



# 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 of a chronic facial pain patient.

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

## January- February 2010

### *Happy New Year*

**Happy New Year indeed!** - we begin our new year with a NEW addition to the family! I would like to extend a very warm welcome to our newly founded Support Group from Tasmania. In December last year, I attended a meeting with our members from Hobart. This inaugural meeting saw the founding of the Hobart support group with Helen Tyzack and Ros Wilkinson agreeing to co-host. Congratulations ladies! I am confident that this group will grow under both your leadership.

### **2011 TNA Aus 4<sup>th</sup> National Conference**

I am thrilled to announce that our next national conference will be held at the **Hunter Valley Cypress Lakes Resort**. Date set is 2011 **September 2nd – 5th**.

For more details of the venue: click on the link: [www.cypresslakes.com.au](http://www.cypresslakes.com.au)

As with previous conferences, we will do our best to raise funds to subsidize members' registration fees. It is my desire that all our members should have every opportunity to experience our unique national conference. Your registration fees will include 3 nights accommodation, all meals, morning and afternoon tea and 2 days of invaluable information. I hope folks in and around Central Coast and the Maitland/Newcastle region will seize the opportunity to attend. I have given you 2 years of notice; plenty of time to save up for it. If you set your heart on it, you will be there.

### **Membership Renewal.**

Thank you for your membership renewal and a big THANK YOU to those who have included gifts. If you have procrastinated we urge you to attend to your subscription as soon as possible. I take this opportunity to also thank everyone who had sent cards or letters over the Christmas / New Year period. Your kind thoughts and words are much appreciated.

***"Learn from yesterday, live for today, hope for tomorrow." -- Anonymous 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.

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## Meeting Reports

### SYDNEY CBD SUPPORT GROUP

5 December 2009

St. James Parish Hall

**Present:** Ingrid K, Patrick & Pam S, David & Joan H, Yolande C, Waren W, John & Nola W, Frank M, Jocelyn S, Alan M, Lois & Reg W, Ray C, May K, Linda K, Kim K, Aubrey K, Irene .  
**Apologies:** Marion A, Alaster McD.

This was our Christmas gathering, the meeting to end meetings for the year. It was great to see a reasonable turn out which included some faithfuls from Toongabbie. As we had some Christmas program scheduled, we settled quickly into members updates.

**Ingrid** is on 600mg of Tegretol. Her TN pain is slowly getting worse, with more intense pain on her bottom lip. She is due to have another MRI end of January to investigate further options.  
**David's** TN started about 6 – 7 years ago, and it has been on and off. However, it gradually got worse. His GP diagnosed TN early and he was referred to a neurologist. He took Neurontin 1200mg and 1000mg of Epilim. In February he had a massive TN attack. The first acupuncture session reduced pain by 50% and after a couple more acupuncture sessions – there was no more pain. Occasionally he gets the gentle reminder that it is still there. David is due for his MVD on the 27<sup>th</sup> of Jan. with Dr. Dexter.

*(Everyone sends their best wishes. I thought of you on the 27<sup>th</sup>. We hope to hear good news soon. )*

**Lois** is going fine. Lois also has pernicious anemia and discovered that B12 injection once a month brings pain under control. She also takes Lamictal 200mg X AM and 100mg X PM.  
**Ray** reports that all is fine since his MVD. He can't understand why he didn't have it sooner.  
**Pam** had her MVD 6 months ago. 4 weeks ago started to get toothache like pain (described as mild) – first thing in the morning. Typical of a good spouse, Pat provides the support.

**Warren:** Pain started 2 months after brain stem stroke. Pain is on the left – chin, jaw, behind eye. Described as severe, hot – sizzling face, extends from back of eye to cheek; and is tender to touch. Sometimes there is stabbing pain and sometimes it is bearable. He is taking 600mg Neurontin. Due to the stroke, he also suffers from vertigo and his tolerance of drugs is also very low, any increase past 600mg makes him very dizzy. Warren is using Capsaicin cream 3 times a day.  
*( Irene suggested trying topical application – perhaps that would negate the dizzy side effects)*

**Alan M** happily reports that all his pain has stopped, and also not on any medication. He has been under (Roman R)- the Chiropractor's care (twice weekly X 8 weeks) and now maintains once a month therapy.

**Mary K's** TN started about 8 years ago with root canal work. Up till her MVD last year in August, she was taking Tegretol and Gabapentin. One month after her MVD – she has completely come off her medications and is pain free.

**Nola** reports that she is no longer taking any oral medication, but applies them topically. Her pain level is decreasing, and she can rest on her chin.

**Jocelyn** has been pain free since her MVD 4 years ago. The only side effect she recalls is the "fussy ear" feeling after the MVD.

**Linda** has been diagnosed as cervical neuralgia – ie stabbing pain in both ears. She is taking Endep 20mg and 300mg Trileptal twice a day. Also with the help of a musculoskeletal therapy, she is feeling a lot better.

**Kim** is still on Tegretol 200mg X Bid. (ie twice daily) and pain is bearable.

**Aubrey** has suffered 3 years of bad pain with at least one dramatic attack each year. Since taking B12, he has not had any dramatic attacks. The pain is still there but not severe. He also joined in the Soy program, and liked the soy, and has continued with taking soy. His pain was reduced to level 2. He decided to try the Reflexology therapy after the Reflexology's lecture. So he had his feet massaged, and has 8 tiny auricular magnets in his ear. He has reduced his Neurontin to 300mg three times a week - as insurance.

With that we ended the business part of the meeting and launched into Christmas mode. After a couple of Power point presentations on Christmas Carols, we adjourned for tea and coffee with all the delectable Christmas goodies. Thanks to all for making this a good end of the year meeting. A special thank you to Kim for minding the \$\$ kitty; Lois and Reg for doing T/coffee roster; and every willing hand.

