

# *Invitation to Attend*

*You are cordially invited to attend a  
Comprehensive presentation by  
**Dr Kim Burchiel MD**  
Head of Division of Neurosurgery  
University of Portland, Oregon*

*Saturday 30<sup>th</sup> April 2011  
12.30 – 5.00pm  
Sydney Mechanics School of Arts  
Level 1, 280 Pitt Street (near Bathurst St)*

## **Agenda:**

- 1:00pm 1. Classification of Facial Pain  
2. 3-D imaging for TN; & “Radiographic evaluation of Trigeminal  
Neurovascular Compression in patients with and without Trigeminal  
Neuralgia”*
- 2:30 Q & A*
- 2:40 Afternoon Tea break*
- 3:15 1. Microvascular Decompression  
2. Predictors of long-term success after Microvascular Decompression (MVD)  
for Trigeminal Neuralgia (TN 1 and TN 2)*
- 4:45 Q & A*
- 5:00 Conclude*

*Sponsored by:*

**TRIGEMINAL NEURALGIA ASSOCIATION AUSTRALIA**

*Cost: FREE - a door donation would be appreciated*

*As seating will be limited, please reserve your seats before 20<sup>th</sup> April*

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Name: .....

Number of people attending: ..... Phone.....



# 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.

## March 2011

*Allow yourself to be inspired. Allow yourself to succeed. Dare to excel." ~ Vince Dente*

### **An afternoon with Dr Kim Burchiel: 30<sup>th</sup> April 2011**

TNA Australia is proud to sponsor this special event with Dr Kim Burchiel, a leading specialist in the neurosurgical treatment of trigeminal neuralgia. He will also be presenting some of his latest work. This meeting is opened to all members of TNA Australia, and all health care professionals who have an interest in trigeminal neuralgia. Please feel free to invite your doctors to the meeting. However, as seats are limited, please book your seats before 20<sup>th</sup> of April.

Those contemplating flying in from other states: The meeting will be held in the Sydney Mechanics School of Arts, Level 1, 280 Pitt Street located towards the eastern side of Pitt Street, in between Park Street and Bathurst Street. (Sydney CBD)

From the airport catch a train to Town Hall or Museum train station. From Town Hall, (walking) exit into George Street, head south towards Bathurst Street. Turn (left) into Bathurst Street and Pitt Street is the cross road at the next intersection. Entrance (glass door) is after Map of World shop. Good luck if you are driving /parking... or MLC Centre Car Park in King Street charges \$25 max. on Saturday.

By the way, Sydney Mechanics School of Arts has a library on level 2. - worthy of a visit. The library is open on Saturday till 1 pm.

### **4<sup>th</sup> National Conference: 2 – 5 September 2011**

Early Bird concession ends on 30<sup>th</sup> April 2011. Take advantage of this reduced rate, and book in now.

We are also proud to announce that Dr Toby Newton-John, Clinical Psychologist and Program Director Of Innervate Pain Management from Broadmeadow Newcastle NSW will be joining us in the Hunter Valley. He will be speaking on pain psychosocial distress and its management.

### **New Trigeminal Neuralgia Patient Support organisations**

There is now a TN support group in **Spain!** - [www.pacientesatm.com](http://www.pacientesatm.com) - "The Official Spanish Association of Patients with Temporomandibular Pathology, Neuropathic Pain and Trigeminal Neuralgia (AEPA ATM) is a non-profit association for patients that suffer any kind of Craniomandibular disorder, Temporomandibular Joint Disorder (TMD), Neuropathic pain, or Trigeminal Neuralgia (TN)  
*Asociación Española de Pacientes con Disfunción de la ATM, Neuralgia del Trigémino y Dolor Neuropático* "

There is another TN group in **Thailand** started by a former student of Prof. Joanna Zak.

We extend our congratulations to both these patients group and look forward to working together to raise the awareness of TN and exchanging information.

**Irene.**

## Trigeminal Neuralgia: Follow-up

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[Contributor Information and Disclosures](#)

Updated: Jul 27, 2010 excerpt from website: <http://emedicine.medscape.com/article/248933-followup>

### Outcome and Prognosis

Accurate data on surgical outcome are still difficult to obtain. Most surgical series do not meet modern criteria for evidence-based medicine. Recently, an evidence-based approach has been applied to both the diagnosis of trigeminal neuralgia, and its surgical management. These results were published in the journal *Neurology* in August 2008 and can be viewed at [Medscape](#).

The challenges of the field are exemplified by a paper published by Zakrzewska and Lopez.<sup>15</sup> They assessed the quality of 222 reports of surgical management of trigeminal neuralgia and found only 3 randomized controlled trials (RCTs) on peripheral techniques. The vast majority of the evidence was of case series reports (class 3 evidence), and a very high proportion was of poor quality.

The difficulties center around the following important issues:

- Lack of clear diagnostic criteria and baseline assessments
- Poor methodology - Low numbers, short follow-up period, high percentage lost to follow-up, mixture of cases (eg, previous surgery, including repeated treatments)
- Lack of Kaplan-Meier assessment of pain relief, poorly defined outcome measures (eg, partial success), incomplete reporting of all complications, and no quality-of-life evaluations
- Lack of independent evaluation

Certain principles seem to transcend even the relatively poor outcomes studies performed thus far on procedures for trigeminal neuralgia. The chance of success is seemingly less likely the longer the duration of symptoms. Of all the procedures, MVD carries the lowest rate of facial dysesthesia at 0.3%. Facial numbness caused by MVD is not common (0.15%) compared with that caused by the percutaneous procedures; in addition, MVD is the procedure of choice in younger patients who desire no sensory deficit. MVD is also the most likely treatment to provide sustained postoperative pain relief.

One study found that 70% of patients had excellent results (defined as a cure or significant pain relief) 10 years after the procedure, with a recurrence rate of less than 1%.<sup>16</sup> Possible reasons for failure include new vascular compression from scarred implants or other sources, but these are rarely identified during posterior fossa re-exploration for failed MVD. After an initial 10% risk of recurrence of TN within one year after MVD, the risk of pain recurrence is about 3.5% every succeeding year.<sup>17</sup> The reasons for this recurrence are not clear.

