

Journal of The Facial Pain Association

Fall 2019

Quarterly



11th FPA National Conference November 2-3
TN Awareness Day October 7



The Facial Pain Association
22 SE Fifth Avenue, Suite D
Gainesville, FL 32601



October 7, 2019 is Trigeminal Neuralgia Awareness Day



OCTOBER						2019
SUN	MON	TUE	WED	THU	FRI	SAT
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FACIALPAIN ASSOCIATION WEBINAR

Hosted by Jeffrey Brown MD Chairman FPA Medical Advisory Board

7:00 pm (EDT) on 10/7/19

Join Dr. Brown as he reviews the top questions patients and their loved ones have regarding Trigeminal Neuralgia, and other neuropathic facial pain.

Registration link can be found at:

<https://fpa-support.org/webinars>

Visit TNAwarenessDay.com for more information and to learn how you can help spread awareness of this disease.

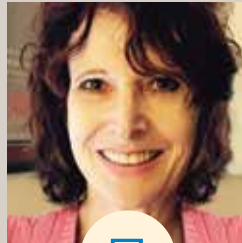
For more details on the 11th FPA National Conference visit facepain.org

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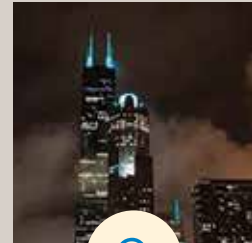
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From the Chairman of the Board

It is a great honor to become the new Chairman. Although there are a number of important transitions underway at the Board level and with management at the Facial Pain Association (FPA), our mission remains foremost: to provide vital information and support to those suffering with facial neuropathic pain and all those who support them.

After 14 years leading the FPA, John Koff is transitioning into a well-earned retirement. Keeping with his dedication to the organization, he has offered to remain in place until his replacement has been selected and then provide counsel to the new CEO. The search for a new CEO is well underway and a number of outstanding candidates have already been identified.

Claude Aldridge and Ray Rivera, two long-standing board members are retiring at the end of their terms in a few months. Ray and Claude have brought their time, passion and wisdom to the board for 5 and 11 years respectively. Although they are coming off the board, both of them have offered to provide their counsel indefinitely.

After 7 years as the Chairman, Jeff Bodington is transitioning out of that role but will remain on the board. Under Jeff's leadership the organization has become even more effective and financially sound. He believes that we can become even better than we are today and he's staying engaged to make sure that happens.

Our National Conference will be held at UC San Diego on November 2nd and 3rd. (Spots are still available. Just call 800-923-3608 or go online at facepain.org to register.) We

will celebrate our 30th year of providing information and support to those of us with facial neuropathic pain, our family, friends who support us, and the amazing medical community that are dedicated to helping us. Again at our national conference many of the leading neurosurgeons and other medical professionals who wake up each day with the goal of helping those of us affected by this disorder will be there to provide advice, perspective and support. Those of us with facial neuropathic pain are both unfortunate to have this condition, and yet extremely lucky to have society's "best and brightest" striving to help us.

This 30th anniversary is also a time to honor the founder of this organization: Claire Patterson. Like many big ideas, I understand that the FPA was birthed at her kitchen table. She then created the organization and led what was then called The Trigeminal Neuralgia Association for 13 years. We all owe Claire a debt of gratitude for her insight, skills and passion to this cause. Claire currently resides in Pennsylvania.

Our focus today is on finding an outstanding new CEO and raising more money so we can do even more for our community. As our outgoing chairman, Jeff Bodington says, "become significantly better at providing information and support to everyone impacted by facial neuropathic pain." Those of you who contribute to the FPA are making a tremendous investment in helping yourself and others in this difficult situation. I thank you.



David Meyers, Chairman of the Board
The Facial Pain Association

A Prescription for

Treating Fake Health News

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Introduction by
Cindy Ezell,
FPA Patient Services Coordinator

The availability of on-line health related support communities, like those on Facebook, are designed to provide you with a safe place to meet others living with facial pain, gain and provide support and share your concerns. Information offered through social media sights is not guaranteed to be sound or accurate. Knowledge is power, but only if the information you

receive is accurate and applies to your particular situation. Remember: look for solid scientific studies, 'Natural' does not always mean safe, beware of sights that assure you with patient testimonials, guarantees and limited offers and beware of a treatment that claims to "Cure-all". When looking for current and accurate information visit the FPA website facepain.org

"Fake Health News".. .continued on page 4

Early in her residency, neurologist Heidi Moawad, MD, ordered a CT scan for a patient who came into the emergency room with a seizure. It showed a massive brain tumor.

