness. All this information becomes relevant in the context of geniculate neuralgia as the surgery on the nervus intermedius involves dissection and manipulation of the seventh/eighth cranial nerve complex.

In some cases, the diagnosis of geniculate neuralgia is quite straight forward, especially if the shooting pain stays exclusively inside the ear canal. More often, however, the pain spreads to the earlobe and the



Depiction of the sensory nerves shows the innervation of the ear and surrounding anatomy. Each box with its corresponding color illustrates each nerve's distribution. Sensory distributions may overlap. Illustration by John Hagen, Mayo medical illustrator.

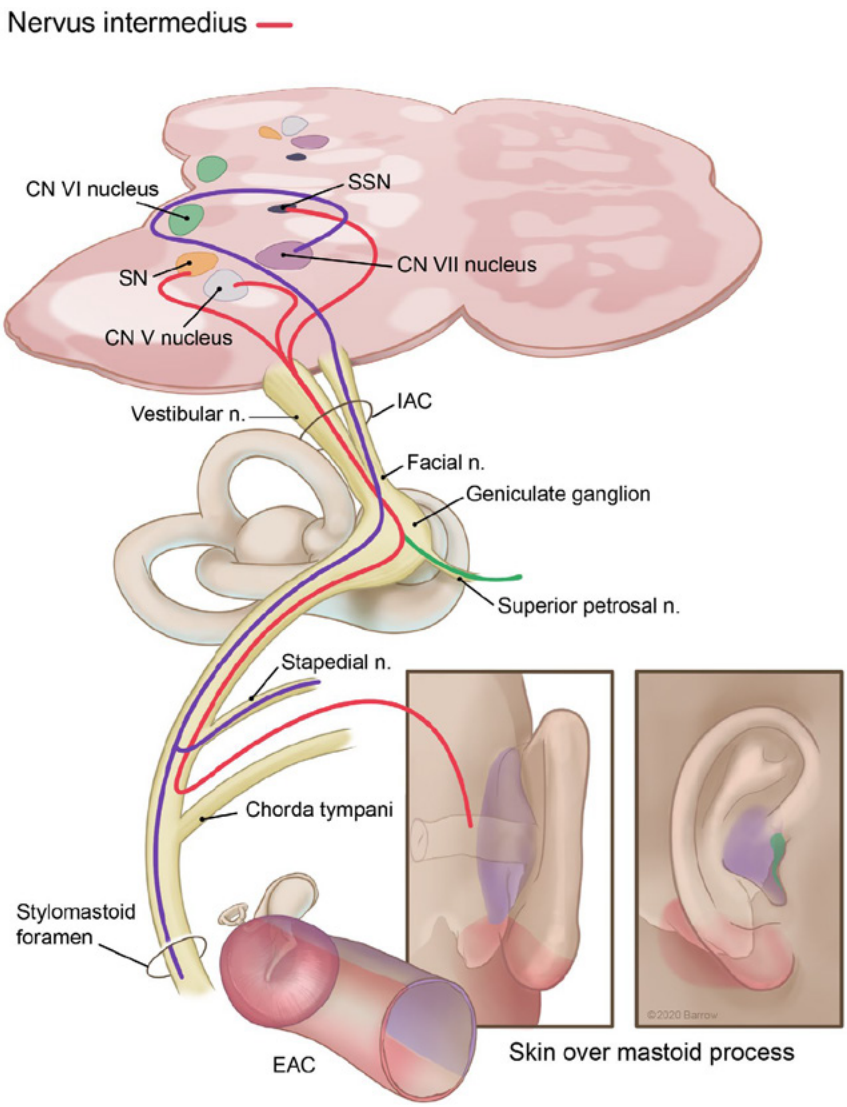
areas around the ear, and then clinician has to decide if the pain location suggests involvement of other cranial nerves, including trigeminal, glossopharyngeal, vagus, etc., or if it stems from adjacent anatomical structures such as temporomandibular joint, the earlobe itself, middle ear contents, and so forth.

For this reason, the physical examination by a qualified specialist becomes important. Sometimes an evaluation by doctors of multiple backgrounds (otolaryngology, oral surgery, neurology) is needed to establish the correct diagnosis and rule out other possible pain sources, each of which would require different treatment. Interestingly, imaging tends to be normal in patients with geniculate neuralgia, although it is not uncommon to discover vascular contact or even compression of cranial nerves that may or may not be in any way connected to the pain's origination.