In a 1999 study, cerebellar injuries and hearing loss occurred in less than 1% of the patients, and CSF leakage occurred in 1.85%.<sup>18</sup> As expected, these complication rates were inversely proportional to the total number of procedures performed.

### Future and Controversies

Once developed, trigeminal neuralgia (TN) is likely to have an exacerbating and remitting course. Over time, the pain-free intervals appear to diminish, and the pain becomes progressively more medically intractable. Temporary spontaneous remission may occur at any time, but permanent remission never occurs.

Without treatment, typical TN (TN1) may transform over time to become atypical TN (TN2), with a change in the character of the pain to more constant and background pain and the development of sensory impairment. Therefore, some authorities recommend early intervention to give the opportunity of pain relief without sensory deficits.

## Meeting Reports

St Cloud Minnesota  
USA.

The St Cloud, Minnesota TN Support Group met today (Saturday Feb 12) on a bright sunny day, something we haven't seen in what seems like a long time. We had 9 people in attendance at our meeting. Our guest speaker, Dr K. Rieke, a Neurologist at the CentraCare Clinic was to have been our speaker today but she was put on bed rest on Wed, expecting the birth of her first child, a girl, the first of March. Everyone had a feeling that little one wanted to come out and see the world earlier.

We wished her well and will keep in touch. She said that she would try and do our April meeting but we will have to see. She was to have been at our December meeting but we had to cancel that one due to a snowstorm. So what's the saying..."Third times the charm".

Since we didn't have a speaker we sat around and talked for a couple hours, catching up on everyone's news.

Ken and his wife Darlene were in good spirits with Ken having no TN pain and taking no medication after having radio frequency lesioning in April 2007. Darlene seems to be doing good with clear cancer screenings so we hope those keep up.

Bernadine also had radio frequency lesioning June 2007 and she is also pain free and taking no medication. She did say that she thinks it might be slowly coming back because when she washes her face or moves it a certain way she will get little "reminders" that she should cherish each and every day which she does. She says it is a burning sensation rather than the sharp jabs she got before.

Ann was concerned because she will be having a tooth that cracked cut out and she is wondering if her TN pain will get worse. She is currently on Tegretol 200 mg 2 times a day and Lyrica 100 mg 2 times a day. She will be put out for having the tooth removed. Her oral surgeon felt it was better to cut it out vs pulling the tooth. He said it was less trauma to the nerve than pulling the tooth. Since she is followed by a GP, I suggested she call him about increasing her medication a couple days before and a week or so after. Her daughter was with her and said they would do that.

Allan said he is doing great and having the best winter he has had in years. He had an MVD done at Mayo Clinic, Rochester Mn in June 2010. He is one of the unlucky one's who has this on both sides ☹ He had the MVD done on his right side. Currently he is taking medication to control the pain on his left side and isn't planning to have surgery just yet on that side. He is thinking about doing acupuncture again to see how that works.

Bea said that she was doing ok as long as she remembered to take her medication. She is planning a trip to Washington State in July so is hoping everything will continue to be good.

Mary is doing fantastic. She is on Tegretol 300 mg twice a day and Neurontin 800 mg a day. The Neurontin she is trying the slowly get herself off of it so is taking 300 mg in the morning and evening and 200 mg in the middle of the day. In her opinion any day without pain is a fantastic day. Working in a health care facility she sees a lot of people that are a lot worse off than she is so she doesn't have any room to complain (most days ☺ )

Mary's husband, Scott, attends most all of our meetings and helps to set up, greet people, finish sentences when Mary can't remember what she was going to say (maybe its because we've been married for 38 years too) and in general being a super supporter.

That's it from St Cloud Minnesota. Been thinking and praying for of allof you and all of the flooding you've had in your beautiful country.

Best regards to you all!

Mary Hall

TNA Support Group Leader St Cloud, Mn

# SYDNEY SUPPORT GROUP

## Toongabbie Public School

29 January 2011

**Attendance:** Henry & Jeanette B, Kim K, Kim S, Marj F, Ann & Laurie P; Stewart & Gundel B; Frank M; Marion A; Irene W.

**Apologies:** Jocelyn S, Jan G, Peter & Rose H, Emily S, Ken F, Hilary & Keith W

Irene shared news from Hilary with an update for them both. Keith had recently had a knee replacement and then suffered a heart attack. They are both recovering and are away at the moment. We wish them both well.

Irene outlined some of her work load such responding to new enquiries and sending out info packs; supporting current members & their request; and producing the monthly newsletters etc. Consequently she is not able to follow up on local support group members as much as she would like to. We discussed setting up a group of people within the support group who could share the role of staying in touch with group members. This would involve reminding members about meetings, and generally keeping in touch and update with members who have gone AWOL. ☺ A few of us volunteered to take on a small group each – a support group within a support group. Anyone interested in helping in this regard please see Irene.

Most of us at the meeting were feeling well at the moment. We had an update from Marj and Kim K.

Marj F has been stable on the same medication for the last 18 months –Tegretol and Epilim. She gets the best results from taking the medication at the same time each day, 12 hours apart. She finds temperature changes can affect her but does not seem to have any effects from food.

Kim K's mum lives in Malaysia and is now suffering TN in her mid 80's. Kim is not sure which medication she is on. She has arranged for methylcobalamin lozenges to be taken over to her. Irene suggested it might be better to purchase locally available methylcobalamin usually a Japanese product for maximum the shelf life. Magnesium supplement might also be of help for Kim's mum.

Irene: TNA Australia newsletters have been carrying news of positive responses to B12 therapy since 2005 - ever since Irene did a study on the "Efficacy of B12 in TN management." It is interesting to note that some research are going into this area. It seems that TNA USA has scheduled a preliminary study in the remyelination; and a recently published book "Trigeminal Neuralgia" edited by Peter Jannetta also carried a paragraph about Vitamin therapy - suggesting that "B12 – an essential component of myelin repair may play a role...." Irene wonders if our evidence based benefits of B12 is beginning to have a sway in this matter.

