



Nerve Center

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Periodical Newsletter of the Pacific Northwest TNA Support Group
Serving the Pacific Northwest Region of Oregon, Washington and Idaho

Medications for TN & Facial Pain

The October Support Group meeting featured discussions about the medications we use for facial pain. We also discussed the controversies that have been in the headlines lately concerning medications that have been recalled, had warnings added, undergone biased studies, and some that have been improperly marketed

There are two excellent reports on antiepileptic drugs, and drug interactions with other common medications that were handed around at the meeting. Since most TN patients take some form of these medications such as Tegretol, Dilanton, or Neurontin, it was found to be very helpful for our members to view. The report can be found on the internet, and if you don't have access at home, ask a friend or your local library and they will help you to get it. <http://mcmahon.med> (follow the links to the pages on CNS Special Edition).

Another resource we have for members is a reference sheet about prescription assistance programs for those who can't afford their medications. It lists the major manufacturers and contact information along with brief details about the individual programs. These are different programs than the Medicare Discount Cards, and they can be of benefit those whose income levels are a bit higher than what many other social programs allow. Please see the P.A.P. report on page 5. (cont. p.2)

The Very Latest Word About TN

Our Support Group Facilitator, *Ruth Purchase*, and other local members who attended the 5th National TNA Conference in Orlando will be presenting the very latest of information regarding TN treatments, medications, and research at the upcoming **support group meeting on December 11th, 1:00pm**, at Legacy Meridian Hospital in Tualatin. This is the only medical convention of its kind in the US, where all of the seminars and demonstrations are centered solely on the topic of TN and related facial pain. Support Group Leaders and patients will spend several days sitting side by side with the world's best experts in facial pain. You've read the names in TNA literature and in the *Striking Back Trigeminal Neuralgia Handbook* – *Dr's. Janetta, Casey, Burchiel, Young, Tew, Appflebaum*, etc... our members will report back to you the details of their interactions with these legendary

figures in the medical world. No matter what your diagnosis, what your treatment, or how you are coping, you can't afford to miss this informative and exciting meeting. Make plans to attend now!

Disclosure of Clinical Trials and Results

There is a recent push by the **International Committee of Medical Journal Editors**, (ICMJE), for *all* clinical trials to be registered and for the results of *all* studies on pharmaceutical and medical devices to be made available and open to the public. Pharmaceutical manufacturers are also pushing for the results of the trials to be reported in detail and made publicly available. Where this will be done and who will oversee them, along with who will fund and operate the databases, and any restrictions involved still needs to be determined. It has been suggest that only www.clinicaltrials.gov, sponsored by the **U.S. National Library of Medicine** (NLM), currently meets all of these requirements, but some still disagree.

Historically, many clinical trials are never heard of, nor are the results ever published. This holds true especially for those that do not present the drugs or devices being studied in a favorable light. This means that we have been hearing the good news, but not the bad news. It is not only the manufacturers who are culpable, but medical journals also; when the editors tend to publish studies that show a large affect of a new drug or that the newer drug has a better outcome than an older one. Negative or inconclusive trials are much less likely to be selected for publication. (cont. on p.2)

Support TNA as They Support You

We have an opportunity to make our donations to TNA count even more between now and the end of 2004. By sending in a contribution before the end of December, a **benefactor to TNA will double the amount** of your gift today. (the amount that exceeds your prior gift amounts.) Make every dollar count – twice - by sending your donations to the TNA National Office without delay!

TNA has recently been approved by the U.S. Office of Personnel Management as an eligible nonprofit organization to participate in the 2004 Combined Federal

Support TNA *(from p.1)*

Campaign (CFC), a program which assists federal employees to make charitable contributions to the organizations they choose to support. TNA is listed as a National/International Unaffiliated Organization and our number is CFC#2908 in the official CFC materials. If you want to designate TNA as a recipient of your 2004 pledge through a one time donation or convenient payroll deduction, you must identify your choice by using this number. Federal employees can refer to your local CFC brochure for more information about how to contribute to TNA through payroll deduction, or can access the Campaign through the internet at: www.opm.gov/cfc. The Campaign season usually takes place every fall in the federal workplace, during the months of October and November, but donations can be made anytime.

Please note that our local Pacific NW TNA Support Group does not receive funds through the National TNA Organization. They do so very much for all of us, through promoting education, research, medical conferences, and keeping the national office ready to handle your inquiries. We rely on our local members' donations to the support group, which are used to provide for our mailings and meetings.



