

## TN: A STRANGE AND TERRIBLE SAGA

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### *Going toe-to-toe with the “face-pain” disorder*

*by Therese Hercher*

*In another attempt to branch out in the Human Interest category, the Coffee Coaster features Ms. Therese Hercher telling her story of a disorder the general public is largely unaware of: Trigeminal Neuralgia (TN), often referred to as the Suicide Disease. Greater public awareness of TN is vital... and the Coffee Coaster considers it a privilege to post this outreach article.*

### **Foreword**

Trigeminal Neuralgia (TN) is considered rare, though I believe it is under-reported. I believe many TN sufferers are simply not diagnosed correctly, because its symptoms mimic many common facial illnesses. Still, it is precisely the rareness of TN that makes seeking communion with other sufferers vital to me. When, in 2004, England’s Dr. Zakrzewska[1] announced plans to write a book about it, incorporating true life stories from sufferers, she solicited stories and histories from around the globe.

I quickly pulled together the notes I had written about my own experience with it since 1997 and submitted them to her. I looked forward to reading how my TN colleagues across the world described their experiences. But more important to me was a concomitant aspect of TN that few who do not have this diagnosis ever think about: the isolating loneliness of a malady that is so painful, yet so widely unheard of.

We with TN do not receive the recognition or sympathy those with Parkinson’s or Multiple Sclerosis (MS) do. We do receive blank-stares. Sometimes if we’re lucky, the stares prompt a corresponding question. And while any interest provides us with an opportunity to educate the public, we mostly long for people who just ‘know.’

So that’s my goal: to familiarize folks with this rare yet agonizing neurological disease, as I’ve experienced it, over the last 12 years.

### ***The Inner Dragon from Hell***

In the spring of 1997, I started feeling tiny electroshocks to the left side of my face, under my nose above my lip, whenever I dried my face with a towel. Nano-seconds in nature, they were more annoying than anything else. Far more upsetting was that no one could explain them to me...least of all the medical profession. The doctor I worked with dismissed my concern as allergy-related. And, though my X-rays were clear, my baffled dentist suggested sinus problems.

A year later, after the shocks disappeared and came again, disappeared again and came back again, imperceptibly stronger and longer each time. I did some research on my own. Thank God I had discovered the internet and the powerful search engines of the time. I entered a few key words (electric, stabbing, face, pain), and within seconds I had the name for my facial shocks, the diagnosis which eluded the medical folks I sought answers from: Trigeminal Neuralgia.

The data said the condition is rare, with an average onset in the 40s and 50s (although there are many exceptions to this); that TN is most often unilateral (mine is on the left side), with pain prompted by the trigeminal nerves in the face. The trigeminal nerve is the fifth (and largest) of the head’s twelve cranial nerves, and has three branches, each

affecting different areas of the face. The mandibular branch at the bottom serves primarily the lower teeth, lip, gums, tongue and part of the ear. The middle or maxillary branch serves the upper jaw and tooth area, upper lip and gums, palate, sinuses, temples and most of the nose. The ophthalmic branch is the uppermost of these three, and includes the forehead, eyes and bridge of the nose. The 'neuralgia' (the medical word for pain) is caused by a blood vessel or artery compressing the trigeminal nerve.

I might have pooh-poohed the search results entirely had it not been for a sentence tucked at the end of one of the definitions that seemed to address me personally: "In 4 to 5% of cases, TN is linked with multiple sclerosis." I never took seriously the "possible MS" diagnosis I was given in a 1996 visit to a neurologist because of some clumsiness and numbness I felt in my left arm/hand. No one in my family has MS and there are other diagnoses that might explain those symptoms. Yet the double-mention of these neurological nightmares cemented into my brain that I had both these disorders.

This hit me like a sledge hammer. What had me reeling was not the MS/TN double-whammy so much as the TN prognosis: It was alarming! There was no good news anywhere in the descriptions, none at all -- TN just got worse: the remissions would get shorter and shorter, then ultimately disappear altogether; the medications would eventually become ineffective; the pain would get more intense until finally it became a round-the-clock nightmare.

Reading this in the wee hours of the morning filled me with dread. My future was being forecast without any upside. No hope was hiding anywhere between these lines. No quantitative translations were offered as to relapse times, no illustrations as to what 'shorter' meant, or 'more intense.' Or how 'pain' was measured.

But the scariest thing was the rareness of it: with whom could I share the horror? And my fears? Who else could I GET information from who would know it from the inside out? How in the world would I find these people? If the medical people I had contacted weren't helpful, how confident could I be that my disorder would even be understood by anyone else? Or my family, and friends? Would other sufferers be as hungry as I for information about it, or as desperate to educate themselves? Having no answers at that early stage of discovery, but knowing everyone's threshold for pain varies, I crossed my fingers and prayed the literature was discussing worst-case-scenarios.