We also reminded the members of the conference at the Hunter Valley in September this year.

Irene has asked each support group to present exhibit for the conference. There were some suggestions made, and plans are underway. Kim and Kim have agreed to lead the project.

The meeting closed with our usual yummy afternoon tea. Thanks to everyone for contributing with afternoon tea, setting up and packing up and also Henry & Jeanette for the raffle.

*Thanks for taking notes Kim S*

Reminder: May's meeting has been brought forward to 30th April.

Next meeting in Toongabbie will be 2nd July... and then it will be conference time!! Arrrg!

*Irene.*

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# MELBOURNE SUPPORT GROUP MEETING

“Ringwood Room” Ringwood Library

1.30 p.m. 12 February 2011

Evelyn began the first meeting of the year by acknowledging the traditional custodians of the land where we meet, the Wurundjeri people. Evelyn then welcomed everyone, especially Irene Wood who came from Sydney for this meeting in our 10<sup>th</sup> anniversary year, new attendees and all returning members; she also wished everyone a happy New Year for 2011 and a happy Chinese New Year to those celebrating the Year of the Rabbit.

**Present: (30)** Barbara A.; Maree & Glenn B.; Alan & Joy C.; Ellayne C.; Evelyn & Din D.; Doug E.; Angela G.; Alf H.; Alan L.; Rose M.; Brian & Helen McC.; Nita & Robert McK.; Beryl O.; Bill P.; Will & Joan R.; Rose M.; Terry S.; Joan & Neil T.; Lisa T.; Rita & Chris W.; Diane & Garry W.;

**New attendees: (11)** Audrey B.; Lyn & George G.; Elwyn H.; Verna McC.; Sue & Ian M.; Maree P.; Susan T.; Elaine A & Kathy T.;

**Guest: (1)** Irene Wood

**Apologies: (5)** Toni B.; Marjory F.; Dorothy M.; Rob O.; Peter S.

Evelyn read extracts from Marjory’s letter about the benefits of the Support Group in making her decision to have an MVD (which was successful). She congratulated the group on reaching its 10<sup>th</sup> year of supporting TN patients and families/carers.

**Treasurer’s report:** Alan reported that we had a carry forward balance of \$258.95. Donations at the December meeting were \$47.40 and meeting room insurance costs were \$16.50 leaving a total in hand of \$289.85. Alan reminded people to please contribute to the gold coin donation box on the front table as this is our only source of income.

**Remembering our past:** Evelyn acknowledged the pioneering members who with Irene’s support set up our Melbourne group – some of whom are present today, in particular those who have carried responsibilities all these years: Joan and Neil, Alan and also Irene. The initiative, commitment and continuing support of these people in so many ways makes our group run smoothly. The role of TNA and the newsletters and the three Conferences so far have also helped maintain momentum for the Melbourne Support Group. Also mentioned were some of the many guest speakers who have visited and shared information with us over the years about many aspects of physical and mental health.

**Recent Newsletter:** Evelyn referred to the February newsletter and thanked Irene and the team for all the work involved in getting it out each month. Membership enquiries/payments direct to TNA Aus please. The fourth TN Conference will be held at Cypress Lakes Resort, Pokolbin, in the Hunter Valley of NSW from 2 – 5 September. Discounts apply for registrations before 31 April 2011 and smaller discount for registrations from 1 May to 31 July. Good location and excellent international speakers – members urged to attend!

**Support Group project for the Conference:** Every Support Group of TNA Australia is requested to prepare something for the Conference that reflects the Group’s experience, hopes, joys, interests e.g. artwork, poetry, collage of relevant information, foods or recipes suitable for TN people etc. We need to think about possible focus and format for our project and have someone take responsibility for it. This will be an agenda item at the next meeting!

## Reports from members:

**Evelyn D.** TN began in 2006 in cool evening air but after short term medication, acupuncture and mindfulness meditation she has been pain free for over 3 years now – no medications but she does take up to 4000mcg sub-lingual B12 daily.

**Angela G.** Has had TN for 20 years on the right side of her face. There were many stressful factors – work, retirement and a move to the Peninsular, bad sinus and bronchitis as triggers but now she feels a small miracle has happened. She has found a local Chinese acupuncturist and her pain is now greatly reduced – despite a little pain she feels she can beat it!

**Will R.** Started to experience TN pain after cleaning his teeth in 2001. He took many drugs and then was taking Tegretol but suffered side effects. In 2007 he found information about TN on the internet and he spoke with Irene. He had a preliminary consultation with an Epworth neurosurgeon in November that year and finally had an MVD in June 2008. Before the MVD every word banged in his head causing TN pain. Even eating chocolate on the non-TN side of his mouth triggered an attack. After the operation he was pain-free – he was home after 3 days and has had no sign of pain since. He was 82 at the time of the operation.

**George G.** spoke for his wife Lyn whose TN is felt from the jaw up to the back of her eye. He described how heartbreaking it is for a husband to see his wife suffer so. Lyn had an operation for sinus problems and was pain free for one year before the pain returned. Her GP sent her to an ENT specialist but the sinus was clear. He listened to her list of symptoms and sent her to another specialist who ordered an MRI, and discovered an aneurism on the brain, although the aneurism was on the opposite to her face pain. She had surgery for this in December and is now taking Baclofen 1 ½ tabs 3 times/day. She is mostly pain free now but has some lurking pain. Her husband suffers as well when she is in pain.

**Susan T's** father has had TN for 52 years that has destroyed his and the family's life. He had an MVD last November but has numbness and constant burning pain around the nose. The pain is worse on the left side of the face and lip and goes up to his eye and the left side of his head. He suffers great pain and has made 10 suicide attempts and adopted disturbing behaviours. Obviously his daughter also suffers in this dreadful situation.

