ANNUAL REPORT 2020

FacialPain Association

A Message From the CEO

Allison Feldman,
Facial Pain Association CEO

As we lean into our mission to provide support, education, and advocacy:

Our support programs are thriving, led by valued volunteers, including Support Group Leaders and Peer Mentors.

Our educational opportunities continue to expand to include more virtual options, providing access to anyone, anywhere, including the FPA Virtual Conference, webinars, Facebook Live events, and Support Groups.

Our advocacy this year took the form of community engagement: outreach to medical community, research support, and creating a community to foster collaboration.

FacialPain Association

2020 was an extraordinary year for many reasons. World events impacted the facial pain community and, in turn, the Facial Pain Association. Despite the challenges presented by the COVID-19 pandemic, which eliminated the options for in-person support meetings and events, created barriers to healthcare provision, and increased isolation, FPA reaffirmed its commitment to serving everyone affected by facial pain. We pivoted to virtual support group meetings, offered more webinars and Facebook Live events, created a network of Peer Mentors to connect with virtually, and held our first virtual FPA Conference.

In 2020 we also honored our 30th year of facing facial pain together. We recognize how important it is not to forget why this organization was founded, and to continue to learn from the medical experts, longtime volunteers, and past leaders of the FPA. We retain our core mission and values as we bring FPA into its fourth decade.

We are excited to share FPA's 2020 Annual Report with you because it is about more than numbers, it is the story of our impact in the facial pain community. If you are a donor, we want you to understand how much impact your gifts have. If you are a person with facial pain, or love someone who has facial pain, you are part of this annual report, too. You read our Quarterly journal, and you likely have participated in one of our programs or have been helped by one of our many resources as well. The annual report offers a chance for us to share all we have done in the past year, and conveys how your ongoing support directly translates to more programs, more resources, and more people helped, supported, and shown they are not alone.

FPA is dedicated to creating an environment where people with facial pain are supported through community, educated about their condition, and empowered to advocate for themselves and others. This past year brought many challenges, but it was the challenge that created opportunities for us to connect with people in new ways. We have learned valuable lessons and these lessons will help us reach more people earlier on their journey to correct diagnosis and pain relief.

Thank you for your continued support in the last year and in the years to come.

Allison Feldman
Chief Executive Officer

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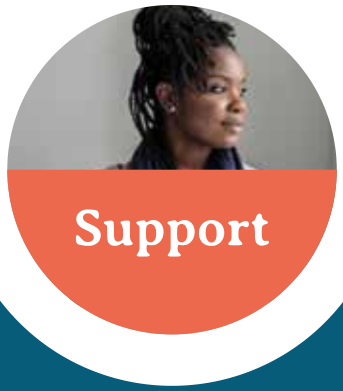


Mission

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, FPA supports patients, their loved ones and caregivers, and healthcare professionals who diagnose and treat people affected by facial pain.

FPA is volunteer-lead 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, and dentistry.

What We Do

We provide personalized support:

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

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 social media 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, event planning, grant writing, patient advocacy, patient research advisory panels, and social media moderation.

We provide education:

FacePain.org includes the latest information about 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 top medical professionals, event notifications, research updates, and more.

We promote patient advocacy:

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

Social Media - FPA maintains an active Facebook Page, Facebook Group, and accounts on Twitter, Instagram, YouTube, and LinkedIn.

The FPA Young Patients Committee (YPC) recognizes the unique issues faced by people under age 40. YPC gives a voice to younger patients and raises awareness that neuropathic facial pain does not only affect older adults. YPC also has a Facebook Page and Instagram account.

2020 Annual Report

FPA's 2020 Annual Report focuses on the three core components of our mission: support, education, and advocacy, providing a snapshot of FPA's impact in each category.

Our Annual Report is more than numbers, it is the story of our impact, and we invite you to read our story through the words of many members of the facial pain community.

Support through Volunteer Programs

Support Group Leaders (SGL) & Peer Mentors (PM) by State

■ SGL ● PM

AZ.....■
CA .....■■■■■■■ ●●●●
CO .....■●●●
FL.....■●●
GA.....■●●
ID .....■
IN.....■●
KS.....■●
KY.....■
LA.....■
MA.....●
MI.....■■■■
MN.....■
MO ....■■■●
MS .....●
NJ.....■■■●●
NV .....■
NY.....■●
OH.....■■■●
OR .....●●●●●
PA.....■■■●●●
RI .....●
TN .....■
TX .....■
VA .....■■■●
WI .....●

Support

Living with a rare disease can be lonely and isolating. It took ten years since my first trigeminal neuralgia attack to meet anyone else with the diagnosis. Our support group is a community diverse in background but unified in helping each other understand the disease and cope in positive ways.

