



# Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

**OUR MISSION:** To advocate for the awareness of Trigeminal Neuralgia and related facial pain.  
**OUR GOAL:** To have a unified understanding of Trigeminal Neuralgia and other related facial pain resulting in better pain management.  
**OUR VISION:** An improved Quality Of Life.

**Support Groups:** Adelaide, Brisbane, Canberra, Coffs Harbour, Gold Coast, Hobart, Melbourne, Newcastle, Sunshine Coast, Sydney, Sydney CBD, Townsville.

## May 2011

*"There is no use whatever trying to help people who do not help themselves. You cannot push anyone up a ladder unless he be willing to climb himself." ~ Andrew Carnegie*

**Good News!** I am happy to inform you that Dr Burchiel has been in touch since his surgery and is given the all clear. We are certainly delighted with his good news and wish him speedy and complete recovery. The other good news is he still has a ticket to Australia, which he has to use in the next 12 months ☺, he intends on visiting Sydney. We will certainly look forward to his visit and an afternoon with the good doctor.

We were determined not to cancel the meeting as many had purchased their air tickets to come to the Sydney meeting. A quick reschedule of speakers and topics and we have an equally informative afternoon.

We are very grateful to **Dr Russell Vickers and Dr Ben Jonker** for agreeing to present at such short notice. It is fantastic to have such wonderful support. I am very proud that, so far, only 3 cancellations, mainly due to family or health issues. Everyone else has confirmed they are still attending. We are anticipating a great afternoon with our rescheduled speakers and their topics.

**2011 Membership:** Thank you all for renewing your membership. Since our April's newsletter membership has been steadily streaming in. We are really encouraged by your response.

**4<sup>th</sup> National Conference:** 2<sup>nd</sup> – 4<sup>th</sup> September 2011@ Hunter Valley. Have you registered for the conference yet? The conference is especially aimed at patients and their carers, it's a great opportunity to learn from doctors and researchers who are interested in your face pain. To allow you to take advantage of the special rate, I will extend the Early Bird rate to the 13<sup>th</sup> of May 2011.

Past conference surveys showed that -

- patients come to the conference to seek answers.
- the conference & answers provided encouragement & Hope.
- The conferences were rated as a valuable experience, particularly in meeting others with TN; and being able to discuss their facial pain with medical and dental experts in this field.

From October 2009 to April 2011 we received 253 new enquiries. Strangely, only 2 from this lot have decided they need answers for their pain and to take control of it. Am I to believe the rest of you are all pain free?

"Criticism may not be agreeable, but it is necessary. It fulfils the same function as pain in the human body. It calls attention to an unhealthy state of things." ~ Winston Churchill.

*Irene.*

## Motor Cortex Stimulation for Trigeminal Neuropathic or Deafferentation Pain: An Institutional Case Series Experience.

Raslan AM, Nasser M, Bahgat D, Abdu E, Burchiel KJ.

Department of Neurological Surgery, Oregon Health & Science University, Portland, Oreg., USA.

### Abstract

**Background:** Trigeminal neuropathy is a rare, devastating condition that can be intractable and resistant to treatment. When medical treatment fails, invasive options are limited. Motor cortex stimulation (MCS) is a relatively recent technique introduced to treat central neuropathic pain. The use of MCS to treat trigeminal neuropathic or deafferentation pain is not widespread and clinical data in the medical literature that demonstrate efficacy are limited.

**Method:** We retrospectively reviewed patients with trigeminal neuropathic or trigeminal deafferentation pain who were treated at the Oregon Health & Science University between 2001 and 2008 by 1 neurosurgeon using MCS.

**Results:** Eight of 11 patients (3 male, 8 female) underwent successful permanent implantation of an MCS system. All 8 patients reported initial satisfactory pain control. Three failed to experience continued pain control (6 months of follow-up). Five continued to experience long-term pain control (mean follow-up, 33 months). Average programming sessions were 2.2/year (all 8 patients) and 1.55/year (5 patients who sustained long-term pain control). Patients with anesthesia dolorosa or trigeminal deafferentation pain who had previously undergone ablative trigeminal procedures responded poorly to MCS. We encountered no perioperative complications.

**Conclusion:** MCS is a safe and potentially effective therapy in certain patients with trigeminal neuropathy.

Copyright © 2011 S. Karger AG, Basel.

PMID: 21293167 [PubMed - as supplied by publisher]

Stereotact Funct Neurosurg. 2011 Feb 2;89(2):83-88. [Epub ahead of print]

It's evening been a big day,  
My itchy head  
I wish it would fade away,  
My itchy head  
I scratch  
My itchy head  
It stings  
My itchy head  
And it's once again  
My itchy head  
It's burning  
My itchy head  
Aching  
My itchy head  
Now I down to sleep  
My itchy head  
I lie left  
My itchy head  
I turn right  
My itchy head  
Can't be comfortable with  
My itchy head  
But I own  
My itchy head

## MY Itchy Head

~ by Peter Huby

Peter's pain developed after herpes zoster infection; he has Peripheral nerve stimulation of the supraorbital / infraorbital branches of the trigeminal nerve to help control his pain.

### Postherpetic itch

The itch that sometimes occurs during or after shingles can be quite severe and painful. Topical local anesthetics (which numb the skin) provide substantial relief to some patients. Since postherpetic itch typically develops in skin that has severe sensory loss, it is particularly important to avoid scratching. Scratching numb skin too long or too hard can cause injury.

## **Trigeminal neuralgia in young adults.**

Bahgat D, Ray DK, Raslan AM, McCartney S, Burchiel KJ.

Department of Neurological Surgery, Oregon Health & Science University, Portland, Oregon.

### **Abstract**

**Object** Trigeminal neuralgia (TN) is a form of facial pain that can be debilitating if left untreated. It typically affects elderly adults and is thought to be related to neurovascular compression. It is uncommon in people younger than 30 years of age, with only 1% of cases reportedly occurring in those younger than 20 years of age. The most common cause of compression in young adults is thought to be venous nerve compression either alone or in association with arterial nerve compression. The objective of this study was to review data in cases of TN in which patients were 25 years of age or younger and to identify TN disease characteristics, demographics, clinical features, operative findings, and outcome.

