TNA Quarterly

The Journal of
The Facial Pain Association

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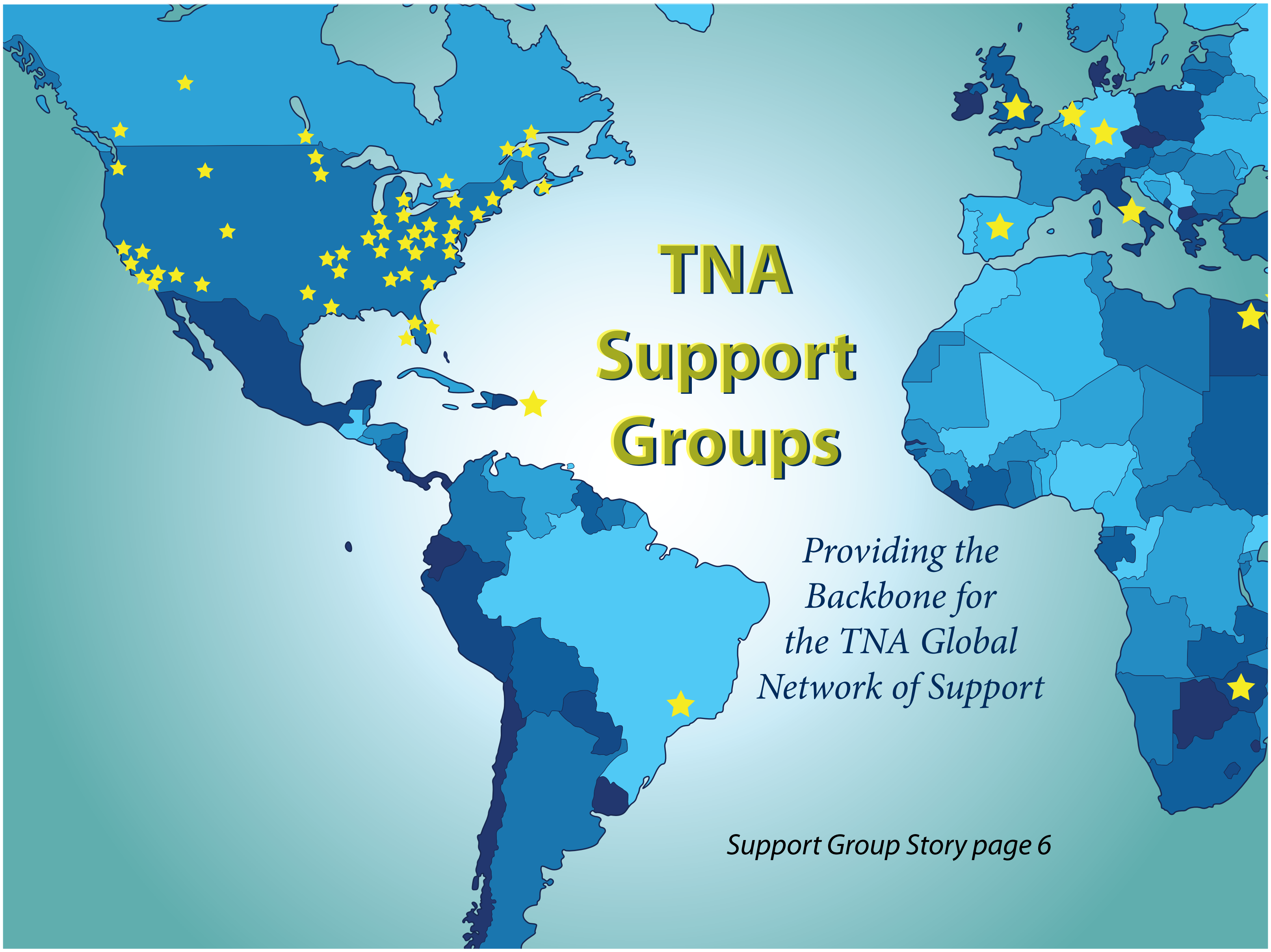

