

2024-2025 Annual Report



Facial Pain Association 2024-2025 Annual Report



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About Us

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 meet you with 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 a 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 meet you with education:

FacePain.org provides up to date information on symptoms, diagnoses, treatment options, pain management, medication, mental health, and information on physicians and medical centers. 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, along with event notifications, research updates, and more.

We meet you with advocacy:

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

We are expanding our efforts, partnering with organizations to advocate for policy changes, and signing letters of support to increase research funding to benefit the facial pain community. Through our advocacy efforts, we aim to bring hope, support, and make a real impact for those living with facial pain.

You're Not Alone The 2024-2025 Annual Report highlights how the Facial Pain Association supports every member of the facial pain community, no matter where you are on your journey. Whether you need support, education, advocacy, or other resources, the FPA is here for you every step of the way.

Leadership

Board of Directors



David Meyers,



John Temple, Vice Chair



Secretary





Ann-Marie Clarke







Jeffrey Fogel, MD



Megan Hamilton



Vince Holtman





Medical Advisory Board



Raymond F. Sekula, Jr., MD



Ramesh P. Babu, MD



Nicholas M. Barbaro, MD



Gary D. Klasser, DMD



Wolfgang Liedtke, MD, PhD



Michael Lim, MD



Mark E. Linskey, MD



Donald R. Nixdorf, DDS, MS



Julie Pilitsis, MD, PhD



Konstantin V. Slavin, MD



Gary L. Stanton, MD



Richard S. Zimmerman, MD

Facial Pain Association Staff



Melissa Baumbick Chief Executive Officer



Regina Gore Manager of Community Volunteer Programs



Christina McCurdy Bookkeeper



Natalie Merrithew Manager of Marketing/ Communications and Events.

Young Patients Committee (YPC) Board of Directors



Lindsey Wallace Co-Chair



Kenzie Winslow



Ellie Eichenlaub



Elaina Jackson



Laura Launderville



Rachel Triay

Volunteer Support

The Facial Pain Association is profoundly grateful to our volunteers whose efforts and selfless dedication help others feel less alone. FPA volunteers serve as Peer Mentors, Support Group Leaders, Holiday Help Line, Awareness Ambassadors, and in other project-based roles.

Volunteers, many of whom live with pain, give their time because of, and often despite, their own facial pain experiences. We are grateful to those who find a true calling in supporting others. We asked our volunteers why they choose to serve, and how they have been uplifted by their fellow FPA volunteers. Their inspiring responses are highlighted below.

"To help other patients with facial pain with what I have learned, to provide support to them to cope better with this painful chronic disease, to let them know that they are not alone."

—Anonymous

"Support group leaders have created a consistently safe space in which to share concerns and resources with others. Having a mentor connection has offered me a sense of being supported on an individual level and also has felt like an emergency first aid kit in the event of an unanticipated need. Her guidance through my decision about how to prepare for and recover from surgery was also invaluable."

—Katie R.

"Makes me feel as though we are collectively battling TN as a team."

—Marsha G.