**Methods** The authors retrospectively reviewed the clinical records, surgical treatment, and long-term outcome in patients 25 years of age or younger with TN who underwent surgery performed by the senior author (K.J.B.) at Oregon Health & Science University between 1995 and 2008.

**Results** Seven patients (2 males and 5 females) met the inclusion criteria. The average age at symptom onset was  $19.6 \pm 3.4$  years ( $\pm$  SD) and the average age at surgery was  $22.9 \pm 1.7$  years. Six patients had right-sided symptoms and 1 had left-sided symptoms. Pain distribution was the V2 in 3 cases, V2-3 in 3 cases, and V3 in 1 case, with no cases of V1 affliction. A total of 11 procedures were performed in 7 patients, and 4 patients underwent a second procedure. Surgery and imaging revealed venous compression in all cases. The average follow-up period was  $35.5 \pm 39.9$  months (median 12 months). Three patients reported a good outcome (no pain with or without medications) and 4 reported a poor outcome (either no pain relief or mild pain relief after surgery).

**Conclusions** Trigeminal neuralgia is uncommon in young adults. Patients tend to present with symptoms similar to those in adults: long periods of pain and venous compression, but outcome unfortunately is not as good as that reported in the older population.

PMID: 21128738 [PubMed - as supplied by publisher]

### **In memory of Lillian May "Pip" Bennett.**

Mr & Mrs B Carter

Mr & Mrs B Antonio

Mrs Judy Hall

Mr & Mrs A Dewhurst

Ocean View Banora Point (Staffs)

Ms L Clement, Mr & Mrs T Harris

Mr & Mrs B Leadbeater

*A gift to the Tribute Fund is a way in which TNA supporters can memorialize dear ones who have passed on, or to celebrate successes or occasions in the lives of special people.*

*All gifts are acknowledged with a special letter of thanks to all those concerned. Gifts are tax-deductible and support TNA's important work.*

*Cheques should be made out to TNA AUSTRALIA INC*

*Postal address : TNA Aus Inc.*

*P O BOX 1611 CASTLE HILL NSW 1765*

*OR, Direct deposit: Commonwealth Bank ( Branch: Richmond, NSW)*

*BSB : 062 595 Account No : 1021 8264,*

*Name of Account : Trigeminal Neuralgia Association Australia Inc.*

## Support Groups Meeting Report

### ADELAIDE SUPPORT GROUP

Burnside Town Hall

Sunday 27<sup>th</sup> March 2.00 p.m.

**Present:** Gary & Lisa R; Angela M; Sue & David H; Kevin Sm; Grace A; Una M; Jan B; Bert J; Ann T; Graham & Liz B.

**Apologies:** June & Roger O; Joan E.

**Welcome:** Graham welcomed all those in attendance, with a special welcome to Sue and David H. who have travelled from Victor Harbour and new member Una.M.

**FINANCES:** Brought Forward: \$34.15. Meeting donations: \$45.00. Gift from member, Richard B. \$500.00.

**Balance:** \$579.15.

#### MATTERS ARISING:

**TN CONFERENCE** Graham reminded members that early bird bookings end at the end of April so book soon if you are going to attend. Graham and Liz will be going.

Irene has requested that each support group produce some form of display to be shown during the Conference. Examples could be paintings, stories, poems, anecdotes, etc. which depict TN pain or pain management through our support group. Please give this some thought and we will follow up at the next meeting.

**GUEST SPEAKERS:** Graham has not organised any for this year, however he advised that COTA have speakers available to talk on various topics including medicines, pain management and depression, etc. As we have already had a speaker talk on depression, he asked if a talk on pain management might be of interest to our Group. It was thought a good idea so Graham will arrange for the September meeting.

**DONATION:** Richard B, a TN sufferer and member who attended our early support group meetings has kindly donated \$500.00 to the Adelaide Support Group. This extremely generous donation will ensure our Group is able to continue for the foreseeable. Graham has opened a Credit Union account in the name of Adelaide Trigeminal Neuralgia Support Group. All members signed a thank you card to be sent to Richard. (Richard's MVD operation was aborted due to fears the blood vessel compressing the nerve might rupture when removed. He has subsequently had two percutaneous procedures.)

#### UPDATE ON MEMBERS:

**JUNE:** (by telephone) June had an MVD in February. Graham and Liz visited her in the Royal Adelaide Hospital 3 days after her surgery and she was pain free and feeling well. She had developed a nasal drip which was initially treated by the spinal drain. This solved the problem and June returned home, however after a couple of days the nasal drip returned which required June to be readmitted to hospital and to undergo further surgery. A small tear was found and dealt with. June is now well and pain free.

**MAUREEN:** Maureen had her MVD the day after June and we visited her in the same ward as June. Maureen unfortunately developed shingles on her face but this was successfully dealt with and we understand she has returned home TN pain free. Regrettably we have been unable to contact Maureen to see how she is progressing.

**SUE:** Is doing quite well at the moment. It is 12 months since her diagnosis. Fortunately her TN was diagnosed quickly while on holiday. On her return home she consulted with Dr Zacest whom she found very encouraging. She had an MRI which showed a compression of her trigeminal nerve. Sue is controlling her pain reasonably well with 200 mg Tegretol daily. She has been told she is a suitable candidate for an MVD but will consider surgery when her pain is less controlled. The more minor surgical

procedures were considered unsuitable. She also takes Endep for fibromyalgia. Sue's husband, David, always knows when she is in pain as her cheek turns brilliant red along the nerve pathway. She enquired if one can come off medication during periods of remission. The general consensus was yes, gradually but discuss with your doctor.

There was some discussion of the benefits of asking advice from chemists, including compounding chemists, regarding combining different drugs to treat TN. This would be in conjunction with one's doctor as a GP would still need to provide a prescription. Graham will send Sue a copy of the article (published in TNA Australia July 2009 Newsletter ) written by Christine, a Nurse setting out her experiences after undergoing an MVD. Graham found this article particularly helpful when he had his own MVD.

