

Journal of The Facial Pain Association

Spring 2018

# Quarterly



## **In this issue . . .**

Tips to help manage  
your TN flare-ups

Dental issues and TN

The efficacy of  
treating TN with  
Cyberknife

# Freedom from the pain of trigeminal neuralgia



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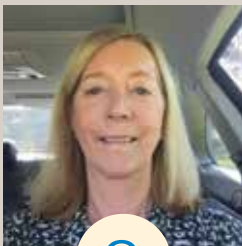
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## Cover: Inspiring Patient Education and Advocacy.

It is in every patient's best interest to become as knowledgeable about their condition as possible. Doing so will make you much more informed – and formidable – when interacting with doctors, nurses, pharmacists, and insurance representatives. If you understand how the disease works, are aware of the variety of treatment options, know your rights (especially as a pain patient), and familiarize yourself with insurance practices, you will be able to take a much more proactive and involved role in your care.

## FEATURES



3

FPA staffer Pam Neff, RN, talks about various ways to help you manage your TN flare-ups.



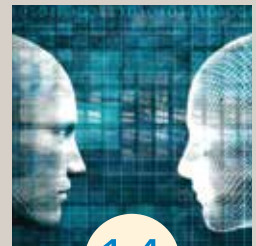
6

Dr. Gary Klasser, a certified expert in orofacial pain, discusses the dental issues associated with trigeminal neuropathic pain.



11

Valuable information on receiving and interpreting your medical tests. Reprinted from Consumer Reports.



14

Research on the efficacy of treating TN with Cyberknife surgery

## IN EVERY Q

2

From the Chairman of the Board

5

From the Editor's Desk

23

YPC & Patient Profile

27

New Members, Memorial and Honorary Tributes

## From the Chairman of the Board

Previous letters from me in the Quarterly have mentioned an effort underway at the FPA to make sure that our services evolve along with technology-driven evolution in how people find information and community. That means the internet has changed everything! Providing information and community to our members is central to our mission, so this effort at the FPA is a top priority. Here is some data.

The FPA began 27 years ago with a newsletter and physical support groups that met four to six times a year. Now, about 300 people participate in our twenty-plus SGs. Several organizations that provide support to other rare-disease populations report declining participation in physical SGs, we see that too. In contrast, 30,000 visit FPA's website every month, we send information to 30,000 email addresses, we have 7,000 members on our closed Facebook page, 7,000 likes on our open Facebook page, 2,500 Twitter followers, 800 people sign up for our email FPA News Wire every month, and 500 people sign up to view our webinars.

Although the data above show that the internet enables us to reach 100 times more people than our SGs, we think that physical meetings remain essential. The FPA's regional conferences are a huge hit, Stanford Neuroscience sponsored our most recent conference and attendance grew to standing room only. Without fail, people who attend our SGs and regional conferences emphasize the importance of physical meetings. Those meetings add elements of community, interaction and focus that can't be achieved through a screen. So the FPA remains committed to SGs and conferences, and we are working to find the best balance of internet-based resources and opportunities for members to meet with each other and with experts in diagnosing and treating trigeminal neuropathic pain.

Yes, I said above that we reach 100 times more people with the internet than through our SGs. Of course the nature and level of engagement is not the same on the internet but, subject to that qualification, our potential is much higher. The the number of people who have trigeminal neuropathic pain disease at one time, known as prevalence, in the U.S. is about 150,000 to 200,000 people. So our 30,000 website visits and email addresses are about 15% to 20% of prevalence. Some of those visits are bots, some are mistakes, and few click through. Some of those email addresses are friends and family rather than patients. Also important is that some of both those visits and addresses are non-U.S. because the FPA is already the global go-to source of information. What % of prevalence in the U.S. and beyond are we actually reaching? Any answer except "a lot less than 15%" is only a guess. As with trends in SG attendance, other organizations that provide support to rare-disease populations report a similar challenge. Getting found and being useful within a network full of noise is not easy, but we at the FPA will not rest.

Even once people find the FPA and what it provides, challenges remain. Much scientific research shows that, due to technology-driven evolution in how people find information and community, the epiphany of finding something like the FPA is now not what it was, that many people are less engaged in community organizations of all types, and that there is less appreciation for the cost and effort associated with creating content. Those forces are changing the FPA's business model and they are making it more difficult to reach some of our constituents. Those forces make it important that we find new ways to reach out, to be useful, and to inspire those that we are here to help.



Jeff Bodington, Chairman of the Board  
The Facial Pain Association





# PREPARATION IS THE KEY TO MANAGING FLARE-UPS!

Researched and written  
by Pam Neff, RN, FPA  
Patient Services



Trigeminal neuralgia pain can be unpredictable in severity and timing. Most days can be managed with treatments specifically targeted for the individual type of neuropathic facial pain that a person has. Other days can bring on flare-ups of extreme, intolerable pain that is debilitating and refractory to current treatments. Pre-planning and team work with patient, family, friends, doctors and other health care providers can go a long way in making flare-ups more manageable. Here are steps you can take to manage potential future flare-ups.

Flare ups can happen out of the blue but most times there are factors that can contribute to bringing on a flare up. One factor is missing a dose of your medication or to stop taking your medication without first consulting your doctor. Missed doses can occur for

any number of reasons. You may want to discuss with your neurologist about using an extended release form of your medication which would allow a more consistent level in the bloodstream and less frequent dosing. If mouth pain is causing you to miss your dosage, you can pretreat your mouth with clove oil or Orajel on a Q tip and also put the pill in the side without pain and swallow with your head tilted to that side. In the second instance, you should never adjust or discontinue your medications without your doctor's direction. It is important to note that many of the drugs used to treat neuropathic pain can have severe withdrawal symptoms.

Knowing triggers that can cause flare ups is also very important so that you can prevent them through avoidance. The first step is to keep a journal. Some people have very detailed journals and some just jot down notes about what is causing their flare up. This way you

*"Managing Flare-Ups"...continued on page 4*



## Managing Editor

John Koff

## Editor/Circulation Manager

Nancy Oscarson

## Medical Editor

Jeffrey Brown, MD

## Contributing Editors

Anne Ciemnecki

Cindy Ezell

Pam Neff, RN

## Art and Design

Caren Hackman

## QUARTERLY

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### ***"Managing Flare-Ups"...continued from page 3***

can connect an increase in your pain with a possible trigger or other event.

Stress is a major trigger for facial pain. Stress can cause facial muscle tension, headaches and increased blood pressure that can contribute to inflammation and increased pain. Anxiety is often associated with trigeminal neuralgia. Not knowing when the next attack will occur or when remission might end plus the intensity of the pain all can contribute to high anxiety. It is important to try to deal with this by talking with your doctor about anti-anxiety medications, biofeedback, meditation and other possible treatments.

Certain foods and alcohol also can cause inflammation and contribute to pain. The most common are sugar, saturated fats, gluten, caffeine, aspartame, cold or hot foods or anything acidic.

