



Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

OUR MISSION: To advocate for the awareness of Trigeminal Neuralgia and related facial pain.
OUR GOAL: To have a unified understanding of Trigeminal Neuralgia and other related facial pain resulting in better pain management.
OUR VISION: An improved Quality Of Life of a chronic facial pain patient.

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

MAY 2010

“When you do nothing, you feel overwhelmed and powerless. But when you get involved, you feel the sense of hope and accomplishment that comes from knowing you are working to make things better.”

Annual General Meeting 2010

The Annual General Meeting of Trigeminal Neuralgia Association Australia Incorporated will be held at 10am on Saturday 5th June 2010 at St James Parish Hall, Level One, 169 - 171 Phillip Street, SYDNEY. Your nominations are invited for positions in the executive committee (bar the President position) and 3 of ordinary committee members. All nominations must have a seconder, being another TNA Aus member and the candidate must sign consent. Please find Form attached on last page of newsletter. Unfortunately the AGM is affixed to the Sydney meeting, for if AGM were to be held on a separate day or venue, we would struggle for attendance. Rules require we have our election before July of each year. The 2 meetings are conducted separately with different agendas; thus AGM is declared closed before Sydney support group meeting begins.

Have you renewed your 2010 Membership?

Thank you to those who have responded with their membership. A BIG thank-you to those who sent in their gifts - your generosity is heartening and much appreciated.

Dear Docs, care to support our work with a donation - please?
Included below for your convenience a Gift Form.



Please make Cheque or Money Order payable to: **Trigeminal Neuralgia Assoc. Aus Inc.**
& send to: **P O Box 1611 CASTLE HILL NSW 1765**

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Yes! I would like to support TNA Australia Inc. in their mission

Name: _____

Address: _____

Postcode _____

Phone: _____ Email _____

This is my gift to the Trigeminal Neuralgia Association Australia Inc. Support Fund to assist in their ongoing work of patients' support and education through information:

- \$25
- \$50
- \$100
- \$250
- \$500
- Others \$ _____

Trigeminal Neuralgia Association Australia Inc. is a tax-deductible gift recipient. ABN 33 914 644 101

"If you're not actively involved in getting what you want, you don't really want it."

~ Peter McWilliams

Do you have burning pain or even type 2 TN?

- We are still seeking participants. If interested - Please contact Irene Wood.

TNA Aus 4th National Conference 2011 September 2nd – 5th in the Hunter Valley, NSW

- Are you planning on being there? Start saving now. You would hate to miss out.

TNA Australia will hold an **inaugural meeting** for Trigeminal Neuralgia sufferers and their carers in the **Townsville area** – all are welcome.

Date: Saturday June 19 2010

Venue: Carville Senior's Villa - Unit Hall
35 - 37 Diprose Street, Pimlico QLD 4812

Time: 13:00 or 1 PM.

Admission is free. Gold coin donation would be appreciated.

For Further Information - Please contact: Local: Sera 07 47516415

Or TNA Australia 02 45796226

E-mail: tna_Sydney@yahoo.com or irene.wood@tnaaustralia.org.au

Irene.

DISCLAIMER

The information provided in this Newsletter is of a general nature only and is not intended to replace medical advice. Any views of a medical or therapeutic nature expressed are the views and opinions of the author and are not necessarily the views of Trigeminal Neuralgia Association Australia.

Before considering or undertaking any medical or therapeutic treatment described please seek advice from a Qualified Medical Professional.

Trigeminal Neuralgia Association Australia does not accept liability for any adverse consequences that may arise from following any treatment or advice described in this Newsletter.

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The Role the brain plays in pain – The Mind Body Syndrome.

The concept of Mind Body Syndrome (MBS) or Tension Myositis Syndrome (TMS) is based on the theory that - “ Your body is producing pain because it's manifesting unresolved stress, possibly from your childhood, or from stressful events in your adulthood, or from your present circumstances, and as a result of your personality traits (which affects how you respond to stress and how much pressure you tend to put upon yourself). Your mind has twisted your body into pain as a way to avoid some of the emotions that are inside you.” – Dr. H. Schubiner

Excerpt from “ The Structural Model of Personality” by Kendra Cherry

According to the founder of psychoanalytic theory Sigmund Freud - the mind can be divided into two main parts:

1. **The conscious mind** includes everything that we are aware of. This is the aspect of our mental processing that we can think and talk about rationally. A part of this includes our memory, which is not always part of consciousness but can be retrieved easily at any time and brought into our awareness. Freud called this ordinary memory the preconscious.

