Dear Friends,

2019 was a transitional year for The Facial Pain Association. Jeff Bodington turned over the reins as Chairman of the Board to David Meyers, John Koff retired after 15 years as CEO, and I took his place in November.

We held our 11th National Conference on November 2nd and 3rd at the University of San Diego School of Medicine, which was sponsored by the UCSD Department of Neurosurgery. Several hundred people affected by facial pain listened to speakers and participated in discussions about a variety of relevant topics, had time to speak with doctors and enjoyed networking time with others. Several members of the FPA Medical Advisory Board also traveled to San Diego to present on topics including diagnosis, treatment, medication and therapies.

2019 also marked a growth in the FPA Facebook community – our closed group, the Official Trigeminal Neuralgia Network, includes more than 15,000 members who can share their experiences, ask questions, support others as they experience new challenges and cheer their successes.

More than 6,000 people seeking information about their condition contacted FPA in 2019. We provided them with a free Patient Guide and connected them to many resources and support. Our educational webinar series also continued to be a popular program in 2019.

2020 marks the 30th Anniversary of our organization. Claire Patterson, the founder of what was originally the Trigeminal Neuralgia Association, graced us with her presence at the San Diego conference and expressed her enthusiasm for our plans to expand our Support Group program and engage new healthcare providers.

The Board of Directors has embarked on a strategic planning process. This work will serve as the roadmap to improve and thoughtfully grow the programs and services that are most important to the facial pain community. In addition, the support of our board of directors, medical advisory board, donors and sponsors will help us to grow in 2020. We are grateful to these dedicated volunteers and professionals who ensure we meet our mission of support, education and advocacy to people suffering with facial pain and their loved ones around the globe.

The FPA Young Patients Committee is a passionate group of people under age 40 affected by facial pain. Their TN Awareness Day video, #ChooseToSmile had 2,600 views and, across all four social media platforms, the group has 3,000 followers. The committee was able to sponsor nine young individuals with facial pain to attend the national conference and began a junior ambassador program.

FPA is incredibly grateful for our wonderful volunteers as we look to 2020 and beyond, we plan to grow our support group program, provide ongoing education and training for volunteers, and support their efforts to help patients and caregivers in their communities.

On this 30th anniversary of FPA, we recommit ourselves to serving every person affected by neuropathic facial pain, becoming more responsive, offering new ways to connect and bringing more programs to you. Thank you to all those who support this wonderful organization and ensure we will be able to continue to help those who so desperately need it.

Allison Feldman, CEO

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.
The Young Patients Committee is comprised of TN patients, ranging in age from 18-39 from across the United States.

Stephanie Blough, President  
Kenzie Winslow  
Ellie Eichenlaub  
Rachel Triay  
Not pictured, YPC Junior Ambassadors:  
Mollie Dyer  
Elaina Jackson
Thank you for helping to further the mission of the FPA in 2019.

**FACIAL PAIN ASSOCIATION 2019**

- **360,000** website visits
- **400** webinar registrants per session
- **20,000** mailed
- **120,000** emailed
- **6,000** downloaded
- **225** National Conference attendees
- **150** national and international personal support resources
- **2019**
- **1,200** active FPA individual members*
- **3,500** followers
- **60,000** impressions
- **2,000** profile visits
- **225**

facebook.com/facialpainassociation
Private group:
- **10,000** likes
- **15,000** members
- **50,000** posts/comments/reactions

twitter.com/facialpainassoc
- **3,500** followers
- **60,000** impressions
- **2,000** profile visits

Young Patients Committee
OVER 3,000 SOCIAL MEDIA FOLLOWERS

- @youngpatients
- @tnaypc
- @tnypc
- @YPCtna

---

*A member is anyone who donated $50 or more in 2019*
As of December 31, 2019

2019 Programs & Support Services

- Educational Materials: 10%
- Social Media: 11%
- Quarterly Journal: 12%
- Conferences: 17%
- Website: 28%
- Telephone Support: 22%

2019 Sources of Revenue

- Donations: 71%
- Conference Fees: 11%
- Professional Memberships: 13%
- Conference: 3%
- Sale of Materials: 2%
- Sponsorships: 8%

Use of Funds

- Patient Programs: 79%
- Fundraising: 13%
- Supporting Services: 8%

FINANCIALS

FACIAL PAIN ASSOCIATION
SUSTAINER CIRCLE

We gratefully recognize all donors who have signed up to become FPA monthly donors, having funds directly charged to their credit card or withdrawn from their bank account automatically each month. These donations provide a reliable source of funding that allows us to sustain the initiatives of the Facial Pain Association while spending fewer resources on fundraising.

We welcome our current monthly donors, listed below, into the newly established Sustainer Circle.