## **Building a support team**

Have your doctor write a letter that you can use as proof of your pain disorder. It should describe your current diagnosis, brief medical history, past and current treatments and a list of your current medications. Also include, blood work done and imaging such as CAT scans and MRIs. This will be helpful if you have to go to the emergency room or are out of town during a flare up. Many times the pain is so bad that you cannot recall your history or medications and this letter can do that for you.

Pull together your support group. This is usually family and friends but also can be a health care provider. Contact the Facial Pain Association for additional support and assistance.

## **Going to the Emergency Room**

Flare ups of extreme pain can send you to the ER ... but what can they really do for you? Trigeminal Neuralgia is considered a rare disorder and many doctors never see a patient with it and do not know how to treat a flare up. There are many types and classifications of trigeminal nerve pain that can make diagnosis difficult. Also, there are many causes of facial pain such as dental disease, sinus infections, trauma and tumors that need to be ruled out before administering treatment. Dr. Gary Gillette, who is the head of the ER at North Florida Regional Medical Hospital in Gainesville, Florida said, "Most of the facial pain patients we see don't have a diagnosis so we may need to do CAT scans, MRIs and have specialists do an exam before we can treat the patient. It is very rare for us to see a patient with trigeminal neuralgia. Often we will send them home with



Tegretol or Baclofen. There are also people who do come to the ER for opioids and will go to great lengths to get them. A written letter of diagnostic, medical and treatment history from the patient's doctor would be greatly helpful."

If you have to go to the ER bring that letter from your doctor describing your medical condition. Your doctor may also want to make suggestions for emergency treatments. It is also good to have someone with you who can speak about your condition and advocate on your behalf.

## **At home management**

In many cases you may want to try to manage the flare up at home. Icepacks can numb the pain as long as cold is not a trigger. Heat can also be effective and many sufferers report that a bean bag heated in the microwave as hot as can be tolerated is very helpful. CAUTION! Be very careful of doing this after using lidocaine cream since you will not be able to tell whether it is too hot or cold and can damage skin tissues.

A compounded cream that you rub on your face with mixture of lidocaine, ketamine and baclofen can be prescribed by your doctor. Tooth pain can be helped with Orajel or clove oil on a Q tip

Protein drinks such as Boost and electrolytes can keep up your energy and hydration if you can't eat or drink. Having some emergency medications at home for severe attacks that have been prescribed by your doctor such as pain relievers and sleep aids might be just enough to get you through until you can contact the appropriate health care provider.

Being prepared for severe trigeminal facial pain can reduce the anxiety that comes with not knowing what to do and give you some control, over your pain. ●

## FROM THE EDITOR'S DESK

### Remembering a Very Special Guy . . .

Early in 2012 I received a call from a guy named Gary Redwine who told me that his son Matt was suffering with trigeminal neuralgia and that Matt had received some very needed support from the Facial Pain Association. Gary asked if it was OK with me if he put together a golf tournament to raise some funds to help support the FPA . . . and of course I said that would be great.



Gary Redwine

Over the years I have had many conversations with people who wanted to put on a golf tournament or other events on behalf of the Association and for the most part nothing really came of these good intentions.

These things are hard to do and even harder to do well. Frankly I didn't expect much to come of this either.

A few months later Gary called again and said he'd like to come up to Gainesville and meet for lunch . . . and by the way he had a check from the golf tournament fundraiser . . . \$19,000. Now that was impressive!

Gary and his family put on five tournaments from 2012 to 2016, raising more than \$225,000 for the Facial Pain Association. In 2017 Gary was in a fight for his life with a Stage 4 cancer diagnosis, but he arranged for his company to provide the FPA with a \$50,000 matching gift in lieu of the annual tournament.

Over the years I got to know Gary a little better. I asked him to join the FPA Board of Directors, which he did. He became a leading voice at meetings, always telling it like it was but with compassion and understanding.

Gary was a self-made guy, building a very successful business from the ground up. Spending a bit of time with him at board meetings and golf tournaments, talking about future fundraising plans, I was pretty sure that Gary knew every single person in the Greater Tampa area.

Gary left us at the very end of 2017. His energy and can do attitude remain an inspiration to me . . . I'm sure he's still showing off his golf swing and keeping an eye on us.

John Koff  
Editor, FPA Quarterly

# TRIGEMINAL NEUROPATHIC PAIN AND DENTAL ISSUES

Gary D. Klasser, DMD, Cert. Orofacial Pain  
Professor, Louisiana State University School  
of Dentistry, Division of Diagnostic Sciences



The International Association for the Study of Pain (IASP) defines neuropathic pain as “pain caused by a lesion or disease of the somatosensory nervous system”.<sup>1</sup> Alternatively, Costigan and colleagues<sup>2</sup> provide a definition describing neuropathic pain as a dysfunctional pain which involves “amplification of nociceptive signaling in the absence of either inflammation or neural lesions”. This dysfunctional pain represents a malfunction (considered a disease unto itself) of the somatosensory nervous system, involving both spontaneous and stimulus-dependent pain (evoked by both low and high-intensity stimuli). This type of pain has no known biologically adaptive characteristics as does nociceptive pain (provides a warning signal to protect against potential or further tissue damage). Trigeminal neuropathic pain (TNP) is a dysfunctional pain that may originate and involve one or more branches (V1 – ophthalmic; V2 – maxillary; V3 – mandibular) from

the sensory distribution of the trigeminal nerve (cranial nerve V). For simplicity and clinical purposes, TNP may be classified based upon a temporal component and therefore divided into continuous and episodic (intermittent periods of pain) types of pain. Continuous neuropathic pains have their origin in neural structures and are experienced as a constant, ongoing and unremitting pain. Patients usually have varying and fluctuating intensities of pain, often without total remission. The pain is often sensed in odontogenic structures or in those that surround these structures and has been previously referred to as atypical odontalgia<sup>3</sup> or phantom toothache.<sup>4</sup> In some cases there may be a sympathetic component associated with this pain.<sup>5</sup> According to the International Classification of Headache Disorders (ICHD-3) these types of pain have currently been categorized as persistent idiopathic facial pain (Table 1) or painful post-traumatic trigeminal

*“Dental issues”...continued on page 7*



neuropathy (Table 2).<sup>6</sup>

Episodic TNP is characterized by sudden volleys of electric-like, severe, shooting pain lasting only a few seconds to several minutes and is referred to as neuralgia (e.g. trigeminal or glossopharyngeal neuralgia).<sup>7</sup> Often there exists a peri-oral or intra-oral trigger zone whereby non-traumatic stimuli such as light touch elicits a severe paroxysmal pain.<sup>7</sup> Interestingly, anesthetic blocking of the trigger zone may completely eliminate the paroxysmal episodes during the period of anesthesia. There are also inflammatory conditions associated with neural tissues and these are labeled as neuritis (e.g. acute herpes zoster). Unfortunately, due to the lack of recognition and understanding of these dysfunctional neuropathic conditions among dental practitioners, they often lead to a misdiagnosis or an incomplete diagnosis resulting in the delivery of well intentioned invasive procedures which may unfortunately be misdirected/incomplete or ineffective.<sup>8</sup> In a retrospective study involving 64 TNP patients, 71% reported initial consultation with a dentist for their pain complaint with 79% receiving dental interventions that were ineffective in pain resolution.<sup>9</sup>

## Dental Issues

### 1. Clinical Implications

First and foremost, it is imperative the dental practitioner establish a differential diagnosis to rule out pain of dental/soft tissue or pathological (peripheral or central) origin. Therefore, the first step in diagnosis is performing a comprehensive history and clinical/ imaging examination. Once the diagnosis of TNP is determined, no further dental procedures should be performed unless very specific findings of dental pathosis(es) are identified. The dental practitioner then must decide whether to treat these individuals or provide a referral to a health care professional who has an understanding of these types of conditions.

