May 2008

Our Mission: To advocate the awareness of facial pain and promote better understanding through information and education.

Our vision: To improve the quality of life of a chronic facial pain sufferer.

Last month we appealed for someone to take over the facilitation of the Gold Coast and the Newcastle Support Group - to date no one has stepped forward yet. I urge you to recall when you desperately needed support and what it meant to you to be able to relate your pain to people who understood exactly what you were going through. How fortunate for you that SOMEONE cared enough to do something. It would be enormously disappointing that this support would no longer be available in your area ...unless YOU!! decide to lend a hand.

The difference between a helping hand and an outstretched palm is a twist of the wrist.

~Laurence Leamer, King of the Night

May I encourage you to turn your once outstretched palm over to a helping hand.

In the words of Martin Luther King “You don't have to have a college degree to serve. You don't have to make your subject and your verb agree to serve.... You don't have to know the second theory of thermodynamics in physics to serve. You only need a heart full of grace. A soul generated by love.”

I am nominating the 19th July at 11 am as the next meeting date for Gold Coast support group. I hope to be able to officially introduce the next support group leader at this meeting. I will organise a Newcastle meeting when I can locate a venue.

Meanwhile, we have Chris in Cairns who desires a support group in his region. In spite of his other health problems, Chris still wants to volunteer his time and effort to support others. We are helping Chris establish a support group for chronic facial pain patients, especially those with trigeminal neuralgia and we hope to hold our first meeting in Cairns soon.

The Annual General Meeting of Trigeminal Neuralgia Association Australia Incorporated will be held at 11am on Saturday 7th June 2008, at St James Parish Hall ,Level One, 169 - 171 Phillip Street, SYDNEY. Nomination Forms enclosed.

Please do not wait till your pain is full blown before you decide you need help, especially with the weekend approaching. Go see your GP or your Chemist and discuss your medications before your TN gets completely out of control. Many of you remain stubbornly defiant and suffer needlessly then try to ring me over the weekend – desperate for help.

I would like to have another collection of artwork re: your expression of pain, for our national conference in 2009. The art group in Sydney under the guidance of Diane presented a wonderful collection of their work at the last conference. I am hoping more of you will participate in this exercise and that by 2009 we will have an even bigger collection to exhibit. Let’s see what Melbourne artists can produce! ☺

Irene.
Global Year Against Pain in Women

Differences in Pain between Women and Men

Sex differences in pain: the evidence
- Women generally report experiencing more recurrent pain, more severe pain and longer lasting pain than men
- Evidence for sex differences in pain is wide ranging, and includes basic science, epidemiology and clinical research
- For example, experimental studies show that women have lower pain thresholds and tolerance to a range of pain stimuli when compared to men

Prevalence of painful conditions in men and women
- There are sex differences in the prevalence rates for some painful conditions
- There are more painful conditions where there is greater female prevalence than male prevalence
- Examples of painful conditions where there is greater female prevalence include fibromyalgia, irritable bowel syndrome, temporomandibular disorder, rheumatoid arthritis and osteoarthritis, migraine headache with aura
- Examples of painful conditions where there is greater male prevalence include cluster headache, coronary heart disease, gout, ankylosing spondylitis, duodenal ulcer, pancreatic disease

Other factors impact on sex differences in pain experience
- Pain experiences vary considerably within the sexes as well
- Changes in sex hormones have been found to moderate pain (e.g., menstrual cycle, pregnancy)
- Sex differences in pain can vary across the lifespan. Many of the observed gender differences in pain prevalence (i.e. headache, abdominal and visceral pain) appear to reduce beyond the reproductive years.
- Sex differences in pain can vary across different cultures as well

Sex differences in pain treatment
- Sex differences in analgesia exist
- There are sex differences in the side effects associated with drugs, including analgesics
- Sex differences in nonpharmacological chronic pain treatments have also been found

Reasons why men and women differ in pain and analgesia
- Biological mechanisms include sex hormones, genetics, and anatomical differences. Some of these biological factors (i.e. gonadal hormones) become less apparent in the postmenopausal years.
- Psychosocial influences include emotion (e.g., anxiety, depression), coping strategies, gender roles, health behaviors and use of health care services

What needs to be done?
- Sex differences should be considered in the investigation of pain
- Raise awareness of the similarities and differences between the sexes when considering pain and analgesia
- Greater understanding of the different health needs of men and women

Orofacial Pain: Prevalence and Impact
- Acute (e.g. toothache, oral sores) and chronic (e.g. temporomandibular muscle and joint disorder or TMJD/TMD pain) orofacial pain are highly prevalent conditions
- Most forms of orofacial pain are more common among women than men, and women report greater impact of oral pain
- The most common form of chronic orofacial pain is TMJD pain, which affects approximately 10% of the population
- TMJD is twice as common in women than men, and a greater proportion of women with TMJD seek treatment for this condition
- Trigeminal neuralgia, while much rarer than TMJD, occurs roughly twice as often in women as in men
- Burning mouth syndrome occurs at dramatically higher rates in women than men

Experimental Models of Orofacial Pain
- Injection of certain chemicals into the masseter (jaw) muscles of healthy persons can produce pain similar that reported by patients with TMJD pain
- Women report more intense, more widespread, and longer lasting pain after such injections
- In response to experimental jaw pain, women show less activation of opioid receptors in their brain compared to men, suggesting a reduced ability to modulate facial pain using the endorphins
- Administration of exogenous estrogen increased women’s ability to activate opioid receptors to modulate experimental jaw pain

