



TRIGEMINAL NEURALGIA ASSOCIATION OF CANADA

Spring 2011 Newsletter

Support Group



Eastern Ontario Support Group

Four years ago three of us met in the corner of a large room in Ottawa. One was on the way to a funeral. Another was about to try to run a 5K race. None of us knew each other. Now, four years later, 8 – 14 of us gather in a variety of places to share a bond of joy, laughter, love and encouragement that has grown through TN.

TN is for most an awful thing. But through the support of friends in local support groups it can become the source of something good. The Eastern Ontario Support Group has grown into a group of friends who are always open to greeting and receiving others.

If you live in Eastern Ontario, from Kingston to the Quebec border and north to Ottawa, we would love to meet with you. We are always open to and welcome new people to our group.

For more information and the time place of our next meeting please contact Jane at cmusicstudio@cogeco.ca or by calling 613.936.6977

If you would be interested in starting up a support group in your area please let us know. Even 2 or 3 people can be the humble beginnings of a wonderful group!

Vancouver and Lower Mainland Support Group Update

Coordinator: Ann Hopkins

Meeting Time: 1.00 – 3.30 pm

G.F. Strong Rehab Centre.

Social Sciences Seminar Room 189,
Main Floor, 4255 Laurel St.
(Laurel at W. 26th, one block east of Oak)

Friends, family members and supporters are very welcome.

It's a longish walk to the meeting room so if you need a wheelchair give me a call and I'll organize one. Or if you want to have a chat or have questions please make sure you call or email me. To get in touch: contact Ann Hopkins, email: annhopkins@dccnet.com, phone: 1 604 741 0662
4945 Laurel Ave, Sechelt, BC V0N 3A2

Lethbridge Support Group

The Lethbridge Support Group meets every second Saturday of the month at 2:00 p.m. in Rm A, Lethbridge Senior Centre, 500 - 11th Street, S.,

Lethbridge, AB. Coordinator: Marion Guzik, past president / founder TNAC email mguzik@telus.net Phone: 403-327-7668

At our May 14th meeting, we had as our guest speakers Bill Alderman from Niagara-On-The-Lake, Ont . , who has TN and MS, Ann Schneider , an MS Ambassador / CCSVI Support Group Leader, and Sheila Shenton, an MS person, spoke on the Liberation Therapy Procedure for MS patients which is still locked away in Canada.

Dr. Paolo Zamboni looked for ways to heal his wife, and so in essence this is a scientific breakthrough inspired by Love. Dr. Zamboni found the veins that flush blood from the brain were narrowed or blocked in MS patients. He and his team began experimental treatments and their preliminary results were encouraging. It is stated the delaying of treatment means MS patients will only get worse.

All of the above persons have had this procedure done and I couldn't help think what a joy it would be if this could also become a positive procedure for TN. They were all so happy and this was THEIR choice of treatment and would do it all over again if necessary.

I asked Bill if he would write his experience on the Liberation Therapy Procedure and I am thrilled that he did .Bill's story will be shared in the summer edition of the TNAC newsletter.

Wishing you all a pain free summer,

Marion



Message from the Editor

This Month we take a journey through the eyes of four people who have had the 'MVD.' The MVD, or micro vascular decompression, is a neurosurgical craniotomy where the surgeon looks for an artery or a vein pressing on the trigeminal nerve. It is inpatient surgery and quite a decision for those of us who have battled with whether or not to have the operation. This edition of the newsletter focuses on the MVD. Though not every person with TN will have or even should have an MVD, we hope the stories and information shared will be informative and helpful to you.



The journey we take through Trigeminal Neuralgia (TN) is not always pleasant or without its bumps and bruises. Often people are told there is nothing more that can be done for them. Often we simply want to give up trying. Below I share with you the story of one individual with TN who refused to give up. With the support of her husband and the members of the Eastern Ontario Support Group, she continued to look for answers. And she found help.

Here is her story, shared with permission and told through an email exchange between the two of us. Some of the names have been shortened to initials for the sake of privacy. The Marion referred to in this story is Marion Guzik, the founder of TNAC, who connected

Cathy and I together resulting in her link to the support group.