Douglas Caldwell
Kelly & Robert Camp
Anne & Stephen Fleming
Lorri Genack
Frank Moreno
Lynn Wendell

ANNUAL DONOR

Individual Membership Program Recognition Levels

<table>
<thead>
<tr>
<th>Membership Level</th>
<th>Monthly Contribution</th>
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<tbody>
<tr>
<td>Chairman’s Club</td>
<td>($15,000 +)</td>
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<tr>
<td>Platinum Supporter</td>
<td>($5,000 to $14,999)</td>
</tr>
<tr>
<td>Gold Supporter</td>
<td>($2,000 to $4,999)</td>
</tr>
<tr>
<td>Silver Supporter</td>
<td>($500 to $1,999)</td>
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<tr>
<td>Patron</td>
<td>($100 to $499)</td>
</tr>
<tr>
<td>Friend</td>
<td>($50 to $99)</td>
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As we celebrate the 30th Anniversary of our founding, the FPA hopes to continue providing support, education and advocacy to those who need it for another 30 years. You can help secure this future by choosing to include the Facial Pain Association in your estate plan.

By including us in your will or living trust, naming us as a beneficiary under an individual retirement account or otherwise including us in your estate plan, you will secure the future of the FPA mission and forever be remembered as a member of our Legacy Society.

Please contact us for further details.
With great appreciation we recognize the following 2019 Donors

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Those who became new or renewed members in 2019 have been incorporated into the appropriate giving level.
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When did you first start having symptoms and what were they?

Two years before being diagnosed with trigeminal neuralgia, I had what has been referred to as “pre-TN” - mainly teeth problems and a constant ache. My dentist knew there was nothing wrong with my teeth. One day I felt a zap of pain on the tip of my nose “like the exorcist” at 38 (50 years ago). An internist diagnosed me with tic douloureux, which means painful tic, a term coined way back by a French physician. In 20th century it became clinically known as TN – connected to trigeminal nerve.

What did you learn about TN?

Medical information on TN was almost nonexistent at the time. At most, you’d find a paragraph in a medical book. Friends helped me find resources and I did a lot of research at the library. Since there was no cause of death listed with TN, most physicians looked at it as “you’re not going to die from this, just take your medications and carry on”. The attitude was that TN is not an urgent disorder.

What treatments did you receive and were they successful?

I had been seeing a neurosurgeon at a prestigious teaching hospital and was prescribed different cocktails of medications for over 10 years that didn’t work. The pain kept escalating. I ended up in the hospital and “the rest is history”.

My internist found out about new surgery being done to sever the nerve. I went to see Dr. Peter Jannetta, world-renowned developer of microvascular decompression (MVD), a procedure that moved blood vessels away from the trigeminal nerve alleviating the pain. An MRI showed that I had a large artery twisted around the trigeminal nerve and I decided to have the surgery because that was the only option at the time. Jannetta worked his magic and I woke up pain-free.

What prompted you to start the FPA (formerly known as Trigeminal Neuralgia Association)?

There were, and still are, patients living years in isolation with the disorder having no information available. I spent 10 years without talking to anyone with the same pain. Speaking with others is a whole validation process. Being in the company of others with the same disorder validates that the pain is really that bad. It’s a real phenomenon. I wanted to create a forum for support and education. Discuss ‘mistakes’ made – sharing laughs and tears. TN is such a unique pain that so many people still don’t know about. It affects all of your most basic functions – licking lips, shaving, cold weather – and is extremely painful.

I wanted to create a nonprofit with the mission of providing resources and support for those suffering. We were not going to give crazy answers, we were going to provide resources and a medical advisory board. Answers. Now patients have a lot more information and there isn’t so much to sift through. It’s not a mystery any longer. There are ways to get educated.

How has the FPA grown over the years?

Dr. Jannetta’s involvement and motivation to grow the organization was a primary push that that we needed to get off the ground. His expertise brought medical credibility to the issue and the organization.

Over the years the FPA has made big changes in how the medical community regards TN. There are so many more treatment options to explore and not a one size fits all. We need to keep providing updates on treatment protocols and ensuring patients have the support needed.

We have grown from the early days of working out of my kitchen in Barnegat Light, NJ to one of the most trusted resources on neuropathic facial pain around the world. We will continue to grow our resources to meet the needs of those who turn to us for help.
When did you first start having symptoms?
At first, I felt strange - sensations – numbness, tooth pain, etc., but didn’t really pay it much mind. At age 42, I had a root canal and felt a lot of pain after that. I don’t know whether the sensations preceding the root canal were early symptoms of TN, but the toothache never resolved, even after the root canal. In fact, the achiness and heaviness were more severe. An endodontist performed an apicoectomy, a root-end resection surgery, which worked to ease the pain initially, but then the odd sensations came back.