TNA Support Groups

Providing the Backbone for the TNA Global Network of Support

Support Group Story page 6

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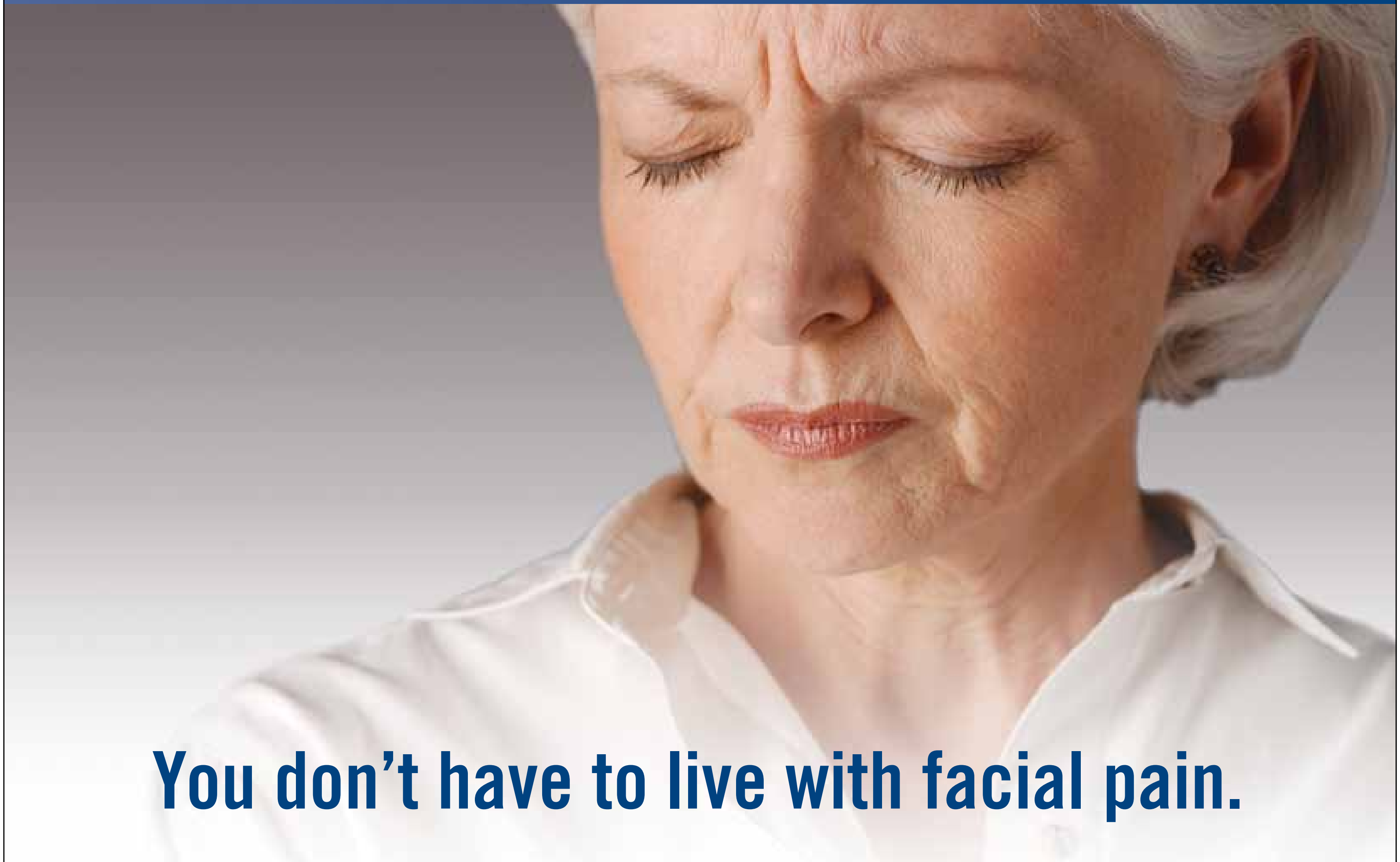

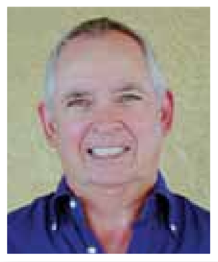

Welcome

TNA, The Facial Pain Association is now in its 21st year and the winds of change continue to blow. Fortunately, the predominant wind is at our back and is a force for improvement. This inaugural edition of the TNA Quarterly is one such change. An enhanced and expanded journal, it will be available on-line in electronic page-turning format as well as in hard copy. We hope that you will enjoy the expanded and enhanced content delivery.

In an effort to improve our outreach to patients and their communities, our Medical Advisory Board (MAB) is now being represented by three regional boards, each with its own chairman. Each regional MAB will work more closely with support groups in its region and focus efforts on regional needs. This will result in a more robust conference program and the development of more support groups, thus providing patients with improved opportunity to share experiences one-on-one, an important way to ward off the isolation that facial pain often brings.

At the same time, the Internet affords another opportunity to distribute information and to bring together people with common interests. Accordingly, our website has been redesigned and allows members to join forums and communities: TNA Connect, Facebook and our new Facial Pain Network. If you have not yet joined one of our online groups, please visit our website www.fpa-support.org and see which of these venues can help you. You won't be disappointed!

Facial pain has been around for centuries and yet we don't know the exact cause and we have no cure. Fostering research has always been part of our mission but, with limited resources, it is difficult for us to have a footprint in this important arena. In an effort to change this situation, TNA has created the Facial Pain Research Foundation as a division of TNA and has appointed a separate board of trustees to raise money and establish a research plan. This is a brand new initiative which will bring hope for the patients of tomorrow. Please take a minute to look at our Foundation's website at www.facingfacialpain.org.

While pursuing basic research through the Foundation, we must also collect data on today's patients to aid clinicians in selecting and administering appropriate treatments. We are therefore reestablishing the TNA Patient Registry and are developing a new survey for patients to complete so that we may gather data on treatments and outcomes. Look for the introduction of this survey later this year.

TNA has also moved its office to a beautiful old building in downtown Gainesville. This results in significant savings and provides our staff with a secure and comfortable workplace. If in north central Florida, please stop by to say hello and to thank our staff for the wonderful job they do.

As I said at the outset, the wind of change is at our backs. I hope you will enjoy this and future editions of the TNA Quarterly and our reports on the initiatives I have mentioned and those to follow.

