Thank you to all of our Professional & Signature Members

**Signature Members**

**AdventHealth Neuroscience Institute**
- Christopher Baker, MD
- Donald Behrmann, MD, PhD
- Melvin Field, MD
- Ravi Gandhi, MD
- David Rosen, MD

**Boston Gamma Knife Center at Tufts Medical Center**
- Julian Wu, MD, FACS

**Hoag Hospital**
- Christopher Duma, MD
- Ali Makki, MD

**New Jersey Neuroscience Institute-JFK Medical Center**
- Joseph C. Landolfi, DO

**Mayfield Brain & Spine**
- Steven C. Bailey, MD
- Vincent A. DiNapoli, MD, PhD
- Yair M. Gozal, MD, PhD
- George T. Mandybur, MD
- Ronald T. Warnick, MD

**Mayo Clinic**
- John L.D. Atkinson, MD
- Bernard R. Bendok, MD
- William P. Chesire, MD
- Chandan Krishna, MD
- Michael J. Link, MD
- Frederic B. Meyer, MD
- Bruce E. Pollock, MD
- Ronald Reimer, MD
- Robert E. Wharen, MD
- Richard S. Zimmerman, MD

**Robert R. Smith, MD**
- Gamma Knife Center
  - E. Thomas Cullom III, MD
  - Howard Holaday, MD
  - James Robert House, MD
  - Adam Lewis, MD
  - Steven Zachow, MD

**Rocky Mountain GK Center, LLC**
- Robert E. Breeze, MD
- J. Adair Prall, MD

**Seattle Neuroscience Institute**
- David W. Newell, MD

**South Sound Gamma Knife**
- Nathan Bittner, MD
- Ryan Halpin, MD
- Anthony Harris, MD, PhD
- Michael McDonough, MD
- Daniel Nehls, MD
- Huong T. Pham, MD
- Randy Sorum, MD
- Herbert Wang, MD

**University of VA/GK Center**
- Jason Sheehan, MD, PhD
- Zhiyuan Xu, MD

**The Valley Hospital**
- William Cobb, MD
- Anthony D’Ambrosio, MD
- Chad DeYoung, MD
- Thomas Kole, MD
- Michael F. Wesson, MD

**University of California, Irvine**
- Mark E. Linskey, MD

**Professional Members**

**Douglas E. Anderson, MD**
- Alan Appley, MD
- Larry S. Arbeiteman, D.C.
- Garni Barkhoudarian, MD
- Samuel L. Barnett, MD
- George K. Bovis, MD
- Michael Brisman, MD
- Andrew P. Carlson, MD, MS
- Edward Chang, MD
- James M. Chimenti, MD
- Jonathan S. Citow, MD
- Aaron A. Cohen-Gadol, MD, MSc
- Alain C.J. De Lotbiniere, MD, FACS
- Paul W. Detwiler, MD
- Bradley Eli, DMD
- Chikezie Eseonu, MD
- David Estin, MD
- Melvin Field, MD
- Brian D. Fuselier, DDS
- Steven L. Giannotta, MD
- Jordan C. Grabel, MD
- Thomas W. Grahn, MD
- Andrew W. Grande, MD
- Stephen Griffith, MD
- Babak Jahromi, MD, PhD
- Sheldon Jordan, MD, FAAN
- Wayel Kaakaji, MD
- Brian H. Kopell, MD
- Varun Kshettrry, MD
- P. Jeffrey Lewis, MD
- Jonathan Lustgarten, MD
- Shamin Masrour, D.O.
- Mark R. McLaughlin, MD
- Robert A. Mericle, MD
- Yaron A. Moshel, MD, PhD
- Stephen Nalbach, MD
- Joseph S. Neimat, MD, MS
- Mark B. Renfro, MD
- James Robinson, MD
- Benjamin Rosenbaum, MD
- Joshua M. Rosenow, MD
- K. Singh Sahni, MD
- Laligam N. Sekhar, MD, FACS
- Francisco X. Soldevilla, MD
- Azik Wolf, MD

For Professional Membership information please contact Amy Turner at aturner@tna-support.org
We are all in this together, figuring out what it means to shelter-in-place, quarantine, home-school or work-from-home. FPA will continue to provide education and support during this time of increased concern over COVID-19. We are proud to continue to offer free public webinars, updates about the latest in neuropathic facial pain news, and a vibrant social media community.

IN THIS EDITION OF THE Q

Meet our New CEO, Allison Feldman
Surgical Treatment of Migraine Headaches
A Conversation with the FPA Founder, Claire Patterson
Top Tips from Other Facial Pain Sufferers

MAB Corner
Snapshot of the 2019 Annual Report
The YPC on Friendship & TN Patient Profile
Memorial & Honorary Tributes

The complete 2019 Annual Report is available on the FPA website www.facepain.org
Everyone should know that the FPA is “Open To Serve You”. Our staff is working remotely, and we stand ready to provide the information and support you need. Please consider donating to the FPA so we can continue to provide our valuable services.

There is much uncertainty in the world today, but at the FPA we are quite clear about our purpose and where we are headed. Our mission is to provide outstanding information and support to those with facial neuropathic pain - usually those with Trigeminal Neuralgia, their caregivers / supporters, and the medical community dedicated to helping us.

