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**TRIGEMINAL NEURALGIA ASSOCIATION  
NORTHEAST FLORIDA SUPPORT GROUP**

**TIC TALK**



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**APRIL 2003**



**SPRING IS HERE!** In spite of the shape the world is in right now and the pain that some of you still experience from your trigeminal neuralgia, there has to be a stirring in your soul at the renewal of the land and our spirits in the spring. As long as we are *alive*, there is always *hope* for a better and brighter future!

**APRIL 12, 2003 MEETING OF THE NORTHEAST FLORIDA TNA SUPPORT GROUP  
IN JACKSONVILLE, FLORIDA**

The meeting was great with 22 members attending. Three interesting reports were presented and informative handouts from Patty Hill, Leader, and member Rita Kelly. Of course we had some delicious refreshments and plenty of camaraderie.

It was good to see Al Hummel and John Dyer back with us, and all our "regulars" that keep our support group alive! Thank you all for coming!

**REPORT ON THE VISIT TO THE McKNIGHT BRAIN INSTITUTE IN  
GAINESVILLE, FLORIDA SPONSERED BY THE TN ASSOCIATION AND DR.  
ALBERT RHOTON, JR., M.D.**



Editor's Note: Because the reports were detailed I will only have space to give you the highlights of each of them and they will be paraphrased. If you would like to hear the full reports I do have it on a tape that you are welcome to borrow.

The first order of business was a report by member Charlie Doolittle assisted by his wife Eva on the information given them at the McKnight Brain Institute.

There were 5 main speakers. The first was *Dr. William G. Luttge, PHD*, and Director of the Brain Institute who gave a wonderful presentation. There was a task force in 1988 that recommended a formation of a brain institute at the University of Florida and 4 years later they formed an organization of 144 faculty members from 8 different colleges and 33 departments. In the year 2000 they got a large donation from the McKnight Foundation. McKnight was an officer of the 3M Company, and this grant was the last brick in the wall to build the Brain Institute at the University of Florida. It is the most comprehensive program in the world.

Dr. Luttge showed a slide entitled "How Big A Problem is Brain Disease? Following is a list of the brain diseases that it covered;

- Addiction, Alzheimer's disease, Blindness/Vision loss, Brain Injury, Deafness/Hearing loss, Depression, Developmental disorders, Epilepsy, Huntington's disease, Multiple

sclerosis, Pain, Parkinson's disease, Schizophrenia, Spinal cord injury, and Stroke ("Brain Attack")

The largest one of all is *Pain* and everyone in our support group is in that category. In the United States there are 90 million cases of pain and they estimate the cost is a 100 million dollars a year.

The Brain Institute is a large attractive building 200 thousand square feet, but it is more than that it is an affiliation with many other departments throughout the University with other task forces that work with them. Following is a partial list of the McKnight Brain Institute and the University of Florida (MBI-UF) Centers/Institutes/Programs;

- Alzheimer's Disease Research Center, Center for Alcohol Research, Center for Autism & Related Disabilities, Chemical Research at Bio/Nano Interface, Center for Mammalian Genetics, Center for Neurobiological Sciences, Center for Neurobiology of Aging, Comprehensive Center for Pain Research, and many, many others.



There are 20 MRI-UF Research and Training Core Facilities located in the building and Charlie spoke about several of these and then listed the MBI-UF High Priority Research Programmatic Growth Areas;

- Memory & Age-Associated Memory Deficits, Traumatic Spinal Cord & Brain Injury, Pain, Neuro-Degenerative Diseases – Alzheimer's & Parkinson's, Brain Attack (Stroke) & other Cerebrovascular Problems, Neuro-Rehabilitation & Plasticity, Functional Brain/Spinal Cord Imaging & Image-Guided Surgery, Neuro-Gene Identification & Delivery in Animals & Humans, Neuro-Regeneration and Repair – Adult Human Stem Cells, Bio-Medical Engineering- - Tissue Engineering, Brain-Machine Interface & Neuro-Imaging/Guidance – BioNano Sensors/Motors

Eva Doolittle spoke to us about the report given by dentist *Dr. Henry Gremillion, DDS.* who reported that the dentists concentrate on three areas (1) The Research, (2) Education, and (3) Treatment. They believe that the most important thing that has been created is the multi-disciplinary involvement that means that not every civilization is doing one thing but they constantly cooperate with each other. All this is fully computerized and first of all they create a fantastic database and all the departments that are cooperating have access to this information and they try to exchange this information and solve problems together. Their main focus is on all aspects of the nervous system. They presently combine over 300 faculties from 51 academic departments. So, within this multi-disciplinary program institute they developed multiple levels of interaction and relationships and this is one technological marvel with equipment and database that has no comparison and that is basically what Dr. Gremillion reported.

