

 **FACIALPAIN**
ASSOCIATION ANNUAL REPORT



2018

EDUCATION ADVOCACY SUPPORT

Welcome



WHO ARE WE?

The Facial Pain Association (FPA), a non-profit, 501(c)(3) volunteer organization, was founded in 1990 by a team of people who were profoundly grateful for recovery from years of disabling trigeminal neuralgia pain. The organization now assists thousands of others around the world. FPA has emerged as the world's leading resource for information and health care guidance for all people suffering from neuropathic facial pain. Both patients and healthcare professionals benefit from its programs of education, personal support, and advocacy. The Association is governed by a Chief Executive Officer and a Board of Directors.

OUR MISSION

To serve those with neuropathic facial pain, including trigeminal neuralgia, through support, education, and advocacy.

VISION

To be the most reliable and comprehensive resource on facial pain conditions for patients, their families and healthcare professionals.

GOALS & OBJECTIVES

To accomplish its mission, FPA will:

- Maintain a support network across the USA and around the world
- Manage a website providing worldwide access to accurate and timely information
- Establish a conference program supported by healthcare experts
- Furnish patients, healthcare professionals and others with educational materials and information
- Create and manage a virtual community of face pain using multiple social media platforms

CORE VALUES

Professionalism: to maintain high ethical standards with a focus on improvement in treatments, procedures and patient care

Compassion: to recognize the impact of chronic facial pain and to treat every patient and family member with courtesy, concern and respect

Objectivity: to act in the interests of our patients without bias

Innovation: to use technology to further FPA's mission

Advocacy: to increase public awareness and promote the interests of our patients



John Koff, CEO

Dear Friends,

The Facial Pain Association enjoyed a transformative year in 2018. We welcomed new staff, new Board Directors and new medical professionals to our Medical Advisory Board. We moved offices, we saw thousands of patients join our Facebook support group and hundreds more become new members of the Association.

These changes, along with the support of our members, donors, sponsors, support group leaders and volunteers, will help us to meet the challenges of 2019. First and foremost of which will be delivering our mission of support, education and advocacy to people suffering with facial pain and their loved ones around the globe.

The highlight of 2019 will be the Facial Pain Association’s 11th National Conference on November 2nd and 3rd at the University of California San Diego School of Medicine and sponsored by the UCSD Department of Neurosurgery. The conference will bring together some of the world’s leading experts on diagnosing and treating trigeminal neuralgia and related facial nerve pain with hundreds of people impacted by this disease. It will also kickoff the FPA’s 30th Anniversary in 2020.

Please join the Facial Pain Association by coming to our conference in November, or by becoming a member, volunteer, donor or sponsor. Become part of our growing voice to raise awareness of this rare and dreadfully painful disease.

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Leadership

Board of Directors



Jeff Bodington
Chairman



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Secretary



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L-R: Jeffrey Fogel, MD, Henry A. Gremillion, DDS, Ally Kubik, David Meyers



Ray Rivera, John Temple, Eric Wertheim

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Pam Neff, Amy Turner

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University of South Florida Health



Richard S. Zimmerman, MD
Professor of Neurosurgery
Mayo Clinic

The YPC Board of Directors is comprised of seven TN patients, ranging in age from 18-39 from across the United States.



Stephanie Blough, Ohio



Nick Foley, Illinois



Rachel Triay, Louisiana



Ellie Eichenlaub, New York



Mandi Ginn-Franz, Illinois



Kenzie Winslow, Colorado



Chris Nolze, New Jersey

Connect

Web and Social Media Resources

Facial Pain Association (FPA) is dedicated to making sure that patients and caregivers have all the support and resources necessary to spread the word and get help. Educated patients can understand options, take advantage of the FPA support network and learn to manage this disease so it does not manage them.



facepain.org

FPA website provides education, support and advocacy for patients suffering with TN and related facial nerve pain.



twitter.com/facialpainassoc

Join the discussion by following our frequently used hashtags:

#TrigeminalNeuralgia
#facepain
#facialpain
#chronicpain



Email: info@facepain.org

Mail: 22 SE Fifth Avenue, Suite D
Gainesville FL 32601

Phone: 800-923-3608

"The best ally in the treatment of trigeminal neuralgia is a well-informed patient."

— Dr. Albert Rhoton, Jr.



facebook.com/ facialpainassociation

Find the latest announcements, as well as interesting articles relating to facial pain and the association.