Cathy's TN Journey:

The last 4 months TN has come back with a vengeance, and with all the other problems makes for not a nice camper. A few procedures I didn't know about till I was sent this info by Marion, like the gamma knife and the rhizotomy injection. What I have had done was Doctor B went in behind my ear and cut the nerves putting a block in, which lasted for about 4 years. After four years the TN started to re-root itself through the eye and the second surgery was done. There were complications from the second surgery and as a result I don't have sight in the right eye, by which the Doctor was amazed I don't have any feeling in the eye at all.

Hi Jane, nice to hear from you, as I thought I was getting better at this laptop, as I just finished saying am getting better with it, and no longer thought it and lost my letter, so here I go again. Dr B, says, 'no more can be done I don't want to see you again.' Well, this Dr A (neurologist) who I just recently saw is looking after me for TN and lower back and spine, so he is sending me back to see Dr B (neurosurgeon), that should be interesting, LOL, as its been 2 month wait but expect many more months to wait, Are you still taking gabapentin? I am only on 3 - 3 times a day at 300 mg, and on melson, and a sleeping pill, so sorry am repeating myself now that I see the other letter, so will leave it there before I screw something up. Thank you for the info about Winnipeg. Now I have to get some homework done or attempt it as the last few days I can hardly hold my head up,

its so frustrating, so take care friend and talk soon.

As for me just getting out of bed this past while is a job an a half, the pain that I have been having for the last few days is beyond all pain that I thought I could handle. I use to hold so tight onto my husbands arms that he would have bruises. This pain last night ... my thoughts were not great. As I type this I am crying as the pain, is so steady and extremely sharp. It would be nice just to have a break, I am even using ice packs to try and freeze it. I am having a day surgery done Monday morning where this Doc is going to put lidocaine through an IV. It has been a help to some and not to others, so I said 'what have I got to loose', and I see Doctor B on the 16 of June so am not sure what is going to happen there. My husband asked what did Doctor B do to you? I probably have to go back to your emails, as my memory is terrible If I mention Doctor K (a different neurosurgeon), he will probably go through the roof. I am not crazy about Doctor B and seeing him again. I am actually scared, but I guess I have to start somewhere again. Maybe the short time I have this IV thing done there will be a change and if there is maybe I will cancel B. Oh by the way, am not sure if age was mentioned, but I am 58. Well I better go as this pain is making me not think so great, and probably rambling on, so hope this email makes sense, bye for now, take care. Cathy

Hi Jane, I am so confused at his point, all I know is what Doctor B wrote down on his paper --- 92 craniotomy with sponge, 96 balloon and repeat craniotomy with cutting nerve # 1 & 2(not #3) / Bugs

=anesthesia dolorosa. My pain is extreme and comes through the right eye and upper cheek area, but mostly through the eye and is almost constant now. I don't want to eat a lot of the time or even smile. I will let out a scream, at times. The eye runs and its this eye that Doctor B thought feeling would be there when he did the kleenex test to the eye. Every medication tried has basically not worked, unless a bigger amount of something, like morphine or gabapentin, but then I am a walking zombie, and can still feel the pain just masked by the medication.

During the email conversations I had shared with Cathy that I had had a balloon rhizotomy with Dr B as well. Like Cathy I did not have good results and my TN was extremely bad. I also had anastehsia dolorosa. I shared with her my follow up experiences with Dr. K (Dr. Kaufmann, the TNAC medical advisor based out of Winnipeg, MB) and encouraged her to initiate contact with him through his nurse practitioner. Cathy also connected with our Eastern Ontario support group. My second surgery, an MVD in Winnipeg, with Dr K, had very positive results. I referred Cathy to Dr Kaufmann's web site for information and also to the Striking Back and Insights books published by the TNA in the United States. At a support group meeting Cathy shared with us that Dr K had accepted her as a patient and she was waiting for her call to head west. Then one day I got the following email. And this is where Cathy's story takes a twist I don't think even she imagined was possible ...

I am in Winnipeg since Saturday and was to have surgery on Tues, but cancelled till thurs, and then cancelled to fri, so

right now its a go for now very early first one in the morning, so cross your fingers. (and then I waited to hear!)