In the past, the International Headache Society included well-defined criteria for geniculate neuralgia in its International Classification of Headache Disorders (ICHD). The current, 3rd edition of this classification [1] divides all cases of pain attributed to a lesion or disease of nervus intermedius into several categories, including the classical (caused by vascular compression), secondary (due to a tumor or multiple sclerosis) or idiopathic (no evidence of compression or other identifiable causes) types of nervus intermedius neuralgia. To qualify for geniculate neuralgia according to ICHD-3 classification, the patient should be experiencing "brief paroxysms (intermittent or sporadic) of pain felt deeply in the auditory canal, sometimes radiating to the parieto-occipital region (near the back of your head, where the top and back parts of your brain meet)."

"Geniculate Neuralgia" continued on page 8

"Geniculate Neuralgia" continued from page 7



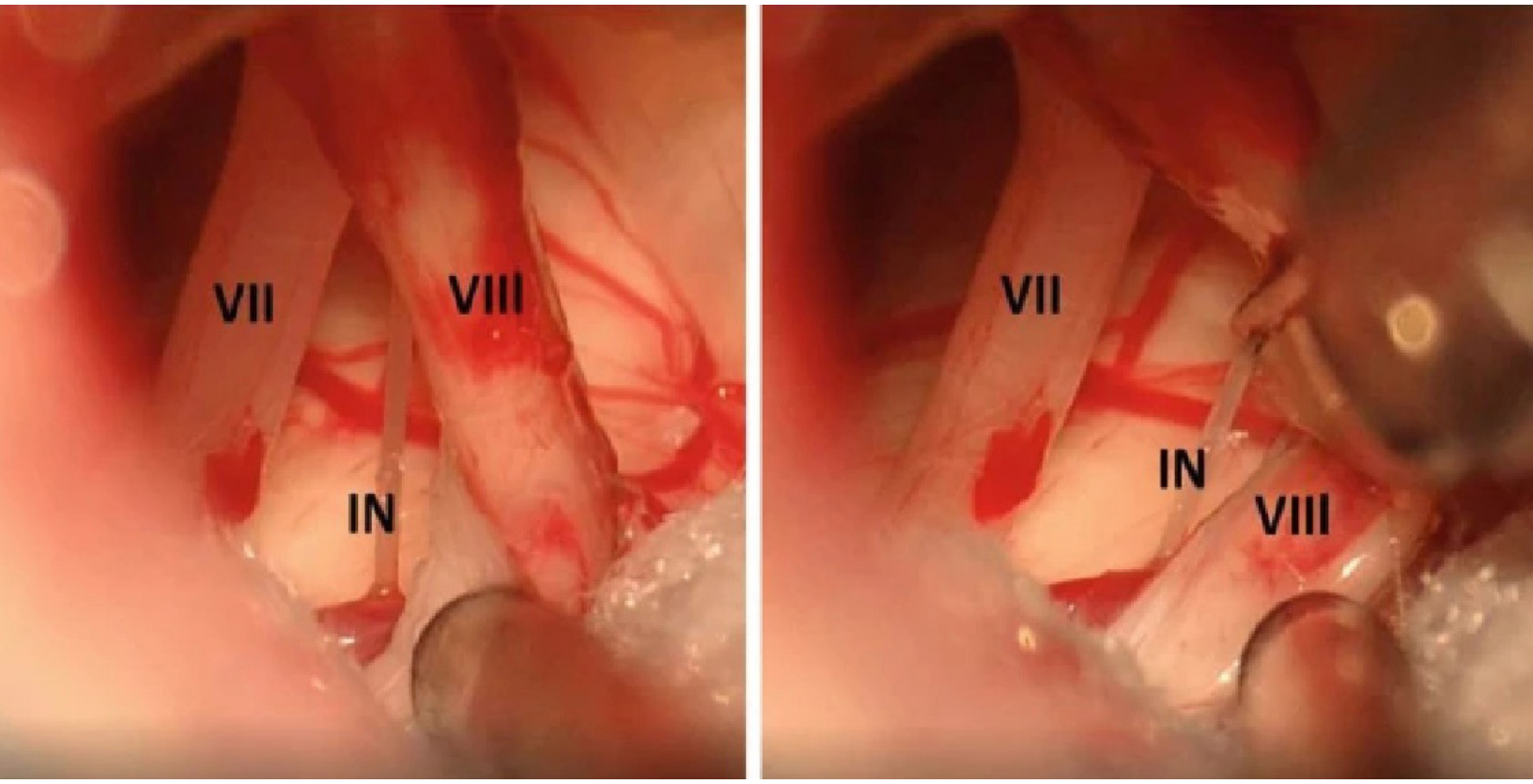
Neuroanatomy of the nervus intermedius, showing the nervus intermedius (red line) and the distribution of its sensory innervation (red shading), the facial nerve (purple line) and the distribution of its sensory innervation (purple shading), and the superior petrosal nerve (green line) and the distribution of its sensory innervation (green shading). CN, cranial nerve; EAC, external auditory canal; IAC, internal auditory canal; n, nerve; SN, solitary nucleus; SSN, superior salivatory nucleus.