2. **The unconscious mind** is a reservoir of feelings, thoughts, urges, and memories that outside of our conscious awareness. Most of the contents of the unconscious are unacceptable or unpleasant, such as feelings of pain, anxiety, or conflict. According to Freud, the unconscious continues to influence our behaviour and experience, even though we are unaware of these underlying influences.

Sigmund Freud's psychoanalytic theory - the personality is composed of three elements - known as **the id, the ego and the superego** - they work together to create complex human behaviours.

The Id

The id is the only component of personality that is present from birth. This aspect of personality is entirely unconscious and includes of the instinctive and primitive behaviours. According to Freud, the id is the source of all psychic energy, making it the primary component of personality. Id is driven by the pleasure principle, which strives for immediate gratification of all desires, wants, and needs. If these needs are not satisfied immediately, the result is a state anxiety or tension. The id is very important early in life, because it ensures that an infants needs are met. If the infant is hungry or uncomfortable, he or she will cry until the demands of the id are met.

However, immediately satisfying these needs is not always realistic or even possible. If we were ruled entirely by the pleasure principle, we might find ourselves grabbing things we want out of other people's hands to satisfy our own cravings. This sort of behaviour would be both disruptive and socially unacceptable. According to Freud, the id tries to resolve the tension created by the pleasure principle through the primary process, which involves forming a mental image of the desired object as a way of satisfying the need.

The Ego

The ego is the component of personality that is responsible for dealing with reality. According to Freud, the ego develops from the id and ensures that the impulses of the id can be expressed in a manner acceptable in the real world. The ego functions in both the conscious, preconscious, and unconscious mind.

The ego operates based on the reality principle, which strives to satisfy the id's desires in realistic and socially appropriate ways. The reality principle weighs the costs and benefits of an action before deciding to act upon or abandon impulses. In many cases, the id's impulses can be satisfied through a process of delayed gratification--the ego will eventually allow the behaviour, but only in the appropriate time and place.

The ego also discharges tension created by unmet impulses through the secondary process, in which the ego tries to find an object in the real world that matches the mental image created by the id's primary process.

The Superego

The superego is the aspect of personality that holds all of our internalised moral standards and ideals that we acquire from both parents and society- our sense of right and wrong. The superego provides guidelines for making judgments. According to Freud, the superego begins to emerge at around age five.

There are two parts of the superego:

1. **The ego ideal** includes the rules and standards for good behaviours. These behaviours include those which are approved of by parental and other authority figures. Obeying these rules leads to feelings of pride, value, and accomplishment.

2. **The conscience** includes information about things that are viewed as bad by parents and society. These behaviours are often forbidden and lead to bad consequences, punishments, or feelings of guilt and remorse.

The superego acts to perfect and civilize our behaviour. It works to suppress all unacceptable urges of the id and struggles to make the ego act upon idealistic standards rather than upon realistic principles. The superego is present in the conscious, preconscious, and unconscious.

What happens when the ego cannot deal with the demands of our desires, the constraints of reality, and our own moral standards? According to Freud, anxiety is an unpleasant inner state that people seek to avoid. Anxiety acts as a signal to the ego that things are not going right.

The Mind Body Syndrome/ Tension Myositis Syndrome theorise that this conflict, this emotional strain, this "energy" has to come out somehow - it needs to be expressed. So it comes out in the body as **emotional symptoms** such as anxiety, depression, panic or worry; in **physical symptoms** such as pain, headaches, migraine etc. These symptoms are real but caused by underlying emotional contents.

What happens in the brain when emotion symptoms are activated? The Amygdala, the autonomic nervous system, the sympathetic nervous system (the fight or flight reactions) and sensory neurons are also activated. This results in a cycle of information and stimulations and reactivations which could continue into days, months or years. The other thing that happens now is - Trigger comes into play. Trigger can be food, time of day, weather, place etc. Part of TMS/ MBS treatment is to recognise these triggers and getting rid of them. How?

