



Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

Making A Difference

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.

November 2012

What is IASP?

The International Association for the Study of Pain (IASP) is the leading professional forum for science, practice, and education in the field of pain. Membership in IASP is open to all professionals involved in research, diagnosis or treatment of pain. ~ (*IASP website*)

Every other year, the International Association for the Study of Pain (IASP) brings together the world's leading experts on the research and treatment of pain, creating a dynamic learning and networking environment to discover, explore, and share the ever-changing advances in the study of pain. This year, IASP returns to Italy for the 14th World Congress on Pain in Milan. ~ (*IASP 14th World Congress on Pain*)

Yes, I was in Milan and attended the 14th World Congress on Pain. It was a very intense learning time for me. Each day began at 8:30 AM with a plenary lecture followed by topical workshops. The day could stretch to 8:30 PM... IF one was greedy for more information gathering - a self-induced punishment.

After doing 2 refresher courses my head nearly exploded when I sat in on the Pfizer Symposium "Pain Perception – a state of mind?" and that was just the first day. Between lectures there were posters to view. Each poster viewing session has around 500+ posters. Each day there were 2 viewing sessions- morning and afternoon. Each session carried a different topic – hence 500+ new posters to see each time, each day. Without exaggeration by the end of the week, my brain cells busted out in zits! ☺

I have been encouraged to share the expenses incurred so you can better appreciate the value of your membership. TNA Australia has very little excess funds and I have always been reluctant to ask for what it cannot afford. Trips like this in the past have often seen me bearing major portion of the cost. This time I was able to claim reimbursement for conference registration, 2 X Refresher Course, as well as my economy airfare from Sydney to Italy. Personally, I was still out of pocket by @ \$2000.00. The information I gathered is strictly for your benefit. We hope you realised that your yearly \$25 membership fee although covers mostly the printing and postage cost, there are expenses beyond printing and posting. Some folks have the misunderstanding that if they were to receive their newsletter electronically- there would be no need to pay membership fee. Also we hope to reaffirm that everyone on the committee and I, are all unpaid volunteers.

It is also becoming tremendously taxing to oversee an organisation, provide patient support & information, keep abreast with pain information / reading and researching, beg for funds, run a conference, and liaise with SGL and others, etc. Whilst overseas, I had to check my E-mail often in case of emails in distress - which there were and quite a few. I wondered how many TN patients when they go on holidays would check their E-mail to provide TN support ? It has been 12 years now, surely it must be time for a new leadership. More hands are also needed to lighten the workload. Please give serious considerations if you can lend a hand or wish to take over.

Prerequisites: Passion & Responsiveness. Reliable; Own & Can use a computer (computer literate)

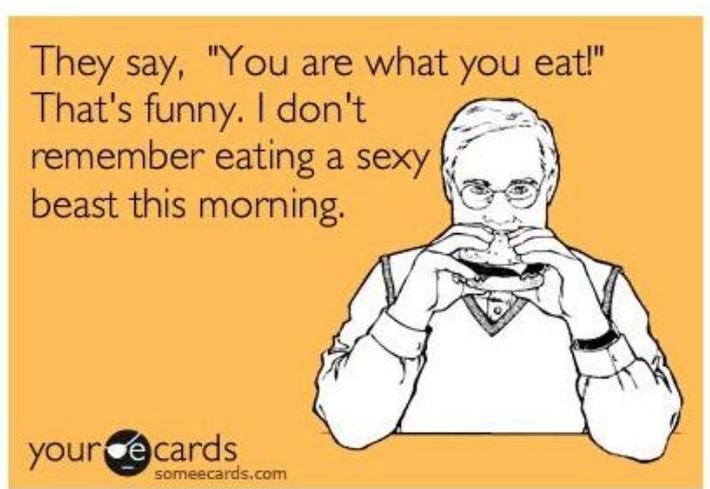
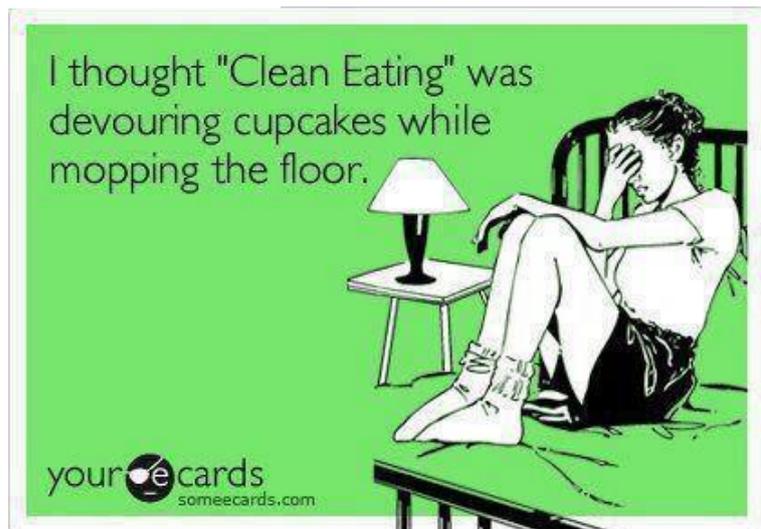
Hands Required Urgently to: 1. Maintain membership database; 2. Send out Information pack 3. Publish monthly newsletter.

