

TNA

Together we will end the pain.

April 2005

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 March's meeting

Hooray! He made it! I think he was beginning to wonder if he was jinxed... but the intrepid Dr. Pollock, in true Minnesota style, braved the 22 inches of snow they had in Rochester to make it to our meeting. The Cities had only a dusting, so the roads were fine the closer he got to his destination. We felt truly honored that he made the journey and taking the time out of his busy schedule to speak to us and discuss the surgical options for Trigeminal Neuralgia. We were also delighted to meet his wife, Kristen, and to see the slide of his children (his son has the same smile!). Dr. Pollock spoke about the types of surgical interventions he does for TN patients: mvd, GK and glycerol. When asked about the age cut-off for mvd, he said that most neurosurgeons now do not look at chronologic age, but rather physical age when considering an mvd. His oldest patient was about 85. He took many questions, and graciously spent a lot of time with individuals in our group after the meeting was over. We presented him with a gift certificate from Barnes and Nobel to thank him. Dr. Pollock's presentation was video-taped. Those of you who could not attend and would like to see his presentation can borrow a copy of this tape by contacting Gail Tudor (name and address at the bottom of this newsletter). We had patients come from Iowa and Duluth to hear his presentation. A special thank you to Denis Linn for video taping Dr. Pollock's presentation. Thank you to Jim Butcher for taking the digital photographs – watch to see if any of these photographs are featured in a future TNA newsletter. TNA in Florida has asked me to forward them – so who knows? You may yet be famous!

Our Next Meeting – May

The notice for our next meeting is attached. The purpose is twofold: Beth Heitman from the National TN office in Gainesville, Florida is coming to meet you, and to welcome Gail as your new Support Group Leader. I will be taking on another role with TNA, so I'll still be around! Beth Heitman represents all of us. Please come with questions and suggestions about the National organization: what are they doing now? What progress is being made in research? What do YOU want from National? The TNA has made tremendous strides in the last 11 years – I can remember it before the internet. The conferences are phenomenal, the information they have to give each of us is sometimes overwhelming. The kindness of Alana, the patient representative, and the generosity of spirit from everyone in the office is incredible, I cannot speak more highly of them. But as I mentioned – the group represents YOU. Come and thank Beth, come and ask questions, come and tell her what you would like to see done.

After Beth has spoken we'll break up and enjoy ourselves! Bring a dish to put on the buffet, and we'll have lunch together, instead of our cookies and coffee. This will give you the opportunity to speak to Gail and Beth individually and give them your thoughts. I'll have everything up so that we can have time and room to mingle.

NEW SERIES FOR YOUR NEWSLETTER! **“GETTING TO KNOW YOUR BOARD MEMBERS”**

Roger L. Levy, Esq., Chairman of the Board, Trigeminal Neuralgia Association

Roger Levy, originally a native of Great Britain, now living in Arizona, is the charismatic, charming and articulate face of TNA. Having suffered from TN for 6 years, he met Claire Patterson, the founder of TNA in 1997. Claire's instincts for good recruits are razor-sharp and, before he knew it, following a successful MVD recommended by Claire, Roger was recruited to help the infant organization grow. Since joining the Board of Directors 7 years ago, Roger has helped TNA to increase its funding, address a broader range of facial pain conditions and offer patients greater learning opportunities. His current duties include presiding at Board Meetings, overseeing TNA's fundraising and, working closely with TNA's President, Michael Pasternak, ensuring that TNA stays true to its Mission.

Roger welcomes input and suggestions from fellow-Tners, and you can e-mail him at rlevy@tna-support.org, or call him at 352-376-9955.

Roger encourages those of you who can to come and meet him at the next TNA conference, scheduled to take place in Portland, OR, next September.

THANK YOU! ☺ FINANCIAL APPEAL & ADDRESSES

Financial Appeal: Thank you to all of you who sent checks to National with monies to go to this support group. Your contributions are truly appreciated. Gail will have about \$400 in her kitty when she takes over in May.

E-Mails & Addresses: **Using e-mail saves \$\$ in postage!** If any of you are new on e-mail or are willing to receive e-mail notices and have not contacted us, please contact Mary Lou Peterson. She is doing a wonderful job organizing the e-mail addresses and keeping track of address changes. Thank you for being so prompt in notifying her, this is a time-consuming and meticulous job, and we are very lucky to have Mary Lou working on this for us. Please continue to let either Mary Lou or Gail know of your e-mail and address changes. (marylou@giftofheritage.com; gmctudor@hotmail.com).

VOLUNTEERS NEEDED.....