In the conscious part of the brain (the frontal lobe) is the dorsolateral prefrontal cortex. Studies have shown that when the dorsolateral prefrontal cortex is activated it can inhibit the autonomic nervous system; this provides the break in the link of the vicious cycle that causes Tension Myositis Syndrome /MBS.

The physical symptoms and emotional symptoms are real, but they are caused by stress, emotional reactions to stress that are built up from childhood into adulthood, exacerbated by our own personality factors. By changing our understanding about what the problem is, having hope, having a positive expectation (that you can get better) – you can take control of this whole situation through working mainly in the mind ie - activating the dorsolateral prefrontal cortex. Break the link between the emotional reactions and the physical and emotional symptoms that have occurred.

– “ The Role the brain plays in pain: Dr. H. Schubiner.”

Please note: the above are my notes from – any error is strictly mine- Irene.

Rx: How to Live Well with Chronic Disease : David S. Sobel M.D.

Mind Body Health : <http://www.healthy.net>.

To live well with chronic conditions you need to learn skills for managing three areas:

- Your illness and symptoms
- Your normal daily activities
- Your emotions

Managing Your Illness

Any illness is a learning experience. You may not even know you have a pancreas gland until you're told you have diabetes. To manage a chronic illness, you need to become an expert in your disease. This doesn't mean you become a doctor, but you need to learn enough about your condition and how your body reacts so you can take action to minimize disability and complications.

Be an Active Partner

Learn about your medical condition. What makes it worse or better? What action plan should you take if symptoms flare? What are the warning signs that you should get professional medical help? What can you expect from medical care and what must you do for yourself?

There may be specific skills you need to learn: how to measure your blood sugar if you are diabetic, how to properly use an inhaler if you have asthma, how to exercise safely with a heart or lung condition, (*"how TN medication should be taken!" – Irene*)

Learn how to prepare for a medical visit - what questions to ask about medical tests, medications, and surgery.

Learn to Cope with Symptoms

Most chronic disease symptoms wax and wane. When symptoms are bad, take some consolation in knowing that "this will pass." Learn and practice the proven techniques for dealing with pain, tension, depression, anxiety and insomnia.

Laughter is the best medicine

Are There Jews In China?

Yitzhak and Moshe were eating in a Chinese restaurant in London.

"Yitzhak," asked Moshe, "Are there any Jews in China?"

"I don't know," Yitzhak replied. "Why don't you ask the waiter? I'd be surprised if there were no Jews in China. Our people are scattered everywhere."

When the waiter came by, Moshe asked, "Are there any Chinese Jews?"

"I don't know sir, let me ask," the waiter replied, and went back to the kitchen.

The waiter returned a few minutes later and said, "No, sir. No Chinese Jews."

"Are you sure?" Moshe asked.

"I ask everyone," the waiter replied. "We have orange Jews, prune Jews, tomato Jews and grape Jews, but no one ever hear of Chinese Jews!"

The Headache.

Sadie goes to see her rabbi and complains about her bad headaches. She whines, cries, and talks about her poor living conditions for hours.

All of a sudden, Sadie shouts, overjoyed, "Rabbi, your holy presence has cured me! My headache is gone!"

To which the rabbi replies, "No Sadie, it is not gone. I have it now."

Exercise Is Good For the Brain By:Jeanna Bryner, LiveScience Managing Editor

posted: 26 April 2010 03:20 pm ET

Working out on a treadmill isn't just good for the body, it's good for the brain, according to a new study, the latest to weigh in on the cognitive benefits of exercise.

Regular exercise speeds learning and improves blood flow to the brain in monkeys, the study found. The researchers suspect the same would hold true for humans.

While there is ample evidence of the beneficial effects of exercise on cognition in other animal models, such as the rat, it has been unclear whether the same holds true for people, said study researcher Judy Cameron, a psychiatry professor at Pitt School of Medicine. Testing the hypothesis in monkeys can provide information that is more comparable to human physiology.

For one, monkeys exercise like people, in that they love getting on a treadmill (well sort of like us), and they won't run all night as rats would do if provided with a running wheel, Cameron said.

"Second, monkeys, like people, have well-developed cerebral cortices and that is the part of the brain used in cognition. Rats have a much less developed cortex, so again monkeys are more analogous to people," Cameron told Live Science.