"She was convinced that the CT scan caused the brain tumor," recalls Moawad, now a clinical assistant professor at Case Western Reserve University School of Medicine in Cleveland, Ohio. "I tried to remind her that she came in because she'd had a seizure. I told her I trusted the people senior to me."

However, the woman refused to accept the terrible prognosis until her family members convinced her.

If Moawad were to encounter such a patient today, she would be better equipped to respond to these irrational fears. Social science researchers have begun to devise approaches for dissuading patients from harmful beliefs.

"Although patients' misconceptions, lack of logic, and superstitions have complicated the work of doctors since the first doctors existed, the advent of social media has taken the problem to a new dimension."

With the return of infectious diseases such as measles on the rise, in part due to the antivaccination movement, the need for approaches to engage with patients about the risk of unsupported medical information has probably never been greater. Although patients' misconceptions, lack of logic, and superstitions have complicated the work of doctors since the first doctors existed, the advent of social media has taken the problem to a new dimension.

With social media, patients can more easily find misinformation, says Dominique Brossard, PhD, chair of the University of Wisconsin-Madison Department of Life Sciences Communication. They can also share that misinformation more easily.

Although search engines such as Google can proficiently identify the most popular and relevant websites on a given topic, they can't distinguish between accurate and inaccurate websites. "People will most likely not look past the first page of search results," notes Brossard. The first page of websites may be optimized to rank high on searches, or they may be sites with outdated information.

Shoddy Science's Viral Effect

Patients could read misleading articles in newspapers and magazines before the Internet even existed, but sharing them with friends and family required photocopying and stuffing envelopes. Now, with a few clicks of a mouse, anyone can pass on an article to thousands of people in seconds.

In a 2017 survey of participants in Facebook Health Communities by WEGO Health, 87% of respondents said they shared health information through public Facebook posts, and 81% shared it through private messages.[1]

Lies may spread faster than the truth. Researchers at the Massachusetts Institute of Technology analyzed a set of about 126,000 news stories disseminated on Twitter from 2006 to 2017. They found that more people retweeted false information than true information. The researchers speculated that people may have passed along the fake news more readily because it was more novel and evoked more emotion.[2]

"We see this all the time," says Sander van der Linden, PhD, director of the Social Decision-Making Lab at the University of Cambridge in England. "Hoaxes go viral."

The wide dissemination means that some patients may receive the same false messages repetitively. In another study, Yale researchers found that the more often people receive the same message, the more likely they are to believe it, even when the message is labeled as disputed by social media fact checkers.[3]

Furthermore, when people are evaluating the reliability of health information shared online, they care more about who shared the information than they do about the original source, according to an American Press Institute study.[4]

"In the face of this disinformation deluge, what can healthcare providers do to make sure their patients are acting on accurate information?"

False health information can have real health consequences. A different team of Yale researchers found that in a cohort study of 1,901,815 patients, the use of complementary medicine was associated with refusal of conventional cancer treatment, and with a two-fold greater risk of death compared with patients who had never used complementary medicine.[5]

Doctors as Gatekeepers

In the face of this disinformation deluge, what can healthcare providers do to make sure their patients are acting on accurate information?

The good news is that most people still trust the medical scientists conducting health research. In 2016, 84% of Pew Research Center survey respondents said they have at least a fair amount of confidence that medical scientists will act in the best interests of the public. By comparison, only 38% said that about the news media.[6]

“Doctors are the number one most-trusted experts as communicators,” adds van der Linden. “They’re more persuasive on climate change than climate scientists.”

However, doctors must make judicious use of that trust, he cautions. “If you make people feel stupid or suggest they’ve done something wrong, it can elicit biases. Especially with controversial topics like vaccines, we find that people are very defensive.”

“Often patients are looking for hope, so doctors must start by acknowledging those emotions,” says Brossard. “It’s crucial to put concern, empathy, and listening as the first step in the conversation.”

Media’s Need for Expertise

The next step depends on what information the patient wants to discuss. Journalists may exaggerate the importance of a study to attract readers. They may not know enough about the scientific process to report on the data accurately. Or, they may simply leave out the caveats that accompanied the original study.

“...a legitimate study might show a correlation between brain health and the microbiome. An article written about the study could then imply that eating yogurt cures dementia.”

“Untrained and inexperienced health reporters are becoming more common because so many news organizations are in financial trouble and have laid off their most experienced staff,” Brossard says. At the same time, the ease of publishing online allows almost anyone to lay claim to the title of journalist.

For example, a legitimate study might show a correlation between brain health and the microbiome. An article written about the study could then imply that eating yogurt cures dementia. If a patient quotes such an article, Brossard recommends responding with something such as, “A lot of studies have been conducted on this topic, but we need to be careful about articles in the media that sensationalize these studies and make them seem more important than they are. Maybe we should look at the original study.”

