



# *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.

## **February 2011**

*Happy New Year!!*

News received from our TN friends in and around Toowoomba and Brisbane area is that they are all safe and were not directly affected by the flood. Our thoughts and prayers also turn to our friends in the south who is facing the ever sprawling inland sea. We hope that they too would be spared from the rising inundation.

Conference Registration Form for our 4<sup>th</sup> National Conference is attached to back of this newsletter. Do take advantage of the early bird rate and send in your registration before April 31<sup>st</sup>.

The conference not only gives you wonderful opportunities to learn from the best, make friends, come out of your isolation, you will enjoy the support of people who truly know your pain.

We look forward to catching up with you at the conference.

Below is a poem that might inspire you -

**The Victor** by C.W. Longenecker

If you think you are beaten, you are.  
If you think you dare not, you don't  
If you like to win but think you can't,  
It's almost a cinch you won't.

If you think you'll lose, you're lost.  
For out in the world we find  
Success begins with a fellow's will  
It's all in the state of mind.

If you think you are outclassed, you are.  
You've got to think high to rise.  
You've got to be sure of yourself before  
You can ever win the prize.

Life's battles don't always go  
To the stronger or faster man.  
But sooner or later, the man who wins  
Is the man who thinks he can.

*Irene.*



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

Mrs Christina Evans, NSW

Mr & Mrs C.R. Seymour, NSW

Bob and Christine Anderson, U.K

### TNA Australia's Memorial Tribute to "Pip" Bennett

The family has requested that in lieu of flowers or other tribute, friends might use this occasion to make a donation in Pip's memory to TNA Australia's Tribute Fund.

*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 activities.*

*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. Please send an email to advise details.*

J Neurosurg. 2010 Dec;113 Suppl:184-90.

### **Trigeminal nerve dysfunction after Gamma Knife surgery for trigeminal neuralgia: a detailed analysis.**

Matsuda S, Nagano O, Serizawa T, Higuchi Y, Ono J.

#### **Abstract**

**OBJECT:** Gamma Knife surgery (GKS) is an effective treatment option for intractable trigeminal neuralgia (TN). The incidence of trigeminal nerve dysfunction, such as facial numbness or dysesthesia, has been reported to be higher than previously published, and the degree and prognosis of trigeminal nerve dysfunction has not been well evaluated. The authors evaluated the incidence, timing, degree, and outcome of trigeminal nerve dysfunction after GKS for TN.

**METHODS:** One hundred four patients with medically refractory TN were treated by GKS. Thirty-nine patients were men and 65 were women; their median age at GKS was 74 years. Using a single isocenter and a 4-mm collimator, 80 or 90 Gy was directed to the trigeminal nerve root. Follow-up data were obtained at clinical examinations every 3-6 months after GKS. Each patient's pain-control status and degree of trigeminal nerve dysfunction were recorded. The incidence, timing, and degree of dysfunction (assessed using the Barrow Neurological Institute facial numbness scale [BNI-N]) and the prognosis and factors related to trigeminal nerve dysfunction were analyzed.

**RESULTS:** The median duration of follow-up in these patients was 37 months (range 6-121 months). At the final clinical visit, a pain-free status was still observed in 71 patients (68.3%). In 51 patients (49.0%), new or increased trigeminal nerve dysfunction developed at a median of 10.5 months (range 4-68 months) after GKS. In 24 patients (23.1%), this dysfunction was categorized as BNI-N Score II, in 20 patients (19.2%) as BNI-N Score III, and in 7 patients (6.7%) as BNI-N Score IV. Among those patients, 18 patients, including 3 patients with BNI-N Score IV, experienced improvement in nerve dysfunction between 24 and 108 months after GKS (median 52.5 months). At the final clinical visit, 43 patients (41.3%) reported having some trigeminal nerve dysfunction: in 26 patients (25.0%) this was categorized

as BNI-N Score II, in 13 patients (12.5%) as BNI-N Score III, and in 4 patients (3.8%) as BNI-N Score IV. The only independent factor that was correlated to all trigeminal nerve dysfunction and also specifically to bothersome trigeminal nerve dysfunction was pain-free status at the final clinic visit.

**CONCLUSIONS:** The incidence of trigeminal nerve dysfunction after GKS for TN was 49%. The severity of the dysfunction improved in one-third of the afflicted patients, even in those with severe dysesthesia at long-term follow-up. A strong relationship between TN and good pain control was identified.

PMID: 21121801 [PubMed - indexed for MEDLINE]

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[J Neurosurg.](#) 2010 Dec;113 Suppl:160-7.

### **Gamma Knife surgery for trigeminal neuralgia: a review of 450 consecutive cases.**

Verheul JB, Hanssens PE, Lie ST, Leenstra S, Piersma H, Beute GN.

