



**TRIGEMINAL NEURALGIA ASSOCIATION  
TEXAS SUPPORT GROUPS  
October 2004**

If there is something you want to learn more about, feel free to write, phone, fax, or e-mail Shelly Wilson, a TNA Support Group Leader, at 604 Aberdeen Way, Southlake, TX 76092, phone (817) 416-7202, fax (817) 416-9871, [kayser-wilson@charter.net](mailto:kayser-wilson@charter.net).

**UPDATE FROM DR. GILLER**

Cole Giller, Ph.D., M.D. has moved his medical practice to Baylor University Medical Center in Dallas where he is directing a *new* Radiosurgery center housing both a gamma knife and Cyberknife. He continues to be active in the treatment of TN. His office number is 214-363-6812.

**E-MAIL ADDRESSES**

Thanks to everyone who's provided us with their e-mail addresses. This saves on our mailing and copying costs. If you have an e-mail address where we can send this newsletter and any updates, please e-mail Shelly Wilson at [kayser-wilson@charter.net](mailto:kayser-wilson@charter.net)

Just a reminder, if you change your e-mail address, please let Shelly know.

**WEBSITE OF INTEREST**

[www.nlm.nih.gov](http://www.nlm.nih.gov) – The home page of the U.S. National Library of Medicine (NLM), the world's largest medical library and the creator of MEDLINE®, provides information about NLM programs and services.

**NUMBERS TO KNOW ... FOR FINANCIAL ASSISTANCE**

Medicaid	800-252-8263
Medicare	800-772-1213
Veteran's Assistance	800-827-1000

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

## **SUGGESTIONS FROM A TNA MEDICAL ADVISORY BOARD MEMBER**

Dr. James R. Nelson, a neurologist on the TNA Medical Advisory Board, in La Jolla, CA spoke at a San Diego TN support group meeting. He ended his presentation with suggestions for Life Style Changes that could help with any pain:

- Focus on the present
- Be realistic
- Get involved in outside activities
- Relaxation
- Value Distraction
- Recognize your thoughts and feelings
- Set Priorities
- Set realistic goals

And most important of all ---Rediscover HOPE.

Source: TNA San Diego Support Group Newsletter, February 2004

## **UPDATES FROM OUR MEMBERS**

Barbara had a Microvascular Decompression surgery, MVD, in mid-September by Dr. White with UT Southwestern Medical Center in Dallas. In surgery, Dr. White found two large blood vessels pressing on the trigeminal nerve. We wish her a speedy recovery!

Don's had several good days once his gamma knife radiation treatment by Dr. Weiner at Dallas Presbyterian Hospital started working. Hurray! We hope he'll have many more of them in the days to come.

Jo Ann had a MVD by Dr. White at the end of August and reports she is feeling fine. She's driving, shopping, and having lunch with girl friends. Once she weans off the rest of her Neurontin with no pain, she'll call the MVD a success. We hope to hear of your success soon!

Charlene had her second gamma knife by Dr. Hutchins at Dallas Presbyterian Hospital in August. She got 90% pain relief from her first gamma knife and has her fingers crossed that the second one will be just as successful. Right now, she's hoping the effects of the second radiation treatment will provide her with pain relief soon.

Larry's TN came out of remission with a real vengeance but his pain is lessening now. He's taking Cilantro each day which he thinks may be the key to getting him out of pain.

Mary has had TN for 24 years. During all of these years she has taken the various prescribed drugs known to help control TN pain. Her latest is Topomax. On August 1,

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

2004, her pain incidence was by far the most severe. On September 3, she got her first peripheral glycerol treatment and got instant pain relief for 4 hours. On September 9<sup>th</sup>, she got her second peripheral glycerol treatment and has been pain-free since then – for 5 days. Let's hope this is just the beginning of many pain-free days for Mary!

Pam reported she's got a great dentist in Fort Worth who's located near Hulen Mall. He understands TN and has successfully provided her with dental care over the years. His name is Amos Ross, D.D.S. His office number is 817-292-2555.

Bryan's MVD by a neurosurgeon up north has failed within the two year period after his surgery. He's back on TN medication but reports the pain isn't as intense as it was prior to the MVD.

After months on Tegretol with disagreeable side effects, Carroll had a balloon compression TN surgery by Dr. Richard Weiner at Dallas Presbyterian Hospital in early 2000. He had no pain for three wonderful years but then, just as Dr. Weiner had warned, the brief electric shock type pain returned big time in January 2004. He's now taking Trileptal twice daily, as prescribed by his neurologist, with great results. (Trileptal is a newer formulation of Tegretol, only available in brand name.)

Bill's TN is slowly coming back on him even though he's had a MVD. Agnes, Jean, Jeanene, Jeanette, John, Karin, Leslee, Martha, Patricia and Stacy's Mom are all having trouble with their TN. Please pray for them.

If you would like to share an update with our group, please let Shelly know about it.

## MEETING NOTES

### **Tyler Meeting – July 21, 2004:**

Barry W. Rath, Ph.D., a neuropsychologist with East Texas Medical Center in Tyler, addressed "How Can A Neuropsychologist Help TN Patients". His practice covers mostly brain injuries, such as MS, Parkinson's, Alzheimers, young victims of Attention Deficit Disorder, and back injuries.

He explained pain is a daily part of life in some form with no safety system and alarm system. Our sense of touch to hot objects or cold that makes one shiver disturbs our normal body temperature of 98.6. TN is telling us something is wrong in our trigeminal nerves. Our ability to tolerate pain is within each individual and suffering is not the same.

He emphasized *not* to let pain rule our lives. Do not let pain be your total focus. Don't let facial pain slow down your lifestyle and keep you from being active. Facial pain is a burden to bear but do not let it destroy your quality of life.