The electrical lightening facial stabs over the next year or so were something I got so used to, I was confident I could control them merely by letting my face 'drip-dry' instead of using a towel. Gee, I thought, that was easy. The books exaggerated after all. They took the most dramatic cases and scared the hope out of me. How irresponsible. Then, on March 8, 1999, after dinner with a friend at a Chinese restaurant, I awoke in the night, and my hand was asleep, so I shook both vigorously.

What happened next came from the depths of hell: I felt an icepick forced deep into my left ear, while a freight train roar became the loudest sound on earth. The noise was trying to outdo the pain, each reaching an intensity I never experienced before. When the train finally stopped (it seemed like forever but was perhaps less than a minute), I realized I had screamed too – not long, nor loud, but that I should hear myself cry out loud from pain is so foreign to me, the scream itself became part of that particular March 8 nightmare.

Tears freely flowed for perhaps a full hour, while I fumbled for the light and slowly found the courage to lie back down on what had a moments before been a torture rack.

I just sat there, not daring to lay on one side or the other, not daring to lay prone. I sat up very slowly---all my movements were in slow motion now – and thus I remained – ever so still - until the light of dawn relieved me of my vigil, and gave me permission to finally sleep. I was terrified the pain-bearer would return, icepick in hand.

As it turned out, I never had that ear-stabbing experience again. I made an emergency appointment with a Southfield neurologist who prescribed Tegretol, a prescription slip I tucked neatly away in my wallet until long after it had expired. No way was I going to start relying on such a powerful, anti-convulsant medication with its mind-dulling, robot-inducing side-effects...not until I absolutely had no choice.

In August 2000, I moved from metro Detroit 100 miles northwest to Okemos. For as long as I've had it, the TN seemed to disappear in the early part of the year and reappear in late summer, early fall. So in 2001, the short electrical jabs were back again, right on schedule. But a new dimension was about to be added. Late on a beautiful Saturday evening, Sept 8, I had just arrived home after raiding my sister's tomato patch.

As I sat on my bed reading, I popped the first of those beautiful, tart juicy tomatoes into my mouth -- and might just as well have sunk my teeth into bubbling electric acid. Lights popped and flashed behind my eyes, and for an instant I recognized nothing except pure sizzling pain. The tomato arginine had tripped a raging electric current in the left side of my mouth. I couldn't figure out how to help myself. No longer split-second jabs, this pain was full-bore high-voltage current, two to three minutes at a time, on and off. Desperately I thought dental floss would help....it was precisely the wrong thing to do, as it merely excited the fury of the newly awakened demons. Once again I found myself catatonic with fright. I dared not breathe too loudly or deeply for fear of being pushed down even deeper into the inferno.

Dustin Hoffman's Marathon Man would know something about this level of pain. Few others on earth can imagine it. My greatest fear that night was not knowing how long this would last, how much I could stand before dying. Fifteen minutes passed before I realized all the synaptic neural 'charges' had been spent.

Thank God I live alone, I thought after the pain let up - it mercifully spared me having to explain what had just happened. To have had to speak right then would have been cruel agony because, as I would find out soon enough, one of TN's constant symptoms is sparks flying with each connection the tongue makes with any part of the mouth. Eventually I got rest, again in a sitting position, desperate for oblivion. I dared not make a sudden movement that might provoke a demon-frenzy.

This event marked the point-of-no-return. I soon realized I had graduated into an advanced phase of TN, one which punishes with deep, mean electric-voltage the everyday functions of talking, yawning, eating, brushing teeth. From this point onward, I would never return to TN-lite.

I was severely depressed the next day and uncharacteristically weepy in describing to my family what happened. Throughout that day and two days past the horror of 9-11, I dealt with the sporadic, yet terrific pain which felt like my teeth were being drilled to the very roots without benefit of anesthetic. I could not brush properly, which caused me severe distress. My mouth would build up to a 'charge,' become hotter and hotter, and I knew all it needed was ANY provocation -- just talk, just inhale, or drink something, POW!! zzzzzZAP, sizzZZZZle!!.

I reached my personal breaking point at work late one morning where, alone in the Ladies Room I observed myself in the mirror, focusing helplessly on my poor unattended teeth. Delicately I began outlining each tooth at the gum with my finger. And, in slow-motion, as if in some bad B-movie, every outline I made started to bleed. I became unglued, rushed to call my internist, then broke down totally as I begged her to prescribe Tegretol for me. It finally was time to capitulate to that 'big gun' of a medication I swore I'd never use.