Roger Levy, Chairman of the Board
TNA – The Facial Pain Association

TNA
The
Facial Pain
Association

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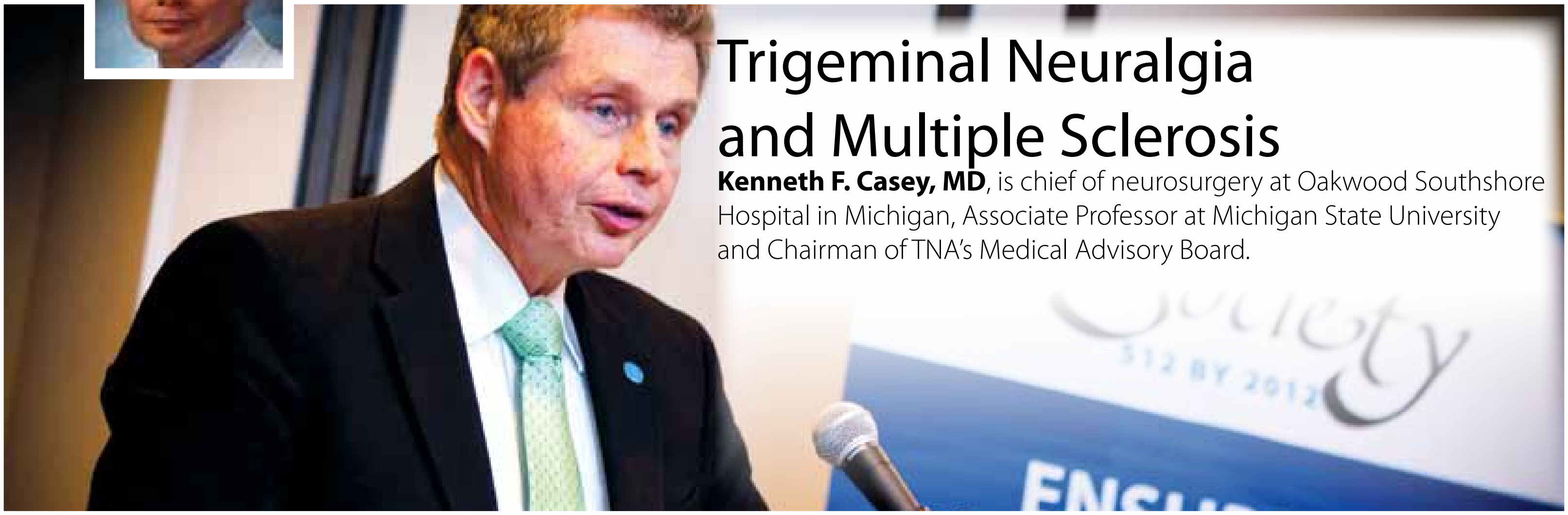

Trigeminal Neuralgia and Multiple Sclerosis

Kenneth F. Casey, MD, is chief of neurosurgery at Oakwood Southshore Hospital in Michigan, Associate Professor at Michigan State University and Chairman of TNA's Medical Advisory Board.

Facial pain occurs in 1.9-6% of patients diagnosed with multiple sclerosis. It can be the sole presenting symptom in a small percentage of patients. For patients with an established diagnosis of Multiple Sclerosis(MS), trigeminal neuralgia (TN) is the most common associated symptom. The diagnosis of TN in MS differs slightly from that defined by the International Headache Society(IHS). Both groups of patients (non MS and MS) present with "paroxysmal attacks lasting from a fraction of a second to several minutes, involving one or more divisions of the trigeminal nerve" on the same side. The pain is characterized as " intense, sharp, superficial, or stabbing" and precipitated by trigger zones. The attacks are stereotypical, and the only difference is that in the MS group the pain is attributed to the underlying disease.

One study demonstrated that trigeminal neuralgia began on average 11.8 years after the first MS symptom but in five patients was the first symptom of MS, preceding the next MS symptom by 1 to 11 years. The onset of MS was later in the patients who had TN, and bilateral TN occurred more frequently than expected (in 14% of TN patients). The age at onset of TN was no younger than in idiopathic TN except when TN was the first MS symptom. In the setting of multiple sclerosis, the pain is more commonly bilateral, and is the most likely setting for the pain to be simultaneously bilateral.

> Symptomatic trigeminal neuralgia (STN) is a term applied to this presentation by Burchiel. MS is a chronic disease of the central nervous system, with symptoms and signs disseminated in space and time.

This means the patient may present with eye symptoms on one occasion, and weakness or sensory changes on another. There can be a wide variety of symptoms and signs, including numbness, parenthesis, pain, weakness, spasticity, fatigue, vertigo, visual difficulties, gait dysfunction, bladder disturbances and cognitive changes. There appears to be a genetic component to this disease. There is a greater risk of MS in first-degree relatives of patients with MS and high concordance rates between monozygotic twins.

In MS, lesions in the pons at the root entry zone (REZ) of the trigeminal fibers have been demonstrated. This is one form of "symptomatic" trigeminal neuralgia related to visible pathology. In a recent MRI study, linear pontine trigeminal root lesions were common (6.8%) in patients with MS and facial complaints(TN-MS). They were associated with various facial sensory symptoms. An English group contrasted these results, observing that half of their seven patients had pathology other than plaques' using MRI studies. This remains a controversial area, that affects recommendations for treatment.