Some of our most important priorities are to

a) substantially increasing the number of people who we reach so we can help more with this condition;

b) become even better at delivering the needed information and support to each person in their particular situation;

c) expanding the healthcare community’s awareness of the FPA and involvement in helping us deliver our mission;

d) developing an even larger volunteer corps for more Support Groups, help with FPA activities, and to staff a large Peer Mentor Group (more to come about this); and

e) raising more resources so we can do this to the best of our abilities and meet the needs of everyone in our community.

What will this mean for those of you impacted by this condition and those of you supporting us? It will mean that we’ll be able to get more excellent information and support to you when you need it. We will engage more healthcare providers in helping you. We are going to leverage the small staff that we have by engaging more capable volunteers to help. The volunteers who help us today bring an impressive level of passion, empathy, relevant experience and skills. Now, we are focused on getting more volunteers like these great people to be available for everyone who needs good advice, support, and on some days just someone to talk to. These are people who when they say “I know how you feel and what you’re going through and here are some things to consider”, they really do, because of their first-hand experience.

Those of you who receive the Quarterly know of the FPA and how we can help. Sadly, we believe that there are many people with severe facial neuropathic pain who are not aware of us, and hence they don’t receive the information and support that we provide. We need to reach these people and do whatever we can to help. Hence, we have more work to do in this area.

Finally, we’ve been planning a conference at one of the world’s great healthcare centers on the East coast for this Fall, but given the coronavirus, these plans are on hold for now. Fortunately, most of the information and support we provide is via phone or the Internet, so as I indicated at the outset, we’re “Open To Serve You”.

David Meyers, Chairman of the Board
The Facial Pain Association
Why Don’t They All Just Agree?

At the recent Facial Pain Association Conference in San Diego, California, a series of clinical vignettes concerning patients with facial pain was presented to a panel of members of our medical advisory board. Many in the audience reported their concern that the physicians universally disagreed on what to do. The thinking was, “If the doctors don’t agree on what to do for us, the patients, then how can we trust them to guide us in our journey to recovery from the terrible pain in our face?”

There is a lawyer joke that one should always seek out one-handed lawyers for help. Why? Lawyers always seem to advise by saying, “on the one hand you could do this… and on the other hand you could do this… Just tell me what I need to do!” is the natural response, but that is not the job of either the lawyer or the doctor.

In a recent neurosurgery journal editorial, Dr. Ed Benzel encouraged physicians to consider the question, “Who is driving the bus?” What we, as doctors, should be doing is teaching our patients to “drive” but with our guidance. After all, the word “doctor,” means “teacher”. A physician is a “healer”. What better way to heal than to teach one to choose the best path?

What are the rules of such an education? The choices offered must be rational, ideally supported by scientific evidence. There may not be sufficient evidence to distinguish between choices. This is certainly true between the success rates of the ablative procedures-gamma knife, Cyberknife, radiofrequency rhizotomy, glycerol and balloon compression. These are differing ways of achieving similar results. Sometimes one is more indicated than another and sometimes none are indicated. These represent “choices.” If you, as the patient, become invested in the decision as to how best to proceed-after being taught (within reason) the principles with which to choose-then it is more likely that you will continue to participate- to “comply”- with the treatment as it proceeds.

What is the best way to proceed with such teaching? It should not be a physician “monologue”, a one-way lecture. The doctor should assess patient understanding by a back and forth dialogue. I do, in my practice, conclude any discussion of what a microvascular decompression involves by stating, “You probably will not remember everything, I have just told you because you may be understandably nervous and having trouble concentrating, feel free to ask more questions at any time.” After all, doesn’t everyone want a “two-handed” surgeon to be looking after them?
In November of 2019, on the eve of the FPA’s 30th anniversary year, Allison Feldman succeeded John Koff as Chief Executive Officer. In her first few months on the job, she has attended our national conference, launched a strategic planning initiative, and hired two new staff members to help bring the Facial Pain Association into its next 30 years. I had the pleasure of sitting down with Allison recently to talk about her first impressions of the organization, what she envisions for the future, and the importance of continuing to support those living with facial pain during this difficult time in the world.

MKA: Allison, thanks for taking the time to allow the FPA community to get to know you better. Tell us a little bit about yourself.

AF: I grew up in New Jersey but went to college in Atlanta, which is where I met my husband Kyle. We live in the suburbs of Atlanta with our two kids, Jake and Jayne. When the kids were young, I stayed home with them and worked part-time in a variety of fields. When they were in elementary school, a friend connected me with a local non-profit that was in need of an administrative person. That position led to other opportunities in the non-profit space, which then prompted me to go back to school for a master’s in public administration. I ran a student scholarship organization, and then, before joining the FPA, I was the CEO of the Acoustic Neuroma Association, a national organization focused on serving those with another rare neurological condition.

MKA: How did that experience prepare you to take over the reins of the FPA?

AF: I was already familiar with a lot of the medical centers and doctors known for treating facial pain. In many ways, it’s helpful that I was starting to develop those relationships before I came to the FPA, and I’m looking forward to expanding them even more. I also attended several rare disease conferences, where I learned about the needs of people who have a rare condition and how difficult it can be not to have people around you who know about your condition, not have a local community, have trouble finding doctors who understand, etc. It opened my eyes to how difficult that can be and the unique needs of people with rare conditions.