FPA | Official Trigeminal Neuralgia Network

• JOIN!

- Share and connect with other patients
- Read patient posts and points of view
- Post to our page if you find an interesting article or have something to share with other patients.



Young Patients Committee facebook.com/tnaypc/

The Young Patients Committee is the division of The Facial Pain Association specifically for patients under the age of 40. Our members range from children to 39 years old.

Thank you for your support in 2018.
Here's how you've helped further the Facial Pain Association mission.

FACIALPAIN ASSOCIATION

2018 IN

Numbers



12,000+
Facebook members
100 new
Facebook friends a
week on average



6,800
Facebook Likes

4,000 - 8,000
feeds/week

Young Patients Committee



2,000+ Facebook members

2,500
followers on Twitter



10k+ Tweets

5,000 journals mailed
quarterly

Quarterly

30,000 journals
emailed quarterly



Provide support to
approximately **60**
incoming callers/week

500
FPA Patient Guides
downloaded monthly



600 books
purchased



25 International
support groups
300+ attendees



500 attendees per session



150 Conferences attendees



30,000 website visits per month



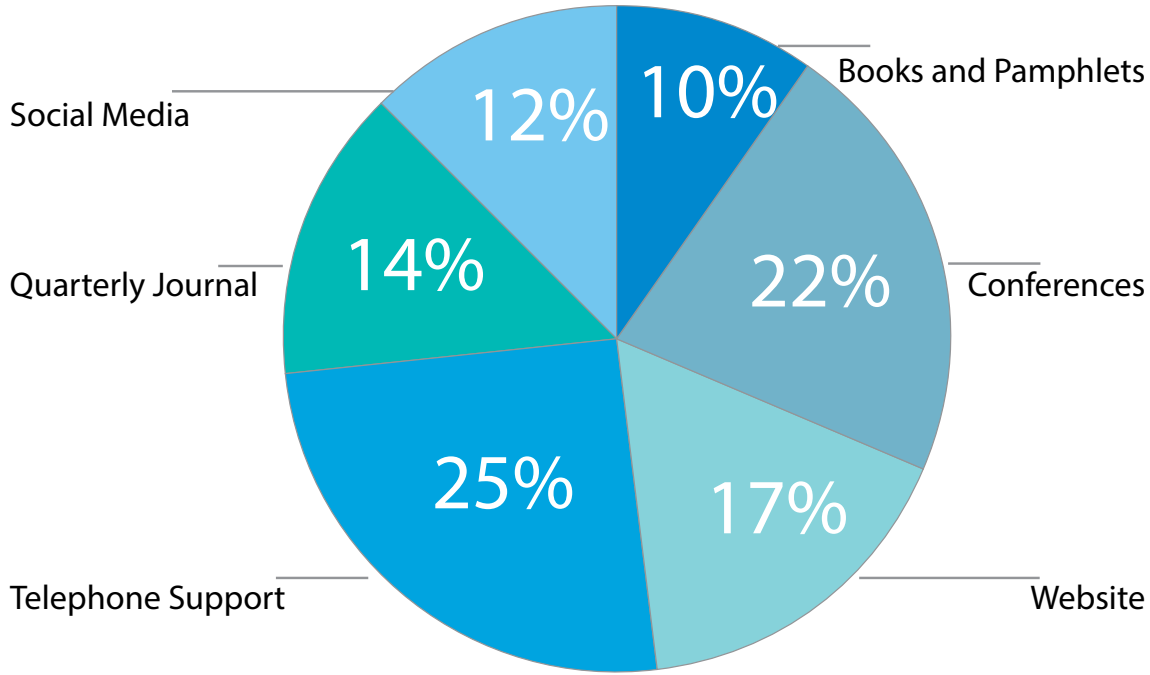
850 Active FPA Members

Financials

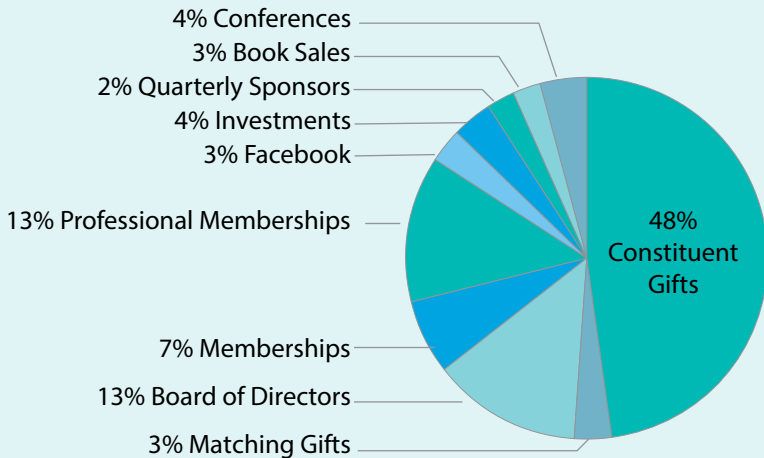


as of December 31, 2018

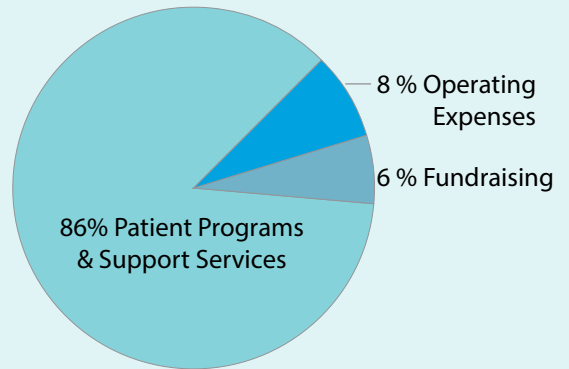
2018 Programs & Support Services



2018 Source of Revenue



Use of Funds





ANNUAL DONOR
Individual Membership Program Recognition Levels

Recognition Levels

Chairman's Club \$15,000-\$25,000
Platinum \$5,000 to \$15,000
Gold \$2,000 to \$5,000
Silver \$500 to \$2,000
Patron \$100 to \$500
Friend \$50 to \$99

Chairman's Club

- Prominent recognition at the Gainesville headquarters office
- 100% Discount on all FPA books
- 100% Discount on FPA Conference Registration Fee

Platinum

- Prominent recognition at the Gainesville headquarters office
- 50% Discount on all FPA books
- 50% Discount on FPA Conference Registration Fee

Gold

- 25% Discount on all FPA books
- 25% Discount on FPA Conference Registration Fee

Silver

- 15% Discount on all FPA books

Patron

- 10% Discount on all FPA books

Friend

- 5% Discount on all FPA books

Benefits – all levels

- Recognition in the Annual Report
- FPA Quarterly Magazine Subscription
- Newswire Email Monthly Subscription
- Access to Live Webinars

With great appreciation we recognize the following 2018 Donors



