

Quarterly

Special Edition Includes the 2022 Annual Report



The Facial Pain Association
7778 McGinnis Ferry Road, #256
Suwanee, Georgia 30024

It Takes All of Us



From the Board Chair

Enduring Benefits

I am happy to report that we have had a very successful year reaching our goals to strengthen how we support you and other community members.

Why should this be important to you? Each year we work to create an organization that is helpful and valuable to you now and in the future, or until you no longer need our support.

Accomplishing these goals has an enduring impact on the FPA – in a way, they create a legacy for years to come. Take a look at these FPA initiatives:

- **Dentist Initiative:** Over 100,000 dentists (around one half of all U.S. dentists) have been informed about trigeminal neuralgia (TN) multiple times this year. Their new knowledge will help ensure that those of us with TN and other forms of neuropathic facial pain will not have to endure unnecessary dental procedures.
- **2023 Virtual Conference:** The presentations by world-leading experts at April's virtual conference will serve our community members for years to come. In addition to the 800+ people who attended this conference, hundreds or even thousands more will benefit from the presentation recordings in the future.
- **Research Assistance:** Some of the eight research projects at major healthcare institutions and pharmaceutical companies that the FPA supported this past year by providing information and recruiting clinical trial participants will undoubtedly result in new medical solutions for us in coming years...hopefully, sooner than later.

- **Patient Registry:** We hope to launch in the coming year. The FPA is ready to enroll thousands of people in a patient registry that can be easily accessed and used by researchers developing new medications and other medical solutions to more effectively address neuropathic facial pain.
- **Enhanced Mobile Website:** We know that many people first access our website from a mobile device, and that other people only have access to a mobile device. So, we are completing an important effort to make this experience easier and more valuable.
- **Filling Information Gaps:** Each year, the FPA identifies existing information gaps and then works to fill those gaps by finding relevant research and/or talking with the relevant experts. Arguably, the most important asset the FPA has is information to help people like you, so we continue to expand and strengthen our educational resources which will be used for many years.

Many of you contribute your time and/or money to the FPA each year. I hope you can see that your contributions are turned into both immediate benefits for our community as well as benefits that will be realized by those who need them in the future. We work to leverage your generous contributions in ways that will have the greatest impact for people like us with neuropathic facial pain. You should take great satisfaction in knowing that your gifts “keep on giving.”



David Meyers
Board Chair
The Facial Pain Association

A Message From the CEO

It takes all of us

As we reflect on the past year and share the FPA's 2022 Annual Report, it seems appropriate to look back at the path we've traveled together and what we have achieved. As I write this, I am finalizing our 2023-2024 strategic plan, working with members of our Board of Directors and staff to determine our path forward. One thing is clear to me – **it truly takes all of us** to succeed in our mission.

The Facial Pain Association is the great connector. We connect people living with facial pain to resources – educational materials, lists of health care professionals who understand and treat facial pain, and other people living in similar situations. We also connect researchers with people interested in participating in their studies. We connect the facial pain community with the latest information available, becoming a trusted and reliable resource for those trying to manage pain and live their lives to the fullest. We couldn't do any of this without you: our volunteers, including our Board of Directors, who are the backbone of our organization; our medical advisors and partners, who provide reliable medical information and updates; our staff, who work behind the scenes making everything happen; members of the community who open their hearts and share their stories; and last, but certainly not least, our generous donors, who support all these efforts. **It takes all of us.**

In 2022, we reached over 100,000 dentists in our effort to educate these professionals about neuropathic facial pain. Over half of the facial pain population undergoes unnecessary dental procedures before getting the correct diagnosis. We are trying to reduce that number and equip dental professionals with the knowledge they need to identify facial pain and understand their next steps. This effort has included our Medical Advisory Board (MAB), the dental community, and partnerships with organizations focused on orofacial pain to make progress. **It takes all of us** and we will continue this work to ensure that patients are identified, and the unnecessary procedures stop.



Our patient registry is almost ready to launch and will provide the opportunity to leave a legacy through your participation – the opportunity to tell your story. **This effort will take all of us.** Members of our MAB and researchers from around the world worked together to create and evaluate effective questionnaires. Our Board Secretary, Anne Ciemnecki, also a retired survey methodologist and third generation woman with facial pain, is working with other researchers to determine what we need to know, how we gather the information and how it is analyzed so it is useful in studies and to the facial pain community. And you – we need your participation to feed the registry. You hold the key to our success and our ability to find trends, affect public policy, support research, and change the face of facial pain.

Looking forward, we will continue our efforts to reach EVERYONE living with facial pain. Our greatest resource is our connections – to reliable information and educational materials, to the research and medical communities, and to you – the facial pain community. We will use those connections to ensure our mission aligns with your needs. We are updating the mobile experience on our website, allowing for increased accessibility to younger populations and underserved communities. We are translating existing resources so we can reach non-English speakers. We are supporting research with the hope that new drugs and treatments will be discovered. We want to educate neurologists, using successful strategies from our Dentist Initiative. These are just a few things we have planned as we move through 2023 into 2024.

