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TNA Quarterly

The Journal of The Facial Pain Association

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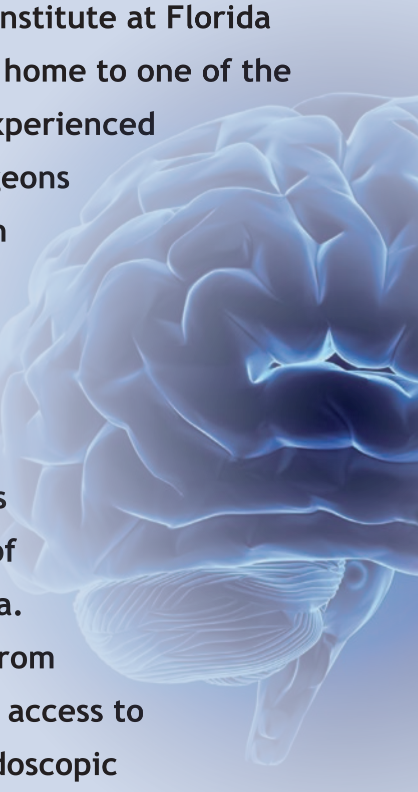

Melvin Field, MD, Physician Leader

Melvin Field, MD, is the surgical director of the Florida Hospital Neuroscience Institute and physician leader of the Minimally Invasive Brain Surgery Program, specializing in the treatment of brain and neurovascular compression syndromes through innovative minimal-access techniques like the endoscopic microvascular decompression approach.

Brandi Ligon, BSN, RN, CNRN, Care Coordinator

Brandi is the care coordinator for the Minimally Invasive Brain Surgery Program and helps navigate patients through the treatment process from scheduling appointments and tests, to coordinating care between multiple physicians, and addressing patients' questions and concerns.

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TNA Quarterly

The Journal of
The Facial Pain Association

Cover

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TNA
The
Facial Pain
Association

From the Chairman of the Board

Much is underway at TNA.

First, our bi-annual National Conference will be held in San Diego on October 5th and 6th. While this issue of the Quarterly is going to press before that date we expect about 300 attendees listening to presentations by experts in diagnosing and treating facial pain disease. Finding an expert in treating a rare disease can be difficult; TNA's conferences put leading physicians in one place to make presentations and speak with patients one-on-one. Attendees in San Diego will learn much from each other and the experts, and patients often report that information gained at TNA conferences helped them to make what can be difficult treatment decisions. Thank you to the physician speakers and TNA staff who will make that conference a success for patients and caregivers. Our next conference will be a Regional Conference in Indianapolis, IN on April 26, 2014. Watch TNA's website for details.

Work to implement several new initiatives continues. A table of contents for an update of the 2004 edition of Striking Back is being drafted. The update will cover diagnosis, coping with intense pain, drugs and their side effects, surgeries and their efficacies, making treatment decisions and many other topics. It will be the up-to-date "go to" handbook for facial pain patients and caregivers. Another initiative is our effort to increase awareness of facial pain disease among those healthcare providers who patients visit first. TNA will have a booth at the American Dental Association's annual conference this November and we are working with the ADA to have a panel of physicians and dentists discuss diagnosing facial pain at the ADA's 2014 conference. Effort on a third initiative is ramping up. Facial pain disease is rare and patients often spend years in pain and have ineffective treatment before they find out about TNA and our services. Extra work to find those patients as soon as possible has begun.

The initiatives summarized above are in addition to the resources that TNA provides to callers and through our website, Facebook and other media. Call our office anytime. In addition, TNA's Facial Pain Research Foundation is funding early-stage work by world-renowned researchers who are in search of better treatments and a cure for facial pain. The FPRF is currently fundraising for a study of the genetic origins of facial pain. Less than 20% of those with facial nerve compression also experience pain and difference in genetics may provide an explanation. That explanation may then lead to a better understanding of what causes the pain and how to stop it. We are very excited about this work and urge your support.

I'd like to end this letter with a special thank you to someone who has done much for TNA. Roger Levy has resigned from our Board of Directors where he was Chairman for 12 of his 14 years as a member. His energy, ideas and efforts helped thousands of patients in desperate pain. Thank you Roger and we wish you much excitement and happiness in the future.

Jeff Bodington

Jeffrey Bodington, Chairman of the Board
TNA – The Facial Pain Association

New TNA-FPA Board member Gary Redwine is seasoned champion of better trigeminal neuralgia treatment

By Arline Phillips-Han
Science Reporter

Gary and Madeline Redwine

In the sunny coastal city of Tampa, FL., business executive Gary Redwine and his wife, Madeline, are movers and shakers in charity golf tournaments, garnering $53,000 from two events named for their son, Matt, who struggles with the stunning pain of trigeminal neuralgia.

Proceeds from two tournaments they hosted in the spring of 2012 and 2013 provided a welcome boost to their benefactor, TNA-The Facial Pain Association, to strengthen its national and international patient support and educational programs. Less visible are the striking behind-the-fairways benefits in raising public awareness of a disease that strikes men, women and children worldwide and is the most painful condition known to mankind.

Today, Gary Redwine prepares for a larger realm of leadership as a newly appointed member of the TNA-FPA Board of Directors. He has defined his goals as crisply as he defined plans for the tournaments--to broaden recognition of trigeminal neuralgia and to better educate the health-care community to recognize the hallmark symptoms so that people who are assaulted by the pain can quickly reach appropriate medical specialists.

"Redwine"...continued on page 4

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"Redwine" . . . continued from page 3

"A lot of our business associates have become acquainted with Matt and the terrible pain he lives with. I find it amazing that so many have asked how they can help---not just as registered golfers, but also as corporate sponsors and as donors of sports memorabilia and a weekend stay at a beach condo, which were auctioned off. At this year's event, 18 sponsors, including Down to Earth Landscape and Irrigation Contractors as the title sponsor, chipped in $1,000 to $3,000 each.

