



Trigeminal Neuralgia Association of Canada

June 2014 Newsletter

Support Group



Eastern Ontario Support Group

Our group consists of people from Kingston through to Cornwall and north to the hills of Gatineau! We are a group of people who enjoy coming together to encourage and support each other along the journey of TN. We share news on where we are at in our TN journeys and what paths we have travelled. Most of all we are always open and looking to welcome new members to our group.

Our group is open to individuals with TN as well as their friends and family. Our next meeting will be for a summer bbq.

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

Vancouver and Lower Mainland Support Group

The Vancouver and Lower Mainland support group met in May at the G.F. Strong Rehab Centre. It was a good group, about 15 of us all of whom had lots of news. One of our members has had a successful rhizotomy and we had some new members with questions and found ourselves still busy exchanging stories, experiences and opinions as the meeting came to a close. The next meeting is planned for October. I am planning to invite a pharmacist, but if you have any suggestions or requests for speakers please let me know. Wishing you all freedom from pain. Ann Hopkins.
annhopkins@dccnet.com

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

London Support Group

Are you in the London, ON area?
We have a new support group serving Western Ontario.

Contact Name: Elizabeth Galbraith
Tel: 519.471.3439
energyworksunnaturally@bell.net
www.tnsupportlondon.ca



NEW!!!!!!

Toronto Support Group

New! We have new members in the Toronto area and are in the process of contacting people to see if there's enough interest and there are enough people to start a support group as one of our new members has come forward to be a Support Group Leader. If you're interested in joining a Toronto support group please get in touch with Ann Hopkins at email: annhopkins@dccnet.com or call 604 741 0662.



NEW!!!!!!

Edmonton Support Group

TNAC's Edmonton, AB support group held their first meeting in April. It was a small group that gathered for the first meeting but the group has now started and for those who came

just knowing they are not alone is enough to bring this group together and help it to grow. If you are in the Edmonton area and would like to connect with others living with TN please contact Kim Krause
donkim.krause@gmail.com



TREASURERS REPORT JOYA DICKSON

July is membership renewal time for TNAC, Kindly forward all membership renewals and donations directly to Susan Forster for processing receipts. Susan Forster at 104-1322 Martin Street, White Rock BC V4B 3W5

This doesn't mean I don't want to hear from members who write such wonderful notes to me every year to keep me up to date on their progress with TN and details or their wonderful gardens & what has happened over the past year in their area. Keep those cards and letters coming please; your words make me very happy.

Susan Forster has been a great help to the Treasurer since she signed on to help our team last year. Susan loves the involvement and we are thankful she has decided to continue to forge ahead and continue to carry the load so that Joya can sit back a little and smell the roses.

Enjoy the Summer



MEMBERSHIP RENEWAL

Dear Member of the
Trigeminal Neuralgia
Association of Canada.

We'd like to thank you for your support in joining TNAC and are asking you to renew your membership for 2014 - 2015. Our membership year is July 1 – June 30th. The TNAC relies on your membership in order to maintain communications like the web page, webinars with neurosurgeons, newsletters and more. As well, we are a registered charity and your dues of \$25 a year and donations have been supporting research by Dr. Honey at the University of BC and Dr. Hodaie at the University of Toronto into ways to better diagnose and treat TN.

We know that many of you are distant from a support group and encourage you to keep in touch with the wider community through our Facebook page -- Trigeminal Neuralgia Canada-- or you can always email or call Ann Hopkins who is our virtual support person at 604 741 0662 or annhopkins@dccnet.com. You are not alone.

Your association is run by volunteers. We have minimal administrative costs such as those necessitated by annual filing with the Canada Revenue Agency and compliance with regulations. If you would like to volunteer for

TNAC we would love to hear from you. Graphics or accounting skills would certainly find a home with us or perhaps you have another suggestion.

Wishing you all freedom from pain.