“Fake Health News”...continued on page 6



Fighting Unproven Therapies

A different approach may be needed when a patient expresses confidence in a clearly unscientific approach; for example, trying to cure brain cancer by wearing crystals. In this case, there is no underlying study to examine. Even so, Brossard recommends tact. "As you know," a doctor could say, "that's not what I'm doing here in this office, so why don't we focus on the approach we are using?"

If an unproven therapy is preventing the patient from taking advantage of a proven therapy but time is not of the essence, Moawad notes, a doctor can suggest a trial period. For example, if the crystals don't seem to work in 6 weeks, the patient might agree to move on to chemotherapy.

If a patient insists on doing something that seems harmful, she says, the best approach may be a personal appeal. "Genuinely explain that you want the person to get better, and you are personally concerned that if they will only do the thing they're talking about, they won't get better."

Doctors face a more complicated challenge when patients have the correct information about a study, but the study itself is poorly designed, preliminary, or outweighed by other research. A few patients may be interested in wading into the nuances of study design and levels of evidence, according to van der Linden, but most will be better off with concepts that are easy to remember.

Preventing Misinformation Outbreaks Dismissive

Van der Linden recommends communicating to these patients using terms such as "the weight of evidence across many studies," "preliminary," "pilot study," and "exploratory research." "We tell people that 90% of doctors agree vaccines are safe, and you should be inoculating your children," he says.

Patients are often convinced that a treatment works or doesn't work because of a powerful anecdote or testimony. "We attach a lot of value to social information," says van der Linden. "It's difficult for people to understand that something they can observe is less valid than a statistic. Often it comes down to telling people what happens to a single person is not descriptive of the average."

The Cambridge lab has also found evidence that doctors can preempt some misconceptions using an approach they call "inoculation." Doctors who are aware of some of the most common misinformation can prepare their patients for it in advance. For example, doctors can counter myths about the danger of vaccination even before the patient, or

patient's guardian, hears them.

The technique is most effective when patients are active participants. Instead of warning them about disinformation, the doctor could ask, "what might be some myths about vaccinations, and what would you say to debunk them?"

Van der Linden's group has even created an online game in which the user plays the part of an Internet troll, learning the tricks used to spread disinformation and thereby becoming a more savvy information consumer.

The National Institutes of Health also provides a set of criteria that people can use to evaluate health information on websites.[7]

However, persuading a patient to make use of such resources depends above all on the strength of the doctor-patient relationship, and that begins with the basics. "I think the biggest thing is to treat people with respect," Moawad says.

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LIVING WITH TN-A Patient's Story

By Naomi Serviss

Naomi Serviss has lived with Atypical Neuralgia for almost 20 years. She is a New York-based freelance writer and regular contributor to BroadwayWorld.com. She's working on a book about Living With Chronic Pain.

It was a beautiful August morning in New Orleans, not yet hot and sticky. My teenage daughter, Emily, and I were there for a celebration of Louis Armstrong's birth. We were crossing a narrow one-way street when I suddenly felt my feet fly and my head crash to the ground.

One of the two speeding bicyclists racing the wrong way, had crashed into me, knocking me to the ground. I must have been in shock, I remember thinking I didn't want my daughter to be scared, so I underplayed how I really felt.

A policewoman asked if I wanted an ambulance, which I declined. The cyclists didn't even stay.

Emily and I made it back to the hotel and I cleaned up my scraped right arm and took an Advil. I spent that night writing a column about the irony of a New York tourist being hit by a cyclist in New Orleans. It would be more believable to be run over in a city where the bicyclists can be as aggressive as a tow-truck driver.

Even with a throbbing headache and a scraped-up arm, the writer in me kicked in. My goal was to publish my account in the next day's newspaper. It wasn't published, but it was a welcome distraction for the intense headache.

When we returned to Long Island, my injuries were healing. The summer was over, the world cracked open on 9/11 and my personal world was about to be rocked. Not in a good way.

It was a horrible, scary time and I remember the city being empty. Posters everywhere, with loved ones' pictures. Who was I to complain because my mouth hurt?

But the annoyance grew more painful and I saw my dentist. He found nothing wrong but sent me to an orthodontist 'just in case.' Just in case what, I never found out. Nothing was wrong and the pain grew more intense.

Soon I was plagued by electric shock zaps, burning, pulsing, throbbing, stabbing, and it was relentless. It grew worse and I learned how to hide my distress because, after all, it was an invisible disease. This is what we do. Meanwhile, the relentless daily pain led to severe depression, which fed off the pain, and so on.

I went from doctor to doctor, including a therapist, trying to find out what was wrong. I was x-rayed and MRI'ed and nothing was ever found. I sometimes would cry in the middle of the day for no other reason than the pain was so intense I wanted to die. It was deemed Facial Pain by most of the doctors I saw, who had no clue as to how to treat it. Now, thankfully, people are more informed.