Cameron and colleagues trained adult female cynomolgus monkeys to run on a human-sized treadmill at 80 percent of their individual maximal aerobic capacity for one hour each day, five days a week, for five months. This regimen is equivalent to what is recommended for improving the fitness of middle-aged people.

Another group of monkeys remained sedentary, meaning they sat on the immobile treadmill, for a comparable time.

Half of the runners went through a three-month sedentary period after the exercise period. In all groups, half of the monkeys were middle-aged (10 to 12 years old) and the others were more mature (15 to 17 years old). Initially, the middle-aged monkeys were in better shape than their older counterparts, but with exercise, all the runners became more fit.

During the fifth week, the monkeys completed cognitive tests in which they had to choose which covered objects contained a food reward underneath. Monkeys that exercised were twice as fast at this task as those who didn't exercise.

However, later in the testing period, learning rate and performance was similar among the groups, which could mean that practice at the task will eventually overshadow the impact of exercise on cognitive function, Cameron said.

Brain tissue samples revealed that mature monkeys that ran had a greater volume of blood vessels compared with middle-aged runners or sedentary animals. (These blood vessels deliver oxygen and nutrients to the brain.) But those blood flow changes reversed in monkeys that were sedentary after exercising for five months.

The results agree with previous studies in this area. A recent review highlighted that exercisers learn faster, remember more, think clearer and bounce back more easily from brain injuries, such as a stroke. Some of these brain benefits are thought to arise out of the mild stress that exercise induces, which triggers the brain to protect against neuron damage.

In addition, it could just be an effect of blood flow. "Physical exercise increases blood flow to the brain," Cameron said. "Blood delivers nutrients and oxygen, and this may be a large part of why exercise increases cognitive function."

She suspects the benefits could be two-fold for humans. "The monkeys were more alert and engaged as well as improved cognitive function in the first task they were tested in," Cameron said. "We expect that people would show similar effects of exercise. In addition, if over time people are more alert and engaged it would be likely that they would learn more from that alone."

SYDNEY CBD SUPPORT GROUP St James Parish Hall 27 March 2010

Present: Irene. W, Ingrid K, Patrick S, Malcolm S, Barbara S, Pam S, Alwyne T, June T, C C Madhusudana, Nathan P, Allaster McD, Alan M, Ben H, Marjorie B, Lois & Reg W.

Apologies: Nelma M, Margaret M, Nagu M.

Bernice rang to say her MVD all went well and that she is pain free.

Our thoughts were with **David H**, and hope he has a similar result. We await his news.

It is very encouraging to see folks from Central coast & Newcastle area making it to the meeting in spite of our early start. Take heart fellow sufferers - distance is no barrier, you too can make the same effort. Amongst us were 4 new attendees, one of whom was still seeking a diagnosis, and one had come to share her good news as an encouragement to others.

After some housekeeping matters, members shared their news and updated their progress.

Ben: Ben has come all the way from Newcastle area to have fellowship with fellow TN members. His red-hot stabbing needles pain started in his left gums about 4 years ago. Thinking that this was a dental problem he sought his dentist who could not find any problem. But when pain persisted, Ben returned to the dentist a week later and insisted that 2 of his teeth to be removed. Unfortunately, as we all know, pain recurred again a week later. Eventually, Tegretol CR was started, and pain now controlled with 1000mg Tegretol. His Doc tried changing him to the newer drug Trileptal but this was not effective and he's reverted to Tegretol CR @ 1000mg.

Allaster: Around Christmas time, was taking Lyrica, and Keppra was added at 30mg to be increase to 60 mg. However, he began to feel "strange, sleepy and weak." Keppra was immediately stopped, and it took about 8 weeks before these symptoms cleared. He is now on sublingual methyl-B12 @ 4mg as well as taking Cymbalta (duloxetine) @ 30mg. He finds that this gives him a good night sleep; and pain is restricted to when he's eating and talking.