Promising Results for New Trigeminal Neuralgia Drug June 16th, 2014 by Pat Anson, Editor

A British pharmaceutical company is reporting positive results from a Phase II study of a new drug in patients with trigeminal neuralgia (TGN), a rare and severe form of facial pain.

Convergence Pharmaceuticals said the drug – a sodium channel blocker known as CNV101480 – significantly reduced the severity of pain and the number of sudden attacks (paroxysms) in TGN patients. Pain severity decreased by 55% and the number of paroxysms decreased by an average of 60% when compared to a placebo.

"Having worked in the field of TGN for over 20 years and managed hundreds of patients with this severe facial pain it is wonderful news to find that there is potentially a new drug to add to our armory which not only is effective but is also so well tolerated," said Professor Joanna M. Zakrzewska, an expert in the field of facial pain at University College London Hospitals NHS Foundation. "This is the first time that we have a drug specifically being trialed in TGN rather than using a previously developed anti-epileptic drug."

A total of 67 patients with TGN participated in the study. Following an initial 21-day treatment period with CNV1014802, patients who showed a reduction in the number and severity of paroxysms were then randomly assigned to a 28-day double-blind treatment period with either CNV1014802 or a placebo. CNV1014802 was well tolerated with no serious adverse events. The full study will be published at the International Association for the Study of Pain's (IASP) World Congress of Pain in Buenos Aires, Argentina in October 2014. CNV1014802 received orphan-drug designation from the Food and Drug Administration in 2013. Convergence said it will use data from the Phase II study to design a pivotal clinical study to start in early 2015, with the goal of commercializing the drug "as soon as possible."

There have been very few well-controlled, randomized, placebo-controlled studies in trigeminal neuralgia, and the majority of drugs have had other primary uses. Due to the severity of the pain, it is not always practical or ethical to conduct a traditional placebo-controlled study.

Trigeminal neuralgia is a severe facial pain condition. Current guidelines for treating TGN recommend sodium channel blockers — carbamazepine or oxcarbazepine — as the first line of treatment. However, the drugs often have severe side effects, especially cognitive ones, and often interact with other medications.

"This is the first well powered, randomized and placebo controlled clinical trial to demonstrate efficacy of a selective state dependent Nav1.7 inhibitor in a chronic pain indication. This follows years of intensive research and provides

huge promise for a better standard of treatment for TGN in the future," the company said in a statement. TGN is a very severe form of facial pain that usually involves sudden and severe episodes of pain, usually on one side of the face, which can be provoked by a light touch or even a breeze. The pain follows one or more branches of the trigeminal nerve, which provides nerve sensation in the mouth, face and the front of the scalp. The severity of the pain and its unpredictability can lead to significant depression or even suicide.

TGN affects about 50,000 people in the U.S alone. The majority of TGN sufferers are over 50 years of age, although cases have been reported in young adults. TGN is more common in women than in men, and for most sufferers, the condition is progressive and worsens over time.



Surviving TN in Toronto

R. Owens.

There are likely a number of the darker elements of the story I'm about to recount that will be familiar to readers of this newsletter — such as the pain, fear and isolation — but there are a number of wonderful elements that I hope may prove to be encouraging for readers. In fact, my hope is that you find in your experience of TN the good fortune I have found in mine.

I had been at our cottage in Maine for only a few days in August of 2010 when I got the first twinges of pain that signalled the onset of TN. I worried at first that I had a bad cavity in one of my teeth or perhaps some sort of abscess, so I visited one of our local dentists. His examination turned up no problems with my teeth,

which left two possibilities, he said. The first and most likely was that I had TMJ, and the second was a 'rare nerve problem', though he indicated that was the least likely of the two possibilities. As the days passed the pain in my jaw grew and much of that holiday was ruined. Before we left to come home I made an appointment to see our dentist the day after we drove back to Toronto.

