## PATIENT GUIDE

Understanding
Trigeminal Neuralgia
& Neuropathic
Face Pain





#### John Koff, CEO

#### Welcome to the Facial Pain Association

There are more than 4.3 million people in the United States afflicted by nerve generated facial pains. At the extreme end of this spectrum of disorders, classic trigeminal neuralgia (TN), commonly referred to as the most painful affliction known to medical science, strikes erratically with sharp shocks of pain.

Although described as early as the first century by Greek and Roman physicians, TN and related facial nerve pain remains a poorly understood and often misdiagnosed disease with no permanent cure.

The Facial Pain Association (FPA), a 501 (c) (3) non-profit health organization, was founded in 1990 as the Trigeminal Neuralgia Association. We have evolved over the last 25+ years into the world's largest organization providing education, support and advocacy for patients with TN and related facial nerve pain.

The FPA website, facepain.org, is the leading resource on the web for people with facial pain our toll free telephone line (800-923-3608) provides one-on-one support from a skilled patient services coordinator. We also maintain a Patient Support Network that provides local contacts throughout the USA, Canada, the United Kingdom, Europe and Australia, as well as a web based interactive community of people with facial pain from around the globe.

We hope you find this resource guide to be an invaluable tool for understanding your diagnosis and helping you to determine your treatment plan. Be an educated patient; understand your options, take advantage of our support network, learn to manage this disease so it does not manage you.

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### Understanding Trigeminal Neuralgia & Neuropathic Facial Pain

#### What is Trigeminal Neuralgia?

Trigeminal neuralgia (TN) is a disorder of the 5th cranial nerve that supplies sensation to the face, eyes, nose, lips, teeth, gums, anterior portion of the tongue and part of the scalp. As the trigeminal nerve exits the brainstem it is most often compressed by a blood vessel. This compression results in a lesion in the myelin coating. Because of this lesion the brain is receiving and sending crossed signals that result in sudden shock-like pain in the area innervated by the trigeminal nerve. It is said to be the most excruciatingly painful human condition in the world. TN's cause remains unknown, but it is often attributed to compression of the nerve by a vessel or tumor.

A primary concern in treating neuropathic facial pain is the appropriate diagnosis.

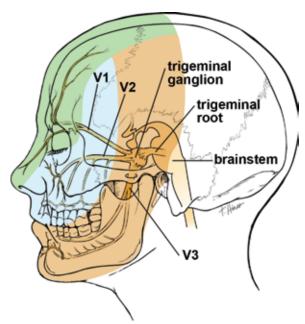
### Classic TN has distinct symptoms which clearly separate it from other forms of facial pain.

- ✓ Classic TN is usually unilateral pain, only occurring bilaterally in 4% of people diagnosed with TN
- ✓ The pain comes in short, acute bursts, rather than in a dull, constant ache.
- ✓ Pain is usually triggered by light touch or sensitivity to vibrations, like brushing teeth, shaving, a light breeze, talking, etc.
- ✓ Pain has a tendency to come and go with periods of intense pain followed by complete pain-free periods of remission lasting from weeks to months or longer.
- ✓ Most people experience pain during the day. Generally, they are painfree while asleep unless triggered by the touch of bed linens or changes in position.

### Neuropathic facial pain is better described as constant, dull, burning or boring pain with intermittent sharp pain.

All maladies that effect the trigeminal nerve are not considered TN. There are many disorders that can affect the trigeminal nerve. Often it proves difficult for the physician and patient to determine the fine differences between classic trigeminal neuralgia and trauma induced trigeminal neuropathic pain. In order to decide on the proper treatment plan it is imperative to recognize these differences. A destructive procedure used for classic TN could make neuropathic pain much worse.

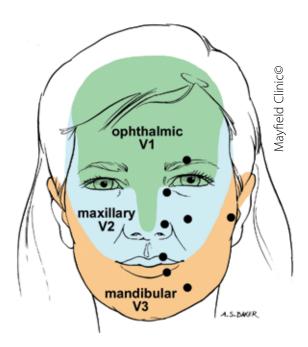
#### Classification of neuropathic facial pain



Printed with permission from the Mayfield Clinic.