Yes it was very long from Tues to Friday and frustrating, even Friday morning I was cancelled as I sat in my bed getting ready to go to the OR, One thing which made it good was looking at Dr K was very easy, as my daughter went with me the first visit, and said just think when you get put out maybe you will see Doc McDreamy, well it was actually the sat night I was sleeping when he came in about 7pm and touched my shoulder and I woke up and went OH its you, I must have been dreaming about him LOL. (for those of us who know Dr Kaufmann ... well you understand!) So surgery was Friday and was letting me out Saturday but after my shower and walking and reading a bit, I had this turn where my temp went crazy and sick and dizzy, so it was said I wouldn't be leaving till Sunday. Sunday we went to the Lennox lodge (a hostel on the hospital campus) and I just slept and most of Monday too. We left Monday at 7pm and arrived back in Ottawa around 2 am, but right now I feel great.

Received a few days later

I am doing great , as with the damage I had from Doctor B, Dr. Kaufmann said probably only 50% he could help, but it was better than no help. But there are things I cannot explain, like my right eye is usually half closed, as it takes a lot of effort to keep it open somewhat, and now its completely open, I can see colors , some tv and for 3 years nothing but a smoke like film. And this bug feeling I have had on my face ... it is very little now and at times none, WHAT IS GOING

ON??? I really am not crazy! The severe pain? ... I haven't had it since the operation, and the other pain (nerve pain) which Dr Kaufmann said he couldn't help whatsoever, because of all the cutting B did, even that pain is less. I haven't phoned the office yet as I wonder what all is happening with me. To me its like a miracle, and maybe I just might wake up some morning, and it was all a dream, but touch wood, I haven't felt so wonderful in a few years. I wish I would have known you a few years back, and Dr. Kaufmann, but like Dr Kaufmann said to my husband, things would have been different, but we can't go back, only deal with the future, and hope this operation will relieve the severe pain. So again thanks from the bottom of my heart for all your help, and getting me out to see this wonderful Doctor. Bye for now friend Cathy

Hi Jane, glad to hear from you and I just finished talking to Dr Kaufmann's secretary, as I told her of all the changes, that I cannot explain, and that I wasn't crazy, and was actually afraid of calling in case the changes to me got worse or something, but so far, miracles do exist. Being told going in to surgery that I may be able to have a 50/ 50 chance, well, as far as I am concerned its 100% worth of every penny spent going to Winnipeg, and only wish I knew of his name 3 years ago, to see out of my right eye (not 100% but can make out what I am watching). Also the bug feeling on the face, is gone, unless I happen to lie on that right side and its like if your leg went numb for minutes, so change sides and am fine. NO NO NO TN pain since operation!!! All that I get at times is a little heavy feeling in the right eye and I think its when I am tired, as now. My

husband said 'wow!, your eye is wide open now, and before it would be almost closed!' Sorry for rambling on, I am so happy I cant stop talking about it. Doctor K made sure every thing possible was done with tests and all before surgery, even when a few days before surgery I was short of breath going for a walk, and we got lost in Winnipeg, he made me go through so many other test before the surgery. The last thing I want to say is WOW he is so easy on the eyes, no wonder my eye opened up! Take care my friend and hope to see you all soon. Cathy

I know every individual's TN story is not the same but I wanted to share Cathy's as hers is one that went from extreme to the other. It went from hopeless to hope filled because of her willingness to connect with other individuals battling TN, to listen to their stories, to draw courage from their journeys, and to continue with the battle. Thank you Cathy for wanting to share your story with those that remain in the battle trenches of TN. Though the MVD is not the answer for everyone those of us who battle TN believe for the day that there will be an answer and a healing for every individual who faces the TN battle!



My MVD February 21 2011 Anne's Story

I had type 2 Atypical Trigeminal Neuralgia. It was triggered in December 1997 and it took 2 years for a diagnosis of Neuralgia I then had a remission of 6 years when it came back again for 2 years. I had another remission that lasted 3 years this is when i found out i had Trigeminal Neuralgia, not from doctors but from my own research.

On February 8th 2011 I was fortunate to be referred to Dr Dhany Charest in Moncton New Brunswick and was informed I could be helped with an MicroVascular Decompression surgery which is said not to work on Atypical but I had to try it even if it didn't fix anything ... it was my last resort.

I woke up in recovery on February 21 feeling groggy but coherent and was asked by the nurses "what do you feel" and I immediately realized I had no TN pain I cannot explain in words the relief I felt I burst into tears and replied "nothing"

I had always had an underlying ache in the right side of my face and my skin felt thicker and very fibrous on that side ...all this was gone!