Alwyne: In February 2009, his severe intermittent facial pain was diagnosed as trigeminal neuralgia. This was characterised by an extremely sensitive right upper lip, which was triggered by touch with accompanying pain on the right eyebrow. Movement of the lip was most painful - making speech difficult and brushing teeth, shaving and eating an ordeal. The doctor prescribed Tegretol 100mg twice daily. After three doses he vomited and collapsed. A brain scan showed no sign of stroke. He was reluctant to continue with Tegretol especially as he was driving grandchildren to school and back. He chose to "just put up with it" with no medication as his pain attacks would last about four hours with two hours pain free. As long as he did not touch or move his mouth it was tolerable. Another doctor whom he was consulting on another problem started him on Gabapentin 300mg X 3 per day and referred him to Pain Management Centre. He saw Dr. P who prescribed a gradual increase of Gabapentin to 6 per day plus a local anaesthetic cream - Amethocaine.

Pain eased and eventually disappeared for over a week and meds was tapered off. However, he now experiences a continuous dull headache which is relieved by paracetamol / Codeine tablets. The headache is located in the middle of the forehead and is particularly pronounced when he bends forward. He had come to the meeting to compare notes to see if this was in any form TN returning.

Lois: TN is much under control with 200mg Lamictal B.I.D. and B12 injection. She receives her injections in the arm - intramuscularly.

Marjorie: After 10 years of TN, and it getting worse, she finally had her MVD in September 2009. Since then, she has been pain free. She has come to the meeting to share her good news and to encourage others.

Mal: recounted his first TN attack 10 years ago, he went to his dentist and had one tooth taken out, then another. He had his MVD 6 years ago, but pain has returned since although not as severe. He's back on Tegretol CR 200mg B.I.D, and also taking methylcobalamin 4mg. One of the side effects he experienced following his MVD was double vision – which eventually cleared.

Ingrid: noted that her attacks are in a 5 weeks cycle. Each attack could last all night from 5 pm onwards. She has decided to cut out chocolate, caffeine from her diet in the hope of controlling her pain. She described her pain as “still the same sharp shooting pain” as pre MVD. She is on 75mg Lyrica X B.I.D and TegretolCR 250mg XB.I.D

Alan: has had no attacks in 3 ½ months, although sometimes during chewing, he get a little reminder. He is on 200mg Tegretol in the morning and Gabapentin 300mg T.I.D. His neurologist has advised tapering off Tegretol due to his low sodium level. Alan also takes 1000mg cyanocobalamin, and also goes to the chiropractor.

Pam: pain has recurred although like a toothache. Chose not to start on any medication instead went to the chiropractor twice a week for 3 weeks and no on a fortnightly visit. She also started on sublingual methylcobalamin but takes no medication at all.

Nathan: knife like stabbing pain started about 3 days ago around his right jaw joint. Chewing and talking would trigger the pain. Nathan had come to the meeting to compare notes, hope to learn about his options.

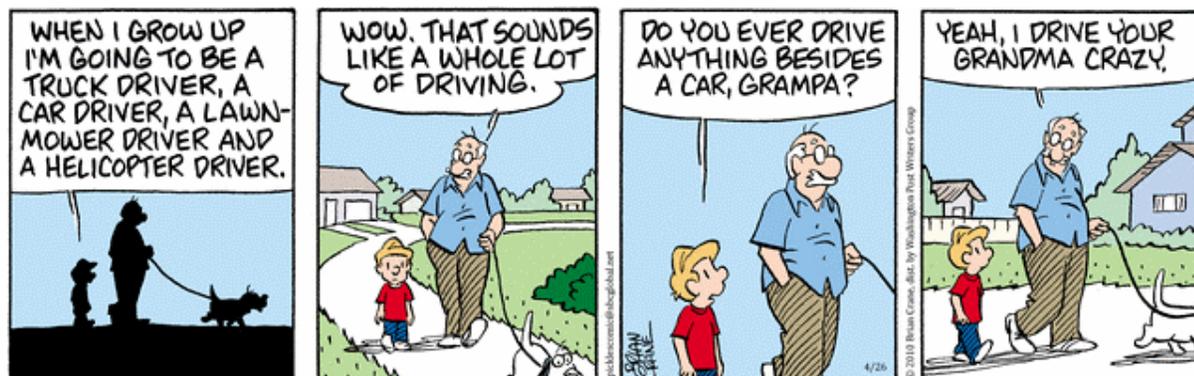
C.V was here on behalf of Nagu. **Nagu's** TN is under control with 2mg of methylcobalamin, however she recently developed toothache and C.V had come to the meeting hoping someone could recommend their dentist so that Nagu could go to this dentist with confidence.

We hope her toothache has been sorted out.