Along the 18 years of living with this, I had some respites. Brief remissions. On a press trip in Arizona the pain disappeared. It was a miracle. I felt cured, and so, so grateful.

While in Tucson I learned about the Facial Pain Association and attended some meetings for people with TN. I bought "Striking Back" and could quote from it.

I returned home to Long Island and slowly, so did the pain. By this time I was on a stew of the typical go-to meds prescribed first. Neurontin, Tegretol, Lamictal, Baclofen, Pamelor, Lyrica, Lamotrigine and the like. The pain pills need their own chapter.

Here are some of what I was prescribed: Hydrocodone, oxycontin, oxycodone, fentanyl patch, Demerol. None worked. Only marijuana seemed to help. The pain was becoming unbearable.

My husband and I talked about my remission in the desert climate. Maybe we should go there. I felt so desperate and he was so anguished, we made the fateful decision to exchange the east coast to the west.

We settled in our ranch house in Tucson and were hopeful my pain would once again disappear. We had nothing left to lose. We both felt my life was at stake. There was no real quality of life left, anyway.

Desert life was wonderful for months and I felt no pain. It was another miracle. I felt energized, and signed up for a Jazzercise Class, which led to friendships and a support system. You can probably sense where this is going.

The pain crept back slowly.

I went to the Mayo Clinic, I had Botox, nerve blocks in the back of my head and in my right cheek. Nothing helped. I was desperate and in more pain than ever.

I tried a series of alternative therapies including acupuncture, acupressure, tapping, visualization, hypnosis, crystal healing, an indigenous shaman who said I had trouble in my stomach, and a social worker who tried to desensitize my eyes.

Nothing worked and the pain was intractable. More pain pills. More doctors, more anguished bad poetry.

But we were not to stay in Arizona.

Fate had another plan in store. We moved to Portland, Oregon. Our children needed us and by that time, it didn't matter what the climate was, the pain was as much a part of my daily life as brushing my teeth. Which made it worse, of course.

Once in Portland, a place whose climate is at best pleasant in the summer but miserable in other months, we tried to adjust.

A bad business decision nearly bankrupted us and the pain and anxiety increased.

I found another therapist who prescribed meds I hadn't yet tried. The state had a love/hate relationship with marijuana and the laws were screwy so I could get a Medical Marijuana card but couldn't buy any. There weren't even dispensaries then. So whatever marijuana I found was a bonus.

I posted on chronic pain Facebook pages and had long conversations with other TN people. Some of whom were suicidal. I always remained helpful and hopeful, but the constant electric zaps were killing my spirit.

One day in the fall of 2010 I had had enough. I was tired of waking in the morning wishing I hadn't. I had plenty of leftover drugs from my unsuccessful bouts with different, powerful pain killers.

I found a bottle way in the back of the bedroom cabinet and took it in my hands. I knew my family would be better off without me. My thinking was so clouded. My complaining, my tears, my inability to speak sometimes. It would be a good way to spare them. And I would be out of pain!

This is how a mind, fractured by chronic pain and depression (who knows which came first?) can lead to such dark despair that suicide seems the only option. The nickname of this disease is cruel, but it is accurate and explains a pain so profound it rips out your guts.

I took 27 of the pills and waited, scared but determined.

Fortunately, there is a happy ending: my husband saved my life, we moved back to New York and we rebuilt our lives, with the help of a wonderful family, therapist and friends.

Am I still in pain? Yes, only marijuana helps, but I finally got my Medical Marijuana card. And I still will buy it whenever I can. The state is on the verge of legalizing it.

My life isn't perfect, but I have one and I am grateful for a supportive and loving family.

And hopefully, one day there will be a cure for this wretched disease. ■

The Importance of Awareness on October 7th

As we are working on sending out Light up Teal Requests in our home towns, we are thinking about October 7th and what awareness means to us. October 7th, and spreading awareness of Trigeminal Neuralgia is important to the Young Patients Committee, and here is why;



YPC Facial Pain Association
Young Patients Committee

Reflecting back on our TN journeys and the connections we have made, we have started to think about how often each of us have been asked about why we volunteer on the YPC Board, why do we work so hard to raise awareness, why we spend our free time working to bring patients together and make sure others know about Trigeminal Neuralgia. Most often our answers to those questions are the same; TN can be a very lonely and powerless illness, but we feel we can take back some control by giving back to the TN community, bringing patients together and creating better awareness in the world. We have all met so many patients that tell us they have never met someone else with Trigeminal Neuralgia. We see and share stories online of people that have been able to find others that share similar experiences and symptoms. We have received messages from people telling us they had never heard of TN but they recently learned of someone else that now has it.