The most common theoretical explanation for TN proposes that high-frequency ectopic impulses are either generated from or, augmented by, areas of demyelination. The areas of demyelination allow for abnormal cross conduction between the nerve fibers in the trigeminal nerve. The over activity is thought to be responsible for the spontaneous generation of pain in the absence of any stimuli, seen in both classic TN (Type 1) and STN.

Carbamazepine is the drug of choice for TN-MS patients, with the caveat that some series show a lower response rate, compared to non MS patients.. Oxacarbamazepine, baclofen,and phenytoin have all had some degree of success in short clinical reports. As pain can be present in other sites in the course of MS, there are several reports of gabapentin, and lamotrigine being useful for pain in MS. These reports did not

specifically detail those patients with TN-MS. In general, patients with MS are less likely to tolerate the medications used for TN.

Surgical therapy for TN-MS is quite controversial of late. The early reports found percutaneous thermo coagulation (radiofrequency rhizotomy) to be quite useful for the initial treatment of pain. In TN-MS patients, however, the recurrence rate was high (up to 40% in one Italian study). Many reports exist that show an initial success rate (pain free, off medications) between 58-81%. The durability of the relief is shorter than patients with non MS TN. The literature for the last ten years suggests that RF for TN-MS is still the procedure of choice for most patients. Following RF, when performed with appropriate training, the patients will experience dense loss of light touch in the face, with preservation of the sense of pressure in the affected face. This is akin to the feeling you might have following injection of a local anesthetic from your dental professional.

When glycerol treatment was first introduced, initial reports found an higher failure rate, with earlier intervals to repeat treatment in the TN-MS patients. The Pittsburgh group then released a report indicating a success rate similar to thermo coagulation,and reported on the ease of repeatability of the procedure. The patients returned on average at 18 months in 50% of the group. Both procedures produced facial numbness, but it was less in the glycerol groups. This became very popular in many surgeons' minds, due to the lower incidence of numbness induced. Burchiel commented that the efficacy of glycerol was related to the degree of nerve injury produced.

In 1999, Broggi reported a series of patients with MS who had undergone a microvascular decompression (MVD). A second, larger series in 2004 raised the question of durability of the success. Taken together, the patients were pain free on average 24 months following MVD. Subsequent series from other institutions reported a similar pattern; good initial pain relief with less sustained results, leading some to state that MVD has no place in the treatment of MS. The case series reported suggest there is a subgroup of patients with vascular cross compression, in addition to their MS. This cross compression may be the proverbial straw or be the sole arbiter of the pain.

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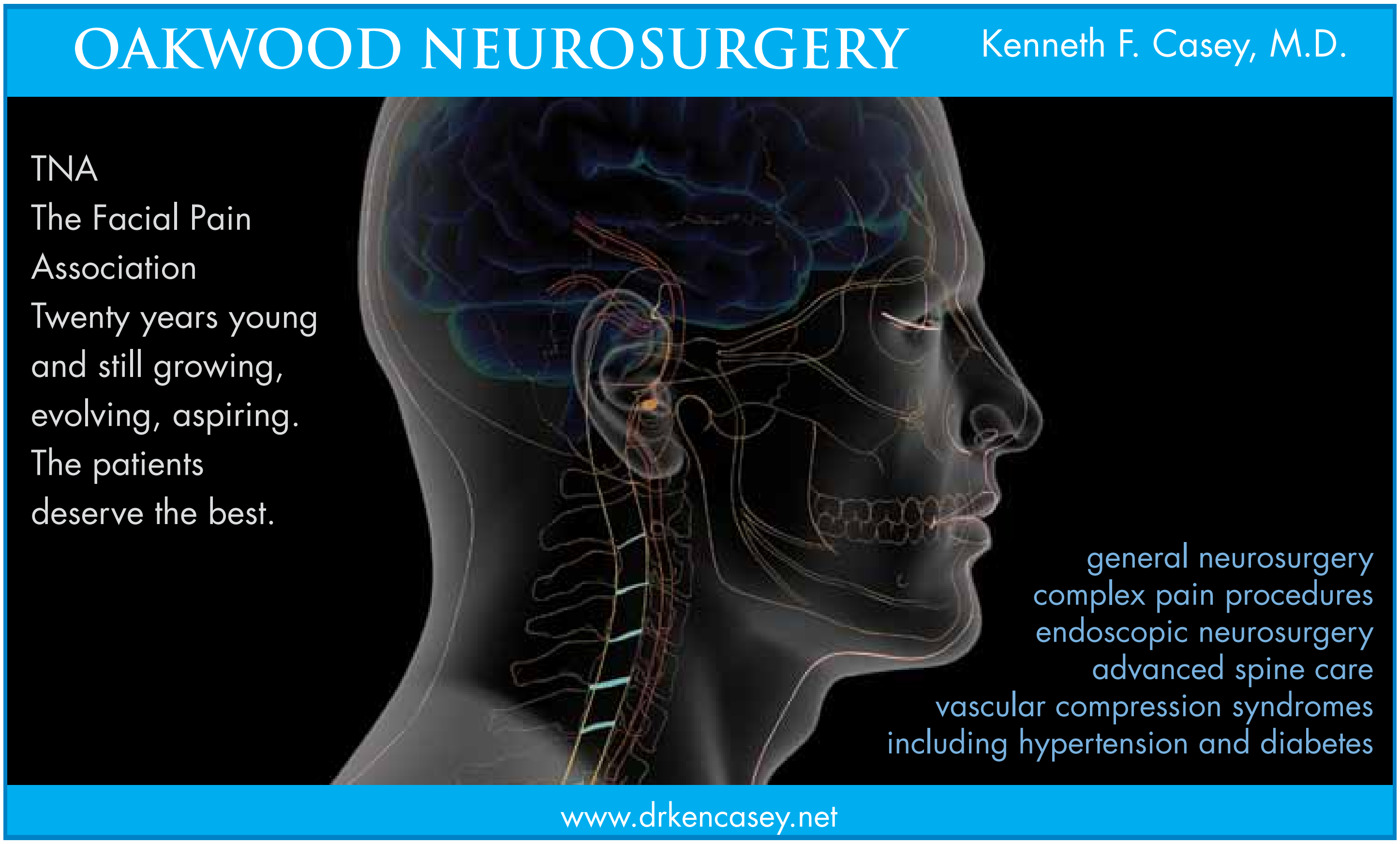