At the tournaments held at Eagles Golf Club, Tampa Bay, more than 200 golfers played on the two championship courses, and large crowds took part in related social events. Redwine describes a high level of enthusiasm for the support of an important cause, even though the words trigeminal neuralgia were new to virtually all of them, except the handful of TN patients taking part. Many of the participants were business associates, vendors and clients of RAMS Inc., an electrical and mechanical construction contracting company of which Gary Redwine is Partner, President and CEO. Friends and associates flew to Tampa from as far away as Bermuda, Kentucky, the Carolinas and Washington, D.C. area.

I find it amazing that so many have asked how they can help.

Redwine closed his office for the days of the tournaments and worked with Madeline to fill a niche that seemed enormously important to helping their son. Through their fundraising initiatives, they became part of a large network of people affected directly or indirectly by the horrific pain of TN, who share a hard drive to relieve the suffering of TN patients.

At the next tournament in the spring of 2014, the Redwines plan to involve a Tampa-based Spanish-speaking radio station, whose programs reach a large listening audience of Latinos along the west coast of Florida. This, along with other news media coverage and a Web site, www.TNgolf.golfreg.com, will sustain a drumbeat of educational outreach to the public.

Redwine said he also will advocate for pharmaceutical research to develop drugs designed specifically to stop or greatly reduce the pain of trigeminal neuralgia. Common medications of choice include anti-seizure drugs, which help to reduce facial pain in many patients, but have limited effectiveness and unwanted side effects.

To this point, Matt Redwine is a voice of authority on the extreme side effects of commonly prescribed medications for TN. After initial prescribed drugs brought on memory loss and severe mood swings, he told his physician, "I no longer know who I am." When the doctor suggested increasing the dosage, he sought the help of Tampa neurologist Eddy Berges, M.D., who helped to establish the lowest possible dosage of carbamazapine, (commonly prescribed for epileptic seizures as well as for nerve pain) that would reduce his facial pain. With the medication, Matt says the pain is under control most of the time. He works in the family business and rarely has an episode of pain that prompts him to take leave.

"I've also learned to control stress levels, since stress can affect every part of life and cause everything to go downhill," he said.

Gary Redwine, who hopes to make the Matt Redwine Charity Golf Tournament even bigger and better next year, brings an entrepreneurial spirit to the TNA-FPA Board. He has declared his willingness to share with others the keys to effective planning and staging of fundraising events.

"Matt went through a terrible ordeal of a useless root canal procedure, treatment for sinus infection and many MRI (magnetic resonance imaging) scans before the day in 2011 when he experienced a debilitating siege of pain and a dangerous surge in blood pressure," Redwine recalls. "I drove him to the hospital where an emergency room physician put us in touch with a neurologist, who identified the problem. Afterward, Madeline and I read everything we could find to educate ourselves regarding TN, and looked for the best ways we could help our son."

Feeling somewhat helpless in fighting a disease that remains stubbornly incurable, the couple discovered fundraising can put the spotlight on trigeminal neuralgia, and help support the medical work that needs to be done to reach the elusive goal of cure.