What do you want to see? What would you like to know? Please contact me – I am here for you, our staff is here for you, and this organization is here for you.

It takes all of us. ■

A handwritten signature in blue ink that reads "Melissa Baumbick".

Melissa Baumbick

Chief Executive Officer, The Facial Pain Association

Leadership

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Derek Steinbacher,
DMD, MD



John M. Tew, Jr., MD



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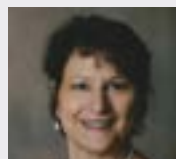


Richard S. Zimmerman, MD

Facial Pain Association Staff



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Officer



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Database & Volunteer
Coordinator



Christina McCurdy
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Brandi Underwood
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Lindsey Wallace
Co-Chair



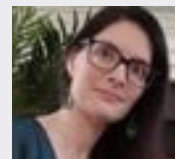
Kenzie Winslow
Co-Chair



Ellie Eichenlaub



Elaina Jackson



Laura Launderville



Rachel Triay

We Are the Facial Pain Association

2022 Annual Report



Mission

Our mission is to serve those with neuropathic facial pain, including trigeminal neuralgia, through support, education, and advocacy.

Who We Are

The Facial Pain Association is the largest patient organization supporting all people affected by neuropathic facial pain, leading the world in resources for information and healthcare guidance. Through programs of education, personal support, and advocacy efforts, the FPA supports patients, their loved ones and caregivers, and healthcare professionals who diagnose and treat people affected by facial pain.

The FPA is volunteer-led and community-focused. Guiding the FPA is a volunteer Board of Directors and a Medical Advisory Board which is composed of experts in neurosurgery, neuroscience, pain management, dentistry, and mental health.

What We Do

We provide personalized support:

Support Group Leaders offer a forum for those in the facial pain community to experience an encouraging, sympathetic group in person, virtually, or in hybrid format.

Peer Mentors offer one-on-one support by sharing their experiences and lending a compassionate ear by phone or email.

Social Media Ambassadors use their voice on various platforms to actively and positively promote what the FPA means to them.

Special Projects Volunteers provide their expertise to assist with projects such as: translating materials, patient advocacy, patient research advisory panels, and social media moderation.

We provide education:

FacePain.org includes the latest information on seeking and receiving a diagnosis, symptoms, treatment options, pain management, medication, mental health, doctor, and medical center information. Our website houses a library of educational webinars, medical articles, and links to a variety of additional helpful resources.

Webinars, Quarterly journals, and Bulletin updates provide ongoing information from medical professionals, event notifications, research updates, and more.

We promote patient advocacy:

The FPA is dedicated to creating a community that fosters collaboration through outreach to the medical community and supporting research efforts.

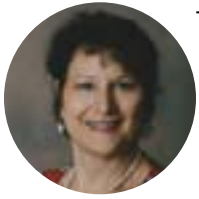
The FPA Young Patients Committee (YPC) recognizes the unique issues faced by people under age 40. The YPC gives a voice to younger patients and raises awareness that neuropathic facial pain does not only affect older adults. The YPC maintains an active Facebook Page, Facebook Group, and accounts on Twitter, Instagram, YouTube, and LinkedIn.

It Takes All of Us to Make a Difference

The 2022 Annual Report is a reflection of you, our incredible community, and how you made a difference through giving your time, raising awareness, learning together, working together, and investing in the facial pain community. It Takes All of Us—including YOU!

It Takes All of Us Giving Our Time

FPA Volunteers



The Facial Pain Association could not do what we do without the dedicated group of volunteers who serve as Support Group Leaders, Peer Mentors, Young Patients Committee members, and on a variety of ongoing and short-term projects,

including conference support, the holiday helpline, and literature review. FPA Volunteers either live with facial pain themselves or are caregivers or family members. They are from 31 US States, Canada, the UK, and Brazil. Volunteers provide support by drawing on their own experiences, as well as training provided by the FPA.

We welcome volunteers from varied backgrounds, life experiences, and medical histories.

No specific skills, educational background, or experience is required to serve as an FPA Volunteer.

FPA Volunteers:

- Help others feel less alone.
- Help the organization reach as many people living with facial pain as possible.
- Build a support network.
- Find a sense of accomplishment.

If you are interested in volunteering with the FPA, contact Regina Gore, Volunteer Coordinator at rgore@facepain.org or call us at 800-923-3608 for more information. ■



Scan this QR code or click here for a special message about volunteering with the FPA.