#### **Abstract**

**OBJECT:** The success rates and side effects of Gamma Knife surgery (GKS) in patients with trigeminal neuralgia (TN) are not fully clear. A comparison of data across previous reports is hampered by differences in treatment protocols, lengths of follow-up, and outcome criteria. The purpose of this paper is to contribute to knowledge of the efficacy of GKS in TN by reviewing data in a large group of patients with this disorder, who were treated with a uniform treatment protocol and evaluated using a well-established pain scale and Kaplan-Meier analysis.

**METHODS:** The authors reviewed 450 treatments in 365 patents with medically refractory TN who were treated between June 2002 and October 2009 at the Gamma Knife Center Tilburg. In all patients 80 Gy was prescribed, with a single 4-mm isocenter located at the root entry zone (REZ). In 79 patients repeated GKS was performed using a uniform dose of 80 Gy, which was delivered, in a highly standardized manner, to a spot anterior to the position of the first treatment. Follow-up was obtained by reviewing the patients' medical records and conducting telephone interviews. Outcome was assessed using the Barrow Neurological Institute (BNI) pain scale and the BNI facial numbness scale.

**RESULTS:** The median follow-up period was 28 months. In the idiopathic TN group, rates of adequate pain relief, defined as BNI Pain Scores I-IIIb, were 75%, 60%, and 58% at 1, 3, and 5 years, respectively. In the multiple sclerosis (MS)-related TN group the rates of adequate pain relief were 56%, 30%, and 20% at 1, 3, and 5 years, respectively. Repeated GKS was as successful as the first. An analysis of our treatment strategy of repeated GKS showed rates of adequate pain relief of 75% at 5 years in the idiopathic TN and 46% in the MS-related TN group. Somewhat bothersome numbness was reported by 6% of patients after the first treatment and by 24% after repeated GKS. Very bothersome numbness was reported in 0.5% after the first GKS and in 2% after the second treatment.

**CONCLUSIONS:** In this study the authors analyzed outcomes of GKS in a large cohort of patients with TN; uniform treatment consisted of 80 Gy delivered to the REZ. The initial and long-term outcomes of pain relief and sensory dysfunction are comparable to recently published results at other institutions, where similar outcome criteria were used. These data should prove helpful to assist patients and clinicians in their TN management decisions.

PMID: 21121797 [PubMed - indexed for MEDLINE]

*Irene wonders: what is "bothersome numbness"? and VERY bothersome numbness?? There are folks walking around today who have developed Anaesthesia Dolorosa from failed Gamma knife treatment yet there is no mention of it at all in any GK papers. At best, it has been described as "persistent numbness."  
These folks may have "bothersome" numbness but are they also in 24hrs X 7 days of relentless pain?*

## Meeting Reports

### ADELAIDE SUPPORT GROUP

2.00 p.m. 28 November 2010

**ATTENDANCE:** (12) Ann T, Angela M, Kevin S, Kerri L, John A, June & Roger O, Grace A, Bert J, Joan E; Graham & Liz B.

**APOLOGIES:** Laurel S, Norma J.

**FINANCE REPORT:** Brought forward: \$73.65. Donations: \$26.50. Balance: \$100.15.

**WELCOME:** Graham welcomed all to the final meeting of the year and introduced Kerri L attending for the first time with her father John (supporter) from Queensland.

**GENERAL BUSINESS:** A list of next year's meeting dates were handed out. At this stage no guest speakers have been arranged. Members were reminded that subscriptions were due in January 2011 and renewal application forms were now available from Graham or could be downloaded from the TNA website. Graham informed members of a radio programme "Talking Health" to be aired that night on Radio 3AW featuring Andrew Danks, Chairman of TNA Medical Advisory Board, who would be speaking about TN, including surgery and TN support. Graham gave instructions how to listen to the program via the 3AW website and said he would be downloading the programme onto his iPod and will bring it to the next meeting. A further reminder was given regarding the next TN Conference which will be held in the Hunter Valley in September 2011. Start planning now.

#### REPORTS:

**GRAHAM:** It is now 18 months since his MVD and is absolutely pain free and well. Angela asked if the operation had been immediately successful. Answer is yes, the minute he awoke from the surgery he was pain free. He takes no medication.

**JOAN:** is very well. Totally recommends the MVD. Should her TN ever recur, she would not hesitate to have further surgery.

**GRACE:** Much the same. Her intense itching is slightly relieved with cold compresses. Grace has a mole on her face (opposite to her TN) and has been advised not to have it removed. An MRI showed narrowing of her carotid artery. She is prepared to have an MVD if her TN returns.

**KEVIN:** Has been attending our meetings since their inception. Two specialists had diagnosed TN by symptoms only. It was only upon consulting Dr. Z and requesting surgery that he was actually diagnosed as having TMJ. He was referred to Professor G who ordered an MRI which showed the cartilage in his jaw was worn. In October he was given a Cortisone injection under sedation which has been completely effective and apart from some early discomfort he is now pain free. He is still taking Valporate, but he hopes to discontinue that after his next appointment with Professor G.