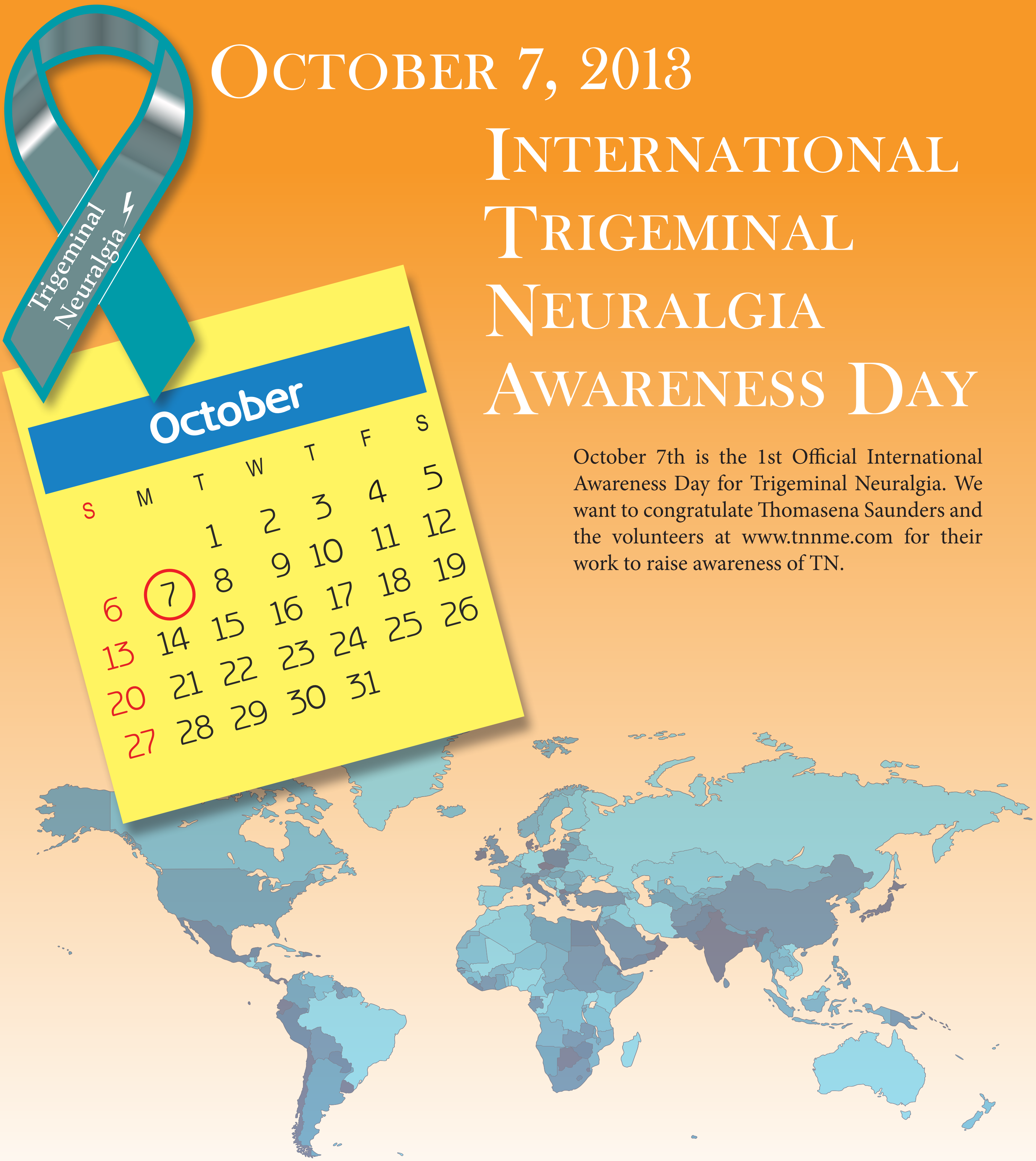

Amy and Matt Redwine at the 2012 tournament

Redwine brings to the TNA-FPA Board a history of 35 years of executive experience in the consulting and alternate workforce industries. Before joining RAMS, Inc., he held various executive positions, ending as Division President for a multi-billion dollar staffing, consulting and engineering firm. He has been an international guest speaker for the China External Trade and Development Council in Taiwan on "International Strategic Alliances--Lessons from the Japan/US Cross Border Industrial Experience." He also served on the CADAM Task Force for the Department of Defense on developing Computer-Aided Logistic Design Standards. He currently serves on the Board of Directors for the Florida Association of Electrical Contractors.

OCTOBER 7, 2013

INTERNATIONAL TRIGEMINAL NEURALGIA AWARENESS DAY

October 7th is the 1st Official International Awareness Day for Trigeminal Neuralgia. We want to congratulate Thomasena Saunders and the volunteers at www.tnnme.com for their work to raise awareness of TN.



TNA News Wire

Rx-Analgesic Overdoses Hitting Women Harder

Distributing scientific and general interest news to patients with neuropathic face pain. A bi-monthly electronic newsletter of TNA - The Facial Pain Association. Look for it in your inbox!

According to just-released data from the U.S. Centers for Disease Control and Prevention (CDC), men are still more likely to die of prescription opioid analgesic overdoses, but the gap between men and women is rapidly closing. Deaths from Rx-opioid overdoses are hitting women harder than ever, and have risen more sharply than among men. Since 1999 the percentage increase in deaths was more than 400% among women compared with 265% in men.

Writing in the July 2013 edition of CDC Vital Signs and Morbidity & Mortality Weekly Report [MMWR, 2013(Jul 2);62, government authorities note that nearly 48,000 women died of Rx-opioid overdoses between 1999 and 2010. Each day, about 18 women die of an Rx-opioid overdose in the U.S. — more than 6,600 deaths in 2010 alone (compared with about 10,000 in men that year). And, for every woman who dies of such overdose, 30 go to the emergency department due to analgesic misuse or abuse.

In sum, the report notes that prescription opioid analgesic overdoses are an under-recognized and growing problem for women, and this relates closely to increased prescribing of these drugs during the past decade. Here are some additional facts from the CDC:

- Women between the ages of 25 and 54 are more likely than other age groups to go to the emergency department due to Rx-opioid misuse or abuse.

- Women ages 45 to 54 have the highest risk of dying from Rx-opioid overdose, whether unintentional or suicide.

- Prescription opioids are involved in 1 in 10 suicides among women.

- Non-Hispanic white and American Indian or Alaska Native women have the highest risk of dying from Rx-opioid overdose.

- Women may become dependent on Rx-opioids more quickly than men.

- Women may be more likely than men to engage in "doctor shopping" (obtaining medications from multiple prescribers).

- Abuse of Rx-opioids by pregnant women can put their infants at risk, and cases of neonatal abstinence syndrome (NAS) grew by almost 300% in the U.S. between 2000 and 2009.

The CDC recommends that, when prescribing opioid analgesics, healthcare providers should recognize that women are at significant risk of overdose from those medications. Practitioners should follow guidelines for responsible prescribing, including screening and monitoring women for substance abuse and mental health problems. They also should use prescription drug monitoring programs (PDMPs) to identify patients who may be improperly obtaining or using Rx-opioids and other drugs. Additional guidance for prescribers from the CDC includes:

1. Consider various pain treatment options, including ones that do not involve prescription drugs.

2. Discuss with patients the risks and benefits of taking prescription opioids, especially during pregnancy and/or when these drugs are taken for chronic conditions.

3. Prescribe only the quantity needed based on an appropriate pain diagnosis.

4. Use patient-provider agreements combined with urine drug tests for people taking Rx-opioids long term.

5. Teach patients how to safely use, store, and dispose of all medications.

6. Avoid combinations of Rx-opioids and benzodiazepines unless there is a specific medical indication.

The CDC adds that the U.S. government is actively tracking prescription drug overdose trends to better understand the "epidemic." Healthcare providers and the public are being educated about prescription drug misuse, abuse, suicide, and overdose, and the special risks for women. Programs and policies are focusing on preventing and treating prescription-drug abuse and overdose, while making sure patients have access to safe, effective pain treatment.

Thank you Roger for your 16 years of service & support of TNA – The Facial Pain Association

Roger Levy
Member ,TNA Board of Directors, 1997 – 2013
Chairman, TNA Board of Directors, 2000 – 2012

Roger will be stepping down from the TNA board at year's end. He has been and will continue to be an ardent supporter of TN patients' right to a fast, informed and accurate diagnosis.

Roger has guided TNA in developing and fulfilling its mission and was instrumental in establishing the Facial Pain Research Foundation, where he continues to be a trustee, to fund research to find a cure.

While Roger will always remain part of the TNA family, his presence at future board meetings will be greatly missed.

To paraphrase the late John W. Gardner, leaders come in many forms, with many styles and diverse qualities. There are quiet leaders and leaders one can hear in the next county. Some, like Roger Levy, find strength in eloquence, in judgment, and in courage.

Roger with Michael Pasternak, past TNA board president, at the 8th National Conference at MAYO Clinic in Rochester, MN

Above: Roger with Dr. Tew of the TNA Medical Advisory Board
Left: with Rich Baron, TNA Board Member

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- hundreds of pages of information on TN and related face pain
- discussion boards and chat rooms

DELIVERING OUR MISSION

85¢ of every dollar TNA receives in financial support is spent delivering our mission: patient support, public awareness, educating patients and medical professionals.