**Audrey B.** developed glossopharyngeal neuralgia in 2002. She described the pain as excruciating. She saw Irene's article about TN in the Sth Oakleigh newspaper and made contact with TNA Aus; Irene helped a lot. She took 2.5 ml Tegretol/day for the chronic pain but this was not effective and she was finally hospitalised. Audrey's neurosurgery was in 2002 at the Emily MacPherson hospital. This caused one side of her face to drop and turn numb. The jaw dropped and she was in hospital 1 month. Finally the pain stopped! Prior to surgery she couldn't swallow, and cold winds triggered pain. She experienced hearing loss in the right ear and her balance was affected. Now she is thankful to be pain-free. She has been caring for her husband for some years but now he is in care and she is pain free and healthy.

**Joy C's** case is a bit different because she has MS and TN. She cannot have an MVD because of MS. During 2010 she had a few bad months and Andrew Danks performed a balloon compression. He warned her that it could make her face numb but she judged that to be the lesser of two evils. The numbness extended to the top of her head but Mr Danks said that was the extent of the effectiveness of the procedure. She was able to go off her meds but gradually the pain has returned. Mr Danks said a stronger compression could be done but Joy needs time to consider. Irene said that 5% of MS patients have TN and 2% of TN patients have MS. In discussion with Barbara A. Irene said that anaesthesia dolorosa occurs where the trigeminal nerve has been destroyed /damaged and half the face is now totally numbed yet there is burning pain from the inside out. Sometimes Endep can be helpful.

*(Amendment: Kim Burchiel et al. - TN occurs in up 4% of MS patients, in whom it is often bilateral. About 2% of patients with TN have MS. – Irene.)*

**Lisa T.** has had TN for 21 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 is now on Lyrica 300mg twice a day and also morphine. She has seen Dr Danks and is on the waiting list for an MVD. Pain has

started on the other side of her face now as well. She has moved house so is relieved of the stress of that issue. Her GP organized a care plan for her which allows her to have help from a pain management team: occupational and physio therapists. She sees a facial-cranial osteopath as well. Lisa's young age is a bonus but more important is to have a neurosurgeon who has significant experience in TN treatment and who does MVD procedures often. Anecdotal evidence points to more people having TN over 50 years of age but Irene is aware of many cases in young people, even a baby 18mths old.

**Gerry W.** Spoke for his wife Diane who has TN. Two years ago she had "toothache" in a molar at first thought to result from grinding the teeth though there was no evidence for this. 12 months later an X-ray revealed a crack in the molar so it was extracted. The pain worsened after the extraction and the injection of anaesthetic into the nerve. Diane's TN pain continued intermittently but was not as bad as some described today. Some treatments disagreed with her and brushing her teeth and wind triggered pain. Now trying Sensodyne toothpaste but probably not helpful. All this is fairly recent so they are hoping to keep out of TN trouble by controlling the environment. There is drifting pain still around the teeth and to the top of the head. Alan C produced an article from a local newspaper where Andrew Danks spoke about TN often being initially misdiagnosed as a dental problem. The article reported that 1 in 25000 people have TN. Mention was made of the most effective medication for most people being Tegretol and MVD as the most common surgical procedure.

#### **Address by Irene Wood:**

Irene thanked us for inviting her to this meeting. She told how her mother had suffered TN so Irene learned as much as she could about it and finally in 2000 took responsibility for forming a Support Group in Sydney. It was obvious that many were suffering - **What is this strange pain? Why Me?**

You suffered alone, You suffered needlessly; "No cause No cure – go home and learn to live with it." & it was hard to tell others about your pain. Others just don't understand what you were going through. It became obvious that there was also a need for support group in other states – Queensland and Victoria, so a preliminary meeting was held in Melbourne in December 2000. Leadership has always been most important – Irene needed people she could rely on. Joan reluctantly agreed and from 2001 led the Melbourne group for five years. Irene personally assessed and chose the group leaders. We are all lay people but we need to be well informed so we do not pass on incorrect information. In 2002 the organization was registered in NSW and then with ASIC as TNA is Australia-wide. A certain number of Board members have to be from NSW – a rule imposed by Fair Trading NSW.

Our Mission : To advocate for the awareness of Trigeminal Neuralgia and related facial pain.

OUR VISION: to give you back some Quality of Life

Our GOAL : To have a unified understanding of Trigeminal Neuralgia and other related facial pain. In order to go forward – we need to be heading in the same direction.

*"Trigeminal Neuralgia at best of times is confusing – no common language"-*

*"To ensure that all patients receive optimal care, a more uniform, consistent approach is required for the management of TN." : Joanna Zakrzewska*

All people running the organization and the support group leaders, including Irene are unpaid volunteers. Most are TN patients willing to help make a difference. We have a Board of Directors, and a Medical Advisory Board. Support Group leaders need the support of their members to gain confidence in their responsibilities of helping others. If you seek comfort, want to feel better – come along to meetings! Irene made the effort to come from Sydney for this meeting so local people have no excuse! *I caught the train all the way to Ringwood; getting to Ringwood seems simple enough – Irene.*

The TN Association serves to empower the patients and carers with information and knowledge so that they can make informed decisions about their treatment choices. This then allows them to cope better and take positive steps to take control of their pain.

Once their pain is under control, their quality of life also improves. They are able to partake in normal activities, socialize, and re-join the work force and contribute to society.

We communicate monthly via our newsletters - we hope to keep everyone informed and updated. The dissemination of information is done biannually through our national conferences, monthly via our newsletters and at local support group meetings.

Please do not copy bits or whole of our newsletters - the Newsletter is copyrighted.

*The moment an idea is put down in a material form, such as on paper, recorded on tape or stored on a computer disk, it is automatically protected by copyright. (Australian Law).*

It is also important to remember to credit the source where the information had come from, or the work or idea. **Plagiarism** is using someone's idea or thoughts or work without crediting the source and is equal to literary theft, and fraud.

Irene answered George's question about meetings in other parts of Melbourne. The need is for manpower and leaders of good character to make this happen. False or incorrect information is be damaging. Evelyn thanked Irene for attending and presenting a persuasive talk on TNA and presented a contribution towards her travel expenses.

**Miscellaneous:** Books can be borrowed from Din on \$40 refundable deposit. Up-date mailing list details with Evelyn. Enjoy afternoon tea together! Thanks to all for attending and participating.