The diagnostic criteria specifically describe recurring pain that occurs in paroxysmal attacks lasting from a few seconds to a few minutes. This pain is characterized by its severe intensity and can feel shooting, stabbing, or sharp. Additionally, there is usually a trigger zone located in the posterior wall of the auditory canal or the periauricular region (area around your outer ear).

The classification also distinguishes geniculate neuralgia from painful nervus intermedius neuropathy. Unlike the intermittent pain of neuralgia, this neuropathy involves continuous or near-continuous pain that is dull and felt deep within the ear.

This condition may arise in cases of herpes zoster, which can occur after a herpetic infection (known as post-herpetic nervus intermedius neuralgia), result from a tumor or injury, or appear without any identifiable cause.

When I talk to my suspected geniculate neuralgia patients about the pain location and try to explain involvement of the neighboring nerves, I frequently refer them to the excellent illustrations from our colleagues at Mayo Clinic in Minnesota [2] or Barrow Neurological Institute in Arizona [3] shown here in this article.



Intraoperative view of dissection (left) and transection (right) of the nervus intermedius (IN) as it travels between the facial (VII) and vestibulocochlear (VIII) nerves. (From ref. 4, https://link.springer.com/chapter/10.1007/978-981-96-0767-9_14, courtesy prof. D.A. Rzaev)

When it comes to the treatment of geniculate neuralgia, conventional wisdom dictates ruling out treatable causes and addressing them to eliminate the pain; this is particularly relevant for cases of secondary geniculate neuralgia. As with any other types of facial pain, the surgery for patients with geniculate neuralgia is reserved only for those who fail to improve with non-surgical modalities, including medications, interventional treatments (such as nerve blocks), alternative approaches (including acupuncture), etc. and are truly impacted by their pain in terms of quality of life and ability to function.

In the neurosurgical practice, most patients have already tried and failed most or all of the available treatments, and therefore our discussions usually focus on confirming the diagnosis, ruling out other conditions with similar presentations and differentiating neuralgia from neuropathy. After that, the patient may be offered surgical options and presented with descriptions of surgical details, risks and potential complications. This allows our patients to weigh all the pros and cons of surgical treatment and make an informed decision on whether to proceed with surgery as the next step.

Needless to say, the surgeon's preference is usually to avoid any kind of destruction and relieve the patient's pain by simply eliminating the source of pain. However, even in those cases where vascular compression of the nervus intermedius may explain the pain, resolving the situation by microvascular decompression – as we do in most patients with trigeminal neuralgia and hemifacial spasm – may be quite challenging, for many reasons. This is why more often surgeons would consider cutting the nerve root (so called rhizotomy) to permanently cure the geniculate neuralgia. The procedure is done through a small skin incision behind the ear on the side of pain; it is done under general anesthesia with the help of a surgical microscope, special cranial nerve monitoring, and dedicated microsurgical instruments [4]. Most patients are kept in a hospital for a day or two after the surgery, and the sutures or staples are removed two weeks after the operation during the clinic visit.