I was wheeled out of recovery and into NICU (neurological intensive care unit). I saw my husband and my parents in the hall as i passed them and don't remember much else except for being outfitted with special socks that massage your legs all night to prevent blood clots. I was also given Dilaudid by injection. At 11 pm I was moved into the ward with 3 other older ladies.

The next morning I woke up and was helped to wash and had catheter removed. I had a couple of glasses of milk and soon vomited. My loved ones visited me in the afternoon and I was in so much pain from having many large neck muscles cut (a necessary procedure) I couldn't talk loud enough for people to hear me well and then had to repeat myself which also hurt so I got angry and upset and started crying which made others cry which just made me feel worse. Eventually the nurses asked everyone to leave and gave me a large dose injection of Dilaudid again and I got relief enough to sleep for an hour or so then

expected my sister but was unaware the nurses sent her away from me being in so much pain.

Wednesday morning I vomited again so I got a Popsicle and turned away breakfast but only had one Dilaudid pill then only 2 Tylenol at 10 am I had dinner and supper and kept both down I had 2 visitors in the morning and 2 at night. Boys from physio got me walking and using stairs and a nurse changed my bandage. I had a bath after visiting was over and spent the rest of the evening walking around the hospital I did not sleep well and very homesick and had no meds since 10 am.

Thursday morning I was up, washed and dressed, had breakfast and was looking forward to seeing Dr. Charest I saw him around 9am he asked how I felt and I quickly said "good enough to go home" !? I told him my progress so far and that I had a little dog at home i missed terribly. He told me the incision looked good and that it was an artery that was laying on my trigeminal nerve and that is where the teflon pad was put. Aftercare instructions were to get the staples (16) out one week after surgery, don't lift anything over 5 lbs, bending will not hurt me but will be uncomfortable, no driving ... and to come back and see him in two months. I was released from the hospital on February 24.

Thursday night at home I was having some "breakthrough pain" but was hoping it was just that also what I think is where the plate now lies feels cooler. Homecoming was very emotional and was good to sleep in my own bed but the nightmares were terrible I think every fear i had about leaving home came true in that night of dreams when i could wake up "safe" in my own bed.

I was only in the hospital for 4 days and 3 nights but having been woken up every 2 hours for this long I woke up at 2 and or 4 and or 6 every night for over a month once i got home. I got some pain if I was up and about for too long. My arm where the heart monitor was was extremely painful for almost 2 weeks. I was able to take off the bandage 5 days after surgery and carefully wash my hair with an antiseptic soap (Dettol) warm water felt really good. I got the staples out and was scared to sleep because of being scared of the incision opening with nothing holding it closed. I was told to put cream Polysporin on the incision but i found this felt like you were rubbing your brain. I had several days of difficulty with my husband in not communicating on both our parts. I found it very hard to allow someone else to take on all my responsibilities no matter how short of time.

I had days I felt like I could do more and then days I felt like I did too much and would feel queasy. Today I am 2 months out of surgery, I have been back to work part time for almost a month I have anxiety but am dealing with it. I am doing full house work now (some tasks I have adapted) I feel sad for my friends who still suffer. I am extremely happy and nervous for my new life since i got TN when I was 22 I didn't really have time to find out who I am but am looking forward to meeting me :) (((HUGS))) to all.



Leslee's MVD
(a letter to Ann, our support group coordinator)

Hi Ann

I just arrived home (N Vancouver) last Friday night after a very

successful MVD microsurgery with Dr. Kaufmann last Monday. The surgery was originally scheduled for Friday, but got bumped to Monday due to an emergency (not unexpected). I scurried around and changed my return flights, but was very grateful to still be on the schedule and not hear the dreaded CANCELED word! :-)

I must say that ALL the HSC staff and everyone I encountered in Manitoba were amazing. Everyone was so kind and helpful. Surgery was 3.5 hours, 4 hours in ICU, then 2 nights in the Step-Down Unit (Neurology Constant-Care Unit). At 3am the 2nd night, I was wakened and told that since I was most stable in the ward, I would be moved to a regular room since another bed was needed in the ward.

The surgery went great. Dr. Kaufmann found a "large tortuous vein" (his words) lying against the Trigeminal nerve that he was able to decompress and pad. He believes that was the source of my TN pain and, if so, should resolve the pain. By 11am, the 2nd day after the surgery, I was released from hospital, spent 2 more nights at the Lennox Bell Lodge (great hostel-like out-patient lodging attached to the hospital, allowing underground tunnel access to all hospital buildings), then flew home Friday.