In one of our Fund Raising projects for 2013, Mary has proposed we do a Saturday BBQ at a major retail store. I am excited at this prospect because besides raising much needed funds, this exercise would also offer the opportunity to raise public awareness on trigeminal neuralgia. **We need volunteers to man the BBQs.** We are hoping to be able to do this in every state, not simultaneously, (would be ideal if we could, and then declare a TN day?) but we would be happy with your willingness to help out – date can be negotiated. If you are prepared to lend a hand let us know, the Association will do the negotiating, and all you have to do is turn up on the day and cook / serve sausage *sangers*, and talk about TN and TNA. I know there are many of you who have cooked a barbeque or two before, so I look forward to your enthusiastic response.

Irene.



If you can't afford a doctor,
go to an airport - you'll get a
free x-ray and a breast exam,
and; if you mention Al Qaeda,
you'll get a free colonoscopy.



Below are my notes from the Trigeminal Neuralgia workshop. These are my notes. Any error is strictly mine. Deciphering one's own scribble a month or more after the event can be mind boggling.

Trigeminal Neuralgia: Recent Advances in Diagnosis and Therapeutic Options

Presenters: N. Attal, G. Cruccu, J. Zakrzewska, M. Sindou

Giorgio Cruccu (Italy) - did the introduction & diagnostic problems regarding TN.

I think he said TN diagnostic criteria still remains almost the same (?) but Europe and American medicals; and Neurologists and Neurosurgeons have come to some important agreement on the guidelines for TN.

Much of these guidelines for the diagnostic criteria for trigeminal neuralgia can be found in these 2 papers

- **Practice parameter: the diagnostic evaluation and treatment of trigeminal neuralgia** (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology and the European Federation of Neurological Societies. *Neurology* 2008 Oct 7;71(15):1183-90.
- **AAN-EFNS guidelines on trigeminal neuralgia management.** *Eur J Neurol.* 2008 Oct;15(10):1013-28. Epub 2008 Aug 21. - Cruccu G, Gronseth G, Alksne J, Argoff C, Brainin M, Burchiel K, Nurmikko T, Zakrzewska JM;

They agreed on the **Terminology**: 1. **Classical TN** and 2. **Symptomatic TN** – these are based on the etiology; whereas Typical and Atypical refers to symptomatology

1. **Classical TN** – is idiopathic or due to a neurovascular conflict. In more than 90% of Classical TN the cause is due to a vascular loop around the trigeminal root and the base of the pons – causing demyelination, allowing for ectopic discharge and cross talking between fibres.

Symptoms: paroxysmal pain, sudden, short very intense pain, **has trigger**, (such as washing face, talking etc). Together with these characteristic of pain, another aspect is territory: unilateral and limited to the trigeminal division. Of special interest is V3 – it is not strange for patients with classical TN to complain of pain in the lower lip, chin, up to the temple. (that is the V3 area). It is important to remember the angle of the mandible is innervated by cervical root (C2- C3) and is no longer a trigeminal territory. **Diagnosis** is based on pain description.

2. **Symptomatic TN** – are patients with secondary neurological diseases.