Special thanks for Lois and Reg for the Morning Tea. They have always provided well for your morning tea – super job.

Next meeting : 5 June at 10 am. I hope to have a guest speaker on hypnosis and pain management. Am awaiting response from hypnotherapist.

Irene.



CANBERRA SUPPORT GROUP
Canberra Labor Club Belconnen
Saturday 20th March 2010

Present: Richard M, Susan M, Cathleen T, Christine R and Jan G.

Apologies: Devi W

Meeting opened at 10.35am. It was noted that the club had put a notice on the door to the Board Room as there were auditions being held in the large function room adjacent.

Jan had a few matters to report:

She had sent out Christmas cards to three members who had been regular attendees. Only one response had been received and that was from Devi. Jan read out her very kind message which included good wishes to Irene.

A card had also been sent to the functions manager of the club and included our thanks to the staff for their help.

Marilyn W had sent a message that due to family circumstances she would not be in Canberra to attend meetings. We do hope that matters improve soon.

A phone call from a Mrs B had informed Jan that her husband was now deceased. He had been a financial member of the Assn but had not attended our meetings.

Devi had phoned and unfortunately, her pain continues.

Another phone call came from a gentleman who wished to bring his wife to this meeting. At a later date the lady herself phoned and was in great pain. Jan made suggestions as to what might help and hoped that had been useful.

One week prior to the meeting date Jan received a phone call from the functions manager of the club to advise her that a fresh application to use the room free of charge this year was required. This was attended to promptly and a favourable reply had been received.

Brian J had made contact and intended to have another course of acupuncture as the first had been a big help. He was grateful for the advice from the group and as he would not be attending for a while asked if he would be able to come back to meetings. He was assured he would be welcome to attend.

Other members had been continuing much the same. **Richard** had other problems health wise and his TN had been worse. Jan agreed that if a virus attacked or there were other conditions present, she had found this was the case.

Happily **Cathleen** remains pain free.

Next meeting **Saturday 24th July**. No meeting in May / June .

Jan

Chinese Proverbs:

A hundred men may make an encampment, but it takes a woman to make a home.

Beauty is the wisdom of women. Wisdom is the beauty of men.

Patience is power; with time and patience the mulberry leaf becomes silk.

The gem cannot be polished without friction, nor man perfected without trials.

Small ills are the fountains of most of our groans. Men trip not on mountains, they stumble on stones.

MELBOURNE SUPPORT GROUP
at the "Ringwood Room"
Ringwood Library 1.30 p.m. 17 April 2010

Evelyn welcomed everyone to the meeting, especially four new people attending for the first time and their support people and our guest speaker for today.

Present: (19) Barbara & Robert A.; Alan & Joy C.; Ellayne C.; Evelyn D.; Doug E.; Alf H.; Nita McK.; Bill P.; Will & Joan R.; Jenny & Kevan S.; Terry S.; Joan & Neil T.; Graeme & Sandra T.;

New: (6) Toni B.; Vicki M. & her sister Suzanne McC.; Carol S.; Dianne W. & her daughter Jessica W.;

Apologies: (8) Lesley B.; Din D.; Marjory & Murdoch F.; Alan L.; Beverley R.; Rita & Chris W.;

Guest Speaker: Fiona Thomas

Notes from some who gave apologies:

* **Alan** is still working on the most effective balance of B12 and Tegretol but is well enough to attend a birthday celebration today!

* **Lesley** has had "an amazing turn-around" since taking B12 with almost no pain now, less stress, and improvement in her memory – this is after seeing 15 medical professionals including 4 neurologists and still experiencing pain. She has had great improvement with compounded methylcobalamin.

* **Marjory** is pain free still after her MVD but the distance from Geelong to our meeting through the traffic is daunting.

Business:

Books for sale and books for borrowing: Please see Joan T during afternoon tea to borrow Striking Back, Manage Your Pain or Insights - \$40 refundable deposit required. Evelyn has Striking Back and Insights for sale at \$39 and \$35 respectively.

Treasurer's Report: Donations at the last meeting totalled \$67.50. Expenditure since then totalled \$110 (insurance, envelopes, contribution to Irene Wood's Feb. travel to Melbourne) leaving a balance of \$98.70. Thanks to Alan for keeping the records so diligently and apologies for omitting this report to all members during the meeting. We are urged to make at least a gold coin donation at each meeting as we have no other source of funds. All are reminded also to renew or take out membership of TNA – send directly to TNA Australia.