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

Dr. Rath told us we have so many energy chips to spend during the day and use them, do not waste them! Get counseling, take medication, learn some stress management and pain management techniques such as relaxation training to get control of your mind. Check with your physician on medications that will assist you in controlling the pain and eliminating depression. If you have a problem with sleeping, ask your physician to prescribe a light anti-depressant which would not be habit forming.

A handout was provided by Dr. Rath for the meeting attendees. It included the following three questions and answers.

*1. Why do I feel so angry and depressed about my physical situation?*

You'd be surprised by the number of factors which contribute to your behavioral response to injury, pain, and illness.

First of all, when your body is assaulted by injury or disease, your brain begins to produce different amounts of chemicals. These chemicals may act like "natural medicine," and they may work to help you get well. Unfortunately, other chemicals can sometimes make you feel depressed.

Your life experiences when you were little can also contribute to your feelings today. If you've seen lots of family members express fear about illnesses, then you might feel fear, too. Fear can make a person very angry, because it makes you think you're not in control.

*2. Does my attitude or behavior have any impact on my health?*

Your beliefs about your condition can literally mean the difference between life and death. If you develop a negative attitude about your treatment plan and fail to follow your doctor's recommendations, you can unwittingly cause your condition to deteriorate rapidly.

If you try to "bury" your feelings and act as though you have no problems, you can make poor judgments that can be extremely harmful.

If your doctor believes you may be struggling, s/he may ask for you to participate in some behavioral medicine sessions so you can begin to "help yourself".

*3. What's it like to go through a behavioral medicine evaluation?*

These evaluations usually fall into two parts:

Part I involves an interview to learn about your medical condition, how you are feeling emotionally, and also to learn about the history of illness in your family. Your doctor has probably asked you the same questions but for a different reason. Your "physician" is interested in the "physical" part of your body, and s/he wants to know what illnesses you might be prone to develop. Your "psychologist" is

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

interested in these illnesses, too, but your psychologist wants to know how you *responded* to these illnesses.

During Part I you will also participate in some personality testing specifically designed to determine how you respond to pain and stress. At the end of Part I, Dr. Rath will tell you if he thinks you can “fly solo,” or if he thinks some follow-up sessions would be helpful.

Part II is the follow-up sessions, if any. If you participate in these treatments, you can expect lots of understanding and education. Dr. Rath will teach you physical and mental relaxation techniques, perhaps some biofeedback techniques, occasionally some “self-hypnosis,” and other stress management and pain management techniques that have helped thousands of other people.

You can't always control the world around you, but *you can always control yourself!*  
Take charge today!

If you would like to make an appointment to see Dr. Rath, call 903-592-6779.

#### **Dallas Meeting – August 4, 2004:**

Davis McAlister, D.C., B.S. of McAlister Family Chiropractic presented “Cranial Adjusting and Trigeminal Neuralgia”. Dr. McAlister explained chiropractic as the science, philosophy, and art of removing SUBLUXATION, a dangerous impairment to the nervous system by misalignments of the skeletal structures of the body. The causes of subluxation are trauma, toxins, and thoughts.

Dr. McAlister explained that by adjusting the cranial bones, pressure is relieved on both the vascular system and the nervous system, including the brain. Cranial adjustments can help with the following symptoms: headaches, sinus problems, intracranial pressure, TMJ, hearing problems, visual problems, and trigeminal neuralgia.

Don Williams, a member of our support group and a patient of Dr. McAlister, gave a testimonial of how cranial adjustments have helped him with his atypical TN. He no longer has background pain that had been a 7 on a scale of 1 – 10. Also, he no longer has breakthrough pain except for when he forgets to take his TN medication.

Dr. McAlister is offering Texas Trigeminal Neuralgia Association members an initial exam for \$37 which includes initial consultation, comprehensive chiropractic examination, X-rays, Static EMG, Thermal Imaging Scan, Reports of Findings and the first Adjustment. To book an appointment, call 469-438-1369. His office is located at 363 West Main Street, Lewisville, TX 75056.

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

## FUTURE MEETING DATES

Dallas at Zale Lipshy Hospital – 10/6, 12/1  
Fort Worth at Baylor All Saints – 11/16  
Houston at Christus St. Joseph Hospital – T.B.A.  
Tyler at East Texas Medical Center – 10/12  
Waco at Hillcrest Baptist Medical Center – 11/1, 1/10

## TREASURER'S REPORT

<b>Beginning Balance 8/27/04</b>		<b>\$3499.26</b>
<b>Donations Received</b>	<b>\$549.00</b>	
Long Distance	24.61	
Postage	145.55	
Supplies	<u>87.59</u>	
<b>Total Expenses</b>	<b><u>\$257.75</u></b>	
<b>Ending Balance 10/1/04</b>		<b>\$3790.51</b>

*Note:* The Houston support group will keep their finances separate. A Houston financial update will be provided in an upcoming newsletter.

## FINANCIAL CONTRIBUTIONS

Local TNA chapters *do not receive* funding from the national office. If you would like your tax-deductible contribution to go toward your local Texas chapter, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put the name of your support group (i.e. North Central Texas chapter, Houston chapter) then mail it to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092 for processing.

Please remember to also support the efforts of the Trigeminal Neuralgia Association's national office. Typically, they are the first ones to make contact with new TN sufferers. They provide us with convention materials, run the national website, promote research, and a host of other activities.

Trigeminal Neuralgia Association  
2801 SW Archer Rd., Gainesville, FL 32608  
Phone: 352-376-9955, Fax: 352-376-8688  
[www.tna-support.org](http://www.tna-support.org)

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

**Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.**

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.