Sex Hormones and Orofacial Pain
- TMJD is most likely to occur in females during the reproductive years, such that sex differences in prevalence are smaller (or nonexistent) prepubertally and postmenopausally
- Some evidence suggests that use of exogenous estrogens (e.g. oral contraceptives, hormone replacement) increases risk of TMJD
- TMJD pain symptoms vary across the female menstrual cycle, and tend to less during pregnancy

Other factors may impact sex differences in orofacial pain
- Chronic TMD pain is often comorbid with other painful conditions, which are also more prevalent in women, such as: fibromyalgia, irritable bowel syndrome, and vulvar vestibulitis
- Psychological factors have been associated with TMJD pain, including somatization, depression, and other indices of psychological distress, and women tend report higher levels of these factors than men in the general population

What needs to be done?
- A better understanding for the reasons underlying sex differences in orofacial pain is needed
- Whether women and men with orofacial pain respond differently to different treatments also needs to be determined
Technique of Microvascular Decompression - Technical note.
Peter J. Jannetta, M.D.; Mark R. McLaughlin, M.D.; Kenneth F. Casey, M.D.

Vascular compression of the trigeminal nerve in the cerebellopontine angle is now generally accepted as the primary source or "trigger" causing trigeminal neuralgia. A clear clinicopathological association exists in the neurovascular relationship. In general, pain in the third division of the trigeminal nerve is caused by rostral compression, pain in the second division is caused by medial or more distant compression, and pain in the first division is caused by caudal compression.

Nuances of the technique are best learned in the company of a surgeon who has a longer experience with this procedure.

We also, of course, maintain monitoring of brainstem auditory evoked responses throughout these operations in an attempt to ensure that we do not hurt the patient's hearing.

The neurovascular relationships in TN generally have a clear clinicopathological correlation. First, it is important that the surgeon understand, except in some cases of multiple sclerosis, that TN is caused by a blood vessel.

Second, he or she must understand that not only is there one blood vessel involved but there may be more, and it is up to the surgeon to find all of them. The involvement of these vessels may occasionally be subtle. The compression may be proximal or distal, and it may be located under the ala of the cerebellum. We have seen three patients in whom the vessel was located totally inside the trigeminal nerve.

The vascular compression causing hyperactive symptoms in the trigeminal nerve can occur anywhere from the brainstem to the Meckel cave. There are approximately 100 fascicles in the nerve just inside the Meckel cave, and they each settle into the fibrous cone of the sensory root of the trigeminal nerve (portio major, Fig. 5).

Compression anywhere, therefore, from brainstem distally, can cause TN. Rostral compression of the nerve causes pain in the V3, and this is most commonly due to the SCA looping downward and upward again (Fig. 6). As the artery elongates, it compresses the middle portion of the nerve, causing pain in the V2 in addition to the V3.

We have seen a long, looping SCA compress the caudal side of the nerve from below without compressing the rostral side and causing isolated pain in the V1.

The relatively rare, isolated pain in the V1 is caused by a vessel on the caudal side of the nerve. Isolated pain in the V1 is most common in older men, cigarette smokers, and patients with dolichocephalic features in whom the verte-brobasilar system arteries compress the nerve from the caudal side.

Isolated pain in the V2 is most common in younger women and is caused by a bridging vein that may be quite distal on the nerve.

In a patient with dolichocephalic features, an enostosis may be present over the distal part of the nerve ("Kamal hump"), hiding the compressing vein that is causing the TN. One must take care to look around caudally, rostrally, and underneath the enostosis, using a mirror if necessary to ensure that there is not a vessel in this region. Compression in this area often softens the nerve and one must be careful not to traumatize it.

Duration of compression as well as location and size of the blood vessel cause changes in TN. In time, an artery that is elongating will stretch the nerve, causing constant pain that may be burning in nature and may cause numbness. A vessel compressing the motor–proprioceptor fascicles distally causes constant pain that is usually burning in character and is hard to localize. If the motor–proprioceptor fascicle is stretched by a blood vessel, the patient can
experience hyperactive autonomic dysfunction and a cluster headache syndrome. If the individual reports a cluster headache syndrome, one must also look for compression of the intermediate nerve, usually on the caudal side of the seventh and eighth cranial nerve bundle or between the nerves. This is treated with section and decompression of the intermediate nerve.

Surface veins cause a special problem, because they are prone to recollateralize if coagulated and divided. Most early recurrences (< 1 year) are the result of these recollateralized veins. Subsequent recurrence (0.5%/year) is due to new blood vessels, especially arteries, pressing on the nerve as a result of the continuation of the aging process.

Postoperatively, the patients are kept overnight in a well staffed nursing unit but not in a continuous care or intensive care unit. If there are any problems, of course, we move them into the intensive care unit. We mobilize the patients the night of the operation or the next day. The mean duration of stay in the hospital is 1.7 days for our patients. If someone has excessive pain, headache, or nausea, we will keep them in the hospital longer. Patients are seen in an office visit on the 5th postoperative day, and those from out of town return to their homes thereafter.

Our patients have had minimal hearing loss problems and infections, and the infections have been superficial in recent years, but occasional leaks of cerebrospinal fluid continue to plague this procedure. These are treated by closed spinal drainage; using the method of simple oversewing of the wound advocated by McCallum, et al.,[23] is not sufficient. Rarely, the wound must be explored, the bone re waxed, and the dura mater resutured. The mortality rate associated with this procedure is 0.1% in our series.