15% of these patients with typical symptoms are secondary to neurological diseases such as MS (plaque on the trigeminal root) or benign tumour of the cerebellopontine angle.

- If tumour is aggressive – you may have anaesthesia or even anaesthesia dolorosa, but never TN.
- In his recent study of 130 MS patients - some have TN, some have other trigeminal sensory disturbances in the TN territory. Using a computer system in 3D, they were able to map the type of lesions that cause trigeminal neuralgia, and the lesions in the rostral part of the spinal trigeminal complex - the cause for constant pain or anaesthesia.

Take home message: do not rely on patient's symptoms. The 2 methods that would confirm diagnosis are: MRI and trigeminal reflexes – reflexes are abnormal in Symptomatic TN (87%). Please run all lab investigations to be sure. Normal classical TN does not have sensory deficit. Bilateral neuralgia and sensory deficits only occur in Symptomatic TN.

Nadine. Attal (Neurology- France): Pharmacotherapy of trigeminal neuralgia

Carbamazepine – block sodium channel - still remains the choice of treatment for TN.

Others she listed : Oxcarbazepine, Lamotrigine , Baclofen.

Insufficient evidence: Tizanidine, Gabapentin, Phenytoin, Clonazepam, topical capsaicin, Valporate.

(Bear in mind that the evidence is only available if someone writes it up...it does not mean these medications do not work for TN)

She then mentioned the use of Botox A, reported by a recently small controlled study done by a Chinese group with an efficacy of 68%. (to my knowledge Botox last for only 3 months- then pain return.) She also mentioned IV therapy but used usually in emergency condition.

Marc Sindou (Neurosurgeon, France): presented an overview of surgical techniques used in the treatment of TN in particular MVD.

“we operate only on patients with long history of pain, and they have been treated by neurologists or pain doctors with medication/s, and good imaging.”

He has done 1857 MVD, and 3250 Thermo- Rhizotomy (*RF to most of us*)

Surgical Options

1. Lesioning Procedures (Percutaneous)

we must take care with these techniques – via Foreman Ovale approach.

- Thermo-rhizotomy
- Balloon Compression
- Glycerol Neurolysis
- Radio Surgery (stereotactic) – Gamma knife, LINAC, cyberknife. (90Gray on the nerve- one isocentre - single dose)

Thermo – rhizotomy: the target should be the Triangular Plexus (Retro-gasserian) – less complication.

By putting the electrode into the V1, V2 / V3 we can target the trigger zone exactly.

Literature Review: Thermo-Rh

	Initial Pain Relief	Recurrence	Cases
Sweet	99%	37%	702
Kanpolat	97.6%	25.1%	1600
Sindou	99%	7%	2352

(perhaps the question to ask here is - How many ended up with Anaesthesia Dolorosa?)

He said his low recurrence rate (7%) is due to the “ strong lesions = low recurrence.”

He said one “must balance between hypoesthesia and recurrence. We must choose and adapt to patient’s choice of hypoesthesia or recurrence.

- Percutaneous Techniques are effective techniques but they have side effects.

The lesser the post op. hypoesthesia = the higher the risk of recurrence.

The stronger the hypoesthesia – the more risk of Anaesthesia Dolorosa.

Stereotactic: - 2 targets ; Trigeminal Root Entry Zone (TREZ) or the Root. Dose is 90 Grays

He quoted Pollock’s paper on radiosurgery for TN – a Review (meta analysis)

Results: pain free / with no meds. = 10 – 61%

New facial numbness = 6 – 54 %

2. Micro-vascular Decompression

90% of TN patients have a compression, & the long term result of MVD proves the significance of this compression.

MVD= moving the artery away from the nerve.

- A keyhole approach – putting the artery away from the nerve.

- “ I try not to insert material touching the nerve –as not to create a new compression. The material just sustain the artery away from the nerve.”
- ...“our results show that with Teflon square touching the nerve – the late results is not as good than if we don’t insert material.” (?)
- Avoid the 8th nerve – can cause hearing loss or vertigo.
- Preserve the superior petrosal vein – veins drain the cerebellum. If we destroy the vein – can cause brain swelling or hydrocephalus
- Free Root of arachnoid adhesions from Root to Meckel’s Cave: thickened arachnoid can block vessels
- Avoid mechanical vaso-spasm: use topical papaverine – 2 -3 drops.
- **Don’t put the prosthesis contacting the nerve – can cause new compression.**

His results - 15 years - long term outcome :

84% pain free **without contact** (contact of prosthesis)

68 % with contact (touching the nerve)

Long Term Efficacy of MVD: Cure = Pain Free : no pain & no medication.