Here's the first bit of good fortune: My dentist — a remarkably competent and gentle man — is quite familiar with TN and gave me a provisional diagnosis and a sense of what lay ahead in the coming weeks and months. I saw my family doctor that same day and was started on Tegretol immediately, though getting to see a neurologist was going to take a few months. I did a bit of research and learned that a neurologist in the west end of Toronto (Dr. Peter Watson) is regarded as a local expert on TN and I called his office. I left a message explaining my situation and — here's the second bit of good fortune — got a call back from him later that night (a Sunday!). He invited me to come see him the next day! I got off the phone and dissolved in tears, feeling a powerful sense of relief.

I worked with Dr. Watson for the next several months trying to get the pain under control, and just as we began to entertain a referral to a local neurosurgeon for the micro vascular decompression (MVD) surgery my TN went into remission. Again, fortune smiled upon me (but not before I crashed my car while pulling out of the hospital driveway after an appointment). I was pain free until this spring (2014) when it began to creep back. I delayed restarting the medication because I was in the

middle of a crucial time at work, which proved to be a horrible mistake. The pain in my jaw came back with a vengeance, and although we increased my dosage and added another complimentary medication, it was out of control. I had trouble talking, swallowing and eating, and was on sick leave from work. Dr. Watson sent me to see Dr. Michael Tymianski, a neurosurgeon here in Toronto, about the MVD surgery. I was seen within 4 days, and another 4 days later was wheeled out of the operating room.

The surgery was a success, which was apparent before the end of the day – it was clear on the MRI and CT scans that there was a vein that was compressing the trigeminal nerve. All TN pain was gone, though it was replaced by post-op pain that was poorly controlled by morphine (turns out, morphine isn't everyone's friend). It's an intrusive procedure, but it has given me my life back. Four weeks later, the 3" scar behind my ear is healing nicely, all pain is gone, and my mind has emerged intact from the fog of medications from which I have been weaned. I am, I know, a very lucky person: I live in a country where healthcare is a priority and funded, and in a city where specialists – all of whom have been highly skilled and compassionate – can be found, even by a layperson. I had a 'typical' form of TN that was amenable to the MVD procedure, and have a family that has supported me throughout this nightmare. Despite all of my good fortune, however, I will likely live out my days with my fingers crossed in the hope that I never have to live with TN again.



The guidelines on trigeminal neuralgia management that have been agreed and jointly published by the American Academy of Neurology and the European Federation of Neurological Societies recommend carbamazepine (CBZ) and oxcarbazepine (OXC) as the first-choice medical treatments in patients with trigeminal neuralgia (TN). The aim of this retrospective study was to analyze the natural history of classical trigeminal neuralgia in a large cohort of patients, focusing on drug responsiveness, side effects related to CBZ and OXC, and changes in pain characteristics during the course of disease. Findings We selected the last 100 consecutive patients with typical TN who began treatment with CBZ and the last 100 with OXC.

All had MRI scans and a complete neurophysiological study of trigeminal reflexes. Among them, 22 were excluded on the basis of neuroradiological or neurophysiological investigations, to avoid the inclusion of patients with possible secondary TN.

The initial number of responders was 98% with CBZ with a median dose of 600 mg (range 200-1200), and of 94% with OXC, with a median dose of 1200 mg (range 600-1800). In a mean period of 8.6 months, 27% of responders to CBZ incurred in undesired effects to a level that caused interruption of treatment or a dosage reduction to an unsatisfactory level.

In a mean period of 13 months, the same occurred to 18% of responders to OXC. Among patients who had a good initial response, only 3 patients with CBZ and 2 with OXC developed late resistance.

During the course of disease, paroxysms worsened in intensity in 3% of patients, and paroxysms duration increased in 2%. We did not observe the onset of a clinically manifest sensory deficit at any time in any patient.

Conclusions: Unlike common notion, in our large patient sample the worsening of pain with time and the development of late resistance only occurred in a very small minority of patients.

CBZ and OXC were confirmed to be efficacious in a large majority of patients, but the side effects caused withdrawal from treatment in an important percentage of patients. These results suggest the opportunity to develop a better tolerated drug.