**KEVIN:** Going really well. On consulting with Dr Zacest last year, he was told he did not have TN and was referred to Professor G. An MRI indicated a worn disc in Kevin's jaw. He underwent a minor procedure where Cortisone was injected into his jaw. This has relieved his pain considerably and he has been told it will probably last up to 3 years. He still takes one Valpro tablet at night.

**GRACE:** No change. No pain but also has no feeling in her cheek which resulted from her second glycerol injection 3 years ago. Half of her face, cheek, eye, tongue, lip and throat is numb. This is permanent. She has been advised not to undergo any further surgery.

**UNA:** Has suffered TN for over 2 years. Endep and Gabapentin had kept her pain reasonably controlled. Sadly, Una's husband passed away 6 months ago and she has become run down and her TN has worsened. She experiences pain in her mouth and up over the top of her head. She feels "like a zombie" on her medication. An MRI has indicated a longer than usual nerve and as the compression is very close to her brain, surgery is not recommended.

**JAN:** Jan is seeing a neurologist next week. Her Tegretol is not helping and causes a disgusting taste in her mouth and feelings of nausea. She takes 4 x 200 mg daily. Her doctor has recommended some form of surgical treatment but Jan is unsure what it entails. Unfortunately Jan had a fall last year in which she broke her cheek bone which exacerbated her TN.

**ANGELA:** Has had no pain for 4 months now. If and when her TN returns she will contact Dr Zacest who has recommended a radio frequency procedure. Angela has already undergone an MVD and glycerol injection, neither of which worked.

**BERT:** After Bert's radio frequency procedure he developed an infection. Eventually he took a course of antibiotics and now he is much better.

**GARY:** Has had TN for 6 years following a stroke. He experiences 3 - 4 shocks a day together with burning. He takes 600 mg Nurontin together with morphine. He suffers pain in the roof of his mouth and around the eye. He finds pressing the site of the pain helps together with distraction. He wishes more research could be made into TN.

**ANN:** Ann takes her topiramate at the same time each day; and stressed the importance of taking control of your pain and the benefit of distraction.

MEETING CLOSED at 4.15 p.m. followed by tea/biscuits and friendly get-together.

NEXT MEETING: Sunday 29th May, 2011 at 2.00 p.m. Civic Centre, Burnside Town Hall.

*Graham & Liz Boyer*

---

" You can close the windows and darken your room, and you can open the windows and let light in. It is a matter of choice. Your mind is your room. Do you darken it or do you fill it with light?"

## MELBOURNE SUPPORT GROUP

“Ringwood Room” Ringwood Library

1.30 p.m. 9 April 2011

Evelyn welcomed everyone to the meeting, especially the folks attending for the first time.

**Present:** (24) Barbara A.; Elaine A. & Kathy T.; Maree & Glenn B.; Toni B.; Alan & Joy C.; Evelyn D.; Elwyn H.; Alf H.; Alan L.; Verna McC.; Nita & Robert McK.; Beryl & Rob O.; Bill P.; Will & Joan R.; Joan & Neil T.; Rita & Chris W.;

**New attendees:** (6) Lenny G & Sugie H.; Derek & Nina L.; Lloyd & Margot Z.;

**Apologies:** (5) Ellayne C.; Din D.; Doug E.; John de M.; Peter S.

Evelyn mentioned that past member Bernadette G., now living in Canberra, had suggested forming an e-mail group so we can keep in contact with each other. After the meeting, Rob O. indicated that he could initiate this after he returns from holidays. Members were invited to leave their e-mail addresses if interested.

**Treasurer's report:** Alan reported that there was a carry forward balance of \$289.85. Donations at the February meeting were \$96.00 and a surrender of a deposit for a non-return of a library book was \$30. Meeting room insurance costs were \$16.50, New Year letter incl. postage \$102 and contribution to Irene's travel \$100, leaving a total in hand of \$197.35.

Recent TN Newsletters: Evelyn referred to the March & April newsletters and urged those who have not paid 2011 membership fees yet to please do so (send payments direct to Sydney or use the direct banking facility). Quite a few of our members have already registered for the fourth TN Conference which will be held at Cypress Lakes Resort, Pokolbin, in the Hunter Valley of NSW from 2 – 5 September. Discounts apply for registrations before 30 April 2011 and there is a smaller discount for registrations from 1 May to 31 July. Good location and excellent international speakers – members were encouraged to attend! Also announced in the April Newsletter were details of the presentation to be given by Kim Burchiel MD in Sydney on 30 April – people urged to attend if possible.

Correspondence: two communications from Maroondah Council – to up-date our Community Directory information (Evelyn to attend to this) and to advise of proposed improvements to the Leisure Centre (no action required).

Books are available for borrowing. Take flyers for members' health/community centres. Newspaper article was shared about neurosurgery performed by Andrew Danks at Monash Medical centre recently for a Fijian girl.

Support Group project for the Conference: Two great ideas were put forward for our submission to the Support Group displays at the Conference. Neil T will present a plan of his project at the next meeting; members asked to leave e-mail addresses so Maree and Glenn can contact people for ideas about Tips and Tricks to further develop their plan. Thanks for the enthusiasm shown regarding this! Post meeting, Toni expressed an interest in some form of art.

### Reports from members:

**Toni B.** had TN for some 10 years before she found the Support Group. Her pain could not be controlled with drugs. Last year she had an MVD done by Andrew Danks and has had no pain since. She no longer takes Tegretol and has had no complications. No impacting blood vessel was found and no tumour but there was an atrophied nerve. Post operation, Toni had herpes but she had read about this possibility in her pre-operation preparation – this was resolved with no neurological deficit. She was in hospital for 5 days and experienced some pain for a few days and then gradually resumed full life. Toni takes 1 tablet of Vit B12 a day.

**Elaine A.** Told us how she has now waited 7 months for her MVD at Monash Medical Centre after being told to be on standby after all consultations were completed. Her description of administrative delays dismayed many and she was strongly encouraged to make direct contact with Andrew Danks rooms rather

than with admin staff at Monash Medical Centre. She suffers TN pain and feels very stressed about this delay.