Kim reports that \$51.00 was collected, and \$40 was paid to the Church, leaving \$131 in the kitty.

Due to the Easter Weekend in April – meeting in April will be moved forward to **MARCH 27th**

*Irene.*

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**HOBART SUPPORT GROUP  
Bellerive (Hobart) private home  
6 December 2009**

**Present:** Irene W, Helen T, Ros & Ian W, Shirley & Pat B, Del & Jean L, Julie H and Sue B, Judith B, Betty & Otto D

**Apologies:** Fran & Bill B, Rodney & Leonie W, Margaret C.

We were delighted that national TNA President, Irene Wood flew down (and back in the day!) from Sydney to demonstrate the support that the Association provides to groups of TN sufferers. In particular, her visit marked the inaugural Hobart Trigeminal Neuralgia support group which was convened with 12 other participants. Seven were sufferers with their partners or daughter, and 4 sufferers were unable to attend. The meeting started at 1.30pm.

Irene started by explaining the history of the Association and what it does and can do for members. Next, she talked about the importance of establishing a formal support group, and it was decided that Helen T and Ros W would become joint group leaders. This recognised the fact that Helen is currently having a TN relapse, and that Ros is not only wonderfully pain free but has recently moved to Hobart from the Perth WA support group with a wealth of knowledge about the benefits of that support group.

To date, a tiny advertisement in one of the suburban free newspapers has led to people making contact from all over – friends of friends see the advert and phone others elsewhere. So while that method of promotion has been very successful in only three months, we know we need to reach out much further. Discussion about other effective ways to promote the support group,

prompted Shirley B to offer to persuade the main southern newspaper to run a regular advert. Del L recommended tapping into the Probus clubs. Irene had lots of ideas for us as well.

Then, individually, each sufferer and some partners told their stories. The expertise of Irene was really important at this stage, because she was able to add information so that everyone understood the bigger picture. At future gatherings, a brief statement of each will be recorded in this newsletter, similarly to those in other States.

Meanwhile, before we can schedule our first gathering "on our own" we need to find a venue that suits our widely dispersed group of sufferers. Helen T will send out a letter to everyone letting them know the details.

The meeting closed at 3.50pm, as Irene needed to be taken to the airport to get back home. Others enjoyed a cuppa and social chat before leaving.

**Next meeting:** Saturday 20th February 2010 at **The Glenorchy Library**, Terry Street; the entrance to the car-park is on the corner of Barry and Cadell Streets. As you look at the main entrance of the Library, our meeting room is to the left and around the corner of the building. The main entrance will be locked. The car park is situated right outside our meeting room door.

**Meeting starts at 2pm.** I suggest you arrive around 1.50 so you have time to find a car-park and to find where we are meeting.

*Helen*

*Many thanks Ros and Ian for collecting me from the airport and showing me Hobart. It was a most delightful morning wandering through the Botanical Garden and checking out Peter Cundall's vege patch. What a shame to just admire the mouth-watering ripened strawberries – so close yet so far! Thanks also to Otto and Betty for delivering me safely and in time back to the airport. - Irene.*

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### **St Cloud Support Group Minnesota USA**

The St Cloud Support Group met on Saturday Dec 12. We had a nice turn out to listen to our speaker LaNae Harms-Okins who is a social worker through our Coborns Cancer Center in town. Her department has put together a wonderful presentation called "How to Make Tough Health Care Decisions". It can apply to any type of health care decision and she said it really can be used for making any type of decision. After her presentation and a bunch of questions we sat around and talked and enjoyed goodies brought by Bea.

We had a new member Allan M come to the meeting. He has TN pain on both sides of his face and seems to be doing ok on medication but is looking into surgical options since having the pain has made him give up some of the outdoor things he enjoys doing, especially during the winter. We filled him full of advice, stories and literature. Hopefully the literature will help his wife understand the disease a little bit better too. She did not attend the meeting with him.

**Frank M** and his wife Doris came to the meeting. It was nice seeing them since we haven't seen them in years. Frank has TN and has managed it well with watching his diet, things they bring into the house like newspapers (the ink triggers his TN) and keeping active. He goes to the chiropractor so he is well adjusted he said.

**Ken R** and his wife Delores came to enjoy the presentation and see how everyone is doing. Ken has been doing really well since his high frequency surgery almost 2 years ago now. He has only occasional twinges and his doctor told him that he has to stay off the ladder now since he has taken a tumble twice. His wife Delores has been undergoing chemo treatments and is doing really well. She looked good

**Bea A** is doing good as long as she takes her medication on time. She does feel like the pain is starting to go into the 2nd branch now so she is a little scared of what that means. She tries to stay as active as she can and finds that the TN pain isn't as bad when she does.

**Betty H** came with her husband, I didn't get his name written down. She thought she had TN but was finally diagnosed at Mayo Clinic with something else that has a long name that no one can pronounce she said. Its all brain related. She had had some form of brain surgery a couple of years ago and they nipped a nerve and she has been having pain ever since then. She didn't want to say all of the medications she was on because she said she wasn't really sure what was for her head pain and what was for other pains. Told her she should really write all of her medications down and either talk to her doctor or his nurse and have them tell her what each medication she was taking was for.

She expressed a great deal of frustration at trying to get answers from her doctor. Since I work in a clinic I was able to give everyone an inside view of what the doctors and nurses are going through each day and sometimes it just takes a word from the patient to say "hey I'm here listen to me." When your doctor walks into your exam room you never know what he was coming from. It could have been an irate patient next door, bad news about another patient he had been trying to help. In regards to the nurse she could have 50 medication refills she needs to get done by the end of the day plus all the phone calls to patients she has to make.