Furthermore, individuals experiencing TNP will inevitably require dental treatment either on an acute basis or for the routine maintenance of oral health. However, due

to the fear of re-igniting the original pain or amplifying the current pain, they may neglect these procedures. Unfortunately, this may lead to progressive dental disease, with the additional consequence of barrages of nociceptive input into an existing dysfunctional nervous system. Effective health maintenance may reduce the need for invasive dental treatments, with the additional benefit of reducing the risk of complications associated with TNP. When invasive procedures are required, it is of the utmost importance for the dental team to recognize and understand these issues, and to select the least invasive approaches to treatment.<sup>10, 11</sup>

**Individuals  
experiencing TNP  
will inevitably  
require dental  
treatment either  
on an acute basis  
or for the routine  
maintenance of oral  
health**

### 2. Patient scheduling

The goal of every practitioner should be to provide maximum comfort during and following the procedure. The intensity of TNP often has a tendency to fluctuate throughout the day; therefore, dental appointments may be best planned during periods of the lowest pain intensity or periods of remission (as is possible with trigeminal neuralgia). Dental procedures should be performed when medication used in the management of these conditions is at its peak level of effectiveness, which requires a thorough understanding

of the characteristics of the medication(s) being used to manage pain.

### 3. Local anesthetic and pre-emptive analgesia

The administration of local anesthetic and the use of needles, although routinely performed on a daily basis and rarely associated with complications, may be a source of pain exacerbation in TNP patients.<sup>12, 13</sup> Furthermore, consideration should be given as to the neurotoxicity associated with each local anesthetic agent.<sup>12, 14-16</sup> Other factors to be considered for choice of local anesthetic are related to its concentration and time of exposure to peripheral neural tissue.<sup>17</sup> In order to minimize the risk for an increase in pain, the local anesthetic should be administered carefully, avoiding undue tissue trauma, using agents that have minimal neurotoxic and ischemic potential, with minimal concentrations and exposure times. The use of pre-emptive analgesia by providing the patient



with "booster" doses of anti-neuropathic medication(s) prior to invasive procedures should be considered.<sup>18</sup> The administration of long-acting anesthetic at the end of the procedure should be done to delay post-operative discomfort.<sup>19, 20</sup> When procedures are performed under general anesthesia, the addition of local anesthesia will reduce or minimize peripheral and central sensitization.<sup>18, 21, 22</sup> Another approach may be the involvement of behavioral medicine to augment pain control or suppression with approaches such as hypnosis and/or relaxation techniques.<sup>23</sup>

#### 4. Preventive/hygiene procedures

Oral hygiene procedures and techniques may require modifications in order to minimize stimulation and prevent an increase in the patient's TNP, and also to prevent avoidance in performing normal daily dental hygiene. Atraumatic oral hygiene may be facilitated by use of an ultrasoft toothbrush and by using a soft foam brush soaked in chlorhexidine.<sup>24</sup> Interdental cleaning may be facilitated with an assortment of devices (various floss textures, dental tape and interdental cleaners). The use of antiseptic/antiplaque alcohol-free mouth rinses, recalcifying and remineralizing agents, and fluoride supplementation (in high risk patients) delivered in soft custom trays and/or pastes/gel/rinses should be considered. Professional scaling and prophylaxis should be delivered with care, and may require local anesthesia to the areas to be treated to decrease nociception.

#### 5. Conservative rehabilitative interventions

The least invasive approach for rehabilitation should be considered. Prevention as discussed above is the first choice. Examples of approaches that may have lower risk in aggravation of pain include:

1. crown amputation and retaining roots rather than extraction;
2. site selection for implants outside of the immediate zone of TNP;
3. use of removable prosthesis rather than fixed prosthetic devices which could also serve as a vehicle for application of transmucosal medication(s);

## Conclusion

Dental practitioners involved with patient care should be able to recognize and understand the concepts of TNP in order to provide appropriate dental interventions so as to avoid any undesirable complications. In order to provide the best quality of dental care for this unique patient population, factors such as communication among all health practitioners and the patient, appreciation and respect for the individual experiencing TNP, and understanding the patient's tolerance for procedures must be incorporated into the overall management plan which may be multi-disciplinary and multi-modal in nature.



*"Pain Relief" . . .continued from page 8*

**Table 1. Diagnostic criteria for Persistent Idiopathic Facial Pain according to the International Classification of Headache Disorders.** <sup>6</sup>

- A. Facial and/or oral pain fulfilling criteria B and C
- B. Recurring daily for >2 hours per day for >3 months
- C. Pain has both of the following characteristics:
  - 1. Poorly localized, and not following the distribution of a peripheral nerve
  - 2. Dull, aching or nagging quality
- D. Clinical neurological examination is normal
- E. A dental cause has been excluded by appropriate investigations
- F. Not better accounted for by another ICHD-3 diagnosis

**Table 2. Diagnostic criteria for Painful Post-traumatic Trigeminal Neuropathy according to the International Classification of Headache Disorders.** <sup>6</sup>

- A. Facial and/or oral pain in the distribution(s) of one or both the trigeminal nerve(s) and fulfilling criterion C
- B. History of an identifiable traumatic\* event to the trigeminal nerve(s), with clinically evident positive (hyperalgesia, allodynia) and/or negative (hypoesthesia, hypoalgesia) signs of trigeminal nerve dysfunction
- C. Evidence of causation demonstrated by both of the following:
  - 1. Pain is localized to the distribution(s) of the trigeminal nerve(s) affected by the traumatic event
  - 2. Pain has developed <6 months after the traumatic event
- D. Not better accounted for by another ICHD-3 diagnosis

\*Note: The traumatic event may be mechanical, chemical, thermal or caused by radiation. Neuroablative procedures for trigeminal neuralgia, aimed at the trigeminal ganglion or nerve root, may result in neuropathic pain involving one or more trigeminal divisions; this should be considered as post-traumatic and coded here.

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# WHAT YOUR MEDICAL TEST RESULTS MEAN

**This important information isn't always delivered quickly or clearly. Here's how to get the answers you need.**



By Orly Avitzur, M.D.

**If you're like most of my patients, you probably assume that no news is good news after a blood test, electrocardiogram, or X-ray. But there is a great deal of variability in how, when—and sometimes even if—medical test results are communicated to you.**

In fact, failure to notify patients of medical test results is common, even when doctors receive the information via electronic health records (EHRs).

You can take steps to ensure that you receive and understand your results, and that this happens in a timely way. Here, the questions to ask and the strategies that can keep you informed.

## When—and How—Will I Get Results?

Ask your doctor when you should expect medical test results. Some tests can take longer than others.