Trigeminal Neuralgia and Multiple Sclerosis cont.

A recent sampling of the MAB of the FPA found there remains two distinct groups in this regard. The majority of the MAB do not favor MVD for TN-MS patients.

Micro compression of the fifth nerve ganglion was introduced by Mulllan and Lichtor, based on earlier work of Spiller., The technique was refined by Brown to detail the time of compression and the range of pressure. This procedure produces an injury in the nerve by means of pressure from an inflatable balloon. Some authors have noted that, in moderately large series, that patients with multiple sclerosis seemed to obtain similar benefit from the procedure as do patients with classic trigeminal neuralgia.

Radiosurgery has long been attempted for patients with TN-MS. However, the series reported have not been clear as to the proportion of patients pain free, off medications with STN alone. The technique's greatest success rate has been in patients with type 1 pain and when radiosurgery is the first procedure.The time to relief can average 30- 90 days. A recent summary paper concluded "Actuarial freedom from treatment failure at 1-, 3- and 5-years was 42.9%, 42.9% and 28.6%, respectively", for patients with TN-MS. The rate of a new, uncomfortable sensation in the face is between 10 and 16%. There are some recent reports that this effect increases over time from treatment.

One theme that runs through all the ablative procedures(glycerol, balloon, radiofrequency and radiosurgery) is that a degree of numbness needs to be produced for the best efficacy and durability of each procedure. Taken together, these procedures produce two to three years of pain control in TN, and somewhat less in TN-MS.

At the current time, radiofrequency ,and glycerol procedures have the clearest indications , with more information needed over time for the remaining choices.

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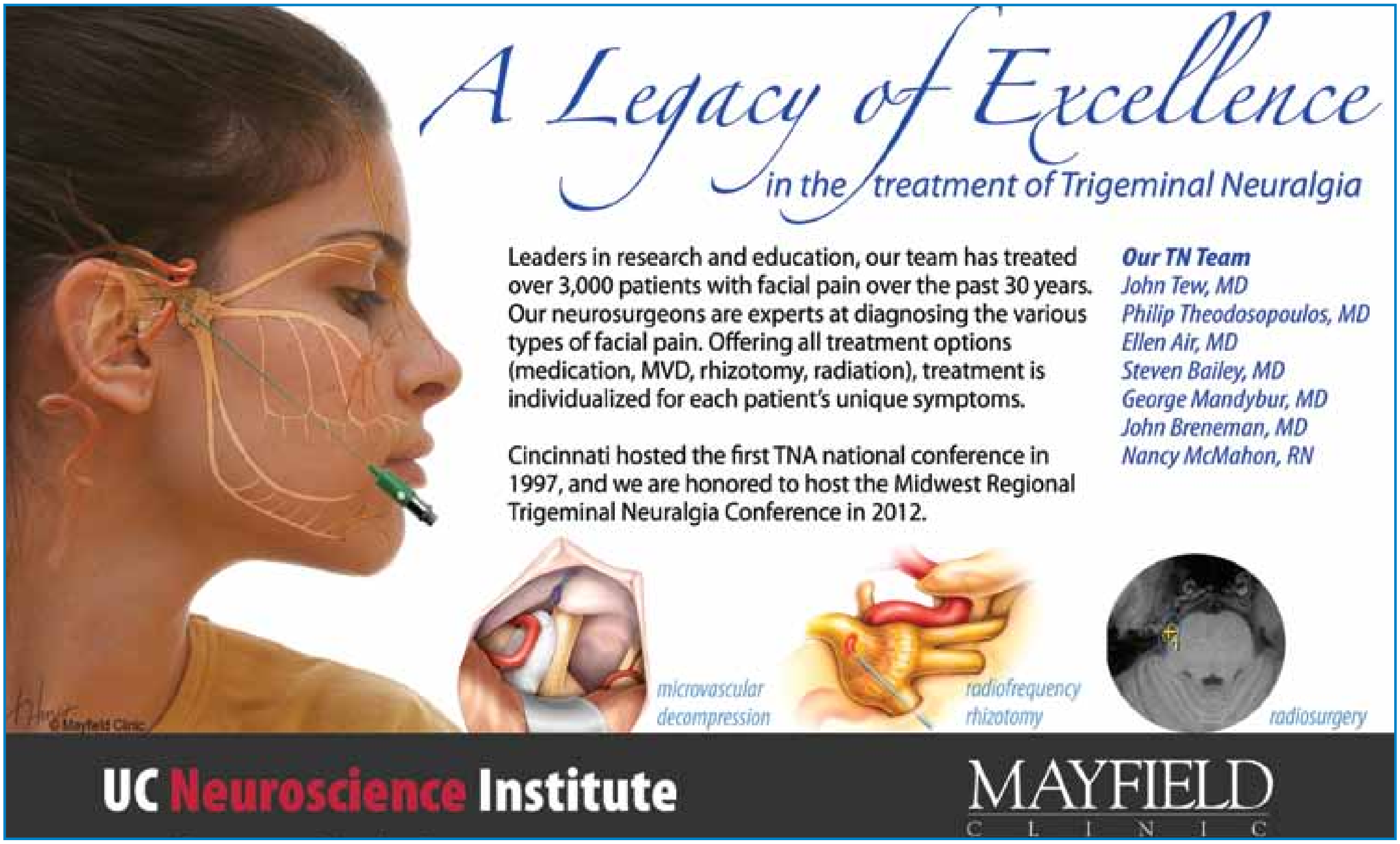