He suggested using high resolution MRI / 3 D imaging when making surgical decisions.

Joanna Zakrzewska (Orofacial pain, UK): What to do when surgery fails for TN:

- there are many patients who have a wonderful response from surgical procedure.
- But there are a small group who don’t do well.
- Looked at evidence for response from quality data and recurrences - from cohort studies.
- Consider patient’s expectations – their confidence and concerns about surgery; and the effect on their quality of life.
- Consider patients who have had surgery and still in pain, how are they coping?
- A patient in despair may commit suicide - we need to still think that this is a disease that can kill.

“GAMMA KNIFE - what is particularly disturbing about the GK events are that **you can get delayed pain relief; but the other thing is delayed sensory loss.**

It’s an enormous kick to feel the GK has worked, but 6 months later – **like one of my patient - get struck down with Anaesthesia Dolorosa.** And now it is an enormous psychological blow to patient - we need to explore more.

Micro-vascular Decompression is purely to address the compression.

Complications: Sensory loss – Anaesthesia Dolorosa – ants crawling her over her face the whole time, or severe Anaesthesia Dolorosa patient that she picked her face till she needed plastic surgery for reconstruction. We need to think of these complications - temporary and permanent.

What about those who failed surgery within 3 months ?

4 patients opted to have no further treatment- and yet after a while the pain receded and they were pain free. **Sometimes no action might be of benefit.**

What happens when a patient returns ?

- Go back to the drawing board - to the diagnosis. Have they been correctly diagnosed?
- Do we listen to the patients – the description of their pain- Is it the same ?
- Do patients have electrical pain, or have the pain become dull? Has it got a burning quality? That is no longer trigeminal neuralgia
- Temporal Feature ? - We have to listen.

- Site of pain? Is it still in the same position? V1 pain is rare.
- SUNCT/ SUNA: major factors - Autonomic symptoms – a lot of patients reported autonomic symptoms.
- **The importance of autonomic symptoms in trigeminal neuralgia** : Neurosurgeon sent questionnaire - 10 yrs postsurgical asking patients if they had autonomic symptoms. 67 % responded. They found a lot of patients reported autonomic symptoms.

Conclusion: take autonomic symptoms carefully, particularly in V1.

If they have a neurovascular compression – MVD may help. But if they don't have a neurovascular compression – manage these patients medically because they haven't got classical TN.

Although MVD patients may have recurrence of pain it does not seem to have as much impact on quality of life.

- **Investigation:** use the high quality MRI; medical management = go back to the medical guideline,
- **Important** for patients to go to support groups so they know they are not alone.
- If they have been hyped up that surgery is going to be the answer, to get a failure is going to be psychological very difficult. Meeting other patients with recurrence, or patients with success – is of crucial importance.

The evidence base is still poor. **Recurrences** – rethink the diagnosis, repeat surgery might be an option still, medical management is also an option.

If you have V1 pain with autonomic features – it is worthwhile doing Indomethacin test.

J. Zak: “after surgery, the paroxysmal pain have gone but the burning pain or constant pain remains - Use Tricyclic antidepressants. “

M. Sindou: **ATYPICAL Facial Pain** – must not be operated on - it is not trigeminal neuralgia.

Differentiate between typical trigeminal neuralgia which is paroxysmal pain and Atypical neuralgia: which is paroxysmal pain plus the burning pain.

Atypical trigeminal neuralgia: MVD if done properly, is able to relieve not only paroxysmal pain but also relieve background burning pain. MVD can relieve the burning pain in Atypical trigeminal neuralgia **if the patient was free of previous surgery”**

After the workshop ended, I took the opportunity to introduce myself to Prof Marc Sindou. Although we have corresponded on various occasions, and I have followed his work with great admiration, I have never met him. What was surprising was he didn't go “Huh? Who? “ Instead he said “I do read your publications (our monthly newsletters), I may not reply, but I do read them and then I file them.” When I left the hall I was beaming and was 10 feet taller.