**Derek L.** spoke for his wife Nina who has had TN for 7 years. This has taken a great toll on her and him. She is in pain much of the time at home and has ice on her eye area. She can't join in social events with him and couldn't attend their joint birthday celebration on 1 April. Nina describes her pain in the region of the left eye as stabbing pain clawing into the face. She has seen 3 eye specialists who all said the eye was normal. None of the 3 neurologists she saw identified TN. One top neurologist said it was just migraine and charged her \$230.00. Her daughter-in-law found TN on the internet. Nina's trigger is nephritis. She tried all kinds of medication.

*Irene wonders who then diagnosed Nina's pain as Trigeminal Neuralgia? Interestingly, "Nina's trigger is nephritis " Nephritis (inflammation of the kidney) is commonly caused by drug hypersensitivity. 7 years ago, which came first? the nephritis or the pain in the region of the left eye? Or even herpes zoster infection.*

**Maree B.** saw her dentist because of pain near the front teeth. TN was diagnosed. For her the trigger points are the top of the palate and tip of the nose. Geelong neurologist Dr Mark King sent her for an MRI but then she was referred to The Alfred hospital for MVD. High dosages of Tegretol caused liver problems for her. The MVD surgery worked for her and she is medication free but infection has been a big problem. Cellulitis in the left leg caused the jaw to clamp. Maree suggested a summary card for patients to present at hospitals or in other situations when TN status needs to be known. Now going along OK and hoping for no further surgery.

**Evelyn D.** TN began in 2006 in cool evening air but after short term medication, acupuncture and mindfulness meditation she has been pain free for over 3 years now, taking up to 4000mcg sub-lingual B12 daily.

**Joan T.** no longer takes Tegretol but used Capsaicin cream to kill the pain on external facial trigger areas. She felt it had done the job so well that she stopped using the cream only to have the pain return so now she has started using it again!

**Will R.** Started to experience TN pain after cleaning his teeth in 2001 then eating, chewing, swallowing and talking were painful. He couldn't control the pain and suffered depression. In 2007 he found information about TN on the internet and he spoke with Irene in Sydney. The first neurologist he saw did not diagnose TN but he had a preliminary consultation with an Epworth neurosurgeon in November that year and TN was diagnosed and he finally had an MVD in June 2008. Before the MVD every word banged in his head causing TN pain. Even eating chocolate on the non-TN side of his mouth triggered an attack. After the operation he tested his face and was relieved to find he was pain-free; he was home after 3 days and has had no sign of pain since. A week later when he was having clamps removed for the surgical site at the back of his head, he heard a doctor refer to the power of prayer. Mr Febini, neurosurgeon, explained that as the artery was lifted away the nerve visibly relaxed. Will was 82 at the time of the operation.

**Bill P.** Has been coming to Support Group meetings for 7 – 8 years and has heard many sad stories but saddest of all is to hear how many medicos, dentists do not know about TN. Bill's GP recognised it because the GP's father-in-law had suffered TN. Neurologist suggested Bill see neurosurgeon and an MVD was planned. It was postponed when the pain disappeared but after the pain returned Bill only had to ring and the MVD was done – no pain since!

**Lenny G.** started getting pain in the upper jaw 7-8 years ago. She saw her dentist, endodontist & G.P. The pain started on a winter night and struck her with such force she could hardly walk. The right side base of nose is the trigger area. Lenny had root canal treatment - \$600 worth – but the pain returned so then she had another root canal treatment. The pain went for a while but then returned. The dentist suggested it might be a sinus problem so she went to her GP but examination showed it was not sinus. She went to the dentist again and to the endodontist who x-rayed all her teeth – showed nothing. He suggested that she stop consuming anything acidic – fruit etc. as acid might be causing the pain. Yet another dentist identified

exposed gum due to brushing so this was sealed but again the pain returned. Last January she had a major TN attack lasting half an hour or so. She couldn't swallow – not even her own saliva. She couldn't touch the area as it was very painful. Lenny had 2 attacks that week so went back to the dentist! He said there was a very long root of a tooth and gave her anti-biotic prior to an appointment for root canal treatment. The appointment was for 11 a.m. but at 10 a.m. she had a major attack and drove to the dentist – he called the endodontist and made a 5 p.m. appointment and took another x-ray. By 5 p.m. the pain had subsided but the endodontist rubbed the gum, which brought on another attack so finally TN was diagnosed!! Now she is taking Tegretol 100mg X AM/PM; and 4/1000mcg sub-lingual B12 daily and has been pain free for 2 weeks after a mutual friend rang Evelyn to ask about an acupuncturist. When Evelyn heard about the pain she recognized it as TN and told Lenny about the Support Group and B12. We were all horrified at this saga but glad Lenny has found some relief now and hope it continues.

**Rita W.** introduced a lighter note with her description of her maxilla-facial surgeon trying to teach her to breathe out/blow out noisily through the mouth to relax all the muscles in the area! When this did not relieve the pain he told her she was not doing the exercises properly! She was in almost constant pain – she couldn't drink and had 56 days of non-stop pain. Her doctor admitted he had misdiagnosed her condition but then made a diagnosis of TN. That was 7 – 8 years ago - Rita also went through all the same scenario as Lenny but is now able to control the pain on ½ Tegretol tablet a day.

**Alan L.** Gave a different view – his dentist recognized TN straightaway and prescribed Tegretol! Alan is doing well now.

As we closed the meeting, people were reminded books can be borrowed on \$40 refundable deposit. E-mail list to be completed by those wanting to communicate with Maree and Glenn about their proposed booklet. Thanks to all for attending and participating so enthusiastically and thanks for preparation and clean-up of the room and helping with afternoon tea and managing the front desk. Happy and pain-free Easter to all!

Next meeting: Saturday 11 June 2011 at 1.30 p.m.

*Evelyn Diradji.*

---

## **ST. CLOUD SUPPORT GROUP**

Minnesota

Our support group met Saturday April 9, 2011 at Centra Care Clinic in St Cloud, Minnesota. Our speaker was Dr K. Rieke who is a neurologist with Centra Care Clinic. She was going to talk about medications. Since only Alan, my husband, Scott and myself were in attendance we did talk about medications a little but mostly about ourselves, although Dr Rieke did stress that if we felt as patient that something wasn't working for us to go to our doctor and see what could be done since there are so many different medications to try; plus reducing a medication and adding another one on. Over time she said the body does adjust to medications so sometimes they don't work as well. We had a great time with her but did feel sorry that other members couldn't have been in attendance. We will be having a meeting in July with no speaker since most people don't show up for that meeting at all.