FPA Volunteer Roles Key

| | |
|-----|--------------------------------|
| C | Counselor |
| PM | Peer Mentor |
| P | Special Project |
| SGL | Support Group Leader |
| YPC | Young Patients Committee Board |

| | | | |
|----------------------|-----|----|-------|
| Alia Aboulhosn | SGL | | P (2) |
| Claude Aldridge | | PM | |
| Jean Aldridge | | PM | P |
| Sarah Ancell | SGL | PM | |
| Sylvia Arroyo | SGL | | |
| Larry Bailes | | | P(2) |
| Shannon Bailey | | | P (2) |
| Amy Barris | | PM | P |
| Anna Beard | SGL | | |
| Carol Bloom | | PM | |
| Chyrl Bowers | | PM | P |
| Diane Boyd | SGL | | |
| Terry Brown | | PM | P |
| Jennifer Byram | SGL | | |
| Joan Cannelli | | PM | |
| Nora Casas | SGL | | P (2) |
| Anne Ciemnecki | SGL | PM | P |
| Cathleen Clay | | | P |
| Christine Cohen | SGL | PM | |
| Michael Cohen | SGL | | P |
| Michele Cohen | SGL | | P |
| Tatiana Colledan | SGL | | P |
| Mabel Contreras | | | P |
| Lauren Corson | SGL | | |
| Diana Crites | SGL | | |
| A. Marie Davis | SGL | | |
| Jill Della Ratta | SGL | | |
| Hosanna Derderian | | PM | |
| Lisa East | SGL | | |
| Ellie Eichenlaub | YPC | | |
| Allan Enis | SGL | PM | |
| Shelby Ennis | SGL | | |
| Thomas Fenstermacher | | PM | |
| Kim Fields | SGL | | P |
| Jeffrey Fogel | SGL | PM | P |
| Darrell Fryer | | PM | |
| Rose Gaffney | | | P |
| Stuart Gause | SGL | PM | |
| Jimena Giudice | | | P |
| Deirdre Glascott | SGL | | |
| Bob Golub | | PM | |
| Kurt Goodman | SGL | | |
| Supriya Goyal | SGL | | P |
| Thomas Guith | SGL | | |
| Neave Halvorson | | PM | |
| Megan Hamilton | SGL | | |
| Sarah Hawbecker | | PM | P |

| | | | |
|---------------------|-----|--------|-------|
| Kathleen Hays | SGL | | |
| Katrina Holliday | | PM | P |
| Vince Holtmann | SGL | PM | P |
| Sara Illsley | SGL | | |
| Elaina Jackson | YPC | | |
| Susan James | | | P |
| Rosa Jimenez | | PM | |
| Tamar Krivosha | | PM | P |
| Tom Kruse | SGL | | P |
| Ally Kubik | SGL | PM | |
| Laura Launderville | | | P |
| Gwen Lias-Baskett | SGL | | |
| Liz Long | | PM | |
| Judy Love-Eastham | | PM | |
| Emmy Macnicol | | PM | |
| Amy Marshall | SGL | | |
| Alexis Mayle | | PM | |
| Mike Mercurio | | PM | P (2) |
| Susan Mills | SGL | PM | P |
| Jessica Mortensen | | PM | |
| Yvonne Omer | SGL | | |
| Julie Parks | | | P |
| Andy Petitjean | SGL | | |
| Mary Pingel | SGL | | |
| Ruth Purchase | | PM | |
| Robert Ramsey | SGL | | |
| Mary Rice | SGL | | |
| Tammy Roberts | SGL | | |
| Lynn Ruppe | SGL | | |
| Rachel Scherer | SGL | | P |
| Abby Scherr | | | P |
| Brittany Shaffer | | PM | P |
| Christine Spor | | PM | P |
| Maureen Stone | | | P |
| Jeanne Tarullo Hays | | PM | |
| Miorky Torres | | | P |
| Rachel Triay | SGL | YPC | |
| Barbara Turczyn | SGL | PM | |
| Ann Voynow | | PM | |
| Lindsey Wallace | YPC | | P |
| Dan Wegner | | C & PM | P |
| Gail Wells | SGL | | |
| Sharon Whitener | SGL | | P |
| Alice Whynaught | SGL | | |
| Mackenzie Winslow | YPC | PM | P |
| Heidi Wittgren | SGL | PM | P |
| George Zack | | PM | |

Three Long-Time Volunteers Stepping Back

The Facial Pain Association wishes to thank three long-time volunteers, Thomas Guith, Lynn Ruppe, and Tom Kruse for their selfless service to those living with facial pain, their families, and loved ones. Your outstanding dedication is an inspiration to all.

Tim and Lynn led the Suburban Detroit Support Group starting in 1998. Lynn's husband, Pete, lent invaluable technical assistance with video conferencing.

Tom started his volunteer service by helping the Tucson, AZ group in the early 2000s. He then continued as the Support Group Leader, expanding the group to all of Arizona, then to the entire Southwest with the use of video conferencing.



Thomas "Tim" Guith
Support Group Leader, Suburban Detroit, MI

Tim was an executive with General Motors for over 30 years who retired on disability at the age of 52 due to facial pain. He credits his wife, Donna, with helping him get through those early months before being diagnosed by packing his face with ice packs. "It has been a pleasure to help those suffering as we did," he says.



Lynn Ruppe
Support Group Leader, Suburban Detroit, MI

Lynn's professional background as a nurse, along with her calm, warm-hearted personality, made her the perfect Support Group Leader. For the first 20 years, the group met at a local medical center that was a 45-minute drive for Lynn, who made the trip every month no matter the weather.



