



San Francisco-San Jose Facial Pain Association Support Group

Saturday, July 11, 2009 Meeting, 1:30 -3:30pm

El Camino Hospital, Mountain View

Conference room behind the Cafeteria, ground floor, Main Hospital Building

NEWS SUMMARY July Meeting Program ~ FPA 2010 Conference ~ FPA Web TN Medical news ~ Member-created Web site ~ Doctor survey: Use of Audio Recording during Doctor Visits ~ Books available ~ May meeting volunteer crew ~ ECH news ~ Recent Dr. Jannetta Study: Microvascular Decompression for TN in Elderly Patients~ North Bay Area Facial Pain Support Group new start request

OUR MEETING will be a roundtable session with all our members participating. We will share our notes and subsequent research with doctors, friends, and Internet searches to supplement information from the May meeting. We will share our knowledge and experiences. As educated patients, we will be better prepared to pursue our goals, and hopefully, help others do the same. A set of all of the Conference DVD's shown in May will be on hand for reference. A copy of the National Conference Notes CD distributed at the May meeting will be available to patients attending our July meeting who missed the May meeting.

BEFORE OUR JULY MEETING, we suggest revisiting FPA site www.endthepain.org and www.facepain.us for current authoritative facial pain information. On the FPA website, log in (free) and look at Headline News. Examples of recently published Medical Journal articles by members of our Medical Advisory Board: Dr. Ken Burchiel's 144 patient study proposes 2 classifications for Trigeminal Neuralgia, TN-1 (shock like) and TN-2 (constant) and treatment considerations. Other articles: "*Research Analyzes Repeat Surgery for Patients with Recurrent and Painful Trigeminal Neuralgia*" by Dr. Bruce Pollock. Also "*A Prospective Cohort Study of MVD and Gamma Knife Surgery in Patients with TN*", a 4 year study led by Dr. Mark Linskey, a distinguished UC Irvine participant at the FPA National Conference.

TN BOOKS Copies will be available at the meeting of TNA's two Face Pain reference books, Dr. Ken Casey and George Weigel's "Striking Back, The Trigeminal Neuralgia and Face Pain Handbook" and Dr. Joanna Zakrzewska's "Insights, Facts and Stories behind Trigeminal Neuralgia".

THANK YOU Emily and Enrique Diaz, Gene Summerville, Adrienne Reeves, and Terra Shelton for the May 9th meeting preparations, donations of refreshments, beverages, and the production by Gene Summerville of comprehensive CD's containing all the

Biennial FPA Conference notes plus added helpful information for our members. They all gave generously of their time and resources to provide our special meeting.

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FUTURE MEETING CONTENT: Emily Diaz and Bennett Bloomfield encourage you to contact them with your suggestions or requests for our upcoming meetings. *Have you had a facial pain procedure recently?* Join us and share your experience.

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???? Would you like the [NORTH SAN FRANCISCO BAY AREA SUPPORT GROUP](#) to restart in Walnut Creek? Contact Bennett Bloomfield at chiefbmb@yahoo.com

Many who suffer the pain of TN have turned to creative activities for hope by developing websites offering inspiration and encouragement. A local member, Jody Baxter, has developed www.worldprayers.org His mission: "Gathering the great prayers from all spiritual traditions around the world into a unified archive for the purpose of inspiration, study and cross cultural appreciation."

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The next Facial Pain Association Biennial Conference is set for August 28-29, 2010. Our host will be The Mayo Clinic in Rochester, Minnesota.

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"MICROVASCULAR DECOMPRESSION FOR TRIGEMINAL NEURALGIA IN ELDERLY PATIENTS". Read a study led by Dr. Jannetta recently published in the Journal of Neurosurgery. To access the article, hold down the Ctrl key and click on the link below.
http://www.ncbi.nlm.nih.gov/pubmed/18377247?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum

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We thank Gene Summerville for asking the question about voice recorders which initiated this helpful National study. Feel free to make a copy for your own use.

Various responses by doctors treating TN concerning patients' Audio Recording during a doctor visit

This information is for your own evaluation and does not constitute a recommendation nor does it reflect a specific geographic area.

- In general, people, including physicians, cannot be recorded without their knowledge and consent. I know of no legislative proscription against recording a patient-physician interview. However, many physicians (especially surgeons) either personally feel, or have been advised by their counsel, that these recordings create the potential for medical liability exposure. Some have been advised by counsel not to agree to recording, and some simply choose not to agree on their own. They certainly have the right to do so. Rather than stress the patient-physician relationship over such issues, it is often best to simply advise patients to bring family and friends with them to the visit. These witnesses can assist in clarifying what was said or intended if the patient is having trouble remembering or retaining.
- I have had many patients record our conversation.

- I personally have no problems with the practice, actually encourage it, but I do not know what the legal ramifications may be. Specifically, I would suspect that consent from those being recorded should be sort of a respect thing, but I don't know the legalities of that...
- I have no problem with patients recording their office visits. It's not uncommon.
- Patients frequently ask me if they can record our conversation regarding complex issues like treatment options and expectations for results of treatment. In our practice, we encourage this opportunity. Moreover, we encourage patients to visit our web site where we discuss or present detailed topics for patient education. I think that education using new technology will become increasingly important in documentation of data and explanation of complex medical topics.
- Many patients come to my office with recorders; other patients take written notes. It's always nice if the patient asks first so the doctor knows that the recorder is being used. Some clinicians may not be comfortable with the recorder being used, and patients should be willing to respect that also.
- If the patient requests it usually as they have memory or cognitive issues. As long as there is a mutual agreement I have no problem with it.
- Clearly there is a place for patient use of a recorder during a consultation with a health care professional. This is especially true in cases where there may be cognitive deficit (medication-induced or otherwise). In some cases the volume of material covered is so great that it would be unlikely that the individual could retain or process the information in a reasonably complete manner. I would think that the most important portion of the visit in which recording would be necessary would be the discussion of findings and treatment recommendations, not necessarily the entire examination. However, it is most important that the patient request such from the evaluating/treating individual. There must be a mutually agreed upon use of the recording which would and should be limited to the patients personal review.
- Certainly, if a recording is made either by the physician or the patient or their family without knowledge of the other party, the relationship is flawed from the onset. Though it may be legal, I would consider it unethical if done by the physician and a cause for discontinuing the physician-patient relationship with the patient if done by the patient and later discovered by the physician.
- My only concern is that when obsessive patients start to analyze the consultations they may read more into it and pick up on certain phrases we may have used inadvertently e.g. degenerating, etc

ECH Health Note: El Camino Hospital is committed to providing a safe and healthy environment that also encourages positive health behaviors. Becoming a smoking-free and tobacco-free campus supports that commitment to the health and well-being of our community, patients, staff and volunteers. Last September the El Camino Hospital Board of Directors passed a resolution to convert all El Camino Hospital campuses to smoking-free and tobacco-free as of July 1, 2009.

SF-San Jose Facial Pain Support Group Meeting Dates for
2009 Saturdays, 1:30-3:30pm: July 11, September 12, November 14

Northern California Support Group Leaders and TNA Contacts

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TNA:	Patient Rep	(800) 929-3608	patientrep@tna-support.org

Changes or Questions???? If you change your e-mail or postal address, added an email address, have questions, or want to be removed from our mailing list, please let us know.

Disclaimer: There are many treatment options for Trigeminal Neuralgia and other facial pain conditions. The Facial Pain Association does not endorse any one over others. This newsletter and the information contained in it are not intended to be medical advice. For that, you must consult your own doctor.