Abbreviation Notes

MVD = microvascular decompression; SCA = superior cerebellar artery; TN = trigeminal neuralgia; V1 = first division of the trigeminal nerve; V2 = second division of the trigeminal nerve; V3 = third division of the trigeminal nerve.

Microvascular Decompression (MVD)

Report of the Trigeminal Neuralgia Association
Second National Conference,
November 11-15, 1998 Orlando FL

An MVD is a major operation, requiring general anaesthesia and microsurgery. (On a scale of one to ten, if ten is extremely serious surgery, an MVD is about a three, according to Dr. Jannetta.)

The surgeon makes a thumb-sized opening in the bone of the skull, exposes the trigeminal nerve and examines it through a powerful microscope, looking for blood vessels that appear to be jammed up against it. Small veins may simply be coagulated and dispensed with, but arteries must be lifted and padding inserted between the nerve and the blood vessel to protect the nerve.

Neurosurgeon Peter J. Jannetta: During the operation, we monitor electrical signals from the auditory nerve in order to prevent hearing loss (a relatively rare complication). An MVD takes one to two hours, skin to skin, and if it gets rid of the pain people generally feel incredibly well incredibly soon afterward.
How often do you fail to find a blood vessel compressing the nerve?
Dr. Jannetta: That never happens. The trick is to find all of the vessels because some very small ones may be involved.

How can I find a skilled neurosurgeon to do an MVD?
Neurosurgeon Stephen J. Haines: Look for someone who regularly performs microsurgery and has learned the MVD procedure from an expert.

Is there a correlation between head injuries and TN?
Dr. Jannetta: I believe there is. I have seen many TN patients who were injured when a car was rear-ended; others fell and hit their head. Some begin to have TN pain right after the accident. The longer the interval elapses, the less likely the injury is to be related to the TN.

Can an MVD cure TN forever?
Neurosurgeon Kim J. Burchiel: The MVD is the only surgery where there's evidence that long-lasting relief is possible. Of patients who have an MVD, 10 to 15% get no relief from the surgery. Eighty-five to 90% feel much better after the procedure but for 5 to 10% of these patients pain comes back within the first year after the MVD. With each year that passes after the operation, another 2% have a return of pain. When that happens, sometimes we operate and re-explore. Often we don't find anything, but the patient still benefits from the surgery, maybe from having the nerve rubbed and slightly injured. The average pain-free interval in our M'VD study was 15 years - patients had a 50-50 chance of being pain-free at 15 years. Dr. Jannetta's data show that after 15 years his patients have a 70 to 75% chance of being pain-free.
In short, the vast majority of MVD patients do very well long-term and don't have a recurrence. However, even with MVDS some patients have a return of pain and we don't know why. Perhaps a new blood vessel begins pressing on the trigeminal nerve, or the nerve was irreversibly injured before the procedure.

If pain returns after an MVD, what kind of surgery should you have?
Neurosurgeon Jeffrey A. Brown: An older person not in good health should probably have one of the percutaneous procedures, while a younger individual who wants to avoid numbness might want a second MVD.

Dr. Burchiel: A patient who had an MVD done by "Dr. Nobody" should see a neurosurgeon with specific training and experience in doing MVDS. Neurosurgeons love this operation even if they do only two a year. A person who does only two a year doesn't have enough experience. Just rubbing the nerve could give you six years pain free even though the surgeon missed the real problem.

What is the success rate for repeat MVDS?
Dr. Haines: Probably 50 to 70% - not as good as the first time.

Is there an age limit for MVDS?
Neurosurgical resident B.T. Ogungbo: Some surgeons refuse to do microvascular decompressions on patients over a certain age. To compare MVD outcomes of older and younger individuals, we reviewed the medical records of 62 trigeminal neuralgia patients who had had an MVD and also contacted them by phone. Forty were over 65 and 22 were under 65 when they had the surgery. Two people in the younger group had serious complications (a cardiac arrest and a brain abscess). In the older group, one patient became temporarily confused, and that was the only severe complication. We concluded that MVD’s are safe for older people, and that patients should be selected based on their physiological, not their chronological, age.
Meetings Report: Sydney CBD Support Group  
St James Parish Hall  
April 5  2008


We started the meeting with some house keeping. Ellayne who has been minding our support group’s kitty over the past few years, has decided she wants some time off and has handed the book in. We thank Ellayne for her help and keeping a neat set of bookwork. Kim has kindly offered to take over. Thanks Kim.

Each year I seem to be busier and this time I have neglected the Tea and Coffee Roster. Every little bit that members do to help out goes a long way to extending my life. ☺ Thanks Lois for volunteering to co ordinate our T/Coffee roster. Now I can be sure there will be a cup of tea for me after each meeting! ☻ Please see Lois if you can help or if you have any last minute change of plan and cannot fulfil your roster. Lois: 02 4973 1171

Treasurer’s report:  
Brought Froward $191.30. Donation collected $36.00. Expenses – Coffee/ tea $11.15  
Balance for April - $216.15.

Members’ Updates  
David had an MVD about 2 months ago done somewhere down south, and unfortunately it has not been a success. David wanted to know what his other options are. I have suggested that perhaps he seeks a neurosurgeon who does a lot of MVD procedures and who also uses the thin Cut MRI – perhaps a missed vessel can be identified.

Claire rang to say that she is well now and she can at last eat properly. She had her MVD for glossopharyngeal neuralgia in August last year and although she has been pain free, she had difficulty with swallowing and for a while lived on mushy food.  Glad that all is well now.