But be aware that there's variability in the way that medical practices provide results to patients.

If your results are abnormal, you should receive a phone call or an email. (If not, you may be expected to wait to discuss results in person during a follow-up appointment.)

But in a survey of more than 2,500 primary-care providers, one in five doctors said they waited until a patient's next visit to notify him or her of abnormal test results.

If you don't receive your test results in the specified time, check in with your doctor's office. Test information sometimes slips through the cracks.

Some offices receive test results on paper, which can get lost, misfiled, or overlooked. And even electronic results may not always be followed up appropriately.

This may be due to the sheer volume of test information that doctors' practices receive daily or because lab results and diagnostic tests often show up in a numerical format that can be hard to read or interpret correctly—even for healthcare professionals at times.

Busy clinicians may also become desensitized to the many patient safety alerts that EHRs display, and as a result ignore or fail to respond appropriately to such warnings.

## Who Will Review Results and Notify Me?

Be sure to find out exactly who will be looking over your medical test results and getting in touch with you afterward. Some practices have physicians or nurses sign off, and others delegate the review to medical assistants or even secretaries.

Uncertainty about who is responsible for checking and then giving you test results can increase in some settings. For instance, if you have tests during an emergency room visit and are then hospitalized for several days, multiple doctors may be responsible for your care.

It's important to clarify who will be getting back to you on any tests you have during that time, especially if some results are not available until after you are discharged. This

is a significant concern because of abbreviated hospital stays.

## What Do My Results Mean?

Although getting your results is the first hurdle, it does not mean that they will be easy to understand. For instance, a test of your cholesterol levels may or may not offer "trends analysis," or show how your results have changed over time.

Some results may also be given in language that's less than patient-friendly or may not clearly spell out what's normal and what's not.

When it comes to lab tests, some seemingly abnormal results may be acceptable in your particular circumstances and others may be critical.

Ask your doctor what your medical test results mean in the context of your health.

*"Test Results"...continued on page 13*



## Advanced Treatment for Facial Pain

**Expert, integrated care for patients with trigeminal neuralgia**  
**Addressing both your physical and emotional needs**



Dr. Philip E. Stieg, professor and chairman of the Department of Neurological Surgery (center) directs the Facial Pain Program at Weill Cornell Medicine. Dr. Jared Knopman (left) and Dr. Michael Kaplitt also specialize in advanced treatments for trigeminal neuralgia and other conditions that can lead to facial pain.

Offering a full roster of advanced options for treatment, including:

- Microvascular Decompression
- Stereotactic Radiofrequency Lesion
- Stereotactic Radiosurgery
- Neurostimulation
- Alcohol Rhizolysis

The Facial Pain Program at the Weill Cornell Brain and Spine Center is an innovative program that focuses on the diagnosis and treatment of trigeminal neuralgia, one of the most disabling causes of facial pain. Our team includes top specialists in vascular neurosurgery and pain disorders—internationally recognized experts in the field who have advanced training in the very latest minimally invasive procedures used to treat facial pain. Find out more at [weillcornellbrainandspine.org](http://weillcornellbrainandspine.org) or call 212-746-4684 to make an appointment.



*"Test Results"...continued from page 12*

## When You're Not Getting What You Need

What if you've asked the right questions and followed up with office staff but are still awaiting results? You may be able to get answers yourself by checking your doctor's patient portal, which provides web-based access to portions of your medical records. You may also be able to see results on the portal of the laboratory that conducted the test.

But different portals have different rules about what they give access to and when it is allowed to be posted.

Some institutions and medical practices deliberately build in a delay so that providers can review test results before you can see them. Others post results immediately. Ask how soon you can expect to be able to access test information on these portals.

The bottom line: You should know and understand your results, and never take anything for granted.

Editor's Note: This article also appeared in the March 2018 issue of Consumer Reports On Health. ●

## "Tips" for seeking a second opinion

1. Let your primary health professional know. It will help preserve your longer-term relationship with them and make sure the new one you are seeing can get all the information they need.
2. Be clear in your mind about what the reason is for the second opinion. Are you seeking an opinion, or possibly ongoing care from the new provider? Are you prepared to re-think the current diagnosis or treatment plan if this is recommended?
3. Be open with the new health professional that you are seeking a second opinion. This will focus the clinician's attention on the part of your care that you're concerned about. There is limited literature about the real-life benefits of second opinions, but if they are mostly being obtained for reasons of communication style and rapport, it would be plausible to assume that you will be more satisfied and do better generally with a clinician you can relate to well.
4. Second opinions may lead to spending more time and effort, especially if you have to travel to another suburb, town or even state. Be aware that you may feel more obliged to follow advice you've gone to so much effort to obtain. This is also one of the reasons that you should have clear in your own mind what the point of the consultation is. Take your time to consider the second opinion as carefully as you did the first.
5. Don't consider the internet to be the final word on second opinions. The smartest people in medicine are not the ones writing on blogs and forums or selling their unique patented products. Stick to reliable, trustworthy sites from established institutions, and use this information to get a "background briefing" rather than to make a diagnosis yourself.

### Doctor's opinions may differ

A different doctor may come up with a different diagnosis, or at least offer a different opinion as to treatment choices. Not every doctor will have the same opinion with regard to diseases and possible treatments. Factors which may have an effect on a doctor's opinion are technology available to that doctor, school of thought, where they were trained, individual methods of treatment and experience in dealing with that particular diagnosis. ●

# CYBERKNIFE RADIOSURGERY IN TREATING TRIGEMINAL NEURALGIA

Bryan M Lazzara<sup>1</sup>, Orlando Ortiz<sup>1</sup>, Ritu Bordia<sup>1</sup>,  
Matthew R Witten<sup>2</sup>, Jonathan A Haas<sup>2</sup>, Alan J Katz<sup>2</sup>,  
Jeffrey A Brown

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## Abstract

**Purpose** To assess the short term efficacy of Cyberknife stereotactic radiosurgical treatment of trigeminal neuralgia (TN).

**Methods** 17 consecutive patients with medically or surgically refractory unilateral TN were treated with Cyberknife radiosurgery. Using superimposed CT cisternogram and MR images, the target segment of the trigeminal nerve was consistently defined as a 6 mm length of nerve approximately 2–3 mm distal to the dorsal root entry zone of the brainstem. A radiosurgical rhizotomy was performed with the Cyberknife utilizing a single collimator to deliver an average maximum dose of 73.06 Gy (range 72.91–73.73) to the target.

**Results** Follow-up data were available for 16 of the 17 patients post-treatment (range 1–27 months, average 11.8 months). Overall, 14 of 16 (88%) patients responded favorably with either partial or complete relief of symptomatology. 11 of these patients were successfully free of all pain at some point in their post-treatment course, with seven patients pain free to the last follow-up visit

(average 5.0 months, range 1–13 months). Symptoms recurred in four patients, taking place at 3, 7.75, 9 and 18 months after Cyberknife therapy. Only two patients reported side effects. One patient developed a bothersome feathery dysesthesia while the second patient reported a non-bothersome mild jaw hypoesthesia. There were no substantial complications related to stereotactic radiosurgery.

