

TNA MASSACHUSETTS NEWSLETTER

SEPTEMBER, 2007

Written by Susan Urban, Western Mass. TNA support group leader

MASSACHUSETTS TNA NEWS

SAVE THE DATE: October 20, 2007 at 1:00 P.M.

Dr. Kamal Kalia M.D. who is the Director of the Trigeminal Neuralgia Care Center at Mercy Hospital in Springfield will speak to our group about treatment options and answer questions from the audience.

The meeting will take place at Noble Hospital in Westfield, Mass in Conference Room A.

It is not often that we are fortunate enough to have a doctor speak at one of our meetings, so I do hope that you will all make an effort to come so we can have a large audience

EMAIL ALERT: If any of you change your email address, please remember to send Christine and I your new addresses. On a recent mailing I had 9 emails returned to me. If we can't find you, then we can't let you know what's happening. So please remember to add us to your list of people that need to receive your new email addresses.

New beginnings for the Boston area

Some of you may already know this, but last spring one of our TNA members from the Boston area has volunteered to take on the task of being a TNA support group leader for the Boston area. Although we haven't definitely decided which areas of Mass. she will serve, it is likely that she will take on meetings and membership from all cities east of Worcester and I will take on all cities west of Worcester. Her name is Christine Canavan and you can reach her at 29 Mystic St, Brockton, MA 02302. Her phone number is 508-588-3566. If you live in the Boston area please email her at cec125@verizon.net and introduce yourself, especially if you have been involved without TN support group for a few years. I have already submitted all your names to her and have given her a list of those of you that have been faithful supporters, but I am sure she would be glad to hear from you.

MASS Group Forum

Did you know that Massachusetts has already instituted a forum where TN and face pain patients can chat with other members and share stories and experiences? Thanks to Keith and Tere Fredericks, who are members of the western Mass. TNA support group, we do have such a forum. They volunteered their services to set up this group so that all can participate. If you wish to access the forum go to <http://health.groups.yahoo.com/group/TNMASS/> In order to participate you must register, but registration is free. We only want people using the website if they are truly interested in sharing and learning about face pain, including TN which is the reason that registration is required.

Massachusetts TNA support group – the year in review

During the year 2006-2007 we held four meetings, three were in western Mass. and one in central Mass. During our previous year we heard a video presented by Dr. Steven Graff-Radford from the Cedars Sinai Medical Center in California answering frequently asked questions about TN and face pain, we established a positive rapport with Dr. Kamal Kalia and the Trigeminal Neuralgia Care Center at Mercy Hospital in Springfield, and some dedicated members came forward to help share responsibilities in our Mass. Support group. We are most grateful for the services of Keith & Tere Fredericks for setting up our Mass group forum and to Christine Canavan for volunteering to run our Boston area support group.

Massachusetts TN support group – the year ahead

This year, I hope to run more meetings both in western Mass. and in central Mass. In addition to meetings where we share our TN and face pain experiences, I plan to have Dr. Cindy Gross, chiropractor be a speaker at one of our spring meetings. With the help of one of our central Mass. members, I am also hoping to get a dentist to speak at one of our central Mass. meetings. If any of you have any ideas for speakers or meetings, by all means please let me and Christine know. We always welcome your help.

Notes about our TNA website

For our newest members

Did you know that our TNA website has a wealth of information about face pain, including TN? Not only does it have information about face pain, but it also contains articles written by both doctors and patients sharing their expertise and their personal experiences. There is also an online store where you can buy our TNA Handbook called Striking Back – the trigeminal neuralgia and face pain handbook . The book offers advice and information about treatments, therapies and surgeries and has a wealth of information about face pain, including TN and the new classifications for face pain, especially if yours doesn't quite fit in to the classic symptoms. You can access the website at www.endthepain.org You must register, but registration is free.

For our regular members

Have you tried to access the TNA website lately? Possibly you have typed in your user name and password that you used previously with the TNA Patient Registry. This information isn't valid for the new website, which has undergone some changes. If your old information is rejected, please register again as a new member in order to access the website. You can still keep the same user name and password that you used previously.

Other TN News

Regional and national conferences have been scheduled for the fall. Check the website for details. Many patients often inquire about disability. The website now has a new disability guide which you can access under the learning center. Some people have also inquired about botox injections as a treatment for classic TN. A study using botox is now underway at New York University and they are currently recruiting patients for participation in the study. Details are on the website home page.

National Membership Drive

Although you do not need to be a TNA official member to access the website, the national TNA is asking all support group leaders to launch a membership drive. Membership is only \$35.00 per year and the benefits are wonderful. If you become a member you receive an introductory packet of information from the national TNA office, the *TNALERT* newsletter from the national office 3 times a year, discounts on items bought through the online store and discounts when attending TNA conferences. Coming in the fall of 2007, a move is also underway to have a part of the website devoted to asking questions and seeking answers from the experts, participation in TNA surveys, and having access to TNA forums and chat rooms. In addition to the individual benefits, more members equals more authority when addressing the public, funding or government agencies, the healthcare community, researchers and local organizations. As a membership organization, TNA will have a stronger voice in the medical community and in turn will be able to have a greater impact on initiating and supporting research to find a cure. Please consider becoming a member.