

CANADA TN ASSOCIATION NEWS

April /May 2009

Canada TNA

Canada TNA (CaTNA) is a network of support groups and individuals who are dedicated towards sharing information and support to people who have Trigeminal Neuralgia and other facial pain. Membership in CaTNA is \$10 per year. Newsletters are available free by e-mail, and for \$6 per year by Canada Post. Contact: Canada TNA, c/o Jan Williams; 15 Everstone Dr. SW, Suite 207; Calgary,

AB, T2Y 5B5. Email: calgary@catna.ca; Phone: Phone: (403) 295-0987. Canada TNA is associated with the TNA Association in the USA.

The information in this newsletter is not intended to diagnose or offer advice on treatment of TN. Its sole purpose is to provide information so that you, working with your doctor, can make informed decisions about your own care.

As I look out at all the fresh snow in Calgary it is hard to believe it is almost April. I hope everyone is feeling well and I really hope we can all enjoy a beautiful spring very soon.

The Saskatoon group is planning a seminar by Dr Anthony Kaufmann sometime this spring. When we have the date we'll share that information. Everyone is invited to attend.

As always we are looking to start support groups across Canada. These groups can be small and informal. If you would like to host some fellow TNers in your town or city, please contact me.

Jan

Notes from the TNA Conference

The following notes were written by Ashley, a 23 year old College student from Boston. Ashley has been diagnosed with TN 3 years ago and is still in pain after an MVD. She has given us permission to share her notes. This is a continuation of the notes from the last newsletter

Gamma Knife:

1. A few years ago there was a lot of excitement over this procedure as being the least invasive of the available TN surgeries, but follow-up results have not been nearly so optimistic. Pain relief drops off significantly years after having the procedure (although some people continue to have excellent results). They are also currently investigating a link with cancer.

2. It is more risky than many doctors make it out to be! There are two prevalent misconceptions: First, that there is no down-side to starting with GK, as the least invasive procedure, and then moving on to the higher risk procedures if GK fails, because, as mentioned above, waiting longer for an MVD may decrease your chances of complete pain-relief. Second, many people believe that if GK doesn't work, you haven't lost anything, when in reality, having any prior Palliative Destructive Procedure (this includes balloon compression, glycerol injections, etc.) lowers the chance of complete pain relief from an MVD, and may increase your chances of having future pain that is more difficult to treat. This is because any procedure that gives pain relief by damaging the nerve has the potential of causing more pain in the future simply because the nerve is damaged.

The doctor giving the GK presentation, who makes his living with GK, concluded that depending on patient age, health, and risk/benefit tolerance, the MVD should be considered BEFORE Gamme Knife.

*** Important for younger patients: I talked privately with the leading Gamma Knife doctor and he said that while he has great faith in this technology and has experienced a lot of success, he would NEVER perform this procedure on someone my age. In fact, every doctor I spoke to advised me to go for a second MVD (I had one that helped a little but the pain has come back), because it is not a good idea to do anything that would damage the nerve in

someone so young (this includes the other palliative destructive procedures), because even if they helped for a little while, the pain would most likely recur, and once you've damaged the nerve it's much harder to treat. Also, research is rapidly progressing. If we can hang in there, there might be better options available in the future that would not damage the nerve.

3. As with the MVD, it is vitally important to go to a very experienced doctor who has performed hundreds of this procedure because the lesion needs to be placed in the exact right place (particularly in regard to the next point -->).

4. Anesthesia Dolorosa is a rare complication, but it does happen, and must be considered. Several people at the Conference stood up to tell how they had Gamma Knife and got AD as a result, and it was absolutely heartbreaking. AD is constant pain (several people described it as much worse than TN... they said they actually MISSED having TN, if you can imagine that!) and cannot be helped by medication or any further procedures. Pretty much the only option is Motor Cortex Stimulation (and happily, several of these people have found relief that way).