MKA: Allison, you attended our national conference in San Diego last fall, before you had even started your job, and many of us on the board observed your hustling to meet with as many constituents as possible in the few days we were all together. What were your first impressions of the organization?

AF: What was amazing about that being my first experience is that I got the full scope of what the organization was all about. I was able to see hundreds of people who needed help, hear their questions and concerns, meet our board of directors, our Young Patients Committee, our support group leaders and other volunteers, our staff, and many of the doctors on the Medical Advisory Board. And it was especially meaningful to get to talk with Claire Patterson, who founded the FPA 30 years ago.

Claire and I had a fantastic conversation in San Diego – it meant so much to me to be able to meet her. For her to have accomplished what she did – especially before the days of the internet – well, that’s impressive. It takes a lot of time and fortitude asking people for money and talking to doctors and not being intimidated. What she created has evolved over
the years... but here we are 30 years later and she still showed up to the conference. That’s a testament to how important the FPA remains to her, to this day.

MKA: Tell me about the significance of honoring the FPA’s 30th anniversary.

AF: In a lot of ways, celebrating the organization's 30th anniversary is a double-edged sword. It’s a shame that we still have to be here, 30 years later. So, in that sense, it’s not really a celebration. But on the other hand, it’s a good thing that we are here because there are still many people who really need education and support. There are so many more options for patients now than there were 30 years ago. It’s important that we continue to serve those who need our help.

Thirty years later, there’s ubiquitous information on the internet of various degrees of validity, but we want people to know that they can contact the FPA for reliable information, be connected with trained staff, the latest knowledge in research, our medical advisory board, support groups, peer mentors, our webinars, and all of our online resources.

It’s important to acknowledge how different the organization looks now compared to 30 years ago. Back then, so few people knew what trigeminal neuralgia was, so, an important part of the mission was to simply educate people on their diagnosis. Now we can do so much more.

Another important evolution has been the creation of the Young Patients Committee. Back 30 years ago, it was believed that young people were not impacted by facial pain, which we know now to be absolutely false. Regardless of a person’s age, we can now provide...
ongoing support on relevant topics, ways to help people live their best life and find their new normal, whatever it may be.

**MKA:** What changes have you made already and do you see coming down the road for the FPA?

**AF:** The board and I are in the process of developing a strategic plan. I joined the team just a few months after David Meyers became chair of the board, and we felt this was a really good time to start on the planning process. With our committee, which is composed of several board members, we’ve been digging into what our opportunities are and thinking about how to thoughtfully grow our programs.

We’re also trying to determine what the next few years look like and setting ourselves up for how we want to grow. So, we are spending a lot of time planning, thinking about ways we could do things, thinking outside the box, with the goals of lowering costs and reaching more people in different kinds of ways.

Another growth opportunity I’m looking at is emerging technologies – and am leaning on the Young Patients Committee for their expertise. They are very keyed into social media platforms and how to reach and engage people. I have a lot to learn from them.

With the world’s focus on social isolation (a concept very familiar to those living with facial pain), more opportunities are presenting themselves for people to connect virtually. But now more than ever – whether it’s due to geography, work schedules, physical limitations, or even social isolation because of the current health crisis, it’s important for the FPA to have information and resources available for people when they want and where they want.

In looking to the future, we are piloting virtual support groups, Facebook live events, and a peer mentorship program, which connects new patients with volunteers who are willing to provide support and share their stories. We have a lot to offer people living with facial pain and their caregivers during this difficult time in our world. We are here to provide support and information, even during a time when people if they can’t visit their doctor or go to a support group.

I think we’re doing a good job by offering so many kinds of programs. We’re going to build on that with the strategic plan – and I think we’re well-positioned to do so. With such great supporters, amazing donors and volunteers, we’re able to accomplish an impressive amount for such a small organization.

**MKA:** You’ve taken on a formidable challenge, leading this organization into its next decade. What do you do for fun or to relax?

We have trails behind our neighborhood, so I love to go for long walks. I hang out with my husband and with our kids when they’ll let me. I love going to the library and listening to podcasts – there are some great ones out there about non-profits, but I’m interested in a variety of topics. One of my favorites is “Stuff You Should Know” – I’ve learned so much from that one, on anything from “what is silly putty” to “how do dams work?” Overall, I just love to learn.

**Thanks, Allison, and welcome to the team. We’re lucky to have you.**
The prevalence of migraine headaches in the United States is 11.7% or approximately 30 million people, affecting mostly women (17.1% of women, compared to 5.6% of men).1-4 Migraine headaches also affect adolescents.5,6 The annual cost of treatment and medications for migraine headaches in the U.S. is $13-$17 billion and the annual cost of work days lost (112 million days per year) is $14 billion.7-9 Approximately ten million Americans suffer from medically refractory migraine headaches.10 Migraine headache patients who have persistent symptoms after medical management or those who cannot tolerate the side effects of medical therapy may be candidates for surgical decompression.

