
**TRIGEMINAL NEURALGIA ASSOCIATION
NORTHEAST FLORIDA SUPPORT GROUP**

TIC TALK



MARCH 2003



Hope ya had *a great* St. Pat's Day! I love this holiday cause it has all these sprightly tunes and sentimental songs for Irish tenors to sing. Everything is so green and it just puts one in a happy mood. We all need that these days. I hope you got out your fiddle and danced a jig for the occasion!

MARCH MEETING

The March meeting was not held due to the planned trip to the McKnight Brain Center in Gainesville, Fl. on March 5, 2003. A report will be given about that trip by Charlie Doolittle at our April 12, 2003 meeting which is the second Saturday in the month, not the first Saturday when we usually meet.

Unfortunately Patty Hill, Support Group Leader, and several others of our members were unable to attend as planned because of the dense fog that covered much of Jacksonville, Fl. and surrounding areas the morning of the 12th. Beth Heitman reported in an E-mail that the event was a great success and she was sorry that so many of our members had to miss it. Perhaps in the future they may plan another one. Let's hope the weather cooperates better the next time.

INFORMATION USEFUL TO TRIGEMINAL NEURALGIA PATIENTS

The following information was taken from the Internet and from several of the TNA Support Groups newsletters that your Editor receives monthly.

ALL ABOUT NEURONTIN – GABAPENTIN

Many doctors prescribe this anti-seizure medicine because it is effective for classic TN pain, the sharp lancinating pain that strikes like a burst of lightening and is triggered by even a light breeze and is usually caused by pressure on the trigeminal nerve by an artery in the brain. It is also used, and perhaps with more success for neuropathic pain that is caused by a damaged nerve.

- The cause for the damage can come from many sources. The percutaneous procedures (through the cheek), radiofrequency, glycerol, and balloon compression, performed for the classic TN all damage the trigeminal nerve using a controlled method so that the nerve can't carry the pain signal to the brain. When the nerve regenerates the pain will return. The length of time for regeneration varies from patient to patient. The procedures can be repeated but if the nerve is damaged excessively it is possible that you will incur chronic damaged nerve pain which is a constant burning, stabbing, pain often in your gums and teeth, the side of your nose and your eye. Neurontin can relieve this pain and has these good points
- Doesn't metabolize – safest drug. Doesn't bind to protein
- Simple drug compound. Doesn't build up in tissue/liver. Excreted through kidneys
- Works by going to nerve endings
- Exact mechanism of action is unknown. Max dosage is 4800mg.
(Facts from an article written by Irene Wood, President of the TNA Australia Incorporated newsletter)

NEURONTIN HELPS POST HERPETIC PAIN



An article on the Internet titled “Neurontin Significantly Reduces Chronic Neuropathic Pain “ states that post herpetic neuralgia (PHN), the chronic neuropathic pain condition that can follow shingles (herpes zoster), in a study in Canada showed a statistically significant reduction in average daily pain after treatment with Neurontin. In the majority of patients the condition is characterized by intense pain that has been described by sufferers as burning, deep aching, tearing and electric shock-like. While the pain tends to fade over a period of time as many as 15 percent suffer from chronic neuropathic pain that persists beyond the resolution of the herpes zoster rash. Pain that persists for three months after resolution of this rash is commonly defined as PHN.

In the TNA Australia Incorporated March newsletter there was a report concerning a 76-year-old woman who had been suffering for three years from post herpetic neuralgia affecting the right breast and inner part of the upper arm. Treatment with painkillers, various other medications, and acupuncture had failed to provide relief. Based on a theory that a component of peppermint oil (menthol) might diminish the body's perception of pain, her doctor instructed her to apply two or three drops of peppermint oil to the affected area three or four times per day. Each application resulted in a stinging sensation that lasted two minutes and was followed by almost complete relief of pain for approximately six hours. When the effect wore off, the pain returned to its original severity; however, the woman was able to control her pain almost completely by repeatedly applying the oil.

After four weeks of treatment, the woman began to develop redness at the site of application. The peppermint oil was therefore diluted by 80% with almond oil. Application of the diluted preparation did not cause redness, but did continue to produce “adequate,” though somewhat less pronounced, pain relief.