Everyone was truly amazed and hadn't thought of all of that. I also suggested strongly that they do not call their doctor or pharmacy on Mondays since that is the busiest day of the week and errors are higher. That would include calling pharmacies on Sat and Sun too since those calls if needed to go to the doctor would end up being taken care of on Monday.

**Mary H** doing really well and continuing to reduce her medication. Finding that relaxation helps a lot and has taken a number of classes that the hospital has been offering just to learn different relation techniques. Now to put them into daily practice.

We wish all of you in Australia a very Merry Christmas and a very Happy Pain Free New Year.

*Mary H*

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**Mondegreen** is generally used for misheard lyrics, - although it can apply to speech as well. These songs will never be the same again – try singing them. ☺

**"Donuts make my brown eyes blue."**

*"Don't it make my brown eyes blue."*

(Don't It Make My Brown Eyes Blue, Crystal Gale)

**"There's a bathroom on the right."**

*"There's a bad moon on the rise."*

(Bad Moon Rising, Creedence Clearwater)

**"Sunday monkey won't play piano song, play piano song."**

*Sont des mots qui vont tres bien ensemble; tres bien ensemble."*

(Michelle, The Beatles)

**"Just brush my teeth before you leave me, baby."**

*"Just touch my cheek before you leave me, baby."*

(Angel of the Morning, Juice Newton)

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**MELBOURNE SUPPORT GROUP**  
**at the "Ringwood Room"**  
**Ringwood Library 1.30 p.m. 12 December 2009**

Evelyn welcomed everyone to the meeting - especially the eleven new people attending for the first time. Most of the new members made contact after an interview with Rita Wagg appeared in the Maroondah Leader and an interview with Evelyn in the Waverley Leader.

**Present:** (25) Barbara & Bob A.; Alan & Joy C.; Ellayne C.; Evelyn & Din D.; Bruce G.; Bernadette G.; Alf H.; Nita & Robert McK.; Rose M.; Beryl & Rob O.; Bill P.; Will & Joan R.; Jenny & Kevan S.; Terry S.; Joan & Neil T.; Rita & Chris W.;

**New:** (11) Rita & Bryan F.; Susan J.; Trevor K.; Alan L.; John & Joe P.; Beverley R.; Bernice W.; Diane & Garry W.;

**Apologies:** (12) Leslie B, Shelley H, Brian & Helen McC; Chris M, Marjory & Murdoch F; Dorothy M & Di S; Peter S; Alison S; Michelle T;

**Guest Speaker: Julia Broome**, Feldenkrais certified physiotherapist.

Evelyn D. advised the meeting of the sudden death of member Evelyn Fuller in September from a non-TN related cause. Evelyn was a member on our mailing list but unable to attend meetings. Her son Graeme replied to a recent letter.

**Treasurer's Report:** Alan reported that \$54.00 was donated by attendees at the Oct '09 meeting and a special donation of \$50 was gratefully received. Expenditure since then totalled \$102.05 (insurance, supplies, gift, two new books) leaving a balance of \$155.40. Thanks to Alan for keeping the records. We are urged to make at least a gold coin donation at each meeting as we have no other source of funds. Also Irene Wood of TNA Sydney has accepted an invitation to speak at our February 2010 meeting and we want to be able to contribute to her trip expenses. Newsletters: People had received the December newsletter – last for the year – and enjoyed the articles and reports in it. Thanks to the Sydney team who produce and send out this valuable resource. Reminder to renew memberships for 2010!

Dates for 2010: Thanks to Joan for finalising dates for meetings in the same venue for 2010. Not all will be on the second Saturday of the month – new flyer available now so please take yours home for future reference.

**Reports from members:**

**Evelyn** has been free of major attacks of TN pain for over 2 years now, just has fleeting stabs which are bearable – no medication, just 1000 mcg sub-lingual B12 daily, other supplements and mindfulness meditation.

**Bernadette** manages her pain with 75 ml Lyrica a.m. – she obtains this for \$5.00 through the Austin hospital (otherwise very expensive). She is free of pain at times but then it returns for unknown reasons. Bernadette has a benign brain tumour around the nerve so cannot have an MVD. Radiation is the only available procedure but because of the location of the tumour around the trigeminal nerve, this is too dangerous. Scoliosis (congenital curvature of the spine) can put pressure on nerves in her neck and trigger TN pain.

**Joan** has discovered a simple trick that works for her. Previously brushing her teeth could easily trigger a horrible response but now she finds that by starting brushing at the back of her mouth on the better side (Joan has bi-lateral TN) and working towards the front, there is less likelihood of a painful reaction.

**Joe** spoke for his father John who has postherpetic neuralgia after having shingles 14 years ago. The pain is severe and constant but worse at night – can be partly relieved with ice packs. John was prescribed Tegretol but this made him very drowsy and his liver was affected.

**Beverley** had sinus problems 32 yrs ago. A new local GP diagnosed TN a year or more ago. She saw two neurologists and was prescribed Epilem and 6 yrs ago had an MRI which showed nothing; she was told her condition was migraine. Since a cataract operation the TN condition became very bad affecting the side of her face above the right ear. At one stage she was on Sirc tablets. Currently Beverly is on antibiotics due to a recent flare up which might be due to an infection but does not take medication for TN.

**Alan L.** Said his experience was ordinary compared to some others! He is hesitant to have an MVD due to a friend's less than successful experience. His dentist prescribed Tegretol – 2 x 200mg daily and he had no problems for 12 months, even went overseas. Then pain returned so he attended ENT at Box Hill – “poked” at his mouth for reaction. A CAT scan showed nothing; re-started Tegretol but not good. Gabapentin stopped the pain but caused very painful ulcers in upper dental area. A dentist put him on Endone but nothing stopped the pain. On a thin cut MRI at Box Hill Doc. saw a twisted blood vessel above the upper lip, pressing on the nerve. Lyrica was very expensive so Doc. prescribed 100mg Tegretol several times a day. Then Alan experimented with 2x200mg Tegretol daily and this worked. Now he has a regime of 1x 200 Tegretol a.m. and 1x 200 Tegretol p.m. and 1x 100mg Tegretol around 3 a.m. when he has to get up. He is managing his pain reasonably well now and has donated his electric shaver to his grandson and gone back to an ordinary razor!