The meeting closed at 3.30 p.m. and a delicious afternoon tea was shared by all present. Thanks to those who collected the key, paid insurance, set up for the meeting, managed the front desk for registrations and name tags on this busy day and to those who pack up and those who provide, serve and clean up after the refreshments. Special thanks to Alan for taking the December meeting for me and to Beryl who took meeting notes for him.

**Next meeting: Saturday 9 April 2011 at 1.30 p.m.**

*Evelyn.*

*I'd like to add my thanks to George and Lyn for the lift back to the airport. ~Irene.*

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## **Townsville Support Group**

**Saturday 19 February 2011**

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

Sera: Welcome everybody and thank you for coming and it's good to know that you have all survived the cyclone except Joan B who is waiting for repairs to her cyclone damage on her house in Ingham. Thank you everyone for their thoughts and prayers during this time – especially Irene. There was a general discussion on the fact that our numbers are not increasing despite the amount of advertising that we do. We all find that the meetings are immensely helpful. (*be patient Ladies, when Sydney group first started our numbers didn't multiply overnight. It will happen through time....take heart. Irene.*)

Apologies from Joan B

Sera: Now on 6 x Gabapantin and 4 Valproate a day. Dr R (neurologist) suggested a new MRI because pain has increased and medication not covering it yet. Started B12 but forgets to take it.

Sue: Because the pain was under control prior up to and during the first 2 weeks in Mt Isa, despite the stress of moving, she dropped back on the medication by 1 Endep at night (she had already consulted with her GP about it). The pain was back within 2 days – very bad shooting pain and so she recommenced her previous level of medication on the third day and after a week everything was back to normal. But then

she ran out of her B12 and couldn't get the same one in Mt Isa so after having missed a few and then having a different one, the pain returned again and took a while to settle. She is going to get 2 bottles in Townsville before returning to the Isa.

Jill: Pain still in her tongue left side. Pain is there all the time and an occasional ping on the right side. Eating only soft food and still on Lyrica, Endep and B12. Unlucky she seems to have it is on both sides.

Mary: Just the same – pain is in her right eye and deep in the ear. Still on same medication, including B12. Sera said being on the medication makes her slow down. (We all agreed).

Jill: We become anti-social at times because of the pain and then talking makes the pain worst. Jill met someone on a trip who realised that she might have the same problem so Jill referred her to the association and told her to go to the Dr. She gave her the contacts for the next meetings in her area.

Sue: reminded everyone that membership dues are due, go onto the website to find the form.

**Our next meeting will be on Saturday 16<sup>th</sup> April at 1:00pm** at the same venue.

Sue's Mum's (Joy's) birthday that week so that is why she is coming that week and it is the weekend before Easter so it shouldn't interfere with anyone's plans.

Jill: Mentioned that there was a good poem in the back of the "Striking Back" book and Sue read it – "Do You Know What I Did Today". Everyone could relate to different parts of it.

Sera asked What suggestions does anyone have about going to the dentist when we have pain.

( This topic would often pop up. In the information pack we send out – we have included Dr. Gremillion's Dental Care; also reprinted in our 2010 October Newsletter..)

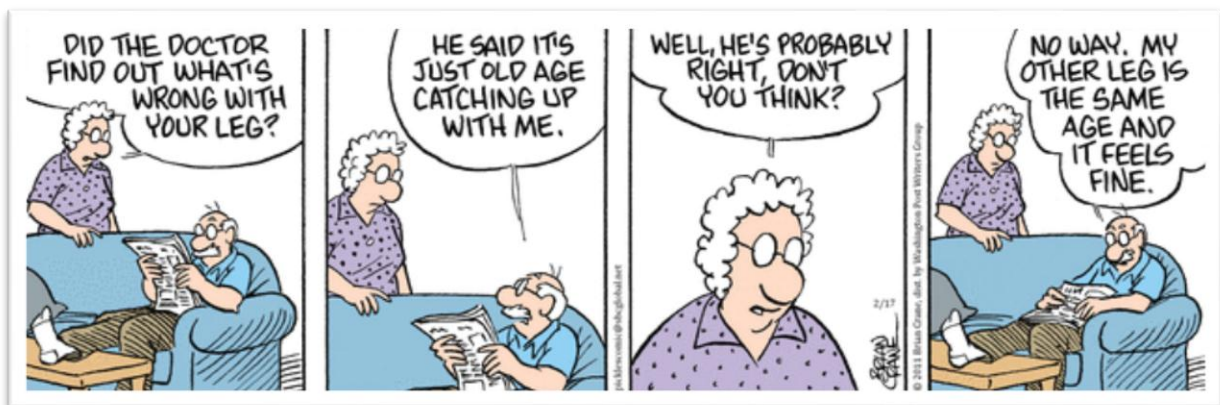
After some general discussion Sue suggested what she does for mammograms which are really painful for her because of cysts. She takes increased pain medication just for that day.

Sera: Thanked everyone for coming.

Whilst we were chatting during afternoon tea, Sera asked if anyone had noticed their hair thinning. No-one had noticed but Sue had noticed that she had very brittle nails when on the drugs. This had improved whilst off the drugs. Everyone enjoyed afternoon tea and informal chit chat. We have all become close friends.

*Thanks, Sue for meeting report.*

*Sera.*



# SUNSHINE COAST SUPPORT GROUP

Kawana Library, Nanyina Street, Buddina.

19 February 2011

Welcome to everybody. Sorry we had to postpone the last meeting due to the floods.

Highly recommend going to the conference in September 2011. The price includes meals, morning and afternoon tea etc. Well worth going, especially the social as well as the medical experts. Irene has asked that all support groups throughout Australia submit a project for the conference, e.g. Poem, Painting etc. So get your thinking caps on. A \$60 return bus has been organized from the airport to the conference.

**Apologies:** Teresa M, Jean B, Trixie & Keith B and Max H.

**Present;** Peter & Pearl R, Joseph A, Lloyd K, Jean Be. Dawn S, Barry F, Jean W, Dorrie H, Jill L, Frank K, Rebecca J, Deana W, Andrea F, Sherryl M, Glenda & Peter W, Jim K and Marie D,

Jean explained how we run our meeting to the new people, by starting with one of the older members first.