The diagnosis of chronic migraine headaches should be performed first by a neurologist or other migraine headache specialist, based on the most up to date criteria of the International Headache Society.11 Next, a migraine headache journal kept for at least 1 month, documenting the frequency, severity, and potential sites of the head and neck where their migraine headache pain may have originated from is key to identifying surgical candidates. Frequent identification of specific site(s) of pain belies “trigger sites” that may benefit from migraine surgery. Diagnostic procedures such as nerve blocks, botulinum toxin injection, or Doppler ultrasound may be useful to confirm trigger sites. At the time of a developing migraine headache, patients may be able to point to one or more sites of tenderness where the pain started or is developing from – if a local nerve blocs performed at these site(s) improves symptoms, the patient would likely benefit from surgery at these site(s). For patients who present without a migraine attack, they are often able to recall and point to trigger sites based on memory. If injecting botulinum toxin into the muscles surrounding these specific site(s) causes significant improvement of symptoms over the next couple months, the patient would likely benefit from surgery at these site(s). On the other hand, patients with vague, diffuse areas of pain at the start of a migraine attack or ocular migraine headaches are not surgical candidates.

The initial surgical treatment for migraine headaches involves thorough decompression of the affected nerves at the identified trigger site(s).12-17 Decompression primarily involves performing myectomies and fasciectomies surrounding the involved trigeminal or cervical nerve branch at the identified trigger site(s). Doppler ultrasound at trigger sites is performed to help identify arterial branches that may be irritating a nerve, where arterectomy should be performed.18 Analysis of computed tomographic images is useful in identifying supraorbital foramen or notches, where osteotomies and fasciotomies, respectively,
are performed to release the nerve.\textsuperscript{19} After decompression, placing fat grafts beneath or around the freed up nerve is performed at frontal and occipital trigger sites to pad the nerve from cicatricle changes and manage dead space after myectomy. Neurectomy of a nerve branch is occasionally performed as a last resort during revision surgery in patients with persistent migraine headache symptoms after initial decompression - some improvement is obtained at the expense of temporary or permanent numbness in the dermatome for that nerve branch. Fat injection may be used as an adjunct at the time of initial surgical decompression, or at a later treatment date for patients with recalcitrant migraine headache symptoms following surgical decompression.\textsuperscript{20}

Traditionally, 73\% of migraine headache patients treated with surgical decompression need multiple trigger sites (average of 2.6 sites) decompressed at the time of surgery.\textsuperscript{21} With fat injection, most patients (76\%) need only one site to be injected (mean of 1.28 sites injected per patient).\textsuperscript{20} Generally these procedures are well tolerated with minimal morbidity. Incisions are small and placed in well-hidden areas to minimize scar burden, seromas or hematomas are rare, and numbness following surgery is almost always temporary unless neurectomy is performed. The most common complaint is worsening of migraine headaches symptoms in the acute post-operative inflammatory period, which generally improves after a few weeks.

Occasionally, successful migraine surgery may “unmask” secondary site(s) that patients describe are new sources of their migraine headaches. In these cases, patients should maintain a new headache journal and be evaluated for surgery at these secondary trigger sites.

The success rate of migraine surgical decompression ranges from 79-90\%.\textsuperscript{12-16} Factors associated with surgical failure are younger age of migraine onset, intra-operative complications, and two or fewer surgical sites.\textsuperscript{22} Factors associated with surgical success are surgery at a frontal or zygomaticotemporal site or at multiple trigger sites.\textsuperscript{22} Secondary fat injection has been shown to significantly improve or completely abate symptoms in 69\% of patients with migraine headaches persisting after surgical decompression.\textsuperscript{20} These procedures improve symptoms likely due to the fact that trigeminal nerve branches in migraine patients are abnormal\textsuperscript{23} and surgical decompression or fat grafting reduces nerve irritation that may otherwise trigger a migraine headache. Successful migraine headache surgery requires working closely with neurologists or migraine headache specialists for appropriate patient diagnosis and medial management. Careful patient selection and thorough analysis of long-term symptoms to determine an appropriate surgical candidate and operative plan also cannot be understated.
REFERENCES


Thank you for helping to further the mission of the FPA in 2019

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

20,000 mailed
120,000 emailed

400 webinar registrants per session

150 national and international personal support resources

225 National Conference attendees

6,000 downloaded

2,000 profile visits

360,000 website visits

1,200 active FPA individual members*

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%
- Sale of Materials: 3%
- Sponsorships: 2%

Use of Funds

- Patient Programs: 79%
- Supporting Services: 8%
- Fundraising: 13%
In honor of the FPA’s 30th Anniversary
we talk with the Founding Director, CLAIRE PATTERSON
by Amy Turner

When did you first start having symptoms and what were they?

Like most individuals with trigeminal neuralgia (TN), I can still remember my first excruciating TN attack in 1976. One morning while putting on my makeup I touched the tip of my nose and a bolt of pain passed through my check. Although the pain was brief, it was not like anything I had ever experienced. Prior to this, I had two years of a dull toothache-like pain on the left side of my face. After many x-rays and visits to the dentist, I was assured that the pain was not a dental problem. Today, this pattern of starting out with vague symptoms before developing into the sharp, piercing attacks of TN is called pre-trigeminal neuralgia. As the attacks became more intense and consistent, a diagnosis of TN was easily confirmed by my internist.