These are the benefits that awareness can bring. Having a rare, chronic, extremely painful disease is lonely. It is scary. It can be depressing at times. By sharing our stories, we have been able to feel less alone, less scared, and less depressed. Having a day that we know TN warriors celebrate together – celebrate our accomplishments and that we are living with our illness every day – is important to us and our community. It is important to the YPC. We love going into our towns to see our cities light up teal every October. It makes us feel like we are not alone in this journey. As we take pictures of the buildings and people walk by wondering why the city is teal, we tell them about our experiences, we explain what Trigeminal Neuralgia is and how it affects our lives. We feel illuminated in the teal love of a city and a bond of the TN community that we would have never known existed if we did not put ourselves out there and fight for awareness of a disease that is not well known.

As most Trigeminal Neuralgia patients do, most of us remember the exact moment of the first time we felt the pain of a TN attack. We can also vividly remember the number of dentist and doctor appointments that followed, and the first time a doctor mentioned the words “Trigeminal Neuralgia”. Maybe you were one of the lucky ones to at least hear TN as a possible diagnosis fairly early on, while many TN patients undergo years of suffering before ever hearing the words Trigeminal Neuralgia. Most of us, like many other TN patients, have even had to spell out Trigeminal Neuralgia to nurses and doctors, and have had to educate ourselves and connect with others to learn and grow with this condition. This is why awareness is important to the YPC, and why connecting with others can be so meaningful in the TN community.

It is not only important to us, we asked our Young Patient Members on Social Media why October 7th and Awareness is important to them and here are some of the responses:

“When I see teal being used to represent Trigeminal Neuralgia it brings Hope... Knowing that the more Awareness is brought one day no one will hurt or live a life as most of us have. No more Pain. One day Trigeminal Neuralgia will have a cure.”
Julia, Iraan, TX

“It reminds me that even though I have this disease, I’ve learned it came with a community that became family. I’ve learned so much, I’ve been able to confide in them my darkest thoughts with no judgment, and I’ve learned how strong I am. We are warriors, and we will always be there for one another fighting the same battle.” Beckie, Fort Worth, Texas

“It symbolizes community for me. It reminds me that I am not alone.” Rachel, Louisiana

"When someone, especially individuals I know, wears teal, it shows that they are supporting me and all others who suffer from this disease. When buildings are lit up in teal, those passing by strike up a conversation. Since TN is a rare disease, there needs to be awareness. That is what Oct. 7 is all about." Ashton, Wichita Falls, TX

"It symbolizes strength, hope, and unity. A reminder that we'll get through this - we've made it from yesterday to today - and we'll continue to... it's a reminder that we have an entire community of others that also suffer from facial pain and are here for support, caring and to listen." Hillary, Morrisville, VT

The Facial Pain Association is hosting a National Conference November 2-3 in San Diego, California and the YPC wants you there! We are offering scholarship assistance to patients under 40. If you are interested in applying, please email us at ypc@tna-support.com so that we can send you the application. Join us in talking to experts, creating community, and making new connections. We can't wait to see you there!

Interested in knowing more about October 7th and Lightning Up Teal, visit www.TNnMe.com ■



PATIENT PROFILES

Lindsey on left and Ashton on right



Name: Ashton Frische

How old are you? 21

Where do you live? My hometown is Dalhart, Texas. I am currently going to college in Wichita Falls, Texas.

When did you first experience trigeminal neuralgia?

I started getting the occasional zap beginning in March of 2017. I had a nerve stimulator placed for ON and chronic, intractable migraines and it got infected. Once the stimulator was taken out, I immediately got much more zaps and I had tons of burning and pressure in my cheeks.

What is your diagnosis? Trigeminal Neuralgia, Atypical Facial Pain

What do you do in your free time? I love to paint on canvases and color for fun in the little free-time I have. I enjoy doing crafts. I recently started doing yoga regularly again. It is hard to figure out the exercise threshold that will not flare up my face. I am also in a long-distance relationship. We typically watch movies or go shopping when we are together.

What has TN taught you? I am definitely stronger than I give myself credit for. The TN community is great and super supportive. I have also learned that before being

Name: Lindsey Thacker

How old are you? 21

Where do you live? I live in Wichita Falls, Texas for school, but I am from the Houston area.

When did you first experience trigeminal neuralgia?

Around February of 2017, I had what I thought at the time was just severe sinus pain, off and on, throughout the semester. In November of 2017, I went in for an SPG block for my auricular nerves and that triggered my full TN. I had extreme pressure pain in my face, zaps across my cheeks, forehead and up the top of my head and my cheeks burned.