**Conclusion** Cyberknife radiosurgery is a viable treatment alternative in patients with TN with competitive efficacy demonstrated in our group of patients while minimizing adverse effects.

## Introduction

Trigeminal neuralgia (TN), also known as tic douloureux, is an idiopathic disorder that is characterized by paroxysmal attacks of sharp, lancinating or electric shock-like pain that occur within the trigeminal nerve distribution, most often unilateral in the maxillary or mandibular nerve divisions. These painful episodes are often brief, lasting only minutes, but occur in bouts over the course of weeks or months with periods of remission that can last years. These





***"Cyberknife"...continued from page 14***

symptoms affect 4–5 people in 100 000. An atypical version of TN involves a constant, or nearly constant, burning and aching pain. Most cases affect patients in their sixties but the disorder can occur in any age.

Firstline therapies include anticonvulsant and antidepressant medications. However, medical therapies fail to maintain relief for many patients and are associated with various side effects, leading patients to seek other treatments options. Surgical alternatives have included percutaneous procedures consisting of balloon compression, glycerol rhizotomy or thermal radiofrequency rhizotomy targeting the nerve at the level of the foramen ovale, while open microvascular decompression has traditionally been the gold standard. Unfortunately, the duration of patients' responses to percutaneous rhizotomies has been variable, and some patients are simply poor surgical candidates.

Since the mid-1990s, stereotactic isocentric gamma knife and linear accelerator radiosurgery has been implemented to perform a rhizotomy targeting various portions of the proximal trigeminal nerve. This modality demonstrated improving success rates although with notable side effects, including numbness and dysesthesias of varying degrees, trismus, anesthesia dolorosa, masticator weakness, diplopia and others. The Cyberknife system, on the other hand, delivers a non-isocentric beam of radiation better suited for targeting the trigeminal nerve with greater target fidelity and enhanced patient comfort. These attributes hold

promise for improved patient outcomes with fewer side effects. The optimal treatment parameters regarding length and target segment of nerve irradiated, treatment dose and various other factors continue to be refined.

We present our experience of patients treated with a Cyberknife radiosurgical rhizotomy targeting a consistent nerve length and narrow dose range. We treated 17 consecutive patients with refractory TN by consistently irradiating a 6 mm length of nerve 2–3 mm from the dorsal root entry zone with a narrow dose range centered at 73.06 Gy.

## Patients and methods

Seventeen consecutive patients with TN underwent Cyberknife stereotactic radiosurgery between May 2007 and July 2009 at our institution. Patients were referred for treatment with a previous diagnosis of TN, reporting paroxysmal episodes of sharp, stabbing or lancinating pain in a trigeminal nerve distribution. All patients were evaluated by an experienced neurosurgeon, interventional neuroradiologist and radiation oncologist prior to radiosurgery. This evaluation consisted of a clinical assessment for pain, a neurological examination and imaging (table 1).

***"Cyberknife"...continued on page 16***

**Table 1**

Patient demographics

**Table 1**

Patient demographics

Characteristic	No (%)
No of patients	17
Women	11 (65)
Men	6 (35)
Age (years) (mean (range))	69.4 (36–90)
Mean duration of symptoms (months)	83
Patients with prior surgeries*	4 (24)
Laterality	
Left	8
Right	9
Distribution	
V1	1 (5.9)
V2	2 (11.8)
V3	6 (35.3)
V1 + V2	2 (11.8)
V2 + V3	5 (29/4)
V1 + V2 + V3	1 (5.9)


\* Microvascular decompression, glycerol injection, balloon compression, radiofrequency ablation, radiosurgery or cranioplasty.

Eleven women and six men were included in the study, with a mean age of 69.4 years (range 36–90). Patients reported TN symptom duration ranging from 1 to 11 years (mean 83 months) and a failed response to medical management, ablative procedure or a combination thereof. All but one of the 17 patients documented an initial trial of medical therapy, each with inadequate symptom relief. Four patients had unsuccessfully responded to surgical interventions. This included one patient who failed to permanently respond to two microvascular decompressions and a gamma knife rhizotomy 8 years before the referral. A second patient's history included microvascular decompression with skull reconstruction and a cranioplasty revision. A third patient reported a history of balloon compression.


The most common distribution of symptoms resided in the mandibular V3 (n=6) and a combination of maxillary and mandibular V2+V3 (n=5) divisions of the trigeminal nerve. No patients reported hypoesthesia or other parasthesia prior to Cyberknife lesioning.

All patients underwent CT cisternography for treatment planning. An experienced interventional neuroradiologist performed a single atraumatic lumbar puncture on each

## Face Pain?



**You're  
in good  
hands.**



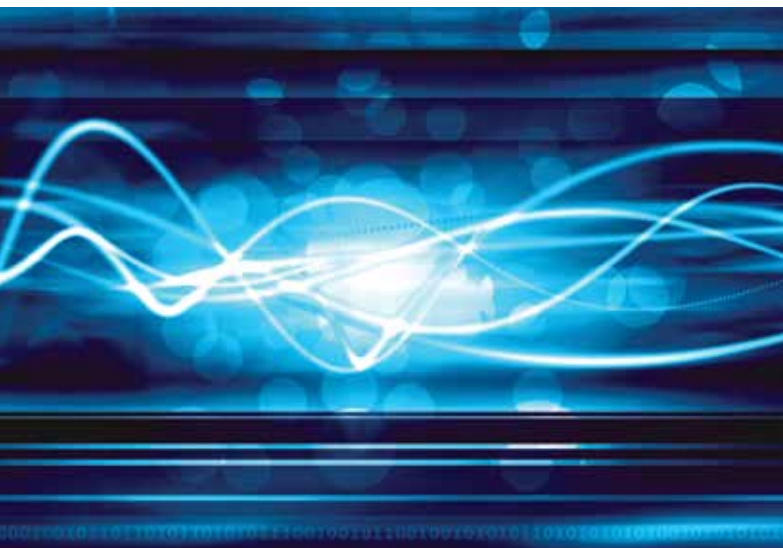
**Ramesh P. Babu, MD**  
Board Certified,  
Fellowship trained  
neurological surgeon  
with 25 years of  
clinical practice

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](mailto:rameshpitti@yahoo.com)

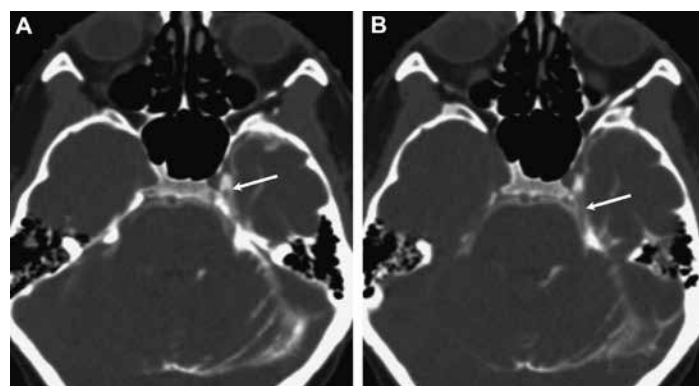


patient and CSF was sent for analysis. Low osmolar iodine contrast media 4–10 ml (300 mg/ml) was injected into the lumbar subarachnoid space. Contrast was subsequently repositioned to the basal cisterns using a gravity technique with a table tilt maneuver and positioning the patient's head toward the side of TN symptomatology. The patient was transferred to a stretcher with the head down in a prone position and immediately transported to the CT scan suite. High resolution CT images (1.5 mm) of the head were obtained with a stereotactic thermoplastic mask secured into place. All patients underwent high resolution stereotactic MR with FSE T1 weighted axial images.