Disclosure *(from p.1)*

The perception about a medication can easily be skewed if the trials that end up with negative results are kept secret, leaving the impression that a drug is effective. The facts could be that it failed as many trials as it passed, and the truth is that the drug does not work. Likewise, the lack of an across-the-board trial registry leaves the impression that many new medications have not been tried, and the researchers aren't aware of the studies that were done before them. This obviously can waste tons of resources like laboratory time, brain power and finances repeating those already tried and/or failed studies, but far worse are the years of delays for effective treatments for patients.

Physicians, clinicians, and researchers financial relationships with the pharmaceutical industry are also controversial because such relationships may pose a conflict of interest. It is unknown to what extent industry support of medical education and research influences their opinions and behavior. At the **University of Toronto in Ontario, Canada**, this issue was studied by searching medical literature published on the safety of a certain class of drugs. The results showed that 96 percent of authors who supported the use of those drugs were significantly more likely to have financial relationships

with the manufacturers. This is compared to the 60% of neutral authors, and 37% of critical authors. Supportive authors were also more likely than neutral or critical authors to have financial relationships with any pharmaceutical manufacturer, irrespective of the product (100%, vs. 67% and 43%, respectively). Complete disclosure of the relationships between authors and manufacturers needs to be included in every study.

On another note, there have been reports in the media lately about the marketing of drugs for off-label uses. (Off-label use indicates that the FDA has not approved the drug for the particular ailment it is being prescribed for, but it has been approved for use and marketing for a different, specific ailment.) It should be noted that medications are regularly prescribed for off-label uses to treat many conditions, but marketing for such is strictly prohibited. Controversially, if TN patients or those with other rare illnesses had to wait for disease specific drug trials, patients would see few, if any, "approved" drugs for their conditions. According to **Joanna M. Zakrzewska, MD**, TNA Medical Advisory Board Member, "*Only 12 controlled trials on the effect of certain medications on trigeminal neuralgia have been conducted.*" (as of 2003). Patients have the right to information about the benefits and expected and side effects of prescribed drugs, along with the results of relevant studies. They should talk with their doctors and pharmacists for information.

Quick, favorable results and rapid entry into the market seem to be a major driving force for pharmaceutical companies. This should not be surprising given that for each day's delay in gaining approval for marketing, the manufacturer may lose, on an average, \$1.3 million in revenue. While most new medications are not harmful and many are lifesavers, patients and doctors still need to weigh the benefits of newer drugs over the older, more proven medications. We will need to take many medications throughout our lives, and we should not be afraid to take them, but do so with the utmost information and diligence possible. When in doubt about any of your medications – check them out.



Medications for TN *(from p.1)*

Patients should get the manufacturer's package inserts on all of their drugs. You can have the pharmacist enlarge and copy them for you, or go to one of the websites where you can look up the complete drug information, such as www.rxlist.com. Although the information sheets have all manner of side effects listed be aware that the majority of patients experience very few of them. You should, however, keep notes of any that you might have and bring

them to the attention of your doctor. The simpler patient information sheets given with your prescriptions will inform you of any allergic reactions or side effects that are serious enough to report immediately.

Here is a brief description of the many medications used for TN and related facial pain. The drugs described in this section are divided into six groups, and they may be prescribed to use in combination with each other. It is not a complete list, so be sure to discuss your options with your doctor and do not make any changes without your doctor's approval.

Anticonvulsants

Anticonvulsants are usually the most effective drugs for treating classical TN pain. Unfortunately, these drugs tend to have serious side effects, including effects on the blood levels and liver enzymes. Other side effects to note are; cognitive difficulties, vision problems, lethargy & dizziness. The most usual anticonvulsant used for TN still appears to be carbamazepine. The other anticonvulsants appear to be mainly in experimental use for neuropathic pain, but are widely prescribed. The differences between them are small, and the choice of one over another is somewhat arbitrary. They appear to be most often used when the side effects of carbamazepine are found to be too disagreeable. Many are used in combination with other drugs

Carbamazepine (Tegretol, Eptol).

Clonazepam (Klonopin, Rivatril)

Gabapentin (Neurontin).

Lamotrigin (Lamictal).