What treatments did you receive and were they successful?
When the sensitivity returned, I went to an oral surgeon to see about having the tooth pulled. He assured me that I did not have any dental issues, so he sent me to a neurologist.

My neurologist diagnosed me with atypical odontalgia, also known as phantom tooth pain (a term no longer used) and tried a series of medications but, ultimately, nothing helped. Frustrated, I stopped seeking treatment and decided just to deal with it. This was going to be my new normal.

While at an orthodontist appointment with my kids, I mentioned my pain to the orthodontist. He referred me to a wonderful oral-facial pain dentist who listened carefully and would not stop trying different treatments and combinations of medications until, after a year, I found some relief. As in the past, this relief was only temporary.

In my research, I came across the name Dr. Steven Graff-Radford, a specialist in head, face, and neck pain and traveled to Los Angeles to see him. He was the first physician to suggest my pain was not atypical odontalgia and suggested an MRI. The MRI showed compression of the nerve.

Eleven years after my initial symptoms, I had my first MVD surgery. Eight years later I had a gamma knife procedure, and then three months later I had my 2nd MVD.

What led you to the FPA?
Interestingly, both my mother and maternal grandmother had similar experiences with facial pain. During my mother’s search for answers, she found Claire Patterson, founder of the Trigeminal Neuralgia Association (now called the Facial Pain Association). I personally connected with the association after an internet search for more information.

Through my family, I have seen how education and treatment has evolved over the years. The FPA has played a significant role in that evolution by providing advocacy and informing the community of treatment options. I went to a conference in Detroit and learned that TN should be treated like other chronic pain conditions. With that, I changed my perspective. I no longer looked for the next best treatment that may or may not work. Instead, I looked for ways to live well in spite of the pain. The FPA saved my life. I then became a Support Group Leader and was later asked to join the Board of Directors.

How does facial pain affect your life today?
I still experience pain but can mostly control it with the use of prescription drugs and medical marijuana. I keep a positive attitude and refuse to let pain stop me from living my life. I’m a wife, mother, grandmother and domestic violence victim advocate. In addition to the FPA, I volunteer at an animal shelter and work with therapy dogs. I am on the Commission that over sees AmeriCorps programs in New Jersey. I help agencies in New Jersey retain and manage volunteers. I live a full rewarding life. My grandmother and mother are my inspiration. They would be proud of how I am living and loving my life.
When did you first start having symptoms?

I remember having pains as far back as standing at the bus stop for school. I had pain in my left ear that would come and go in quick succession. I didn’t mention it to anyone because I thought it was normal. Like having a stitch in your side.

The first debilitating, stop me in my tracks pain came when I was 24. I was getting out of the shower when the worst stabbing pain I have ever felt hit me. It was as if someone was taking an ice pick and stabbing the side of my face. It took me to my knees.

What steps did you take to seek treatment?

I went to see my family physician and was diagnosed with chronic sinusitis and allergies. I was prescribed various allergy medications which eased the pain for about 2 weeks. When the pain returned, I went back to my family physician who repeated the treatment. This cycle continued for 5 years.

How and when were you diagnosed with TN?

I finally took it upon myself to see an ENT in January 2012. After a 2 ½ minute conversation about my symptoms, he was able to tell me I had a neurological condition and referred me to a neurologist. The neurologist ordered an MRI and was able to determine that I did not have any tumors causing the pain, but that I had a condition called trigeminal neuralgia.

What treatments did you receive and were they successful?

When migraine medications were unsuccessful, I was prescribed Gabapentin, an anti-convulsant, which helped ease the pain. But as the pain continued to progress, doses were increased, and I found myself struggling as a student, wife and fur-parent. So I decided to see a pain management specialist. I was treated with nerve blocks every 6 weeks and, while I responded well to these in combination with the medications, I was still experiencing pain. At that point, I went back to see my neurologist who ultimately suggested a Rhizotomy.

In October 2013, I had an outpatient Rhizotomy on a Friday, slept over the weekend and was back at work that Monday, 99% pain free. I weaned off all my medications and have been pain-free since.

What led you to the FPA?

Thankfully I have a very supportive family and husband, but I still felt alone and wanted to find other people who could relate to my journey. So, I started googling “face pain” and “TN support” and came across the FPA website, which had loads of information. I received a warm welcome when I reached out for a patient packet and started following FPA communications. I felt a sense of community – someone else gets it.

I learned about the Young Patients Committee through social media and when I saw a callout for new members, I sent in my resume, was chosen for interview and asked to become a member in 2014. In 2017 I was voted in as president and have been with YPC in total for 6 years.

What do you foresee as the future of the FPA?