- Classic Trigeminal Neuralgia, type 1, (TN1): (also known as tic douloureux) is facial pain of spontaneous onset with greater than 50% of the pain occurring during a limited episode of pain (temporary pain). TN1 is often caused by loss of or damage to the nerve's protective coating, (myelin). The most widely accepted view is that myelin damage results from irritation of the nerve, usually a blood vessel that causes the nerve to be compressed.
- Trigeminal Neuralgia, Type 2, (TN2): facial pain of spontaneous onset with greater than 50% of the pain being constant.
- Secondary Symptomatic Trigeminal Neuralgia (STN): Pain resulting from another condition such as a tumor or multiple sclerosis.
- Post- Herpetic Neuralgia (PHN): pain resulting from a herpes zoster outbreak (shingles) along the trigeminal nerve.

#### Classification con't.



- Trigeminal Neuropathic Pain (TNP): facial pain resulting from unintentional injury to the trigeminal system from facial trauma, oral surgery, ear, nose and throat (ENT) surgery, root injury from posterior fossa or skull base surgery, stroke, etc. This pain is described as dull, burning, or boring and is usually constant because the injured nerve spontaneously sends impulses to the brain. The injured nerve is also hypersensitive to stimulation, so attacks of sharp pain can also be present. The area which is sensitive to touch and triggers these sharp attacks is the same area where the pain occurs. Numbness and tingling are also signs of a damaged nerve.
- Trigeminal Deafferentation Pain (TDP): facial pain in a region of trigeminal numbness resulting from intentional injury to the trigeminal system from neurectomy, gangliolsys, rhizotomy, nucleotomy, tractotomy, or other denervating procedures. Despite the loss of sensation, constant pain is felt in the numb area(s), which varies in intensity and can include sensations of burning, crawling, tingling, boring, stinging, and/or unpleasant aching.

# Is there a test to diagnose TN and other forms of neuropathic facial pain?

Neuropathic facial pain is diagnosed almost exclusively by the individual's description of the symptoms. Dr. Kim Burchiel, on staff at OHSU Brain Institute, has developed a list of questions to help doctors determine exactly which classification may describe a patient's pain. You may want to complete the Burchiel Questionnaire for your physician as a way of helping to determine the correct pain classification. *This questionnaire in the hands of experienced neurologists and neurosurgeons can be very powerful.* 

- 1) When you have pain, is it predominately in your face (i.e. forehead, eye, cheek, nose, upper/lower jaw, lips, etc.)?
- 2) Do you have pain just on one side of your face?
- 3) Is your pain either entirely or mostly brief (seconds to minutes) and unpredictable sensations (electrical, shocking, stabbing, shooting)?
- 4) Do you have constant background facial pain (aching, burning, throbbing, stinging)?
- 5) Do you have any constant facial numbness?
- 6) Can your pain start by something touching your face (e.g. by eating, washing your face, shaving, brushing teeth, etc.)?
- 7) Since your pain began, have you ever experienced periods of weeks, months or years when you were pain-free? (This does not include periods after any pain relieving surgery or while you were on medications for your pain.)
- 8) Have you ever taken Tegretol, Neurotin, baclofen, Trileptal or other anti-seizure drugs (AED's) for your facial pain?
- 9) Did you ever experience any major reduction in facial pain (partial or complete) from taking any of these AEDs?

- 10) Have you ever had surgery for your pain? (e.g. neurectomy, radiofrequency, lesioning, glycerol injection, balloon compression, rhizotomy, microvascular decompression or radiosurgery)
- 11) Did your current pain start only after trigeminal nerve surgery? If this is a recurrence of your original pain after successful trigeminal nerve surgery, the answer is, "no".
- 12) Did your pain start after facial herpes zoster or "shingles" rash (not merely "fever blisters" around the mouth)?
- 13) Do you have multiple sclerosis?
- 14) Did your pain start after a facial injury?
- 15) Did your pain start only after facial surgery (i.e. oral surgery, ear/nose/throat surgery or plastic surgery)?
- 16) When you place your index finger right in front of your ears on both sides at once and feel your jaw open and close, does the area under your fingers on either side hurt?





#### Diagnosis Through Imaging

Doctors typically order an MRI scan when TN is suspected, in order to rule out multiple sclerosis or a tumor and look for an offending vessel that might be causing the pain.

Special MRIs, known as high-resolution, thin-slice or three-dimensional (3D), have demonstrated the ability to predict fine trigeminal neurovascular compression. Newer more finite scans might show an artery pressing on the nerve, but not always a vein. Moreover, some images can be used to determine the "degree" of compression. Be sure to get this type of MRI.