Look for TNA's annual appeal letter in your mailbox this holiday season!

Whether you've just been diagnosed or are finally pain free, our growing facial pain community provides online support when you need it. It's free. Sign up today!

"Today I feel like my own enemy."

"Anyone else feel stabbing pain behind their ear?"

"My TN started after dental surgery"

"Just wanted to let everyone know how acupuncture went."

Finding the Perfect Doctor

By Cindy Ezell

Cindy is in charge of patient services for TNA and has been a TN patient and patient advocate for more than 25 years. As a patient Cindy has undergone just about every surgical treatment available in dealing with her facial pain.

In a perfect world there would be no need for a doctor because there would be no neuropathic facial pain or trigeminal neuralgia. Unfortunately, that is not the scenario; so in my opinion, the most important decision you can make with this disorder is to find a doctor that you trust and respect. As yet, there is no cure and so for many patients, trigeminal neuropathic pain must be managed. Effective long term patient/doctor relationships include knowledge and cooperation by both the doctor and the patient.

If you feel the pain on your face or scalp you will probably visit a GP or neurologist. However, most of us who feel pain in their mouth will go to the dentist. It can be very difficult to diagnose trigeminal neuralgia as many of the symptoms mimic a cracked tooth, damaged nerve root, TMJ, the results of poor dental hygiene, etc. When no evident dental issues are present, many dentists today will recognize the symptoms of trigeminal neuralgia. You might be referred to an endodontist, oral and maxillofacial surgeon or an EN&T for a second opinion.

Here it is important to differentiate between classic trigeminal neuralgia and the symptoms of someone who has a true dental issue and undergoes corrective treatment that inadvertently damages the end of the trigeminal nerve resulting in neuropathic facial pain. You can review the classification of facial pain, which appears in this issue of the Quarterly, to determine these differences. If the damage is recent, you might want the opinion of an oral and maxillofacial surgeon that specializes in trigeminal nerve microsurgery. Long term damage may best be managed by an orofacial pain specialist, pain management doctor or a neurologist.

Many of us are from the era of "doctor knows best," and accept the diagnosis and treatment without questions.

But a rare condition requires special knowledge, experience and in the case of a surgeon, skill. There are even times when a second opinion is not only appropriate but necessary:

- It is a rare condition – Neuropathic facial pain including trigeminal neuralgia is encountered so infrequently that the management is best handled by a physician that is experienced in its treatment.

- You lack confidence in the offered opinion. You find yourself questioning the diagnosis or treatment plan.

- The diagnosis is unclear. Neuropathic facial pain has many classifications and a correct diagnosis must be obtained for proper treatment.

- Your concerns are dismissed. You know your symptoms and how the pain feels. You have to advocate for yourself to avoid needless suffering or poor care.

Treatment methods may differ

Some doctors prefer to monitor the situation and use less aggressive procedures before moving to surgical intervention. Some doctors like to use more aggressive treatment methods from the beginning. By getting a second opinion, you can expand your options about different treatment methods which may be most suitable for you and your situation. Being informed is always your best option!

Second opinions don't hurt and in fact may even help

It never hurts to get a second opinion. Keep in mind that doctors are human and they too can make mistakes or be faced with unusual or challenging cases. When the first doctor's opinion is the same or similar to the second doctor's, your confidence will be increased.

A valid opinion and appropriate course of treatment is your best option for return to good health or grasping control of the chronic disease.

"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[1]

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.

"Doctor" continued on page 16

"Doctor" continued from page 15

While second opinions may be awkward for doctor and patient at times, studies have shown that 30 percent of patients, who sought second opinions for elective surgery and 18 percent of those who were required to obtain a second opinion by their insurance company, found that the two opinions were not in agreement. These studies are one more reason why you need to make sure you are educated properly to make the best decision for your health.

Patient Rights

Second opinions are a way to learn about your diagnosis and choices for treatment options. Some doctors are more conservative while others tend to be more aggressive. A patient has rights and one of your most important rights is the ability to get a second opinion about your diagnosis. Being informed is critical in deciding your choice of treatment.

Statistics show that over one third of adults in the United States will never seek a second opinion and almost one tenth of newly diagnosed patients rarely, or never understand their diagnosis. A second opinion means you are consulting with another doctor to confirm a diagnosis and/or find possible different treatment choices available to you.

It is recommended to get a second opinion immediately to avoid delays in your treatment and recovery.