Newsletters: Great value – keep copies for future reference though the article on "omega 3 for dogs" in the April issue came under suspicion!! Keep the dates in September 2011 available for the TNA Conference in the Hunter Valley NSW.

Reports from members:

Terry can talk now so he offered his TN story which began at Easter 2009. A doctor friend diagnosed TN so he went on the Internet and made contact with Irene and the support group. He began taking Tegretol which turned him into a weird person. Terry continued his search for information from people and changed to Lyrica, then a further change to a derivative of Tegretol but with this medication he couldn't talk or sleep. His neurosurgeon had given all the advice he could. Terry also went to the TNA Conference in the Yarra Valley in his search for information. Finally on 23 Feb 2010 he had an MVD although his MRI showed nothing. Terry knew this was a gamble but being in pain still and unable to talk properly or touch his face he thought he had nothing to lose. Andrew Danks performed the surgery and moved two arteries, one of which was on the trigeminal nerve, using Teflon to separate them. Good results at first after the surgery but after a few days the "electrocution" pain returned, which he knew was a possibility, so Terry adopted his Option 2 which was to take B12. With compounded lozenges of B12 and 10 mg injections to help with recovery of the nerve and Trileptal, Terry still has some problems but is way ahead of where he was last year. The brain takes a battering in the operation but since the MVD he has been able to think clearly, to walk without falling, tolerate shopping centre noise and talk for more than 30 seconds without pain. Christine, a nurse who is a TN member who had an MVD told

Terry her brain was affected in the same way. Terry is now returning to who he was before TN. It was good indeed to see how Terry dealt with his TN by learning as much as possible about it and the different treatments, how he approached his decision making and implemented a second option when not everything went the way he would have liked. Thank you for sharing your story Terry, and let's hope you continue to experience reduced pain until you are pain free!

Some general discussion followed in which Terry said he did not regret having the operation but will not do it again. He is progressively keeping the pain under control: the "electrocution" type pain has not returned but some specific areas of the face are still painful but nothing like before.

Bill has taken no Tegretol since 4 weeks after his MVD. He commented that MRIs and medications are not necessarily adequate and surgery is not always successful.

Barbara stopped having B12 injections and takes 3x1000mcg B12 daily as well as 1x200mg slow release Tegretol a.m. and p.m. 2 monthly injections of B12 are less expensive than 1. She is not 100% pain free.

Doug was taking 6-8 Panadol and Panama x 2 months ago but has good pain control now. His MVD at Cabrini Hospital was done by Dr Davis and Doug woke to no pain. Prior to that he was on 300mg Lyrica 2x day for two years.

Toni's TN started 10 years ago and she went to a dentist, then a neurologist. 100mg Tegretol controlled the pain for some years, then last year she had increased pain and started taking 200mg Tegretol, then 2 weeks of 800mg Tegretol. After getting information about sub-lingual B12 (1000mcg x 4 times a day) Toni has been able to reduce her Tegretol dosage to 200mg. She found out about the Support Group from a friend in the UK!

Vicky first experienced TN pain 2 days before Christmas 4 years ago. She had extensive dental root therapy treatments from an endodontist but was still in pain so went to a neurologist (Robert Helm at the Epworth). An MRI showed nothing so she did her own thing and eventually had a mouth guard made. Finally she found Michael Stubbs, a TN savvy dentist. She took Epilem, Endep, Gabapentin and still had pain so returned to the neurologist and had five months pain free. She is very interested in what she has heard today about the positive effects of high doses of B12 for some people.

Dianne has had TN pain for 12 months, diagnosed by a GP, and it is worse now than before. She is not on medication so is looking for support in the group. Her pain starts in the morning and stops at night. She lost her job at Christmas time so has been on a double dose of anti-depressants. Vicky is certainly interested to hear about the variety of ways people have dealt with TN pain and B12 in particular.

Carol has had TN for 9 years. It first started out of the blue when she was travelling in the outback where the worst attacks happened. She went to a dentist and a doctor who thought it might be a neuralgia. A neurologist, in Ashburton, prescribed 400mg Tegretol a day. She still has some attacks and doubles the dosage if necessary. Carol saw the article on TN in her local paper late last year and has made contact with Irene. She is very interested in the B12 program. Carol had her teeth capped last week and was not too apprehensive – there was some left facial pain but not full-blown TN.