Mary De rang to say she will be having her MVD on the 16th of April at Westmead – Thinking of you and hope to hear good news soon.

Ingrid and Ieuen are away on holidays in Europe. Ingrid reported that she her mouth was still playing up – but slightly. “ In fact at last meeting it started to become a little worse on the Friday before, but everybody was in such bad shape, I wanted to be positive. Anyway not too bad, but still can’t reduce medication yet.”

Lois is having a great time with no pain. She is still on Lamictal @ 200mg X 3 a day ( T.I.D) and once a month B12 injection.

Amanda TN started 5 years ago in her V2 and V3. She had her MVD in Sydney a year ago and although pain free and is on no medication, she said that her side of the face feels “tight” and still have some odd sensation in the area of the op. site

Fran said that all is well. Her last pain period lasted 4 months but went after Christmas. She is currently on 300mg of Tegretol and tapering down. She was also using B12 at one stage.

Nola has been to see Dr. Vickers as her Epilim was not helping. Dr. Vickers started her on topical cream, a combination of Amitriptyline, Neurontin and Lidocaine.

Joan has TN for 27 years. After she went on to B12 injection ( once every 3 months) and oral B12 @ 100mcg daily, she has been pain free for the past 2 ½ years. She takes half a tablet (100mg) of Tegretol each day.
Madeline is taking 600mg of Tegretol (300mg X B.I.D) and that is suppressing her pain. However she is ever fearful as the pain threatens to come back.

Ellayne episode of pain had lasted 8 weeks. She is now pain free and has cut back her Tegretol to 400mg. Although pain free, she is careful when washing face and applying makeup as she can feel little twinges.

Allaster has pain in his left lip and gum. He is using B12 sublingual, Neurontin @900mg and Endep @ 12.5 mg at night. It helps him sleep.

Kim said that a month ago her pain was bad but is better now. She describes her pain as burning and sharp and manages with sublingual B12 and Tegretol. She gets ulcers with Tegretol but that seems to be the only medication that controls her pain.

We then watched a PowerPoint show re: Conference 2009 and with the help of some slides, we learned a bit more about neurons. I also did a touch up on my B12 project, what we have learned from the results. By then, there were these stunned looks starring back at me ☺, so we decided that it was time for caffeine infusion. Many thanks for Reg and Lois for bringing the sandwiches – YUM! Your effort and your thoughtfulness are greatly appreciated. Thanks also to everyone, especially John W for always landing a hand in tidying up.

Hope to see all of you at the next meeting June 7 at 11 am – St James Parish Hall.

Irene.

ADELAIDE SUPPORT GROUP
BURNSIDE TOWN HALL
SUNDAY 6TH APRIL, 2008 AT 2.10 p.m.

ATTENDANCE: Bert J, Garry & Lisa R, June & Roger O (new members), Anne & David S (new members), Kevin S, Graham & Liz B.

APOLOGIES: Barbara S, Ann T, Joan E, Jan S.


WELCOME: Graham welcomed members and particularly first time attendees June & Roger and Anne & David. He outlined the aims of the Support Group and stressed that we were not medical experts but fellow TN sufferers sharing our first hand knowledge and experiences in coping with the pain of TN. He said that because TN was not common it was not always diagnosed correctly. Graham explained the usual course of TN and the problems associated with a misdiagnosis including (sometimes) extensive/expensive and unnecessary dental treatment. He advised that obtaining a correct diagnosis is crucial since this would dictate future treatment options as some types of facial pain do not respond to treatments which benefit true TN suffers. Graham briefly summarised the categories of treatment options and referred to the books “Fighting Back” and “Insights” which contain as much information that TN sufferers need to have.

Graham referred to a TNA Headline News article from America which reported that pregabalin (Lyrica) may be beneficial in patients with neuropathic pain who have had an unsatisfactory response to treatment with other medications. Also, a article from Germany which reported that Pregabalin appears to be effective in the treatment of patients with trigeminal neuralgia; almost all patients that responded well to the drug reached their maximum pain reduction within the first 4 weeks. Graham pointed out that feedback from our own members who are taking or who have tried Lyrica is probably more meaningful and reliable than claims contained in these reports. Lyrica is expensive and has side effects.
which can cause weight gain and blurred vision. (Graham is taking Lyrica himself with good results - so far.)

Graham showed the meeting some pamphlets produced by Irene promoting the Trigeminal Neuralgia Association which members were asked to distribute to their local medical centres, surgeries, libraries, etc.

ANNE: has been experiencing pain, itchiness and numbness since February commencing with earache and toothache. Her dentist realised it was not a tooth problem and thought it might be Neuralgia. She was unable to get an appointment to visit a neurologist until late April so went to a physician in the interim. Anne said she received a very negative response from the physician when mentioning to him her intention of attending our support group meeting. A thin cut MRI and CAT scan have failed to show anything conclusive, the comment was “Nothing abnormal apparent considering her age!” Her Doctor prescribed 400 mg. Tegretol and she feels the pain is under control with the Tegretol, Panamax and heat packs. Anne’s main concern and frustration is the numbness she experiences together with itchiness around the nose (even though she can’t feel it when she scratches) and she has also lost the sense of taste on her affected side. Because her pain is not particularly severe, together with negative MRI/CAT scan results, she is not sure whether TN is actually the correct diagnosis. Hopefully her appointment with the neurologist later in April will resolve this and put some light on her intolerable numbness. It was stressed that the group was there to offer support to persons suffering any facial pain. Graham loaned Anne his copy of Striking Back so she might be better prepared when she visits her neurologist.