Tom Kruse
Support Group Leader, Southwest

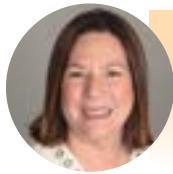
Tom describes himself as a "happy caregiver" to his wife who was diagnosed with trigeminal neuralgia in 2003. He says: "As a caregiver, I have always felt like an outsider, but your organization realizes that caregivers need support, too. I wish to give you all a BIG THANK YOU for your time helping all in this community."

Counselor (C),
Peer Mentor (PM),
Special Project (P),
Support Group
Leader (SGL),
YPC Board (YPC)
by US State

▼ C ● PM ◆ P
■ SGL * YPC

AL▲
AZ■▲
CA■ ■ ■ ■ ■ ■ ■ ■ ■ ■
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WI● ◆

FPA Volunteers



“One attendee turned off her camera so she could cry because she felt so validated to hear others’ stories. This group is powerful.”

—Anne Ciemnecki, Support Group Leader

“I am always excited for the next Support Group Meeting! It has become a special and precious part of my life! And I am so grateful because you [FPA] gave me this opportunity!”

—Tatiana Colledan, Support Group Leader

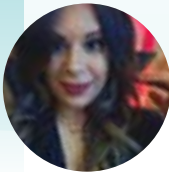


“...there is nothing like working with passionate people who care about their mission, especially one as noble as the FPA. Collaborating with dedicated, passionate people makes my work very easy to do.”

—Rose Gaffney, Project Volunteer for Video Productions

“This has been so rewarding for me. I remain pain free and being able to support others is something I truly want to continue doing, especially during my healing process. I believe we heal when we help others heal.”

—Miorky Torres, Project Volunteer for Holiday Helpline and Conference Support



“I can’t describe how it felt to be helping someone. Almost like I was the one benefitting from it.”

—Larry Bailes, Project Volunteer for Holiday Help Line and Conference Support

“I really feel this is a good thing and the more people we spread the information to through the year will help next season. Thanks for the opportunity to be here. It helps us all.”

—Julie Parks, Project Volunteer for Holiday Helpline



“All I can say is “WOW” We are getting the word out and people [are] connecting with us! So awesome! If there’s anything else I can help with, let me know!”

—Christine Spor, Peer Mentor, Project Volunteer for Holiday Helpline and Conference Support



Counselor (C), Peer Mentor (PM), Special Project (P), Support Group Leader (SGL), YPC Board (YPC) by Country

BRAZIL■
CANADA●
UK.....●

FPA Young Patients Committee

We have had such an amazing time as Co-Chairs of the YPC!



Lindsey Wallace

We've both been part of the YPC for years and taking on a larger role within the committee has been an exciting challenge.



Kenzie Winslow

Our goal has always been to advocate for people for facial pain and with these new roles we've had the chance to really increase our impact. Over the last year, we've had the chance to get to know more patients on a deeper level. We've taken those conversations to heart and tried to implement more impactful projects within the YPC. The FPA as a whole has always supported the YPC's mission, but

we've both loved the opportunity to take part in the broader facial pain discussions and speaking up for young patients. We hope to continue to be a voice for everyone over the next year! We have so many exciting projects in the works, so keep an eye out. We're so thankful for this community and all of the love and support we receive from you all!

— Kenzie and Lindsey ■



@youngpatients



@youngpatients



@youngpatients



@tealribboncrafts



Newsletters



4,600

Followers across social media



135

Members receiving email newsletters from the YPC

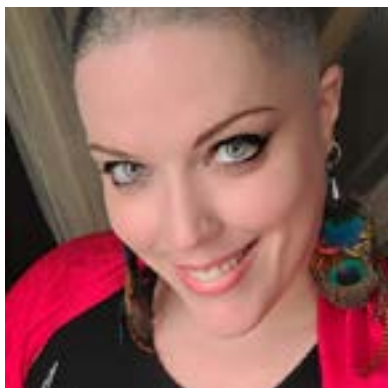
Connect with the FPA Young Patients Committee!

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

Congratulations Hannah and Colette,
the FPA Young Patients Committee Facial Pain Resiliency Scholarship recipients for Fall 2022!
We invite you to read a portion of their winning essays on the following page.



Young Patients Committee Facial Pain Resiliency Scholarship 2022



Scan QR code or click HERE to read Hannah's essay in its entirety.

Hannah Crazyhawk

I needed help and realizing that it is okay to ask for that help when I need it has been one of the biggest challenges in my college career and life. Through this journey, I have learned that I am more resilient, intelligent, proactive, and resourceful than I ever could have imagined. If you battle chronic illnesses and endless pain, asking for help is frightening. Our medical system is not designed to help patients like us. We are seen as too young to be in pain and too healthy looking. That is ableism; chronic pain and illnesses do not discriminate. We are complicated, and it is not our fault. We are fighting enormous, invisible battles every single day. Facial pain can rip your life away. I know that people like me are strong enough to succeed in our educational goals because we are fighters. We fight the most excruciating pain and are still here with hopes and dreams. College is difficult, but it is no match for us. ■



Scan QR code or click HERE to read Colette's essay in its entirety.