Graham asked Kevin if Tegretol had helped him initially, but as he was allergic to Tegretol. Kevin could not confirm that it had been helpful or given relief. June asked if his jaw clicked, answer = yes, slightly. Kevin wondered if other TN patients might in fact have TMJ and that this be more fully looked into before TN treatment commences.

**ANN:** Hasn't been very well lately. She had to have a tooth crowned which affected her TN badly. Her dental treatment is not yet complete so she has increased her medication until things settle down. Because Ann has a diagnosed chronic illness, namely TN, she is able to access free dental health care. Ann continues to have a very positive, happy outlook.

**KERRI:** Kerri is a young woman with 3 young children. Her TN began 3 ½ years ago. Tegretol caused severe allergic reactions, including rash and swollen tongue. She was then prescribed Dilantin. Her first TN bout lasted over 6 months. She saw Dr. N who recommended a cryofreeze. This was done but

she was pain free for only 6 weeks and now continues to experience excruciating pain on a daily basis. After the cryofreeze she experienced "bugs crawling on her face" and was told that this was due to the nerves regenerating. Her whole body would jump which alarmed her family. She was referred to the neurosurgery department at the RAH and is undergoing an MVD next week. She is understandably apprehensive about the operation. Graham gave Kerri a copy of an article from the July 09 newsletter by Christine M, a registered nurse describing her experience of undergoing MVD surgery. Graham had found this article very useful and reassuring when he had his own MVD. We wish Kerri well and look forward to hearing that she is much better. A rather sweet postscript - Kerri's 9 year old daughter when asked what she wanted for Christmas replied, "that Mum not have that terrible pain, that's all I want". Let's hope her wish is granted.

**ANGELA:** Came to the July meeting when Graham was overseas. She was in extreme distress with her TN and had been so for 7 months, spending time in and out of hospital. She came to the group for support and heard about Dr. Z, she then asked her neurologist for a referral. During the two weeks waiting for her appointment she felt her TN was waning so when Dr. Z suggested a radiofrequency procedure she decided to delay the treatment. At the present time Angela is quite well, just experiencing facial sensitivity. She avoids getting over tired and cold wind. She described her TN attacks as mind blowing pain like a needle through her face which leaves her face tender. She has recently experienced terrible pain on the other side while in bed, but not during the day and asked if it was possible to have TN on both sides of the face. TN pain is almost always limited to one side but unfortunately it can happen on both sides though this is very uncommon. Angela has a plan of action if and when her TN returns. She will go to Dr. Z immediately and undergo a cryofreeze. An MVD is not an option for Angela.

**JUNE:** Had been quite well for 3 months but unfortunately her TN has returned and she was having great difficulty speaking. Roger, speaking for her, said she is having an MRI next week and has an appointment to see the specialist the following week. Medication doesn't agree with her, she is just taking anti-depressants. June is considering a glycerol procedure if offered. She is not prepared to undergo an MVD at this time. We wish her well with her decision.

**BERT:** Bert underwent a radiofrequency procedure a few months ago after which he developed a sinus infection. His face is still sore. He still has slight 'flashes'. He still experiences pressure pain in his temple area which he thinks was due to being restrained during the procedure. Bert is seeing a jaw specialist next week. Cold wind affects Bert badly – everyone agreed to that. He is not taking any medication and his 'flashes' are bearable.

The meeting closed at 3.30 p.m. and the group continued chatting over some delicious Christmas goodies and a cup of tea. Thank you to everyone for coming along and providing such lovely treats. (Joan, your fairy cakes were heavenly!! Liz). MERRY CHRISTMAS AND HAPPY AND HEALTHY 2010 TO TNA STAFF AND ALL SUPPORT GROUPS.

NEXT MEETING – 2.30pm Sunday 30TH January 2011 at the Burnside Town Hall Civic Centre, corner Portrush / Greenhill Road,

### **Program for 2011**

Sunday 30th January 2011

Sunday 27th March 2011

Sunday 29th May 2011

Sunday 31st July 2011

Sunday 25th September 2011

Sunday 27th November 2011

# MELBOURNE SUPPORT GROUP

"Ringwood Room" Ringwood Library

1.30 p.m. 4 December 2010

In the absence of Evelyn who is travelling overseas, Alan C. welcomed everyone to the last meeting of the year, on a warm summer Melbourne afternoon.

**Present: (15)** Barbara & Robert A.; Maree & Glenn B.; Alan C.; Doug E.; Bruce G.; Nita & Robert McK.; Beryl & Rob O.; Bill P.; Joan & Neil T.; Stephen Z.

**New: (2)** Lisa T. Accompanied by her mother Irma..

**Apologies: (6)** Evelyn & Din D. (overseas); Joy C. (ill); Toni B. (wedding); Alf H.; Tom P. (phoned for clarification of dates).