Oxcarbazepine (Trileptal)

Phenytoin (Dilantin)

Levetiracetam (Keppra)

Topiramate (Topamax)

Antidepressants

Antidepressants tend to be particularly effective for atypical forms of TN. Especially good results are obtained when antidepressants are used together with anticonvulsants. Tricyclic antidepressants are most commonly used. Most often noted side effects may include weight gain, dry mouth, sunlight sensitivity, and lethargy.

Amitriptyline (Elavil)

Protriptyline (Vivactil)

Nortriptyline (Pamelor)

Fluoxetine (Prozac, Seronil, Fontex,...).

Trazodone (Desyrel)

Anti-spasticity drugs

Anti-spasticity drugs are somewhat related to anticonvulsants, but act on the muscles rather than the nerves themselves. They can be effective in the early stages of TN and are often used in conjunction with other drugs, especially tegretol. They help reduce the spasms that TN often causes. In particular, atypical TN sufferers may benefit from these drugs.

Baclofen (Lioresal)

Painkillers

The most hellish thing about TN is that few ordinary painkillers are effective for the shock-like pain. Even moderately strong opiates often do not help typical TN, let alone over-the-counter NSAIDS (nonsteroidal anti-inflammatory drugs such as aspirin). There are reports of pain relief for Atypical TN, Trigeminal Neuropathy, and Anesthesia Dolorosa symptoms such as burning, aching, and stabbing with the use of sustained release and transdermal Opiates. These are usually used in conjunction with other medications for treating TN. NSAIDS and other pain relievers can help with inflammation that can accompany trigeminal nerve pain.

NSAIDS (Aspirin, Naproxin, Tylenol, Ibuprofin)

Opioids (Morphine, OxyContin, Methadone, Fentanyl)

Other analgesics (Ultram, Benzodiazepines)

Topical Medications

These medications can influence the painful symptoms of TN and related disorders, but have no official reports of long lasting results for the typical trigeminal neuralgia shock-like pains. Most of them help with atypical pain, and although initial relief lasts only a short while, there are reported cases of some having continued relief with repeated applications. Some of these drugs can be detrimental to those with heart conditions or high blood pressure due to the "caine" derivative in the ingredients. These are usually used in addition to regular medications.

Capsacin (Hot pepper cream) Used to "burn" the nerve endings, causing the pain to be replaced with light numbness. Often mixed with other agents to lighten the initial burning sensations.

Lidocaine Available in a patch or gel. Can be used inside the nose, mouth, or on the face. Temporarily relieves some symptoms, causing transitory numbness. There are reports of intra-nasal lidocaine being used over several weeks and then having lasting pain relief for many months post-treatment.

Benzocaine Commonly found in "OralGel" and other oral numbing agents. Can be used inside the mouth and nose for temporary relief of minor pain.

Proparacaine A liquid formula used to numb the eye; it follows the tear ducts into the sinus and tear glands. Some reports of ongoing relief after continual usage, but mostly for Atypical Pain.

Compounded Formulas These are combinations of topical medications that are mixed with other medications in a compounding pharmacy and then applied to the face. Individual formulas are usually designed by the doctor and with the patient in mind. They may include anti-convulsants, anti-depressants, opiates or other medications. They work initially at the source of pain, with on-going systemic effects in many cases.

Experimental Medications

There are some drugs that could have conceivable effects on TN, but no official link has yet been established. It is important to note that *most of the drugs in this category have not been medically tested for TN.*

Cafergot A migraine medication. Use for TN is anecdotal.

Mexiletine Ordinarily used for heart rhythm problems. Also in experimental use for neuropathic pain. Use for TN pain has been suggested.

Misoprostol (Cytotec) This anti-ulcer drug shows promise for patients whose TN is the result of multiple sclerosis.

Pimozide (Orap) Used primarily for chronic schizophrenia and Tourette's Syndrome. Use for TN has also been suggested.

Sumatriptan Used for migraines and cluster headaches.

Valproic acid A new epilepsy and migraine drug. Use for TN is experimental.



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2005 Pacific NW TNA Meeting Schedule

**February 12th - April 9th - June 18th
August 27th - October 22nd - December 10th**

*All meetings are held on Saturdays at 1:00 - 3:30
in the Community Health Education Center at
Legacy Meridian Park Hospital - Tualatin, OR.*



Cut out on the dotted lines and attach to your calendar.



Treasury Report

We are searching for a member to take over the banking tasks and treasury reports. Until then, the treasury report will be published twice annually. If any members have questions regarding the current finances of the group, they are encouraged to contact us for an updated accounting.