Colette Miller

My goal is to become a pediatric nurse. I am not sure what specialty, but maybe the Intensive Care Unit (ICU), Emergency Room (ER), or maybe helping kiddos who have the same conditions I have. I would be able to give them a personal and compassionate perspective and so much other knowledge that comes over time from living with these conditions. It has personally affected me, making me learn to be strong and to have perspective through medical challenges. I taught myself that it may seem hard now, but that it will get better later. These opportunities have also given me so much knowledge about my medical conditions and treatment options, ways to make it better, and so much other information I would have never learned in nursing school or life. ■

The Young Patients Committee Facial Pain Resiliency Academic Scholarship is available to students in the US between the ages of 18-40 attending school, college, or university that have facial pain. An exception to age will be made if you are 17 and entering college in the semester following the application. Applicants must complete this application in full, including upload requests, to be deemed eligible for award consideration. Be on the lookout for the next application round!

Changing the Face of Facial Pain — The FPA’s Patient Registry



Anne Ciemnecki

FPA Board of Directors Secretary, Peer Mentor, Support Group Leader,
and co-editor of Facial Pain: A 21st Century Guide



About eighty years ago, my grandmother heard the words trigeminal neuralgia for the first time. As a third-generation woman with facial pain, I intimately understand the daily struggle and long-term impact of this condition. My name is Anne Ciemnecki and I am honored to serve on the Facial Pain Association’s Board of Directors, where my experience propels my passion.

Trigeminal neuralgia and other neuropathic facial pain conditions are rare, with little dedicated research and even less funding. Last year, our board decided to create a forum where your voice can be heard, where everyone’s voice can be heard. **The Facial Pain Association’s Patient Registry** will be a platform where we can securely and confidentially gather data about your experience.

The registry must be designed so that the data you submit can be extracted and analyzed. For more than 30 years, I served as a survey methodologist working for foundations and the federal government. In the decade before I retired, 80% of my work focused on collecting data from people with disabilities to inform the Social Security Administration (SSA) of their needs. The combination of my personal and professional experience makes me uniquely qualified to spearhead this project.

As part of the rare community, we must combine our individual experiences into a symphony of voices. This is your opportunity to affect change!

Using questionnaires designed by researchers and survey professionals, we can collect data over time to help inform clinical trials and affect public policy to better help the facial pain community. We hope to launch the registry in the coming year to start making progress in these impactful areas and we need your support.

When you participate in the registry, the questionnaires will:

- Ask about YOUR experience. There are no right or wrong answers.
- Take approximately 15 minutes with a new questionnaire every 4-6 months.
- Include questions about your pain, medications, treatments you have tried, side effects, and family history.
- Inquire about your daily function. For example, can you exercise, carry a bag of groceries, participate socially, or talk on the phone?



This registry will help transform anecdotal data into evidence, which is vital in the rare community. Information from the registry could help connect people with appropriate clinical trials and assist Social Security Disability determination.

Photos from top right: Anne Ciemnecki today (photo by David Ciemnecki), top left: Anne’s grandmother and mother, bottom left: Anne with her grandmother, next page: Anne with her mother.



Unfortunately, it is not free. There are significant costs associated with launching and maintaining a patient registry, and just like we can combine our voices, we can combine our resources to make this happen. If we invest in this today, we can make life better tomorrow and leave a legacy for the future.

Warm regards,

Anne B. Cierniecki

We want to hear from you!

What is one question you would like to see included in the FPA's Patient Registry?



Please use the enclosed envelope, click [HERE](#), or scan the QR code to make a contribution. When you send in your gift, please tell us what information you would like to see included in the patient registry.

You can also email your suggestions to info@facepain.org.

Give to FPA with Confidence

The Facial Pain Association (FPA), formerly known as the Trigeminal Neuralgia Association (TNA), is a registered non-profit, 501(c)(3) volunteer organization founded in 1990.

GuideStar

Platinum
Transparency
2023

Candid.

The Facial Pain Association earned GuideStar's highest level of recognition, the Platinum Seal of Transparency

GuideStar is the world's largest source of information on nonprofit organizations. It gathers and provides access to the most comprehensive, up-to-date, and accurate nonprofit information available. GuideStar's mission is to revolutionize philanthropy by providing information that advances transparency, enables users to make better decisions, and encourages charitable giving. GuideStar is a 501(c)(3) public charity.

It Takes All of Us Raising Awareness



Facial pain can be a silent but debilitating condition, often misunderstood and misdiagnosed. **It takes all of us** to increase public knowledge about neuropathic facial pain, including trigeminal neuralgia, and emphasize the urgent need for early diagnosis and effective treatment options.

Facial Pain Awareness Month and Rare Disease Day serve as beacons, rallying communities, healthcare professionals, and advocacy groups to shed light on

trigeminal neuralgia. Increasing awareness also plays a vital role in providing support and solidarity.