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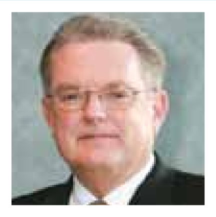


Support Group

Claude M. Aldridge, Co-Support Group Leader
Kansas City Facial Pain Association Support Group

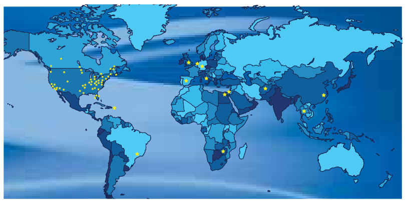
Twenty years ago, The Trigeminal Neuralgia Association, now the Facial Pain Association (FPA), was started with the development of a Support Group to help patients and caregivers who were suffering from Trigeminal Neuralgia. At the time TNA had no infrastructure, printed materials, newsletter or website, but TNA had a personal relationship with those suffering with facial pains. Claire Patterson founded the first support group in order to help those suffering. This personal relationship continues to form the power of the Support Groups around the country.

For most, the first contact with FPA is through involvement with local support groups or telephone contacts. In my case, I had no idea that there were others suffering from TN; it felt like a lonely disease. What I found is a national organization which encouraged and fostered Support Groups around the country. When I realized that there were others, in my community, suffering from TN, I was able to take comfort in knowing I wasn't alone and that there were others willing and anxious to share their experiences and successes.

This is the basis for the TN Support Groups. Our Support Groups are comprised of caring individuals, many times they are actual facial pain patients who want to share experiences, successes and failures with others in their community. The power of these groups cannot be overstated. Many meet on a regular basis, with speakers or presentations which are meaningful to their members. Many of the Support Groups provide resources to their members or other interested parties including the names of local and national physicians who specialize in treating various facial pains, including trigeminal neuralgia. For others, the Support Group Leaders and Telephone Support Contacts are the friendly voice on the phone who listen to the patient who is suffering; the fact that someone is interested and willing to listen can help many get through a crisis. Regardless of their motives, the fact is that the Facial Pain Support Groups are helping patients and caregivers to feel a part of a larger group. They truly form the basis for our Association.

One other element cannot be overlooked; either directly, or indirectly through their families and friends, our support group member donations to TNA are critical to our success as an organization. These donations allow our Association to provide meaningful regional and national conferences for all who suffer facial pain. These donations fund our award-winning website which includes a multitude of information on facial pains of all types. The donations help us to have a presence at appropriate medical and dental conventions, and they are helping with our research efforts.

Our support groups are an integral part of TNA and will continue to be as long as we have leaders and patients who need one another. TNA needs our donations if this is to continue. Please be a part of this invaluable help by making an annual contribution to TNA. Remember, we need each other.



TNA Support Groups

Meeting and sharing information and experiences with other face pain patients, knowing you are not alone in battling this disease, is one of the most important things a patient or caregiver can do. TNA – The Facial Pain Association has more than 50 active support groups throughout the USA, Canada, Europe, Australia and New Zealand. Currently new groups are being formed in Spain, Afghanistan, Thailand and China. If you are interested in joining a local support group, or perhaps starting one, call Aggie in the national office at 800-932-3608 for more information or post your interest on our facebook page at www.facebook/facialpainassociation . If you are unable to attend a support group meeting, join a virtual meeting or discussion on TNA's Facial Pain Network. Just go to our website at www.tna-support.org and click on the Connect tab at the top of the page. ●

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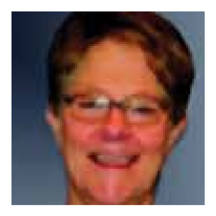


Can Face Pain Effect Your Identity?