What treatments did you receive and were they successful?

The first few years of my TN journey were managed by medication. As the attacks became more frequent and intensified, additional prescriptions were added to the mix. Over time, this cocktail of medications became less effective and the side effects more debilitating. It was evident that medical management was no longer doable, and I was eventually hospitalized in a university teaching hospital.

While there, the only surgical option offered to me was to sever the nerve. In the meantime, my internist had read about a new neurosurgical procedure being pioneered by Dr. Peter Jannetta – the microvascular decompression (MVD). Luckily, I chose to decline severing the nerve, left the hospital, traveled to Pittsburgh for a consultation with Dr. Jannetta and had an MVD on December 1, 1987. I have been pain-free ever since – 33 years!

What prompted you to start the TNA?

Before being discharged following my MVD, I met another TN patient who had also never talked with anyone else with TN. How different my TN journey would have been if I had been able to connect with others like her who had the same disorder. Being in the company of others to share information and experiences provides the unique opportunity to validate what you are experiencing. When I mentioned to Dr. Jannetta that there should be an organization for people with this disorder, his answer was simply “Why don’t you start one?” Who could decline such a request from the doctor who had given you back your life?

How has the Association grown over the years?

My initial vision of the organization was one whose primary focus was to provide information and support to those afflicted with TN and to their families. Once TNA’s nonprofit, tax-exempt status was secured, I enlisted Dr. Jannetta’s support to chair and appoint a Medical Advisory Board (MAB). His enthusiasm and support were indeed inspiring. Many of the key specialists in the treatment of TN that he appointed are still actively involved with the Association today. Dr. Jannetta’s leadership and MAB participation established the medical credibility that was so vital to the growth of the Association.

A great deal of progress has been realized since TNA’s founding in 1990, when the national office consisted of a wall phone and my kitchen countertop in Barnegat Light, NJ. At that time, our mailing list consisted of 13 individuals and the operating budget was less than $500. Yes, we have come a long way!

As the Association has grown in its ability to serve those who turn to us for help, it has also achieved increased awareness and recognition by the medical/dental community for TN and neuropathic facial pain disorders. TNA/ the Facial Pain Association has grown from its humble beginning to become a world-wide resource for information and support. Technology has certainly changed the operations of the Association; however, its mission remains unchanged and will continue to be the guiding light for the challenges faced both now and in the future.
Being diagnosed with a rare condition like trigeminal neuralgia and/or other type of facial pain can be a scary and overwhelming experience. We polled our social media followers on the top tips they would offer to newbies and, much to our surprise, we received over 150 very thoughtful, raw and honest responses. We’ve compiled many of them here, with only minor editing for clarity and brevity.

It is worth noting this advice has come from others living with facial pain, not from medical professionals. These tips are intended not to prescribe but rather give you ideas for you to research yourself and discuss with your medical team. We hope you find this advice from the veterans to be useful.

On educating and advocating for yourself

- Be your own advocate; no one knows your body like you.
- Educate yourself about all kinds of drugs being used for nerve pain – you have to be smart to live with TN.
- Get the best doctor you can find (one who listens to you) and never stop looking for what works for you.
- Know your triggers and respect them.
- Learn as much as you can about the disease because you are going to run into many doctors who won’t know what you’re talking about. You will need to be the educator.
- Be your own best advocate. Educate yourself and don’t settle for a doctor, neurologist, neurosurgeon, or any medical professional who you don’t feel is listening to you. At some point, you may find that you know more about it than some doctors. Educate yourself, understand medications, procedures and surgeries. Ask questions within a TN community for reference to your own experience, but don’t compare your journey with anybody else’s.
- FacePain.org is your best friend!

On getting support

- Join the FPA’s Facebook group to learn and be surrounded by others going through the same journey.
- Go online and find others with TN. Knowing you’re not alone and that someone else truly understands is invaluable.
- Join a TN discussion platform. Hearing other testimonials is helpful.
- Gird yourself with support from every direction. If someone doesn’t believe your pain, minimizes it or ridicules you, let them go. TN requires all of your energy.
- Don’t be afraid to tell those around you what you are dealing with; let others become informed so they know what to do, how to help and what is going on.
- Let family know and be a part of your journey, as it affects them, too.
- Attend a Facial Pain Association conference and/or support group meeting – there is nothing more powerful than being in the same room as others who “get it.”
On finding the right doctor

• Your first appointment with a new doctor is nothing more than a job interview for the doctor – you get to decide whether they are hired. Don’t give them the job if they’re not the right person for you.

• Find a neurologist who has experience with TN – ask him/her upfront how much they know about it.

• Amateurs will take you on as a patient because they are curious and use you as an experiment to help them learn. You need an expert TN neurologist, not a beginner.

• Do not have any teeth pulled – if a dentist suggests extractions or root canals, get up out of that chair and run.

• Consider an examination by a qualified dentist in craniofacial pain.

• Find a doctor who will work with you and has your best interest in mind. Don’t give up because the first, second or tenth thing hasn’t worked. Keep trying something new.

• Don’t give in to the first doctor willing to take you as a patient; give in to the first one willing to listen and stay at your side. Then you’ve got it all.