**Trevor** travelled by train from Geelong to be with us today! He has SUNCT (Short-lasting, Unilateral, Neuralgiform headaches with Conjunctival injection and Tearing). Trevor had sinusitis three years ago, then problems began so he returned to his GP and was prescribed Tegretol. He also tried Gabapentin and was hospitalised at one stage and used ice packs for relief. He saw neurologist in Geelong twice a week when he was having 40 attacks a day like electric shocks. Injections into the back of the head were ineffective. This unbearable painful SUNCT condition was so bad he at times spent the day with his head in a pillow. The ice pack on his head was the only slight relief. An MRI showed nothing. Trevor then searched SUNCT on the internet and found that an Italian doctor had treated SUNCT with lamotrigine so he takes 400 mg of that and Epilim now. At times of severe pain he couldn't talk or eat and had an inflamed eye and nasal discharge. Trevor's control of pain has been good for a month now – may this continue! Trevor is an example of how we have to be pro-active in searching for and exploring our own treatments!

\* *Doc. at our conference uses Indomethacin for SUNCT – check November2009 newsletter – Irene*

**Diane** declined to tell her story – she is right at the beginning of her TN experience having only been to a GP so far.

Evelyn introduced Guest speaker, Julia Broome, who has a Diploma of Physiotherapy and is a certified Feldenkrais practitioner. The Feldenkrais method facilitates learning about movement, posture and breathing to ultimately increase the ease and range of our movement. It was developed by Moshe Feldenkrais (1904 – 1984) and is taught in classes called Awareness Through Movement lessons or a hands on process to deal with individual problems called Functional Integration where the practitioner moves a person's body to see where resistance lies and limits are – like “having a conversation” with the person's body. Julia spoke of the

interesting connections between movement and pain. In her work she saw many patients with chronic pain but could not offer a permanent resolution if people were unable to change their posture and movement habits.

After some Feldenkrais training Julia saw how we take our bodies for granted and how this approach was a way to explore and get to know our own movements. Feldenkrais was hospitalised for a long time with a knee injury and that's when he began exploring ways to develop awareness of posture and movement and he discovered the possibility of changing movement habits at a deeper level. In a Feldenkrais lesson one becomes aware of the subtleties of movement. At the recent TNA conference in the Yarra Valley Julia heard of chronic pain such as TN being described as due to physiological and many other factors. This pain increases sensitivity to touch or movement. Different parts of the brain influence different aspects of being e.g. emotional, behavioural, making meaning. The whole brain is working – all aspects inter-related. A pain management specialist at the conference, Phyllis Berger from South Africa, described how different emotional states can trigger excitation of the nervous system in different ways. Muscular tension can result from over-excitation of the nervous system. Medications were discussed e.g. meds that lower excitation levels, thus lessening the degree of nervous activity. Helen Babcock, pain management specialist, spoke of the psychological issues associated with the experience of pain. There are ways to lessen activity in the nervous system e.g. exercise lessens nervous activity.

In a Feldenkrais class we can become aware of painful and pleasurable movements. Then change can be effected to make movement smoother. The body is a system and if all the body can participate, movement is smoother. We are taught how to look for small subtleties and to know that we cannot change habits if there's too much anxiety. We can learn to change habits – as a baby explores and learns possibilities of its own body.

Julia's explanation was made really meaningful when we all participated in some standing activities to become aware of different postures e.g. if we stand with knees locked or not, some sitting activities moving weight from one sitting bone to the other, movement of the back imagining the spine as a rod and then not as a rod. It was amazing to notice how the body felt and responded. Many people felt relaxed after this! Julia said the body reflects our emotions which we can change through awareness. She distributed very useful brochures and explanatory notes. On behalf of the group, Evelyn thanked Julia for giving up her time to present such an engaging talk and interesting and beneficial experience.

Susan spoke briefly of the benefits of the Feldenkrais method for her as she explores ways of dealing with her TN pain.

Book borrowing: members were reminded of books available for borrowing on payment of \$40 refundable deposit.

Thanks to all who attended and those who helped this afternoon – Joan and Neil for collecting the key, arranging insurance, and all who helped setting up the chairs and table and loudspeaker; Alan for looking after our finances; Rose and Rita and helpers for looking after afternoon tea and to all who brought goodies to share, Neil on the front desk and all who helped clean up; Din on the loan desk and for so much help with data bases, phone calls etc. There is wonderful team work though we do not have a committee as such! Most of all thanks to all TN patients and those who accompanied them to the meeting – each person's experience and pain journey is important as we strive to learn more and support each other. Evelyn wished everyone

a Happy Christmas and a pain free festive season and invited all to share the Christmas afternoon tea!

**Next Meeting: Saturday 13 February 2010, 1.30 – 4 p.m.** Irene Wood, head of TNA will visit our group. Mark the date on your new calendar and be sure to come along with a supporter/carer if you wish. All TN people urged to attend – you will be most welcome.

*Evelyn*

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**ADELAIDE SUPPORT GROUP MEETING  
SUNDAY 29<sup>TH</sup> NOVEMBER, 2009 AT 2.00 p.m.**

**PRESENT:** Kevin S, June & Roger O, Laurel S, Ann T, Garry & Lisa R, Jill W, Joan E, Grace A, David K & Christie, Ria D & Chris, Dennis & Sue G, Graham & Liz B.