Leesa Morrow, PhD, JD, LP, is a Health Psychologist and Clinical Assistant Professor, Division of TMD and Orofacial Pain, Department of Diagnostic and Biological Sciences, University of Minnesota, School of Dentistry. Dr. Morrow maintains a private practice in clinical health psychology treating chronic pain disorders.

I have been treating chronic pain patients for twenty years. Before joining the faculty at The University of Minnesota School of Dentistry, Division of Temporomandibular Disorders and Orofacial Pain, I saw the rare case of Trigeminal Neuralgia (TN) – now I treat TN patients on a regular basis. I've learned a lot from my TN patients; I'll try to summarize some of what I've learned in this article.

I'll begin with what you already know: TN is different from other chronic pain disorders. Chewing, talking, smiling, brushing your teeth, refreshing yourself with a cold drink, these are ordinary human activities; but, when you have TN, they can trigger pain. Because TN involves the face, it is unique among chronic pain disorders. I often tell my patients that the face is the organ of self-expression. We show our emotions through facial expression. Even when we try to hide our feelings, those who know us best can read them on our faces. We talk with our faces, sing with our faces, cry with our faces, laugh with our faces – to a very great extent we communicate and experience our humanity through our faces. In a psychological sense, it doesn't get more fundamental than this. It is not exaggerated to say that TN tears at the fabric of identity.

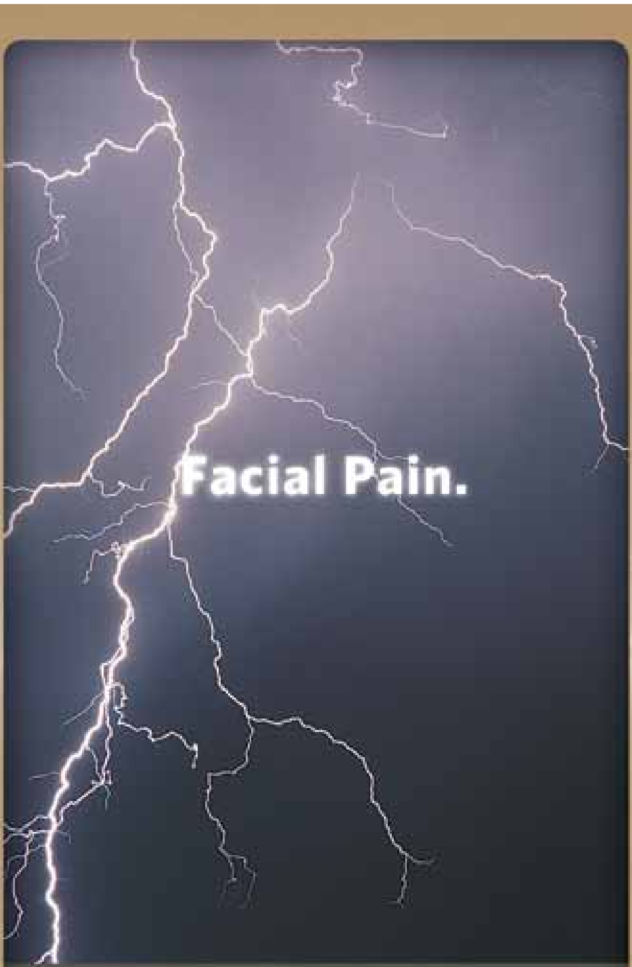
TN patients understandably think of their lives as divided into two parts: the part before TN, and the part after TN. Before TN things generally make sense. It is possible to ascertain cause and effect relationships in your life, allowing you to avoid those that bring pain while enhancing those that bring pleasure. After TN, cause and effect relationships as you have always understood them break down. There is no longer a clear, predictable relationship between your effort, and the outcome of your effort. Things make much less sense. You struggle to control your life only to experience bouts of lancinating pain that are intense enough to distract you from everything else. It can feel as if your body – now an alien force – has turned against you. This is where the real tragedy of TN begins.

With TN there are forces at play that, over time, threaten to distort the way you see yourself. Bit by bit you lose yourself to the disease. You gradually let go of important relationships and activities as you become more and more paralyzed by fear of pain. Before TN your identity was made of blended roles: you were parent, grandparent, child, brother, sister, friend, employer, employee, democrat, republican, church-goer, golfer, ball-room dancer. After TN, you may feel reduced to being mostly a patient, who remembers being a person. Having pain and avoiding pain thusly become the defining features of your life.

