



**TRIGEMINAL NEURALGIA ASSOCIATION  
NORTH CENTRAL TEXAS SUPPORT GROUP  
May 2004**

Good news! The Southlake Newcomers Club donated \$250 from their Holiday Home Tour proceeds to our local support group. If you hear of any funds being made available to non-profit organizations, please think of TNA and let me know the specifics. I'll be happy to follow-up on the application process.

Please let me know if you attend meetings where a guest speaker can be invited to present "Trigeminal Neuralgia and Related Facial Pain". Don Williams, one of our support group members, has been successfully reaching out into our community by making 15 minute presentations.

Also, if you know of someone with TN or related facial pain that is not getting our support group newsletter, please let me know. I'll be happy to add them to our list.

Feel free to write, phone, fax, or e-mail me at: 604 Aberdeen Way, Southlake, TX 76092, phone (817) 416-7202, fax (817) 416-9871, [swilson@tna-support.org](mailto:swilson@tna-support.org).

Shelly Wilson  
Support Group Leader & National Conference Chairperson

**ANESTHESIA DOLOROSA ADVICE**

The Suburban Detroit TNA Support Group reports Actiq, a prescription medication, is providing pain-relief for their Anesthesia Dolorosa members. For Actiq information, go to [www.actiq.com/patients/aboutbtcp/default.asp](http://www.actiq.com/patients/aboutbtcp/default.asp) or consult your doctor.

**WEBSITE OF INTEREST**

[www.quackwatch.com](http://www.quackwatch.com) – Guide to Health Fraud, Quackery, & Intelligent Decisions

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## **MEDIGAP INSURANCE**

One of our support group members reported she has an automatic draft drawn against her bank account for Medigap insurance. She learned that after her birthday, on the anniversary date of her Medigap policy, the State of Texas allows the premium to be increased a small amount on each birthday thereafter as long as the policy is in force.

This was the first time she learned of this situation. She was supposed to have received notification in the mail about this but never did.

## **E-MAIL ADDRESSES**

Thanks to everyone who's provided us with their e-mail address. 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.

## **REGARDLESS OF RACE, PAIN FEELS PRETTY MUCH THE SAME**

### ***But study confirms gender differences***

A new study that measures pain sensitivities among Whites and African-Americans suggests assessment procedures may be to blame for reported racial differences in the amount of pain experienced.

Previous research and anecdotal clinical evidence have suggested that African-Americans tend to be more sensitive to pain than Whites, but the latest research study shows the two groups simply interpret standard pain rating scales differently. The new study also confirms earlier findings that women are more sensitive to pain than men.

University of Calgary psychologist Dr. Tavis Campbell led the research project while at Duke University Medical Center in Durham, North Carolina. The results are being published in the April issue of the medical journal, *The Journal of Pain*.

“Many pain medications are addictive and have unpleasant side effects, so it's important for physicians to be able to understand exactly how much pain their patients are experiencing,” Campbell says. “This research supports well-established findings of slightly higher sensitivity to pain among women compared to men, but revealed no differences between Whites and African-Americans.”

Campbell and his research colleagues tested 135 men and women aged 25-45, a group that included 72 African-Americans and 59 women. Researchers inflated a blood pressure cuff on each subject's arm and left it inflated for several minutes, creating an

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aching sensation not unlike many clinical pains. The participants were then asked to rate their pain according to standard pain rating scales, which measure both the unpleasantness and intensity of the sensation.

Pain rating scales use terms ranging from 'neutral' to 'very tolerable' for the unpleasantness of the sensation, and words ranging from 'nothing' to 'extremely intense' for its intensity. There are 11 gradations in between.

“If we used the standard pain scales, women reported more pain than men, and African-Americans reported more pain than Whites,” Campbell says. “But if we first gave them some cards with the descriptors on them and said, ‘You arrange these in any way that you want, from the least painful to the most painful,’ then women became more similar in their pain reports to men, but there was no difference between African-Americans and Whites.”

Socio-cultural variables, such as differences in vernacular, may be worth investigating further, Campbell suggests. “One possible explanation is that African-Americans and Whites just describe painful sensations differently.”

Source: American Pain Monitor, April 2004

## **UPDATES FROM OUR MEMBERS**

Joan had a successful radiofrequency rhizotomy performed by Dr. Phil Williams, Jr. at Dallas Presbyterian Hospital this month. This was done as an out-patient procedure. She went into the hospital with TN pain and left with no TN pain. Hurray!

Linda had a successful MVD in February 2004 and hasn't experienced any TN pain since. However, she has been battling a spinal fluid leak that is now under control. We wish her a speedy recovery and hope to see in her the fast lane again soon.

Please continue to keep Jill in your prayers as she continues to have a difficult time with a life-threatening, non-TN related health issue. Lee also has a non-related TN health issue and could use your prayers at this time. Joan's husband, a TN supporter, is battling cancer and could benefit from your prayers as well.

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

## **MEETING NOTES**

### **Dallas Meeting – April 7, 2004**

Our guest speaker, Cole Giller, MD, a neurosurgeon at UT Southwestern Medical Center in Dallas prepared the following information for us regarding “Treatment of Trigeminal Neuralgia with Radiosurgery”.