—Kim

32 Support Group Leaders

31 Peer Mentors

26 Support Groups

26 US States & Canada

I just wanted to thank you for the virtual support group meeting. Ever since I was diagnosed I felt alone with this. It was good to share with others who understand.

—Bettyann

Thank you for your response, I will be contacting the Peer Mentors. It is a relief to have the sense that I may have some support with this awful condition.

— Gwendolyn

Volunteer Spotlight - Rosa Jimenez

My name is Rosa Jimenez. I am a licensed massage therapist working in Eugene, Oregon. I am 45 years young and have dealt with chronic pain since childhood. I am inspired by beautiful things, my fulfilling work as a licensed massage therapist, working in the garden alongside the hummingbirds and my cat.

My goal is to live happily, even with facial pain. I am choosing every day to engage in the things that create joy and fulfillment for me. In the next few years, I hope to travel frequently when my daughter begins to have my grandchildren. I hope to return to outdoor photography, cycling, hiking, and teaching in the local community college massage therapy program. I hope to be able to tolerate cold weather and wind more.

Over the years many providers gave me differing opinions of what was causing my pain. Finally, early in 2018, I was diagnosed with TN1 but I sought out different opinions as recently as December 2020.

I have tried over 30 different pain relief treatments including topical and nasal lidocaine, hyperbaric therapy, 12 different modalities of bodywork, several types of breath work, meditation, stress management, light therapy, ice/heat, nutritional supplementation. essential oils, Chinese medicine, various modalities of physical therapy, chiropractic, acupressure, prolotherapy and platelet rich plasma therapies, nerve suppression injections, high frequency micro-current, and dental work.

Hyperbaric therapy has always given me the fastest and most lasting pain relief. After a session, I may have up to five weeks without pain. Massage has been less successful; although I know many talented bodyworkers and physicians, only occasionally would I get short-lived temporary relief from massage therapy.

I was prescribed Oxcarbazepine, on which I function well. For the most part, medications did not help as much as they harmed. Although I have had some temporary and minor pain relief, I have also suffered multiple side effects. It amazes me how intent I am on taking medications to relieve facial pain flares. I have avoided pharmaceuticals before this time in my life.

It's very important to me to advocate for my own health and bring as much information with me when I see doctors. Recently, I went to an appointment with my neurosurgeon, carrying my copy of the new FPA book, and wearing my TN Warrior t-shirt with

its white ribbon on the front and “Keep Calm and Fight On” on the back. As my doctor leafed through the book, he said he has known and/or has worked under all the physicians mentioned. I had no idea! At the beginning of his career, he even worked under the doctor who created the balloon compression surgery I had in June 2020. I thought to myself, “No wonder you are so good with this and with me!” It made me want to hug him.

To anyone who is newly diagnosed, I would say there is hope. You are not alone, and you have this whole community who loves to be here for you. Perhaps the first things you try may not work but there are still many solutions for you out there. Don’t give up trying for relief and solutions. Please be kind to yourself with your incredible suffering. Use any coping mechanisms you have and try to learn new ones. They help!

I connected with the FPA while I was doing a national search for resources for facial pain sometime in 2019. I called the FPA office at a time when I was feeling desperate for solutions. When I called, I felt so very supported. They really live up to their goal of education, advocacy, and support. They really do care and they really do help!

I volunteer with the FPA so I can offer support, friendship, and advice on pursuing care to those also suffering with this horrible monster. I have immense fulfillment from supporting those in a pain crisis and living with this disease. I have felt such honor in being there for those like me who are suffering with this mysterious and difficult disease.

I fill my dance card daily and have never felt over-used as a Peer Mentor. FPA appreciates any time and energy you are able to give. The times I have been able to offer my support and listening heart were convenient, and the folks who have reached out to me have been wonderful to connect with.

I feel like what I can do best is offer validation, treat other facial pain sufferers with credibility, and honor the vast effects facial pain has on a person’s life. Those have all been things that have helped me through the hard times with this pain. Sharing our stories, validating each other’s experiences, and offering one on one support to help— these are the things that keep us going.