GARY: Gary’s TN is the result of a stroke. An MRI showed damage to a nerve. He has had to learn to live with his pain with the aide of 2,700 mg. Neurontin and 5 mg. Morphine nightly - not 500 mg. nightly as stated in the last newsletter. He is seeing a neurologist for an update next week. Eye pain is a further problem for Gary.

KEVIN: Is the best he has been for a long time. When his pain first arose he went to the dentist who ground down two high spots in his fillings. His pain went. However it returned, Tegretol caused a rash and no improvement in his pain. A chiropractor suggested it could be compressed nerve and treatment produced an improvement in his pain. Facial exercises were also recommended. He visits the gym and visits to the chiropractor are helping and he feels well. Kevin’s pain was confined to his jaw.

JUNE: New member. June first experienced symptoms 3 years ago. A swarm of flying ants in a holiday shack seemed to be the catalyst of her problem. Symptoms are tingling and short sharp pain on touching her top lip. Applying lipstick is difficult. She was prescribed Tegretol but cannot tolerate this. She believes stress worsens her symptoms. June is able to tolerate her symptoms at this time and it is hoped it will not worsen. She experiences pulsating sensations in her neck – the side not affected by her TN. Bert also has this symptom but it was considered not part of the TN problem. In fact most of the group experienced pulsating at various times.

BERT: Continues to take B12 and is having a “quiet” time.

GRAHAM: Following very severe attacks he started to take Lyrica (2 x 75mg.) and commenced the B12 program in October 07 He had been pain free since Christmas however his symptoms have returned over the past two weeks and is he experiencing occasional medium pain at the side of his tongue and slight numbness and itchiness of the cheek. He has started to take an extra 75mg of Lyrica each evening. He is very concerned with the amount of weight he has put on since starting Lyrica. He is also taking Prednisolone which tends to cause increase weight.

KEN: Graham reported that he had spoken with Ken who is a carer and unable to get to our meetings. Ken had been in severe pain and experienced little help and no relief after visiting several specialists. After reading the book Striking Back he was able to understand TN and
the alternative medical options much better. He saw a new doctor and after raising his Tegretol to 2 x 400mg a day (his own suggestion) has been pain free since late January. He does have bad side effects but these are preferable to the pain and he is willing to tolerate this. Ken was very appreciative of the help he has received from the TNA Support Group. Graham suggested he should have a contingency plan of action should his pain return and be uncontrollable when he is not able to get urgent medical attention due to his situation.

MEETING CLOSED at 3.45 p.m. with most members leaving to watch the Crows and Power footy game.

NEXT MEETING: Sunday 25th May, 2008 at 2.00 p.m. at the Burnside Town Hall - Community Centre.
PS (THE CROWS WON!!!!).

Graham & Liz.

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MELBOURNE SUPPORT GROUP MEETING
At “Ringwood Room”
Ringwood Library, 1.30 p.m., 12 April, 2008

Welcome to the meeting on this beautiful autumn afternoon. Especially we welcome Irene Wood who has come from Sydney to address us and to new member Chris H who travelled from Warragul in Gippsland to attend a meeting for the first time.


Apologies: (7) Nancy B.; Bernadette G; Nita and Robert McK.; Beryl O. Peter & Liz S.

Member deceased: Evelyn reported that she had been informed that former member Giselle H had passed away about a month ago. A sympathy card had been sent to Giselle’s husband on behalf of the group, many of whom remembered Giselle well.

Treasurer's Report: Alan reported that $33.00 was donated by attendees at the February ‘08 meeting. Expenditure since then totalled $11.70 (insurance, supplies) leaving a balance of $189.55. Thanks to Alan for the report.

Reports from members: We heard from several people as follows:

Joan T. recently had a cataract procedure performed and was delighted to have a surgeon and an anaesthetist who understood TN and her apprehension that an attack might be triggered. Her mask was cut in such a way to avoid touching a trigger point and all went very well. Thanks for being with us so soon after the procedure, Joan, and may your rapid recovery continue!

Barbara A. is happy to still be able to control her pain on just 2/100mg Tegretol/day. Rita W. takes only 1/2 Tegretol every other day. She is going overseas soon so will be sure to keep up the medication. Rita still feels the benefit of some early morning quiet time of meditation each day. Enjoy your travels!

Joan H. has been feeling down and her morphine dosage has been increased to 50mg patches and 1/2 morphine tablet daily. She feels fortunate not to have to pay the full price for this expensive medication. Good to see Joan continuing to come to our meetings. We hope you feel some benefit from the support of the members, Joan.

Joy C. used to have a Lignocaine patch which also required permission from Canberra as Joan’s (above) do. Joy used to cut the patch into smaller pieces to make it last longer but now does not need this medication.

Mary H. said she has to push herself to go out of her home as she still experiences severe, icy pain. She is to see Prof. Stark at the end of April. She is not feeling very optimistic because so
far nothing has helped, but members encouraged her to be proactive in seeking relief. Mary
knows that wind on her face and getting upset or feeling stressed can trigger an episode of
pain.
Freda’s 70+ yr old neighbour was in so much pain he could not work but after an MVD he is
fine now and does not need to take Tegretol at all.
Chris H. started experiencing pain three years ago. She found she was allergic to Tegretol so
now takes 600mg Lyricane daily. She still suffers some pain but manages daily life including
family.

Newsletter: All members had recently received the April newsletter and found it and the
March newsletter also, very interesting. Thanks to Irene and those who assist in the regular
compilation and distribution of this widely circulated and much appreciated publication.