"Geniculate Neuralgia" continued on page 10

"Geniculate Neuralgia" continued from page 9

Multiple surgical series reviewed the results of operative treatment of geniculate neuralgia. The consensus, based on decades of experience and many professional publications, is that most patients benefit from their surgeries. More than 90% of patients report either complete resolution or significant improvement of pain due to geniculate neuralgia after their surgery, and the results tend to be long-lasting and consistent among many reporting centers all over the world. Interestingly, some patients who had successful treatment needed help with more than one nerve causing their pain. Because of how their pain was spread out, doctors had to treat multiple nerves at the same time during surgery — combining rhizotomy on the nervus intermedius, with related intervention on either the trigeminal nerve or the glossopharyngeal / vagus nerves.

Based on these excellent results, one may state that there is a definite hope for people who continue to manage the pain associated with geniculate neuralgia, and if the severe pain inside the ear canal becomes disabling and does not respond to conventional treatments, surgery is a consideration. The risks of surgery should not be downplayed or ignored, but the risk of complications should be weighed against the potential benefits of surgery, especially if it is done by an experienced surgical team that specializes in management of complex facial pain patients. ■

Learn more about geniculate neuralgia

Geniculate Neuralgia Support Group:
Contact Leader Jeff Fogel
215-651-2861
docfog4308@yahoo.com

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Depiction of the sensory nerves shows the innervation of the ear and surrounding anatomy. Each box with its corresponding color illustrates each nerve's distribution. Sensory distributions may overlap. Illustration by John Hagen, Mayo medical illustrator. (From ref. 2, https://www.neurology.org/doi/pdfdirect/10.1212/WNL.0000000000000893, courtesy of Mayo Foundation for Medical Education and Research)

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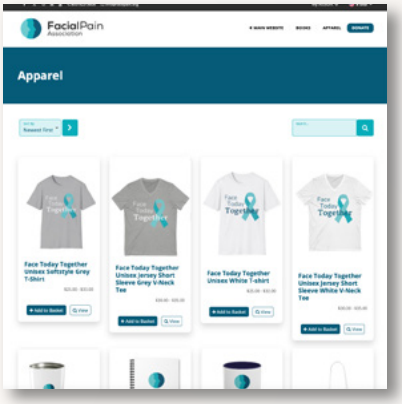
Intraoperative view of dissection (left) and transection (right) of the nervus intermedius (IN) as it travels between the facial (VII) and vestibulocochlear (VIII) nerves. (From ref. 4, https://link.springer.com/chapter/10.1007/978-981-96-0767-9_14, courtesy prof. D.A. Rzaev)

Website Updates

To better accommodate and simplify how to do research on our website, the FPA has been adding updates to improve your experience. By simplifying our navigation bar and improving our search capabilities, adjusting content so it is concise and easy to understand, and adding more relevant/quality content, we have created a more robust website that is easier to navigate. We added an online chat bot system to speed the process of finding the content that you need This system will also offer the opportunity to chat with volunteers during our Holiday Help Line dates and times. We have improved and added new pages. Here are some highlights below:

There are now three ways to connect with a Peer Mentor: in addition to calling or emailing the FPA you can connect directly by using new search tools on our website. Members of the facial pain community can search for support using areas of common interest and other relevant characteristics. The new website tool can generate an email pre-populated with the volunteer's email address along with a standard subject line identifying the contact as coming from the FPA. Volunteers can respond and share additional contact information at their discretion.

The international page aims to assist individuals outside the United States in establishing and developing a supportive facial pain community in their region. We provide resources, guidance, and connections to help people create local networks. By fostering communication and collaboration, we hope to empower those affected by facial pain overseas to connect with others, share coping strategies, and promote awareness of this often-misunderstood condition. Together, we can create a compassionate and informed community that addresses the challenges of living with facial pain.



The online shop is where you can purchase FPA books, merchandise, and event tickets. You can add donations to your purchases if you choose to do so. The online shop requires the user to create an account.

Ena Bromley, MD

Behind the Numbers:

How Data Can Change the Future for People Living with Facial Pain

When you take the time to complete the Facial Pain Registry, you are doing far more than entering symptoms into a form – you are helping shape the future of care, research, and understanding for everyone in our community.

Launched in partnership with the National Organization for Rare Disorders (NORD®)'s IAMRARE® Program, the Facial Pain Registry is a bold step forward in capturing the real-world impact of living with facial pain. But once the data is entered, what comes next? How do we transform thousands of data points about lived experience into something that drives change?