Peter R: had an MVD on the right and now has major trouble on the left. He has made an appointment with Dr Dexter in March after checking with the dentist that there wasn't anything wrong with his teeth.

Sherryl M: TN patient since 1982 and has had a MVD. After a couple of years the pain has come back. There has been an incredible improvement since going to a chiropractor (Drew Glendenning) who specializes in cervical chiropractic.

Jean Be: Jean first came to our meetings last December. She has been reading about Trigeminal Neuralgia and Bell's Palsy. The question she asks, is it neuritis or neuralgia? Had Bell's Palsy many years ago. After having a scan the doctor has told her that she had had a stroke, but she feels it is Bell's palsy. Her dentist is now untangling her problem and is now going to a TMJ specialist.

Rebecca J: Rebecca had a facial injury 6 years ago. It has taken time to manage the pain. She is now left with her lip and part of her nose being numb. At the moment she is going to a pain clinic at the Royal Brisbane Hospital. Rebecca feels that Gabapentin makes it better and is now taking 400 mg a day.

Deana W: Has a numbing internal pressure after a bump with a BBQ. Her doctor has said she has TN. Currently seeing as acupuncturist. Deana had a MRI after the bump which found bruising and swelling. It took a while to clear and is now left with this pressure. Again it was suggested to see a Neurologist to get a true diagnosis. She takes Osteo, Panadol and Tremal. It has been 2 months since the incident.

Dawn S: Not sure whether her rash is from Tegretol? Her pain is no better, no worse. Has a continuing problem in her jaw, her doctor has explained it as (like tennis elbow in her jaw). The pain seems to come after eating. She has stopped Tegretol and is now less sleepy, staying on Endep 25mg X2 a day.

Barry F: Barry has swelling of his feet and rashes from Tegretol. His neurologist prescribed Dilantin instead of Tegretol. He feels as though it made him depressed so he stopped dilantin and was put on Lyrica (200X2) – that made him feel "unreal". He has now gone back onto Tegretol, it keeps the pain away, but causes swelling and rash. His history- had TN for four years, then went off Tegretol. After 9 months, this terrible electrical shock happened while he was taking a shower.

*(swelling and rash can be allergic reaction to the antiepileptic drugs – Barry must stop the Tegretol and change drug. These rash or allergic reactions could lead to more serious problems such as Steven Johnson Syndrome or toxic epidermal necrolysis. Click on the link - [http://www.medscape.org/viewarticle/413205\\_3](http://www.medscape.org/viewarticle/413205_3) - to see how nasty it can get. I also remember reading that Sodium Valporate (epilim) is considered safe from such skin rash ~ Irene..)*

Andrea F: About 2 years ago she had the pain in her right side. She went to Sydney last September and met with Dr Dexter. After a successful MVD, she just feels wonderful.

Jim K: His TN is controlled by Gabapentin. Eating is a trigger for his TN. After having an attack he took a couple of Gabapentin and it seems to have dulled the pain. "Water Slushing" is something that seems to help to relieve the pain.

Marie D: feels that Lyrica wasn't doing anything for her. She has added Endep (20X2) and finds that it has the same effect, so she has stopped Lyrica all together. She has faith that it will go away.

Dorrie H: 12 months ago the pain started on her left side, knew it wasn't her teeth as she has dentures. At the moment she is managing on Tregretol (200X2) slow release. Her doctor has said that she can increase if needed. Dorrie asked about an MRI and it was explained that it will only rule out a tumour, MS etc. (*MRI for neurovascular compression is different to a general MRI.- Irene*). Keeping a diary, regarding the pain allow a clearer picture of what is happening. Sometimes just putting down how you feel, lets off a bit of steam and is a little easier on your family. Stress can also exacerbate pain. Meditation, yoga can offer relief to some.

Jill L: About 18 months ago her problem started. Her dentist confirmed that there was nothing wrong with her teeth. After explaining her symptoms as red hot poker into her ear and electric shocks after washing her face, & hardly able to eat, Jill's doctor diagnosed TN. Lyrica was prescribed, but that made her sleepy. It was changed to Tegretol (100X2). Slowly everything stopped and she has been able to stop all medication. Jill terrified of the pain coming back.

Lloyd K: couldn't eat or talk when his pain was so bad. He had his MVD in November 09 with Dr Dexter and everything has been good since.

Glenda W. It has been 10 years since her TN first started. She had an MVD last July in Brisbane but it was unsuccessful. At the moment Glenda takes 300X2 Gabapentin per day and 1800 Tegretol a day. It was suggested she might want to try B12, & acidophilus and bifidus probiotics.

Frank K: pain started 6 years ago on his left side, his doctor diagnosed TN. Tegretol (400X2) keeps the pain at bay. Frank is over 80y.o and has given up driving the bus and has eased off the "busy things" in his life. He tried to ease off the Tegretol and found that the pain increased and is now back on (400X2) again.

Joseph A: 3 years ago his pain started and he went to the dentist and had 2 teeth removed. Still the pain continued. Joseph went to his doctor and explained his symptoms – he couldn't eat or drink, & had electric shocks on his left side). The pain would go away but return after a few months.

Jean talked about alternative therapies that may help relieve TN pain.

- |                                |  |
|--------------------------------|--|
| *Alternative medical systems.  | *Mind-body intervention.               |
| *Biologically based therapies. | *Manipulative & body based treatments. |
| *Energy Therapies.             | *Hot pepper creams.                    |
| *Tens units.                   |  |

Everyone was asked to join us for a "cuppa" while we went through the different therapies. If you have any questions, feel free to ask. So sorry the meeting had to be kept to a time frame, the room had someone else following closely behind us.

Next meeting: 9th April @ 1pm, Kawana Library. Please note **1pm start time** (Irene Wood- Guest).

Special thanks to Pearl for taking the report.