**National Conference 2011:** Alan reminded all present of the next Conference to be held in the Hunter Valley of NSW and urged everyone to seriously consider attending as these conferences are a wealth of information available through local and international presenters. The conference cost is also very affordable to members as the 2 day 3 night conference, including all meals and accommodation, is heavily subsidised by TNA Aust. for the benefit of members. Conference details will be available in future newsletters.

**Treasurer's Report:** Alan donned his Treasurer's hat and gave the financial report. A cash in hand balance of \$222.35 was carried forward into the October meeting and donations from attendees totalled \$53.10. Expenses totalled \$16.50 for meeting room insurance leaving a balance of \$258.95 carried forward to this meeting. Alan stressed the importance of a gold coin donation by those attending each meeting, as this is our only form of income which we need to function as a Support Group in our mission to support TN sufferers and broaden the awareness of TN in the wider community.

**10<sup>th</sup> Anniversary:** Alan was requested by Evelyn to discuss with members, ways that we might care to recognize or celebrate the 10<sup>th</sup> anniversary of our Support Group at the February meeting in 2011 (12 February). Irene Wood has accepted an invitation to attend. Neil T. suggested that Professor Andrew Danks also be invited to attend. Bill P. suggested a list be compiled of members on our books who have had an MVD and how long ago. This would be of interest to new sufferers when contemplating various alternatives of treatment.

**Meeting dates for 2011:** Joan T. has booked this same venue for our meetings in 2011. Dates are: February 12<sup>th</sup>, April 9<sup>th</sup>, June 11<sup>th</sup>, August 13<sup>th</sup>, October 8<sup>th</sup> and December 10<sup>th</sup>. Evelyn will be sending out this schedule of dates to all members on the mailing list in the New Year.

## **Reports from members:**

**Alan C.** Reported for **Joy** that the balloon compression procedure done by Andrew Danks in June was not successful. However, Mr Danks advised that it could be tried again but with a longer compression time for the procedure.

**Toni B.** Reported via e-mail that she after much deliberation, she had a MVD done by Andrew Danks in August. MVD was successful. She will report personally to a meeting when she is able to attend.

**Nita McK.** Has constant pain in her top jaw. She saw her neurologist at Cabrini but he was no help to her at all. She does not have MS. The meeting suggested she seek other opinions to try to get relief from her pain.

**Maree B.** phoned Dr Danks after our last meeting and had an appointment two weeks later and she was happy with discussions. Maree works at a Call Centre and has met another worker who has TN. She is keen to get the message out into the Barwon area about our Support Group. Maree now has pain in the

top of her palate – Neurofen helps in small doses. She has now obtained her MVD file from The Alfred which details her medical journey with TN. She advised others to also get their files if they move their treatment to another provider.

**Bruce G.** has had 3 years pain free controlled by 100mg Tegretol a.m. and 100mg p.m. The pain has now returned and after changing his blood pressure medication his GP suggested increasing Tegretol to 200mg morning and night. Unfortunately he started having double vision and vertigo. On one occasion he collapsed and was taken to hospital by ambulance. He spent a pleasant day on his back, staring at the ceiling, between all sorts of tests which proved nothing. By that time he went home. His GP then suggested 100mg a.m. and 200mg slow release Tegretol p.m. The double vision problem continued p.m. but the am treatment was okay. He then looked up the Tegretol data sheets and found that his problem was one of 40+ side effects this drug can have, but he considered this was minor compared to the pain of TN. Bruce now takes his 200mg nightly dose just before going to bed so the Tegretol can enjoy its own dizzy spell by itself while he sleeps.

**Stephen Z.** has had a second MVD and has dropped Tegretol down from 600mg to 200mg per day. This MVD has been successful. His operation was done by Dr Mark Dexter at Westmead Hospital in Sydney, so he could be close to his son for post-op. assistance.

New sufferer **Lisa** from near Albury has had TN for 20 months. She was misdiagnosed as having a sinus problem through her pregnancy. The TN pain was much worse after the birth of her son so she saw an ENT surgeon who was no help. She then saw a neurologist who said she was too young to have TN. She took 900mg of Tegretol daily initially but is now on Lyrica 300mg a day and also morphine. She has seen Dr Danks and is on the waiting list for an MVD. Lisa also has some allergies.

The meeting closed at 2.30 p.m. and a delicious afternoon tea of Christmas cheer was enjoyed by all present. Thanks to all those who set up for the meeting, packed up and those who provided and served the refreshments. Alan wished everyone a happy Christmas season and a safe New Year.

Next meeting: Saturday 12 February 2011 1.30 p.m – our special 10<sup>th</sup> anniversary meeting!



# SYDNEY SUPPORT GROUP

Toongabbie Public School

4 December 2010

Present: Cecelia C, Harista K, John K, Stuart B, Gundel B, Frank M, Ingrid K, Ieuen R, Brian H, Mary K, Lilian B, Vera R, Wilma C, Jan T, Brian O'D, Dutch D, John D, Kim K, Jeanette B, Henry B, Rose H, Peter H, Elizebeth T, Lloyd T, Anne P, Laurie P, Nola W, John W, Jocelyn S, Oscar, Max P, Beryl T, Reg McB, Margaret McB, Kerry G, Tom G, Ken F, Bernice R, Jeanette F, Emily S, Jesse T, Lois W, Reg W, Kim S, Irene W, & Dr. Mark Dexter.