To help answer this question, we have partnered with Oyanalytika, a data analytics firm with a mission grounded in both expertise and empathy. I recently sat down with Dr. Ena Bromley, their co-founder and CEO, who brings not only deep knowledge as a statistical geneticist and genetic epidemiologist, but also personal insight as someone directly impacted by facial pain. I first met Ena during Headache on the Hill in Washington, D.C., and together, we serve on the Alliance for Headache Disorders Advocacy Policy Committee advocating for the headache disorder community.

I asked Ena to help lift the veil on what happens behind the scenes and how the stories behind the numbers can fuel progress for the facial pain community and I am excited to share our conversation with you.

Interview with Dr. Ena Bromley, CEO of Oyanalytika

by Brandi Underwood

1. Why does data matter in our efforts to improve care for people with facial pain?

Data is our collective voice, quantified. For a long time, facial pain has lived in the shadows of medicine. It was misunderstood, misdiagnosed, and underfunded. When we gather and organize patient-reported data, we're building sound evidence that researchers, clinicians, and policymakers need to take us seriously. It's how we move from anecdote to action. Data allows us to tell a cohesive, credible story about what patients are really experiencing—and how care can and must improve.

2. What happens to the information once someone enters their data into the Facial Pain Registry?

Once data is entered, it's securely stored and de-identified to protect patient privacy. From there, our team at Oyanalytika works with the Facial Pain Association to clean, standardize, and analyze that information. We use statistical and machine learning tools to look for trends—things like time to diagnosis, treatment responses, or common comorbidities. The goal is to turn individual data points into shared knowledge that can inform better clinical practice, guide research priorities, and support advocacy.

3. When you look at patient-entered data, what kinds of stories are you hoping to uncover?

I'm looking for patterns that reflect what patients have known all along but haven't had the tools to prove—stories of delayed diagnosis, ineffective treatments, or journeys marked by resilience and trial-and-error. We want to uncover subgroups that might respond differently to certain therapies or share similar symptom clusters. Most of all, we're listening for the common threads that unite this community across geography, diagnosis, and time.

4. What can we learn from patterns in the data that individual patients or clinicians might not see on their own?

A clinician sees a handful of patients at a time. A patient knows their own story in intimate detail. But when we zoom out with the registry, we can start to see broader signals—like which symptoms are most predictive of diagnosis, how long patients typically wait for effective treatment, or which treatments have high dropout rates. These patterns can guide everything from clinical decision-making to drug development strategies.

5. How can the registry help us advocate more effectively for research funding or policy change?

Policymakers and funders respond to data—especially when it's well-structured and humanized. The registry provides both the statistics and the real-world context that make a compelling case for investment in research, treatment development, and healthcare access. It helps us say not just *"people are suffering,"* but *"here's how many, here's what it looks like, and here's where the gaps are."* That's powerful.

6. Facial pain can be incredibly isolating. How does seeing data from hundreds or potentially thousands of patients begin to change that narrative?

It shows people they're not alone. There's immense validation in realizing your experience isn't unique or inexplicable—it's part of a broader pattern. Data has the power to connect, to affirm, and to destigmatize. For many patients, simply knowing that others have walked a similar path can be a turning point in how they see themselves and their condition.

"Behind the Numbers" continued on page 14

"Behind the Numbers" continued from page 13

7. For people who feel like their story has never been heard, how can data help amplify their voice?

Every entry in the registry is a voice added to the chorus. When those voices come together in structured data, they become impossible to ignore. They shape research questions, change treatment guidelines, and influence health policy. For someone who's felt invisible in the system, contributing to the registry is an act of reclaiming agency—and knowing your experience could help someone else in the future.

8. How do you balance the technical aspects of analysis with the deeply personal nature of what this data represents?

With deep respect. Behind every data point is a person—a story, a struggle, a hope. As analysts, we bring rigor to the process, but we never forget the humanity in the numbers. Our team at Oyanalytika was founded on the principle that empathy and expertise must go hand in hand. Every model we build, every pattern we analyze, is done with the understanding that it represents real lives, and real suffering—and hopefully, real solutions.

9. Looking ahead, what excites you most about the potential of this registry to create meaningful change?

I'm excited by the possibility of precision care for facial pain—of moving beyond trial-and-error medicine to treatments that are tailored to subtypes, genetics, and individual needs. I'm also deeply inspired by the idea of building a lasting foundation for research—something future scientists can build on. But most of all, I'm excited for patients to feel seen, supported, and empowered. This registry isn't just about data—it's about dignity.