Author: Giulia Di StefanoSilvia La CesaAndrea TruiniGiorgio Cruccu
Credits/Source: The Journal of Headache and Pain 2014, 15:34



Wingin' It!

Cathy Graham
Translated in French by Jean Banville

“There are two things in life that motivate you, the fear of pain and the desire for pleasure”

I do not know who wrote the above quote, but I must say; when it comes to air travel and trigeminal neuralgia, I personally feel it is right on! It is vacation time for many... How wonderful it would be to fly to that special destination we keep putting off due to our fear of the pain

intensifying. Myself, I have had TN for sixteen years now and the thought of flying, well let's just say; I am writing this article as much for me as others who share the same anxiety. So, assuming we are going to give plane travel a try, here are some tips and tricks:

Travel insurance - Don't leave home without it! Comfort lies in knowing there will be good care, if needed.

Take your time – Pack early in the week of your trip and arrive at the airport in advance. Stress can exacerbate pain, give yourself time.

Plug it – ‘**Ear Planes**’ are ear plugs which are specifically designed for flying. They reduce noise and help with the “drag” one feels as the cabin pressure changes. These plugs are only good for one flight, so buy a couple. You can find them at on-line pharmacies or airport stores. Swimmer's ear plugs are another option. If you are able to wear a headset, then the noise-cancellation headphones may be for you. Note: the cost is much greater. These headsets are not to be worn until the plane takes off and just before landing, so the flight crew can be heard.

Freeze - **Emla** cream is a topical anesthetic consisting of lidocaine and prilocaine, which can be applied to the face and covered with an air tight transparent dressing. It is available at any pharmacy, no prescription required.

You can also use a **compound cream** (lidcaine, ketapohen, ketomine). There are lidocaine nose sprays and oral sprays. **Xylocaine Endotracheal** spray is precisely what is used to numb the throat of a person having to be intubated. You do need a written prescription from your doctor. It does not go deep

enough to reach the nerve but the areas this drug does reach seem to help some people. The taste is not pleasant at all, but it works in seconds, while the creams can take much longer to have an effect. Be aware that swallowing may be impaired and thus enhance the danger of aspiration. For this reason, food should not be ingested for 60 minutes following use. Also, be conscious of your tongue, it could be numb, which may cause unintentional biting trauma.

More tricks – Remember your trusty **scarf** on the aircraft. A breeze from the plane depressurizing can send you into a whirlwind of pain!

Alcohol wipes when breathed in at the slightest sign of a headache do help, even eyeglass wipes work. Inhalants with Eucalyptus oil work well. Apply to a tissue and breathe in the vapours. Your ears and nose will clear out. Hand sanitizers are effective but not allowed on an aircraft.

Always carry a **list of medications** you are taking, even the ones which are ‘as needed’, along with your doctors’ names and phone numbers.

Relieving the pressure you may feel in an aircraft is crucial! Carry a jug of water; keep drinking it during takeoff and landing. This helps with the pressure and keeps your ears from clogging. Or try drinking through a straw. The constant sucking on a lollipop also helps balance out pressure.

Anxiety, stress, distress, fears... When we tense up, the pain of trigeminal neuralgia can become much worse! You may want to try a muscle relaxant. We often think of **Valium** as an anti- anxiety drug,

Valium is now widely prescribed as a muscle relaxant. There are non prescription products as well, **Robaxacet** is one brand. **Pensaid** is a prescription topical anti-inflammatory. Apply 10 drops or so to the nerve area when it is swollen and also to the rest of the affected side of the face. It does help to bring down swelling and thus aids in relieving the pain. **Neuragen** is a natural nerve pain reliever and requires no prescription. It is usually found behind the counter at any pharmacy. The little bottle is pricy, but you do not require much. It is most definitely worth a try.

