



## San Francisco-San Jose Support Group

Supporting and serving all San Francisco Bay Area members

**Meeting, Saturday, September 11, 2010, 1:30-3:30pm, El Camino Hospital,  
Mountain View**

**Park-Pavilion (YMCA) Building, Room "K" on the ground floor.**

### MEETING PROGRAM

**How I made the decision to have surgery.**

**What was my surgery experience? What was my recovery experience?**

Several members will speak and then answer questions. Emily Diaz will be our moderator.

**Discussion by participants in the FPA Patient Registry survey**

Four of our members participated in completing a comprehensive 10 page prototype questionnaire developed by Dr. Joanna Zakrzewska to be used for the redevelopment of the TNA-FPA Patient Registry data base. Included were questions to help define 9 types of facial pain to help make a treatment decision.

~~~~

### Our July meeting 15<sup>th</sup> anniversary celebration with Susan and Cindy

Our San Francisco-San Jose Support Group was warmly greeted by TNA-FPA Gainesville guests Susan Cupp, Chief Executive Officer and Cindy Ezell, Coordinator of Patient Services of TNA-The Facial Pain Association at our meeting on July 10, 2010. Their visit brings recognition to our 15<sup>th</sup> Anniversary as a support group that continues to build community between TN patients, their caregivers and medical professionals.



Ms. Cupp pointed out common themes between people who suffer from facial pain and how valuable a group like ours can be when it benefits from active volunteers who are committed to staying current.

The annual Trigeminal Neuralgia conference will be in Rochester, August 28-29, 2010 at the Mayo Clinic. We have continued to provide scholarships for people who want to attend but have financial constraints.

She informed us that the national organization is working hard to expand the regional conference program. The regional conferences coming up are October 23, 2010 in New York, March 5, 2011 in New Orleans, and May 2011 in Richmond, VA.

**Ms. Cupp was happy to announce that plans are being worked on to have a TN regional conference in San Francisco in September or October of 2011.**

Also, the national organization has received funding to resurrect the National TN registry. The national website, [www.tna-support.org](http://www.tna-support.org), currently has over 4000 people registered and is currently being redeveloped and enhanced. Overall the National TN Foundation has weathered the nations' financial woes well.

Ms. Cupp informed us that the national organization is working hard to keep itself going strong for many years to come by adding board members to the Board of Directors and Medical Advisory Board that reflect a continued commitment to research, education and treatments.



Cindy Ezell spoke of her commitment to promoting progress for better treatments, better MVD's and better medications for all facial pain sufferers. She expressed her hope for treatments that are successful for more people, more of the time.

She encouraged us to use "TNA-Connect" on the website to share our experiences and to keep communicating with other patients and their caregivers. She graciously shared her own story of facial pain and, along with

Ms. Cupp, patiently answered our questions and concerns.

*[Our thanks to Sue Miller for her meeting report.](#)*

#### **Northern California Support Group Leaders and Facial Pain Association Contacts**

|                              |                |                                                                                                    |
|------------------------------|----------------|----------------------------------------------------------------------------------------------------|
| S.F. - San Jose: Emily Diaz, | (408) 846-0618 | <a href="mailto:iemily@mac.com">iemily@mac.com</a>                                                 |
| Bennett Bloomfield           | (650) 573-6292 | <a href="mailto:chiefbmb@yahoo.com">chiefbmb@yahoo.com</a>                                         |
| North Bay: John Porter       | (510) 501-5550 | <a href="mailto:sfnorthbay.tna.support.group@gmail.com">sfnorthbay.tna.support.group@gmail.com</a> |
| TNA-FPA Office               | (800) 923-3608 | <a href="http://www.endthepain.org">www.endthepain.org</a> (click on Contact us)                   |
| TNA-FPA Patient Rep          | (800) 929-3608 | <a href="mailto:patientrep@tna-support.org">patientrep@tna-support.org</a>                         |

***CHANGES OR QUESTIONS:*** *If you change your e-mail address, have questions, or want to be removed from our mailing list, please let us know.*

-----

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.