The stories shared through the Facial Pain Registry have the power to change what's possible — for research, for care, and for how facial pain conditions are understood. Thanks to Dr. Bromley and Oyanalytika, we are beginning to connect the dots in ways that can lead to real progress. Every person who adds their voice is helping to create a clearer picture of life with facial pain. Thank you for being part of this important work. ■



2025 FPA In-Person Conference Recap

The 2025 FPA Annual In-Person Conference was a resounding success! On June 7 and 8, the facial pain community came together to provide patients and healthcare professionals with opportunities to connect, share knowledge, and build stronger relationships. We had over 130 participants and 25 volunteers in attendance. Volunteers, several of whom brought their partners, came from as far away as Hawaii, British Columbia and Texas to attend.

"It was an incredible privilege to be in the room with so many members of the facial pain community—to hear their stories, listen to their questions, and witness the powerful connections being formed as they supported one another," said Melissa Baumbick, CEO of the Facial Pain Association. "The experience was truly moving. It was equally inspiring to watch the physicians collaborate so thoughtfully with each other and engage so compassionately with patients. Their attentiveness, kindness, and genuine investment created an atmosphere of learning, support, and community unlike anything I've ever experienced."

Attendees had the option to choose between two presentation tracks, which offered foundational information about neuropathic facial pain as well as the latest innovations, treatments, and technologies for managing this condition. This approach emphasized the importance of multidisciplinary care. Furthermore, patients had the invaluable opportunity to engage in meaningful conversations with healthcare professionals outside of the presentations, enhancing their understanding and connections. ■

"The power of multi-disciplinary care was front and center at the FPA's first in-person meeting in over six years—and the impact was undeniable. Attendees had the rare opportunity to see, firsthand, the benefits of collaboration across specialties, not just in theory but in practice. One of the most meaningful aspects of the event was the direct, unfiltered access patients had to the experts—an exchange that went both ways. While patients gained insights and understanding, clinicians were equally moved by the chance to connect with peers from across the country and hear real-time feedback from those living with facial pain every day. That kind of dialogue doesn't happen often—and it was truly transformational for everyone involved."

— Donald Nixdorf, DDS, MS




A big THANK YOU to everyone who participated, including:

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Jack Botros, DDS, MS
Nicholas Boulis, MD
Ena Bromley, MD
Anne Ciemnecki
Jeannine Conway, PharmD
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Most of all, we are grateful for you, our attendees, who inspire us to continue to serve. The mission of the Facial Pain Association is to provide support, education, and advocacy to all who live with facial pain, and this conference was a convergence of these efforts.

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Your story. Your values.
Leave a Legacy with the Facial Pain Association.

Our Legacy Society members are an instrumental group of supporters who have included a gift to FPA in their estate planning.

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If you would like more information on joining the FPA Legacy Society, please call 800-923-3608 or email development@facepain.org.

FacialPain Association | Sustainer Circle

The Sustainer Circle is an incredible community of monthly givers who help ensure that FPA meets our mission of support, education, and advocacy of the facial pain community.

Jerry Adkins
Nicole Aiken
Melissa Baumbick
Joan Beelen
Carol Bender
Carol Berardi
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MAYO
CLINIC
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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Returning You to Your Fullest Life.

The UPMC Neurological Institute, based in Pittsburgh, provides comprehensive, compassionate care to patients from across our region and around the world. We take pride in our reputation for innovative, high-quality patient care and honored to provide that care to our patients.

Watch "Facing the Facts: Managing Trigeminal Neuralgia & Hemifacial Spasm," a virtual lecture presented by Dr. Georgios Zenonos, director of the Center for Cranial Nerve Disorders at the UPMC Neurological Institute.

Learn more about UPMC's approach to the diagnosis and treatment of patients with trigeminal neuralgia and hemifacial spasm.

UPMC | NEUROLOGICAL INSTITUTE

SPONSOR SPOTLIGHT

Libra
Trigeminal Neuralgia

Thank You!

The Libra Study team at Noema Pharma would like to take this opportunity to thank the staff and members of the FPA for their continued support over the past 4 years of partnership.