Commercial names for high resolution images are:

Steady-State Free Precession (SSFP)

**GE:** FIESTA (Fast Imaging Employing Steady-stateAcquisition)

Siemens: FISP (Fast Imaging with Steady-statePrecession)

Philips: FFE (Fast Field Echo), b-FEE (Balanced Fast Field Echo)

Note: Recent information suggests that many people have compression of the nerve, but do not develop TN. The existence of compression alone should not be the only reason for surgery.

#### Will TN or facial pain go away on its own?

Sometimes, but it's not likely. TN pain typically runs in cycles, it is common for individuals with TN to experience periods of remission. Remission can last for weeks, months, and even years. Over time, the attacks tend to worsen with fewer and shorter pain-free periods. Other forms of neuropathic facial pain do not usually go completely away.

#### Treatment of Neuropathic Facial Pain

Once you and your doctor have determined the appropriate diagnosis, medication will usually be the first line of treatment. Anticonvulsants, which slow down the nerve's conduction of pain signals, will most likely be prescribed first. In trigeminal neuralgia and several other forms of neuropathic facial pain, the pain is of lightning like intensity and the attacks are of brief duration, therefore analgesics, i.e. aspirin, Tylenol, ibuprofen, etc. and narcotics are not usually effective in addressing the pain.

In trigeminal neuralgia, carbamazepine (Tegretol, Carbatrol, Epitol) is often the most effective treatment. Initial relief with carbamazepine is so readily achieved that many physicians consider its use as a means to confirm the diagnosis of TN. The drug is introduced slowly and increased to a level where the patient is pain-free or side effects occur.

#### Medication

Anticonvulsants such as: Carbamazepine (Tegretol), oxcarbazepine (Trileptal), Phenytoin (Dilantin, Phenytek), gabapentin (Neurontin, Gralise), lamotrigine (Lamictal). Other drugs, including clonazepam (Klonopin) and lacosamide (Vimpat) also may be used.

Antidepressants: Tricyclic antidepressants: (Amitriptyline)

**Antispasmodic agents**: Muscle-relaxing agents such as baclofen (Gablofen, Lioresal) may be used alone or in combination with carbamazepine. Side effects may include confusion, nausea and drowsiness.

**Opioids** are helpful in some cases of trigeminal neuropathic and deafferentation pain.

Anti-depressants or drugs that may help stop seizures are only being prescribed because of the way that they can also stop pain being felt within the body. They are not being prescribed because the patient is either depressed or potentially will have seizures, it is their pain control role that is being used here, nothing to do with their primary function. In a sense their pain control is a 'by product' and it is the by product which is being used.

#### Managing Medication

Please advise your medical professional of any other prescription medications, over-the-counter medications, "herbals," dietary supplements, etc, that you are taking. Adverse drug events are linked to polypharmacy. If you require opioid medications, the prescribing physician should consider the potential for metabolic drug to drug interactions which can cause serious adverse reactions that can be fatal.

If the anticonvulsant you are using begins to lose effectiveness, your doctor may increase the dose or switch to another type. Side effects of anticonvulsants may include dizziness, confusion, drowsiness and nausea. Also, carbamazepine can trigger a serious drug reaction in some people, mainly those of Asian descent.

During all phases of medical treatment, patients need to communicate their pain level and/or drug side effects to their healthcare professional, so that medications can be regulated effectively.



#### Surgical alternatives for TN

PLEASE NOTE that the surgical treatments listed are for Trigeminal Neuralgia (TN1 and TN2) and Symptomatic Trigeminal Neuralgia (STN), caused from MS.

These surgical procedures are not useful for Related Facial Pain such as: Trigeminal Neuropathic Pain (TNP), Trigeminal Deafferentation pain (TDP) and Post-herpetic Neuralgia (PHN).

#### Non-ablative (non nerve damaging)

**Microvascular Decompression Surgery (MVD)**: The Microvascular Decompression (MVD), was designed to cause no additional nerve damage, and offers the best chance of long-term relief. The surgeon enters the brain at the base of the skull and relieves the compression. The nerve is wrapped in a Teflon-like material and the opening to the skull is closed.

#### Ablative (damaging the nerve)

Several procedures can be done to stop the transmission of pain signals to the brain. These procedures actually cause damage to the nerve and can be effective for varying lengths of time. Procedures that go through the cheek with a needle (percutaneous) are glycerol injections, balloon compression, and radiofrequency lesioning. These treatments can be done in the X-ray suite or operating room.