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I am just so thankful that people like you are helping the healthcare industry to realize TN is a real and major problem for people with pain. Thank you for all you do. It is really appreciated.

— S. D.

Thank you so much for your continued help and support! My condition is complicated (ATN) and I am very limited in my ability to read and research as this is one of my triggers. I have been losing hope that I will ever get some pain relief. Your words of encouragement and suggestions have literally saved and changed my life.

— C.H.

Your support helps connect the TN community in our shared effort to end the pain.

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Gwendella Walker
Claire Waller
Cathy Walters
Howard Webb, MD
Bryant Whittaker
Sonya Williams
William Williams
Teri Wong
Robert Zawacki

*Just wanted to thank
FPA for the webinar on
Neuroplasticity. I've been
trying to incorporate this
as part of my daily routine.
I really enjoyed the insight
on how Neuroplasticity can
help me manage pain.*

**Much appreciation,
M. F.**

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Steven Zachow, MD
Lucia Zamorano, MD
Arnold Zeal, MD
Mario Zuccarello, MD

In April I emailed you requesting help in finding a surgeon to help with my TN. You recommended several neurosurgeons in my area. In April I had surgery and I am very pleased to tell you the pain is GONE.

*Thank you for your help,
— T.C.*



Professional Member Organizations 2018

Anchorage Radiation Therapy Center	Johnston-Willis Hospital	Rocky Mountain Gamma Knife Center, LLC
Austin CyberKnife	Mayfield Brain & Spine	South Sound GK Center
Boston GK Center	Mayo Clinic	Springfield Neurological & Spine Inst.
Central Wyoming Neurosurgery	MiamiNeuroscienceCenter at Larkin	St. Luke's The Woodlands Hospital
Emory Saint Joseph's Hospital of Atlanta	Neurological Surgery, P.C. "NSPC"	St. Vincent's HealthCare
Advent Health-Neuroscience Institute	New Jersey Neuroscience Institute	Thomas Jefferson University Hospital
Goodman Campbell Brain and Spine	Northwell Health	UC Irvine Medical Center
HCA Midwest Health	Parkview Health	University of VA, GammaKnife Center
Hoag Hospital	Robert R. Smith,MD Gamma Knife Center	University of Cincinnati
House Neurosurgical Associates	Robert Wood Johnson University Hospital	Valley Health Systems
The Johns Hopkins Hospital		Weill Cornell Brain and Spine Center

Having TN is terrible. Having the support from Facebook and from you and the other staff/volunteers has been a blessing from heaven.