In October we are having a meeting with a speaker, Leesa Morrow, who spoke at the TNA National Convention in Rochester. At that time we will decide depending on the attendance if we will continue to have support group meetings or turn this into a telephone support group.

Best Wishes to all of you and have a Very Happy Easter.

*Mary Hall*

*Irene: Sorry to learn of the poor show in attendance. You obviously had a neurologist who is interested in trigeminal neuralgia to agree to give up her time to speak at a TN support group meeting – a rare find.*

*What a shame TN folks can be so indifferent.*

*This is not unique to St Cloud Minnesota. We get the same frustration here too. First we put in the effort to find a speaker; then we put in the effort to remind members of the event.*

*Speaker comes to find an empty room. The Support Group Leader is terribly embarrassed for wasting the speaker's time and effort. (One does not just turn up to talk – one has to spend time to prepare the talk.)*

*In the end, Support Group Leader loses heart, Speaker would NEVER come back again, and folks who could do with the information and knowledge continue to suffer in ignorance; and spend their life whinging that doctors are not helping them or interested in them.*

To educate yourself for the feeling of gratitude means to take nothing for granted, but to always seek out and value the kind that will stand behind the action. Nothing that is done for you is a matter of course.

Everything originates in a will for the good, which is directed at you. Train yourself never to put off the word or action for the expression of gratitude.

- Albert Schweitzer

*Allow me to add "in our case -your gratitude would be better expressed in person." IW.*

---

## **BRISBANE SUPPORT GROUP**

30 Ridley Road, Bridgeman Down

9 April 2011

**Attendance:** Jennifer D, Helen W, Rod W, Leo L, Neil F, Jeff B, Lorraine B, Margaret B, Colin B, Henry C, Eileen C, Sue R, Digby R, Tony M

**Apologies:** Rob and Tamara J, Margaret H, Doreen T, Noela K

Tony welcomed our new members and urged all members who have found the path to wellness to keep in touch and share stories of healing and hope with others. Again, the benefits of the conference were shared and our homework task concerning our poster was described. All Brisbane members, past and present are urged to attend our next meeting for an activity involving this project.

The newsletter article involving oral vs intramuscular B12 comparison was discussed with reference to member anecdotes. We chatted about the range of medical opinions available with regard to treatment using B12. Thanks to Irene for her ongoing dedication in sourcing consistently high quality relevant research material for our benefit. The jokes are appreciated too!!

We also discussed use of Epsom salt baths as a muscle and nerve relaxant and its main ingredient magnesium sulphate.

Tony then shared the stories of members not with us today.

**John L** continues to be pain free and is maintaining monthly neo cobalamin injections.

Rob J has seen Dr Sharma, as suggested at our last meeting and is now much better with the treatment change. Rob and Tamara send their gratitude to our group for our support thus far.

Doreen T is having some dental work done at the moment, but continues with her usual joyful approach that helps her through the day and lifts the spirits of those around.

We then shared our stories.

**Jennifer** is now generally much better since our last meeting .She has had 3 methyl cobalamin injections in that time. Her migraines have also reduced in severity. She is seeing Dr Aggarwal in June to discuss medications. She has had some bad days this week with burning in the teeth and ear. She is taking magnesium and lysine. Medical history includes two failed MVD' s.

**Helen** had her MVD last March and was completely pain free until a recent plane trip and has wondered if this could have been the trigger for some sensations returning. She has recommenced tegretol 100mg am and pm and all pain has stopped. She continues the oral B12.

**Leo** entertained us with his characteristic cheerful banter. He described the after effects of his MVD 6 years ago, anaesthesia dolorosa as a sad numbness. He tells us that he has a condition that sounds like an Italian film star! We discovered that he is also a Terrace old boy and that he flies the flag by wearing black and red undies. Being the cultured and respectable group that we are, I told Leo that we would take his word for it. **Neil** continues to sing the praises of frequent exercise.

**Mary M** has been really well since February. She has followed the advice of Dr Aggarwal and adjusted medication and altered the endep dose up to 25 mg at night and the Neurontin dose down to only 300mg. She continues B12 therapy.

**Lorraine B** is not well at the moment and is experiencing pain and swelling in the jaw. She is on 50 mg endep, 150 Lyrica, methyl cobalamin injections, zinc, magnesium, lysine and fish oil. Following the meeting, Lorraine was able to get an appointment almost immediately with Dr who has been of assistance for a member with similar pain.

**Margaret B** continues to be well. Since commencing neo cobalamin injections, she has reduced her daily medication from a cocktail of 22 tablets down to just two 200mg tegretol. She really enjoys coming to our meetings and says there is always an extra tip that she can pick up to add her remedy list.

**Henry** continues to be really well and has been almost entirely pain free since commencing monthly neo cobalamin injections. He continues to take 100mg tegretol.

We welcomed new member **Sue** who was first diagnosed by a dentist fifteen years ago following onset of sharp electric shocks into the teeth. The dentist said there was no cure! Pain intensified and a doctor prescribed tegretol which did not ease the pain. Sue found that chewing gum helped to reduce the effects of the nerve firing. Six years ago, the 300mg am and pm tegretol was replaced with two 300mg lyrica per day and pain vanished. Three years of pain free remission followed. Pain returned, with teeth brushing and eating. Sue has found that a combination of both tegretol and lyrica has been of benefit.

**Tony** added that the chewing of cloves can significantly reduce pain in teeth. Cloves carry a natural anaesthetic as well as many beneficial ingredients.

Tony again reminded us of our task for the conference this year where we can each say a little about our TN journey. It would be great if as many members as possible could be present at our next meeting for a photo and to celebrate our return to wellness.

Greetings and good wishes to our friends who can't be with us today.