Nowadays, I experience extra fulfilment when I can treat a client’s pain I relate to with massage therapy, and I get “extra-extra” fulfillment when I can support someone who is living with this terrible suffering. ■

Educational Programs

In 2020, the FPA hosted a virtual conference with 1000 attendees from 47 states and 14 countries

"I just wanted to say that this conference for me personally was life changing. I felt for once not alone. Like there were doctors who understood me, like I shouldn't be afraid to be the expert or to fight for what I need."

— Melanie

Education

"I was able to view the virtual conference and learned so much. I feel I have a better idea of the next step in my treatment."

—Jane

360,000+
Website visits

288,000+
Bulletins emailed

17,000+
Facebook Group Members

10,000+
Quarterly journals mailed

7,000+
Patient Guides downloaded

2,500+
Email requests for information

1,200+
Webinar/Facebook Live registrants

1,000+
Calls for information

Advocacy

"I just wanted to say what an absolutely wonderful website you have. The Facebook group has helped me so much. I am so grateful I found your group."

—Member in Western Australia

Advocacy through community engagement: outreach to medical community, research support, and creating a community to foster collaboration and partnerships.

Community Of Collaboration

Biohaven Pharmaceuticals

Coalition for Headache and Migraine Patients

Facial Pain Research Foundation

Geo Pain App

Harvard Brain Integrative Health Clinic and Research Program

Migraine World Summit

Noema Pharma

PRAXIS Precision Medicines

Rare Disease Day

Stanford University Byers Center for Biodesign Innovation

TMJ Association

University of Minnesota Health

@facialpainassociation | @facialpainassoc | @facialpainassoc | Facial Pain Association | Facial Pain Association

720,000	15,000	13,000	3,000	2,000
Reach/Impressions	Likes/Follows	Reactions	Shares/Retweets	Comments/Mentions
Reach/Impressions measures the people who see FPA's content.	Likes/follows measures the people who support FPA on social media.	Reactions measures engagement with FPA's content.	Shares/Retweets measures the amplification of FPA's content.	Comments/Mentions measures interactions with FPA content.

Meet the Young Patients Committee

By Stephanie Blough

Meet the YPC! With the launch of the new FPA website, logo, and branding, we thought it best to reintroduce ourselves. We are the Young Patients Committee, a committee designed to advocate for people with facial pain under the age of 40.

Our primary goal is to make sure that no one ever feels alone in their diagnosis. From our new monthly support group, to supporting young patients at facial pain events, to everything in between, we are here for you.

On the new FPA website, we have our own page that has links to all of our social media accounts and articles our board members have written through the years to make the world of chronic pain more manageable. Make sure to follow us on Instagram, Facebook, and Twitter! We also have an Etsy store with tons of items that help to start the conversation about trigeminal neuralgia. After all, awareness starts with one conversation about a cute teal ribbon decal!

Our email account and social media accounts are always open for conversations and questions. Feel free to send us a message if you need some extra love. Always remember that you are never alone. Each of our board members have experienced different paths since our diagnosis, so we're always here to help you through what you're experiencing. Even though no two diagnoses are the same, if we have each other, we can get through anything.

If you've known about us for a while, we're glad you're here! And if you're just being introduced to us now, welcome to the family!

All our love and support,

The YPC: Steph (Chairwoman), Emmy, Lindsey, Meredith, Kenzie, and Rachel
youngpatientscommittee@gmail.com

YPC Facial Pain Association
Young Patients Committee

@tnaypc | @tnypc | @youngpatients | @tealribboncrafts | Happy Mail

$5,000+
Revenue from sale of awareness merchandise

4,500+
Followers across social media

600+
Awareness masks sold

30+
FPA YPC members sharing happy notes via mail

A Project of Art and Maybe Some Healing

My name is Erika Greenup, and I have atypical trigeminal neuralgia/idiopathic facial pain. I was 24 when the pain started, and I am now 30. Since this began, I have only had 28 pain-free days, after a trigeminal node nerve block last summer. Unfortunately, it was not effective long enough to be a long-term treatment.

The pain on the left side of my face has slowly developed from aching/crushing pain, mostly located in my mouth, lower jaw, and cheek bone, to almost the entire left side of my face. My pain is likely caused by damage from an oral surgery, but this has not been proven. I have clean scans, and my doctors and I agree MVD is not a good option. I have tried 11 medications, and only Nortriptyline has really worked without making me horribly ill. It took five months to get accurately diagnosed, and I barely slept during that time. The pain was a constant level 10, nothing really helped. The stress and lack of sleep nearly killed me.