Resources: Evelyn reminded people of the books available for borrowing on a $30 refundable
deposit and of one new copy of Striking Back for sale.

Irene Wood’s presentation:

2009 TNA Conference: Irene presented a short video on the 2009 TNA Conference which
will be held in Victoria from 27 - 29 August 2009 – either in the Dandenong or Marysville.
The line-up of local and overseas experts in various aspects of TN diagnosis and treatment as
well as pain research and management who have already accepted invitations to attend is
very impressive! The conference in Victoria will be followed by a winery tour in the Yarra
Valley on 30 August and then a short holiday on Dunk Island in the Barrier Reef, south of
Cairns. Everyone is urged to plan to attend the conference. The social events following the
conference are optional. Exact costings are not being made public until the final decision on
venue is made – watch out for more news!! Conferences such as this, with recognized experts
in a wide range of related areas, encourage people to take hold of their own pain. Joan T.
supported this!

B12 Program for treatment of TN: - notes by Evelyn- may not be accurate.
B12 (cobalamin) is found in natural sources such as red meat, fish, eggs, dairy products. B12
supplement can be taken in oral form either in tablets or sublingually; and through intra-
muscular injections. If B12 is taken orally, for maximum absorption, an acidic environment
in the stomach is needed and also the Intrinsic Factor, secreted by cells of the stomach lining.
The B12 combined with the IF then passes into the alkaline environment of the duodenum
and small intestine. Some causes of low B12 might be vegetarianism, improper digestion (e.g.
some medications reduce stomach acidity), reduced IF (anaemic patients), pancreatic
defects, and intestinal parasites.
B12 has neurological effects e.g. as a mood up-lifter, as well as being important for health of
the nervous and cardio-vascular systems.
Probiotics are live, good bacteria (acidophilus and bifidus) which help re-balance and
improve the micro-flora of the gastro-intestinal tract.
The trigeminal nerve is part of the peripheral nervous system where the Schwann cells
myelinate the axons. Prof. Marshall Devor (speaker at the Australian 2007 and 2009 TN
conferences) has proposed the ignition hypothesis based on his research together with
Rappaport. This theory proposes that with de-myelination of the axons, ephaptic cross-talk
or cross-excitation can occur resulting in strong pain.
Irene’s own data:
In 2002, following her mother’s TN pain, Irene began collecting data from some 94 people
who suffered TN - 63 female and 31 males. People on the program have their B12 levels
measured. A high level of methylmalonic acid indicates a low level of B12 in the body.
According to Fishbach, 450pg/ml of B12 is acceptable. 84% of the people tested were below
that level. 15 who were above the 450 level were already supplementing on B12.
Irene’s hypothesis - Could a Low B12 fail to sustain repair to the myelin (sheaf of the nerve)
particularly if the nerve is continuously being pounded by a blood vessel.
The 18 month program aims to build up B12 and to see if the myelin rebuilds and reduces TN. Of 44 people surveyed, 61% showed positive results of reduced TN, 3 were in remission, 3 stopped to have surgery, 9 showed no difference. 
(There are no known side effects of high levels of vitamin B12).

Questions: Irene handled many questions from the floor e.g. about burning mouth syndrome where she referred to having attended a talk by Dr. Nixdorf at the TNA Conference in Portland. He suggested that spicy food could exacerbate the condition and also introduce his patients to B12 supplement. It might enhance absorption if B12 is taken at the beginning of breakfast and probiotics at the end of the meal; increase B12 by intra-muscular injections, if unable to take orally. Maintain B12 level of 450 pg/ml.
Irene’s presentation was greeted with a warm round of applause for the sustained effort she invests in the B12 program and the support of so many TN sufferers.

The meeting concluded so we could enjoy afternoon tea and continue the discussion and conversation with others.

Thanks to all who helped this afternoon – collecting the key, arranging insurance, setting up, afternoon tea, welcoming members and for clearing the room before 4 p.m. Such generous co-operation makes it easier for all. Special thanks to Alan for having his data projector set up and working for the presentation and huge thanks to Irene for travelling from Sydney for the meeting, for the presentation about the 2009 Conference and the very informative talk on the B12 Program. Members were informed of the general TN three-fold brochures now available to be put in public places.

The next meeting will be on 9th June, 2008, at 1.30 in the Ringwood Room, Ringwood Library (Mel 49 H8).
John Woolmer, compounding chemist from Eltham is to be our guest speaker. He will tell us of ways that a compounding chemist can make some medications individually tailored and more readily available to the body.