Big question! How is the TN pain?? I was thrilled that there was NO TN PAIN directly after surgery -- maybe because of the anesthesia...

Anyway, Dr. Kaufmann warned me that it is very normal for the pain to come back and it did -- for a few days.

But I am thrilled to say that for the past two day I have had taken NO Tegretol and had NO TN PAIN!!!

Yea!!! I'll give it another week before I definitively declare the surgery a success, but at this point it looks very good.

Thanks again for all your stories and support. I felt very loved and supported throughout the whole process.



Cordelea's Story

I initially learned of TN when, as a small girl growing up in MB, there lived a woman near our home who frequently displayed facial twitching which caused her body to writhe in response to the pain it caused her. My mother, who was a nurse, in answer to my enquiries, told me the lady suffered from "tic douloureux" also known as trigeminal neuralgia where the trigeminal nerve was affected and for which there was no cure. Years later, in the 1950's, when I was studying at the Winnipeg General Hospital School of Nursing to become a nurse myself, I was dismayed to learn that TN warranted no more than a sentence or two in any of the texts I examined. No cure—no treatment—no help.

My own journey with TN began in the autumn of 2004 when my husband, Win, and I were heading east to Ontario as part of a longer holiday we'd planned in the eastern United States. We were on the plane and just about to descend into Toronto when I felt a severe attack of toothache in my left eye tooth. Although I hadn't felt it before, I immediately suspected an abscessed tooth. In a trip to a dental clinic it was discovered that I did, indeed, have an abscessed tooth but, as the clinic was about to close for the day, I could not be treated until the next day. The

following morning while waiting for my appt. with the dentist, I began feeling occasional stabbing pains running up one side of my face. Thinking it was due to the abscessed tooth, I was relieved to have it attended to soon afterwards, all the while feeling it would cure the problem.

That was my personal painful introduction to TN. The tooth had been looked after, but over the next several months the stabbing pain would recur at non-regular intervals. Because my mother had died some years earlier due to a brain tumour, my doctor recommended an MRI of the head. Subsequently, this was done in June of 2005, but the neurologist I was referred to said he could detect no sign of a tumour or of what might be considered trigeminal neuralgia. Being reminded of the woman from my childhood, I became thoroughly suspicious of it being TN, whatever the MRI showed. My GP offered me prescription meds to help with the pain but, because of side-effects, I was resistant to taking meds of any kind. I told him that somehow I would try to 'beat' this condition and live normally without them. He replied that if I ever felt the need for the medications, to come back and he would prescribe them.

By this time, the pains were striking very frequently (up to 100+ times per day). I did notice, however, that though painful in the extreme, each 'stab' was very short-lived, and I found if I remained calm when one hit, it would pass without notice and without alarming those around me. I had become very proficient at fooling myself and others. Each time I would go into remission, I was sure I had, in fact, 'beaten it'. When the TN recurred, I would go back into my state of accepting it with as much

equilibrium as I could muster, although I said to my husband on more than one occasion that I was very thankful the stabbing was so short-lived because I was sure I could not withstand it if it were any longer.

And so life continued on for about three years. We lived full and busy lives, including the planning and building of a new home. However, as the saying goes, all good things come to an end sooner or later, and one April day in 2008 while standing alone in my new kitchen I had the first of one of the worst experiences that is indelibly inscribed in my mind: the pain struck again but this time it did not stop for what seemed a very long time. I doubled over and had to hang onto the counter for fear of falling. I was incapable of calling out for help. Finally, when I returned to a form of normalcy, I staggered into the room where Win was sitting to try to describe what had just occurred. I knew this as-yet-undiagnosed condition now had moved into a very serious realm, but strangely, I could not step outside of wanting to deny it. I thought if the pain would just occur when I was in my own home, no one would ever know of it, and I would be able to live with it by sheer denial and determination. However, I did stop driving any motor vehicle, and slowed down some of my activities. In spite of my best intentions, one day the world caved in when I suffered another severe attack while I was shopping for groceries. No one was in the aisle, no one saw me, but I knew I had to get back to the doctor and get a definite diagnosis and start looking at what relief I could be offered. By now, long years of frequent and on-going pain had exacted its toll and I had little fight left in me. When the pain struck, it was excruciating in the