Thank you from the bottom of my heart.

— C.H.

I appreciate the encouragement this organization has given me when I needed it most.

— L.W.

For information on professional membership please contact the Facial Pain Association
800-923-3608
info@facepain.org

Patient

Profile



Name: Karl Kroeppler

TN Story:

It started about 10 years ago. I was toweling off after a shower one night and I felt a small spark in my forehead. I didn't think anything of it at the time but was concerned. Over the next 2-3 weeks, it turned into full blown electric shocks on the right side of my face. I screamed and swore uncontrollably when the episodes occurred.

Art Integration:

I've always considered myself an artist. I was the kid who was always drawing and painting. After high school, I studied at Arizona State University and received my Bachelor of Arts Degree in Studio Art. Thirteen years later I returned for my Master of Fine Arts Degree in Drawing and Painting.

When everything got worse at the end of 2015, I told my wife from here on out I would only create work about TN to educate people. When you go into an emergency room – or anywhere, really – people have no idea what you're talking about. The ER had no understanding of how to treat me and told me to take Tylenol for my headaches. I made the decision then that this has to stop. Not only is it terrifying to have episodes of facial pain, it's more terrifying to have an entire hospital staff not know how to treat you.

It's awful.

I decided to make art my full-time career and all of the art I create deals with trigeminal neuralgia in one way or another. I'm putting myself out there to educate the general public, in all of the forms of art I produce.

Ultimate Goal:

My goal in life is to educate people. I want to show them there's a formally trained artist, working in the fine arts, trying to reach out to the general public and educate them about trigeminal neuralgia. This is my life from here on out, and I can't imagine doing anything else other than this kind of imagery. I realize the power of art. Art truly can heal and provide comfort. I know there are people out there who are expressing their experience with this affliction through various media and I encourage them to continue in order to help them find some peace or comfort during their darkest days.

I want to show people that there's someone out there making lemonade from lemons.

To learn more about Karl's art and see more examples of his work, visit <https://kroeppler.weebly.com>



Patient Profiles



Name: Linda Perdue

In August of 2016 I was diagnosed with trigeminal neuralgia. I had relief for 2 months with tegretol but became severely allergic to it. My neurologists tried all combinations of drugs for pain relief and when that failed, I even opted for cervical chiropractic care and acupuncture. My active lifestyle became severely curtailed. I was battling severe pain that made even eating, brushing my

teeth and washing my face a total nightmare. I honestly did not know where to turn next as I was in so much pain and depressed.

I searched the Internet and came across the FPA. I don't know where I would be today without that connection. I called and Mitzi became a compassionate listener and patiently started sending me lists of doctors, alternative treatments and videos of past trigeminal conferences.

It was a great educational resource and enabled me to start moving forward in my search for healing. I was surprised to find out there were so many positive choices to move towards healing. I loved the video by Dr. Alksne explaining what to look for in a surgeon who will be performing a MVD.

Mitzi and Pam Neff, the nurse at FPA, told me Dr. Alksne was in my area and that would be a good place to start. After meeting with Dr. Alksne and having several tests, he performed my MVD surgery in late 2017 and I can say that it was life changing.

I had an MVD done on a vein with 3 strangled nerves. The minute I came out of surgery I was pain-free and have remained so 3 months later. MVD's are typically only done on arteries, but there is always hope and different procedures available... with the many good doctors out there and the compassionate and empathetic help of the FPA, you too can find help and healing. I feel so blessed to have been treated by Dr. Alksne and to have had the direction from the FPA. Without their help I truly don't know if I would still be here today .



Name: William Clark

Where do you live?
Willingboro, NJ

How old were you when you were diagnosed? Age 30

What was your diagnosis? My initial diagnosis was trigeminal neuralgia, type 2, on my right. Two months later, the pain started on my left, fast forward two years later and add on the diagnosis of occipital neuralgia, on the left.

What do you do for fun? When the pain allows, travel and go to the movies.