Clear out your sinuses. If you have suffered with sinus pain, then you know how it can affect trigeminal neuralgia! Prescription steroid sprays such as **Fluticasone (Flonase)** and **Beclomethasone (Beconase AQ)** can be very beneficial. There are also your standard cold and sinus medications. Always take before boarding the plane.

It has been suggested to me to take a short (one hour) flight. This idea seems plausible to me. I would be armed with my own flight arsenal and a prayer or two!

I do want to state that there are many people with TN who fly and have no problems at all or very little. Maybe it is even you or I? ☺



Quand la douleur s'envole

Écrit par Cathy Graham
Traduit par Jean Banville

"Il ya deux choses dans la vie qui nous motive, la peur de la douleur

et le désir pour le plaisir"

Je ne sais pas qui a écrit cette citation, mais je dois dire que lorsqu'il s'agit de "*voyage en avion*" avec la névralgie du trijumeau, cette phrase devient très pertinente!

C'est le temps des vacances pour la plupart d'entre nous. Comme ce serait merveilleux de voler vers cette destination rêvée dont nous continuons de remettre à plus tard en raison de la peur de la douleur. J'ai la NT depuis seize ans maintenant et juste la pensée de voler ... et bien umm...dit que j'écris cet article autant pour moi que pour d'autres qui partagent la même inquiétude. Donc, en supposant que nous allons tenter un essai de voyage en avion, voici quelques conseils et astuces:

Assurance Voyage - Ne partez pas sans elle. Votre confort dépend aussi bien du fait que vous savez que vous serez pris en charge, si besoin il y a.

Prenez votre temps - Commencer à préparer vos valises au moins une semaine avant votre voyage et arriver à l'aéroport à l'avance. Pour plusieurs le stress aggrave la douleur. Donnez-vous le temps.

Bouchez vos oreilles – Il existe des bouchons d'oreille qui sont spécifiquement conçus pour l'avion. Ils réduisent le bruit et diminuent les sensations désagréables des changements de pression de la cabine. Ces bouchons ne sont bons que pour un vol, il est donc préférable d'en acheter plusieurs. Vous pouvez les trouver en pharmacie, sur internet ou dans les magasins de l'aéroport. Les bouchons d'oreille de nageur sont une autre option. Si vous êtes en

mesure de porter un casque d'écoute, le casque antibruit pourrait très bien vous être utile. À noter que le coût est supérieur.

Gelez-vous - La crème **Emla** est un anesthésique pour la peau composé de lidocaïne et prilocane qui peut être appliquée sur le visage et recouverte d'un pansement transparent étanche à l'air. Il est disponible dans toutes les pharmacies, sans ordonnance.

Vous pouvez également utiliser un **onguent composé** (lidcaine, ketaprohen, ketomine). Il existe des sprays lidocaïne pour le nez et par voie orale. **Xylocaine endotrachéale** en spray est précisément ce qui est utilisé pour engourdir la gorge d'une personne qui doit être intubée. Pour celui ci, vous avez besoin d'une ordonnance écrite de votre médecin. Son effet n'est pas assez profond pour atteindre le nerf mais les zones touchées semblent aider certaines personnes. Le goût n'est pas très agréable, mais il fonctionne en quelques secondes, alors que les crèmes peuvent prendre beaucoup plus de temps pour faire effet. Soyez conscient que la déglutition peut être altérée et créer un risque d'inspiration. Pour cette raison, les aliments ne doivent pas être ingérés pendant 60 minutes après l'utilisation. En outre, soyez prudent car votre langue pourrait être insensible et vous risqueriez de vous la mordre et de vous blesser et de créer un nouveau traumatisme.

Soulager la pression que vous pouvez ressentir dans un avion est crucial! Gardez-vous toujours une bouteille d'eau avec vous et buvez pendant le décollage et l'atterrissage. Cela vous aidera

contre la pression et évitera vos oreilles de se boucher. Ou essayez de boire avec une paille. La succion constante d'un suçon contribue également à équilibrer la pression.