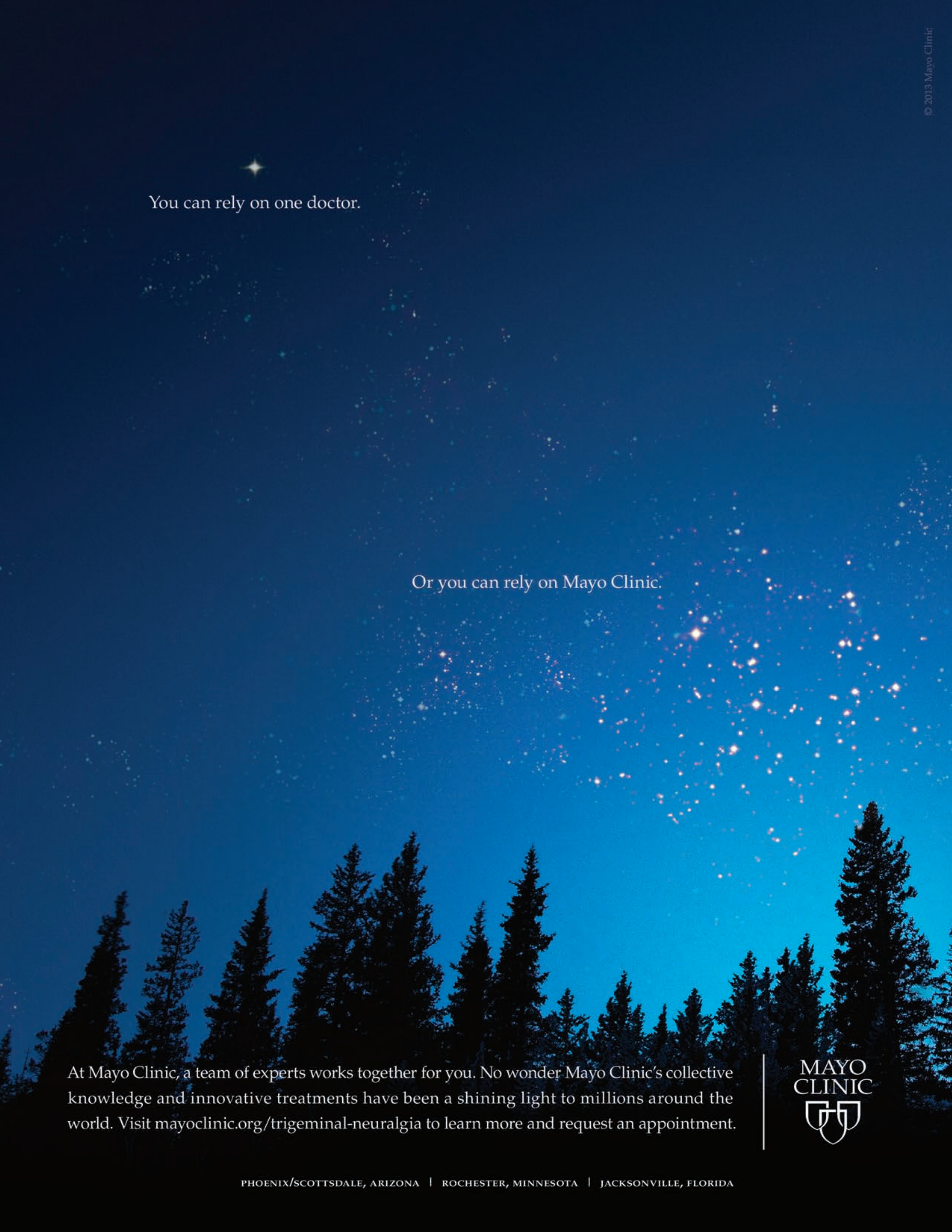
What will it cost me?

Call your insurance provider before going for any treatment or second opinion to prevent any confusion or denial of the bill. You need to know exactly what will be covered, such as an out of network provider, any lab work or testing that may be required and what your responsibilities are before seeking the second opinion. Diagnostic tests can be very costly and many insurance providers will not pay for them if they were completed for the initial diagnosis.

CLASSIFICATION FOR FACIAL PAIN

- **Trigeminal neuralgia, type 1, (TN1)**: facial pain of spontaneous onset with greater than 50% limited to the duration of an episode of pain (temporary pain).
- **Trigeminal neuralgia, type 2, (TN2)**: facial pain of spontaneous onset with greater than 50% as a constant pain.
- **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.
- **Trigeminal deafferentation pain, (TDP)**: facial pain in a region of trigeminal numbness resulting from intentional injury to the trigeminal system from neurectomy, gangliolysis, rhizotomy, nucleotomy, tractotomy, or other denervating procedures.
- **Symptomatic trigeminal neuralgia, (STN)**: pain resulting from multiple sclerosis.
- **Postherpetic neuralgia, (PHN)**: pain resulting from trigeminal herpes zoster outbreak. (SHINGLES)
- **Atypical facial pain, (AFP)**: facial pain of unknown origin

"Doctor" continued on page 18


You can rely on one doctor.
Or you can rely on Mayo Clinic.

"Doctor" continued from page 16

You have the right to have copies of the tests you already had done. Be an informed consumer and arrive for the second opinion with all of your previous medical records, contact information about the first physician, insurance card, list of prescribed medications and allergies, and any diagnostic test results.

A Doctor's View of Patients with Chronic Disease[2]

As scary and frustrating as it can be to have a chronic disease, especially chronic pain, it is often equally frightening and concerning for the providers who care for such patients. One practitioner offers his viewpoints on what it is like to care for patients with chronic disorders and offers some helpful and practical advice for patients to follow. There also is much for healthcare providers to learn from this as well.

The following "Letter to Patients" is reprinted in its entirety from the blog, "Musings of a Distractible Mind (Thoughts of an odd, but not harmful primary care physician)" written by Rob Lamberts, MD, who practices in Georgia. It is reproduced by permission under a Creative Commons Copyright License agreement.

Dear Patients:

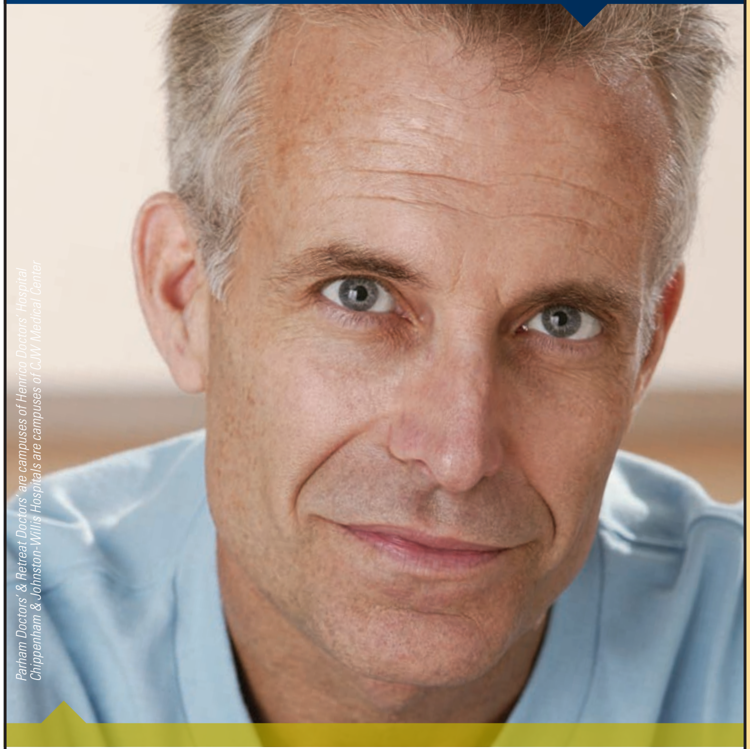
You have it very hard, much harder than most people understand. Having sat for 16 years listening to the stories, seeing the tiredness in your eyes, hearing you try to describe the indescribable, I have come to understand that I too can't understand what your lives are like.