FPA Volunteer Roles Key

AA AA — Awareness Ambassador

C C — Counselor

cs CS — Conference Support

IR IR — Information Request Assistant

P P — Special Project

PA Peer Advocate

PM — Peer Mentor

SGL SGL — Support Group Leader

YPC YPC — Young Patients Committee

Alia Aboulhosn	SGL		
Sylvia Arroyo	SGL		
Virginia Arsenault			
Ronni Barrios		Р	
Amy Barris			
Carol Bloom	PM		
Chyrl Bowers	AA	PM	Р
Terry Brown	PM		
Natalie Buscavage	IR	Р	
Jennifer Byram	SGL		
Dorian Carbone	PM	_	
Nora Casas	SGL	Р	
Jeanie Chamberlain	PA	_	
Danielle Clements	AA	Р	
Alessandra Coccaro	PM	Р	
Michele Cohen	SGL		
Christine Cohen	PM	SGL	
Michael Cohen	SGL		
Tatiana Colledan	SGL	Р	
Hosanna Derderian	PM		
Jennifer Dinet	PA		
Lisa East	SGL		
Ellie Eichenlaub	YPC		
Sherry Ellis Nixon Allan Enis			
	PM		
Shelby Ennis Thomas Fenstermacher	SGL		
Kim Fields	PM		
	SGL	661	
Jeffrey Fogel		SGL	
Darrell Fryer	PM		
Rosalie Gaffney	P P		
Tom Gallagher Marsha Garcia	PM PM	SGL	Р
Ramona Garrett	AA	PM	P
Stuart Gause			
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Cavill Maze		Р	
Margaret McGaughey	SGL		
Terry McNally	SGL		
Erik Mello	SGL		
Mike Mercurio	PM	Р	
Susan Mills		SGL	
Brian Mistler	SGL		
Jessica Mortensen	AA	РМ	Р
Amy Myers	SGL		
Suma Nambiar	PM		
Yomna Nassar	SGL		
Tomoya Ogura	P		
Yvonne Omer	SGL		
Dawn Onderak	PA		
Dana Overland	PM	Р	
Michelle Paff	AA	Р	
Theresa Perlman	PM		
Andy Petitjean		Р	
	SGL		
Penny Prosperi	SGL	514	
John Pumphrey	SGL	PM	
Ruth Purchase	PM		
Katie Reitemeier	SGL		
Mary Rice	SGL		
Susie Roller	AA		
Aaron Running	SGL		
Danielle Running	SGL		
Anthony Saturno	PM		
Rachel Scherer	SGL	PM	
Judy Schiffbauer	SGL		
Linley Schmarkey	AA		
Warren Selko	SGL	Р	
Brittany Shaffer	PM		
Christine Spor	SGL	Р	РМ
Mags Stamp	SGL	PM	
Maureen Stone	Р		
Jessica Tagle	PM		
Jeanne Tarullo Hays	PM		
Miorky Torres Peraza	PM	SGL	Р
Rchel Triay	SGL	YPC	
Barbara Turczyn	SGL	PM	
Robert Tyler	PM	CS	
Ann Voynow	AA	PM	
Lindsey Wallace	YPC	FIVI	
James Warner			
Dan Wegner	AA	DM.	
	C	PM	
Mary Welborn	AA		
Gail Wells	SGL		
Sharon Whitener	SGL		
Alice Whynaught	SGL		
) (G	
		YPC	Р
Anna Williams Mackenzie Winslow Elizabeth Wolski George Zack	SGL PM SGL PM	YPC	Р

Volunteer Recognition

"To help others feel less alone. I've got a lot of help, from FPA, social network, therapists, physicians, and my own knowledge. And I am more or less pain free now. Even then it was a hard journey and I know, that I was very privileged. I'm sure suffering would be less if people felt understood from the very first moment of their journey. I really like the approach of the FPA to support, to understand, to guide and to educate. I like the feeling of being little part of the change for people with neuropathic facial pain."

—Anonymous

"I've learned about treatment options and ways to cope with living this painful and life changing condition."

— Miorky T.

"We can make the difference in this hard world of facial and invisible pain. We need to help people reconnect with life and society and show them they are not alone. It's an honor to be an FPA Volunteer and be able to work to help these people. I used to say that God has permitted TN to give me the opportunity of help people to never give up! Giving up will NEVER be an option for us!"

—Tati C.

"Having TN and going through a successful MVD procedure would not have happened without the support from fellow TN sufferers. I volunteer to give back the support I received."

— Rob T.

"It's rewarding to be able to help and offer some support, so people affected by TN don't feel isolated."

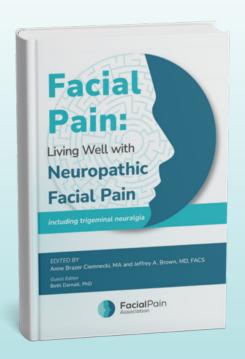
-Michael C.

"My role as an FPA volunteer was rooted from the thought of not wanting facial pain patients to feel alone in their journey as well as a possibility for a diagnosis."

—Jessica M.

"A volunteer years ago saved my life just by listening to me. At that moment I learned I wasn't alone."

—Amy B.



Our newest book, Living Well with Neuropathic Facial Pain takes a comprehensive, "whole-person pain relief" approach, focusing on proven medical treatments, the psychology of pain, and accessible solutions to eliminate or mitigate the pain. The book aims to empower individuals to live their best lives by providing insights into various types of neuropathic facial pain, finding the right medications and surgical solutions, and navigating the challenges of affording medication and disability. It also dives into the more personal aspects of pain that can impact daily life. It provides coping strategies, including important and less frequently discussed areas such as mental health, support groups, sleep, relationships, and more.