Donations: \$44

Next meeting: Saturday June 11@ 1:30

*Tony MacPherson*



## TOWNSVILLE SUPPORT GROUP

Saturday 16 April 2011

**Present:** Sera A, Peter A, Jill S, Mary C, Sue M.

The meeting had to be moved when we got to the venue as it was double-booked. We regrouped at Sera's house. Sera handed out membership forms for those who haven't remembered to renew it.

**Sera** welcomed all of those who arrived and said that it was wonderful to catch up with others who have the same difficulty. She has increased her medication to Gabapentin 400mg X 6, Epilim 500mgX + 2 at 200mg. She still has pain in her upper lip and mouth sometimes difficult to brush teeth. She is very tired and if she sits down she falls asleep after a busy day. She has had another MRI and the local doctor cannot interpret it so he has sent it to the neurosurgeon and Sera has an appointment with him on 28<sup>th</sup> April. Sera says that the medication is giving her an awful taste in her mouth.

**Sue:** Lyrica appears to control the pain better, along with Endep and B12, but she cannot drop off any tablets and it makes her tired.

**Jill:** Says that the same combination works for her along with Vitamin B12, magnesium and Fish Oil. Best she has ever been.

**Sue:** What strength magnesium?

**Jill:** Just the normal dose. It helps if you can slow down and be still for a while.

*Irene: rather than the blind leading the blind.. please see **MAGNESIUM** below included for your benefit.*

**Mary:** Says that she puts on a meditation tape when she finishes things and that helps. Mary's pain is not as bad as everyone else but Cymbalta works for her by putting the Serotonin back in the brain.

**Sue:** Sera are you still thinking of going to the conference?

**Sera and Peter:** Still considering but the cheap flights don't match up with the buses available. It looks like a car would have to be hired from Newcastle.

A general discussion ensued about the disadvantages of living in a regional area regarding conferences. Another discussion ensued about the benefits of sublingual B12.

**Sue:** Saturday 18<sup>th</sup> June at 1:00 is fine for the next meeting. Sera will be back from her holiday and would be happy to have it here next time and we will look at other venues after that. The CWA hall might be available (\$20.00) and Peter talked about an available church hall. Jill suggested that we could come to her place. Some churches are only used as churches. We broke for afternoon tea at 2:30.

*Thanks Sue for the meeting report.*

**MAGNESIUM:** Krispin Sullivan is a clinical nutritionist

<http://www.krispin.com/magnes.html>

Please refer to her website for more information on Magnesium

**If you are taking any medications, prescription or non-prescription, check with a health care professional before using magnesium supplements.** If you are currently experiencing any type of kidney condition or disease, **do not** use magnesium supplements without the full knowledge and approval of your physician. Magnesium is necessary for life and can protect the kidney from disease but **if kidney damage has already occurred magnesium supplementation could be harmful, even life threatening.**

### **Recommended Dietary Allowance**

To compensate for deficiencies and/or losses the new RDA is expected to be 500 mg. per day.

My Krispin- RDA is a total of 500-700 mg magnesium daily.

This document may be copied and distributed with the copyright and my personal information intact. © Krispin Sullivan, CN 1997 Last modified on: 03/02/11

## SUNSHINE COAST SUPPORT GROUP

Kawana Library, Nanyina Street, Buddina.

9th April 201, 1pm.

**Attendance:** Jean W, Teresa M, Peter & Pearl R, Sherryl M, Irene W, Jean B, Andrea F, Dawn S, Jim K, Rebecca J, Frank K, Joseph A & Jill L M. Special welcome to Irene, our guest today. Thanks for bringing a little sunshine, we haven't seen much of it since last November 2010.

**Apologies:** Dorrie, Trixie, Max, Jane & Maree. Late phone call received from Patricia.

Special note: If you can't make it to the meeting, where possible please send apology as early as you can, so Jean isn't receiving apologies via phone diverted to her mobile. An email would be just as good.

### Phone calls:

John saw the information in the local paper- he hasn't come to today's meeting.

Jenny also read it in the paper- not here at the moment.

Kelly caught the information on the Community Notice Board on Channel 7 - wasn't able to make it.

It was suggested that we need a couple of signs made to direct new comers to the meeting room. Teresa has volunteered to organize them. We meet in Kawana Library, but entrance via the rear doors.

### General Business:

\* \$200 cheque has been sent to the TNA Ass. We do hope that Irene will place a reimbursement for her flights to the Coast. *Yes, I forgot to hand over the receipt from TNA Aus but have by now sent via post ~ Irene.*

#### \* Conference Exhibition:

Dawn will look at doing a poem. Irene has asked that an A1 sheet size be used for presentation of exhibits. As it closer to the conference, one month out preferably, we are to let Irene know the amount of space that is required.

Jean has volunteered to use one of her bonsai's and incorporating someone's face. Teresa will be able to do the printing using her business equipment.

\* Irene has brought the book "Striking Back" with her, it is for sale if anyone wants to purchase it from the association. Joseph has placed a hold on it.

\*At the last meeting the topic "Therapies Which May Help Relieve TN Pain" had been taken from the book "Striking Back".

\* The Caloundra Weekly wants to do a story on TN. We need volunteers to tell your TN tale. This is free advertising for the group and TNA Australia; it would be a waste if we didn't take the opportunity.

### Members Report:

**Sherryl M:** Has found that a sinus infection has aggravated her TN but she is happy to be here. Irene noted folks who attend support group meetings have a better handle of their pain, even when it is aggravated.

**Jean B:** She has been free from pain since July 2010. Great news. Jean is still taking all of her medication.

**Joseph A:** The pain started after going to the dentist. He went to his doctor then after 8-9 months the pain was gone. Joseph finds the Support Group helpful. At the moment he takes B12, nothing else as the pain is nearly gone. Before he eats, he prays to be able to eat without pain. And he is very thankful he is able to eat without pain. He isn't taking any acidophilus at this stage.

Irene responded: acidophilus/bifidus are good bacteria that helps rebalance the eco-system in your gastro intestinal track; and can enhance B12 absorption (*instead of the parasites having first choice*).

We discussed the necessity of taking Folic acid. Irene said that for the purpose of remyelination, she is not aware that folic acid is of any relevance. On the other hand, too much folic acid can be counter the B12 benefits.