Together we can unmask the challenges faced by those living with this condition by amplifying the voices and sharing the experiences of people with facial pain. Through this collective support, we can help break the isolation often felt by those affected by facial pain during awareness month and throughout the year.



Scan this QR code or click [HERE](#) for a special message from Brandi Underwood, the FPA's Marketing and Communications Manager.



@facialpainassociation



@facialpainassoc



@facialpainassoc



Facial Pain Association



Facial Pain Association



795,000+

Reach/Impressions

Reach/Impressions measures the people who see FPA's content.



18,600+

Likes/Follows

Likes/follows measures the people who support FPA on social media.



18,600+

Reactions

Reactions measures engagement with FPA's content.



4,200+

Shares/Retweets

Shares/Retweets measures the amplification of FPA's content.



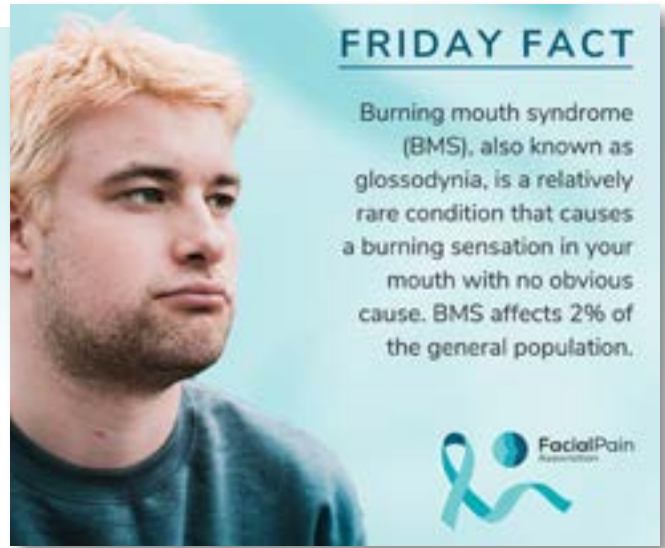
1,100

Comments/Mentions

Comments/Mentions measures interactions with FPA content.

You Educated Your Community

Throughout October, you shared facts about facial pain and promoted grassroots awareness events.



You Shared Your Story

“My #TNStory has not been a walk in the park by any means. As many of you know, one year ago this month I underwent brain surgery in hopes of parting ways with this pesky affliction. Unfortunately, things don't always go to plan...”

– @ayaleslie2

You Turned Social Media Teal

You shared others' stories, awareness day posts, fundraising efforts, and more over 1,200 times in October, reaching more than 75,000 people.



#FaceTodayTogether

It Takes All of Us Learning Together

More than 800 people from 6 continents and 23 countries participated in the 2023 FPA Conference.



2023 FPA Conference

Your generosity not only allowed us to keep the cost of admission low, but also provided complimentary admission to 112 attendees who reached out to us for support.

“Essential information delivered with clarity and heart. Thank you!”
— Katie



80,000+

Website users



530,000+

Bulletins emailed



17,500+

Facebook Group Members



10,000+

Quarterly journals mailed



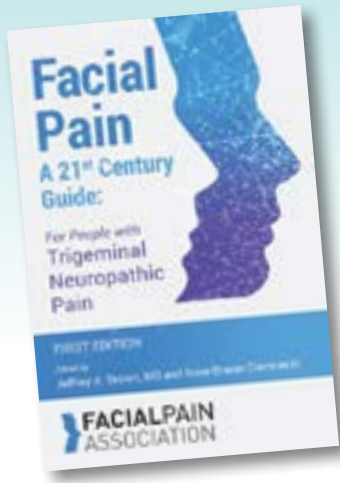
8,000+

2022 FPA Video Series views



2,500+

Calls for information



Facial Pain: A 21st Century Guide

Thanks to the tremendous generosity of our donors, we have provided a complimentary copy of Facial Pain: A 21st Century Guide to more than 130 people who reached out to us in need.

If you know someone in need, please call the FPA office at 800-923-3608 or email info@facepain.org to request a copy.

“I’ve been battling TN for 6 years. Thanks so much for this very valuable resource.”

— DeeAnn

2022 FPA Video Series

The FPA’s Video Series, based on presentations from the 2022 Virtual Conference, has been viewed more than 8,000 times. All FPA webinars are free and available in our library at www.facepain.org/tag/webinars.



2022 FPA Bulletins

More than 530,000 FPA Bulletins were received by the facial pain community in 2022.

You can receive the latest facial pain news, upcoming events, and information in your inbox when you sign up at www.facepain.org/sign-up/.

Find a Doctor

The Facial Pain Association is fortunate to have the guidance of the Medical Advisory Board composed of experts in neurosurgery, neuroscience, pain management, dentistry, and mental health.

If you have facial pain, it is important to find the best doctor for you who knows about your condition. Although we do not recommend specific doctors, you may start your search with the facial pain experts on our Medical Advisory Board and the Find a Doctor list on our website at www.facepain.org/find-support/find-a-doctor

Please Note: The doctors on our Find a Doctor list pay a fee to be listed on our website; FPA does no independent examination of the professional qualifications, education, experience or other credentials of those with whom we have linked, the validity or suitability of the services or products



they offer, or of the accuracy of the content of the linked sites.