NUCCA (National Upper Cervical Chiropractic Association):

1. An amazing presentation was given on people who have been entirely cured by having a specific procedure done by an Upper Cervical Chiropractor. I don't remember if the procedure had a special name, but it's a simple, non-invasive, gentle-touch method to realign the Atlas. Several audience members stood up to tell how they had tried everything to no avail, then tried NUCCA and have been pain-free since. I wouldn't have believed it had I not witnessed their stories. The theory is that properly aligning the spine can correct blood vessel inflammation in the head and/or reduce blood pressure, or relieve a vessel that has been stretched and thereby falls on the nerve. It's definitely worth a shot, since there are no complications. Visit nucca.org or atlasorthogonality.com.

2. Try to find an Upper Cervical Chiropractor who has had experience with TN, and MAKE SURE that they take before and after MRI's to see the placement of your Atlas. This is very important.

Other:

1. Be careful with medication! The anti-seizure meds in particular can cause significant damage to your internal organs. This is especially important for younger people -- you don't want to be on these medications all your life if you can avoid it. One woman stood up to tell us about her friend who was supposed to attend the Conference, but nearly died and had to be hospitalized for liver failure due to the anticonvulsants just before her flight.

2. Note of interest: A few people noted that TN runs in their families. They are trying to do more research on a genetic link, and if 1000 participants with TN and a family history can be found (and if funding can be obtained), they might be able to determine what gene causes it (if there is one).

3. If your Insurance won't let you see a more experienced neurosurgeon, you should compile information that shows how important experience is with TN doctors, and give statistics regarding the doctor you wish to see, because who you see really does make all the difference. I believe that the Trigeminal Neuralgia Association is willing to help you do this (endthepain.org).

News from the TNA

Recently the TNA (now called the Facial Pain Association) announced a new Director and CEO – Susan Cupp. Since Canada TNA came into existence the TNA has provided us with excellent support and advice and we hope to maintain the same positive relationship with the TNA as we have in the past. Their conferences are great and anyone who can is encouraged to attend one.

A TN Story from BC

Around the age of 17 or so, I started to have seizures. Then one day I had a grand Mal, at home and a CAT scan revealed a tumor in my front right temporal lobe.

They figured that the tumor was a slow growing type called ganglioglioma. It typically starts in infancy and is accompanied by a cyst.

The tumor had fused on the 5th cranial nerve (the Trigeminal Nerve) and although the tumor was successfully removed there was damage done to that nerve.

Initially the surgeon thought the numbness I had on my face would return as the nerve healed over the next 18 to 24 months.

Instead of feelings coming back what started slowly growing and growing in intensity, has been pain. At first it didn't feel too bad as I was on Tegretol as a prevention of seizures. After 7 or 8 months of no sign of seizures, I was advised that I could start weaning off of the Tegretol. As I dosed down, the pain dosed up.

So for the past 4 years I have been dealing with this constant burning pain combined with numbness. I had been treated with Tegretol but really didn't like the effects as it slows me down more than I prefer. I have 2 young children, own and operate my own business and like to play a competitive level of squash and too much Tegretol robs me of enjoying these aspects of my life. So I tried a battery of other drugs all without success and some with some frightening side effects like thoughts of committing suicide. I chose to stop playing guinea pig and have returned to Tegretol and have been making the best I can of things.

I met with a local neurosurgeon, but he wasn't prepared to do anything and referred me to a fellow in Vancouver which the referral got lost and my meeting wasn't set for almost a year after meeting this local guy.

So I decided to go to the TNA conference in Dearborn last Sept in the hopes of finding a surgical solution to my dilemma quicker in the US. I was prepared to just have the nerve cut and that would be the end of it. It was there that I discovered that that would be the worst thing I could do. That essentially what I had as a result of my original tumor surgery and damage to the trigeminal nerve was Anesthesia Delarosa (AD) and any more trauma to the nerve would make it worse. I'd never heard of AD until this conference. I missed the section on this in the Striking Back book I'd purchased off the Internet. The combination of constant deep burning pain accompanied by numbness. Bingo, finally after 4 years I had the right diagnosis and I found it myself.

I also found out about the motor cortex stimulator option and the name Dr. Chris Honey

in Vancouver was mentioned as someone I should see.

So I met Dr. Honey and he feels the Motor Cortex Stimulator is a good option for me. I am now waiting for the surgery date. I will keep you posted.

From Jan – we all wish you good luck and look forward to hearing the rest of your story.