The target segment of the CN V and target volume were defined during treatment planning on a work station. The retrogasserian cisternal segment of the involved trigeminal nerve was identified on the superimposed CT cisternogram and MR images. The target segment was consistently defined as a 6 mm length of nerve approximately 2–3 mm distal to the dorsal root entry zone of the brainstem (figure 1). Dose to the brainstem and the gasserian ganglion within Meckel's cave was minimized to decrease the likelihood of post-treatment related hypoesthesia. The Cyberknife (Accuray Inc, Sunnyvale, California, USA) was then used to perform a radiosurgical rhizotomy utilizing a single collimator (5 or 7.5 mm) to deliver an average maximum dose of 73.06 Gy (range 72.91–73.73) to the target and a mean marginal prescription dose of 57.17 Gy (range 54.75–58.50). The mean target volume was 73.01 mm<sup>3</sup> (range 39.74–145.74). A typical radiation plan is shown in figure 2.

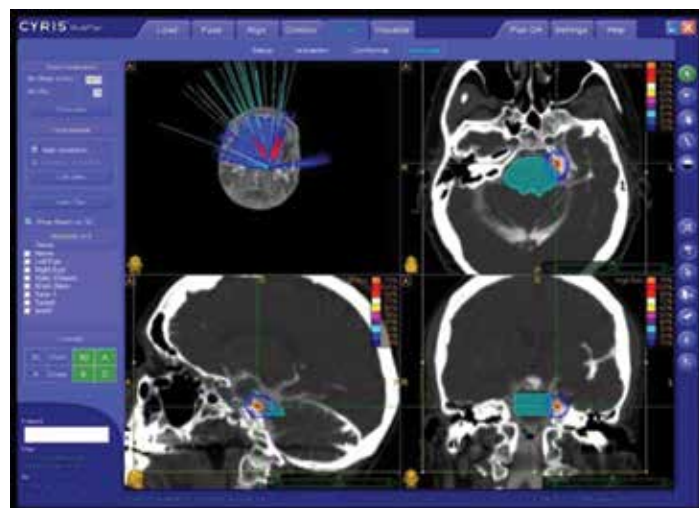


**Figure 1**



(A) CT cisternogram image shows the trigeminal nerve entering Meckel's cave (arrow). (B) CT cisternogram image shows the cisternal segment of the trigeminal nerve.

**Figure 2**



Example of treatment plan with isodose distribution. Light blue, brainstem; red, target, anterior portion of the trigeminal nerve in the prepontine cistern; orange, prescription isodose line.

Initial follow-up visits were scheduled for 3 weeks post-radiosurgery treatment and then subsequent visits in the following months on an outpatient basis with both a neurosurgeon and radiation oncologist. Patients were physically examined and asked to provide a self-assessed degree of improvement regarding pain severity and frequency. A retrospective review of the results evaluated

*"Cyberknife"...continued on page 18*

***"Cyberknife"...continued from page 17***

time to pain relief, degree of pain improvement, intensity and time of symptom recurrence, and assessment for side effects related to the procedure, including hyper- or hypoesthesia and anesthesia dolorosa.

## Results

### CT cisternography

The most optimal CT cisternographic technique employed 10 ml of iohexal contrast agent (300 mg/ml) for superior and consistent trigeminal nerve visualization. All CSF analyses were negative. Only one transient complication related to the CT cisternogram was encountered. One patient experienced transient aggravation of her symptoms during the table tilt and also developed post-procedure spinal tap headache for 2 days, successfully managed with conservative treatment.

### Clinical follow-up

Follow-up data were available for 16 of the 17 patients post-treatment (ranging from 1 to 27 months, average 11.8). One patient was lost to follow-up. Overall, 14 of 16 (88%) patients responded favorably to Cyberknife

radiosurgery with either partial or complete relief of symptomatology. Eleven of these patients were successfully pain free at some point in their post-treatment course, whether continuing or having withdrawn their medication use, with seven patients benefitting from this positive response through to the last follow-up visit (average 5.0 months, range 1–13). The average time to achieve maximum response was 1.9 months, with a range commencing with the first follow-up visit at 3 weeks to as late as 6 months after radiosurgery.

Four patients in total experienced a relapse in their symptoms, occurring at 3, 7.75, 9 and 18 months after Cyberknife therapy. The first patient, whose history did not include any prior procedures, gained only a moderate degree of relief before submitting to a balloon compression procedure 3 months after Cyberknife radiosurgery. Two other patients underwent balloon compressions after pain free intervals of 6 and 7 months post-treatment (7.75 and 9 months after Cyberknife treatment). The fourth patient with the more durable pain free period reported only mild occasional symptoms that were successfully relieved with medical management.





In the more refractory cases of TN—that is, those four patients with prior ablative procedures—one demonstrated near complete pain relief by 2 months and a second patient mild–moderate improvement by 5 months of follow-up. Insufficient follow-up (3 weeks) for the other two patients (the non-responders in this series) did not allow for proper assessment. To emphasize the refractory nature of these two patients who did not attain pain relief, one had previously undergone two microvascular decompressions and a gamma knife radiosurgery while the other failed treatments ranging from ethanol/radiofrequency ablation to orbital neurectomy.

## Side effects

Only two patients reported side effects related to the Cyberknife radiosurgery. One patient remained pain free after treatment of her mandibular TN but developed a bothersome feathery dysesthesia in the V2 and V3 distribution after 13 months. A second patient reported a non-bothersome mild jaw hypoesthesia at 2 months. This second patient also only achieved moderate pain relief while still continuing her medication with 5 months of follow-up available. There were no substantial complications related to stereotactic radiosurgery, including anesthesia dolorosa, trismus, masticator weakness or diplopia.

## Discussion

TN is a debilitating disease that is often refractory to the firstline treatment of pharmacotherapy. Alternative treatment options have included percutaneous procedures targeting the nerve at the level of the foramen ovale and craniectomy with microvascular decompression. These invasive procedures have proven successful with a low rate of side effects and recurrences. However, not all patients are candidates for anesthesia and others are simply unwilling to elect for an invasive treatment modality.