A single case report does not prove that peppermint oil is effective, and in the absence of a control group, a placebo effect cannot be ruled out. However, the fact that the woman had previously failed to benefit from a wide range of conventional and alternative therapies makes “placebo effect” an unlikely explanation for her improvement.

Peppermint oil does not cure post-herpetic neuralgia; rather, it appears only to control the symptoms. However, for many individuals coping with this chronic condition, symptom relief would be welcomed. It may be hoped that this case report will stimulate researchers to perform a more definitive study. Because the long-term effect of topically applied peppermint oil has not been studied, individuals wishing to try this treatment should consult a doctor. (Thanks Irene Wood for the use of your material.)

INFORMATION FROM THE WEBMD WITH AOL HEALTH FOR PATIENTS **TAKING NEURONTIN**



- Gabapentin affects chemicals and nerves in the body that are involved in the cause of seizures and some types of pain. The exact way that it works is unknown.
- Gabapentin is used with other drugs in the treatment of some types of seizures and for the management of postherpetic neuralgia (nerve pain caused by the herpes virus or shingles).
- Before taking this medication, tell your doctor if you have any other medical conditions, especially kidney, liver, or heart disease. Also discuss any medicines that you take, including over-the-counter preparations.
- Take gabapentin exactly as directed by your doctor.
- Take each dose with a full glass of water. Can be taken with or without food.
- Gabapentin is usually taken three times a day. The maximum time between doses should not exceed 12 hours. Follow your doctor's orders.
- If you miss a dose take it as soon as you remember. The maximum time between doses should not exceed 12 hours. However, if it is less than 2 hours until your next dose, take the missed dose right away, and take the next dose 1 to 2 hours later. Then go back to your regular dosing schedule. Do not take a double dose of this medication.
- Do not stop taking this medication even if you feel better. It is important to continue taking the medication to prevent seizures.
- Carry or wear a medical identification tag to let others know that you are taking this medicine in the case of an emergency.
- Use caution when driving, operating machinery, or performing other hazardous activities. Gabapentin may cause dizziness or drowsiness.
- If you experience any of the following serious side effects, stop taking gabapentin and seek medical attention or contact your doctor immediately:
 1. an allergic reaction (difficulty breathing, closing of the throat; swelling of the lips, tongue, or face; or hives).
 2. Other, less serious side effects may be more likely to occur. Continue to take gabapentin and talk to your doctor if you experience
 - Dizziness, poor coordination, or drowsiness;
 - Blurred or double vision;
 - Irregular back-and forth movements of the eyes;
 - Nausea and vomiting; or tremor.
- This medication does not interact with other commonly used antiseizure medications.
- Antacids will decrease the amount of gabapentin that is absorbed in the stomach. Do not take it for at least two hours after a dose of antacid.

MISCELLANEOUS



NEWS ABOUT THE NEXT CONFERENCES The fifth national conference will be held in Orlando, Florida November 10-14, 2004 and will be sponsored by the University of Florida and Dr. Albert Rhoton. If you have never attended a conference now is your chance to go as it is practically in our own backyard!

They are so informative with all the top doctors that are specialist in Trigeminal Neuralgia and members from all the support groups around the country. It is also a lot of fun meeting new people, staying in a beautiful hotel and maybe staying over for a few days to visit Epcot, Sea World or the Studios. Get a big piggy bank and start saving now so you will be prepared to go!

The sixth conference will be held in Portland, Oregon in 2006. Now that is a little far for us but I am sure that Charlie Doolittle will probably be driving out there as he did last year when he drove to San Diego from St. Augustine, Fl. Maybe we could hitch a ride with him. How about it Charlie?

(This information courtesy of the TNA Alaska Newsletter. Thanks Audrey Parker, Editor)

WHY MEDICAL COSTS ARE SO HIGH! This story may shed some light on that!

A woman brought a very limp parrot into a veterinary surgery. As she laid her pet on the table, the vet pulled out his stethoscope and listened to the bird's chest.