This book is a companion to the FPA's first book, Facial Pain, A 21st Century Guide: For People with Trigeminal Neuropathic Pain, which provides essential information across a broad set of subjects to serve as an introduction to this condition. Both books are valuable resources for individuals living with neuropathic facial pain, as well as caretakers and loved ones.

2024 FPA Video Series

The FPA's Video Series, based on presentations from the 2024 FPA Conference, has been viewed more than 6,500 times. All FPA webinars are free and available in our library at www.facepain.org/tag/webinars.





2024 FPA Bulletins

More than 500,000 FPA Bulletins were received by the facial pain community in 2024.

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/.

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.

FPA in the Community











@facialpainassociation

@facialpainassoc

@facialpainassoc

Facial Pain Association

Facial Pain Association



748,000+

Reach/Impressions

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

21,600+

Likes/Follows

who support FPA on social media.

23,500+

Reactions

Reactions measures engagement with FPA's content.



4,000+

Shares/Retweets

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



2,100+

Comments/Mentions

Comments/Mentions measures interactions with FPA content.



256,000+

Website views



500,000+

Bulletins emailed



18,000+

Facebook Group Members



9,000+

Quarterly journals mailed



6,500+

2024 FPA Video Series views



1,700+

Calls for information

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

AdventHealth

Alliance for Headache Disorders Advocacy & The Headache Alliance

American Academy of Orofacial Pain

Association of Migraine Disorders

Attune Neurosciences, Inc.

Cefaly Technologies

Cleveland Clinic

Clusterbusters

Coalition for Headache and Migraine Patients (CHAMP)

Columbia Neurological Surgery

Curonix

EveryLife Foundation for Rare Diseases

Facial Pain Research Foundation

Harvard Medicine

Johns Hopkins Medicine

Jonathan Greenberg, PhD

Hsinlin Thomas Cheng, MD, PhD

Juan M. Hincapie-Castillo, PharmD, MS, PhD

Massachusetts General Brigham

Mayfield Brain & Spine

Mayo Clinic

Migraine World Summit

National Headache Foundation

National Organization for Rare Disorders (NORD®)

NeuroOne

North American
Neuromodulation Society

Noema Pharma

NSPC Brain and Spine Surgery

Oyanalytika Inc.

Rare Disease Day

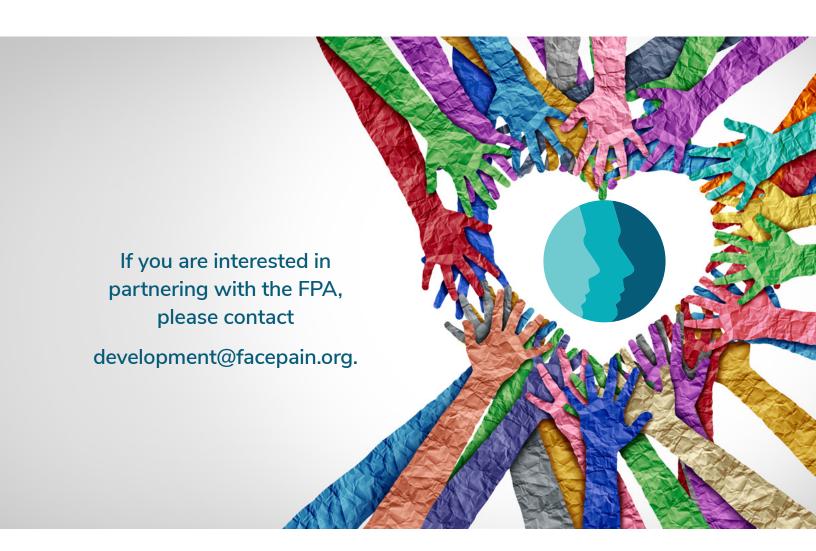
Stanford Medicine

TMJ Association

University of Minnesota

UPMC

U.S. Pain Foundation









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:

Presenters:

Rushna Ali, MD

Cheryl Bemel, PhD, LP

Jack Botros, DDS, MS

Nicholas Boulis, MD

Ena Bromley, MD

Anne Ciemnecki

Jeannine Conway, PharmD

David Darrow, MD

Jeff Fogel, MD

Andrew Grande, MD

Juan Hincapie-Castillo, PharmD, PhD

Marshall Holland, MD

Robert Lasser, MD

Alan Law, MD

Wolfgang Liedtke, MD, PhD

Michael Lim, MD

Mark Linskey, MD

Ann Messer, RN

Abby Metzler, MD

Monique Montenegro, MD

Ana Moreno, MD

Kellen Mulford, PhD

Donald Nixdorf, DDS, MS

Can Özütemiz, MD

Will Schmalstieg

Raymond F. Sekula, Jr., MD

Clarence Shannon, MD

Konstantin Slavin, MD

Angelyn Sloan

Michael Staudt, MD, MSc

Maram Taema, DDS

Saranya Varun, BDS, MS

Anna Williams

Richard Zimmerman, MD

Conference Volunteers:

Jeff Buscavage

Natalie Buscavage

Carrie King

Sierra Peebles

Wesley Peebles

Rob Tyler

Sponsors:

American Academy of Orofacial Pain

AdventHealth

CEFALY Technology

Columbia Neurological Surgery

Curonix

EveryLife Foundation for Rare

Diseases

Mayo Clinic

NeuroOne

Noema Pharma

NSPC Brain and Spine

Nura Precision Pain Management

Oyanalytika, Inc.

UPMC

Staff:

Melissa Baumbick

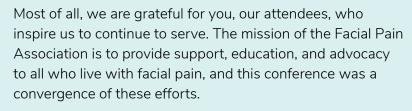
Regina Gore

Natalie Merrithew













2024 in Review







Lindsey Wallace

Kenzie Winslow

The past year has again been focused on growth for the Young Patients Committee (YPC). With help from the FPA, we've started to think bigger, which is an exciting premise for us! Our community is large, and we want to support you all the best way that we can.

One of the highlights this year was helping with the 2025 FPA Conference. It was so meaningful to connect with others in the facial pain community face-to-face, especially seeing other young patients in person again. Moments like these remind us of the importance of community and shared experience. We're excited to bring in new voices and fresh perspectives to our community. We are incredibly grateful to everyone who contributes to our group.

The YPC strives to foster meaningful connections, and hopefully, we're able to do that for you all! As always, everyone is more than welcome to reach out to us directly with ideas for our community. Getting to work with you all towards advocacy worldwide is what we love to do!

—Kenzie and Lindsey

Co-chairs, Young Patients Committee

Connect with the FPA Young Patients Committee!



1,002 Followers @youngpatients



55 Followers @youngpatients



6,700 Likes + Followers @youngpatients



561 Followers X (Twitter)



31 Members WhatsApp Group Chat



179 Recipients Mailing List



114 Recipients Happy Mail

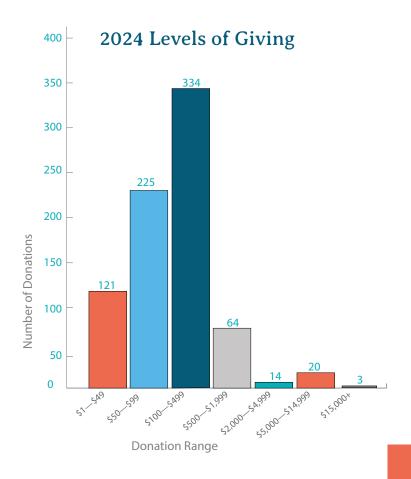


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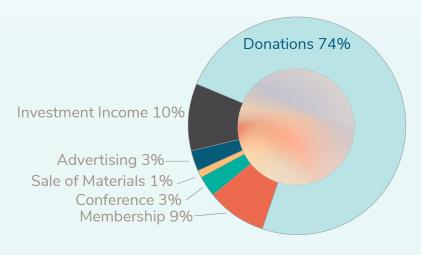


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^{*}Every effort has been made to ensure the accuracy and completeness of this list. We regret any errors or omissions that may have occurred. If you see something incorrect, please email development@facepain.org.

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

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Hope for the Future

As we reflect on the past year of pursuing our mission of support, education, and advocacy at the Facial Pain Association, we acknowledge both the challenges and the progress in our shared journey. The pace of change can be frustrating, yet even in the face of that frustration, we find tremendous hope. The launch of the Facial Pain Registry marks a new chapter — one that brings us closer to the insights, data, and research opportunities that have long been out of reach. We remain steadfast in our commitment to provide education, support, and advocacy for every person living with facial pain. The hopes that new treatments are on the horizon only strengthens our resolve. With your continued support, we look ahead with optimism — knowing that together, we can drive change, inspire progress, and offer real hope for the future.



Melissa Baumbick Chief Executive Officer, The Facial Pain Association



Let Data Tell Your Story





Join the Facial Pain Registry Today!