The next speaker was *Dr. Rhoton, Jr. M.D.* who had wonderful slides about the MVD operation that were in 3D and polarized glasses were passed out to view them. New techniques in not only the MVD operation but others as well were shown. He also spoke about the radiofrequency procedure and said he prefers that procedure for those over 65 and had their TN pain in the First Division.

The group then broke for lunch and enjoyed some delicious Sub Sandwiches and conversations with the other support group leaders that had attended.

Dr. Robert Yeziarski, MD was the next speaker whose topic was *Pain*. Eva reported the information he gave on this important topic. The question "How is the brain involved in pain?" The brain in itself does not give pain but only registers it from everywhere in the body. The pain travels from the peripheral nerve to the brain and this is how we know that we are hurt. A brief history of pain was given. The early humans related pain to evil, magic and demons. The Greeks and Romans were the first to advance the theory of sensation and that the brain and the nervous system had a role in producing the perception of pain. It wasn't until the Middle Ages that

evidence started to accumulate in support of this theory. Leonardo da Vinci who came to believe that the brain was the central organ responsible for the sensation it was not the source of the sensation but responsible for the sensation. He also developed the idea that the spinal cord transmits sensation to the brain. More progress was made in the 17<sup>th</sup> and 18<sup>th</sup> century and finally in the 19<sup>th</sup> century pain came into the brand new domain of science. So suddenly it was no longer in the domain of demons, but was pure science.

There are basically two types of pain, acute and chronic. Acute pain does not usually cause many problems because it can be treated and after a period of time the pain will stop. The real challenge for the scientist is chronic pain. Trigeminal neuralgia is a classic example of chronic pain. It usually persists for a longer period of time, and is resistant to most medical treatment. It has now been discovered through the newest research that there are biomarkers that allow the measure of changes in the molecular or cellular level so if you suffer pain the doctors can now establish a lot more on the molecular level. We will be hearing much more about this important discovery of biomarkers so there is *hope*.

The last speaker was *Dr. Michael E. Robinson PHD.* who gave an informative presentation that *Charlie* said he could sum up in two sentences. Let's say you go to a doctor and he prescribes a medicine. What is the probability that that medicine will help you? The answer is 30% and his point was that half of the 30% is the placebo effect, which means that in all probability only 15% of that medicine will be helping you.

One of the doctors had a little ditty for the audience that Charlie related to us. *"Doctors treat diseases they know little of, with drugs they know less of, on patients they know nothing of!"*



Charlie closed the presentation given by Charlie and Eva Doolittle with a quiz question and the prize was a gold dollar. The question was "How much does the human brain weigh?" There were many different guesses, from 30 pounds, to 8, 6, and 3 pounds. Phil DiStefano had the right answer, which was 3 pounds. Good for you Phil.

The members showed their appreciation by their applause and their personal thanks. Because most of us missed going to the Brain Institute we are grateful that we had the opportunity to learn what the five doctors who participated in the program presented. Thanks so very much Charlie and Eva for your time and effort in bringing us this information!



*Editor's Note: At this point in the meeting member Rita Kelly gave us a report on the nutritional diet called The Lemole Program for Trigeminal Neuralgia. Because space is limited in this issue of Tic Talk Rita's report will appear in the May issue. Being on this program has helped Rita keep the pain of TN controlled and she has also gained the benefit of improving her health as well.*

### **The BOOKLET "BUT YOU LOOK GOOD" HANDED OUT BY PATTY HILL, LEADER**

The booklet is a guide to understanding and encouraging people with chronic illness and pain. It was ordered through the Internet and paid for by our treasury. It was written by a lady named Sherri Connell that lives with Multiple Sclerosis and Lyme Disease and to most she does not look disabled. Even so she has been disabled for many years and now struggles just to wash her hair or go to a doctor's appointment. Therefore, she and her husband discovered the imperative need to educate others on how to be a source of support and encouragement to those with "invisible disabilities."