Stereotactic radiosurgery targeting the trigeminal nerve has demonstrated improved efficacy in the treatment of TN over the past few decades. Time to pain relief, durability of response and the incidence of side effects were early criticisms of this treatment method. Initial pain relief has been reported in 50–90% of patients treated with radiosurgical rhizotomy performed with (isocentric) a gamma knife and the linear accelerator,<sup>1–8</sup> with long term (>1 year) pain relief observed in 58.5–83% of patients treated with radiosurgery.<sup>6,9–12</sup> These improved successes

have come as the treatment parameters have been better refined, specifically the length of nerve targeted, radiation dose and distance from the brainstem. However, facial numbness continues to be an issue, with higher rates of sensory loss apparently correlating with better pain relief. Facial hypoesthesia and parasthesias have been demonstrated in up to 54% of treated patients.<sup>6,9,12–19</sup>

With the objective of improving stereotactic radiosurgery pain relief and reducing the incidence of side effects, the relatively recent Cyberknife system has been implemented



with the inherent improvement in patient comfort and targeting. The stereotactic Cyberknife does not require the fixation of a frame onto the patient's skull but rather instead uses a non-invasive thermoplastic mask, an advanced image tracking system and a linear accelerator on a robotic arm. Periodic real time images are acquired during the course of treatment and compared with digitally reconstructed x-rays from the computerized treatment plan, with tracking of head movement and re-registration of the radiation beam to the initially designated target. Fused images from a CT cisternogram and MRI were accurately used in this study to define the TN target. Of note and for the future, Adler et al comments in his group's most recent publication that the cisternal segment of the TN could be reliably defined on T2 weighted MR images alone, eliminating the need for an invasive procedure for the Cyberknife treatment.<sup>20</sup>

*"Cyberknife" ...continued on page 20*



The ability of the Cyberknife to deliver a non-isocentric beam has advantages for treating elongated structures such as the TN nerve. The isocentric gamma knife system may require more than one overlapping spherical isocenter to treat longer nerve lengths, thereby delivering a non-conformal radiation dose with a theoretically greater incidence of side effects by irradiating adjacent structures, such as the brainstem. The non-isocentric Cyberknife,

on the other hand, can radiate non-spherical structures with greater dose homogeneity and fidelity to the target. Adjacent structures are thereby less affected, potentially reducing the likelihood of adverse events.

The initial rate of pain relief achieved in this cohort of patients is competitive with the published clinical series using Cyberknife non-isocentric rhizotomy, especially in those patients with more refractory neuralgia. Fourteen of 16 patients (88%) demonstrated meaningful relief after treatment, with 11 patients (69%) reporting complete pain relief at some point in their follow-up course. Published preliminary (short term) meaningful response rates (moderate to excellent) have ranged from 70% to 96% with more recent outcomes tilted toward the higher end as treatment parameters have been better optimized.<sup>20-24</sup> Within these groups, however, patient inclusion criteria, prescribed dose, length of nerve treated and number of treatments have varied in addition to a lack of a standard definition of treatment response, making comparisons somewhat difficult. The target length of nerve has ranged from 3 mm to 12 mm,<sup>20-24</sup> with optimization nearing 5-6 mm.<sup>20,21,24</sup> Adler et al's most recent series of 46 patients demonstrated 96% good to excellent pain relief by consistently targeting a 6 mm length of nerve with a mean maximal dose of 73.5 Gy.<sup>20</sup> The value with our series of patients resides in the narrow treatment parameters; a consistent target length of nerve (6 mm) was lesioned with a relatively narrow range of maximum radiation dose (mean 73.06 Gy, range 72.91-73.73). The outcomes were simply favorable with few reported side effects.

Hypoesthesia is the most commonly encountered complication following radiosurgery, with factors related to the length of nerve treated, distance from the brainstem and dose. Our rate of numbness is more than competitive with most previously published groups using the Cyberknife, which have ranged from 0% to 51%, likely from a shorter length of nerve treated (6 mm) and lower doses.<sup>20-24</sup> The measurement and evaluation of numbness, dysesthesia and patient inclusion varied among groups, making reliable comparison difficult. One patient in our series reported a non-bothersome jaw hypoesthesia approximately 2 months after treatment, and a second patient was affected by a bothersome dysesthesia after 13 months. As facial numbness has typically developed as a delayed side effect of treatment, longer follow-up in this series is necessary for a true assessment. One of

the shortcomings in the clinical evaluation was that no formalized scale, such as the Barrow Neurologic Institute Facial Numbness scale, was instituted in this assessment. As patients were requested to revisit if any new adverse effect occurred later in their follow-up course, not all mild hypoesthesias were likely accounted due to non-compliance. No major adverse effects related to the Cyberknife radiosurgery were noted.

The approximate time to achieve the maximum response was on average 1.9 months (range by the first follow-up visit at 3 weeks to 6 months). Four patients (25%) experienced a relapse in their TN symptoms 3, 7.75, 9 and 18 months after Cyberknife radiosurgery, which is similar to the rate in other Cyberknife treatment groups (2–33%).<sup>20–22</sup>,<sup>24</sup> The relatively short period of follow-up for several patients in this group may predate complete assessment for recurrence.

Microvascular decompression, along with other invasive procedures, has historically been the means of treating patients with TN failing medical therapy. However, the minimally invasive nature of radiosurgery is an attractive alternative with improving efficacy, particularly in those patients without vascular compression and as the first lesioning procedure. Further investigation and future comparative studies between Cyberknife, gamma knife and surgical treatment potentially will show Cyberknife's viable role in treating TN.

## Conclusion

Our cohort of patients treated with Cyberknife radiosurgery for TN targeting a consistent nerve length and dose demonstrated effective and safe outcomes in terms of initial pain relief and incidence of sensory loss. Non-isocentric radiosurgery can be used as an alternative to more invasive treatments and warrants further follow-up and investigation.

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**Ethics approval** This was a retrospective review of short term treatment outcomes with patient data recorded in a non-identifiable manner. A standard Health Insurance Portability and Accountability Act compliant protocol was followed.

**Provenance and peer review:** Not commissioned; externally peer reviewed.

**Data sharing statement:** Data are available on request.

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## Having trigeminal neuralgia as a parent can be tough!

Having trigeminal neuralgia as a young patient is tough! Having trigeminal neuralgia as a parent at any age can be even tougher! The YPC reached out to several young parents to find out how they manage on a daily basis. We asked them what advice they have for other TN parents. We also asked

them how they approached sharing information about their condition with their children. Whether you are currently a parent, thinking about having children, or just curious about how these warriors battle both TN and parenthood, check out their responses.

*"TN Parent"...continued on page 24*

## **Aimee:**

From one TN parent to another TN parent, I would say that it's okay to express how you feel (without giving too much detail). You'd be surprised how much kids really understand.

## **I HAVE TALKED TO MY DAUGHTER ABOUT TN SINCE SHE WAS BORN**

They are observant, aware little humans. We want to create a safe, loving atmosphere where our kids can be open and honest with us, but if we are teaching them early on to internalize our physical and mental status (as they often mimic how we respond), then we are setting the stage for repressed thinking/feeling. There's a way to explain it without giving graphic detailed information. For example, explain that Mommy is having a pain day, so we need to be gentle. This is our life, right? Well it becomes their lives as well. We need to find our new normal, and the entire family unit does, too. Express that on the good days, too. Life has its ups and downs, right?

I tell my child as much as her young brain can understand, first telling her around age 4. My daughter calls it "TN," like most of us do. Without giving detailed information, just a basic idea of it, "Mommy has pain in her face from a nerve. The nerve of that nerve," making light of it. And when I had to undergo two MVDs, "Mommy has to have surgery to help the pain." I then let her drive the conversations

and she would ask questions. Then, I would provide her with innocent answers, but only if she asked.