extreme; I wondered how one could continue to live with this sort of outlook. My former doctor had retired and his replacement wanted me to try drugs first (before ordering another MRI) knowing that if the meds worked, the diagnosis would be sealed. Indeed, I had great relief from the pain from the first day I took the meds. However, the side-effects were worse than anything I had imagined and I was struck with each and every one described in the medication profiles. I became incapable of walking alone; I could not cook or entertain and certainly could not drive a car; I experienced profound exhaustion, headaches, memory loss, severe nausea with subsequent loss of appetite and weight, and hand tremours. The best I could hope for was to lie around on the couch watching occasional TV. In the meantime, luckily for me, the drugs worked and I was pain free, thus now making me reluctant to stop taking them despite the horrible side-effects.

Fortunately, my family pulled me through all this. Their support was non-ending and they were relentless in their search and asking for help. The people who helped me are too numerous to mention, but much of it began with Win learning of the TN Support Group in Vancouver through their website which he immediately contacted. Soon after, Ann Hopkins called me and introduced me to further support from Marion Guzik in Lethbridge, AB, and Joya Dickson in Vanc. What we learned through them and with help in following up, was of immense value in every way. The recurrent theme in their speaking to me was to get an MRI as soon as possible and have a diagnosis verified. Finally, with persistence, I was granted a requisition for an MRI but the waiting list was so long that after several

weeks of not hearing anything, my son purchased an MRI for me in late October at a private Vancouver facility. As soon as that was done and the result was available clearly showing TN, things began to move quickly in my favour.

I was referred to see a neurologist, Dr. Pathak, in Victoria who referred me to Dr Honey in Vancouver (where I was told the waiting list just to see him was going to be 3 years). Win then contacted Dr. Casey in Detroit, Michigan, who kindly answered our e-mail enquiries with a personal call and, having seen the MRI results, said he would be willing to do an MVD for me the following week, if I would be willing to go to Detroit to have it done. I was certainly willing but the cost by entering the USA medical system without private insurance was going to be exorbitant. Marion Guzik then strongly recommended I contact Dr. Kaufmann's office in Winnipeg which my husband did and having sent them a copy of my MRI, again we received a quick response from Dr. K's right hand nurse, Janice. She was wonderfully informative and shared her knowledge with us. She told us Dr. Kaufmann had examined the MRI, and considered me a good candidate for an MVD. She and Win and Dr. Kaufmann's office receptionist, Andrea, began setting the stage for our input in getting to Winnipeg. for MVD surgery.

To make a long story short, in late February of 2009 I had my surgery in Winnipeg (at the same hospital, now called the Health Sciences Centre, where I had trained as a nurse 50 years earlier). I would like to say I was treated with the utmost care and consideration that any patient could hope for in any setting. I returned to Victoria a week later, still having headaches that were

quite severe, but resting and gaining strength now I could do so without the medication side-effects to sidetrack me. Friends and family were generous to a fault. Flowers and cards and calls of well-wishing poured in and our freezer was filled to overflowing with gifts of delicious, nutritious, food. Approximately six weeks later, the headaches finally subsided, leaving me in such a state of euphoria, it is difficult to describe. I could think straight, walk straight (and by myself) and generally live life as I had remembered it before. In short, having been on a terrible journey with TN, I had had my life returned to me. I was able to sing and dance and laugh again, full of exuberance about this lovely world we live in. The sun seemed to shine all the time, and life was there for me to live to the full. I loved it and could not state it often enough for anyone who wished to hear it. I was one of the truly lucky ones!

And then, in December of that same year, 2009, I had my first recurrence of facial pain. Win and I were returning from a flight where we had attended a wedding in the States when I suddenly felt that awful pain along with the terror it had struck in me in the past. It was the same kind of stabbing, quick pain which I had denied years earlier, and because it was so fleeting, I was actually of the belief that it might only be a passing thing. However, over the next few months, it recurred infrequently, but persistently, so we contacted and spoke with Dr. Kaufmann's office again. He recommended we see a neurologist and go back on the medication, if necessary, with no further surgery being required at this time. Again, I waited to see the neurologist, but an appt. was not available until August 10, 2010.