Some of my other highlights:

- Orofacial Pain Refresher Course: “Burning Mouth Syndrome”
 - Drugs can cause burning sensation on the tongue.
 - Geographic Tongue: 69% associated with dysgeusia (altered taste) – clonazepam 1st drug
No treatment but Good news is that it last for about 10 years, after that it goes away on its own.”
 - Taste buds are surrounded by pain neurons -the ability to taste bitter -pre menopause
 - May be related to chorda tympani hypofunction
- **Patient Education** was listed in a few lectures as an important tool under Treatment
- Prof Phyllis Butow: “give patients the opportunity to make informed decision in partnership with you.”
- “Optimism lowers pain: best possible self-management.”

Irene

SUPPORT GROUP MEETING REPORTS

ADELAIDE SUPPORT GROUP

Burnside Civic Centre

Sunday 30th September, 2012

PRESENT: Kevin, Bert, Sue & David, Faye, Ann, Kerri, Kim & Alan, Graham and Liz.

APOLOGIES: Kerryn, Kelly, Angela.

FINANCES: Opening Balance: \$307.22; Interest \$0.75; Donations: \$37.50. Balance: \$345.47:

WELCOME: Graham welcomed all in attendance

MEMBERS UPDATES

Kelly and Kerryn are both unwell and unable to attend today however we have a brief update provided by telephone.

KELLY: is still waiting for an appointment at the RAH Pain Clinic. She is seeing a naturopath and taking natural remedies. She is trying to cope without taking prescription medication.

KERRY: Has an appointment at the Flinders Pain Clinic in Mid October.

KERRI: Was diagnosed with TN 5 years ago and prescribed Tegretol to which she was allergic. She then tried Gabapentin. She had a cryofreeze procedure at the RAH which gave relief for six weeks then the pain returned. She had an MVD soon after and was pain free for 18 months after which her TN returned much worse. She has pain along the V2.

Kerri does not experience "tics" and it was thought that she might have anaesthesia dolorosa. When Kerri's pain returned her husband took her to the hospital and as she was very hot as a result of her extreme pain they put a fan on her. Kerri was told there was nothing more that could be done for her and to take Endone. Although worried about the risks of another MVD, she already has numbness in half her face and horrible bug crawling sensations, Kerri said she would have a second MVD but her Doctor wants to get her pain under control with medication. The group suggested Kerri get a second opinion as some of our members have undergone second MVDs which have been successful. (Graham mentioned that in the latest newsletter there are articles on TN management after failed MVD operations). Kerri has read "Striking Back" and is familiar with her illness. She gets information from Facebook and finds American sites particular helpful. She is seeing a pain specialist who has a sister with TN, he also has 3 other patients suffering from TN.

Irene: The whole purpose of MVD is to decompress. A high resolution thin Cut MRI with contrast should help determine such a compression. But as Kerri said – she doesn't have tic. Also, please note that the ablative / percutaneous- procedures used to treat TN are only helpful in true tic. I would like to stress **Not all face pain is trigeminal neuralgia**. Look up "paraesthesia" and deafferentation pain."

My suggestion is to have an MRI done – so to eliminate tumours such as Meningiomas - tumour development after MVD is not uncommon – which can cause such face pain.

FAYE: Continues to be really well and considers herself fortunate after hearing some of the horror stories within the group. She doesn't take any medication. Faye had a percutaneous procedure. When she was in hospital she met a lady who also had suffered TN for 35 years and was taking Tramil drops, so Faye now takes them as a precaution. She has a plan should the pain return and has medication on hand.

SUE: Also gets very red and feels burning when her pain is bad. She has been told it is to do with toxins that are released during pain. Sue feels relatively lucky as her medications are holding her TN at a bearable level. She experiences little 'bursts' but they are not too bad.

DAVID: David's neuralgia was caused by shingles. He has had no pain for 6 weeks and has reduced his medication, however his pain is returning. He has been told it can take 5 years to recover from Post Herpetic Neuralgia. He is also taking B12. He cannot tolerate Tegretol.

