



Treatment Strategies and Pitfalls Discussed at May Meeting

The May 31st meeting format was a helpful one for the many members who attended, with plenty of information and personal help available. The meeting began with people in the group introducing themselves and giving a short history of their face pain trials and triumphs.

One of our members – retired from the medical profession – came all the way from Yakima, Washington, to tell us about his victory over TN pain after many years of suffering. He gave us many good pointers in his description of the winning strategy that he used to make decisions regarding his care.

Early in the course of his TN, while the medications were still controlling the pain, he began to read about TN. This enabled him not only to learn about his treatment options, but also to make sure his diagnosis was correct so that he could obtain the right treatment. A trial of anticonvulsants, along with an MRI, made the TN diagnosis a certainty. Through the National TNA Medical Advisory Board and his reading of published TN research, this member was able to obtain the names of neurosurgeons skilled in treating TN. While attending the 3rd National TNA Conference in Pittsburgh in 2000, he made it a point to talk with all of the experts there, asking about their surgical outcomes, their facilities, and their opinions about his case. He emphasized to us the importance of getting a second opinion.

When the time was right for him, this member underwent Microvascular Decompression Surgery (MVD) with the confidence that the doctor he chose was the best. His only regret was that he waited as long as he did. He advised us not to be afraid of the surgeries, but to be certain that we obtain the very best care possible. His well-informed decision has left him happy and pain-free, able to really enjoy the golden years of retirement!

Another member drove to the meeting from Eugene. Although it was only a two-hour drive, she considered it to be a treacherous one, requiring all her energy and
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August Meeting to Include Video and Discussion

Please join us at our next meeting on August 9, 2003 at 1:00 PM at Legacy Meridian Park Hospital. The topic will be **“What Can You Do if the Pain Comes Back”**. We will view a video from the 2000 TNA conference in Pittsburgh, PA, of a panel discussion on recurrence of TN pain. Panel members are TNA Medical Advisory Board members, including *Striking Back!* co-author, Ken Casey, M.D. Group discussion will follow the video.



TNA Seeks Members’ Experiences With Medications

In the Summer, 2002, edition of their *TN Alert* Newsletter, TNA asked members to send in information on their experiences taking certain new medications that are being prescribed for TN. Since they haven’t received as many responses as they had hoped, they have put out another call to members. Your experiences can be a valuable resource for ongoing medical studies and testing. If you have experience with Carbatrol, Keppra, Lamictal, Neurontin, Tegretol XR, Topamax, Trileptal or other new medications, please email the TNA national office with a brief comment on your experience with these drugs at: tnanational@tna-support.org If you prefer, you can write down your experiences and then mail them to: TNA, 2801 SW Archer Rd., Suite C, Gainesville, FL 32608. TNA would appreciate the feedback to provide the pharmaceutical companies encouragement for further clinical testing.



Seattle Group to Meet in July

The Seattle Chapter will hold its next small group support and organizational meeting on Saturday, July 26, 2003 at University of Washington Medical Center in Conference Room BB 389 at 1:30 PM.



Remembering Frank

We are sad to announce that long-time TNA member, Francisco (Frank) Ceballos, Jr., of Silverton, Oregon, passed away quietly on Sunday, July 6, 2003, of natural causes. Everyone who has ever attended a Pacific NW TNA support group meeting will recall Frank, age 60, as a gentle and kind man who made it to almost all of the meetings despite having to use a wheelchair to get around. His lovely wife Sandy often accompanied him to meetings and took an active role in the group as a supportive spouse.

Sandy called to tell the group of Frank's passing, commenting that he had told her that the group was a comfort that meant a great deal to him. He felt relieved to belong to a group of people who understood what he was going through, and to learn that there was more he could do for TN than to just continue to take medications. In fact, Frank was scheduled to have MVD surgery on July 17th, and was very excited at the prospect of beating the pain for good. We are grateful to know that up to the end he still had hope in his life, and that we were a part of the reason for his hope.

Frank, born in Waimea (Kauai), Hawaii, on June 5, 1943, was of Philippine ancestry and proud of it. He often corrected people who mistook him for Samoan because of his large stature. Frank served his country in the US Navy, including two tours during the Vietnam war, and remained active as a US Navy Veteran throughout the rest of his life. He is survived by his wife Sandy, mother Lucy, 3 brothers, 2 stepchildren, and dozens of family members. His family flew his remains home to Hawaii, where he will be laid to rest at Kauai Memorial Gardens in Lihue.

Frank and Sandy recently celebrated their 20th wedding anniversary on July 2nd. Early in their marriage, they lived in California, where Frank worked as an oil-well pump repairman. He was diagnosed with Multiple Sclerosis (MS) 18 years ago, and kept it under control until 1991, when it caused him to leave the oil well business. He took early retirement and disability, thinking more of avoid accidents and hurting others than of his own loss. Frank and Sandy used the opportunity to relocate to a place with greenery and mountains similar to those in Frank's beloved Hawaii. They packed up everything and headed north on I-5 until they pulled over for a break in Silverton, Oregon. When Sandy took a look around the quaint town she said, "We are home". Frank had to be persuaded to stay, but the Pacific Northwest eventually became one of his favorite places.