- Balloon Compression is an outpatient procedure, although sometimes the patient has an overnight hospital stay. It is performed in the operating room, with the patient receiving general anesthesia. In this percutaneous procedure, a cannula is inserted through a puncture in the cheek and guided to a natural opening in the base of the skull. A soft catheter with a balloon tip is threaded through the cannula. The balloon is inflated, squeezing the nerve against the edge of the dura and the petrous bone. Balloon compression works by selectively injuring nerves which mediate light touch.
- Glycerol Injection is also an outpatient or overnight procedure. It is performed with intravenous sedation. A thin needle is introduced through a puncture in the cheek, next to the mouth and guided through a natural opening in the base of the skull. Just inside this opening is the trigeminal ganglion where all three nerves come together. Glycerol bathes the ganglion and affects the demyelinated fibers.

- Radiofrequency lesioning is usually performed in an outpatient setting. The patient is sedated for a few minutes while a needle is passed though the cheek, up thorough a natural opening in the base of the skull. The patient is awakened and a small electric current is passed through the needled causing tingling. When the needle is positioned so the tingling occurs in the same area of TN pain, the patient is sedated again and a radiofrequency current is passed through the needle to intentionally destroy part of the nerve.
- Radiosurgery (GammaKnife, CyberKnife) is a non-invasive procedure performed on an outpatient basis; it requires no incision but may require the attachment of a head frame. Highly focused beams of radiation are directed to the area where the trigeminal nerve exits the brainstem. The radiation causes the slow formation of a lesion on the nerve that disrupts the transmission of pain signals to the brain. However, pain relief from this procedure may take several months.

The majority of people with TN may find relief with pharmaceutical and/or surgical protocols, however, a significant number of people have persistent facial pain from, dental procedures, auto accidents, sports injuries, exposure to toxic chemicals and other unknown causes. For these patients, the standard medical and surgical protocols are often inadequate.





#### Other treatments

**Motor cortex stimulation** is a type of neuromodulation used for neuropathic and deafferentation facial pain. This is a surgical procedure that implants electrodes in the body to change how the nervous system works. Motor cortex stimulation involves placing the electrodes on the surface of the brain to control pain signals. It is an off-label procedure, which means it is not yet FDA-approved.

**Deep brain stimulation** is more complex than motor cortex stimulation because it involves implanting a device deep inside the brain rather than on the surface of the brain.

With all of these surgical procedures, there is the possibility of TN returning. There is a slight chance of numbness with MVD, but some degree of numbness is expected in the other procedures.

# Complementary and alternative medical (CAM) treatments:

Many people find CAM options that offer some relief. These therapies include things like Acupuncture, Biofeedback, Capsaicin, Homeopathy, Nutritional therapy, Electrical Nerve Stimulation, Transcutaneous Electrical Nerve Stimulation (TENS), Upper cervical chiropractic (UCC), Vitamin B-12 Injections, Vitamin Therapy, Botox, Low Intensity Laser Therapy (LILT), herbal remedies and vitamins, special diets, and neurostimulation.

#### Determine a treatment plan

- Confirm your diagnosis
- Choose a physician who has considerable experience in treating TN/ Neuropathic facial pain
- Choose a physician who will present all treatment options that are appropriate for your type of face pain
- Consider your general health and ability to tolerate surgical stress.
- If surgery is an option choose a surgeon that is experienced and skilled in treating TN.
- Choose a physician that is willing to work with you do not hesitate to seek a second or third opinion

#### Understanding the Risks

- Do you know what the risks are?
- Do you accept the particular risks of the procedure you're considering?
- People are very different in the way they deal with risks; therefore, this needs to be a personal decision, not a medical one.
- Ask questions and get complete answers, talk to people who have had the procedures.
- Destructive procedures can cause numbness. A chronic pain syndrome can develop, involving the effected side of the face. At this point, there's no good medication that's effective. The nerve, which has already been densely injured, can't be manipulated or interacted with in any way that's going to affect the deafferentation pain.

#### What to Expect at the Emergency Room

- ullet The ER Staff may be unfamiliar with TN
- If possible, patients should ask their doctor to call and advise the ER physician about their TN
- Keep a brief record of your TN medical history, including medications taken, allergies and your doctor's name and number.
- ER treatments may include morphine administered by IV or injection. Opioids may be useful in controlling acute pain. Dilantin may be administered by IV or in a newer form called Cerebyx (fosphenytoin).