Calgary Group Members News

The most exciting news from Calgary comes from Christa and Bev – both have had successful MVDs – Christa by Dr Kiss in Calgary in July and Bev by Dr. Kaufmann in Winnipeg in January. Both are pain free and drug free.

A TN Story from Saskatchewan

My name is Jenine Norman. I moved to Canada from California in 2003. I now reside with my husband on a ranch near Avonlea, Saskatchewan.

For many years I had suffered from severe facial pain but was repeatedly misdiagnosed by physicians and dentists. Finally, I was diagnosed with TN by my family doctor. She referred me to a local neurologist in Regina who confirmed the diagnosis.

I then began several years of experimenting with different medications, only to find they would eventually no longer work or had too many unpleasant side effects. My doctor and I began searching for alternative ways of dealing with the TN. She referred me to Dr. Anthony Kauffman in Winnipeg, Manitoba. I was, shortly thereafter, also fortunate enough to meet Dr. Kauffman in Regina while he was conducting a TN seminar. I then met with him in his office in Winnipeg this past December. He approved me for MVD (Micro Vascular Decompression) surgery the 7th of January.

I flew to Winnipeg on the 5th of December and had surgery on the 7th. Dr. Kauffman informed me that he had found not one, but two blood vessels pressing and pinching on either side of one of the nerves. Following my surgery, I had some minor complications with the initial healing process. The lining of the brain was leaking at the

incision point and, after an unsuccessful spinal tap which was intended to reduce the pressure at the incision site to allow healing, a second surgery was required to seal the leak. This second surgery was successful, with almost immediate results, and I was able to go home right away after being in the hospital about a week longer than expected.

I was overwhelmed by the kindness and attentiveness of Dr. Kauffman and his staff and all the nurses and other doctors in the hospital who helped me with my recovery.

Since coming home from the hospital I have been pain free and am now completely off all medications. I am very thankful for all the little things I am once again able to do, like brushing my teeth and washing my face or even enjoying the smallest breeze blowing across my cheek. I no longer feel that extreme, burning, shocking pain.

I am so grateful to Dr. Kauffman and all his wonderful staff. They have given my life back and I thank them for that with all my heart.

Support Group News

Calgary

New dates: Meetings are the 20th day of each month (if the room is available) at 1:30 pm in the Heritage Meadows Superstore. Contact Jan at 295-0987 or calgary@catna.ca for more information.

Calgary Meetings scheduled for 2009:

Monday, April 20

Thursday, May 21 **

Saturday, June 20

** note date change

Regina

The next scheduled meeting will be Saturday, April 18 at 9:30 am – Wascana Center. There will be a guest speaker at the next meeting: a Pharmacist will talk about drugs used in TN. Contact Faye at (306) 751-0761 or regina@catna.ca for more information.

Saskatoon

Meetings are held the second Sunday of each month. Contact Dee at (306) 382-5666 or Saskatoon@catna.ca for meeting information.

Toronto

Meetings are the last Sunday of the month at 9:30 a.m. in the THORNHILL COMMUNITY CENTRE, 7755 Bayview Ave. Thornhill.

Apr 26/09	May 31/09	June 28/09
July 26/09	Aug 30/09	Sept 27/09
Oct 25/09	Nov 29/09	

The Toronto Chapter has decided to do the MS walk on **Sunday April 19/09** at Sunnybrook Park 1132 Leslike St. if anyone is interested in joining us, contact Sandra or kathy. It's great exercise. We challenge other support groups in Ontario and the rest of Canada to join us on the MS walk in their area.

Niagara Region

Contact Brenda at (905) 937-6178 or Niagara@catna.ca for location and/or directions.

Peterborough

Contact Marilyn at (705) 742-1486 or peterborough@catna.ca for meeting information.

Winnipeg

Contact Marion at (204) 697-9459 or Pat at (204) 269-2003 by phone or email at Winnipeg@catna.ca for meeting information.

Don't forget – we would love to hear from you and to include your story in the next newsletter.

If your group is doing something special, please let us know so we can include the information in this newsletter.

You can post your story and comments directly on the forum – go to www.catna.ca/talk. It would be great to have more discussion on that message board.