What is your diagnosis? Trigeminal Neuralgia, Atypical facial pain

What do you do in your free time? Free time is nearly nonexistent between work, school and doctors appointments. I live 2 hours away from my boyfriend, so I travel there frequently. I enjoy DIY crafts, projects and traveling. My projects this summer consisted of teaching myself to sew, painting, and making wreaths and floral arrangements. This summer, I traveled to Kansas, Oklahoma, Houston, Dallas, Weimer and throughout the Texas hill country.

chronically ill, I took numerous things for granted. I used to love cooking, and now the heat flares me. Eating is also a challenge. I have had to learn to adapt my life to make it more "TN-friendly." I have become way more compassionate since getting diagnosed with TN as well. It took the whole "invisible illness/disability" to a new level. You never know what another individual is going through. They could be fighting an invisible battle just like me.

What non-surgical procedures have you tried? I have tried nerve blocks, trigger point injections, infusions and GammaCore vagus nerve stimulator.

Have you had any surgical procedures? No. My scans came back clear. I got referred to Mayo Clinic in Scottsdale, AZ and saw a great neurologist there. She looked at my imaging and told me that with my stimulator history, especially the type of infection that came with it, surgery wouldn't be an option for me. The stimulator surgery definitely made me weary of having another optional surgery in the first place. If there was a clear compression on my scans or if I didn't have the infection trauma, this may be different. For the time being, I do not plan on going the surgical route.

How has your facial pain changed you? It has changed me in more good ways than bad. I am super resilient. I had no idea that I was capable of going to college full-time, working part-time, and being Admin for a migraine support group and a Spoonie page on Facebook. I love being an advocate for others. Although I do not know what my specific graduate degree will be, I do know that it will be in the medical field. It will allow me to somehow be an advocate for those who are too scared to speak up. No one should have to go through what I have in the past year and a half. I also love raising awareness for invisible disabilities. So many people give me dirty looks for using a handicapped placard because I am 21-years-old and I look healthy, but since it hurts to be outside, I keep using it. Once educate them on my facial pain I can tell that they didn't realize the possibility of someone being that sick who looks so healthy.

What tips do you have for other young patients? I feel like I have so many. Young patients' parents or legal guardians need to advocate for them. If you are old enough, you have to be your own advocate. If you aren't getting adequate medical treatment, speak up. Because of my age many medical professionals do not believe my situation. A huge benefit for me is joining support groups on Facebook and following other inspirational individuals on Instagram. It makes me realize how much of a chronic pain community is out there. We aren't alone, even if we feel like we are some days. Being nice to your doctors, pharmacists, and insurance providers gets you what you want, faster. Ask for help when you need it, no matter how

What has TN taught you? TN has taught me to never take anything for granted and to make the most of the life I have. It is easy to get caught up on all the things I can no longer do because of TN but I have learned that dwelling on this doesn't get me anywhere. Focus on the things that you can do and make the most of it.

What non-surgical procedures have you tried? SPG block, nerve blocks, infusions

Have you had any surgical procedures? Peripheral Nerve Decompression of the supratrochlear, infratrochlear, supraorbital, zygomaticotemporal, auriculotemporal and zygomaticotemporal nerves

How has your facial pain changed you? I am still the same person that I was before facial pain, but how I go about my life is a little different. My personality, attitude, and mentality are still the same. I am still shy, adventurous, hard-headed and faithful. I used to love hanging out with family by a campfire, but now we hang out inside and play games. I used to go out with friends, and now I would rather stay at home and watch movies or talk to friends online from support groups.

What tips do you have for other young patients? The biggest tip I have for other young patients is to have a strong support system. Find people that you can trust and that will always be there for you on the good days and bad days. These people can be family, friends, and even those on online support groups. Facebook has been amazing at bringing people into my life that are like me and go through and understand the struggles I go through on a daily basis.

The second biggest tip I have is to find your triggers. It is so beneficial to know what triggers your pain. If you know, you can prevent. For me in the summer, I wear hats to shade myself from the sun. In the winter, I wear beanies and scarves to shield myself from the cold. When it is windy, I wear face shields. All of these things don't 100% prevent pain, but they help reduce the severity of the flare.

I know Ashton has already said it, but a HUGE tip is to advocate. Be able to advocate for yourself and have others that will advocate for you.

What does it mean to you having a roommate with TN? It means our house is a hot mess. Between both of us having TN, chronic migraines, and an array of other medical problems, and my dog having pulmonary hypertension and seizures, there is never a dull day in our house. But with all of our medical problems comes understanding. I never have to sit here and explain myself. We get each other. We understand how you can be perfectly fine one moment and then in killer pain the next. We understand that

"Patient profiles"...continued on page 12

big or small the task is. When you are hurting, doing the smallest task seems overwhelming. Find the people who genuinely care and want to help you when you need it. It isn't giving up or being weak, it is letting your body recover.