Within minutes of chewing my first Tegretol-100, I got relief. A veil of gray and black lifted just like that! From here on out, in one form or another, I would rarely be free of pain-abating medications again.

### ***Trying to slay "The Dragon" with medical pitchforks***

I met with U of M neurosurgeon Dr. Greg Thompson the following month. I was still in a panic about a future in the grip of this hideous tormentor and I needed to know my surgical options. I wanted specifically to meet with him because he is likely to be the only nerve doctor as close to TN and MS as I'm ever going to know: his elderly mother has both. That fact alone gave me an invisible kinship with him that allowed me to trust him. He reviewed the two sets of MRIs I brought with me, confirmed what he saw as 'MS,' assured me that I appeared to be 'well-managed' by Tegretol, and gave me what I perceived to be very bad news: because of the MS diagnosis, I was NOT a good candidate for MVD surgery.

MVD is MicroVascular Decompression, a surgical procedure for TN, pioneered by Dr. Peter Jannetta from the University of Pittsburgh's Dept. of Neurosurgery. The surgery 'decompresses,' (separates) blood vessels or arteries from the trigeminal nerve. The pain is thought to be caused by the nerve being too closely situated to, or having wrapped itself around, a pulsating artery or blood vessel. But as I was to discover, TN in MS patients has an altogether different dynamic. The pain is caused by the nerve's loss of myelin. One unsheathed 'wire' (nerve) exposed inside my head, in my jaw/teeth where my particular TN manifests itself—well, that's a live multi-volt current coursing through my gums for minutes at a time when medication loses its effectiveness. There's nothing to decompress, with MS patients.

2002 was unremarkable insofar as my TN was concerned. I had two remissions, during which I dared to stop taking my medication. With the onset of electrical jabs, I began taking medication again in 2003, a year it was ratcheted up to 200 mg. That was also the last year I had a remission.... a short one at that -- just three and a half months -- from February to May. In October 2003, I experienced a TN pain episode, triggered by eating an egg. It lasted three full minutes, during which I almost passed out from what felt like some high voltage electrical current. My Tegretol wasn't kicking in at all anymore. Furthermore, my liver enzymes were (as indicated for Tegretol users) dangerously elevated.

I needed a neurologist. Until now, my primary care physician was addressing my TN complaints. But I wanted a specialist--one on Michigan State University's campus where I work. Dr. G saw me immediately after that third TN episode. I asked to be switched to Trileptal, a 'cousin' of Tegretol without the liver-elevating side-effect. The conversion to Trileptal was slow and torturous. I was not at all confident it would be up to the task. But eventually I became stabilized on it, 300 mg at night and another tab at noon. Three months into that schedule I was able to get away with just one 300 tab daily, before bedtime to blunt the sleep-inducing side effect. Taking more than one a day

produced headaches and nausea, as it would throughout the exacerbations. For four years Trileptal would manage my pain in this approximate fashion.

My neurologist was young and I established an easy rapport with him immediately. Early on he blindsided me during my follow-up visit. After his routine exam Dr. G, without preamble, changed direction entirely. Upon seeing my Providence Hospital MRIs, the very first brain MRI I underwent, he pronounced decisively that I have MS and began a 15-minute digression to interferon-based medication, injectible daily. The costs, about \$11,000 to \$15,000 a year are covered by most insurances.

I was baffled. My initial complaint to him was about my TN. I was in his office now to discuss TN medication. His non-sequitur about MS was akin to a bait-and-switch tactic to my thinking. I asked how an injectible regimen would benefit me since my subsequent 2 MRIs have shown no progression since my 1996 'possible MS' diagnosis. He said one did show a slight plaque increase. 'Slight' is exactly what he emphasized. I thought to myself: he wants to use a cannon to kill a fly! He said the gauzy film I once mentioned in my left eye was evidence of an MS 'attack,' stating this host of interferon medications would slow down these attacks, (which I didn't even recognize as problems). I asked Dr. G: if I started these meds he was recommending I take daily with a needle, how long would I have to continue with them? Forever, he said.

I am no longer the great advocator of 'proactive,' where my health is concerned. Especially where someone is saying something to me that my instincts tell me is all wrong—that he may, in fact, be thinking of his previous patient, in fact, that's how wrong it sounded for me. My current philosophy about anything – health, car, you name it – is: 'if it ain't broke, don't fix it.' I'm all too familiar with iatrogenic treatment.