ANN: Winter has been a challenge. She is 'ticking' more. She had an MVD about 20 years ago and has been told she cannot have further surgery due to damage and scarring. She is now having terrible stabbing pain in both eyes. She doesn't think it is regular TN. She wants an answer. She has increased her Topiramate to 850 mg. Ann feels she is in a better place mentally through learning about her condition and she feels she is responsible for managing her illness. Ann stressed the importance of relaxation with massage and/or chiropractic treatment to ease the tension around the neck and shoulder areas where tension can cause pain.

KEVIN: Kevin attends the RAH Pain Clinic and is doing well. His TN is due to a problem with his jaw. He takes 4 x 150gms Lyrica daily. If he tries to lower the dose he feels 'jolts'.

BERT: Bert is taking 300 mg Slow Release Tegretol tablets daily but is not sure if he is taking them correctly as the package does not give instructions. It was suggested Bert speak to his chemist. *(Extract from MedicineNet.com:-Take this medication (Tegretol slow release) by mouth, usually two times a day with meals, or as directed by your doctor. Swallow the tablets whole. Do not crush, chew, or break them, which can destroy the drug's long action and may increase side effects. .For the treatment of trigeminal nerve pain, do not take more than 1,200 milligrams per day. Avoid eating grapefruit or drinking grapefruit. Take this medication regularly at evenly spaced intervals in order to get the most benefit from it. Remember to use it at the same times each day to keep the amount of medicine in your body at a constant level. Inform your doctor if your condition does not improve or worsens .- Graham).*

Bert also wanted to know what to say when seeing a Doctor. Graham referred to notes from the last National Conference and said that Doctors appreciate well prepared patients who are able to give a complete summary of their symptoms. He suggested members keep a pain diary and record when, where and frequency of attacks, description of pain, e.g. stabbing, burning, crawling, etc., medications taken, dosage and times, what relief, if any, was experienced.

GRAHAM: Continues to be well after his MVD two and a half years ago.

OTHER BUSINESS: At this stage no one has come forward to take over the role as Support Group leader but two members have indicated they will "help out" as required. It was agreed that meetings be continued on a bi-monthly schedule and that Graham book the venue for 2013 meetings. Graham advised the group that at our November meeting we will have a specialist from the Flinders Pain Clinic to give a talk. He encouraged all members to attend and asked that they advise him so that adequate seating arrangements can be made. It will be our final meeting for the year and our Christmas break up so bring a plate to share if you are able.

MEETING CLOSED AT 4.10 p.m. with lively chat and friendship and delicious cake (thanks Ann!).

NEXT MEETING: 2.00pm Sunday 25th November 2012 at The Civic Centre, Burnside Town Hall. Guest Speaker: Dr P Cornish, Senior Consultant, Pain Management Unit, Flinders Medical Centre. **Please advise Graham if you are attending ☎ 8392 2781**

Irene is coming to this meeting and look forward to catching up with members.

Funny Doctors Quotes:

- * By the time he was admitted, his rapid heart had stopped, and he was feeling better.
- * On the second day the knee was better and on the third day it had completely disappeared.
- * She has had no rigors or shaking chills, but her husband states she was very hot in bed last night.
- * The patient has been depressed ever since she began seeing me in 1983
- * Patient was released to outpatient department without dressing.

MELBOURNE SUPPORT GROUP
Maroondah Federation Estate Ringwood
13 October 2012

Evelyn welcomed everyone especially new TN patients. We hope their first meeting will be beneficial.

Present: (13) Gail A.; Alan & Joy C.; Evelyn D.; Richard & Verna H.; Nita & Rob McK.; Bill P; new attendees: Brenda Y., Jennifer M., Willy P. and his wife Sri S.

Apologies: (8) Barbara A.; Audrey B., Din D.; Alf H.; Beryl & Rob O.; Neil & Joan T.
Apologies by phone: Will Renshaw, Bruce Graham.

Treasurer's Report: There was a carry forward balance of \$1010.60, donations of \$51.00 at the last meeting, credit for deposits for library books not returned \$140.00; expenses of \$61.50 for stamps and insurance for use of the meeting room for three occasions, leaving a balance of \$1140.10.

Evelyn reported that an e-mail from Rob O explained that the planned co-operation between himself and Jo Z had not progressed, so the application of some of our funds for community outreach has not proceeded yet. Irene had expressed doubt to Evelyn about the use of funds in dental and medical journals, saying this had been done with some limited benefit by members of TNA Medical Advisory Board.