The latter can provide rapid temporary relief, but requires heart and blood pressure monitoring, so the patient may stay overnight. The ER physician may also order Depacon intravenously or an injection of local anesthetic applied to the trigger zone.



#### Tips for Caregivers

- First step is acceptance. Learn everything you can about TN and neuropathic facial pain.
- Be the medical advocate and record keeper; obtain copies of everything; medical correspondence, test results, record of medications tried, dosages, length of time taken, side effects.
- Record conversations with physicians, hospitals and insurance providers.
- Keep an observation journal so you can deliver precise information to doctors. Include medical visits, conversations, questions and answers, date entries.
- Educate and inform: help people to understand what TN is and how it effects people who have it. Education is the best way to advocate for TN sufferers.
- People often mask their pain, notice non-verbal cues that indicate pain and discomfort or the need to retreat.
- Have an extended support system, for example FPA support groups and Networking Lists

#### About Oral Health Care



#### It is important for people with TN to:

- Schedule routine dental care to prevent extensive dental treatment
- Schedule oral hygiene visits when medication is at its peak level of effectiveness
- Use a soft toothbrush
- Stay away from tartar control and bleaching products

# Discuss the following considerations with your dental professional before you begin treatment

- Schedule routine visits when your pain is in remission.
- For someone who must have major work done, schedule shorter appointment time during the time period in which medication is at its highest level of effect.
- Discuss a short-term preoperative increase in the patient's neuralgia-directed medication with the health care provider prescribing the medication
- If a patient is very nervous, suggest nitrous oxide gas or IV sedation to reduce emotional trauma.
- Use pre-emptive anesthesia by providing a long-acting anesthetic block at the end of the procedure.
- Inject the anesthetic at a site as far as possible from the trigger point for TN pain.
- Utilize dry mouth products.
- If tooth-brushing is intolerable, prescribe viscous lidocaine, a typical anesthetic as an anesthetic camouflage, or Peridex mouth rinse.

#### For Students and Young Adults with Face Pain



The YPC was created to give a voice to younger patients and to address the unique issues they face. These are suggestions from the YPC board for school age patients For more in depth articles about living with TN please visit the www.facepain.org

#### Getting Help at School

Children are entitled to a Free and Appropriate Education (FAPE). Students with medical conditions such as TN are entitled to the Individualized Education Plan (IEP) or the 504 Plan. Your child's current functioning will determine which plan will best serve his/her needs.

For more information, visit www2.ed.gov/about/offices/list/ocr/504faq.html



### Possible accommodations for a student with TN:

- Extended time for testing
- Larger font
- Guided notes
- Allow student to record class (audio or video)
- Allow oral response
- Have work read to student
- Option to re-take tests
- Preferential seating (due to lighting, sound, breezes, etc.)
- Use technology such as Echo Pen and DRAGON to help a student with TN.

#### Mobile Apps:

- "Doctor Visit Manager" keeps track of appointments
- "My Pain Diary: Chronic Pain & Symptom Tracker"

#### A Guide for Parents

- Involve your child in discussions regarding their treatment
- Be prepared to travel for treatment. You will need surgeon experience at treating TN in children.
- Be aware of isolation, bring social events to the patient, stay connected, reach out to other young patients on YPC Facebook

#### Frequently Asked Questions

#### Q: I have never heard of TN, is it a relatively new disorder?

**A:** TN was first described in medical literature as early as 1672. Some people know the disorder as Tic Douloureux. TN is often misdiagnosed as a toothache or TMJ. Many people go undiagnosed for years. Some people are misdiagnosed with TN although what they have is actually neuropathic facial pain.

#### Q: Do I have the suicide disease?

**A:** No, to the best of our knowledge the description of trigeminal neuralgia as the suicide disease originated in the late 19th century when general brain surgery incurred a mortality rate of 90%. This label was born from the limitations and desperation of 19th century medicine. Today there is an arsenal of pharmaceutical, surgical and non-invasive treatment modalities that enable people with TN to live a pain free life.

### **Q:** I have atypical facial pain, which has also been called neuropathic facial pain. What can be done for this type of pain?