• Be ready to explain your symptoms 500 times.

On choosing treatment options and medications carefully

• Know the different types of facial pain to ensure you have the correct diagnosis before having any procedures done.

• Opiates are ineffective and can be addictive. Be wary.

• Please don’t have your teeth pulled unless you have a very definitive disease to your teeth. I had some pulled and it had nothing to do with my teeth. MVD worked fabulously for me after seven years of sheer suffering.

• Consider MVD before any nerve damaging treatment.

Practical advice

• Write a log of episodes of pain and medication to share with specialists.

• If I overdo it, I will pay for it!

• Keep a pain diary. Go to the doctor regularly and let them know how physically and mentally affected you are. Try and be prepared for change. Accept help. Never give up.

• Stop googling; everyone’s symptoms are different.

• Try not to look up stuff too much, as it may make you worry.

• Understand this will go on for a long time. Some advancement in treatment options is being made, but don’t expect it any time soon so learn to live with it.

On lifestyle changes

• Get plenty of rest.

• Stress triggers pain, usually instantly.

• Food is medicine. Explore functional medicine.

• Diet changes may make you feel better overall, but they will not fix TN.

• Change your diet, do your research on what triggers the nerve pain.

• I used an app called My Pain Diary. It helped me find patterns in the pain, even tied to weather… I also found that a heating pad, on as hot as I could stand it, really helped out with the pain.

• With my depression, I couldn’t read a fiction novel. This was one way I loved to escape. Now I love audio books. The bonus is I got off sleeping pills! I listen as I fall asleep.

On complementary and alternative treatments

• Explore all avenues of relief – pharmaceutical and naturopathic – until you find what works for you.

• Meditation practices can help you find a safe mental and emotional center and help you restore mentally, which helps you corral energy to deal with pain.

• Consider upper cervical chiropractic care.

• Try to keep a heated pad on your face to relieve the pain.
• Fill a sock with rice, tie the end, and microwave for 30-60 seconds. The form fits to my face with warmth and softness and helps ease the pain for me.

• Myofascial release saved my life.

• Get a tinge machine/TENS unit.

• Deep breathing and exhaling will ease some of the pain.

• Take Vitamin D3, B12, magnesium, B complex and omega.

• Medical marijuana works for me – it’s anti-inflammatory, anti-spasms, and helps chill me out.

• Reflexology has significantly helped me since my diagnosis 12 years ago.

**Encouraging words**

• Don’t panic! Everyone is different and you’ll need to stay positive & hopeful to find what works best for you.

• Don’t suffer in pain. There are many options available.

• Remember that TN makes you stronger.

• Never give up. There will still be moments of joy and life is still worthwhile!

• Don’t worry about how others treat you. No one knows pain like this until they actually go through it...just take care of yourself and your needs!

• It’s not the end of the world. You will find relief.

• Your crippling fear will pass. Start a file and keep all the info you can find so when you can digest it you can learn a little more. The most important thing I have learned is not to be afraid of being in charge of my own trajectory because now I know more about my condition and the options than the docs. It’s a better place to be than helpless and afraid.

• You are still you. The diagnosis does not define you. Accepting limits will take some getting used to. Be gentle with yourself.

• From what I’ve found what works for one person does not work for another. Don’t be disheartened if it didn’t work for someone else.

• Think in a positive direction, avoid stress, and stay away from negative people.

• Buckle up; you’re in for a wild ride. You don’t have to learn to like the roller coaster but you can learn to tolerate it and expect it to end until the next one. In the meantime, know you are a superhero.

• Fight is a big word when you are battling TN ...but keep fighting.

• Fight! Fight to stay “you.” TN changes your life but don’t let it take ‘you” away. In the end, you will WIN! (From one who is 3 years post MVD and pain free).

• I’ve had TN since 1998, and it hasn’t stopped me from enjoying life & my family. (It HAS stopped me from eating bagel sandwiches and chewy candy bars, but hey- there are softer things that I CAN enjoy eating!) Hang in there.

• It may be necessary to grieve the loss of your old life - the one you were blessed with before TN came along. But do grieve if you must. It’s cathartic and cleansing and helps you to learn to accept your “new normal.” Then, instead of focusing on all the things you can no longer do, take stock of the many blessings and gifts that remain in your life, and by God, make the most of it. Shine on, Warrior! Shine on.
The Huffington Post published an article listing the “11 secrets to choosing the right friends.” Though they meant in terms of everyday life, this list is composed of many values those who live with chronic pain need in a friendship.

1. **Associate higher.** Choose friends that will bring out the best in you and push you outside your comfort zone (within reason).

2. **Choose friends with similar values.** Choose friends that value you in the same way you value them. In this way, you know you have a person you can go to for anything.

3. **Choose friends with common goals.** Common goals often lead to common values, which creates connections on a deeper level. If you and your friends have common goals, they will be more likely to support you in achieving them.

4. **Choose friends who can bring balance in areas where you are weaker.** A friend who understands what you are going through will support you when you need it. Choosing a friend with this attribute is vital to a personal connection.

5. **Choose friends that stretch, motivate and encourage you.** Living with TN is challenging, and often leads us to think less of ourselves, this is dangerous behavior. Having friends who want to see you succeed is valuable. A constant support system of friends can make life more bright.