**APOLOGIES:** Bert J, Jan S. Marie F, Ken E

**FINANCES:** Donations: \$52.00. Expenses: Venue hire for today's meeting \$26.00. Venue hire for next three meetings in advance \$78.00. In hand: \$91.10.

**WELCOME:** Graham welcomed members, particularly new members Dennis, David, Sue, and their partners and was pleased to see an increase in our numbers.

**GENERAL BUSINESS:** Graham issued a program of next years meetings to all members present and will arrange a post out to others who have attended meeting during the last twelve months. We have been fortunate to secure a second visit from Neurosurgeon Andrew Z for our May meeting and also a visit from a Compounding Chemist at our January meeting. President Irene has been invited to attend any of our meetings next year and has indicated she may be available to come in July. Graham asked members to advise him if they knew of other speakers who might speak to group.

Ken showed the group an article from the Advertiser regarding research into shingles pain which asked sufferers to get in touch with the Pain Clinic at the Royal Adelaide Hospital. Also, several member brought an article from today's Sunday Mail concerning Colleen McCullough, author of The Thorn Birds, who is suffering from TN and is about to undergo brain surgery.

**MEMBERS UPDATES:**

**JOAN:** Has undergone two MVD's and would recommend it to anyone. Her TN returned suddenly twelve months after her first operation. Her second MVD was 18 months ago. She now has no pain and is living a good life.

**GARY:** Does not have classic TN, his is a complication from a stroke which damaged the Trigeminal nerve. His pain is controlled somewhat with 800mg. Nurontin supplemented with morphine. His attacks are normally of short duration and he has been told an operation will not benefit him.

**LAUREL:** Has had TN for 26 years. She describes her pain as "like having ants crawling in her face". She has had 2 glycerol procedures the last one being 6 years ago. She finds Tegretol's side effects intolerable. She is taking B12 in jelly form. Should she experience severe electric shock pain again Laurel will seriously consider an MVD.

**DENNIS:** One of our new members, has suffered TN since he was 42. He was diagnosed by his dentist. He tolerates Tegretol quite well which is fortunate as he takes up to 2200mg per day. Dennis underwent an MVD in April this year and was told by his surgeon that it could take up

to a year before he feels any improvement. This surprised him as he thought the operation would give him instant relief. He has improved slightly in that he no longer has a trigger point and is able to shave, also, his attacks don't last as long. Unfortunately he has found the medical profession unhelpful. His GP had not even heard of Lyrica being used for TN. He finds information on the internet confusing. Dennis is unsure what actually causes his TN. He definitely cannot tolerate any air conditioning. He has tried Lyrica but not sure if it helps although when he tries to wean himself off it he experiences shocking attacks. He thinks he is becoming paranoid fearing debilitating attacks. He has found the TN newsletters very helpful. He is seeing his Neurosurgeon in the near future and will insist that something be done. He may consider a glycerol procedure.

*( Be mindful that such percutaneous procedures or " damage the nerve" procedures are ONLY helpful IF your symptoms are still that of classic TN. Then again, if it is classic TN, why not seek a neurosurgeon who is well versed with MVD for a second opinion. It may prove to be a better option - Irene.)*

**JILL:** Has undergone two glycerol procedures however the second one has not helped. She has started seeing an acupuncturist. It has been suggested she wears a mouth guard as she grinds her teeth at night. (David, Kevin and Graham also grind their teeth). Jill still takes 200mg Tegretol 3 or 4 times a day. Since having her mouth guard she has been able to ease off the Oxycontin. Her mouth guard was quite expensive but has helped somewhat.

**ANN:** Commented on how nice it was to see so many people at the meeting. Unfortunately Ann hit her head very hard the day before which triggered off a nasty attack. She bought along a sample B12 spray which her chemist had recommended. It is not found at all chemists and as it is kept "behind the counter" you have to ask for it. It is not harmful at all. Ann feels very well on her B12 regime. Graham told the group that the Brisbane Support Group is having very good results with B12.

*(Actually most of our TNA Aus members who are on B12 therapy since my B12 studies are doing very well on B12. – Irene.)*

**DAVID:** Is in his 20's and has suffered from TN for 18 months. He found the TN web site but thought he was too young to have TN. Initially it was thought to be a dental problem and had a tooth extracted but his pain continued. He was referred to who diagnosed TN. David was started on 50mg Tegretol which "kind of worked". However he was not able to brush his teeth and could only eat mashed potatoes. Eventually he could not eat at all and lost 10kg. Tegretol was increased to 100mg which helped but he was continually afraid that his dreadful pain would return, which it did, 3 months later while in the UK - after taking a ride on a roller coaster! Tegretol was increased to 200mg morning and night and he has been relatively pain free for 3 months. David is considering trying B12. He has seen a neurosurgeon, who has not recommended an MVD. David relies on medication to control his pain at this point in time.

**GRACE:** Still experiences facial numbness. She has had two glycerol procedures. She finds she cannot chew on her right side as she has no feeling and fears choking. Wind, cold weather effect her. She does not take any medication. Grace's emergency plan is to have an MVD should her TN return.

**RIA:** Ria's facial pain began 2 years ago. Her dentist told her she had muscular overload. She takes 300mg Gabapentin. She has constant nerve pain and finds talking difficult. She has undergone several dental procedures resulting in a huge infection. She has had to take a leave of absence from her nursing course because of her unrelenting pain. She was told by doctors "it's

all in your head” and that exercise might help. She has been warned against taking Tegretol because of her Asian heritage (she has heard it can cause skin problems in some cases). She has been fitted with a mouth guard to prevent teeth grinding (at a cost of \$500.00). Ria has yet to see a Neurologist and has not had a formal diagnosis. It was suggested that she should do this as a matter of urgency as this will confirm whether or not she has TN and determine what treatment options are available.