Anxiété, stress, détresse, peur ... Quand on est stressé notre douleur de NT s'aggrave. Essayez un relaxant musculaire. Souvent le **Valium** est considéré comme un médicament anti-anxiété, puisqu'il est maintenant largement prescrit comme relaxant musculaire. Il ya aussi plusieurs produits sans prescription comme Robaxacet. **Pensaid** est un anti-inflammatoire pour la peau. Appliquer 10 gouttes ou plus dans la région du nerf quand il est enflé et aussi pour le reste du visage. Il aide à réduire l'enflure et la douleur est ainsi soulagée. **Neuragen** est un analgésique naturel pour les nerfs et ne nécessite pas de prescription. Il se trouve généralement derrière le comptoir à la pharmacie. La petite bouteille est dispendieuse, mais vous n'en avez pas besoin de beaucoup. Il vaut la peine de l'essayer.

Nettoyage de sinus. Si vous avez des douleurs au sinus, vous savez donc à quel point cela peut affecter la névralgie du trijumeau! Les sprays en prescription stéroïdes tel que **Fluticasone (Flonase)** et **Beclomethasone (Beconase AQ)** est très bénéfiques tout comme le sont vos médicaments contre le rhume et sinus standard. Toujours le prendre avant de monter dans l'avion.

Il m'a été suggéré de prendre un court vol d'environ une heure. Cette idée me semble plausible. Je serais armé de mon arsenal de vol ainsi u'une prière ou deux!

Je ne tiens à mentionner ici qu'il existe plusieurs personnes avec la NT et qui n'ont pas de problème du tout ou très peu à voyager en avion. Ca pourrait être vous ou moi?



Botox May Ease Facial Pain

By Miranda Hitti
WebMD Health News

Oct. 24, 2005 -- A shot of Botox may ease a type of facial pain called trigeminal neuralgia, doctors report.

Trigeminal neuralgia is also called "tic douloureux." It's marked by intense, stabbing facial pain.

Botox contains a tiny dose of the botulinum-A toxin. Besides its cosmetic uses against wrinkles, Botox has also been studied in patients with migraines and temporomandibular joint syndrome (TMJ) pain.

The new Botox study was short and small. It included 13 trigeminal neuralgia patients in Brazil.

The results justify a bigger, longer trial, write the researchers. They included E.J. Piovesan, MD, a neurologist at the Hospital de Clinicas da Universidade Federal do Parana in Curitiba, Panama.

The study appears in *Neurology*.

Botox Study

Before Botox, all patients reported severe facial pain from their trigeminal neuralgia. Then, they got one Botox treatment targeting the affected facial areas.

Facial pain eased in all 13 patients over the next 60 days, the researchers report.

Ten days after Botox treatment, patients' reports showed a significant drop in facial pain. Twenty days after treatment, patients were "almost symptom free," write the researchers.

Pain intensity dropped, and all patients curbed their use of preventive medications for their facial pain.

Four patients quit using those medications. The other patients cut their use of medications for facial pain by more than half, the study shows.

Botox didn't seem to have any bad interactions with those other medicines. It also didn't appear to make those drugs more effective, the researchers note.

Two Months of Relief

The effects of Botox on facial pain lasted for 60 days. That's when the study ended.

How much longer might the benefits have lasted? The researchers don't know.

"Our patients should have been followed for a longer period of time, so that the precise duration of the effects of [Botox] could be determined," write Piovesan and colleagues.



One of the challenges of TN is that you do not look sick. There is no cane or crutches. No visible scar. It

comes on suddenly with no apparent injury that caused it. Friends, family, co-workers struggle to understand or accept that you are truly sick. The below article is not TN specific but talks about the challenge of dealing with people who do not believe you are sick.