Newsletter: Evelyn described the benefits of the newsletter and urged that everyone be paid-up members to support the Association and learn from the experience of others.

Support Group Leader: Evelyn has given notice that she will retire from the position of SGL at the end of 2012 so she again outlined some of the duties of an SGL and encouraged everyone to think seriously about taking on this role in 2013 to keep the Support Group going. New members keep coming indicating there is still a need for the group! So far no one has indicated any interest in replacing Evelyn.

Reports from members:

Evelyn was happy to report that she has remained pain free despite fleeting stabs of pain during winter. Now taking 2 x 1000 mcg sub-lingual B12 daily, probably will drop to one tablet/day in summer. First experience of TN was in 2006 in the right jaw. This was followed by treatment with the anti-epileptic drug Valpro for a short time (stopped due to intolerance to side-effects), then traditional acupuncture, laser acupuncture, mindfulness meditation and Vitamin B12 as above. Now happy and grateful to be pain free!

Brenda had facial shingles in 1999 as a result of an emotional situation. Five years later she suffered awful pain but put up with it for 18 months til it went away. She recalled that an uncle and his cousin had experienced similar pain. For 13 months she had no pain but an emotional trigger brought lightning bolt, electric shock attacks which lasted for many months followed by another long period of no pain when she could sleep well. A few months ago the pain returned – this time a deep pain. She had found a Trigeminal Neuralgia booklet in a library when in WA and was amazed to find that other people had the same painful condition. Three months of acupuncture did nothing; sessions with a chiropractor didn't help; her husband suggested botox but she did not follow this through – now at this meeting she has met someone who has botox treatment! Brenda experiences sharp pain on the right side when she begins to eat – after the first few chewing actions the pain settles. Now she has found a chiropractor in Camberwell who focuses on neurological conditions. He has taken her on as a project and Brenda has had marked improvement – now down to 8 – 9 attacks a day. She sees him twice a week for a month and has jaw, head and neck exercises to do in between treatments as well as massaging the affected side of the face. Brenda couldn't keep taking the drugs Endep, Tegretol and Trileptol. Triggers: touch, speaking, starting to eat, wind and going out in the cold, shower water on the right side of her face. Brenda has also practised Transcendental Meditation. The

support group was brought to Brenda's attention by naturopath Christine Gozlan, a former guest speaker at our group.

Bill had an MVD in 1998 – he was lucky that his GP had family experience of someone with TN so diagnosed Bill's TN straightaway. Acupuncture and laser treatment were not effective so Bill was referred to a neurologist. The drugs prescribed were no good and after some episodes of intense pain Bill saw a neurosurgeon, who was excellent. He had an MVD and has experienced no pain at all since.

Verna recalled that a person at a recent meeting, Peter R., had an MVD but still had pain and was on Trileptol. Verna herself has Botox treatments and she has to take 50 mg/daily of Endep, taken at night and even though it slows her down the pain has gone. If she does not keep up these medications, her blood pressure goes up.

Willy first had TN pain on the right side 10 months ago and after having two teeth extracted still experienced 40% pain. A neurologist prescribed Tegretol. This was later increased and was then fairly effective. Triggers for Willy are eating hard things, talking too much/long. An MRI done 2 weeks ago identified a lump on the brain so he is to see a neurosurgeon next Friday with a view to removal. He will have a more detailed MRI. Willy taught himself an ancient form of Chinese meditation which has helped him. Wife Sri also did the same meditation (1 hour a day for a month – sitting quietly, hands on thighs, tip of the tongue behind the upper teeth, complete focus on the breath). After experiencing migraines for 16 years she is now free of them. Willy found TNA on the internet and contacted Irene Wood. We wish him well and look forward to a further report at the December meeting.