**JUNE:** Has had TN for 5 years. She tried Tegretol but had dreadful side effects. Lyrica was helpful but too expensive to take long term. After the last meeting June tried B12 and found her pain went away however it seems to be coming back. She is not taking any medication at the moment and just suffers the occasional twinge. She is managing now but dreads the thought of her TN returning.

**KEVIN:** Kevin was extremely sympathetic to Ria’s awful story. He suggested to her that the RAH Pain Clinic would welcome her with open arms. (Ria replied that no one had suggested the Pain Clinic to her). He also informed the group that Private Medical Insurance gives rebates on Lyrica and also you have to shop around for the cheapest prices. Kevin has been pain free for a year. Some months ago it started again with electrical “zaps” when he spoke - Lyrica didn’t help. He now uses HP Zostrix cream which does help but you have to be careful you don’t get it in your eyes.

**BERT:** is managing on 200. Tegretol daily. He sent his best wishes to everyone.

**GRAHAM:** Graham’s TN began 15 years ago. He had a glycerol injection which lasted 18 months. His TN returned and was controlled for a while with Tegretol and Lyrica but eventually became too painful. He underwent an MVD in July this year and has been pain free ever since. He had headaches, light headedness and depression post operatively but that has all stopped now. He has slight numbness to the face due to the previous glycerol injection but is very happy with the outcome of the MVD. Graham still takes B12 to help repair the myelin but is on no other medication.

MEETING CLOSED AT 3.50 p.m. Graham wished all members a Merry Christmas and Happy New Year. Everyone then enjoyed a sumptuous Christmas afternoon tea with lots of friendship and chatting and comparing TN stories. HAPPY NEW YEAR EVERYONE!

**NEXT MEETING:** Guest Speaker David Crici - Compounding Chemist.  
Sunday 31<sup>st</sup> January 2010 at 2.00 p.m. BURNSIDE TOWN HALL- CIVIC CENTRE, CORNER OF PORTRUSH AND GREENHILL ROADS, BURNSIDE.



**SUNSHINE COAST SUPPORT GROUP**  
**Kawana Library, Nanyina Street. Buddina**  
**Saturday, 15th January 2010.**

**Apologies:** Sheryl M & Jean B

**Present:** Jill LeM, Graham W, Trisha O, Max H, Jim K, Jane K, Jean W, Teresa & Stuart M, Bob & Kay C, Trixie & Keith B, Peter & Pearl R and Sandra G.

Teresa welcomed everyone back and wished us all a Happy New Year. She took the time to ask all the new faces where they found out about us. Jill-Internet. Kay-newspaper. Trisa-magazine which she followed up on the Internet.

Everyone is reminded that their membership is due. You can find the form for renewal on your last newsletter.

**Trixie B:** Is a suffer for a couple of years now. It came back a few months ago. Her right side is effected. It hits her nose and into her ear and her eye will run. She is going to Sydney on the 8th February to have a MVD done by Dr. Mark Dexter. Trixie isn't looking forward to the operation. At the moment she is on 450 Tegretol X2 and is looking forward to stopping the medication as she feels as though she has had a couple of glasses. Both Keith and Trixie are looking forward to their holiday in Europe after Trixie recovers from the operation.

**Jim K:** No trouble at the moment. Just one stab since his last visit. Dr Neugenbauer article that was in a pervious newsletter is a great help. He has a slow build up of pain, so he has time to take his medication. Jim had a previous attack of 3 days and 3 nights where he was put in hospital to recover. October 13th 2008 he had a pain which he thought was a stress pain. It wasn't until then that a Doctor diagnosed TN.

**Trisha:** Has followed the same pattern as Jim's. She has had trouble going to the dentist. Since she was a little girl her name has been "face ache". Trish has had 17 root canals and they are starting to rot. She has had part of her jaw repaired. As a child Trish was sent to a psychologist. After having an eye tooth taken out it took 5 months before it closed up. She can't touch that area. Trish has had brain and nasal scans and a camera up her nose. The pain was triggered when the camera went up her nose. That's when TN was diagnosed. Trish believes that she was born with it. Her pain is on the left side and describes it as being like an electric shock. The only relief she gets is by putting a ice block on the inside of her mouth and jamming it up into the area. Her medication is Tegretol, Lyrica 75X2 (stopped) and Endep. Feels as though she has lost her taste and smell with some noises being intolerable. Because she has had trouble chewing she has had an eating disorder. A dentist in Geelong, numbed her whole face so she can have some work done on her teeth. This is a unique story and we are very sorry she as suffered for so long, our heart goes out to her.

**Jane K:** The story sounds familiar with regards to the dental part. Her first pain was in 1992 and it was sharp, strong and shooting. An Oral GP didn't know what it was. Jane only takes medication when she has had a bad bout and she slowly builds up. She knows her pattern and triggers (air-conditioning, drop in temperature, draft and thunder storms). Capsicum cream, hot shower and a hot drink through a straw seem to help. It obvious Jane is able to manage her condition well. At the moment her Doctor is ill and is in need of a new Doctor. She has been

diagnosed with neuralgia of the ear. Jane has shooting pain into her ear and is slowly losing her hearing. Teresa asked would she consider any other treatment. Jane can't have an operation due to other medical conditions. Jane concentrates on her breathing so she can relax and is very pleased that she doesn't have it in her jaw.

**Jill LeM:** About 8 months ago she had sharp stabbing pain and she thought it was an abscess in her tooth. Went to the Dentist and had an Xray, nothing was found. Was then sent to her Doctor and he diagnosed facial neuralgia. Jill still believes that it is still in her tooth. The pain is on her cheek and into her tooth on the right side and also in the jaw line. The pain is also on her left side. If she touches her face too lightly the pain starts but if she clasps it tightly it's OK. The pain is waking her up in her sleep. Teresa recommends borrowing the book "Striking Back" it may explain a few things.