While he lived uncomfortably with both MS and TN for many years, Frank faced additional problems. He had two heart attacks and two strokes beginning in 1996. Although he fought hard to rehabilitate, the damage and disease was too great for complete recovery. He lost a little more of his physical and mental abilities after each event, but he kept pushing to regain every part of himself that he could.

During the last few years, Frank had to depend on a wheelchair as the effects from his ailments became more impairing. He and Sandy attended MS support groups until they found our TNA group. At that time, they decided to concentrate on obtaining information on the more painful problem of TN.

Frank was a quiet man, but a strong fighter. He approached the battle with TN with the same determination as his previous problems, although the TN medications made him constantly tired and wore him down. In the end, Sandy said, he was hurting a lot and very tired of it all, and looking forward to his MVD. She told us not to be sad that he has passed away. She believes that he is in a perfect body now without any limitations or pain, and he need not walk anymore because he now has wings to fly.

May/June Treasurer's Report

Thanks to all the members who so generously contributed money to our Pacific NW TNA Support Group. We rely on our members for our mailing and meeting costs. Unfortunately we are not allowed to give a tax deduction for donations made directly to our local support group. However, donations sent to the national TNA and designated as being earmarked for our Pacific NW TNA Support Group are tax-deductible.

Beginning balance 5/01/03 -- \$858.90
Donations and Book Sales -- \$58.95
Expenses:
Meeting Refreshments -- \$18.11
Postage and Supplies -- \$98.44
Ending Balance, 6/30/03 -- \$801.30

Deanna Fowlks, Treasurer, 6209 SE 34th, Portland, OR 97202.

*I get up. I walk. I fall down.
Meanwhile, I keep dancing.*

Strategies & Pitfalls (Cont. from p. 1)

concentration. Because she had to time her medications to leave her with a clear head for driving, she risked experiencing more face pain during the drive.

This member has been on a long journey with face pain. She attended the meeting to find answers for herself and to relate her experiences to help others. An MVD performed many years ago gave her only one year's relief from her TN pain. Neither Tegretol nor any other medications she tried worked very well after the surgery. Despite the persistence of the shocks, she didn't want to have another surgery.

After a year or so she had a rhizotomy procedure and the mastoid branch of the TN nerve was cut. The procedure often has mixed results, and that is exactly what resulted. It brought her some relief from her more intense shocks in exchange for some numbness in her cheek and mouth, but she also contracted meningitis and a cerebrospinal fluid leak that wasn't found for quite some time. She had been informed of these risks prior to the procedure, but tried to overlook them at that time. It was a reminder for us to watch out for even rare symptoms after a procedure and to inform the doctor of them without delay.

Eventually her TN shocks were gone, but she started having constant pains she hadn't experienced before. Still on medications, she had a bad reaction to some a few months ago, and came to the meeting to find out if there were other medications that might help her. She advised us that it can take trial and error to find the right medications, and she even brought a bag full of her discontinued medications to show how many she had tried. One of her challenges is that she has had TN for so many years that her body now reacts differently to the medications because she has aged. One day she found herself being overtly emotional and crying uncontrollably, and discovered that the medications can cause strong emotional upset as a side effect. She recommended that if you find yourself acting out of character, you should take a closer look at your medications. As the years have gone by, she now finds herself needing to start lower and go slower with medications, something we should all be aware of.

Lately, this member has begun investigating the topical compounded medications as an add-on to her oral medications. No matter what it takes, she will keep on trying to achieve as much pain relief as possible. She is a great example for us. Despite her many years of coping with TN, she still has a sparkle in her eyes and a strong determination to continue living a full life.

Another member came to the meeting from Salem to share her story of winning out over the pain that plagued her for many years. Although she had been keeping her typical TN attacks under control with medication, she experienced side effects. When her doctors added more medications to treat high cholesterol, she couldn't tolerate the combined side effects of the drugs. Always conscious of living a natural lifestyle that included using herbal supplements and vitamins whenever possible, the thought of being on strong medications forever didn't appeal to her. She sought out a better way to handle TN pain.

When she began taking baby aspirin for her heart and Omega-3 oils for her high cholesterol as recommended by her internist, she noticed that her TN pain began to diminish. After only two months, the TN shocks subsided completely and she was able to stop taking Tegretol altogether. She believes that getting her heart and blood vessels in better condition must have lessened the compression on the trigeminal nerve. She has adopted a diet based on better nutrition and maintained her supplements and vitamins. At the meeting, she stated that she's been pain free over a year and healthier than she's felt in a long, long time. We admire her enthusiasm for her new lifestyle and appreciate that she came to the meeting to share it with the group.

After other members shared their stories and asked their questions, the group gathered near a whiteboard where we wrote down our ideas on managing face pain, with strategies in one column and the corresponding pitfalls in another. Everyone pitched in and gave opinions as to what they had found helpful and what to watch out for along the way. The group's collaborative efforts are depicted in the chart on page 4. We hope our efforts will encourage others take a close look at where they are in the process, and give them some helpful ideas to pursue.

The Pacific Northwest TNA Support Group is sponsored by the national Trigeminal Neuralgia Association (TNA), 2801 SW Archer Rd, Suite C, Gainesville, FL. (352)-376-9955. <http://www.tna-support.org>.

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the services of your health care provider. TNA does not endorse any one treatment over the other. Please discuss any information in these pages with your own physician.

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