I took home the full bag of drug-company sample, spirited them away in a duffel bag in my bathroom cabinet and never thought about them again in any serious way. To start such drastic treatment for what surely must be the mildest form of MS progression on record---IF I even have MS---would be insane. Besides, who knows how adversely TN medication might interact with interferon....the last thing I need is to have some medication leech the potency from my own TN meds, rendering them less powerful or totally ineffective.

I suspected Dr. G. veered off into MS territory because that was his specialty, and TN wasn't. I realized I'm not surprised or offended by this. I don't think too many neurologists exist who want to specialize in TN. It doesn't have the medical moxie – nor the celebrity spokesfolks that the more well known neurological disorders such as MS and Parkinsons have.

Nonetheless, Dr. G's digression agitated me into a fine snit. If he's interested in me as a TN patient, why was he so aggressively pursuing something I was not complaining about?

I asked this important question on my next visit, and was satisfied with his response that he was obligated to mention the MS remedies, though I don't think he had trot out a full grocery-bag full of interferon-based and other medications).

### ***Epiphany***

Toward the end of this visit I realized: I care more about TN than he does – physiologically, experientially and psychologically, I have more practical knowledge of it. This was an empowering realization for me, an almost 'duh' moment, when I wanted to

hit my head (and everyone else's), and say: Doctors do NOT have all the answers to every question, every illness, of their patients. How could they? They rely on their patients to inform them of what's happening, what medications they're taking, and when the medications stop working. We need to tell them the other factors in our lives which may affect our disorder, like stress and food and sleep, etc. These things add to our doctors' base of knowledge and will benefit us ultimately.

And, just as in any relationship, chemistry enters the equation. It's in a patient's best interest to seek a mutually satisfying professional 'fit.' Ask questions. Bring a list. Bring someone else to the consultation: often patients are so busy absorbing what the doctor just said, they can't hear or understand what he said next, so having an extra ear is helpful. Doctors nowadays are being trained to listen to their patients. The best doctor/patient relationships are built on mutual trust and respect.

According to one neurosurgeon, not every neurologist is interested in TN as a sub-specialty. Strong words. I want a neurologist who understands--and loves--this curse I'm stuck with. That's my particular mission right now: to find and partner with that doctor.

More valuable to me than my neurologist on a day-to-day basis is my TN support network. I count myself extremely blessed that I discovered my TN about the same time Tim Guith formed his Metro Detroit TN support group in Royal Oak's Beaumont Hospital. My first visit alarmed me no end. The stories the few attendees told were frightening and sad beyond description. These were people in their 50s and 60s, folks who trusted the procedures their practitioners were carrying out. Five or six of the handful of attendees spoke of the teeth their dentists pulled, or treated with root canals, only to have their TN pain continue. Often worse than before. One woman had all her teeth pulled. The pain droned on. She lost her teeth for nothing.

That first meeting really depressed me. But at that time I was still in TN-Lite. Once I joined their level of agony, I was on the inside looking out. In the years since, I've met wonderful people through Tim's Support group. One is Frank Sherwood, not a sufferer himself, but so consumed by the pain of his dear friend, he campaigns against saturated fats, which he contends is a primary TN trigger. In May of 2005, Frank and I manned the TN booth at the Grand Rapids Dental Convention, where he kibitzed with many dentists. We learned dentists should always (emphasis on 'always') include Trigeminal Neuralgia in their 'differential diagnosis.'

As I proceed with my TN history, I find myself merging my personal story with those of fellow TN sufferers. The "I" is being interchanged rather seamlessly with "we." I realize this is part of that communion I seek with my fellow-travelers into that nightmarish journey of pain. It is so good to know we're not alone. I and TN sufferers all over lower Michigan are united – if not at the actual meetings – then through Tim's taped videos, and his listserv network. We are appreciative beyond words for this forum.

Tim Guith, on full-disability for his atypical TN, has made this support group a major part of his life. He provides an ever-ready collection of handouts on the subject, provides a forum where those patients who have had various TN procedures can share their experiences with the group, and Tim always has an incredible line-up of quality speakers, neurologists, neurosurgeons and medical experts in pain-relief. That Tim is able to routinely get commitments from high-stature guests like Drs. Ken Casey, Ghaus Malik, Peter Ianni, Brian Copeland and other Michigan experts in Trigeminal Neuralgia, attests to his leadership effectiveness. He converses with these speakers at the clinical

level as easily as if they were discussing weather. I have always considered TIM my lay-neurologist-on-call.

### ***Addendum, February 1, 2008***

The worst of the four episodes I've had since 2000 happened last night, three minutes before I left for a party. It caught me totally by surprise and immobilized me 100%. I was brushing my teeth-- Out of nowhere indescribable pain exploded in my head – and I THOUGHT I knew what was coming: (but what hit me defied any of my past experiences) a solid wall of pain swept over my face, left side, including the top of my head, nothing was spared. It was as if an electric cord was held in my mouth and the switch was turned on.