Evelyn

Canberra Support Group.
Weston Creek Community Centre
Saturday 12th April 2008

Louise had come to the meeting at the suggestion of her husband who had seen the notice in the Canberra Times.
Louise had two MVD’s. One three years ago and another on the opposite side two years ago. To date she is pain free. Her husband had seen an item on TV and she decided to have surgery and was thrilled with the results, so much so she and her husband decided to start their family and it was during this pregnancy that TN affected the other side.
Once the baby was safely delivered she underwent the second operation. This one was not straightforward, although the thin slice MRI showed the blood vessel causing the problem it did not show that the vessel was actually embedded in the nerve. After this discovery the surgeon took time to consider the options and consult with her husband before completing the procedure.
This was successful and after four days in hospital Louise was able to return home. Apart from some numbness on both sides of the face she has tingling on the second side but does not find this troublesome.
At a question from one of our members Louise gave some figures as to the cost involved at a private hospital. Louise pointed out that the rare genetic disease she has causes weakness of the muscles so she did not see a problem with older patients undergoing the operation for this reason. As Louise is anxious to help our members the meeting agreed she should come to
another meeting to speak to those who were missing today. She is happy to do this and will
be at our August meeting as guest speaker.
Brian continues to be pain free after having a glycerol injection and hopes to continue so.
Barbara is currently in Japan and so far has not had a bad episode. She has started yoga
to help her with the pain.
Marilyn’s doctor feels it is time to reduce her Epilim as she has been doing so well.
Jan reported that she had received leaflets from Irene to distribute to doctors and members
were happy to take some each.
Devi had been in touch and not feeling well enough to attend. She is still having treatment
after her falls and we do hope she is feeling better soon. Her dentist feels that if she has a
denture fitted to do away with uneven pressure when she eats she will have less pain and she
intends to do this.
Nicola G has more problems with her arthritis than with TN and since the meetings clash she
has opted to attend the first one. Her dentist wants to undertake oral root therapy as he
expects this to reduce her facial pain. Hopefully this will be successful for both.
Jan had been contacting Clubs re meeting rooms but of the four contacted so far the cost is
much higher than the Community Centre and some do not have small rooms for our group to
use. Louise offered to look into this for us as her husband has contacts in some clubs who
may be helpful. This offer was gratefully accepted. In the meantime we will continue to use
the Community Centre.
Once again our usual meeting room is booked every Saturday morning in June but the
meeting felt that the extra expense of the larger room was worth it so meeting room 1 has
been booked for 14th June at 10.30am at the Weston Creek Community Centre.

Jan

SUNSHINE COAST SUPPORT GROUP

Unfortunately, we had to cancel our meeting scheduled for the 19th April. The dental surgery
who so kindly let us use their premises for previous meetings has changed hands. Due to
insurance issues and also the fact that they will now be open on Saturdays, the new owners
will not make these premises available to us for any future meetings.

Our apologies to anyone who did not receive the message in time - we only found out two
days before the meeting. However, we do believe that most people did get the message
thanks to Jean phoning around on Friday (see her phone report below), and also thanks to
David & Gloria who went along to the surgery on Saturday in the pouring rain and waited to
see if anyone turned up. We also need to thank David & Gloria for picking up and returning
the key for all our meetings - as well as setting up, locking up, and tidying up etc. They have
come to the rescue once again by offering their home as a venue for our next meeting.

We have scheduled a meeting for the 17th May, 1pm. As mentioned, this will be at the home
of David & Gloria, 20 Plymouth Quay, Maroochy Waters. - (Map 33 G8 Sunshine Coast
Telephone Directory) Please note we will still have our June meeting.

We need to find a new meeting place for our regular meetings, so please ask around, or if you
can offer your home for one or two meetings in the interim, we would be most grateful.

Teresa & Jean.

Results of phone call ring around

Mark H. Haven’t heard from him for quite a long time, thank goodness we took the time to
ring. Mark had a M.V.D. Few years back. He suffered a stroke, his wife said he was the
happiest stroke victim out. He was able to eat again. He has now fully recovered, back at
work, life is good. His young family are thrilled too bits.
Pamela C. Has been without pain for 12 months after having her M.V.D. She won’t be coming to the meetings as she is free from pain.

Merrilyn G. Is being operated on in Sydney. We wish her well. She will recover in Sydney, staying with relatives until her checkup in May.

Peter R. Has been given the all clear from his neurosurgeon after operation. Peter fell back while playing with his grandchildren and hit his head. He bleed around the brain. His TN has flared slightly and he hopes it will settle. Peter and his wife are off to Melbourne for a break. (Peter its cold down there come back to the warmth).

Neil W. Is doing well, still cutting back on his commitments. Having a lovely day in the sun at Noosa. Way to go Neil.

Jane K. The wind is playing up with her T.N. She has a thinking cap on regarding a new venue.

Max H and Evelyn R. - Both doing well, we will catch up with them next time.

Lloyd K. He has learnt so much more in the last couple of weeks than he has since he first was diagnosed with TN. Sorry we were only able to leave a phone message, he turned up at the venue. It was teaming with rain. As we don’t have big sign posts on our foreheads we were passing ships in the night. Teresa and Jean have been able to catch up via phone. Hang in there Mate.

Jean W. - Life is good, couldn’t be better. MVD does work, but it does take courage. Teresa M - Doing really well since having her M.V.D in February. Now off all medication and enjoying life.

Jean Williams.
I am much inspired by your effort. Well Done ladies esp… with such short notice. that you were able to contact so many and also get a report from them. I do appreciate your hard work. It helps me to know that there are people like you both who DO care.
Thanks heaps,
Irene.

A woman’s dream car
Laughter is the Best Medicine

A lady bought a new $100,000 Mercedes and proudly drove it off the showroom floor to take home. Halfway home, she attempted to change radio stations and saw that there appeared to be only one station. She immediately turned around and headed back to the dealer.

Once at the dealer, she found her salesman and began to excitedly explain that her radio was not working, and they must replace it since she only had one radio station. The salesman calmed her down and told her that her car radio was voice-activated, and that she would only need to state aloud the type of music that she wanted and the car would find it.

She got into the car and started the engine and then said the word "country," and the radio changed to a station playing a George Strait song. She was satisfied and started home. After a while she decided to try out the radio and said "rock ‘n’ roll;" the radio station changed and a song by the Rolling Stones came from the speakers. Quite pleased, the woman continued driving.