**A:** Medications sometimes help control neuropathic facial pain. People with neuropathic facial pain may be prescribed anticonvulsants such as Lyrica or Neurontin. Anti-depressants, such as Elavil or Cymbalta, can also help with the pain. Many people find that complementary alternative medical (CAM) treatments can bring some relief. These therapies include things like upper cervical chiropractic (UCC), acupuncture, herbal remedies and vitamins, or special diets.

### **Q:** I am having difficulty at work because of my pain. Is TN or neuropathic facial pain a disability?

**A:** Yes, both disorders are considered impairments, which can limit an individual's ability to function on the job. You and your employer can work together to find accommodations such as a later start time or telecommuting.

#### Q: Does TN ever go away on its own?

**A:** Sometimes, but it's not likely. TN pain typically runs in cycles, and it is common for individuals with TN to experience periods of remission. Remission can last for weeks, months, and even years. Over time, the attacks tend to worsen with fewer and shorter pain-free periods.

**Q:** Where do I find a doctor who treats facial pain?

**A:** Refer to the medical directory on the FPA website www.facepain. org for physicians who treat TN and neuropathic facial pain.

**Q:** I have a consultation with a neurosurgeon. What should I ask him or her about a procedure?

**A:** It is important to be informed about possible risks or side-effects and what to expect the first week or so after surgery. Some procedures may take months before the individual with trigeminal neuralgia notices the results, so you may want to ask your doctor how much time it will take to know if your procedure has helped your pain. Another important thing to ask is what the surgeon's success rates with this procedure are. You can follow up that question by asking what results the surgeon considers to be successful as well as unsuccessful.

**Q:** Is there anything I can do to avoid common triggers?

**A:** Don't become overtired - Get plenty of rest and ask for help from your doctor if you are not sleeping well.

Avoid cold wind and drastic changes in temperature - Wear a jacket with a hood or a scarf, even when making a quick trip to the mailbox. Do not let your body and face get cold. This only takes a minute to avoid, but once the pain is triggered it make take hours to become bearable again.

**Avoid stress** – Now this is a big trigger and difficult to manage, but it is very important to reduce stress. Say "No," and Ask for Help! Take time out of your day for You. Read, listen to a book-on-tape, watch a movie, take a hot bath, light candles, play relaxing music. Ask your doctor about an antidepressant, it can make a big difference in how you cope.

Be aware of changes in barometric pressure - not much you can do about the weather, but it does help knowing that it is temporary and will stabilize



deductible as allowed by law.

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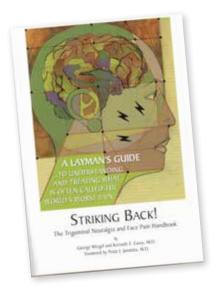
Support the FPA Become a member			
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# Striking Back! The Trigeminal Neuralgia And Face Pain Handbook.

Published by FPA in 2004 and authored by George Weigel and Kenneth F. Casey, M.D. *Striking Back* is written in layman's terms, describes all aspects of TN and facial pain, and provides information and resources for patients, family, and medical professionals.

A must-have guide for every facial pain patient! \$24.95 + \$4.00 Shipping



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#### Web and Social Media Resources

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#### facepain.org

The primary site on the internet for people with trigeminal neuralgia and related face pain conditions. Here's why.....

- Learn about the diagnosis and treatment of TN and other forms of facial pain.
- Connect with patients around the world on the Forum.
- Watch people talking about and living with their TN on the Video Project.
- Read articles from medical experts in the Quarterly Journal.
- Hear from some of the world's leading experts on TN, chronic pain and pain management by watching the Webinar Series.



#### facebook.com/facialpainassociation

- Find the latest announcements, as well as interesting articles relating to facial pain and the association.
- Post to our page if you find an interesting article or have something to share with other patients.



#### twitter.com/facialpainassoc

Join the discussion by following our frequently used hashtags:

#TrigeminalNeuralgia

#facepain

#facialpain

#chronicpain

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

Dr. Albert Rhoton, Jr.

We make a living by what we get, but we make a life by what we give.

— Winston Churchill

Patient Guide is provided free of charge thanks to a generous donation from the estate of Mary Ann Neri, a TN patient.

Please consider including the Facial Pain Association in your estate plans. A legacy gift costs nothing now, yet it gives you the satisfaction of providing for the FPA in the future. You can designate the FPA as a beneficiary of a retirement plan, life insurance policy or donor advised fund. Gifts from your estate are exempt from federal estate taxes.

