



Trigeminal Neuralgia Association of Canada

Fall 2007 Newsletter



Support Group



Eastern Ontario Support Group

Due to difficulty getting people together the Eastern Ontario group did not meet in the fall. But that doesn't mean we don't care about each other or hope to get together. We may end up meeting only once or twice a year but still ... we WILL meet! If you would be interested to meet with us please let me know!

For more information contact Jane at president@tnac.org or by calling 613.936.6977

Vancouver and Lower Mainland Support Group Update

Coordinator: Ann Hopkins

I am always available for phone and email support so please don't hesitate to get in touch with me if you need someone to talk to or are feeling isolated. Bruce Smillie is also a contact person (Ann Hopkins: annhopkins@shaw.ca, 604 732 1673; Bruce Smillie 604 594 4231.)

Lethbridge Support Group

Coordinator Marion Guzik

The Lethbridge Support Group meets every second Saturday of the month at the Lethbridge Senior Centre, 1100 – 11th St. South, Lethbridge, AB at 2:00 p.m.

A cordial invitation is extended for anyone who happens to visit Lethbridge to call me at 403-327-7668 , email- mguzik@telus.net, or better still, come out to our meeting. We would love to have you.

Ask Dr. Kaufmann

Dr. Kaufmann is the medical advisor of TNAC. If you have questions about TN and/or TN interventions send them to "Ask Dr. Kaufmann"



What did you say?? Part TWO

I looked forward to reporting that I was successful in being fitted with and using a hearing aid but ...

When we last met I had just sent the hearing aid back to be remade. The remake sure looked different then the first one! AND I was actually able to wear it. I couldn't put it really deep in my ear and sometimes I really wasn't convinced it was helping but at least I could get it in and leave it there. I carried a HA case with me all the time though, so if I had to take it out I could. Some days the TN just makes me very sensitive.

Well late in October I went back to the audiologist for some adjustments. Every time the HVAC kicked on in my office it was all I could hear. I was taking the HA out to hear people talk over the roar! I hoped she could adjust the frequency levels and even it out some. The audiologist checked my HA and said 'this is not what I want for you' and next thing I knew she was doing yet another new mold! This one HURT! She

put the mold stuff in really deep. I was very glad to have it out.

Late this week I picked up HA number three. I think this one is better then the last one. I can put it a bit deeper, it is comfortable, and it seems to be working but ...

I have an appointment with the audiologist next week to see how it fits in her (expert) opinion. I'll know more then.

So one more thing I learned ... always go back to the audiologist and have them check how the HA fits – where it sits in your ear etc. I thought I was doing OK but in truth I wasn't. The aid needed to sit deeper in my ear for me to really benefit from it. She had them make the little part that sticks down your canal longer so that I don't have to push the top part deeper (that triggers the TN)

Hard to believe it is taking me a year to get a HA. Just today I spoke with someone whose mother just got her HA. She hates it. She puts it in and takes it out. They try to get her to wear it but she says it's not comfortable. I told her to tell her mom to take it back and COMPLAIN! They can and will do something about it. Yet most people just put them in the drawer and give up.

I have been fortunate to have an audiologist who is sympathetic to the TN and working with me to find a HA that I can wear and use. It has not been easy but hopefully by next newsletter all will be resolved. In the meantime if you find yourself visiting a hearing clinic or audiologist I hope my 'Great Hearing Aid Adventure' will have been of some assistance in your own Adventures!



Medic Alert?

Should a person with TN wear a medic alert bracelet? Well ... it depends.

TN in and of itself does not require a medic alert. However, the medications you are taking may cause interactions with other medications and that may be a reason you want to wear a medic alert bracelet. Or you may have another condition that does require the use of a medic alert.

BUT ...

A formal medic alert bracelet including their registry is not inexpensive, especially for the nicer or gold bracelets. The least expensive (sports edition) are \$80 for the first year. The nicer gold ones start at \$169 (this includes the jewelry and one year's membership).

The alternatives?

Well you can buy a medic alert with one condition on it (e.g. diabetes) or you can buy one from a jewelry store and have them engrave something on it (e.g. penicillin allergy). You can also buy one from a jewelry store and have them engrave 'see card' on it. Then you carry a card with you at ALL times with your full medical information.

The last method is what I have done. I am allergic to stainless and nickel so require the most expensive of the medic alerts. I refuse to pay \$300 – 400 for something that will inevitably break in 2 or 3 years and have the engraving rub off. Like all jewelry, if you wear it every day, it will wear out and have to be fixed. And the engraving will fade and have to be redone.

Another option ... subscribe via the least expensive method, get your number, then buy a bracelet you do like and have that number engraved on it.

You will still have to do deal with breakage and wearing out but ... that is what I was going to do but ...

I recently discovered an other option. Road ID is a medic ID system similar to Medic Alert. It is used by athletes, mainly cyclists and runner. The premise is you wear one when you are out for a run or a long bike ride. Then if something happens you have ID on you. They come in various styles, all VERY casual and sports. The most dressy is a 'dog tag' styles (like vintage war dog tags).

Road ID is not for everyone but for \$19.99 you can purchase one including one year of interactive web information. The renewal cost is \$9.99 per year. If you purchase the interactive style you can list multiple conditions, medications (including dosage), doctors, and contact. The 1 – 800 for information does work in Canada.

I purchased the shoe version. This is a small Velcro strip that attaches to the laces of your shoe. I wear it on my running shoes (which I almost always wear). I did get an ankle bracelet as well without the ID tag (you can interchange the ID tag to other styles). If I am going out without my runners or shoes that lace up I put the ID on the ankle bracelet and either wear it (it is hidden under pants) or carry it in my purse (since in an emergency they will often check out your purse for information).