**Lloyd K:** Feels as though he is the luckiest man alive. After 7 years he has been able to close the Pandora's box. Lloyd ended having his MVD with Dr Dexter 15 months ago and since then he has been pain free. He feels as though he has won the lottery.

**Kay C:** Wants to constantly lie down as that is when the pain goes away. Kay feels as though the pain is a 9 out of 10. She has had the nerve cut above the eye tooth. It doesn't seem to follow a pattern and she thinks it could be due to stress. Kay has been in constant pain for 5 years and is starting to put off so many things that she once loved to do. The treatments so far are: a sinus operation (that hasn't cured it) and a MRI (that didn't show anything). Teresa explained that there needed to be a thin cut MRI taken and a Neurologist that is able to read it correctly. Kay is going to see another Neurosurgeon. The only thing that seems to help is Panadine Forte and the pain drops to a 6 instead of a 9. It is recommended that she starts keeping a diary so when she goes to the new specialist she can show him what is going on. Our thoughts and prayers are with Kay at this trying time.

**Max H:** Has had his TN for 10 years now. He was admitted to hospital when he couldn't eat or drink. The Neurologist at the time had remarked "No cause, no cure". That was his parting quote. This year so far the pain has practically gone. Max is on 400X1 Tegretol per day and he is trying to cut it back to 200 per day (slow release). In the past he has used compounding cream. He used to put it on the top of his forehead, not on the pain as it would make it a lot worse. When he has it made up again he feels as though he needs to have it made a little stronger.

**Peter R:** 10 years ago in the middle of the night the pain hit him. It gradually got worse until 5 years ago he heard about this group. Peter has had a MVD done. Everything was fine until he had a fall and hit his head. As the pain has returned (not as bad), he wonders if the fall didn't stir it up again. At the moment he is on Tegretol 100X2 NeurontinX1.

**Teresa M and Jean W** are fairing well.

We are glad to see a few faces and sorry to hear that they have been having a hard time of it. Everybody stayed for a cuppa and a chat.

**Next meeting: 20th March 1.00pm Kawana Library.**

*Jean & Helen*

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“A strong positive mental attitude will create more miracles than any wonder drug.”

- Patricia Neal

## BRISBANE SUPPORT GROUP

Saturday January 16, 2010

**Attendance:** Mary M, Joan F, Lorraine B, Jeff B, Neil F, Lorraine G, Peter G, Helen W, Margaret H, John H, Noela W, Alison W, Dorreen T, Tony M

**Apologies:** Margaret and Colin B, Joan M, Shirley P, Leonie G

Our meeting opened with a brief discussion regarding recent correspondence from the Aspley-Albany Creek Anglican Parish. A new license agreement for insurance purposes was tabled, which is required for our group to continue using the hall.

Tony then spoke of the recent book by Rugby League great Wally Lewis "Out of The Shadows", which describes Wally's long term battle with epilepsy. Wally has, like many of us, endured years of anti-convulsant medication with the usual side effects. He described his torment attempting to conceal his illness, and his eventual success with surgery. This book shows he truly has the heart of an inspirational champion. We wish him well in his ongoing recovery.

Tony then again outlined the four common forms of B12 therapy that have been used by group members: - low dose(1mg or 1000 mcg) B12 tablets and B12 plus folic acid tablets readily available from health food stores and supermarkets.

-methyl cobalamin lozengers. These are a higher concentration at 4mg/ml and can be purchased from compounding chemists. A script is not necessary. Several in our group have purchased these via Sydney-approx \$44 per month. Probiotics should be used in addition to these oral forms. -neo(or hydroxy) cobalamin injections. Low dose at 1 mg/ml, and are purchased from chemists with a script for approx \$20 for 3.No need to refrigerate, and can be retained by patient at home. Painless injection into arm.

-methyl cobalamin injections. Highest available concentration at 10 mg/ml. Must be kept frozen until just before use. A slow injection into buttocks-alternate side each shot. Approx \$110 for 6 vials delivered to your doctor's surgery, though some doctors may have this medication on site. He stressed that we should read product statements included. A quick show of hands at our November meeting indicated that the vast majority of the Brisbane group use the injections. Almost all have reported significant pain reduction and many have reduced medications, frequently to zero dose. A daily pain diary is an essential part of TN management-better still, write a journal and include one section for TN issues. A clear picture can then emerge as to cause and effect for the patient.

The guest speaker at our next meeting, March 13, will describe the use of quadrapole magnets.

**TN Association Australia does not endorse any of this product or its trials.**

We then shared our stories.

**Neil** said his troubles have continued, with the usual pain with eating, brushing teeth, shaving and the initial early jolts when running. He has noticed that even though there is some initial pain when attempting to exercise, all pain eventually subsides during his runs. He believes a healthy diet and regular strenuous exercise are essential in combating TN. He has not tried B12 injections. Others commented on the benefit of exercise and the reduction, and often complete elimination of pain, through strenuous activity. Perhaps endorphins play a significant role here.

**Joan F** continues to be pain free using methyl cobalamin injections, magnesium tablets and fish oil. She has only had one small brief bout in several years while on this treatment and had previously tried acupuncture and several drugs.

**Helen's** pain returned last October following seven pain free months. She tried several acupuncture treatments with little relief. She is now on neo B12 injections and 900 mg neurontin.

**Lorraine G** has had TN for ten years and has had some pain free periods in that time. She is currently on 600 mg tegretol and this has caused her to be very dopey. The bottom of her face is very sore. She has recently started using neo B12 injections and magnesium and says she has felt a little better. Peter, her husband told us that he has suffered with her through this illness.

