

TNA

Together we will end the pain.

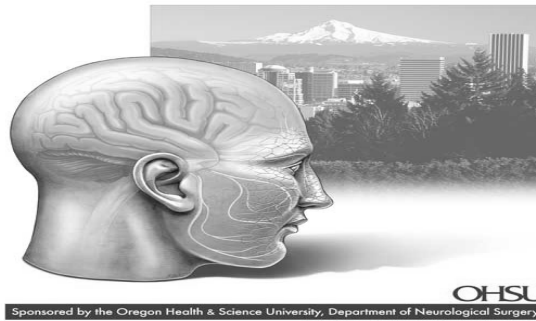
Kansas City TNA Support Group Newsletter

Sixth National Conference

On September 14-16 the Trigeminal Neuralgia Association will be sponsoring their 6th bi-annual conference for patients, medical professionals and caregivers. The meeting will be held in Portland, Oregon at the Doubletree Lloyd Center Hotel. Highlights of the meeting will include medical discussions of the current research being done for trigeminal neuralgia and other facial conditions, sessions with patients sharing their experiences with the various medical and complementary alternative medicine (CAM) treatments, and a live telecast of an actual Microvascular Decompression surgery.

Many of the top medical practitioners in the field

Trigeminal Neuralgia Association
TNA
Sixth National Conference
September 14-16, 2006 — Portland, Oregon



Sponsored by the Oregon Health & Science University, Department of Neurological Surgery

will discuss the newest advances in treating TN and related facial pain conditions. Invited speakers include Dr. Peter Janetta, Dr. Ken Casey, Dr. Bruce Pollock, Dr. John Alksne, and Dr. Joanna Zakrzewska among many others.

For members who might

be interested in attending this conference, please let us know and we'll be sure to send you a brochure including full registration information. Support Group Leaders, Jean and Claude Aldridge, will be attending this conference again this year and will report back to the group at a later Group Meeting.

July Meeting Announcement

Our next regular meeting is scheduled for Sunday, July 16, 2006. Again, we will be meeting in the Abell-Lorenz room in the Community Center of St. Joseph's Hospital, I-435 and State Line Road. The meeting will begin promptly at 2:00 pm and end around 3:30 pm.

We will have a taped pres-

entation by Dr. Joanna Zakrzewski (aka Dr. Zak) who will speak on "What To Do When The Pain Returns". This presentation was made at the last National Meeting held a little over a year ago in Orlando, Florida. It is an excellent outline of how and why we need to be prepared, both from the patient's and the care-

giver's perspectives. Dr. Zak provides many excellent ideas we can all take from her presentation that can help us deal with our next spike.

If time permits we will show tapes from recent *Inside Edition* and *Discovery Channel* shows involving TN. If not, we will work these into future meetings.

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July 1, 2006

Local Meeting Schedule

- July 16, 2006 from 2 to 3:30 pm
- August 27, 2006 from 2 to 3:30 pm
- October 15, 2006 from 2 to 3:30 pm

All meetings are currently held at the St. Joseph's Hospital Community Center in the Abell-Lorenz Room

St. Joseph's is located at I-435 and State Line Road in Kansas City, Missouri

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TNA Silent Auction

The national Trigeminal Neuralgia Association (TNA) has announced that this year, for the first time, it is soliciting donations for a silent auction to be held at the TNA National Conference. Specifically, they are looking for new items that most people in the U.S. could use. For example, a gift card to Blockbuster, Chili's Restaurant, Marriott Hotel, Sam's Club or Best Buy, to name a few. What they are not looking for is a gift like a free carwash at a local car wash or a gift certificate to a local restaurant, or anything used. Anything that is too bulky or heavy is also not suggested as you would have to pay to have it shipped to Portland and

the person who wins it must get it home.

Other potential donations might be a piece of original art or a piece of jewelry. If you know of someone who is an artist or craftsman, please ask if they might consider making a tax-deductible donation to TNA to help raise funds for research and support.

In return for donations, the donors will be listed in the TNA National Conference program and will receive a thank you letter from TNA to recognize the value of the gift. Please indicate the value at the time of the donation.

Please help us by taking a few mo-

ments to think of any friends, relatives or acquaintances who might consider such a tax-deductible gift.

Call Jean Aldridge at (913)681-8360 with any questions about this gift program.

Call For Help

Our local Support Group is now approximately 18 months old. Our meetings are generally well-attended and the speakers have been outstanding. Now we need to move forward with our mission and begin the process of educating medical professionals in the area about TN and other related facial pain. To that end, our Support Group will be enlisting volunteers who would be willing to become part of a Steering Committee charged with the responsibility

of developing a program to contact doctors and to distribute educational pieces about how to identify trigeminal neuralgia and what treatment options are available.

By being more proactive in getting the word out to the local medical communities we not only can help ourselves but those who will become afflicted with TN in the future.

Just a few hours of your time will go a

long way in this endeavor. If you would be willing to help form a Steering Committee for this effort, please contact Jean Aldridge at the following:

Daytime: (913) 681-8360

Evenings: (913) 491-1133

Email: jean.aldridge@frkc.com

Thank you for your willingness to help.

Acupuncture Success Story

By Claude Aldridge

After 3 Balloon Compressions, 3 MVDs (Microvascular Decompressions), more than a dozen anti-seizure medications and various other treatments, I've finally found a treatment that has given me some pain-free days. Soon after Dr. Tapan Chaudhuri spoke to our Support Group, I decided I had nothing to lose by trying acupuncture.