6. **Choose friends that share the same interests.** If your friends share your interests you will be more likely to say yes when they invite you to do something. As people living with chronic pain, having a reason to get out of the house makes the decision to go out easier.

7. **Choose friends that have a thirst for knowledge.** If your friends are knowledge hungry, then learning about TN and facial pain will be of interest to them. They won’t shy away from the uncomfortable and new, they’ll embrace it. And therefore, they’ll embrace you.

8. **Choose friends who you can be purpose partners with.** According to the Huffington Post, “a purpose partner is someone who you can share your goals and dreams with, and they will encourage you toward achieving them.” This taps into the accountability aspect of friendships. Friends who are your purpose partners will keep you accountable for your goals.

9. **Choose friends who will celebrate your success.** Celebration is a key aspect to a healthy friendship. Your friends should celebrate every part of your life. For those who live with TN, celebration of the small things is a way we fight back against TN. So, when choosing a friend make sure they love parties!

10. **Choose friends who are “get-it” people.** Friends who “get-it” are ultimately more sympathetic towards our specific needs. Though no one can truly understand the pain we endure, having friends who want to learn and are understanding of our situation creates a more inclusive environment.

11. **Give what you expect to get.** Every friendship is a give-and-take. A friendship is a relationship and in a relationship it’s important to realize that both sides have strengths and weaknesses. It cannot be all on one person to push the relationship forward, so it’s important to be there for your friend when you can. Communication is a key aspect of a relationship and that will help both parties to navigate your friendship in a healthy way!

If you want to read the full Huffington Post article, visit this link: https://www.huffpost.com/entry/11-secrets-to-choosing-th_b_6038658
Name: Lilia Millner

Current age: 27 years young!

Where do you live? I am currently in Spartanburg, South Carolina, but begin classes in Raleigh, North Carolina starting in May!

When did you first experience trigeminal neuralgia? I was 19 years old, sitting on my couch, minding my own business when I collapsed in pain. I could never describe how excruciating that first flare was, and how scared it made me feel.

What is your diagnosis? I was diagnosed with Trigeminal Neuralgia on my right side.

What do you do in your free time? Currently, I do not have a lot of it! I am about to begin a post-baccalaureate program, after that I will be off to medical school. I have three beautiful children, a 6 year old son, 3 year old daughter, and a 2 year old son. My youngest, James, was born with multicystic dysplastic kidney syndrome and a UPJ obstruction. My past two years have involved juggling the last part of my bachelor’s degree and spending time in the NICU learning a vast amount about nephrology, neonatology and many other exciting specialties. Being a patient and being a caregiver has put me in a position where I feel I could be useful as a physician. Experiencing all three sides will be a unique view that I hope to bring to the field of pediatric nephrology. When I do get time to myself, I enjoy puzzles, watching hockey, and attending unique medical conferences.

What has TN taught you? Honestly, so much. It has taught me how to be kinder. Before my TN diagnosis, I was a very healthy person. Even with TN, I looked like a regularly healthy young lady. So, having TN taught me not to judge people on their exterior. You can never know what pain they are feeling. It has taught me to be more patient. I know there are times when I was in pain that I required a lot of help. That kindness that was shown to me could never be repaid, but I will try every day for the rest of my life. It has made me realize my strength (it even made labor feel like a piece of cake!). It has made me realize that our healthcare system needs a lot of work. I faced some medical professionals that dismissed me due to my age.

What non-surgical procedures have you tried? I spent a little over a year and a half cycling through Gabapentin, Oxcarbazepine, Tegretol, and Lyrica. I found myself struggling with what I call “zombie brain” and decided I couldn’t live the next 60 years that way.

Have you had any surgical procedures? So, I decided to go forward with my microvascular decompression surgery! It changed my life. I decided to do the procedure after my oldest was born. He turned one year old and I realized I wanted to be able to do more. I wanted to be able to play with him without the fear. I had my surgery August 2015 and have had minimal pain that only occurs on very rare occasions. This is a massive difference from the hundreds of daily zaps I was experiencing beforehand.

How has your facial pain changed you? I have come to realize how much I took things for granted. Brushing my teeth was a regular carefree routine. Kissing my husband was never anything to flinch about. Driving around with the windows down was a favorite pastime. Once my flare ups began, every little thing I did, I expected to feel pain afterwards. Kiss my husband, face the consequences for the next 4 hours. Brush my teeth, forget about...
it. What’s make up? Can I drink it through a straw? No, I can’t come to your birthday party. These things change in a blink of an eye. I have learned to appreciate that fact, and I try to live my life each day to the fullest of my ability.

What advice do you have for other young patients in college/higher education? Just do it! Yes, you will have to work a little harder than some of your classmates. One thing that I found that helped was to get ahead of my work early on. You may not know if the pain will rear its head, but you can prepare yourself by getting ahead in your work. Also, be honest with your professors. I found that explaining my situation was always welcomed. Don’t use it as an excuse, but instead use it as a drive. Let it fuel you, even when it is draining.