This book would be a good one for all those who suffer from TN to give to their families and friends. It also gives them simple pragmatic ways to truly be an encouragement, "what to say," "what not to say" and "why", along with "how to help." There may be some extra copies if you are interested in obtaining one. We can order more if enough members would be interested in having one.



**NORTHEAST FLORIDA TNA TRIGEMINAL NEURALGIA  
SUPPORT GROUP QUARTERLY FINACIAL REPORT**

DATE: March 2003

**PREVIOUS BALANCE:** \$ 966.27

**INCOME:**

**MEETINGS**

DATE: January 2003 \$ 26.00

DATE: February 2003 101.00

DATE: MARCH 2003- NO MEETING 0.00

MAIL IN DONATIONS 25.00

MISC. BOOK SALE 13.95

**TOTAL INCOME** \$ 165.95

**TOTAL FUNDS AVAILABLE** \$ 1132.22

**EXPENSES:**

NEWSLETER, STAMPS, PRINTING ETC. \$ 99.10

MISC.: BOOKLETS "BUT YOU LOOK GOOD" 68.00

CONNELL

DONATION TO TN ASSOCIATIION 100.00

**TOTAL EXPENSES** \$ 267.10

**ACCOUNT BALANCE AS OF:**

DATE: MARCH 3, 2003

AMOUNT \$ 865.12

SUBMITTED BY JOHN VIGNEAUX, TREASURER



*THANKS JOHN! YOU DO A GREAT JOB!*

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## REFRESHMENT TIME

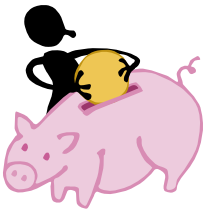


Thanks to Phyllis DiStefano for furnishing the "goodies" for this meeting! She made her delicious bowl cake of strawberries and vanilla pudding with vanilla wafers. There wasn't any left after the gang got to it. There were also cookies and soft drinks! Everyone enjoyed it and appreciate the trouble that you went to Phyllis!

## SUPPORT GROUP LEADERS OF THE TNA RECEIVED THE DAILY POINTS OF LIGHT AWARD ON MARCH 26, 2003.

This award is designed to honor individuals and organizations who have made a commitment to connect Americans through service to help meet critical needs in their communities and in the nation. President George W. Bush and former president George Bush have endorsed the revived *Daily Points of Light Award*, and their congratulatory letters along with a frameable copy of the award enclosed were sent to each support group leader to enjoy and share with others. (These will be shared with you at the next meeting.)

In your Editor's opinion I believe that this award belongs to all the members that through the 9 years that the Northeast TNA Support Group has been formed, have helped the many members that have come to us in pain, confusion, and depression. They have been there for support and understanding. A letter from Beth Heitman the Support Group Coordinator, wrote a letter explaining why this award is given and she ended it by saying, "You are, indeed the hands and feet of the association working with people in pain every day, and we commend you! (But, if there were no members there would be no need for Support Group Leaders! We work together! *We are a team!* So, many thanks to all of us.)



## TREASURY REPORT

Pinky says that once again the members were very generous in their donations to the treasury fund. He thanks you and all the members' thank you! As you can see by the quarterly report we are doing well and have found a few things to buy and are supporting the newsletter. You deserve my three Oink salute! OINK OINK OINK!

For Your Funny Bone!  
Brain cells come and brain cells go, but fat cells live forever!



**DISCLAIMER:** This newsletter is not intended to diagnose, prescribe, or to replace the services of your physician. We offer information about our member's experiences, medicines and procedures for TN. This Support Group is not advocating any particular course of action for anyone and our speaker's opinions are their own.

**TRIGEMINAL NEURALGIA ASSOCIATION  
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**THE NORTHEAST FLORIDA TNA SUPPORT GROUP  
MEETS THE FIRST SATURDAY OF EVERY MONTH FROM 2P.M.TO  
4P.M. IN THE MEMORIAL HOSPITAL, JACKSONVILLE, FLORIDA**

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**MAY 3, 2003 IS OUR NEXT MEETING DATE**

We will meet in Room 2 as Patty Hill wants to show a video that was taken at the Conference in San Diego last year. If enough new members come there will also be a Panel of members that will speak of their procedures. Please come and support your friends and learn more about this affliction!



**Northeast Florida TNA Support Group**

Ruth Eisen, Editor

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**CELEBRATE SPRING!  
IT'S GOOD TO BE ALIVE!**