Jenny experienced searing pain and found this group on the internet – she just wishes it was closer to East Keilor! She has MS but finds too many side effects from the drugs. She started taking Gilenya for MS then had pain in the left side back tooth and in that jaw and earache on that side. She was in contact with her neurologist who confirmed that TN can be associated with MS. (Three ladies at today's meeting have MS and TN – both conditions involve breakdown of the myelin sheaf that protects nerves.) Painkillers do not help and Tegretol was no good for Jenny. Triggers were eating a roll, eating hot or cold foods, wind. Jenny had an MRI as part of her MS treatment but no MRI since then. That MRI confirmed white spots of plaque on nerves. Jenny has had MS for 25 years and TN for 10 years. She is very particular about diet now – no saturated fats at all, no bread, no carbs – she eats mostly greens and fish and is happy with the unintended benefit of weight loss. She takes no drugs for TN and only Gilenya for MS.

Gail also has MS and TN. She is making progress now with one injection of Copaxone a day for MS. She is able to play bowls again, though still has facial numbness as a result of a surgical procedure for TN. This has also resulted in dry eye condition requiring eye drops four times a day. Gail sent Evelyn a letter from a NSW MS sufferer about the effectiveness of Cytotec for TN – the sender refers to it as 'miracle medication'.

General discussion: Gail suggested placing books such as *Striking Back* in public libraries. Brenda emphasised the usefulness of booklets/pamphlets in community/general information sections of libraries.

Thanks to Neil and Joan for leaving all necessities in the meeting room, to Alan and Joy for setting up and afternoon tea and all who helped pack up.

The last meeting for the year will be on Saturday 1 December 2012, 1.30 – 4.00 pm at Maroondah Federation Estate, 32 Greenwood Ave Ringwood, Mel 49 H10.

Guest speaker : Dr Anthony Coxon B. App. Sc (Chiro), DACNB, Chiropractor of Camberwell who focuses on neurological disorders. A new member at the October meeting reported great results from his treatment so come along and hear what he has to say. Irene Wood will be visiting as well. Hopefully this will not be the last meeting of the Melbourne Support Group!

Evelyn Diradji

CORRESPONDENCE

Dr Ticklay (Zimbabwe): Hi Irene, I have had my MVD done on the 20th September . Am in Capetown waiting to be able to travel by air on the 18th Oct back to Zimbabwe. Have tapered the dose of Tegretol gradually to 100mg at night only from 600mg/day. I am hoping to stop it by the time I get back to Zimbabwe. Thank you for your assistance, much appreciated.

F. Snell (NSW): Many thanks for the information that you sent me. In particular your experience of viewing Dr Dexter in operation is extremely helpful, as is the personal experience of Christine's M. I am very grateful to have all these information before my surgery next Wednesday.

Kim: Hi there Irene, I just wanted to let you know that it's been nearly a year for me now on the Tegretol. I still have some pain in both sides of my face, but do not want to increase the dose as it will make me too tired. I also wanted to say thankyou for sending me the emails and in some small way i think it makes me feel a little better, knowing that I am not alone.

Marilyn W: I had a MVD on 30th May - The whole experience was amazing. I was in hospital 8 days. If anyone wants to ask about the recovery I found it took about 2 months till I was 100% longer than I anticipated but it is a big operation. Wonderful now.

In Memory in of:

ROD TAYLOR

Loving daughter: Susan Taylor

Gifts made in memory of dear ones to TNA Australia are acknowledged with a special letter of thanks and are also Tax deductible.

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.

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2012 Meeting Dates

<u>State</u>	<u>Group</u>	<u>Date & Time</u>	<u>Venue</u>	<u>Group Leader/s</u>
ACT	Canberra	TBA	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 6254 6640
NSW	Sydney	1 st December 1:30 – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Rds	Kim Koh ☎ 02 97431279 Kim Smith
	Sydney CBD	1 st December 1:30 – 4:00pm	Combined Christmas meeting at Toongabbie	Irene Wood ☎ 0413 363 143
QLD	Brisbane	Please ring Tony /Leonie to confirm 1.30 -4.00pm	30 Ridley Road BRIDGEMAN DOWN	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	17 th November 1:00pm	Kawana Library, Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	TBA 1.00 – 4:00pm	Carville Senior's Villa 35 – 37 Diprose St PIMLICO	Sue Macey; Sera Ansell ☎ 07 47516415
S.A	Adelaide	25 th November 2:00 – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush /Greenhill Rd	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	TBA	Glenorchy Library Enter via Barry and Cadell Streets	Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989
VIC	Melbourne	1 st December 1.30 – 4:00pm	Maroondah Federation Estate, 32 Greenwood Ave RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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