As I said Road ID is not for everyone but it is an alternative for those who would like the support of a medic alert type system but just can't afford the cost! You can find out more about Road ID at www.roadid.com



TNAC Bank Account

Wonder what happened to your check? As we mentioned last time we are changing over our banking to a new branch and treasurer. We have discovered that the process of setting up a charitable organizations banking is NOT an easy or a fast one. At present it looks like we are in the final stages and things should be up and running soon. In the mean time we thank you for your continued patience. Thanks also to Joya, Anne, and Marion for dealing with the hassles of the changeover!



TNAC Membership

Did you know that TNAC's membership year is July 1 – June 30th each year? Did you know that our next membership year started on July 1?

Thank you to everyone who has renewed their membership for the July 1, 2007- June 30, 2008 membership year. If you have not renewed your membership and would like to renew please go to www.tnac.org and click on 'join tnac' to get a copy of the membership application.

Thank You



Individual and Telephone Support

In our membership application we ask people to sign to indicate permission to use their name as a telephone support person. In the next several weeks I will be compiling this list and setting up the support area of the web site. Names will not be listed online in order to preserve privacy. Instead there will be a list of areas where people live. People looking for support will be able to contact TNAC directly and then be linked with the person closest to them.

If you would be willing to talk with someone about TN please indicate so on your membership renewal form. If you are open to talking with someone about a specific topic or topics only, then just write that down and we will make note of it (for instance, MVD, or a different procedure). If you prefer to communicate only by email or regular mail, let us know that too.

We hope this will help to address the challenge of confronting TN alone as well as the challenge of not being able to access a support group.

Of course, never forget, the TNAC board is always open, available, and willing to talk with you so please do not hesitate to be in touch with us!



Neuragen

Neuragen is a blend of essential plant oils designed for effective and immediate relief from the pain associated with diabetic neuropathy, shingles, fibromyalgia, spinal compression disorders and other chronic neuropathic pain. They define neuropathic pain as "usually characterized by burning sensations or shooting pain, it may also occur as numbness or itches. Often the area affected highly sensitive to touch." They list "trigeminal / myofacial pain" as one of the clinical uses of neuragen.

I recently received the following email about neuragen from Stella MacDonald who battles TN ...

Neuragen has been wonderful and ok. In the beginning it was wonderful. I would apply it to my cheeks, and I could actually enjoy the wind, the day, outside without head gear. I already take 4 trileptal 1200mg/day, 200mg clomipramine/day. I apply Neuragen about 4 to 5 times per day. I do it automatically now. I carry a bottle in my purse, in my car, have a bottle by my bed and in my bathroom. It has a powerful smell and either people like it or they don't. It now cause a tingle feeling, and I have to wear head gear all the time when I am outside. It still works, I think but not like it used to. You can order 20 ml for \$60.00 from Shoppers Drug mart, much cheaper than 5ml for \$15.00. I wouldn't be without it. You know how it goes with this pain. Some days are worse than others, some days we get a reprieve. I only use my Capsacian(?) cream when I

really need to, so the Neuragen has helped with that. Before I used Capsacian(?) cream 3 to 4 times per day. I would take Neurage over Capsacian(?) any day. Would I advise trying Neuragen? You bet. I like the smell and it has no side-effects, and it does help.

I hope this has been helpful. Feel free to quote me. If you asked me about Neuragen 6 months ago, I would tell you to buy stock in the company because it was a miracle. Now it just part of what I do in the day to help ease the pain.

I have also been trying Neuragen for Anesthesia Dolorosa pain residual to my Balloon Rhizotomy three years ago. I agree with Stella, the smell is strong! It is made from the essential oil of the gladiola combined with lavender and eucalyptus. Because it is an essential oil it does not usually cause allergic reactions such as other perfumes but it does take getting use to.

On a good day the Neuragen is wonderful all but taming the AD symptoms. On a bad day, if I use with Zostrix (capsaicin) it helps to dull the roar of the discomfort. It is easy to use, easy to carry around (like Stella I carry a bottle in my purse to have on hand) and since it helps, worth the smell (which I have gotten use to and no one else has commented on – and it helps clear you sinuses too!).

Is neuragen the wonder drug we all look for? No, I don't think so. But if you struggle with burning, tingling, numbness etc. it might be worth a try!

For more info or to order check out their web site www.neuragen.com

Thanks to Stella MacDonald for sharing her story!

If you have a story to share about your battle with TN please contact Jane at

613.936.6977 or president@tnac.org We would love to hear from you!



Contacting TNAC

Want to know how to reach us? We can be reached by using the following email addresses:

For information on membership or general information:

president@tnac.org
613.936.6977
TNAC, 1602 Walton Street
Cornwall, ON, K6H 1W2

For information on support groups:

support@tnac.org

For information on advocacy:

advocacy@tnac.org

To reach our past president

treasurer@tnac.org

To talk with someone about TN you can contact any or all of us. We are here to help!

If you have suggestions for future newsletters or would like to volunteer with the board, please let me know. Also, if you do not have internet access but would like to connect with a TNAC board member, just contact me.

Jane McLaren
TNAC President



Please note that I (Jane) will be away from December 15 – January 10th. I will have a 'house sitter' so if you call or mail messages will reach me when I return. If you need support fast please contact one of the other board members listed above.

Wishing everyone the best of holiday seasons and a New Year that begins, continues, and ends PAIN FREE!!!!