About a year into the pain, I realized if I was going to heal emotionally from the trauma of the pain, drug side effects, and deep depression, I needed a project to change my thinking about my ATN. I began to paint my pain areas daily, took photos, and posted them to a blog called “masking the pain” (www.maskingthepain.wordpress.com).

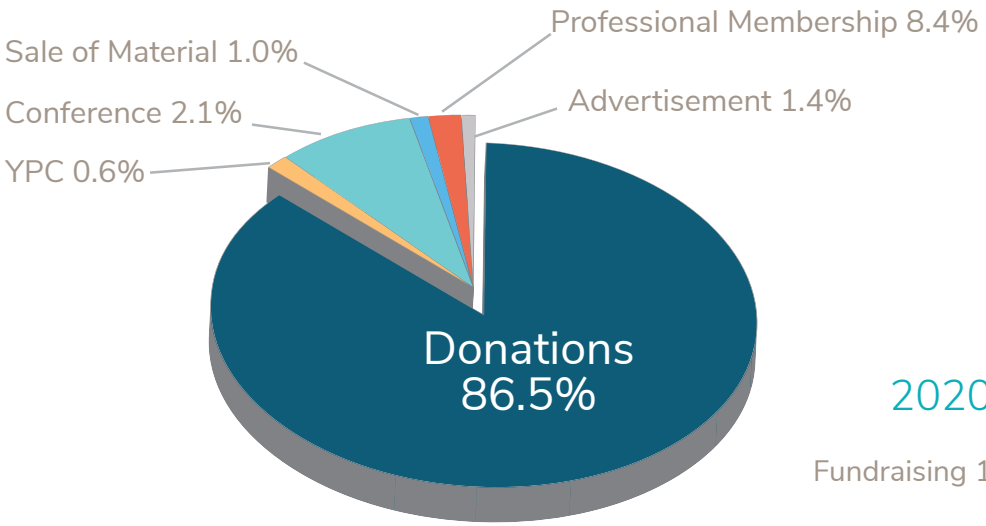
Each time I painted, I felt that I reclaimed my face by turning the aching, crushing pain into beauty and color. It made my pain visible. I didn’t need to talk about it with family and friends because they could actually see it, so they stopped asking me how I was feeling. Strangers asked questions, and I was able to raise awareness. I also found that as meds lowered my pain levels that wind was a trigger, but touch was not. The paint sealed my skin from the air and helped keep pain levels lower. The paint patterns also became a record of where my pain was and how it was growing over time.

As life got busy again— getting married and trying to work odd jobs here and there, I painted less, but I still do it when I feel I need a lift emotionally or when I have a new symptom and need to come to terms with it. ■

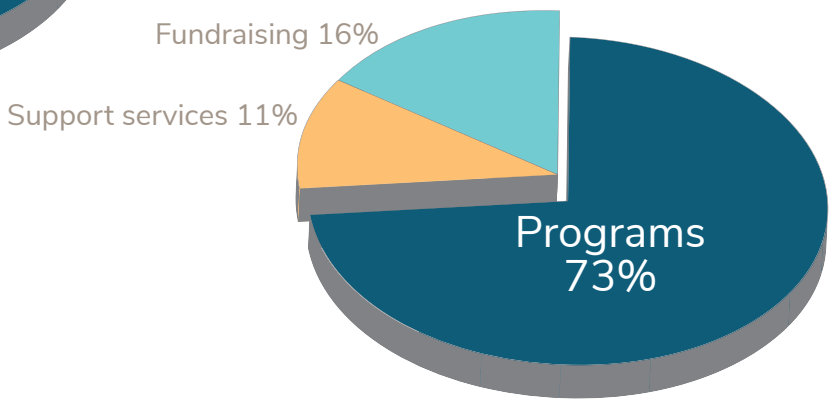
Financial Snapshot

The FPA Annual Report is more than numbers, it is the story of our impact in the facial pain community.