*Jean Williams. ( Stay pain free)*

**ADELAIDE SUPPORT GROUP**  
**BURNSIDE CIVIC CENTRE.**  
**SUNDAY 30<sup>th</sup> JANUARY, 2011**

**PRESENT:** Martin Y and partner Helen, Kevin S, Graham and Liz B.

**APOLOGIES:** Ann T, Bert J, Joan E, Garry & Lisa, June & Roger O. Eileen P. Sue H

**FINANCE:** Donations: \$12.00. Expenditures: \$78.00 for hire of room for 3 meetings Jan, March and May 2011. Total on hand: \$34.15.

**WELCOME:** Graham welcomed Kevin and new member Martin with partner Helen and apologised for the lack of numbers but as the temperature was over 42C it was difficult for many to travel today.

**MARTIN'S STORY:** He has suffered facial pain for 20 years. He has been diagnosed with Trigeminal Neuritis. He feels pain most of the time and his face becomes puffy. He has consulted Professor G and been prescribed various drugs from Voltaren to anti-depressants and pain killers but nothing works really well. He also tried magnesium which made him worse. He does not eat or drink anything that contains caffeine/stimulants as these seem to worsen his pain and cause facial puffiness, he also has tension headaches. Martin has had an MRI which did rule out other possible problems, tumours, etc. Professor G feels his pain is related to muscle cramp. It was suggested that Martin consult his GP and request a referral to a neurologist for a second opinion and advice on other treatments and drugs available. Also to talk with a compounding chemist. Graham loaned Martin his copy of the book "Insight."

**KEVIN:** Related his story to Martin. He had a sensitive face for 15 years, experiencing stabbing pain. He consulted various neurologists who diagnosed his symptoms as TN. He was prescribed Tegretol which caused severe rashes. Later, when visiting Dr. Z to request surgery it was considered his pain was due to a jaw problem TMJ rather than TN. He then saw Professor G who ordered an MRI which showed degeneration of cartilage in his jaw. Kevin was given a cortisone injection under sedation in hospital and is now much improved. He continues to take Valpro night and morning. He tried discontinuing the evening tablet however, the stabbing pain reoccurred. He restarted the night time tablet and continues to be pain free.

As the weather had been predicted to be very hot several members phoned their apologies and gave a quick update over the phone.

**ANN:** Unable to attend today's meeting but in her telephone report stated she had recently undergone dental treatment which initially caused serious worsening of her pain but on her second visit found that increasing local anaesthetic to the area being treated produced a much better outcome.

**SUE:** Has recently had an MRI which eliminated any tumour but has identified a couple of offending blood vessels above and below the trigeminal nerve. Dr Z is recommending decompression surgery in the future but at this stage she is holding well with the Tegretol. Will talk to June and Maureen first.

**BERT:** Is not able to venture out in extreme heat. Is still getting some pain after his radiofrequency procedure but is managing without the need to take drugs. He has seen a jaw specialist who thinks he may be clenching his jaw.

**JUNE:** At our last meeting June informed the group that she was awaiting a date for a glycerol procedure. In the meantime she thought seriously about having an MVD instead. A thin cut MRI had shown a blood vessel contacting the nerve and her surgeon had considered she was a suitable patient for the operation. After much thought and discussion with Graham, she decided to have the MVD and this is to be done next Tuesday 1<sup>st</sup> February at the Royal Adelaide Hospital.

**Post Note:** Graham and Liz visited June on Friday 5<sup>th</sup> to find her very bright and TN pain free. She had soreness from the operation and a nasal drip problem that was being looked into, but generally felt relieved it was over and no pain. It was later found that the nasal drip was being caused by leaking brain fluid which required a further operation to repair a small tear. All is now well and June is pain free.

**MAUREEN:** A new TN member underwent an MVD on Wednesday 2<sup>nd</sup> February. We visited her also - being in the same ward as June. Maureen wasn't quite as well as June, but her operation was more recent. She was TN pain free but experiencing nasty headache and neck stiffness.  
(We wish both ladies a speedy recovery and enjoyment being neuralgia pain free.)

**MEETING CLOSED** AT 3.40 p.m. followed by biscuits and tea/coffee.

**NEXT MEETING:** SUNDAY 27<sup>th</sup> MARCH, 2011 AT 2.00 p.m. AT BURNSIDE CIVIC CENTRE.

*Graham & Liz*

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## **BRISBANE SUPPORT GROUP**

**Saturday February 12**

**ATTENDANCE:** Henry C, Eileen C, Colin B, Margaret B, Helen W, Joan F, Doreen T, Jennifer D, Neil F, Leo L, Margaret H, Lorraine B, Jeff B, Rob J, Tony M  
**APOLOGIES:** Alzira, Leonie G

Our meeting opened with an invitation to all to attend this year's conference. The quality of speakers was again praised. The importance of sharing each of our experiences and management strategies cannot be under estimated .Our group agreed to making a financial contribution to this year's conference. We have also just made another \$100 donation to the local parish for the use of the church hall.

We then shared our stories.

**Henry** has been essentially pain free for two years since beginning monthly neo cobalamin injections. He had one hit out of the blue on New Year's Eve. Apart from that, he continues to be really well.

Margaret B is going well. She did experience a couple of bouts of pain, with only one hit per day. She then lifted the Tegretol up to 500mg from 400mg. She continues neo cobalamin injections and this had a very positive effect on pain reduction. She takes lecithin, flaxseed oil, zinc, magnesium complex, Bio C, and folic acid.

**Helen** has been pain free for a full year now since her MVD performed by Dr Coyne. She has now stopped Tegretol. She takes magnesium, oral B12 and fish oil.

**Joan F** has been pain free for eight years since commencing methyl cobalamin injections. This provided instant relief following several years of severe pain despite using Lamictal and Tegretol.

**Doreen** endured pain since 2004.Following her first meeting with our group, she commenced neo cobalamin injections and pain left her almost immediately. She reduced her Tegretol to 50mg morn and night and is now drug and pain free.