I see the FPA evolving more globally. The association has hit the ground running and is doing a phenomenal job connecting and supporting people. With continued education and outreach, we will find more and more people out there who are suffering. I also see an increase in the involvement of younger patients. Neuropathic facial pain is often thought of as being a disorder predominately affecting those in their 50’s and 60’s. I see an increase in much younger patients suffering and want to assure them that they are not alone. We are a strong, supportive community as a whole. Ultimately, I see the entire facial pain community connecting, through any means, so we can grow together.
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Lauren Wert
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Janice Witkowski
Diane Dee Wood
David Yost
Yifu Zhu

Active members are individuals who became members prior to the 2019 updated program.
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Adele F. Abramson
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KC Support Group
Kathleen Warren
Edmund L. Kelley
Janice H. Kelley

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Cele LaChance
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Angela Briggs
Kelley Weeks
Douglas Weeks
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Dr. Robert J. White
Jane A. Irving
Kenzie Winslow
Floyd Winslow, Jr
Linda C Wright
Amy Wolf
Stephanie Duke
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<td>Dr. Steven Graff-Radford</td>
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<td>Mr. &amp; Mrs. Daniel Acquaviva</td>
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<td>Felix Mintskovsky</td>
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<td>Diane Lipenholtz</td>
<td>My father, Ahmad Mokhtarzadeh</td>
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<tr>
<td>Mitra Perel</td>
<td>Michael O’Brien, Statesman</td>
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<tr>
<td>The Colletta Family</td>
<td>Jacqueline Ogilvie</td>
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<tr>
<td>Meg Floyd</td>
<td>Emily Bradley</td>
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<tr>
<td>— 19 —</td>
<td>2019 FACIAL PAIN ASSOCIATION ANNUAL REPORT</td>
</tr>
</tbody>
</table>
Mary Paris
Judith & John Ashby
Cecilia & Bradley Jacobson
Teresa & Osmond Kemp
Marina & James Lounds
Peggy & Norm Munson
Michael Richards
Rose & Allen Sunne
Lynn Symons

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Dorothy Willis
Dorothy Rainwater, RN

Daisy Mae Young
Mr. Robert Young
ADDITIONAL WAYS TO SUPPORT

In addition to making a donation to the Facial Pain Association, there are other ways in which you can support the organization. For more information, visit facepain.org and click on “other ways to support.”

- Start a Support Group in your area
- Raise Funds
- Ask others to donate
- Create an Online Fundraising Event
- Create an In-Person Fundraising Event
- Create a Fundraising Campaign on Facebook
- Volunteer With FPA
- Use AmazonSmile when on Amazon
- Help Raise Awareness
- Visit Our Social Media
- Celebrate TN Awareness Day
- Attend or Host an FPA Conference

Donate Online
Visit facepain.org

Donate by Mail
Use the enclosed donor envelope

Donate by Phone
Call us M-F between 9:00 am - 5:00 pm ET
800-923-3608 or 352-384-3600

Donate through PayPal
PayPal.me/facepain

Donate through Facebook
Donate directly through Facebook by visiting our page and clicking the "donate" button @facialpainassociation

Become a Monthly Donor
Join the Sustainer Circle by becoming a monthly donor. Monthly donations are a great way to show your support while helping to defray administrative costs.

Employee Matching Gifts
Many companies will match employee donations which can double or even triple your impact.
Ask your HR representative or visit the following website to see if your organization participates: matchinggifts.com/rit

Donor Advised Funds
When you give, you want your charitable donations to be as effective as possible. Donor-advised funds are the fastest-growing charitable giving vehicle in the United States because they are one of the easiest and most tax-advantageous ways to give to charity.

Stocks, Bonds or Mutual Funds
A gift of appreciated securities like stocks, bonds and mutual funds can be a great way to support our mission.
When you transfer ownership of securities, you will receive a charitable deduction for the full market value and incur no capital gains tax subject to IRS deductible limitations.

Planned Giving Opportunities
By including us in your will or living trust, naming us as a beneficiary under an individual retirement account or otherwise including us in your estate plan, you will secure the future of the FPA mission and forever be remembered as a member of our Legacy Society.

Workplace Giving/CFC
Workplace Giving Campaigns give employees, their spouses and retirees a convenient way to give to the Facial Pain Association through automatic payroll deduction.
Check with your employer today to find out how you can designate the FPA through your Workplace Giving Campaign (FPA EIN#: 22-3071645).

Text
“SupportFPA” to 243-725 to donate

Tribute Gifts
Make a donation in honor or in memory of someone. You can also ask for donations to be made in someone’s memory in lieu of flowers for funeral services.
THE FACE OF HOPE FOR 30 YEARS

FACE OF HOPE 30

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