How do you answer the question, "how do you feel?" when you've forgotten what "normal" feels like? How do you deal with all of the people who think you are exaggerating your pain, your emotions, your fatigue? How do you decide when to believe them or when to trust your own body? How do you cope with living a life that won't let you forget about your frailty, your limits, your mortality? I can't imagine.

> *Second opinions are a way to learn about your diagnosis and choices for treatment options.*

But I do bring something to the table that you may not know. I do have information that you can't really understand because of your unique perspective, your battered world. There is something that you need to understand that, while it won't undo your pain, make your fatigue go away, or lift your emotions, it will help you. It's information without which you bring yourself more pain than you need suffer; it's a truth that is a key to getting the help you need much easier than you have in the past. It may not seem important, but trust me, it is.

"Doctor" continued on page 20



The Doctor's Perspective . . .

The following highlights are from a recent discussion with two doctors and two dentists, specialists in neuropathic face pain, on what they like to see in a doctor – patient relationship.

- I like it when a patient brings another person with them because it is well known that maybe $^{2}/_{3}$'s of information given is retained. And then there is the difference in how that information is interpreted.

- Patients who read about their condition and healthy lifestyles in general, are better motivated to work with you in a partnership.

- If the treatment is not helping in a reasonable time period they should move on.

- Patients should be encouraged to seek care in a multidisciplinary fashion. Not one treatment works for all.

- Patients need to be able to give a clear description of pain characteristics since onset.

- Patients need to be open minded to recommendations in spite of what they have read on the Internet.

- An understanding patient will grant that you are not "Marcus Welby" so things might not always get better, but the doctor and patient need to be a team working together the best they can.

"Doctor" continued from page 18

You scare doctors. No, I am not talking about the fear of disease, pain, or death. I am not talking about doctors being afraid of the limits of their knowledge. I am talking about your understanding of a fact that everyone else seems to miss, a fact that many doctors hide from: we are normal, fallible people who happen to doctor for a job.

We are not special. In fact, many of us are very insecure, wanting to feel the affirmation of people who get better, hearing the praise of those we help. We want to cure disease, to save lives, to be the helping hand, the right person in the right place at the right time.

But chronic unsolvable disease stands square in our way. You don't get better, and it makes many of us frustrated, and it makes some of us mad at you. We don't want to face things we can't fix because it shows our limits. We want the miraculous, and you deny us that chance.

And since this is the perspective you have when you see doctors, your view of them is quite different. You see us getting frustrated. You see us when we feel like giving up. When we take care of you, we have to leave behind the illusion of control, of power over disease. We get angry, feel insecure, and want to move on to a patient who we can fix, save, or impress. You are the rock that proves how easily the ship can be sunk. So your view of doctors is quite different.

Then there is the fact that you also possess something that is usually our domain: knowledge. You know more about your disease than many of us do — most of us do. Your MS, rheumatoid arthritis, end-stage kidney disease, Cushing's disease, bipolar disorder, chronic pain disorder, brittle diabetes, or disabling psychiatric disorder — your defining pain — is something most of us don't regularly encounter. It's something most of us try to avoid.

So you possess deep understanding of something that many doctors don't possess. Even doctors who specialize in your disorder don't share the kind of knowledge you can only get through living with a disease. It's like a parent's knowledge of their child versus that of a pediatrician. They may have breadth of knowledge, but you have depth of knowledge that no doctor can possess.

So when you approach a doctor — especially one you've never met before — you come with a knowledge of your disease that they don't have, and a knowledge of the doctor's limitations that few other patients have. You see why you scare doctors?

It's not your fault that you do, but ignoring this fact will limit the help you can only get from them. I know this because, just like you know your disease better than any doctor, I know what being a doctor feels like more than any patient could ever understand. You encounter doctors intermittently (more than you wish, perhaps); I live as a doctor continuously.

So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship:

1. Don't come on too strong — yes, you have to advocate for yourself,

> **So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship.**

but remember that doctors are used to being in control. All of the other patients come into the room with immediate respect, but your understanding has torn down the doctor-god illusion. That's a good thing in the long-run, but few doctors want to be greeted with that reality from the start. Your goal with any doctor is to build a partnership of trust that goes both ways, and coming on too strong at the start can hurt your chances of ever having that.

2. Show respect — I say this one carefully, because there are certainly some doctors who don't treat patients with respect – especially ones like you with chronic disease. These doctors should be avoided. But most of us are not like that; we really want to help people and try to treat them well. But we have worked very hard to earn our position; it was not bestowed by fiat or family tree. Just as you want to be listened to, so do we.

3. Keep your eggs in only a few baskets — find a good primary care doctor and a couple of specialists you trust. Don't expect a new doctor to figure things out quickly. It takes me years of repeated visits to really understand many of my chronic disease patients. The best care happens when a doctor understands the patient and the patient understands the doctor. This can only happen over time. Heck, I struggle even seeing the chronically sick patients for other doctors in my practice. There is something very powerful in having understanding built over time.

4. Use the ER only when absolutely needed — Emergency room physicians will always struggle with you. Just expect that. Their job is to decide if you need to be hospitalized, if you need emergency treatment, or if you can go home. They might not fix your pain, and certainly won't try to fully understand you. That's not their job. They went into their specialty to fix problems quickly and move on, not manage chronic disease. The same goes for any doctor you see for a short time: they will try to get done with you as quickly as possible.

5. Don't avoid doctors — one of the most

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"Doctor" continued from page 21

frustrating things for me is when a complicated patient comes in after a long absence with a huge list of problems they want me to address. I can't work that way, and I don't think many doctors can. Each visit should address only a few problems at a time, otherwise things get confused and more mistakes are made. It's OK to keep a list of your own problems so things don't get left out — I actually like getting those lists, as long as people don't expect me to handle all of the problems. It helps me to prioritize with them.