Nutr Rev. 2007 Oct;65(10):451-8.

### **If high folic acid aggravates vitamin B12 deficiency what should be done about it?**

Johnson MA.

Source: Faculty of Gerontology, Department of Foods and Nutrition, Dawson Hall, Building 1010, University of Georgia, Athens, GA 30602-3622, USA.

#### **Abstract**

The most common cause of vitamin B12 deficiency in older people is malabsorption of food-bound vitamin B12. Thus, it is suggested that the recommended daily allowance of 2.4 microg/d be met primarily with crystalline vitamin B12, which is believed to be well absorbed in individuals who have food-bound malabsorption. There is concern that high intakes of folic acid from fortified food and dietary supplements might mask the macrocytic anemia of vitamin B12 deficiency, thereby eliminating an important diagnostic sign. One recent study indicates that high serum folate levels during vitamin B12 deficiency exacerbate (rather than mask) anemia and worsen cognitive symptoms. Another study suggests that once vitamin B12 deficiency is established in subjects with food-bound malabsorption, 40 microg/d to 80 microg/d of oral crystalline vitamin B12 for 30 d does not reverse the biochemical signs of deficiency. Together, these studies provide further evidence that public health strategies are needed to improve vitamin B12 status in order to decrease the risk of deficiency and any potentially adverse interactions with folic acid.

PMID:17972439[PubMed - indexed for MEDLINE]

**Jill:** Three weeks ago, Jill was diagnosed with Diabetes 2, not great news. Her face pain stopped about 3 months ago, although she only has finished her medication 3 weeks ago. She is still pain free. Jill asked if anyone uses an electric toothbrush and thinks that the vibration has brought on some morning pains. A few nodules were seen about the room. Irene suggested the use of a small toothbrush instead. She also commented that there were studies that indicated Vitamin D deficiency is common in diabetes 2.

**Andrea:** Excellent news, it has been 6 months since her MVD and she is feeling great. (Irene) This is testimony of a good outcome and is important for the group, especially newcomers. We need folks with successful treatment to come back to support and inspire others in the group. Being empowered with knowledge allows discussion and planning your pain journey with your doctor.

**Dawn:** Her pain at the moment is 2-4 out of 10. Dawn is coping and knows her triggers, she takes Endep. Irene: Hasn't got TN, her mother had the condition. This made her investigate the condition on her mother's behalf.

**Jim:** He has been pretty good since last meeting. Gabapentin helps him as he finds he has a slow build up of pain. Takes 300mg X1 and has coping mechanisms when the pain starts. He has long gaps between bouts of TN. Irene explained how the drug works -peaks and trough. By taking the medication on a set time basis, it helps the medication stay on an even level. Jim is learning to self-medicate.

**Rebecca:** The medication that she is on is 200X2 Gabapentin, 1X125 mg Endep taken at 8.30 pm. Sometimes she has electric shock and stabbing pain of her lower right side; also stabbing pain in her eye with a constant ache. She has side effects when she takes too much medication. Rebecca also has some numbness across her face. This has been caused by a glassing attack, our hearts go out to her. Rebecca finds that 125mg Endep puts her straight to bed, so if she wants to go out, she would have to forgo her Endep at 8:30 pm, bears her pain till she comes home. Irene suggested perhaps she could spread out the Endep, have some control of her pain and still be able to go out. It was suggested Rebecca discussed this with her doctor, and to help her remember such things on her next visit to her doc – she should go with a written list.

**Peter:** Peter has been pretty good for the last 3 weeks since his MVD. This is Peter's second MVD, one on each side. He now joins that small group of TN patients that have the condition on both sides of their face.

At the moment Peter is reducing his medication (Tegretol 6X200 mg) weekly. He will know for sure if he is OK when he is fully off his medication.

**Frank:** 'All quiet on the western front', so the saying goes, in other words all is well. He is careful with his left side. The medication regime he is on at the moment is 800mg Tegretol spread out during the day. Frank is mindful that it can strike at anytime.

**Teresa:** Fantastic celebrations, it has been 3 years and 2 months since her MVD, but who is counting? Teresa ended by saying "We are normal aren't we?"

**Jean W:** Jean is taking 2100mg Gabapentin per day. There is scar tissue behind her eye and Jean has to put up with the stabbing pain in her eye and severe head pain. Her T Nerve is fine both on her right and left side after having MVD's on both sides.

**Irene** was welcomed and had been asked to give a talk on the Conference or "When medications and alternative therapies haven't worked for you." .. So for her talk, she decided to combine both topics.

"When medications and alternative therapies haven't worked for you - sounds rather grim doesn't it?.. so what's next? Well, let me start by saying nothing ever seems so simple as it hasn't worked."

When things don't work you need to explore why? But to be able to do that you need to have knowledge to even question why.

When you say you the medications haven't worked...

1. Was it because it was not taken properly?
2. Was it because the medication had too many undesired side effects?
3. Was it the correct medication?
4. Was EVEN the diagnosis correct? We can't even begin to treat until we have a diagnosis.
5. There are many mechanisms of action for pain.. does your physician know enough to trial these different actions of stopping pain?

Before you head out towards your destination you need to **PLAN**.

Plan – your mode of transport. Plan your route, plan for stops; plan what happens after you get there ; but to plan requires **Decision making**... to make decisions you need to have information... ah! but inaccurate information would lead to poor decisions and can have ill consequences. So you need **Good accurate Information**: The information allows you to **Choose wisely & accurately**. It also allows you to **Explore** your options fittingly.

You need to make your plans when you can, definitely not when you are in pain or heavily drugged. Don't wait till you are in dire pain, and in tears, or desperate... for a desperate person tends to make desperate decision – which is not usually the best one.

*So where would you get all these information?*

*Where can you gather this knowledge from? And from who?*

**TNA Aus National Conference !!**

At our conference – I don't just bring you the TREATMENT!! I know that's all you care about... you want to have the problem fixed overnight..., but unfortunately, that is not going to happen.

**To help you choose wisely,** I have brought in research scientists besides physicians, because I want you (and your doctors) to understand the science of it ☺

Sadly many GPs may only see one TN case in their life time so they don't think TN is their daily bread Understandably they are not about to invest their time attending TN conferences over one patient ...so the onus once again falls back on you.