## **William:**

Parent to parent, I would tell them to try to incorporate the family as much as possible. There will be everyday struggles as far as dealing with this disease and trying to raise your kids. Make some time for yourself, especially when you come home from work. In those first twenty minutes, take time to try to decompress from your day, and if you are in pain, go sit somewhere quiet. I try to tell [my son] little by little, as he is too young to really understand what is going on. But I do say, "Don't touch Daddy's face," and at least he gets that part. Give your child as much information as possible so he or she can understand and be a help to you when you are going through a pain attack. There's nothing worse than dealing with the attack on your own. I would say five would be a good age [to share more details with your children], as they are able to comprehend more at that point and should be able to understand the do's and don't's of why they should not touch your face. Try to make it like a school lesson they have to learn.

## **Sara:**

I don't know if I have any specific TN parenting advice, but I can tell you the general parenting advice people give about dealing with frustrating moments: "Don't be afraid to call for help," "Walk away if you need to," and "Be kind to yourself." That advice takes on a whole new significance when you are parenting with chronic pain. Before I moved in with [my partner], I identified a friend who could pick [my daughter] up from daycare and/or take her for a few hours if I was

having a particularly bad face pain day. She was different from the person I identified if I was having a bad Daughter-Day (if my daughter was extra cranky, or general parenting stress was getting to be a little much). I parented alone for a year, so it was important to have an identified person to help who understood both aspects.

## **I THINK THE APPROACH AND THE WAY WE TALK ABOUT TN WILL CHANGE AS THE KIDS GET OLDER**

It is also important to be kind to yourself. Lately, because I have been having much more pain, [my daughter] has been spending more time than normal with the iPad. I used to cook a big dinner every night, but I have been relying more on easy meals and pasta. We also used to spend a lot of time at indoor playgrounds and outside when we were able, but it has been difficult to do any of that recently. The indoor playgrounds are overwhelming and exhausting and outside it is cold. I have made a point of reminding myself that self-care comes in all forms, and if the iPad for an hour and pasta two nights in a row gives me the energy to give her a bath and read her a story before bed, then it is OK.

I firmly believe children need to be told things from the beginning, so I have talked to [my daughter] about TN since she was born. She only recently has begun to somewhat understand. She says things like “Mama owwie face”. I think the approach and the way we talk about TN will change as the kids get older. They don’t need to have it explained in technical details before they have reached a place developmentally where they are able to understand the specifics.

## Brandi:

From one TN parent to another, go easy on yourself. There will be bad days, HARD days, days when you feel like you are failing yourself and your children. But you are not. You’re doing the best you can and that’s all you can do. Be open with your kids. Accept their help if they offer it. And know that even though

**YOU’RE DOING  
THE BEST YOU  
CAN AND THAT’S  
ALL YOU CAN DO.**

today is bad, a better day is coming. I tell my children everything, to their level of understanding of course. I encourage questions and answer them honestly. They appreciate being in the loop, no matter their age. I don’t think age matters as much as what they are able to comprehend. If they start to ask questions, they are old enough to know.

**The YPC commends all the parents out there battling both Trigeminal Neuralgia and parenthood! There is not one perfect answer, but we genuinely thank William, Sara, Aimee, and Brandi for sharing their advice and tips! Check out the YPC and FPA on social media to connect with other patients and parents!**

More information about the YPC can be found at



**Mother and daughter,  
Megan and KatieRose**

## Young Patient Profile

### Megan

#### •What advice would you give another parent of someone with TN?

- First, never, ever give up on finding the help you need. I know it’s not easy to find the doctors that will give you hope and fight for the best for your child, but they exist. Find them, and don’t settle for second best. Keep hunting for long term solutions.
- Secondly, you have to be strong for your child and carry them through so much in the TN journey. There will be days you don’t want to face it, but you have to. However, you also have to find that place you can fall apart.

Fall apart in the shower. Then clean yourself up, go back out, and keep being the incredible parent you need to be for your fighter.

#### • How much do you tell your family and friends?

- Wow. Great question. That was a really hard thing. Honestly, most people don’t really want to know how truly hard it was on a daily basis. No one wants to think about a child in horrible, excruciating pain for hours. Especially when it will happen the next day, and the next, no matter what encouraging words they say. We didn’t go in to all the detail with almost anyone. We would say she “had pain today” or “another

**“Patient Profile”...continued on page 26**





KatieRose on the right – with other YPC members at the FPA National Conference October 2015

### ***“Patient Profile”...continued from page 25***

attack this morning” but wouldn’t really explain what that meant and what it was like. Once we were on the road to surgery, and then the second one, we kept people updated on that process. It was more concrete and easier for everyone to grasp.

- For really talking about the nitty gritty details, I saved that for other TN Mamas when we started finding each other. It changed the journey so much to find other parents who really understood what I meant by “pain.” We laughed, ranted, and cried together. We texted and called from ERs and ICUs and would help to calm each other down or figure out the next step to take. They saved my sanity.

### **•At what age do you tell your other children?**

- Katie’s younger sister, Lydia, is only 2 years younger than she, and the two have always been close. When Katie was going through all of this, there was no way to hide what was going on. Sometimes while I was laying in bed with Katie through an attack, Lydia would be sitting on her Daddy’s lap right beside us. Plus, Lydia was often being dragged from appointment to appointment while we tried to figure out how to help Katie. Honestly, the siblings of our TN Kids are huge unsung heroes. Lydia just had to be ok with it being ‘all about Katie’ so much of the time, but she took it in stride and never complained.
- We tried to be honest with her about what was going on with Katie, as gently as possible. We didn’t want to scare her, but we had to answer her questions or the unknown would be pretty scary, too. The whole thing is a balancing act.

## **KatieRose**

### **•Age at diagnosis?**

- I was 11 years old when my TN started, and diagnosed a couple months after it started.

### **•What has TN taught you?**

- I’m a lot stronger than I ever thought I was. I never knew someone could go through so much pain and still be ok after it stopped. And before TN, I never thought I would be strong enough to get through the surgeries and physical therapy, and all I had to do to get better.

### **•What do you do for fun?**

- I wanted to take archery lessons since I was really young, but couldn’t do it with TN because it actually involves a lot of face touching. I’ve been taking Olympic recurve archery lessons since a few months after my second Microvascular Decompression surgery. Just last month, I shot in States and the National competition.
- My other favorite things to do are to draw, and play video games with friends online.

### **•What advice do you have for other young patients?**

- They are not alone. I know it seems like it sometimes, but there are others of us out there. And never give up. Don’t waste your life by giving up. There is help out there, it just takes a lot of work to find it sometimes. Keep looking until you find the people, the doctors, who will understand and help you.



# FPA's 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 December 1, 2017 - February 28, 2018*

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"normal" life  
Maria Christina Restrepo

TN Warriors, like me  
Brenda Cody

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Mackenzie Winslow  
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*"Tributes"...continued on page 28*

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Alan Mechanic, M.D.

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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