What has TN taught you? TN has taught me alot, but I have learned who will be in your corner and who won't be in your corner. Most of all, it has taught me that I was given this disease for a reason, to advocate and educate others.

What treatments (non-surgical) have you tried?
Acupuncture and massage

Have you had any procedures? No

How has your facial pain changed you? Well, I go into what I call "hibernation" from November to March because of the cold weather. So this has taken a toll on my social life. I also have a two year old son. What I can do for and with him has changed because of my pain. It is definitely hard, for me to say "no, daddy can't do that."

What tips do you have for other young patients? Get a good support system around you, meet other TN patients- they are dealing with the same thing you are and can be a great addition to your support system, don't let TN stop you from doing what you want, and attend conferences, they are very informative.

Young Patient Profile



Name: Mackenzie Winslow

Where do you live? Highlands Ranch, Colorado.

How old were you when you first experienced facial pain?

I was 11 years old and playing softball when I first experienced TN.

How old were you when you were diagnosed?

I was diagnosed pretty quickly, just weeks after I first experienced

pain. I was still 11 years old. It was an emergency dentist who first uttered the words “trigeminal neuralgia” to me and my parents. The diagnosis was confirmed at an emergency room later.

What was your diagnosis? My diagnosis is TN1.

What do you do for fun? For fun, I read, hang out with my friends, color, and model in California!! I’m also applying to colleges currently. College was something I never thought I’d be able to do, especially not out-of-state. But now, after my MVD, I have the chance to really chase my dreams. It’s so rewarding to receive admission into some of my top choice schools (I’m still waiting for most!) and to see how much they believe in my ability to succeed. Middle and high school was difficult with TN, yet the hard work has paid off and I have been awarded scholarships I never thought possible. Looking to the future like this has really been a great experience that I’m lucky to get to have!

What has TN taught you? TN has taught me that I AM capable of adapting to new situations. I had to change much of my daily routine and it was hard at first, but it became my new normal. It also taught me the power of family and friends. I lost a lot of friends along the way, but the friends who stayed

by my side proved to me that they were true friends. TN helped me see the true side of people sooner than I would have if I didn’t have TN.

What treatments (non-surgical) have you tried? MAGO (Maxio Anterior Guided Orthotic), acupuncture, upper-cervical chiropractic treatments, massages, trileptal, gabapentin, steroids, chinese herbs, marcaine injection, biofeedback, valtrex, a TENS unit, tegretol, oxtellar, and gralise.

Have you had any procedures? I had a microvascular decompression on March 4, 2014.

How has your facial pain changed you? I had to grow up a lot more quickly. I don’t wish my diagnosis never happened because I think it shaped me into the person I am today. Because of what I’ve been through, I’ve realized that I want to use my life to help people. And it helped me see people’s true colors, which has given me the chance to form stronger bonds and friendships with people who are worth it.

What tips do you have for other young patients? I think that having an open mind is vital. If I didn’t have the optimism I did when I was going through pain it would have been much more difficult. I’ve experienced healing pain since my surgery that I think a lot of people have post surgery and it’s been extra tough to stay optimistic through that, but it’s also been incredibly important. I know that with four years of pain comes four years of healing and I’m ready to face that. But you have to stay optimistic and happy throughout the healing process or you’ll only cause more challenges for yourself. Also, I realized that tough love from significant others is still love. I struggled with the tough love my parents gave me, but in the end I realized that they only wanted the best for me and were trying to help me. Take one-on-one time with those you love because it can be overwhelming for them too and it’s important for them to know that even amidst your pain you can still love them.



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I want to thank you so much for being there for me on Wed. I so needed someone to talk to and get some advice. Thank you for being my angel that day. I will never forget that.

— L. F.



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You have NO idea how much today's News Wire meant to me, I received this story when I needed it most. In a time of severe isolation, I can read this to my husband and hopefully open his eyes. Thank, thank and thank you!! Kind Regards,

M. L



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- Raise funds on Facebook or through a peer-to-peer platform (like Crowdrise)
- Make a donation
- Read and share materials available in our FPA Journal or posted on our website
- Attend our National Conference in November
- Social media
 - Interact with other patients and their loved-ones
 - Share your story
 - Help spread the word about facial neuropathic pain like trigeminal neuralgia



 **FACIALPAIN**
ASSOCIATION
UC San Diego

November 2-3, 2019
San Diego, CA



**Connecting patients, supporters
and medical professionals**

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