Meanwhile, a friend stated she knew someone who had had neurofeedback treatments for what she thought were the exact symptoms I described, and further, she stated, he said he had found relief from all his TN symptoms. She was also able to give me the name of the person who had administered the neurofeedback treatments to him. By this time, feeling distraught at the thought of suffering a further future of ongoing pain or medication side-effects, I began enquiries into what neurofeedback might be. I found it supposedly created good results for persons with ADD, ADHD, sleep disturbances, post-traumatic stress disorder, anxiety, mild depression, and other conditions, although I found nothing about it helping TN. Still, with little more to go on than the anecdotal evidence of a person I never met, I decided that it seemed benign enough to warrant trying it out. I sought out the person who had administered neurofeedback treatments to him in Victoria. I learned the cost of each treatment, and how often it should be administered (it varies from person to person and depends upon the condition being treated). In my case, each treatment was to be approx. ½ hour long. I also learned that if it is appropriate for a certain condition, it is suggested that the results can be permanent. I began my first session on May 26, 2010, and continued on through 38 sessions, ending on December 1, 2010. It, indeed, did prove to be a benign, non-invasive procedure. I would begin each ½ hour session by having three electrodes attached to my head. Then I sat quietly in a comfortable chair looking at a television screen which displayed moving patterns to watch, with music playing in the background. All the while, the practitioner sat

monitoring my brain waves on a separate TV out of sight from me on another side of the room. The only instruction he gave me at our first session was to "pay attention to what you see." I usually took along something to drink such as water or herbal tea, but it wasn't required. At the end of the session, once disconnected from the electrodes, I would leave the office feeling neither tired nor anything other than normal and carry on with the rest of my day as planned. At first, I did not notice any change in the TN pain pattern, but after six weeks or so, I noticed I no longer felt any pain. Later, there were a couple of times in early autumn when a slight twinge came to my face, but it was fleeting and only appeared about once or twice. I now write this on May 10, 2011, and am happy to state that to date I have had no further pain from TN.

Did neurofeedback 'work' for me? I am not aware of any evidence to back up my claims, so I can only state what happened to me. Maybe I am in a long-term remission. Or perhaps it is the MVD which is successfully preventing my cranial artery from striking at my trigeminal nerve thus causing it to settle down after all. Because of having had the MVD first, it is difficult to say unequivocally whether neurofeedback would have worked for me. I may never know the answer to these questions. One thing I can state without question is that in my experience with neurofeedback did not cause me any discomfort, and that I have been pain free for many months. However, both the time and the cost is not insignificant. To date, at least in BC, it is not covered by medical insurance.

The exhaustion and fear generated by having Trigeminal Neuralgia

cannot be over-stated. It's a terrible condition from which to suffer! I will never forget the perilous journey it took me on and, just as strongly, I will never forget all those that helped me through it. I still respect all the little things I learned not to do to aggravate the TN, like covering up my face when I shower, or keeping out of sudden gusts of wind as much as possible, or not chewing on hard objects (I still eat almonds that are cut up), and so on. Never will I forget the horror and debilitation it causes. I write this with tears in my eyes thinking of all those who are still suffering and am in eternal gratefulness to all those who reach out to help. It's a long and rocky road but we have come very far from where we were in those days when I first learned about tic douloureux. Maybe, just maybe, one day soon we'll have even more answers and my mother's friend from so long ago will be able to rest in peace at last.



Contacting TNAC

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

Deadlines for next newsletter submissions :

August 30th

Jane (president)

613.936.6977

cmusicstudio@cogeco.ca



Annual General Meeting

The Annual General Meeting for TNAC will be held on Thursday June

15th at 7PM EST. The meeting is held by teleconference in order to allow all TNAC members who wish to attend to participate. To attend the meeting please contact Jane for the teleconference phone number and access code (613.936.6977 or president@tnac.org) The agenda will be forwarded to all registered participants shortly before the meeting.



Joining the Board

Would you be interested in being a member of the TNAC Board of Directors? Membership is open to any TNAC member. Time required is minimal. Work includes phone call and email support to those with TN, helping to find articles for the newsletter, board meetings (done by teleconference), and other duties. If you would be interested or would like more information please contact any current board member!

Remember, TNAC is a volunteer organization and we require new members coming alongside to help us keep this organization moving ahead! We greatly appreciate any support and assistance you can offer!



Renewal Time!

TNAC membership is July 1 – June 30 yearly. This year our membership chair will be sending out a reminder to renew your membership. Look for it arriving soon in your mailbox!

Thanks everyone!