**Apologies:** Marion A, Ben H, Pam & Pat S; Van B, Alaster McD; Jan G & Christine R (Canberra)

Von later rang to say she got lost and by the time she made it to the school, she could not locate the hall. Sorry, you missed us.

Kim K and Irene welcomed everyone to our Christmas meeting which was a combined meeting for Toongabbie and Sydney CBD members. We also extended a special welcome to members from Canberra who had come to hear Dr. Dexter speak. It was great to see new faces, especially those from Canberra.

Member Updates:

**Harista K**- Had MVD 6 months ago. She is pain free, but does have some numbness,

**Marg F** –pain is controlled with 600mg Tegretol and 400mg Epilim without side effects.

**Kerry G** - from Canberra. Has had TN for 2 years. The pain is tolerable with 600mg Tegretol but does find it causes sleepiness and forgetfulness at work.

**Wilma C** –Just joined the Association but has had TN for 14 years with some remissions. The pain has returned recently. She is considering trying Botox as suggested by her neurologist.

*Irene: there is no long term study of repeated Botox injections for face pain. We know that each Botox injection provides up to 3 months of pain relief. But what happens if the toxin was injected at regular intervals of 4 times a year. Financially- it would cost \$500 each time.*

**Brian H** from Port Macquarie. Has had TN for 5 years with some remission periods he has used a range of drugs. He had an MVD 5 weeks ago and has been pain free since his surgery.

**Dutch** – is currently in control with 1200mg Neurontin 3 times a day. She receives the Neurontin through the pain clinic which makes it available at the pensioner rate.

**Cecelia** –had MVD 6 months ago and is pain free. She believes she should have done it 9 years ago

*Irene: many MVD patients make that same comment on hindsight. Usually it is the fear of surgery and it takes time to overcome this fear, and you also need to have faith in the doctor.*

We then welcomed **Dr Mark Dexter** who gave an extremely informative presentation on the MRI scan. We enjoyed a beautiful selection of Christmas goodies. Thanks to all the members who contributed to the afternoon tea, helped to set up and pack up and also to Henry and Jeanette for providing the Christmas raffles. *The notes above were provided by Kim S. – many thanks.*

## **Thin Cut MRI : Dr Mark Dexter.**

(thin cut MRI with 3 D volume acquisition)

Dr. Dexter began with a brief anatomy of the Trigeminal nerve. He then went to explain that an MRI scan is a basically a high resolution of your brain, and the difference in machines such as 1.5 Tesla vs 3 Tesla. (strength of the magnets). A 3 Tesla gives an even clearer picture, on the other hand, if one has foreign body such as a stent/pacemakers – then you might not be able to have this MRI.

The big advantage of MRI is that there is no radiation at all, hence no risk of malignancy. Down side is a high strength magnet which causes problem to pace makers etc.

Often time there is an injection of dye for contrast, but it has no iodine in it.

Normally it takes about 40 minutes, but it is a very narrow tunnel and could be claustrophobic.

Quality of the scan also depends on the experience of technician taking the pictures, and the quality of the machines.

When we do a MRI for face pain we ask for the “Thin Cut sequence” focused on the trigeminal nerve. This is different from the standard MRI ordered by your GP or your neurologist. The Trigeminal nerve is about 2 mm across & won't see on a standard scan.

### **Why should you have an MRI scan if you have face pain?**

To make sure nothing else could be causing the pain.

There are lots of things that can cause face pain, one of them is trigeminal neuralgia, but anything else along the course of the trigeminal nerve can cause a similar type of pain; eg: tumour in your brain or the back of the skull or a scar in the brain stem.

The **MRI scan is not a diagnostic tool for TN**. The diagnosis of trigeminal neuralgia is based on the history, where you get the pain, the type of the pain.

1 % of those with face pain have tumour.

MS – 2% have TN

Both sides of face with TN – 1 in 5 chances you have MS.

He then showed us in various slides the difference between standard MRI and Thin Cut MRI, as well as the many nasties that could be causing the same TN pain.

Some of the secondary causes of TN are: trigeminal schwannoma; tumour in the covering of the brain called meningioma- these tumours were pressing on the trigeminal nerve causing the typical TN type pain. Tumour inside of the cerebellum causing distortion of the cerebellum and pressing on the Trigeminal nerve also can cause TN pain; as well as Multiple Sclerosis - white plague in the brain stem- showing demyelination. A rare condition called petrous apex granulomatosis – was another that could cause the same pain as trigeminal neuralgia.