Listing on our site does not constitute an FPA endorsement of any physician, surgeon, medical procedure, medical institution, or its staff.

The Research Initiative

We aim to empower patients and caregivers with the knowledge that helps you be educated partners in your healthcare and to encourage more research on facial pain and relevant issues faced by those with facial pain.

As part of FPA's research initiative, we are committed to keeping you informed of efforts that may result in better treatment options for trigeminal neuralgia and other neuropathic facial pain.



To reach these goals, FPA will provide four resources:

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

Visit <https://www.facepain.org/research/> to learn about clinical trials and studies, opportunities to get involved with research, articles on published studies, and more.

Please Note: The FPA is enthusiastic about medical research for facial pain patients, and encourages those with TN to consider participation. It is important to note, however, that the FPA is not offering, nor is it qualified to offer, a scientific or medical endorsement of any Institutional Review Board (IRB) approved patient study. An IRB is a committee established to review and approve research involving human subjects. The purpose of the IRB is to ensure that all human subject research be conducted in accordance with all federal, institutional, and ethical guidelines. All studies and trials

listed have IRB or Ethics Committee approval where relevant. The safety and scientific validity of the study is the sole responsibility of the study sponsors and investigators. Patients should use the contact information provided to contact the research organization for more information.

Choosing to participate in a study is an important personal decision. Before you participate in a study, discuss all options with your health care provider. Although study sponsors may donate to the FPA, such donations do not influence or guide our decision about the studies we identify.

It Takes All of Us Working Together

In 2022, Melissa Baumbick and Brandi Underwood applied, interviewed, and were selected to participate in Headache on the Hill, an annual advocacy event organized by the Alliance for Headache Disorders Advocacy (ADHA).

On February 14, 2023, Melissa and Brandi joined 300 other ADHA advocates from 48 states, meeting with the offices of US Senators and Representatives from Georgia.

Neuropathic facial pain, including trigeminal neuralgia, is diagnostically classified by the International Headache Society in The International Classification of Headache Disorders. Headache on the Hill brings together health professionals, advocates, patients, caregivers, and researchers in support of the common goal to make life better for all those living with or otherwise impacted by headache disorders in the United States.

Our primary goal and reason for participating in this event is to raise awareness about neuropathic facial pain in the larger headache space.



"As CEO of the Facial Pain Association, the largest patient organization supporting all people affected by neuropathic facial pain, I am here to be a voice for those in our community, some of whom literally cannot speak because of their relentless pain."

— Melissa Baumbick, CEO



"I hope to work together in pursuit of equitable policies, research, and funding for people living with headache conditions, including neuropathic facial pain. Through sharing our stories, we can help reduce barriers and stigma, especially in rural and underserved communities."

— Brandi Underwood, Marketing and Communications Manager

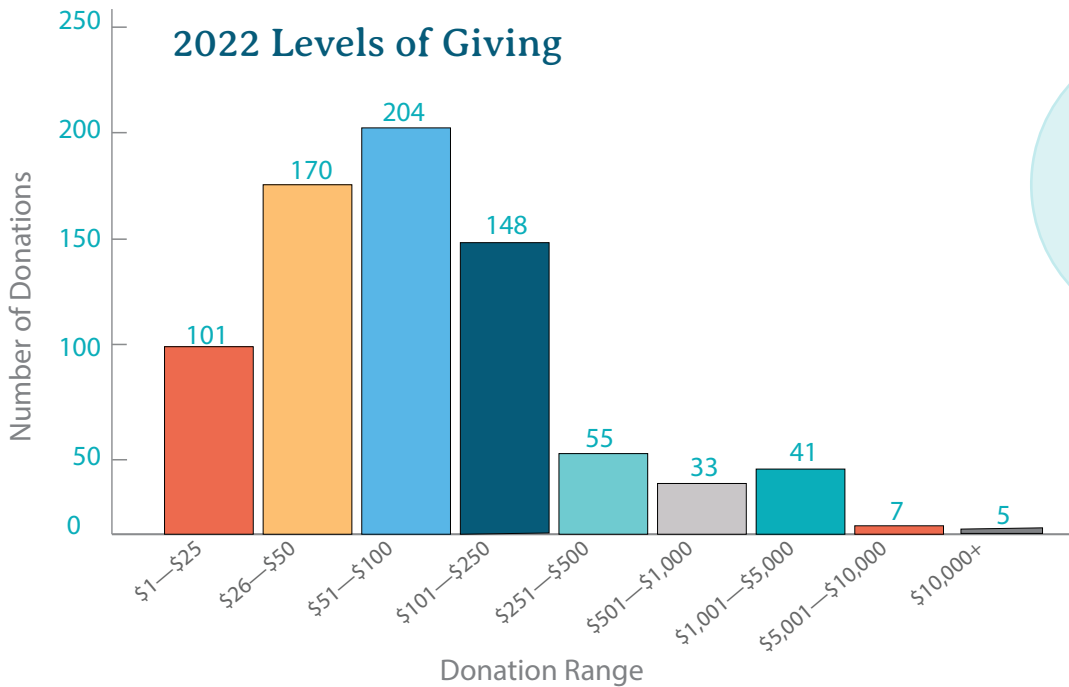
We are grateful for all centers, organizations, companies, researchers, and individuals who collaborate and partner with the FPA to spread awareness about neuropathic facial pain.

