



TNA

Together we will end the pain.

December 2004

NEWSLETTER AND MEETING NOTICE

Special note to those who can't get to meetings: The leadership team is available by phone or email whenever you have questions or concerns. Mary has videos to loan out and print resources which she can copy and send to you.

Brief Report on TNA Conference, Nov. 2004

This year's conference was noticeably bigger – in every respect. More attendees, more doctors, more dentists. A huge amount of information. The days were packed 7 am – 9 pm, too much to take it all in. We have a new celebrity spokesperson – Kathryn Crosby, Bing Crosby's wife. One of her close friends has TN, so she has agreed to help the organization. There is a New Striking Back! Book, (I will have a copy for you to preview at the next meeting). I was able to sit down personally with Dr. Bruce Pollock of the Mayo Clinic, Rochester, and I have answers for many of your questions. I will be telephoning those of you who gave me written questions personally with the answers. I will be ordering tapes/cds of some of the presentations as soon as they are available (not until mid-January at the earliest), so we will have those in our "library". From a personal standpoint, one thing that stood out for me as being quite different from previous conferences is that there is some funding out there now, under the auspices of the NIH. A consortium, made up of an alphabet-soup of acronyms for various organizations, (National Institute for Brain Disorders, NIBD, etc.) who are conducting some very basic research, right at the molecular level, on why the trigeminal nerve does what it does, what chemicals are released when it fires. So for the first time, there seems to be some true research into the nitty-gritty science behind the pain. In fact, during his own separate presentation, Dr. Ken Casey said there is a major shift in pain research, away from neuroception to understanding the "inflammatory soup", as he called all the components. So, although none of this will help those of us right now, down the line though this basic research will help the drug companies figure out new drugs, and the surgeons new techniques. At the next meeting I will come prepared to answer your questions as best I can of what I have learned this month.

A SPECIAL THANK YOU AND WELCOME

As mentioned in a previous newsletter, after 6+ years, I believe it time to bring in "new blood" and new ideas to the support group leadership of the Twin Cities Group. To that end, beginning in January 2005, I will be working with a wonderful individual to transition out of my current role, though I will continue to volunteer and host the picnic if everyone still enjoys it. **Gail Tudor**, has generously agreed to take up this baton. I will be working with Gail to set up a good program of speakers for us in 2005. Gail is a caring, loving, individual, and I know you will enjoy her enormously. Gail's pain journey, like so many others, was not straightforward. After an initial diagnosis, medications and no relief, she found another neurologist who took an MRI and found a cyst on the left side of her head. She was pain free for about 9 months after that was removed, but the pain returned. After finding our support group and educating herself on all the options, Gail went to Dr. Stephen Haines at the University of Minnesota for a microvascular decompression procedure in June of 2004. She is medication free and pain free now, with slight numbness. She is looking forward to meeting all of you and getting to know you.

Mary Lou Peterson has generously agreed to join the team and will be keeping up the e-mail list and addresses for us. Mary Lou came to the conference, and will give you her personal impression of what it was like at one of our meetings. Please join me in welcoming Mary Lou and thanking her. This support group is a team effort.

Maggie Jenniges had hoped to begin a support group in Mankato, but her health precludes this at the present time. Please e-mail her with your best wishes as she struggles with her pain. (Maggie's e-mail: dmc169@chartermi.net) She is very anxious to help others, but understands she need to look after herself first. Her goal is to attend the conference in Oregon in 2006.

As we draw to the end of another year, I know you join me in thanking the following for their dedication to TNA and supporting those in pain: Telephone Support: Mary Lou Ackleson, Laurie Redmann and Maggie Jenniges. Copying services: Mary Lou and John Ackleson; Collating & mailing: Karen Data. Yummy Homemade Treats at the meetings: Mary Lou Ackleson And of course... a special thank you to Jim Butcher for his unfailing support to all the spouses, caregivers, for making the coffee, for all the boat rides at the picnic, the technical guru at the meetings, and his constant good humor.

MONEY, MONEY, MONEY!

Our bank balance stands at about \$300, with mailings costing \$148.00 each time, I will be down to the bottom of the barrel soon. If you can donate something, it would be greatly appreciated. In order for it to be tax deductible, you must make your check payable to the National organization, Trigeminal Neuralgia Association, and then specify in the corner how much you want to come back to me.

The National organization then forward the funds to me. Apparently it is too expensive and complicated to have our group registered directly as a charitable organization.

IMPORTANT DATES FOR YOUR CALENDAR! 2005 MEETINGS

Sat. January 22 – Dr. Bruce Pollock, Associate Professor, Dept. Neurosurgery, Mayo Clinic, Rochester, MN.

Sat. March 19

Sat. May 21

Sat. July 16 – Annual picnic

Sat. Sept. 17

Sat. Nov. 19

Apart from the Picnic, all are scheduled at North Memorial Hospital, Pine Crest Room.

OTHER INFORMATION

We have talent in our group! Every conference, TN patients are asked to “Paint their Pain”, in an artistic format – any kind. This year the display included poetry, sculpture, painting, prose. Our own Laurie Redmann’s piece was prominently displayed. I include it here, with her permission, since I know so many of you are riding the same roller coaster. Other notable quotes I picked up from the conference:

“The reign of pain rests mainly in the brain”.

“There currently exists a lack of consistency in terms of decisions in dental and medical care.”

“Pain crosses all boundaries – the problem is how to bring all the medical communities together and help patients.”

“The tulips are too excitable, it is winter here.

Look how everything is, how quiet, now snowed-in

I am learning peacefulness, lying by myself quietly

As the light lies on these white walls, this bed, these hands

I am nobody, I have nothing to do with explosions

I have given my name and my day-clothes to the nurses

And my history to the anaesthetist and my body to surgeons”.

From “Tulips” by Sylvia Plath – “Ariel”.

LAST, BUT NOT LEAST.....

To each and everyone of you, I wish you a wonderful holiday season. I wish for each and everyone of you a pain free kiss, a pain free 2005, and peace. Look after yourselves, look after each other, I look forward to working with you and Gail in the New Year. As our slogan goes: “Together we will end the pain”.

IMPORTANT NOTICE REGARDING E-MAIL

Reminder to those of you on the e-mail distribution list (you do NOT receive a hard copy of the notice): Mary Lou Peterson, or Gail Tudor know if your e-mail address changes. (marylou@giftofheritage.com; gmctudor@hotmail.com).

Twin Cities TN Support Group Purpose

- (1) To support and encourage patients and families of those who suffer from trigeminal neuralgia and related facial conditions;
- (2) To assist and educate the medical and dental community in understanding the effects of these conditions.

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the services of your health care providers. It provides information

National TNA Contacts

National’s Patient Information Representative: Alana: 352-376-9955.

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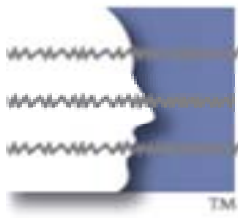
Twin Cities Leadership Team

Leaders: Mary Butcher – 763-753-3018. e-mail: butcher70@earthlink.net and Gail Tudor - tel: e-mail:

gmctudor@hotmail.com. **Copying Services:** Mary Lou Ackelson– 651-451-6249. **Phone Team:** Mary Lou Ackleson 651-451-6249.

Laurie Redmann. Tel: 763-370-8135 and also email: RedmannL@msn.com and all others listed above. **Collating:** Special thanks to

Karen Data of Oak Grove, MN.



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From: Mary Butcher
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