He did his best to teach us how to read a Thin Cut MRI scan, how and where to look for the Trigeminal nerve and how to look for vascular compression. I hope those present have learnt how to spot their trigeminal nerve on their MRI.

He then took us through the MVD procedure, and introduced us to blood vessels that compressed the trigeminal nerve in various TN patients undergoing MVD.

The inconvenient truth is that no matter what treatment – pain can come back. What happens when pain comes back? Dr. Dexter outlined some points and basically emphasised that “you need to have a plan for when pain comes back.” Some of these pointers were:

Make the plan when not in pain, Avoid emergency rooms, Know what works, Know how to use it (your medication). He also gave tips on how to be a good patient.

For more details of his talk – you will have to attend the national conference in September. ☺

*The above is a summary of Dr Dexter's talk. Any error is mine.*

*Irene.*

Attention - SYDNEY CBD next meeting is on the 5<sup>th</sup> of February starting at 10 AM.

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## SUNSHINE COAST SUPPORT GROUP

Saturday, 15th January, 2011

Meeting Postponed.

Irene and I felt that it was better to postpone the meeting to allow folks who had suffered losses, and those who wished to help in the recovery effort, the time required to achieve those objectives. My heart goes out to those who have suffered personal losses, a loved one or loss of their home.

Irene was able to defer her visit and will see us all in April, with a little bit of sunshine in her handbag.

Our next meeting will be **Saturday 19th February**. Keep safe.

*Jean Williams.*

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## Canberra Support Group

Canberra Labor Club, Belconnen

Saturday 15 January 2011

Present: Wilma C and Jan G

Apology: Brain W

Meeting was not convened due to lack of numbers.

Wilma attended the Toongabbie meeting in December and was able to confirm that others from Canberra had also attended. We discussed various options available to treat TN, and as Wilma was interested in pain management, she was given Dr Aggarwal contact details.

Jan had been contacted by 2 people who suffer from face pain and hopefully had been of some help.

Next meeting is set for **19 March** in the Barbara Byrne Room at the Canberra Labor Club, Belconnen.

*Jan G.*



### 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.

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## Correspondence Corner

**Lynette W.** - I would like to wish you a merry safe Christmas and happy New Year. This is the time of the year to express appreciation to you for the dedication you have given to your newsletters & TN assn. I am a CFS /fibromyalgia sufferer for many years. 2 years ago diagnosed with TN; now polymyalgia rheumatica these past few months. I am unable to get to any meeting here in Brisbane as my body says NO.

I have learnt so much from the newsletters (even though I was a registered nurse for 50 odd years) and they make me feel almost human again. I make a cuppa and absorb each article every month. Please take care have a nice few weeks away from such a full on agenda. May God bless you & keep you

**Joy de M.:** thought I should tell you that since my last bout of neuralgia and coming off my prescribed drug from Neurologist, I have been taking B12 - Methylcobalamin, @ 5000mcg tablet form for the past 30 months and have had no pain recurrence whatsoever. I miss a tablet now and then due to the strength but I figure this doesn't matter. I am so HAPPY. Do not want another MVD - had one about 18 years ago.

**Allaster McD :** Read with the usual interest your November Newsletter. However, I did discover a slight error in your report on the last CBD Support group meeting which perhaps should be corrected lest it misleads someone. It relates to my own case regarding the drop in pain level. It occurred, not in taking the new "Vimpat" but in tailing off the Trileptal. When I was down to a mere 75mg morning and night, the pain began to reduce and has continued to remain so with an occasional surge. Needless to say I have not commenced taking the Vimpat despite have \$110 worth sitting here.

**Hilary W:** typical man had sealed the letter before I could explain why we haven't been to meetings. (*so she scribbled them on the outside of the envelope ☺!*) Keith had knee replacement on the 11 of Nov 2010, then 2 days after he came home he had a heart attack – still very fragile. No driving for 6 weeks. I am still on crutches, can't sit down; AD still the same.

*We send our love and wish you both full recovery; hope to see both your smiling faces at our meeting soon.*

**Margaret W.:** having been a sufferer of trigeminal neuralgia for 25 years, thought I'd write and tell you I finally plucked up courage and had MVD done 11 months ago, by Dr. R. Ferch at John Hunter Hospital. He had done some training with Dr. Dexter. In my case the operation was a great success and life is so much better.

**Beth C.** I have often wondered how many other members of TNA there are who like me are too isolated to ever attend any of the meetings and why we never hear about their experiences with TN.....

*Irene: That's a good question. And I have an equally good answer. Unless they write to me, I am not able to publish their experiences! ☺ Fact is also, those who are isolated do not do as well as those who attend meetings. Folks who attend meetings enjoy learning together; and benefit from the mutual support.*

.....I am 77 but still doing accountancy work so I found taking medication interfered with my brain. I was only taking small amount of Tegretol. I have had TN for about 12 years. Three things finally made me decide to do something about it. One was that you don't ever recover from TN. The second was that if I was finding it hard to cope with the pain at this age how would I be as I got older and the final thing was that the younger I was when I had the operation the better. TNA Newsletter led me to Dr. Dexter and I had my operation on the 26<sup>th</sup> November. I am completely free of pain now, take no medication and my blood pressure is quite low.