Gail needs your help! 2 Opportunities to help your group:

1. For over seven years now John Ackleson has been photocopying all our meeting notices/newsletters. This has saved us LOTS of \$\$\$\$. John has sold his business now, and this newsletter will be the last one he can copy. If you or your company is willing to donate copying of these newsletters, please contact Gail. Otherwise we will have to pay for Kinkos, and that runs about \$80+.
2. Writing the newsletter – Laurie Redmann has said she would like to try and do this, but not until her 2nd mvd is done and she has healed properly. (By the way, she is doing very well after the first one – you may remember that Laurie has bilateral TN). The second mvd will probably be done sometime in the fall. In the meantime, Gail needs a volunteer to write a short newsletter and prepare the meeting notice. This is not difficult, many of you who have been long time members remember that Evelyn and I started with just the barest essentials, a meeting notice, then an extra paragraph, and now we have our own short newsletter. I know there are many creative souls amongst us – so call Gail and let your imagination soar! My attempts have been very prosaic, someone out there can do much better!

IMPORTANT DATES FOR YOUR CALENDAR! 2005 MEETINGS

Sat. May 21 – Beth Heitman, National Support Group Director, Trigeminal Neuralgia Association, Gainesville, FL. & Party to welcome and meet Gail Tudor at your new Support Group Leader.

Sat. July 16 – Annual picnic – everyone welcome, family and friends.

Sat. Sept. 17

Sat. Nov. 19

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

PATIENT NEWS AND QUESTIONS

I received a call from one of our members. He is asking for help and information from any of us who may have a similar problem to his. He suffered a rare form of stroke that affected his Trigeminal Nerve. His condition is called Wallenberg's Syndrome. He does not feel hot and cold on the right side of his body, but on the left side of his face he has burning and pain. The pain is getting worse. If any of this resonates with you and you have information that can help him, please call me, or e-mail me, and I will put the two of you together. (Mary Butcher 763-753-3018, butcher70@earthlink.net).

Many of you know Laurie Redmann, one of our Telephone Support volunteers and a TN sufferer – she has bilateral TN. Laurie is doing well after Dr. Haines performed an mvd on one side, but she still has another mvd to go later this year. Laurie is a regular attendee at our meetings, a gifted writer who has eloquently expressed the despair of living with TN, and her work has been shown at the National conferences. Gail and I thought you would like to know that Laurie's husband, Gregg, has had to undergo bypass surgery. We know you join us in wishing them both a speedy recovery. We sent a card on your behalf to both of them, telling them that we were all thinking of them during this stressful time. Get well soon, Laurie and Gregg! We hope to see you at the picnic.

For those of you living in the far northern parts of Minnesota, I learned that there is a Canadian doctor who has been working with TNA national office and is willing to travel and speak to TN patients in Northern Minnesota. I have received a couple of calls from patients in the far north, the doctor's name and contact information is as follows: Dr. Anthony Kaufmann, University of Manitoba, Winnipeg. http://www.umanitoba.ca/cranian_nerves/kaufmann/

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

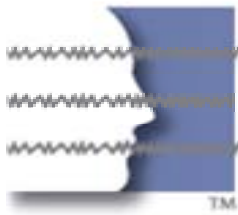
National TNA Contacts

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

National TNA Office: 2801 SW Archer Rd, Suite C Gainesville FL 32608. Phone: 352/376-9955 Fax: 352/376-8688. www.tna-support.org. Office email: tnanational@tna-support.org. Staff: Michael Pasternak, President/CEO; Beth Heitman, Support Group Coordinator.

Twin Cities Leadership Team

Leaders: Mary Butcher – 763-753-3018. e-mail: butcher70@earthlink.net and Gail Tudor - tel:763-533-6030. Address: 3916 Florida Avenue N., Crystal, MN.55427 e-mail: gmctudor@hotmail.com. **Copying Services:** Mary Lou Ackleson– 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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Meeting Notice

Date: Saturday, May 21, 2005

Place: North Memorial Hospital, Pine Crest Room
Address: 3300 Oakdale Avenue N., Robbinsdale, MN.
Tel: 763-520-5200

Time: 10:30 a.m.

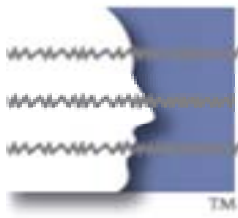
It's A Party!

Special Guest: **Beth Heitman, National Support Group Coordinator, Trigeminal Neuralgia Association, Gainesville Florida.**

Please come and welcome Beth Heitman, who will speaking about the work of the TNA nationally and the importance of support groups around the country. Beth will also be welcoming and introducing Gail Tudor as your new support group leader. Instead of our usual coffee and cookies, please bring a dish to pass and after Beth has spoken, we can all enjoy a light lunch together. This will give you a chance to talk individually with Gail and Beth.

Our telephone support members and administrative help also plan to be there. These wonderful individuals are also unsung heroines. Mary Lou Ackleson has been taking calls from people in pain for over 8 years now (not to mention making all those delicious cookies at our meetings!). Laurie Redmann, despite her own struggles is in touch both by 'phone and e-mail with patients. Mary Lou Peterson, as mentioned in the newsletter, is providing much needed administrative help. Please chat with these heroines, and let them know how much they are appreciated.

Come and celebrate two special individuals, Beth and Gail, in our fight with TN – as the national motto says “Together we will end the Pain”.



TNA

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From: Mary Butcher
Twin Cities Trigeminal Neuralgia Support Group
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Anoka, MN.55303