Dr. Chaudhuri, who is an M.D. as well

as an acupuncturist, explained that because I had already had several destructive procedures (namely the Balloon Compressions) he didn't hold out much hope for success in my case. After the first 30 minute acupuncture treatment though, I knew that this treatment was different. I actually was pain-free for two days! I went for my second treatment and I was pain-free for a week! Now, after 5 treatments, I've

been essentially pain-free for the past month! I say "essentially" because I realize that I am still holding my breath, waiting for another tic. So far, that worry has been groundless.

Can Dr. Chaudhuri help everyone? I doubt it, but for some like me, this is one more chance to be pain-free.

Dr. Chaudhuri can be reached at his Raytown office at (816)353-2400.

Definitions of Facial Pain

There is much confusion about what the various types of facial pain are, but the TNA has provided us with clear definitions:

Trigeminal Neuralgia (Type I): This is pain in areas served by the trigeminal nerve that comes on spontaneously and is more than 50% sharp, stabbing, come-and-go attacks.

Trigeminal Neuralgia (Type II): This also is pain in the areas served by the trigeminal nerve that comes on spontaneously, but more than 50% of it is a constant pain as opposed to sharp and fleeting.

Trigeminal Neuropathic Pain: This is pain that originates in the trigeminal nerve due to unintentional injury, such as trauma.

Atypical Facial Pain: This is face pain that has no known physical cause and is thought to be psychogenic-generated by the brain itself.

Trigeminal Deafferentation Pain: This is pain that occurs when parts of the nerve are injured to the point where they're completely disabled, such as complications from surgeries done to selectively injure the trigeminal nerve in an attempt to treat TN pain, i.e. glycerol injections, radiofrequency

lesioning, balloon compressions, neurectomies and the like.

Post-Herpetic Neuralgia: This is face pain that follows an attack of shingles (herpes zoster).

Symptomatic Trigeminal Neuralgia: This is pain that's secondary to another condition, primarily multiple sclerosis and tumors.

If you're still confused as to what type of pain you are suffering from, you can call Alana Greca, R.N., Director of Patient Support at TNA. She can be reached at (800) 923-3608.

May Meeting Very Popular

For our May Support Group Meeting we were fortunate to have Dr. Valorie Wells address our group with a presentation on the use of self-hypnosis for pain management. Dr. Wells pointed out some of the common misconceptions about hypnosis and the reasonable uses for it.

At the meeting Dr. Wells took the group through an exercise where she taught us how to perform self-hypnosis to give us a break from the chronic pain

that plagues so many of us.

If you'd be interested in knowing more about Dr. Wells and self-hypnosis you can contact her at:

Dr. Valorie J. Wells
4430 State Line Road
Kansas City, KS. 66103
(816) 590-1200



Look for new TNA logo items for sale on www.endthepain.com

Medical Resources

Recently John Koff, Director of Development at TNA, announced a new initiative in which TNA invites Board Certified Physicians, Universities and Medical Centers who are active in the treatment of TN and related facial pain to post their professional credentials on the TNA website where they can be accessed by individuals who are seeking treatment for this condition. For a

modest annual fee, these organizations and individuals can be included in this effort to better connect TNA patients with medical professionals who are interested in and knowledgeable about TN and face pain.

The TNA currently receives over 600 phone calls each month requesting information, patient support and medical referral. TNA also receives over

2,000 emails each month requesting the same information. TNA's website records more than 50,000 visitors each month!

Please encourage your physician to be listed on the TNA website. It could help others find help and the fees will help fund TNA's mission.

Contact Jean or Claude Aldridge for more details: (913) 681-8360

Buy for Charity

Raising Money For Your Cause and Saving Money For You



The Trigeminal Neuralgia Association has announced a new agreement with Buy for Charity. Now you can shop online at hundreds of stores including Amazon.com, Walmart.com, Best Buy, Eddie Bauer, eBay, Dell Home Systems, etc. and TNA will receive up to 35% of each purchase at no extra cost to you!

All you need to do to sign up for this amazing offer is to logon to: www.buyforcharity.com, select A Cause, click on General Disabilities and Diseases, scroll down and select

Trigeminal Neuralgia Association. That's it!

Then whenever you buy everyday items for yourself or your business whether it be books, CDs, clothing, office supplies, flowers, airline tickets and just about anything else from one of their popular online stores they will make sure TNA receives up to 35% of each purchase at no extra cost to you!

Buy for Charity is probably one of the most member-friendly Web sites out there. Becoming a supporter is entirely free and Buy for Charity's amazing

Coupons and Specials section will allow you to save money on your own purchases while helping TNA at the same time. Help make a difference today through your online shopping.

Please pass this along to friends, relatives and co-workers as the more people we have using this site, the more money is refunded to TNA. Be sure to have everyone designate the Trigeminal Neuralgia Association as their cause/charity to benefit from the purchase.

Do You Use E-mail?

In an effort to reduce mailing costs for our Support Group, we are asking our members to allow us to use email to correspond with you about upcoming meetings rather than using traditional mailings. If you have an email address that you use regularly, would you permit us to advise you by email of upcoming meetings?

If you are receiving our postcards by mail but have an email address you use regularly, please let us know so we can send you updates and meeting

The TNA does not share your email address with any other organization.

announcements that way. If you're already on our email list, you do not need to do anything. Our Support Group relies solely on donations to cover our expenses so we would appreciate your cooperation in our attempt to reduce

our expenses.

If you have an email we can use, simply send us an email at jean.aldridge@frkc.com and state "Okay to use my email for announcements." We will notify you of meetings using that address.

If you don't use email, we'll still send you meeting notices by U.S. mail.

Support Group Contact Information

Claude M. Aldridge, Kansas City TNA Support Group Leader

Jean E. Aldridge, Kansas City TNA Support Group Leader

Day: (913) 681-8360

Night: (913) 491-1133

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Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.