6. Don't put up with the jerks — unless you have no choice (in the ER, for example), you should keep looking until you find the right doctor(s) for you. Some docs are not cut out for chronic disease, while some of us like the long-term relationship. Don't feel you have to put up with docs who don't listen or minimize your problems. At the minimum, you should be able to find a doctor who doesn't totally suck.

7. Forgive us — Sometimes I forget about important things in my patients' lives. Sometimes I don't know you've had surgery or that your sister comes to see me as well. Sometimes I avoid people because I don't want to admit my limitations.

Finding the perfect doctor, or more importantly, the right doctor for you is often a process. Just remember, how many dealers do you visit before you buy a car or how many quotes do you get from contractors before you renovate your kitchen? You get the point. As a patient, it is your absolute right to seek advice and to be in charge of what happens to your body. Seeking multiple medical opinions is not a betrayal of trust. Many doctors welcome the chance to have a fresh set of eyes on the problem at hand.[3]

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(1) www.patientadvocate.org

(2) Pain-Topics.org News/Research UPDATES , visit: http://updates.pain-topics.org/2013_06_01_archive.html

(3) "A guide to a second medical opinion" http://theconversation.com/au/health

TNA's Memorial Tribute Fund

There are special people in our lives we treasure. Increasingly, TNA 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 TNA's growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received between June 1, 2013 and August 31, 2013.

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Ally Castellano
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Louise Freedman
Roger Freeman
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Sue Jameson
Darlene Kasten
Sandra Kurtz
Cindy Lincoln
Annette Ludlam
Arlyn Lyons
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Gayle Moeller
Jean Newlin
William Nist
Jeff Oldenburg
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Richard Stephens
Ronald Tripp
Beverly Trojan

July 2013

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Pat Akerberg
Janine Benedict
Sherry Birkby
James Blodgett
Bennett Bloomfield
Christa Bolton
Thomas Bowler
Barbara Britt
Evelyn Burry
Christine Calabrese
Joanne Carter
Nancy Clark-Locklin
Ann Clayton
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Debbie Crowe
Barbara Daniels
Allan Enis
JR Eshleman
Thomas Espineda
Mike Fadel
Tom Fenstermacher
Ken Foster
Virginia Fugate
Donald Hansen
Ken Holmes
Serena Hunter
Mary Ann Kelly
Carol King-Wansley
George Kohan
Larry Lieder
Lynn Marquess
Larry Matthews
Mary Ann McCann
Mary Lou McEver
Charlcie Montgomery
Jan Montgomery
Maura Nolan
Janice Przystal
Mary Jane Pych
Kathleen Reid
Peter Rubin
Joe Shafer
Brenda Sharp
Robin Steinberg
Coracel Suratos Templo-Johnson
Marianne Thompson
Carol Warren
Allan Waxman
Kenneth White

August 2013

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Susan Ayres
Helen Babyak
Burton Becker
D. E. Billingsley
William Bivens
Floria Cardona
Tom Concialdi
Kay Cousineau
Bronwyn Cowell
Susanne Eberle
Sandra Erece
Lisa Eschleman
Tom Evert
Diana Genther
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Mariah Kahler
Candace Kahn
John Keys
Natalie Koss
Rathna Lingamaneni
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Julie Murphy
LeRoy Nelson
Charles New
Karen Ott Mayer
Dain Paxton
Jeff Shrifter
Herb Smith
Cheryl Snidar
Charlene Taylor
Annette Toledano

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Lifetime 2013

Claude & Jean Aldridge
John Alksne, MD
Linda Lee Alter
Gwen Asplundh
Denise Ayers
Ramesh P. Babu, MD
Nicholson Barbaro, MD
Richard Baron
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Michael Brisman, MD
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Ken Casey
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Douglas and Joy T. Daugherty
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Dorothy Erwin
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Steven Giannotta
Mary Glynn
Denise Gorman
Ron Greiser
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Gayathri Rao
Jean Raymond
Gary Redwine
Aaron P. Running
K Singh Sahni
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Help us learn the real cost of this disease.

If you are a face pain patient, please go to www.fpa-support.org and click on the Patient Registry link at the top on the page to complete the Patient Registry Questionnaire.

This simple action will take only minutes of your time, but will help us gather definitive data to measure the effectiveness and cost of various treatment modalities.

By providing your answers, you can help us to empower patients and educate policymakers.

It is crucial to gather data so that we can play an important role as an advocate for facial pain issues, and win the battle against neuropathic face pain.

Your information will be stored securely, and you can save a questionnaire in progress. Return as many times as you need to, to finish and update answers.

Complete the TNA Patient Registry Questionnaire today and take an active role in the battle against trigeminal neuralgia and related face pain conditions.

www.fpa-support.org/patient-registry

‘Suicide Disease’ often misdiagnosed

By Victoria Colliver
Reprinted from the San Francisco Chronicle
June 19, 2013

Joan Cannelli leads a Bay Area support group for people who have trigeminal neuralgia.

It’s known as the “suicide disease” because of the intense electric shock-like burning or stabbing nerve pain that runs along the side of the face, and it can be triggered by talking, eating or even a light wind.

Trigeminal neuralgia, which causes such a fierce pain that sufferers may contemplate suicide, is a rare neurological disease that is often misdiagnosed for years as an earache, dental or jaw problem - or just something that’s all in the patient’s head. For those who have the disease, the problem is indeed in their head, and it causes a pain that’s very real.

“You can’t move your tongue, you can’t move your face, you can’t eat or drink and you can’t talk,” said Joan Cannelli, 70, of Oakland, who developed trigeminal neuralgia in 2007 after undergoing a root canal.

“I remember crying trying to brush my teeth,” she said.

Unlike some patients who have to go from doctor to doctor before getting a diagnosis, Cannelli was quickly referred to a neurologist who diagnosed her problem, but it would be many years before she decided to undergo surgery that would finally resolve the pain.

Trigeminal neuralgia typically affects one of the two trigeminal nerves on each side of the face. And while just one in about 15,000 or 20,000 people suffers from it, experts say the numbers may be significantly higher because of frequent misdiagnoses. The enigmatic condition has no known cause, but is most frequently associated with abnormal blood vessels that compress the nerve, triggering the pain.

