



San Francisco Bay Area
TRIGEMINAL NEURALGIA ASSOCIATION
Support Group

MEETING NOTICE:

SATURDAY, MARCH 8, 2003

1:30 pm-- 3:30 pm

Place: El Camino Hospital
Main Hospital, ground floor
Conference area behind the cafeteria

Speaker: Gary Heit, Ph.D., M.D.
Director, Functional Neurosurgery
Stanford School of Medicine

Dr. Heit's clinical interests include the surgical treatment of chronic pain, movement disorders, and epilepsy. Among the more than 45 diseases Dr. Heit treats are Trigeminal Neuralgia, Glossopharyngeal neuralgia, neuropathic pain, brain tumors and Thalamic pain syndromes. Dr Heit's work in motor cortex stimulation parallels that of the Trigeminal Neuralgia Association's Medical Advisory Board member Dr. Jeffrey Brown.

Brain Awareness Week:

Dr. Heit's presentation also precedes Brain Awareness Week, March 10th through March 16th. It is an annual information campaign that seeks to link scientists, clinicians, and educators to communicate to the public the importance of the brain and brain research. Time permitting, we will play a segment of a tape recording from the Dana Alliance for Brain Initiatives about Dr. Benjamin Carson Sr., a neurosurgeon at Johns Hopkins Hospital. You can read about Dr. Carson in co-author George Weigel's preface in "Striking Back". He gave a life back to George, a chronic TN sufferer.

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Meeting Itinerary for May, 2003: We will meet our new members first.

I. Meeting Program:

The program will follow with selected segments of the excellent videos of presentations at the San Diego TNA Conference.

Among the featured speakers were Dr. Peter Jannetta, Dr. John Alksne, Dr. Jeffrey Brown, Dr. Ronald Brisman, Dr. Ronald Apfelbaum, Dr. James Nelson, and others of the TNA Medical Advisory Board.

We have ordered 7 of the 20 videos produced at the Conference, numbers 1200, 1201, 1203, 1205, 1209, 1211, 1218. Your suggestions for circulation and viewing of the videos would be helpful. We have over 350 on our mailing list and want to share these informative videos. Possible locations are homes, El Camino Hospital, and the Masonic Lodge in South San Francisco. We will have a full set within the next few months. Individuals may also order their own copies from the TNA. Prices vary. View the list at www.tna-support.org or contact Bennett Bloomfield.

II. Gamma Knife Tour at UCSF Hospital, February 13, 2003

Thirty-three support group visitors were given the opportunity to learn, step by step, about the Gamma Knife-TN procedure from Dr. Nicholas Barbaro and his clinical staff as we gathered around the Leksell Gamma Knife equipment.

A series of MRI scans from a procedure performed just prior to our tour was also shown to enhance the procedural descriptions.

All of our questions were thoroughly and thoughtfully answered. The staff was obviously aware of the pain endured by TN sufferers. Since TN is rare, the Radiology Department group was impressed by our large numbers.

At UCSF in 2002, 20 TN patients elected the Gamma Knife treatment. For information on the Gamma Knife at UCSF call 888-689-8273 or see their website at www.ucsfhealth.org. For Kaiser Permanente members, there is a Gamma Knife installation in Sacramento.

A footnote: Dr. Barbaro recently worked with Dr. Jeffrey Brown at Wayne State University on approaches to atypical TN. Dr. Brown is a member of the TNA Medical Advisory Board. We have ordered a video presentation he made on intractable facial pain. (Video#1211).

III. Proposed San Francisco and North Bay TN Support Group

Dr. Barbaro has kindly offered to provide a room at UCSF for meetings of a proposed TN support group. Establishment of a support group in San Francisco is being considered to better serve San Francisco and North Bay residents, and East Bay residents who may be able to use BART.

Tentative plans would be to meet on alternate months from meetings in Mountain View, probably on Saturdays, early afternoon. Many with TN have been unable to attend Mountain View meetings because of lack of transportation access or distance.

Please contact us by phone, email or postcard with your suggestions to help us get started. Contact Ken Faulk, 34 DeLaurenti Court, Walnut Creek, CA 94598-4602, phone 925-939-2242 or Tom Stimac gultens@attbi.com, or Bennett Bloomfield, 621 Caribbean Way, San Mateo, CA 94402-3418, e-mail b.m.bloomfield@att.net

V. Next Meeting:

SATURDAY, MAY 10, 2003

1:30 pm

Place: Meeting Room “N”
Ground Floor, Park Pavilion Building
El Camino Hospital Campus

Please keep this letter to cover both meetings. This letter is being e-mailed to members with e-mail addresses in a first time cooperative effort with the TNA office in Florida. Please notice the meeting rooms are different for these two meetings. **Refer to the attached map.**

“Striking Back”

Long-time TN group member Edie Fisher has had a lot of experience with TN medication and treatment. She is doing well now thanks to her Gamma Knife procedure at UCSF last year. Edie recommends “Striking Back” should be read repeatedly as you continue your research. It’s her basic reference. Order “Striking Back” by calling the TN Association at 352-376-9955 or download an order form at www.tna-support.org or you can send a check for \$16.95 to Trigeminal Neuralgia Association, 280 SW Archer Road Suite C, Gainesville FL 32608. For 2-day priority mail send \$18.95.

Maps and Directions:

From San Francisco via Highway 101:

- Exit at Highway 85 South
- Exit at Grant Road/El Camino Real North
- Cross El Camino Real
- El Camino Hospital 1 mile on Right

From San Jose via Highway 101:

- Exit Highway 237 West (not East)
- 237 becomes Grant Road
- Cross El Camino Real
- Hospital 1 mile on Right

From San Francisco via Highway 280:

- Take Magdalena Exit
- At stop sign, turn left onto Magdalena
- Right on Foothill Expressway
- Left on Grant Road
- Hospital 2 miles on left

From San Jose via Highway 280:

- Take Foothill Exit
- Right on Foothill Expressway
- Right on Grant Road
- Hospital 2 miles on left