In order to help yourself the best way possible you need to know the basics, the root of the problem and the way out. You need to keep learning, keep searching ... so that when you hit what seems the end of the road, you might spot a light at the end of a tunnel. Just as after every storm there is a rainbow... you need to search the sky to see it.

I have done the work in organising the venue, done a deal so that you can afford to attend, planned the program, invited the experts to speak to you; they are prepared to give up their days, and travel to the venue at their own expense to teach you.... **Can you afford not to be there?**

**Financial report to date;**

Funds misplaced from September 2010, Due to change over of support group leaders, this money was found in a business envelope. It is now in the correct place, let's hope that that doesn't happen too often. That is why it is important to have regular help from someone in the group. The position is still vacant.

Amount being.	\$ 32.00 +
Funds taken from meeting 09.04.11	
Amount being.	\$ 37.50 +
Expenditure, milk.	\$ 2.00 -
Previous balance.	\$214.55 +
	-----

Balance at end of meeting. \$282.05

Next meeting: **21st May 2011** (Rear entrance to Kawana Library).

Thanks Teresa for taking the meeting notes.

*Jean Williams*

*My personal thank-you to Jean for the lovely lunch and chauffeuring me to and from the airport.~ Irene.*

**DISCLAIMER**

The information provided in this Newsletter is of a general nature only and is not intended to replace medical advice. Any views of a medical or therapeutic nature expressed are the views and opinions of the author and are not necessarily the views of Trigeminal Neuralgia Association Australia.

Before considering or undertaking any medical or therapeutic treatment described please seek advice from a Qualified Medical Professional.

Trigeminal Neuralgia Association Australia does not accept liability for any adverse consequences that may arise from following any treatment or advice described in this Newsletter.

This Newsletter remains the property of Trigeminal Neuralgia Association Australia. No part of this Newsletter may be copied without the express written permission of the Trigeminal Neuralgia Association Australia. ©



“ Man had always assumed that he was more intelligent than dolphins because he had achieved so much...the wheel, New York, wars, and so on, whilst all the dolphins had ever done was muck about in the water having a good time. But conversely the dolphins believe themselves to be more intelligent than man for precisely the same reasons.”

## Laughter is the Best Medicine

These are from a book called Disorder in the American Courts, and are things people actually said in court, word for word, taken down and now published by court reporters that had the torment of staying calm while these exchanges were actually taking place.

ATTORNEY: What was the first thing your husband said to you that morning?

WITNESS: He said , 'Where am I, Cathy?'

ATTORNEY: And why did that upset you?

WITNESS: My name is Susan!

---

ATTORNEY: What gear were you in at the moment of the impact?

WITNESS: Gucci sweats and Reeboks.

---

ATTORNEY: Are you sexually active?

WITNESS: No , I just lie there.

---

ATTORNEY: This myasthenia gravis , does it affect your memory at all?

WITNESS: Yes.

ATTORNEY: And in what ways does it affect your memory?

WITNESS: I forget..

ATTORNEY: You forget? Can you give us an example of something you forgot?

---

ATTORNEY: Do you know if your daughter has ever been involved in voodoo?

WITNESS: We both do.

ATTORNEY: Voodoo?

WITNESS: We do..

ATTORNEY: You do?

WITNESS: Yes , voodoo.

---

ATTORNEY: Now doctor , isn't it true that when a person dies in his sleep , he doesn't know about it until the next morning?

WITNESS: Did you actually pass the bar exam?

---

ATTORNEY: Were you present when your picture was taken?

WITNESS: Are you shitting me?

---

ATTORNEY: So the date of conception (of the baby) was August 8th?

WITNESS: Yes.

ATTORNEY: And what were you doing at that time?

WITNESS: Getting laid.

---

ATTORNEY: How was your first marriage terminated?

WITNESS: By death..

ATTORNEY: And by whose death was it terminated?

WITNESS: Take a guess.

---

ATTORNEY: Doctor how many of your autopsies have you performed on dead people?

WITNESS: All of them.. The live ones put up too much of a fight.

---

ATTORNEY: Do you recall the time that you examined the body?

WITNESS: The autopsy started around 8:30 PM

ATTORNEY: And Mr. Denton was dead at the time?

WITNESS: If not, he was by the time I finished.



## 2011 Meeting Dates

<u>State</u>	<u>GROUP</u>	<u>Date &amp; Time</u>	<u>Venue</u>	<u>Group Leader/s</u>
ACT	Canberra	21st May 10.30am-12.30pm	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 6254 6640
NSW	Sydney	2nd July 1:30 – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads, Toongabbie.	Kim Koh ☎ 02 97431279
	Sydney CBD	4th June 10:00 – 12:30 pm	St. James Parish Hall Level One, Phillip Street	Irene Wood ☎ 0413 363 143
QLD	Brisbane	11 <sup>th</sup> June 1.30-4.00pm	30 Ridley Road Bridgeman Down	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	21st May 1:00 pm	Kawana Library, Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	18 <sup>th</sup> June 1.00 – 4:00pm	Venue: Please contact Sera	Sera Ansell ☎ 07 47516415
S.A	Adelaide	29 <sup>th</sup> May 2pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush /Greenhill Rd	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	21 <sup>st</sup> May 1:50 – 4:00 pm	Glenorchy Library Enter via Barry and Cadell Sts Speaker: Dr Tony Eldridge	Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989
VIC	Melbourne	11 <sup>th</sup> June 1.30 – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

This Newsletter remains the property of Trigeminal Neuralgia Association Australia. No part of this Newsletter may be copied without the express written permission of the Trigeminal Neuralgia Association Australia Inc. ©

The Publisher reserves the right to reject, alter, or refuse to use any material supplied in the Publisher's sole discretion or disapprove of any information that is deemed not suitable.

Contact: TNA Australia P O BOX 1611, CASTLE HILL, NSW 1765 Australia ☎: 02 4579 6226;

Email: tna\_sydney@yahoo.com or irene.wood@tnaaustralia.org.au

Website : www.tnaaustralia.org.au