**Lorraine B** is again having some trouble. She is on 150 mg lyrica and 150mg endep and this low dose combination generally keeps the worst bouts at bay. If the dose of lyrica is higher, she gets a rash. She is now also using methyl cobalamin injections. Husband Jeff says she is not as bad as she used to be.

**Margaret** is now going really well. Summertime, with the high humidity, does cause some problems with her face pain. Being a southerner, she found our heat to be quite a trigger. Breakouts of TN haven't been nearly as bad since beginning methyl cobalamin injections. She says these have definitely helped and she has been able to drop from 2000mg to 800mg tegretol. She has had very low sodium levels and the high dosage cause frequent drowsiness. She said that when attacks were bad she always found it helpful to hold husband John.

Tony commented on the benefits of this strategy, ie just holding someone post or during an attack, as cited by Deepak Chopra in his book "The Deeper Wound. Recovering the soul from fear and suffering". Partners, you are needed!!

**Dorreen** continues on 100mg tegretol. Even on this extremely low dose, she had to be hospitalised with low sodium complications and so has frequents blood tests. Some blurred vision occurs also. She uses monthly neo cobalamin injections and finds these very helpful. One bad bout all weekend ceased with an injection and three acupuncture visits.

**Noela** is now completely pain free. The pain with teeth brushing and face washing flared up following some dental work and an abscess. Anti-inflammatory assisted in pain reduction. Noela manages her condition now with monthly methyl cobalamin injections, fish oil and magnesium. She uses no drugs.

**Mary M** is going fairly well at the moment on 2700mg neurontin. She has recently added endep at night as the TN would keep flickering after going to bed. This has assisted in dulling the pain. The pain does play up first thing in the morning each day. Her recent thin cut MRI revealed no nerve-artery contact. She is currently reading "The brain that heals itself" and has found this to be an informative guide in comprehending the amazing healing powers of the human brain.

Though Leonie is not with us, she says mum **Corry** continues to be well! After two failed MVDs, several procedures and lots of drugs, neo cobalamin injections proved to be very effective.

**Tony** has had some recent troubles, with pain on eating, teeth brushing, shaving and talking. He continues with methyl cobalamin injections, magnesium, folic acid, and flaxseed oil. Pain is still much less than when using more conventional drug therapy.

To our dear friends who can't be with us today, we wish you well. A special hello to Joan and Shirley, and Corrie and Rod. Gold Coin donation \$27.00

**Next meeting Saturday March 13**

*Tony*

**Canberra Support Group  
Labor Club Belconnen  
Saturday 20th January 2010**

**Present:** Brian J, Jan G.

**Apologies:** Brian W, Cathleen T, Chris R.

We waited until 11.15 but as no further members arrived the meeting was not convened.

However, **Brian J** has remained on a reduced dose of medication which is good news. He has started taking BI2 and is going to have another course of acupuncture in the near future.

Brian also was able to inform us that Dr T has appointments through till May and will continue with his practice to fulfil these.

When giving her apology **Cathleen** also stated she had started on BI2 and her pain had settled down. Her doctor pointed out that it could stop but return at a later date.

**Jan** had heard of "pre T N" at the conference and wondered if this applied to Cathleen. In any event it is good to hear she is pain free.

Unfortunately **Chris R's** news was not quite as good. Jan is only experiencing reminder stabs when eating.

Next meeting: the **Labor Club on 20th March** at 10.30am in the Barbara Byrne room.

*Jan*

*Thanks Jan for not giving up on these people. It must be so very disheartening to prepare for a meeting and no one shows up.*

*Folks! – don't wait till its gone before you realise you how much you need it. - Irene.*

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Irene: Since the book 'The Brain that changes itself' has been mentioned, I think these terminologies and what they mean would be of interest.

\* **Neuroplastic Pain:** Refers to pain cause by, OR pain increased because of changes within the nervous system. These structural and functional changes can occur at every level of the nervous system.

\***Neuroplasticity:** refers to the ability of the nervous system to alter its structure and function. Neuroplasticity (also deals with brain plasticity, cortical plasticity and cortical re-mapping) refers to changes that occur in the organization of the brain and entire nervous system as a result of experiences. "Plasticity" relates to the learning by adding or removing connections, or cells.

\* Neuroplastic changes related to pain can occur at multiple levels of the nervous system. More pain receptors may be in an area, the area of the brain that feels pain increases, the pain sensory system becomes more efficient, and the brain can learn pain.

"Neuroplasticity can make it easier for you to feel tissue damage (acute) pain."

\* Reference - Petersen-Felix S, Curatolo M. Neuroplasticity – an important factor in acute and chronic pain - Swiss Medical Weekly 2002: 132:273 – 278.

## 2010 Meeting Dates

<b>State</b>	<b>GROUP</b>	<b>Date &amp; Time</b>	<b>Venue</b>	<b>Group Leader/s</b>
ACT	Canberra	20 March 10.30-12.30	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 62474508
NSW	Sydney	6 March 1:30pm – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Irene Wood ☎ 0413363143 Kim Koh ☎ 02 97431279
	Sydney CBD	27 March 10:00am –12:30 pm	St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413363143
QLD	Brisbane	13 March 1.30-4.00pm	30 Ridley Road BRIDGEMAN DOWN	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	20 March 1:00 pm	Kawana Library, Nanyima Street, Buddina	Teresa Miller ☎ 07 54912487 Jean Williams ☎ 07 54911978
	Gold Coast	No date set	The Palm Beach Surf Club,	Ann Papandreas ☎ 07 5522 6892
S.A	Adelaide	28 March 2:00pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Road	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	20 February @ 2:00 pm	The Glenorchy Library Terry Street Car park entrance via cnr. Barry & Cadell Streets.	Helen Tyzack ☎ 08 6245 0429 Ros Wilkinson ☎
VIC	Melbourne	13 <sup>th</sup> February 1:30pm – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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