Not all patients have the nerve compression, nor do they have the same type of pain or frequency of attacks. Some treatments, such as medications and surgery, can relieve the symptoms, but not for everyone.

Hard to pinpoint

“Unfortunately, this disease can manifest itself in different ways in terms of pain,” said John Koff, chief executive officer of the TNA-the Facial Pain Association, a patient group for people with all types of facial pain. “People see doctors who don’t recognize it and they often can’t establish where it’s coming from.”

Depression and isolation are major problems for patients with this debilitating disorder, Koff said. “When they get it, no one ever heard of it, they don’t know anyone who has it and they suffer in isolation, which is the worst thing for people with pain," he said.

Joan Cannelli is happy to enjoy favorite activities again after successful surgery for trigeminal neuralgia.

Trigeminal neuralgia is difficult to diagnose because there's no one test for it. It's typically diagnosed based on symptoms and by ruling out other causes such as a tumor or multiple sclerosis. That can be done through magnetic resonance imaging, MRI, which may or may not also show a blood vessel pressing on the trigeminal nerve.

Two types

Most people have what's known as "typical" trigeminal neuralgia, which has the nerve compression and the stabbing, shock-like pain. But some people have the more difficult or "atypical" form that may involve different sensations such as a burning feeling. This type lacks the compression and doesn't respond to surgery.

Regardless of type, patients generally try medications, such as drugs to treat pain, seizures or depression, before resorting to surgery. Sometimes drugs can control the symptoms, but over time they can become less effective.

Cannelli, who managed large development projects, tried various medications for nearly five years. In 2010, the pain had forced her to resign from her demanding job. Last year, after she had to cancel a trip to New York on the morning she was supposed to leave, she opted for surgery.

"The thing I was most fearful of was waking up and still having the pain," she said. "This is not always successful."

She underwent a 4 1/2 hour surgery last June called microvascular decompression, which involves making an incision behind the ear and going in to take the offending blood vessel, which is usually an artery but can be a vein, and move it away from the nerve. A small piece of teflon felt is placed between the nerve and the vessel as a buffer.

"The thing I was most fearful of was waking up and still having the pain," she said. "This is not always successful."

Joan Cannelli, here with German shepherd Drake.

But Cannelli woke up completely pain free.

The intended result

Her neurosurgeon, Edward Chang, chief of epilepsy and pain neurosurgery at UCSF, said that's what is supposed to happen. "When you decompress it, people wake up from surgery without pain. Instantly," he said.

Chang said the majority of his patients - 70 to 90 percent - with typical or classic trigeminal neuralgia stay pain free after surgery. But in a small percentage the pain can return for no known reason.

For Heather Stanton, 48, her case has been complicated by the fact she primarily had the atypical form of the disease with some classic symptoms.

After undergoing microvascular decompression surgery at a Peninsula hospital in 2007, the Oakland resident was pain free for just a short while. She has since had to undergo numerous surgeries and procedures to try to address the atypical pain, including having electrodes implanted along the peripheral nerves of her face.

Stanton is now working with a pain doctor to control her symptoms, but hopes to take advantage of new procedures as they develop in the future. She said she has occasional pain-free hours or even a full day, for which she is grateful.

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"I kind of didn't believe in chronic pain before all this," she said. "I couldn't fathom the idea that someone could have pain every day of their lives."

New treatments and procedures have become available in recent years. One of those options includes radiosurgery or precisely targeted radiation with a device called the Gamma Knife, Chang said.

Last resort

As a last resort, he said he has on rare occasion cut the nerve to reduce the pain. But he said he prefers not to do that because, in addition to causing loss of sensation in the face, the procedure can cause a different type of nerve pain.

Researchers are also working to identify which genes are involved in neuropathic pain, which could lead to newer, more effective treatments.

Since her surgery, Cannelli has been able to return to many of the activities she loves. She began a pet-sitting business and is involved with Golden State German Shepherd Rescue. In January, she started a bimonthly support group for people in the East Bay with trigeminal neuralgia.

"I want to be able to help people because there are people out there who do not have any support," she said.

About trigeminal neuralgia

What is trigeminal neuralgia? Also called tic douloureux, trigeminal neuralgia is a rare, chronic and painful condition that affects the trigeminal nerve, one of the largest nerves in the head.

What are the symptoms? Extreme, sporadic, sudden burning or shock-like face pain that can last for a few seconds or much longer and can vary in frequency and duration.

What causes it? Typically a blood vessel pressing on the trigeminal nerve as it exits the brainstem, but there also may be no known cause.

How is it treated? Options include medication - pain, antiseizure or antidepressant drugs - as well as surgery, radiosurgery and alternative approaches.

For more information: The TNA-the Facial Pain Association at (800) 923-3608 or www.fpa-support.org.

Support for Bay Area patients: Patients in the East Bay can contact Joan Cannelli at (510) 531-3490. The group meets bimonthly on the first Saturday of the month from 1:30 to 3:30 p.m. at Alta Bates Summit Medical Center in Oakland. The next meeting is July 6.

A San Francisco-San Jose support group meets every other month on the second Wednesday of the month from 5:30 to 7:30 p.m. at the Stanford Cancer Center. For more information, contact Bennett Bloomfield at (650) 573-6292.

Source: TNA-the Facial Pain Association; National Institute of Neurological Disorders and Stroke

Victoria Colliver is a San Francisco Chronicle staff writer. E-mail: vcolliver@sfchronicle.com

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Of the 40 physicians that are part of Goodman Campbell, the following six surgeons specialize in treating trigeminal neuralgia:

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

Dr. Brisman is Chief of Neurosurgery at Winthrop-University Hospital and Co-Medical Director of the Long Island Gamma Knife at South Nassau Communities Hospital.

Dr. Brown is Northeast Regional Director and immediate past Co-Chairman of the Medical Advisory Board of TNA-The Facial Pain Association.

Dr. Mechanic is the Chief of Neurosurgery at Huntington Hospital in Huntington, NY and the Chairman of the Nassau Surgical Society Section of Neurosurgery.

For more information about trigeminal neuralgia and face pain or to make an appointment, please call (516) 255-9031.

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