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## Laughter Is The Best Medicine

Sign over a Gynecologist's Office: 'Dr. Jones, at your cervix.'

\*\*\*\*\*

In a Podiatrist's office: Time Wounds All Heels.

\*\*\*\*\*

On a Septic Tank Truck: Yesterday's Meals--on Wheels

\*\*\*\*\*

At a Proctologist's door: To expedite your visit, please back in.

\*\*\*\*\*

On a Plumber's truck: We Repair What Your Husband Fixed

\*\*\*\*\*

On another Plumber's truck: Don't sleep with a drip; Call your plumber!

\*\*\*\*\*

On a Church's Billboard: 7 days without God makes one weak.

\*\*\*\*\*

At a Tire Shop in Milwaukee: Invite us to your next blowout.

\*\*\*\*\*

On an Electrician's truck: Let Us Remove Your Shorts

\*\*\*\*\*

In a Nonsmoking Area: If we see smoke, we will assume you are on fire and take appropriate action.

\*\*\*\*\*

On a Maternity Room door: Push. Push. Push!

\*\*\*\*\*

At an Optometrist's Office: If you don't see what you're looking for, you've come to the right place.

\*\*\*\*\*

On a Taxidermist's window: We really know our stuff.

\*\*\*\*\*

On a Fence: Salesmen Welcome! Dog Food Is Expensive!

\*\*\*\*\*

At a Car Dealership: The best way to get back on your feet: miss a car payment.

\*\*\*\*\*

Outside a Muffler Shop: No appointment necessary; We hear you coming.

\*\*\*\*\*

In a Restaurant window: Don't stand there and be hungry; come on in and get fed up.

\*\*\*\*\*

In the front yard of a Funeral Home: Drive carefully! We'll wait...

\*\*\*\*\*

At a Propane Filling Station: Thank heaven for little grills.

\*\*\*\*\*

CHICAGO RADIATOR SHOP: Best place in town to take a leak

\*\*\*\*\*



## 2011 Meeting Dates

<b>State</b>	<b>GROUP</b>	<b>Date &amp; Time</b>	<b>Venue</b>	<b>Group Leader/s</b>
ACT	Canberra	19 March 10.30am-12.30pm	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 6254 6640
NSW	Sydney	5 March 1:30 – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads, Toongabbie.	Kim Koh ☎ 02 97431279
	Sydney CBD	5 February 10:00 – 12:30 pm	St. James Parish Hall Level One, Phillip Street	Irene Wood ☎ 0413 363 143
QLD	Brisbane	12 February 1.30-4.00pm	30 Ridley Road Bridgeman Down	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	19 February 1:00 pm	Kawana Library, Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	19 February 1.00 – 4:00pm	Carville Senior's Villa 35 – 37 Diprose St Pimlico	Sera Ansell ☎ 07 47516415
S.A	Adelaide	27 March 2pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Rd	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	26 February 2:00 – 4:00 pm	Glenorchy Library Enter via Barry and Cadell Sts	Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989
VIC	Melbourne	12 February 1.30 – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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**Trigeminal Neuralgia Association Australia**  
**4th National Conference**  
**September 2<sup>nd</sup> – 4<sup>th</sup>, 2011**  
**Cypress Lakes Resort Hunter Valley NSW**

**Who should attend?**

- Patients
- Care givers
- Physicians
- Psychologists
- Dentists
- Nurses
- Pharmacists
- Other health professionals.

**The Meeting provides the opportunities to**

- Learn from some of the world leading experts in pain
- Learn about TN management from our local experts
- Learn about the latest treatments and resources available
- Participate in formal and informal discussions on facial pain and management
- Better patient care
- Be better prepared to travel your pain journey

**Network ..... Learn ..... Enjoy!**

A scientific program led by international and local TN & Facial Pain experts:

- Professor Marshall Devor – University Jerusalem, Israel
- Dr. Donald Nixdorf – University Minnesota, USA
- Mrs. Claire Patterson – Founder of TNA. ( USA)
- C/A Prof. Andrew Danks – Monash Medical Centre Vic.
- Dr. Mark Dexter – Westmead Hospitals. NSW.
- A/Prof. Arun Aggarwal – Royal Prince Alfred, NSW.
- Dr Helen Boocock – Pain Management RNSH, NSW
- Dr. Andrew Zacest – Royal Adelaide Hospital, S.A
- A/Prof. Bob Smee - Prince of Wales Hospital, NSW

For more information -

Email: [irene.wood@tnaaustralia.org.au](mailto:irene.wood@tnaaustralia.org.au)

# TNA Australia 4th National Conference

**September 2011 : Cypress Lakes Resort Hunter Valley, NSW**

- 2<sup>nd</sup> Friday** – Arrival.
- 3<sup>rd</sup> Saturday** – Conference Begins
- 4<sup>th</sup> Sunday** – Conference Concludes
- 5<sup>th</sup> Monday** – Departure

**TNA Aus Members Conference Rates are subsidised.**

**Conference Registration** - includes:

- 3 nights accommodation
- All meals - Friday Dinner to Monday Breakfast.
- 2 days of conference - with morning & afternoon tea and Lunch.