A few blocks from her house, another driver ran a light causing her to slam on her brakes to avoid a collision. The woman angrily exclaimed, "Asshole!"

...The radio cut over to George Bush’s press conference.

THE NEW YORK TAXI DRIVER

Father O'Flannagan dies due to old age. Upon entering St. Peter's gate, there is another man in front, waiting to go into heaven. St. Peter asks the man, "What is your name what did you accomplish during your life?"

The man responds "My name is Joe Cohen, and I was a New York City Taxi driver for 14 years"

"Very well," says St. Peter, "Here is your silk robe and golden sceptre, now you may walk in the streets of our Lord."

St. Peter looks at the Father, and asks "What is your name and what did you accomplish?"

He responds, "I'm Father O'Flannagan, and have devoted the last 62 years to the Lord."

"Very well," says St. Peter, "Here is your cotton robe and wooden staff, you may enter."

"Wait a minute," says O'Flannagan, "You gave the taxi driver a silk robe and golden sceptre, why did I only get a cotton robe and wooden staff?"

"Well," St. Peter replied, "We work on a performance scale, you see while you preached, everyone slept, when he drove taxis, everyone prayed!"

With the help of a fertility specialist, a 65 year old woman has a baby.

All her relatives come to visit and meet the newest member of their family. When they ask to see the baby, the 65 year old mother says, "Not yet."

A little later they ask to see the baby again. Again the mother says, "Not yet."

Finally they say, "When can we see the baby?"

And the mother says, "When the baby cries."

So they ask, "Why do we have to wait until the baby cries?"

The new mother says, "I forgot where I put it."
2008 Meetings

ACT
14 Jun 10:30 am CANBERRA SUPPORT GROUP
Venue: Weston Creek Community Centre, Room1
Support Group Leader: Jan Goleby – 62474508

NSW
7 June 11:00 am – 2:00 pm SYDNEY CBD SUPPORT GROUP
ST James Parish Hall, Phillip St.  
Support Group Leader: Irene Wood 02 45 796226  
Speaker- TBA

5 July 1:00 – 4:00 pm SYDNEY SUPPORT GROUP
Toongabbie Public School,  
Cnr. Fitzwilliam and Binalong Rds, TOONGABBIE  
& Kim Koh 02 97431279

TBA COFFS HARBOUR SUPPORT GROUP
Sawtell Uniting Church, 24 Elizabeth Street, SAWTELL  
Support Group Leader: Ailsa Braid 02 6658 3051

NEWCASTLE SUPPORT GROUP
Meeting - suspended till further notice

QLD
10 May : 1:30pm - 4:00pm BRISBANE SUPPORT GROUP
30 Ridley Rd., BRIDGEMAN DOWN  
Co- Support Group Leaders: Leonie Gall 0407 55 44 07;  
Tony MacPherson 07 3822 2286  
Speaker: Irene Wood.

19 July 11:00 am – 1 pm GOLD COAST SUPPORT GROUP
The Palm Beach Neighbourhood Centre, 16 Third Avenue, Palm Beach.  
Contact: Irene Wood.

17th May: 1pm SUNSHINE COAST SUPPORT GROUP
20 Plymouth Quay, Maroochy Waters  
Support Group Leaders : Teresa Miller: 07 54912487  
Jean Williams : 07 5491 1978

S.A
Sunday 25th May : 2:00pm ADELAIDE SUPPORT GROUP
Burnside Town Hall, corner of Portrush/Greenhill Road  
Support Group Leaders : Graham/ Liz Boyer: 08 8392 2781  
& Barbara Stentiford 08 84452019

VIC
14th June 1:30pm MELBOURNE SUPPORT GROUP
"Ringwood Room" Ringwood Library, RINGWOOD  
Support Group Leader: Evelyn Diradji 03 9802 6034  
Guest Speaker : John Woolmer, compounding chemist

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NOTICE TO MEMBERS

The Annual General Meeting of Trigeminal Neuralgia Association Australia Incorporated will be held at 11am on Saturday 7th June 2008 at St James Parish Hall, Level One, 169 - 171 Phillip Street, SYDNEY

Agenda:
To confirm minutes of previous AGM held on 2nd June 2007.
To receive committee reports on the activities of the Association since last AGM
To elect office bearers of the association (except the President) and 3 ordinary members of the committee.
To receive and consider the statement which is required to be submitted to members under Section 26 (6) of the Associations Incorporation Act 1984.

Members may submit nominations for the positions of Vice President, Secretary and Treasurer. Also for 3 ordinary member positions.
Nominations must be seconded by another member and accepted by the nominated party.
Nomination form printed below.
Nominations must be received by the Secretary, 14/247J Burwood Road, Concord NSW 2137 by 31/5/2008

NOMINATION OF CANDIDATE FOR ELECTION AS OFFICE BEARER

I,........................................ of..........................................................
being a member of Trigeminal Neuralgia Association Australia Incorporated hereby
nominate ........................................ for the position of ......................

Signed ...................................... Seconded......................................

Print name ..................................... Print name.................................

Nomination Accepted..............................

------------------ FORM OF APPOINTMENT OF PROXY ------------------

I,........................................ of ..........................................................
(full name) (address)
being a member of ......Trigeminal Neuralgia Association Australia Incorporated

hereby appoint ................................. of ........................................
(full name of proxy) (address)
being a member of that incorporated association, as my proxy to vote for me on my behalf at the annual general meeting of the association to be held on the 7th day of June 2008 and at any adjournment of that meeting.

.....................................................
Signature of member appointing proxy

Date..............................................