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At the heart of the pain of trigeminal neuralgia is an abnormality of the trigeminal nerve, the main structure serving sensation to the face. Unfortunately, this nerve is quite small and is tucked away in an inconvenient location deep within the brain, making efforts to reach the trigeminal nerve for treatment exceedingly more difficult. Fortunately, a way of delivering radiation called Radiosurgery has been developed in which small structures – like the trigeminal nerve – can be precisely targeted with focused beams of radiation to provide treatment. The good news is that this offers a way to alter the pain of trigeminal neuralgia without surgery; the bad news is that the treatment does not work quite as well as more invasive methods.

The idea of Radiosurgery is to use many weak beams of radiation, all aimed at a single spot to provide a large dose at that target. The gamma knife is a device that uses 201 such beams, aimed through holes that are precision drilled in a large metal helmet. Devices such as the CyberKnife use a large number of beams by moving an x-ray machine around the patient, emitting one beam at a time.

In either case, the idea is to focus a beam of radiation directly onto the trigeminal nerve, although there is controversy about which part of the nerve gives optimal results.

Treatment with gamma knife placement involves placement of a rigid head frame attached to the skull early in the morning, followed by an MRI scan and followed by a painless and quiet treatment lasting about one hour. Treatment with devices such as the CyberKnife involve a CT scan obtained several days before the treatment, and require a treatment time of about one to two hours. In either case, there is no hair loss or fatigue as commonly occurs with standard radiotherapy.

The list of complications that can occur with Radiosurgery include those of any surgery – death, brain damage, damage to nerves, numbness, etc. – but the risk of any of these is much lower than that of other procedures. But although Radiosurgery may be safer than surgical procedures, the results are not quite as good. Excellent results can be obtained about 50-60% of the time, and there is a recurrence rate that can be as high as 30%. It is important to know that the results of Radiosurgery are not immediate – it may take several weeks or even months to obtain pain relief, so that Radiosurgery might not be the best treatment for those in crisis. The good news is that Radiosurgery for trigeminal neuralgia can be repeated, conferring benefit to an additional 10-20% of patients.

In addition to the very small risk of catastrophe, any Radiosurgery (and any radiation treatment) carries with it a risk of future malignancy. The risk is very small, but not zero.

The advantages of Radiosurgery, however, are real. It is not a surgery, so that there is minimal danger of infection and no danger of bleeding. It can be repeated in case the first treatment does not work, and can be used when other medical conditions prevent ordinary surgery. It is often tried and often successful when other surgery for trigeminal neuralgia has failed, and can confer benefits for trigeminal neuralgia due to multiple sclerosis and facial pain due to tremors.

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Radiosurgery is therefore a good option for those that cannot have other types of surgery, and might be considered for those not wishing to undergo conventional surgery. Although the risks are small, the percentage of success is not as great as other methods, but it can be repeated as necessary. With a realistic eye open as to its advantages and disadvantages, Radiosurgery can be a viable option.

#### **Tyler Meeting – April 23, 2004**

The meeting opened with Ramona Smith informing the group that the scheduled speaker was unexpectedly called to Europe on another matter and a panel of four people who have had successful microvascular decompression (MVD) surgeries would be sharing their experiences. The panelists were Randy, Bill, Priscilla, and Linda.

Inez shared by taking Vitamin B-50, she has reduced her TN pain. She purchases 60 tablets for \$3.84 at Wal-mart. Ramona also noted that B-12 seems to help heal the myelin sheath.

Randy, 48 years old, had TN for four years before learning about Dr. Jonathan White at UT Southwestern Medical Center in Dallas through the East Texas TNA support group. Randy had a MVD in December 2003 and after surgery has had little or no pain since.

Bill had TN for eight years before having a MVD. Bill explained how through the years he had on-going pain and had gone to several dentists requesting teeth to be extracted thinking that his problem was dental. After having lost all of his lower jaw teeth on the right side and still experiencing pain, he continued to look for an answer. In January, he attended the East TX support group meeting and learned of Dr. White. He had a MVD by Dr. White on February 5, 2004. After surgery, he had headaches off and on for a few days. Since that time, he has had some numbness in his incision area and in his lower jaw but is now pain-free.

Priscilla had a MVD on May 20, 2003. She was unable to go without TN medications for three years and then it came back full force. She on the Internet and discovered Dr. Kopitnik (formerly with UT Southwestern Medical Center in Dallas) and underwent the surgery. It was successful and she is now pain-free.

Linda had a MVD in December 2003 by Dr. White. Upon waking from surgery, she was pain-free with no numbness except for the very tip of her tongue. She now feels she has regained her life after having this painful malady for four years.

#### **FUTURE MEETING DATES**

Dallas at Zale Lipshy Hospital – 6/2, 8/4, 10/6, 12/1  
Fort Worth at Baylor All Saints – 7/20, 9/21, 11/16  
Tyler at East Texas Medical Center – 7/21  
Waco at Hillcrest Hospital – 7/12, 9/14, 11/1

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## TREASURER'S REPORT

Every other year, the Trigeminal Neuralgia Association holds its National Conference. The registration cost only covers the cost of each participant's meals. It does not cover any of the additional conference expense (i.e. audio visual rental, printing of brochures, postage, handouts, Continuing Education accreditation fees).

Since our support group will greatly benefit from the information presented at this year's TNA National Conference, we have contributed \$1,000 to help cover expenses.

**Beginning Balance 4/25/04** **\$4876.66**

**Donations Received** **\$500.00**

Copies 44.56  
Long Distance 43.28  
Natl. Conference 1,000.00  
Postage 42.50  
Supplies 138.50

**Total Expenses** **\$1,268.84**

**Ending Balance 5/11/04** **\$4,107.82**

## FINANCIAL CONTRIBUTIONS

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

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.

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