What advice would you give to other mothers, or want to be mothers that have TN? Surround yourself with a compassionate and supportive group. Family, friends, strangers on support groups who will become your closest friends. Find people who understand and talk to them. It is okay to break down and cry (this is also true for any mother, pain or not)! Be patient with yourself, it may not all be rainbows and sunshine, but do your best and your child will know. I ended up having four months, starting the day I delivered, where I experienced no facial pain. It was magical. It also gave me the push I needed to try other treatment options. I know I should always fight for myself, but it really helped having someone else to fight for. Your child will love you and you will be a wonderful mother.

Weill Cornell Medicine
Brain & Spine Center

Our Facial Pain Program includes internationally recognized experts in the field who have advanced training in the very latest minimally invasive procedures used to treat TN.

Advanced Treatment for Facial Pain
Expert, integrated care for patients with trigeminal neuralgia, addressing both your physical and emotional needs

DR. PHILIP E. STIEG
Chairman of the Department of Neurological Surgery
Microvascular Decompression
212-746-4684

DR. MICHAEL KAPLITT
Director of Movement Disorders and Pain Neurostimulation, Alcohol Rhizolysis, Stereotactic Radiofrequency Lesion, Microvascular Decompression
212-746-4966

DR. SUSAN PANNULLO
Director of Neurosurgical Radiosurgery Stereotactic Radiosurgery (Gamma Knife)
212-746-2438

DR. JARED KNOPMAN
Neurosurgeon and Interventional Neuroradiologist Microvascular Decompression
212-746-5149

Find out more at weillcornellbrainandspine.org/facial-pain-program or call one of our specialists to make an appointment.
FPA’s Honorary and Memorial Tribute Fund

There are special people in our lives we treasure. Increasingly, FPA supporters are making gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support FPA’s growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received from January 2020 – March 2020

In Honor:

- 10th Anniversary
  - Deborah Lockwood
  - Tyler Bandtell
  - Laura Ortiz
  - Eileen Clark
  - Daina Coury
  - Lisa East
  - Shannon Crawford

- Cindy Ezell
  - Carlin Lagrutta

- Erica Glackman
  - Kathlyn Andert

- Myself
- Andrew Buck
- Faith Klein
- Norma J. Sacca-Antonakos
- Vickie Dance and Stephen Goolsby
- Joyce Forcke

Memorial Tributes:

- Pam Boone
- Jean and Claude Aldridge
- Gwendolyn Boone
- Lloyd Boone
- Sherry Henseler
- Jerri Knight
- Connie Lohr
- Lee Parks
- Judy Smith
- Stephen Wolf
- Valarie Carr
- Brenda Verle Marshall and Tom Kruse
- Roy Crane
- Mr. and Mrs. David Collard
- Michael O’Boyle

- Margaret Femister
- Renee McShane
- Morton Milden
- Doris and Jerry Newman
- Laura Nicholson
- Christine Belock
- June Burrell
- Corbel Capital Partners
- Jennifer and Shawn Gentle
- Gwin’s Printing
- Sara Mackey
- St. Paul’s Class of 2004
- Kevin McCallum
- Joey Morgan
- Laura Mumblow
- Forbes Sirmon
- Peter Susman
- Bob Sweeney
- Mark Woelke
- Kimberly Stump
- William Hendrickson

Face Pain?

You’re in good hands.

Ramesh P. Babu, MD
Board Certified, Fellowship trained neurological surgeon with 25 years of clinical practice

Lenox Hill Hospital • 110 E. 36th Street, Suite 1A • New York, New York 10016
Office: 212-686-6799 • Fax: 646-454-9148 • Email: rameshpitti@yahoo.com
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

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.
facepain.org

Now Marilyn really has something to smile about.

For over 40 years, Marilyn was treated for the excruciating pain of trigeminal neuralgia. When medication and surgery no longer provided relief, she and her neurosurgeon turned to Gamma Knife® at St. Joseph Medical Center in Tacoma.

To learn if Gamma Knife is a solution for you, call 1 (866) 254-3353 — and see Marilyn’s story at endtrigempain.com

South Sound Gamma Knife at St. Joseph
BRAIN SURGERY. Without the surgery part.

1802 South Yakima, Suite 103
Tacoma, WA 98405
Phone: (253) 284-2438
Toll-free: 1 (866) 254-3353
southsoundgammaknife.com
WAYS TO DONATE TO THE FACIAL PAIN ASSOCIATION

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.

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 Facebook Fundraising Campaign
• 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
Dr. Michael Brisman, Dr. Jeffrey Brown and Dr. Alan Mechanic perform all of the different procedures for trigeminal neuralgia, and are leaders in the field of facial pain surgery.

Dr. Brisman has served as Chief of Neurosurgery at NYU Winthrop Hospital, Mineola, NY, and is Co-Medical Director of the Long Island Gamma Knife® Center at South Nassau Communities Hospital in Oceanside, NY.

Dr. Brown is the chairman of the Medical Advisory Board of TNA-The Facial Pain Association. He serves as the Neurosurgery Director of the NYU Winthrop Hospital CyberKnife® Program in Mineola, NY.

Dr. Mechanic served as Chief of Neurosurgery at Huntington Hospital, in Huntington, NY, from 1996 to 2014. He is Chairman of the Nassau Surgical Society Section of Neurosurgery.