Community of Collaboration

| | | |
|--|--|--|
| Alliance for Headache Disorders Advocacy | Columbia University | North American Neuromodulation Society |
| American Academy of Orofacial Pain | Facial Pain Research Foundation | Noema Pharma |
| Association of Migraine Disorders | Juan M. Hincapie-Castillo, PharmD, MS, PhD | NSPC Brain and Spine Surgery |
| Biohaven Pharmaceuticals | Jonathan Greenberg, PhD | Rare Disease Day |
| Brotman Facial Pain Clinic | KORTX | Stanford Medicine |
| Cleveland Clinic | Mayfield Brain & Spine | TMJ Association |
| Coalition for Headache and Migraine Patients | Mayo Clinic | U.S. Pain Foundation |
| | Migraine World Summit | |

If you are interested in partnering with the FPA, please contact Brandi Underwood at bunderwood@facepain.org.

It Takes All of Us Investing in the Facial Pain Community




Every support group, every webinar, every phone call, and email of support is made available through the generosity of people like you.









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.

 Pledged

 Claude and Jean Aldridge
 Anne & John Ciemnecki
 Kaarina Ederma
 Susan H. Gay

Doris Gibson
 Regina Gore
 Ronald David Greenberg
 Carlin Lagrutta

Miriam Leinen
 Mary Ann McCann
 David & Jody Meyers
 Charles Muchnick

Mary-Ann Neri
 Arlene & Bernard Richards
 Paula Rosenfeld
 Arthur & Ann Schwartz

If you would like more information on joining the FPA Legacy Society, please call 800-923-3608 or email Brandi at bunderwood@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
 William Albert
 Heidi Battistini
 Melissa Baumbick
 Joan Beelen
 Carol Bender
 Cynthia Bennett
 Carol Berardi
 Susan Blowers
 Erika Blumberg

Jennifer Byram
 Joey Callahan
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If you would like more information on joining the FPA Sustainer Circle, please call 800-923-3608 or email Brandi at bunderwood@facepain.org.

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WHA International, Inc.
Cynthia Woods

"I would say that the support group is almost as important as taking the right medication. I'm so appreciative of you organizing this..."

—Robert

Chair's Club
(\$15,000+)

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Gold Supporter
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Patron
(\$100 to \$499)

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(\$1 to \$49)

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Tina J. Grimm
David & Rita J. Gross
Thomas Guith
Linda & Paul Gysen
Rita Halverson
Kenneth & Sandra Handel
Donald Hansen
Robert Harlow
Eugenia T. Harrington
Frederick Harthen
Frances Haskin

“Support Groups are such a source of information and comfort!”
—Rosanne

Sarah Hawbecker
Richard & Stephanie Hawley
Madison Hayes
Kathleen Hays
Therese M. Hercher
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Sandra Kravetz
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Sharon Krevor-Weisbaum
Harriet Kulis
Cele Lachance
Kathy LaForest
Lisa Lagregio
L. Paul Lanctot
Janean E. Langham
Anne Lastimado
Sara Jane Lee
Rebekah Lehtonen

“The information that you have sent us will greatly help us in our decision making. It helped me tremendously to begin the journey of providing relief for my wife, who has been dealing with trigeminal neuralgia. Additionally, I had a very nice conversation with [volunteer] Tom Kruse who also provided valuable information.”

—Dan

“Donors” continued on page 31

"Donors" continued from page 30

| | |
|-------------------------------|----------------------------|
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| | Amy Reyer |

"I really appreciate all the resources. I am interested in contacting other people who have and have had similar issues."

—Susan

| | |
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| Charles A. Taylor | |

"THANK YOU for our conversation and all your help! I really felt heard and seen by you and it was so nice to be validated. I'm so happy to know there is a kind community out there..."

—Holly

**Pathfinder
(\$50 to \$99)**

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“Your lovely emails have really helped me. I am really struggling to come to terms with this being something that isn’t going to go away. Thank you again, you really have made a huge difference to me already.”

—Laura

“Thank you for finding me an awesome FPA Peer Mentor... I [also] attended FPA Zoom meetings. Thank you and all the wonderful FPA volunteers!”

—Annamarie

Friend (\$1 to \$49)

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Frank Alibozek
Rita Aron
Heidi Battistini
Carol Bender
Ellen Berg
Perry Bergman
Michelle Bergstad
Harry & Dorothy Bertschy
Paula Brown
Frima Burger
Teresa L. Burnett
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