**Accommodation Format: You will be sharing a villa.**

Cypress Lakes Resort offers villas with 2 or 3 bedrooms. Each villa comes with all the creature comforts, including air conditioning and heating, private bathrooms, large living and dining rooms, a gourmet kitchen with refrigerator, tea and coffee making facilities and high tech entertainment units with satellite television.

**2 Bedroom / 2 bathroom Villa** = Quad occupancy (2 couples)

**3 Bedroom / 2 bathroom villa** = Double occupancy (1 couple) + 2 Twin occupancy.

Twin occupancy = 1 person per room but shared bathroom.

**2 Bedroom / 2 bathroom Villa** - Single Occupancy / per bedroom

**1 bedroom Villa** .

All quotes are in Australian Dollars (AUD)

Villas	By 30/04/11	01/05/11 - 31/07/11	01/08/11 – 15/08/11
<b>2 Bdrm + 2 Bathrms Villa</b> Quad Share	Members Only \$425 p/person	Members Only \$550 p/person	Members Only \$650 p/person
<b>3 Bdrm + 2 Bathrms Villa</b> 1 Double + Twin share	Members Only \$425 p/person	Members Only \$550 p/person	Members Only \$650 p/person
<b>1 Bedroom Villa</b> Double Occupancy	Members Only \$635 p/person	Members Only \$685 p/person	Members Only \$750 p/person
<b>2 Bdrm + 2 Bathrms Villa</b> Quad Share	Non Members \$600 p/person	Non Members \$700 p/person	Non Members \$775 p/person
<b>2 Bdrm + 2 Bathrms Villa</b> Single person per room	Non Members \$800 p/person	Non Members \$900 p/p	Non Members \$1000 p/p
<b>1 Bedroom Villa</b> Sole Occupancy	\$1500 p/person	\$1600 p/p	\$1800 p/p
<b>1 Bedroom Villa</b> Double Occupancy	\$810 p/person	\$880 p/p	\$950 p/p



## Conference Registration Form

**TNA AUS 4th NATIONAL CONFERENCE**

ABN33914644101

**September 2<sup>nd</sup> – 4<sup>th</sup> 2011**

**Cypress Lakes Resort Hunter Valley NSW**

TNA Aus members and partners conference fees are subsidized. If your partner is not attending the plenary sessions, please use the “Not attending Conference Sessions” column.

Heads / seats counts. It is appreciated if we are not charged for what is not used.

All quotes are in Australian Dollars (AUD)

Accommodation - Please Write Type Required			
Conference Registration	No/ People	Arrival Date	Amount
TNA Aus Members			\$
NOT attending Conference Sessions			\$
Non TNA Member			\$
Health Professionals			\$
Day Delegate @ \$220 per person	3 <sup>rd</sup> & 4 <sup>th</sup> September 2011		\$
Coach Transfer	No/ People	Estimate	
Domestic Airport to Conf. Venue		@ \$30 p/p	\$
Conf. Venue to Domestic Airport		@ \$30 p/p	\$
<b>TOTAL</b>			\$ AUD

Name : \_\_\_\_\_ (list names of all guests)

Address : \_\_\_\_\_

\_\_\_\_\_ State \_\_\_\_\_ p/code \_\_\_\_\_

Tel : (H) \_\_\_\_\_ (W) \_\_\_\_\_

I accept that Trigeminal Neuralgia Association Australia Inc. is not responsible for any loss or damage to person/s or personal belongings while travelling to and during the conference; or to any of the holiday venues. This disclaimer applies irrespective of the cause.

Signature : \_\_\_\_\_ Date \_\_\_\_\_

Return completed forms with payment to: **Conference Registrar**  
**Trigeminal Neuralgia Association Aus.**  
**359 Terrace Rd, Nth Richmond, NSW 2754**

Cheque or Money Order made payable to: TNA AUSTRALIA Inc.

Please state if you have any special diet. We will do our best with the Resort to cater for you.

**Day Delegate = NO Dinner and NO Accommodation.**

## **Coach Transfer from Airport to Conference Venue**

From Sydney Domestic Airport

We will be organizing a coach to transport delegates from the Domestic airport to Cypress Lakes Resort Hunter Valley.

Cost is estimated at \$30 per person each way.

If you are making your own way : Cypress Lakes Resort, McDonald Road  
Pokolbin 2320 NSW (Cnr McDonalds & Thompsons roads)

We look forward to joining us then.

### ***Irene.***

President

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Australia

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