After a moment or two, the vet shook his head sadly and said, "I'm so sorry, Polly has passed away". The distressed owner wailed, "Are you sure? I mean you haven't done any testing on him or anything. He might just be in a coma or something?" The vet rolled his eyes, shrugged, turned and left the room returning a few moments later with a beautiful black Labrador.

As the bird's owner looked on in amazement, the dog stood on his hind legs, put his front paws on the examination table and sniffed the dead parrot from top to bottom. He then looked at the vet with sad eyes and shook his head...the vet patted the dog and took it out but returned a few moments later with a cat! The cat jumped up and also sniffed delicately at the ex-bird. The cat sat back, shook it's head, meowed and ran out of the room. The vet looked at the woman and said, "I'm sorry, but like I said, your parrot is most definitely 100% certifiably...dead.

He then turned to his computer terminal, hit a few keys and produced a bill that he handed to the woman. The parrot's owner, still in shock, took the bill. "\$150!" she cried. "\$150 just to tell me my bird is dead?" The vet shrugged. "If you'd taken my word for it the bill would only have been \$20, but...what with the Lab Report and the Cat Scan..."

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.

WHEN YOU GO TO THE EMERGENCY ROOM WITH EXTREME TN PAIN

(Information from the 2002 TNA national conference compiled by Evelyn Burry)

Be aware that TN is the most rare of all the neuropathic pains. Emergency room personnel are not likely to have dealt with it before.

Strategies:

- Avoid the emergency room if possible!
- Be sure you have the proper diagnosis in the first place.
- Educate yourself, be proactive, and know the facts.
- Comply with your medication regime.
- Avoid exacerbating factors – i.e.: things that set your pain off.
- Get surgical evaluation and treatment when appropriate.

If you cannot reach your own doctor, do go to the emergency room when:

- The pain is so bad you cannot eat or sleep.
- There is a sudden change in your pain pattern.
- The medications you are taking stop functioning.
- There are severe side effects from overuse of medications.
- You have been off medication and have a severe attack.
- Or if your doctor tells you to go to ER – but ask him to call the ER in advance of your arrival and meet you there.



When you get to ER:

- They will need information about you (medications, doctors' names, medical history etc.)
- They may need to perform a work-up (MRI/CT, blood work etc.)
- They may not know what TN is and how it is treated.
- There may be a delay in treatment.

ER may use:

- Opioids (Demerol, etc.) even in an IV
- Dilantin (IV), with a heart monitor, which may give a dramatic and rapid relief.
- Depacon (IV) or injections of local anesthesia.

To manage your TN treatment in ER they will:

- Communicate with your usual TN doctor:
- Review current medications (both RX and OTC)
- Pay attention to medication overuse and toxicity.
- Develop a maintenance plan for your discharge.

For better ER treatment:

- Prepare a one-page medical history to take with you to ER. (Make it to the point – the essentials about your self and insurance coverage, all current medications, that have not worked for you, TN doctor's name and phone number, etc.)
- Go to a medical records Internet site and enter your medical history. (To find one, search through Google.com for "medical records.")
- Wear an alert bracelet.
- Ask your doctor to write an RX telling about your TN and medications that may help. Carry this with you at all times.

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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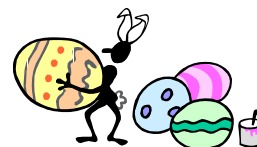
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APRIL 12, 2003 IS OUR NEXT MEETING DATE



PLEASE REMEMBER THIS IS THE 2ND SATURDAY OF APRIL!
WE USUALLY MEET THE FIRST SATURDAY! MARK YOUR CALENDAR FOR

APRIL 12, 2003. Our meeting will include a talk by Charlie Doolittle about the McKnight Brain Center tour and Rita Kelly will speak about the nutritional diet she follows that has controlled her TN pain. Other informative subjects will be discussed. Please plan to attend!



Northeast Florida TNA Support Group
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*May those who love us, love us and
those that don't love us, may God turn
their hearts, and if he doesn't turn their
hearts may he turn their ankles so we'll know
them by their limping!*