What does it mean to you having a roommate with TN?

It means that I don't have to act like I feel better than I really feel. We can tell how each other feels just by how we look or sound. No one else picks up on it, but your close support system. We are perfectly content watching movies "for fun" instead of going out like typical college girls. We get that we cannot mix our medications with alcohol because of the interactions they have. If I don't want to go out to dinner, we'll grab take-out instead. It doesn't make me feel guilty because I know she actually does get the situation. When we are in a flare, the other person picks up the slack around the house without asking for anything in return. She also makes me feel like I'm not crazy. I'll be having a low-pain day and then all of a sudden, I get a huge flare. I ask her if she did too and 99% of the time she says yes. We can talk about all things medical for hours and think it's normal. We get how much harder it is going to college and working with a chronic illness. I know that I am never alone with TN because Lindsey is literally across the hall when I need her. ■

plans aren't always set in stone. Things can change at any moment and we are okay with that. We understand that some days you just have to stay in bed. We understand that some days housework has to be put on the back burner and saved for another day.

Having a roommate with TN is such a blessing. It is honestly hard to explain our relationship and how our house functions. It just works. It makes life easy. I know that I always have someone here for me that understands what it is like to be chronically ill, still work, and go to school full time. There are few people that completely understand the struggles that I go through on a daily basis and I am blessed to live with someone as rare as me. ■

Did you know that there are other ways to donate beyond making a cash gift?

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**Please contact us at (800) 923-3608 or
info@tna-support.org for more information.**

The Facial Pain Association launches TNAwarenessDay.com and talks to Toni Saunders, TN patient, founder of TNnMe.com



**Megan Hamilton, FPA Board member
interviews Toni Saunders, the creator of TN Awareness Day**

The Facial Pain Association thanks Toni for all her hard work around TN Awareness Day and inspiring the TN community to get involved. This year, for TN Awareness Day, FPA launched TNAwarenessDay.com to provide online tools, awareness swag, and thoughts on how the TN community can have a bigger

voice. The site provides a portal to a number of partner organizations where you can read about opportunities to get involved with other likeminded groups.

When and How did your Trigeminal Neuralgia Start?

I had a lot going on health-wise in the early 1990s. I had Bell's palsy, ringing in my ears, headaches, and then I had facial pain, too. I had a LOT of symptoms, so it made it difficult to get a diagnosis. I went over 10 years without a diagnosis, even after an MRI and other scans were done. Doctors thought it was due to stress, or all in my head.

I got to the point that I even had many teeth pulled trying to get to the source of the pain, but that never helped. I was taking so much Motrin and other NSAIDs that it ate a hole in my esophagus, and I wound up with GERD.

Ultimately, it wasn't until July 2010, when I had an episode where we thought I was having a stroke, and I did wind up having a light stroke, that I finally had an MRI with contrast. That gave me my Trigeminal Neuralgia diagnosis. Later, after some of my own googling and going to another doctor, we determined that I also have cluster headaches.

How did this long journey to diagnosis affect you?

I realized how much those initial doctors I went to didn't know. Once I had a diagnosis, the pieces started falling into place. I wanted to go back to all those doctors, and I wanted to explain. I wanted to teach them. Show them what I have learned and how they can do better for the next patient who comes to them.

Once you were diagnosed, were things better between you and the medical professionals?

Well, not completely. The first doctor I went to just said there is nothing we can do for you. There's no cure, just manage the pain. That's it. Then the first neurologist just wanted to roll me into surgery, but didn't educate me at all on what was going on with me. He scared me to death.

It was my second neurologist who walked me through what cranial nerves are, how they work. What Trigeminal Neuralgia is and how it works. Talked to me about what was happening during attacks and that during the actual attack there wasn't anything I could do in that moment for the pain, that wasn't how my medications worked. I was finally being educated about me and my conditions.

How did TNnME.com start?

I started TNnME.com originally for myself. I had to write about what I was going through and what I was learning. I found out I wasn't depressed – I just don't deal well with doing nothing. Being told there was nothing I could do, learn to manage the pain, this was the wrong message for me. I have to DO something.

Initially I kept a diary of pain attacks, everything going on around them, things like that. My friend Kate was the first



Left: Adelaide Oval Stadium, Adelaide Australia, Middle: The Big Dam Bridge, Little Rock, Arkansas, Right: Bank of America, Dallas, Texas, all lighting up teal for Trigeminal Neuralgia Awareness Day

person with TN who reached out to me. Knowing I was not alone was a relief! Kate and I realized there is no awareness for facial pain, nothing to let you know you are not alone.