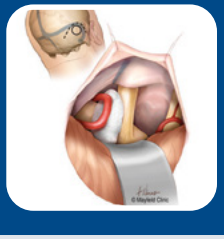
MAYFIELD
Brain & Spine

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

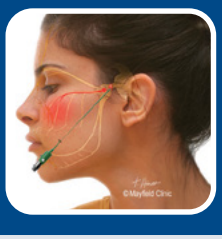
Our treatments include:

Gamma Knife radiosurgery

Microvascular decompression surgery (MVD)

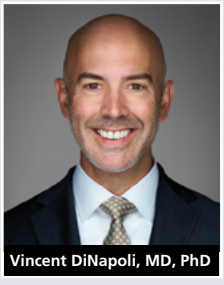


Percutaneous stereotactic rhizotomy (PSR)



Mayfield's Nationally Recognized Trigeminal Experts


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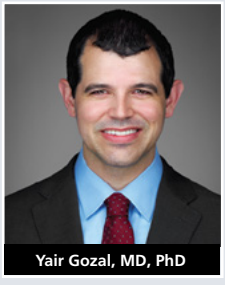
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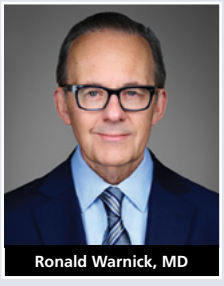
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For more information, visit **mayfieldclinic.com/trigeminal** or call **513-221-1100** to make an appointment.

YOUR VOICE MATTERS

Let Data Tell Your Story

THE FacialPain REGISTRY

Learn More about the Facial Pain Registry

What is the purpose of the Facial Pain Registry?

The purpose of the Facial Pain Registry is to bring the facial pain community together and collect data. By contributing their stories, participants play a crucial role in helping researchers, doctors, and policymakers gain deeper insights into the true impact of facial pain, ultimately paving the way for better outcomes.

Goals of the Facial Pain Registry:

- To describe the people who have neuropathic facial pain and to better understand the stages of the conditions and the different ways they affect people. To do this, we will ask about symptoms, diagnosis, treatment, medical history, social and economic environment, and treatment outcomes.
- To understand how neuropathic facial pain changes over a person's lifetime and to learn about clinical practice patterns and variations over the course of treatment.
- To help to develop best practices, management guidelines and recommendations so that clinicians can know how to give the best care to improve the quality of life and outcomes of people with facial pain.
- To identify people with facial pain who might be willing to take part in other research studies or clinical trials. You will be able to choose whether you want to hear about these other studies.

What is a Patient Registry?

A patient registry is a collection of standardized information about a group of patients who share a condition. The information may be used for a variety of purposes such as conducting natural history studies and supporting disease specific clinical trial recruitment.

How is the data collected?

Data is collected through a secure web-based application (that can be accessed by computer, tablet or phone) developed by the National Organization for Rare Disorders, Inc. (NORD®). Study participants respond to questions grouped within a series of surveys developed per study standards and in collaboration with disease specific experts.

YOUR VOICE MATTERS

Let Data Tell Your Story

THE FacialPain REGISTRY

Learn More about the Facial Pain Registry

What types of data will be collected in the Facial Pain Registry?

The data collected includes but is not limited to:

1. Socio-demographics
2. Medical and diagnostics
3. Treatment and disease progression
4. Management of care
5. Quality of life

Who can join the study?

This study is open to anyone who lives with neuropathic facial pain and meets the study inclusion criteria for participation. Our study will include all forms of craniofacial neuropathic pain, including, but not limited to trigeminal neuralgia, geniculate neuralgia, glossopharyngeal neuralgia, occipital neuralgia, anesthesia dolorosa, burning mouth syndrome, post-herpetic neuralgia, and persistent idiopathic facial pain. People with headache disorders or facial pain experiencing symptoms that overlap or co-occur with cranial neuralgias including but not limited to trigeminal autonomic cephalalgias, temporomandibular disorder, and migraine with accompanying facial pain may participate in the study.

Is there a cost to participate?

There is no cost to the patient to join this study.

How long will this study last?

A registry on the IAMRARE® platform will typically be open for **at least** five years with the option to extend beyond that time. Participants will be asked to return to the registry periodically to update their information.