2020 Sources of Revenue

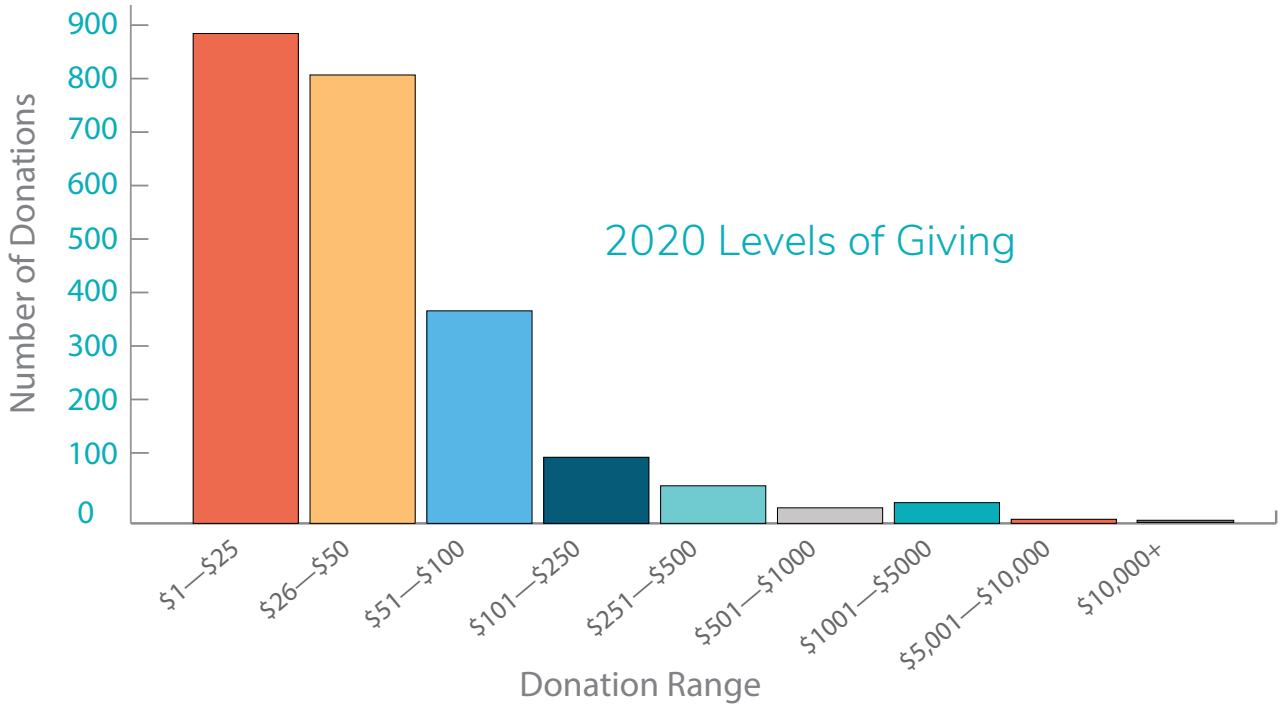


2020 Expenses



We retain our core mission and values as we bring FPA into its fourth decade.

2020 Levels of Giving



Donor Acknowledgement

LEGACY SOCIETY

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.

Anne and John Ciemnecki
Doris Gibson
Carlin Lagrutta
Miriam Leinen
Mary Ann McCann
David and Jody Meyers
Charles Muchnick
Mary-Ann Neri
Paula Rosenfeld
Arthur and Ann Schwartz

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.

William Albert
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Douglas Caldwell
Joey Callahan
Robert Camp
Daniel Desmedt
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I am deeply grateful for the education and hope the FPA has provided to me. It is a privilege to give a few dollars each month to say thank you and to help sustain this crucial organization.

— Cynthia

As a third generation woman with trigeminal neuralgia, the Facial Pain Association has helped my ancestors. I joined the Legacy Society to be sure the association can continue to educate and advocate for future generations."

—Anne

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I can operate, but FPA gives hope and support to so many people. That is priceless. Thank YOU!

— Dr. Chang

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I appreciate you and your help very much. Our chat yesterday was like a ray of sunshine for me. I have been suffering alone for too many years so your kind words of encouragement mean a lot to me.

— Bob

Something really special is happening in the FPA and it is thrilling for me to be part of it. I have also gained a great deal of wisdom from the people in my group. Moderating the group has helped me in surprising and unexpected ways. Thank you for giving me the opportunity to be part of this worthy endeavor.

— Michele, Support Group Leader and Peer Mentor

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Thank you so much for the info! That will give us a peace of mind. What you are doing is really great. May God bless you more so you can continue helping others with this condition.

—Rachel

It was a pleasure speaking to you over the phone today. Thank you for your time and kind words. I truly appreciate your help. I will go over everything one by one and I will let you know if I have any questions. Thank you again for being so kind and helpful. The Facial Pain Association is definitely the right place for me to seek medical help with regards to my facial pain.

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Thank you for your email. I have a friend battling trigeminal neuralgia and it's horrible. I feel helpless so thought this was a way to help her and others dealing with this.
I appreciate your reaching out and all the work your organization is doing.

— Sarah

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