How did TN Awareness Day and October 7th come out of that?

Once we realized how important it was to know you are not alone, to raise awareness, I wanted to do something about that. At this point, I knew nothing about social media or anything like that. I just wanted to see what I could do. So, I decided to give myself a year to see what I could accomplish – and the day I decided to give myself that year was October 7, 2012. Our first TN Awareness Day was October 7, 2013.

At the time there was no agreement in the TN community about awareness including a ribbon or color. There were a few people using different colors on their own. I had a friend who was using a teal ribbon, so I took that idea and it became our color.

Then, I was driving across the Leonard Zakim Bunker Hill Bridge with my husband one night, and it was lit up purple. I suddenly wondered if I could get them to light up teal on October 7th. I emailed them and they agreed – the first site to agree to do so. I started reaching out to other places, and that year we had 13 places light up teal for TN Awareness Day. Since then, people have gotten involved all over the world, contacting bridges and buildings and asking them to light up teal. There's a whole team of people who do it each year.

In fact, I have to stop you here and give a special thank you to Kathy Somers, Sarah Heavey, Brenda Sharp, and Mandi Ginn-Franz for their relentless work on the Light Up Teal Campaigns. And a thank you to Nellie Realejo and her GAT Marketing Department for their work!

Where does the work of TNnMe.com stand today?

This year, our goal is to have 200 locations light up teal for October 7th, and as of our talk today we are at over 175 locations around the world. Sometimes people I don't know will send me an email that they have gotten a sight near them to light up, and then send me a picture. It's wonderful. It's a purpose, it's something tangible people with TN can do to say to the world that we are here and show each other that we are not alone.

I have also sent a petition with over 20,000 signatures to the World Health Organization (WHO) to add Trigeminal Neuralgia to its Health Topics list. I've tagged and emailed WHO repeatedly about this issue. On May 25th of this year the WHO announced it will have a new classification system with diagnostic coding for chronic pain. Trigeminal Neuralgia will be coded under neuropathic or orofacial pain so that these patients will be able to more easily have payments authorized, and researchers can track effectiveness in therapies in these categories.

Is there any point you will feel like your goals are accomplished?

When Trigeminal Neuralgia and Facial Pain are on the health topics list of the World Health Organization. It has been said the 4.6 million people have some form of facial pain disorder. If our conditions are on the health topics list and hospitals give data on how many actually are being diagnosed – I think it will blow their minds. Then there will be more funding for treatments and research and help.

What is your wisdom or encouragement to the TN community?

Don't say your life is over because of your diagnosis. It's like any other illness or challenge. Facial pain is a situation you have to deal with and manage. You have to accept it. Your life is not over. Learn from it. Don't get mired in "the old me used to do" whatever. Any time life changes you can't do what you used to, you have to change, adapt, and keep living. You just live differently. ■

Note from the Departing Chair

Still fresh in my mind are those stabs of excruciating pain. They would knock me to my knees and sometimes it took all of my concentration to just keep breathing. There were times when I'd lie on the floor, either in too much pain or too affected by the side effects of pain medications to do anything else. Couldn't chew, couldn't talk, couldn't laugh. I couldn't be the husband, father or employer that I wanted to be. Many of you are on or have been down that road. Providing information and community to people on that road is the mission of the FPA, and it was a joy for me to serve you as Chairman of the Board for the last seven years.

We got a lot done. We pulled young people into the FPA and infused it with energy and ideas, we invigorated our Medical Advisory Board and the expert advice that they provide to our constituents, we rationalized the FPA's support for research to find better methods of diagnosis and treatment, we improved the FPA's use of the internet to provide support and information, and we are working to improve the FPA's many programs for people with TN and for those that care about them. Our new Chairman David Meyers is very capable and I am excited about the future of the FPA.

Much is written in our press and bookstores by and about politicians, athletes and business titans who accomplish big things. To me, those people chose their challenges. Who among you chose TN? Who among you chose to be knocked down by the most painful disease known to humankind? Yet, in spite of that challenge you did not choose, many of you muster the ability to stand up and to then help others. Thank you, you are my inspiration.

Jeff Bodington, Chairman Emeritus
Facial Pain Association Board of Directors



Now Marilyn really has something to smile about.

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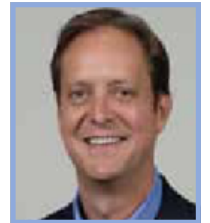
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Dr. Brisman has served as Chief of Neurosurgery at NYU Winthrop Hospital, Mineola, NY, and is Co-Medical Director of the Long Island Gamma Knife® Center at South Nassau Communities Hospital in Oceanside, NY.



Alan Mechanic, M.D.

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.



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