She takes zinc, magnesium, ginkgo, cider vinegar and Epsom salts. Tony commented that Epsom salt is actually magnesium sulphate and that this could well be assisting in relaxing the nerves and therefore assisting pain reduction. *Please refer to our December 2010 Newsletter on Magnesium~ Irene.*

**Jennifer** has had two MVD's without pain reduction. She is unable to take Tegretol. Xylocaine provided some benefit in reducing the pain. She has found the Association helpful and is about to take on some of the remedies used by members.

**Neil** likewise extends his thanks to the association for its efforts in assisting members.

**Leo** says he is "fairly brilliant!!" He had an MVD six years ago following a month of terrible pain. The MVD stopped the TN pain instantly, but left him with the numbness associated with anaesthesia dolorosa. He can now lead a normal life and recently addressed a crowd of 1500. Distraction is a great help. He also

quoted the advice offered by one of our members from another meeting "I get great relief from a spoonful of whisky"

**Margaret H** continues to be really well following 30 years of TN pain. She describes her monthly methyl cobalamin injections as marvellous. She is now down to 800 mg Tegretol and will reduce this further in the cold weather. She is affected adversely by summer heat, winds and humidity. Her sister and first cousin also have TN.

**Lorraine** had been well up until last week when she experienced a couple of bad days. Methylcobalamin has worked well in reducing the pain along with Lyrica and Endep. She also takes zinc, fish oil and magnesium.

**Rob's** TN pain began two years ago when it was first triggered by a fan. As teeth pain was prominent, a visit to a dentist resulted in TN diagnosis. Tegretol was of assistance up until a week before Christmas and he had to stop work with the pain. Attacks frequently are from 9am to 11.30am with pain through teeth brushing and shaving. He is currently on 1000mg Tegretol and 150 mg Lyrica.

**Tony** continues to be essentially pain free. Hits are only minor when cycles come and all normal activities can be performed. He is on monthly methyl cobalamin injections, flaxseed oil and magnesium and maintains a very healthy diet and lifestyle with lots of laughter.

We wish our friends who can't be with us today our sincere thoughts for ongoing wellness.

**Next meeting: Saturday April 9**

*Tony McP*

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## SYDNEY CBD SUPPORT GROUP

St James Parish hall

5 February 2011

Attendance: Kim K, Ingrid K, Ieuen R, Lois W, Reg W, Alan M, Margaret M, Allaster McDougal, Irene.W

Mary K got to the hall late, rang Irene's mobile..which in her haste that morning had left her phone at home so poor Mary was unable to enter the building. In future if you are late – use the intercom, button 1 - on the left hand side of the wall if you were facing the glass door.

Our first meeting for 2011 – attendance was small in numbers but it allowed more time to share more personally with each other.

**Lois:** has been good, only one brief attack about 5 -6 weeks ago, although it was a level 9/10 pain, which lasted about 10 minutes. During such attacks, she would go and lay down and prefers to be alone while she rides the waves. She takes 200mg Lamictal every morning and night, and another 100mg at noon; plus 75 mg Lyrica at night. She has a B12 injection every 2 months.

**Ingrid** had a good run from August till December. 10 days before Christmas and she was experiencing pain when eating and chewing or talking. She described these as little zaps about a 6/10 level of pain; left side stabbing pain and this morning it throbbed. She is on 75mg Lyrica am/pm and 100mg Tegretol am /pm as well.

This is a footnote for the next newsletter if it's not too late.– from Ieuen R.

Last Wednesday 9th Feb 2011 Ingrid had a severe TN attack, followed by several more. She was in pain Wed, Thu, Fri (Wed & Thu the worst). The pain was constant and not only when she ate or spoke. This resulted in an increase in Tegretol from 200mg to 600mg per day. Today, Sunday, is the first day she has shown signs of improvement with less shocks.

This is now the third year that she has had pain Jan – Feb. We will follow it to see if the pattern continues that the second part of the year is relatively pain free. Don't know if this is a pattern or coincidence.

Alan: his pain returned 3 weeks after he came back from his holidays over in Western Australia. Alan reckons that the "*diet*" - (Irene's eat your way out of pain diet) stopped all his pain. Before he went on the diet, even with medication, he was still experiencing 7/ 10 level of pain. After starting the diet he was able to attain pain free for 3 months. However, his holidays in WA, he was unable to get *the diet* ingredients – so he did without. Pain came back as "little hits" and he is now back on 300 Tegretol and 1800 mg of Gabapentin. He does not want to increase his Tegretol to 400mg – as that caused his serum sodium level to drop dramatically "nearly had a heart attack."

Alan had been encouraged to start *the diet* once more to see if he could still achieve no pain.

Irene: I only had a handful of participants in this study but the results were encouraging. Interestingly, some participants are so well they don't come to support group meetings anymore. I will need to do some follow up on them. But as no one else was interested, I didn't want to waste my time.

Kim K : was also on *the diet*, and said that by September "all pain went". In December, when she went on holidays, she even forgot to take her morning does of 200mg of Tegretol. She now remains on the evening dose, take the diet religiously, and also soya milk. No pain.

Allaster: reducing Trileptal lasted a month. Pain came back and so he was started on the Vimpat @ 50 mg to titrate up 50mg till he achieve 100 am /pm. He didn't noticed much difference – pain remained the same at between levels 2 – 3 /10. If he takes the medication @50mg on an empty stomach he feels nausea; 100mg makes him sleepy. He finds he can tolerate the medication better in the evening dose. Pain level remains at 3/10. He described his pain sensation as dull nagging pain.

Please Note: Meeting in April is moved to the 30<sup>th</sup> April – An afternoon with Dr Kim Burchiel  
Next meeting in St James Parish Hall will be 4<sup>th</sup> June at 10:00 am.

*Irene.*

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#### 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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## 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	02 July 1:30 – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads, Toongabbie.	Kim Koh ☎ 02 97431279
	Sydney CBD	4 June 10:00 – 12:30 pm	St. James Parish Hall Level One, Phillip Street	Irene Wood ☎ 0413 363 143
QLD	Brisbane	9 April 1.30-4.00pm	30 Ridley Road Bridgeman Down	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	9 April 1:00 pm	Kawana Library, Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	16 April 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	TB A 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	9 April 1.30 – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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