How to Deal with People who Don't Believe You're Sick

By Kelly O'Brien, Mind, Body, Green

I look perfectly healthy, but the truth is, I suffer from a rare health condition called postural tachycardia syndrome (or, POTS syndrome). I can sit in front of you at lunch and I can safely promise you that you would not see a single symptom that is raging beneath my smile. Yet I can be thriving for three hours and curled up in my bed nauseated, dizzy and weak for the next six hours. I can be on the go for days and lying in a hospital bed the week after. My body throws me a surprise party often and as surprises go, you don't see them coming. And if it is difficult for others to understand, imagine what it's like me to live with the fact that I don't know what's coming next.

If you have a chronic health condition, chances are you've dealt with people who refuse to believe that you suffer from your illness (as if you need yet another thing to deal with on top of your illness). If you don't have a chronic health condition, chances are you know someone who does and you've watched this happen to them.

Adding a layer of skepticism to an illness is not something that anyone should have to deal with, but it may be worth taking a moment to explain

your condition to those around you.

Below are my best tips as to how to effectively communicate with people who question your illness. Once you master this, you are going to feel less stressed, more confident in your speech and much stronger.

Ready to change how you handle those who doubt?

1. Be concise. Be clear. Be confident.

You are going to master the 'three Bs' when you respond to anyone who doubts your health condition. And what you are not going to do is apologize for it. It's not your fault.

When someone says, "You don't even look sick," you're going to respond kindly: "Thank you, but I am and it's a daily challenge. If you want to learn more about my health condition, please just ask'." Period.

If you have to cancel that party you are going to? Try, "I'm symptomatic this evening and will not be able to come. I am looking forward to seeing you next time." Period. Focus on how you react to what others say. Don't waver. Look people in the eyes and speak sincerely with the added 'three Bs.'

2. Silence the skeptic.

This person just refuses to believe you. Often, they come out and tell you, "Maybe you're just depressed," or, "Mind over matter!" Kindly Educate. You are going to kindly educate but are only going to do this once.

So, an appropriate response to

someone blatantly questioning your illness at all is, "I'd love to educate you on my health condition and symptoms if and when you would like to listen. Would you like to go to lunch to talk about it?"

You are not going to defend yourself. You are not going to justify. And you are especially not going to mention any of their alternative theories. If they say yes, then you grab a bite to eat and explain to them what is going on. If they continue to question you, get the check and politely leave — no explanation necessary.

3. Create boundaries.

Create boundaries with yourself and others. Be upfront with your friends and family that because your health is unpredictable, you typically will be a "maybe" at events. Set expectations for people that are realistic. This will save you a tremendous amount of frustration.

Secondly, create boundaries regarding who you are willing to surround yourself with. Before getting mad at those that question you, ask yourself if you have thoroughly explained what you're going through. If people continue to question you, my best advice is to distance yourself or remove them from your life. Do not be harsh when creating and sharing boundaries. You want to make others feel loved and not stonewalled.

4. Lose the guilt.

This is a simple tip. When you cancel or pull back on your busy schedule, do so with the utmost love for yourself and with self-care. Lose the guilt and especially lose the worry of

what others will think. WRevel in your healing!

5. Join a support group.

Joining a support group is going to aid in buoying you. This will help you while you are changing the way you communicate with others. Research and try out a few support groups because what you want to do is surround yourself with others who are focused on healing and living life.

When you combine these five steps, I absolutely promise you that, without fail, your confidence level will soar while your communication skills are refined and you'll feel better dealing with this difficult part of your illness!



TNAC AGM

In 2014 CRA and Industry Canada has issued new regulations for all registered not for profits in Canada. TNAC is currently working through these new regulations. As part of the process we are required to revise our by laws. As a result we will be delaying our AGM this year until the fall. We thank you for your patience. It is a lot of work for any organization let alone a small group run by volunteers. TNAC, however, is committed to accountability and part of that is maintaining our charitable status as a registered not for profit in Canada. Therefore we are taking the time to make sure we meet the new requirements as set out by CRA and Industry Canada.

TNAC will send out a notice to members with the date of the AGM later in the summer.