Every MOVEMENT was unbearable, including moving my head—even my eyes this way or that. But I found my medication bottle...I was going to start taking one pill after another, despite the pain of bringing them to my mouth and swallowing them.....I was taking no chances now, yet I had no guarantee the medication would stop the current...and if so, how quickly? Trileptal is NOT a fast medication. All the moves to get warm water, a straw, and the pill, then a second, and finally a third, into my mouth and down my throat were excruciating--accompanied with ongoing electric currents. My family was expecting me at this party shortly – and would have shown up at my door if I didn't go...but I could NOT talk without searing pain from the effort. My trigeminal nerve was a sizzling unsheathed cord going crazy in my head. Moving and talking were unthinkable.

I sat with the phone in my lap, waiting for any sign of pain abatement. Instead it felt as if my face and head was being rearranged internally by electrical currents. I was able to email anyone who might be at a computer on a Friday evening (yeah, right!) who might call and alert those at the party that I wasn't coming, At all costs, I wanted to avoid anyone showing up at my door. I wouldn't have – COULDN'T have – answered vocally...I did not want people around – they would expect me to explain things to them, and be receptive of their sympathy...I had descended the lowest rung of hell.....and just wanted the pain to stop.

Twenty five minutes into this torture, and not knowing where it would end, something changed in my head. And I realized my head wasn't hurting. Did I dare move my tongue to my tooth, did I dare flex my face muscles to test whether it really had left? I did, and, lo and behold, the pain had disappeared as lightning fast as it came -- wholly and entirely, gone, just like that. It had lasted an excruciating, nonstop 25 minutes. More than anything else, I need to know how that happened: was it the monstrous active nerve just petering out after half an hour of firing off its fireworks? Or did the succession of linked-up pills finally and totally take effect?

I called the party hostess to explain I wouldn't be coming over, quickly wrote into my journal what had happened (making bigger mistakes as I wrote, realizing how the medication was tempting me into a deep slumber, then went to bed, wary still that the medication may wear off during the night.

Aside from the automatic tearing in my left-eye the episode provoked, I could have really indulged in some justified crying...I was senseless with fear and unpredictability about this new dimension of TN, my inability to control it, and no one out there in the medical field to trust or rely on. But I would not have stopped crying once I started, so I just did what my body was begging me to do, I went to sleep.

After last night, I no longer feel optimistic nor empowered nor confident about anything, as I was in places when I wrote earlier in this journal. I am anxious and afraid, and have no confidence in anything or anyone other than a half-inch featherweight pill.

My sole comfort (and a huge one) in this TN nightmare lies with those who share it with me...the members and friends of my TN support group. We're connected in our agony and fear, a connection surprisingly strong and intimate, and allows us to share our misery, and maybe, as time and science press forward--hope.

I'm involved in a Longitudinal Patient-Centered Experience program which I volunteered for, in the hopes of educating medical students about my rare disorder. In the process, they'll learn much about my interface with the medical community, and my triumphs and disappointments within that milieu.

Through the powerful resources at my disposal (my support group, the internet and my neurologist), I have empowered myself to aid in my own treatment, I have written articles about TN in hopes of providing information to others, just like information was made available to me at the cost of a few keyboard strokes.

My efforts at getting a handle on this monstrous disorder brings me great relief and satisfaction. It brought me information and friends with whom I share a powerful and intimate enemy.

### ***Afterword***

On November 9, 2009, National Public Radio aired a segment describing TN, which may be heard via this link. Actually, the link takes you to an NPR Web page that documents another personal story... of Sandra McGee, a TN sufferer who underwent successful surgery. You can click on the audio segment embedded on that page.

Reading the page and listening to the segment, I'm struck by the similarity between Sandra's description of the course of the affliction and my own. I'm also deeply gladdened that TN has finally reached a nationwide stage to push the darkness back another increment. — th

For more information or to share your knowledge and experiences with TN, please contact the author via email. Also the Trigeminal Neuralgia Association welcomes your interest and support... together, let's put an end to this horrifying, insidious "screaming and suffering alone in the dark" affliction. — ed.

[1] Joanna M. Zakrzewska, M.D., *Insights: Facts and Stories behind Trigeminal Neuralgia* (Gainesville, Florida, Trigeminal Neuralgia Association, 2006), 403 pgs.

[2] Kenneth F. Casey, M.D., and George Weigel, *Striking Back!* (Gainesville, Florida, Trigeminal Neuralgia Association, 2000), 507 pgs.