My work with patients involves reconstructing the sense-of-self that has been distorted and weakened by pain and the fear of pain. It is possible to do this reconstructive work and in the process put TN in its place, but moving TN off center-stage is complicated. In the beginning of psychotherapy, it is natural to "borrow" hope from the therapist, who has seen others like you succeed in their effort to overcome

"...Identity?"cont.

the personally destructive effects of TN. All the same, good psychotherapeutic work is highly individualized; there is no one else quite like you. The work of psychotherapy is a shared journey of discovery. Real losses should be appreciated and grieved. Real sources of strength and renewal can always be found and they should be celebrated. New meaning must be created in a way that accommodates not only physical suffering but also physical pleasure. The majority of TN sufferers experience some pain-free time; days, weeks or months may go by without pain. It is obviously best not to contaminate the pain-free moments with the fear of pain's return, but this takes genuine courage and an equally genuine belief in your capacity to endure pain without being destroyed by it. Like a Sherpa who has climbed Everest many times, a good psychotherapist travels the way of adversity with you alerting you to dangers and reminding you of your strength when you most need it and are least certain of it. ●



The following individuals joined or renewed their TNA membership

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Mary Anderson
Bennett Bloomfield
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Mark Goldstein
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TNA National Conference, Rochester, 2010

Fredy Agir, TN patient and professional singer and composer

It's 2:30 on a Rochester summer afternoon and I just got back to my hotel room following the concluding ceremonies of the TNA's national conference, their 20th. I wasn't here five minutes and I experienced the first TN "shock" of the week, albeit a mild one. I went out for a Greek lunch and presto, another one, maybe a tad more substantial. Oh, that's just great…

But I digress. This convention was a major experience for me in a variety of ways. What a truly remarkable group of people! The patients, the caregivers, the medical professionals, the TNA staff, everyone involved with this event shared a similar focus in a way that most individual TN patients have never experienced. I hadn't conversed with more than three or four TN patients in my life, and yet here was a huge room full of people with a shared experience listening to the experts speak directly to them and address their important and personal issues.

If you know anything about TN, you know that information is hard to come by, and so to assemble an approachable roomful of experts on the subject is surely beyond impossible. But here they all were, most of the big guns and heavy hitters, spending three days with an international group of articulate, motivated TN patients. The air was relaxed but purposeful, and the smooth pace of the convention itself mirrored that. To call this a rare opportunity is understatement.

So what did I learn this week? I guess I finally realize that I will never be "cured" of trigeminal neuralgia and it's more a matter of "managing" it going forward. Okay, those are my cards I've been dealt by an unknown dealer. I also learned that, considering where I had my first MVD done, a second MVD is really not an option. I learned that there are some very fine minds dedicated to TN and it was very reassuring to witness their degree of commitment and dedication.

There was a lot said about other surgical options as well, from balloons to radiosurgery, areas in which I personally have little interest but conversed with many who'd been through them with mixed success. I was amazed by the volume and combinations of anticonvulsant medications that some folks ingest on a regular basis, sometimes as many as three or four simultaneously. A lot of people at the convention had not yet had any surgery, and there were quite a few folks who'd had been through many procedures with the full range of successes.

I picked up a truckload of new terminology. Made dozens of new acquaintances, many whom I expect to see again. Certainly confirmed my respect for all the TNA people and the vital work they do on a daily basis. Dr. Casey would have a decent shot making it as a standup comedian with that superb timing and excellent natural delivery. But I would hasten to add, don't quit your day job. We need you here!

Am I going to the next TNA pow-wow in 2012? Simply put, I don't ever plan on missing one again. But next time, I'll bring my caregiver with me, it's really as much for them as it is for us, and I think she'd really enjoy meeting this unique ensemble. As one caregiver put it Friday night, "I wouldn't wish this disease on anyone, but I would have hated to miss meeting this group of people." Amen.

A year ago, I came to the Mayo for an MVD. I returned a year later to understand it. I came away grateful, thankful and hopeful. Thank you, TNA! ●

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Facial Pain
Association

Regional Conference
Trigeminal Neuralgia and Chronic Facial Pain Symposium
Richmond, Virginia
May 21, 2011

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Registration fee includes; welcome reception, conference admission and materials, lunch and refreshments.

If you want to become a member before you register please visit **tna-support.org** or call 800-923-3608

Cancellation Policy: All conference registration refund requests must be submitted in writing to the TNA national office via mail or fax. The mailing address is TNA, 408 W. University Avenue, Suite 602, Gainesville FL 32601-3248. The fax number is 352-384-3606. All cancellations are subject to a $50 per person service fee. Cancellations received after May 7, 2011 are not refundable.

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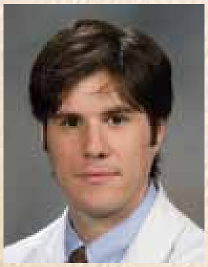

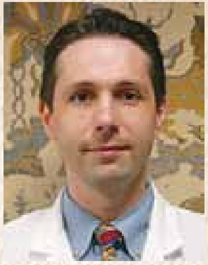

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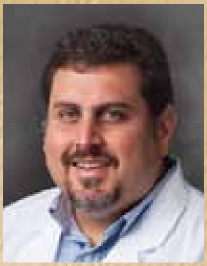

For questions or referral please contact:

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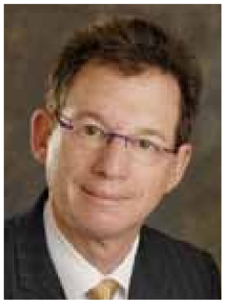
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Dr. Brown is Northeast Regional Director and immediate past Co-Chairman of the Medical Advisory Board of TNA-The Facial Pain Association.

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

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