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 are tax-deductible, and those earmarked for our Pacific NW group will be passed on to us.



**"Self pity is our worst enemy and
if we yield to it, we can never do
anything wise in the world."**

- Helen Keller



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 or healthcare provider over the others. Please discuss any information in these pages with your own physician.

Patient Assistance Programs for Prescriptions

One of the challenges many patients' face is the expensive medications they need and often can't afford. Here are some programs that have been designed to help those who have financial difficulties obtaining their prescription medications. A few programs also help those patients with higher incomes based on their overall medical costs, diagnosis, or other factors.

The main types of assistance programs available are **Prescription Discount Card Programs, (PDC)**, and **Patient Assistance Prescription Programs, (PAP)**. All of the program benefits are determined by the manufacturers and are made readily available to the public through industry groups, consumer advocacy groups, or information resource services that access several programs at once. One way to find them is to ask the pharmacist for the manufacturer's name of each medication along with the patient assistance phone number, and then call and ask for an application. (Be certain to ask the pharmacist about generic equivalents to the medications also.) Most manufacturers' PAP or PDC websites will have applications available to download online or the phone numbers to call for them by mail. If the patient is without access to the Internet, they can go to the library and ask for help finding the websites. Many public and private Social Service Agencies give free help to the disabled or elderly finding programs and filling out applications. There are also fee-based services that help patients find suitable programs and assist them with the application process.

Prescription Discount Card Programs (PDC) - For patients that do not have prescription coverage and receive Medicare. (Some of these programs may be different as of Jan. 06 due to the new Medicare discount drug cards.) These card programs offer discounts up to 40% or more, or they may have small a co-pay charge.

Glaxo-SmithKline Orange Card: 1-888-672-6436
(also participates in together Rx);

Eli Lilly - Lilly Answers Card: 1-877-795-4559
www.lillyanswers.com;

Novartis Care Card: 1-866-974-2273
www.NovartisCarePlan.com;

Pfizer For Living Share Card: 1-800-717-6005
www.pfizerforliving.com;

Together RX Card: 1-800-865-7211 www.together-rx.com (Includes: Abbott Laboratories, AstraZeneca, Aventis Pharmaceuticals, Bristol-Myers Squibb Co., Johnson & Johnson, & Novartis)

Patient Assistance Prescription Programs (PAP) -

Manufacturer's programs that provide medications at low or no cost to qualified applicants without prescription

insurance coverage. Most need the doctor's involvement &/or signature. Patient's income is usually limited, with verification required. Most manufacturers have individual programs also, which are too numerous to list. Contact your doctor or pharmacist for drugs that are not included here.

www.BenefitsCheckUpRx.com -Free web-based service with 260 PAP's for 1,450 drugs. Provides a confidential report of qualifying programs for each patient. From The National Council on the Aging.

www.NeedyMeds.com -Free web-based information source for 859 drugs and 180 PAP's. With links to mfg. sites and program applications.

www.RxAssist.org -Free web-based PAP information source from Volunteers in Healthcare Organization. With additional support for medical & service providers.

www.HelpingPatients.org - Web-based information source for hundreds of drugs and links to 48 PAP's. From the Pharmaceutical Research and Manufacturers of America (PhRMA)

www.medicare.gov/Prescription/Home.asp -Free web-based information source from Medicare. With links to PAP and PDC program websites and information on government programs. If no Internet access, patients can contact their local Medicare office for help.

www.themedicineprogram.com ph. 1-573-996-7300 - The Medicine Program has a fee of \$5.00 per medication for a service that will find the mfg. PAP's suited to the patient. Includes personalized letter to doctor, the patient fills out some paperwork.

www.getfreemed.com ph. 1-770-643-5347 -The Free Med Connection charges a fee of \$5.00 per medication for service that will find the mfg. PAP's suited to the client. Packet of materials sent includes letter for doctor, patient provides some paperwork. Website also has legal Canadian Pharmacy discounts & shipping for a fee.

www.institutedc.org ph. 1-202-318-0770 -The Institute sells a 48 page booklet for \$5.00, listing 1200 drugs and most PAP's contact information. A good resource for service agencies and patients without Internet access.

Please Note: This list not have all of the prescription discount services available for all medications. Patients are urged to continue looking for help if they do not find it here. Patients are responsible for making sure that any information shown here is updated, as the programs do change regularly.