Evelyn introduced **Guest Speaker, Fiona Thomas**, whose original background was in occupational therapy but who has had much experience in pain management and hand therapy amongst others and now works at the Caulfield Pain Management Clinic. Fiona gave a very interesting and informative presentation on neuropathic and other pain and the various approaches to finding strategies for the management of acute pain - there is not just one cure. The doctors look for a diagnosis and offer medical treatment but there may still be pain. Chronic pain that persists longer than 3 months is a disease entity in itself and features in the list of top diseases. Pain with no known cause is mysterious. Pain changes the way we function and has ripple effects which impact on our behaviour, relationships, our roles. Fiona

looks at how to deal with these effects. 20% of people with pain have persistent pain – neuropathic pain being one type.

Pain is an individual experience as we do not all react in the same way to the same stimulus. Our perception of pain is a function of the brain – the brain weighs up the impact in the harm issue and attempts to restore homeostasis of the body. Unique responses can include behavioural changes, altered sensation, inflammation and emotional responses. There is not necessarily tissue damage. Sensory and emotional responses have to be taken into account in pain management. Neuropathic pain involves injury to nociceptive pathways in the peripheral or central nervous system. Nerve damage leads to increased excitability of the nerve.

Pain or dyesthesia in the neural zone is a protective sensation so we don't want to cure pain but we want to discover and treat the cause and thus manage/lessen the pain. There is burning pain, nocturnal pain, pain in the stimulus/response relationship, hypoalgesia, allodynia, exquisitely sensitive areas. The brain is wired differently at different times – it responds to changing situations. We can re-wire the brain to reduce the pain connection. Integration of pain mechanisms into clinical reasoning to take into account symptoms related to input arising from tissues and symptoms related to processing.

Patho-biological mechanisms:

Up-modulation reactions

- physical (extent of injury, sensitization)
- emotional (fear, anger, depression)
- mental (focus on pain, boredom, lack of control, beliefs about the meaning of pain)

Down-modulation reactions

- medication (counter stimulation, appropriate activity, reduction of muscle tension, breathing techniques)
- relaxation (rest, positive emotions, optimism, love, humour, laughter, support)
- increased interest (life activities, social interaction, active coping)

Pain is a guide but can lead to a fear of moving.

A pain management program includes recognition and treatment of depression, cognitive behaviour therapy, a shift from passive/reactive to active, resourceful and competent. We can teach ourselves self management techniques which give the patient confidence to control their own pain. The patient has to tackle fear and avoidance and have graded exposure to activities. Exercise, relaxation and activity pacing are important because the endorphins released offer natural pain relief. By exploring movement possibilities habits can be changed e.g. by doing Tai Chi. Stress management and practical problem solving are also included. The patient has to be confident with the program of pain management in order to return to life activities and a better quality of life.

There was some discussion about responses to pain we have adopted at different times of flare-ups and referral back to some of the above as suggestions in future.

Evelyn gave a small gift and thanked Fiona for such a valuable talk accompanied by Power Point notes to help us understand the nature and benefits of pain management. Apologies to Fiona and readers for any inadequacies in my notes.

Thanks to all who attended and those who helped this afternoon – Joan and Neil for collecting the key, arranging insurance and setting up the chairs, tables and loudspeaker; Alan for looking after our finances and bringing a laptop and data projector; Joy and all who helped with after afternoon tea and to all who brought goodies to share, Neil on the front desk and all who helped clean up. Most of all thanks to all TN patients, especially the four new people today and those who accompanied them to the meeting (and Jesse who started Power Point) – the attendance and story of each person is very important.

Next Meeting: Saturday 12 June 2010, 1.30 – 4 p.m.

Evelyn.

**ADELAIDE SUPPORT GROUP
BURNSIDE CIVIC CENTRE
SUNDAY 28TH MARCH, 2010**

PRESENT: LAUREL S, BERT J, EILEEN P & FRIEND JEAN, KEVIN S, GARRY & LISA R, JOAN E, GRACE A, GRAHAM & LIZ B.

APOLOGIES: ANN T, JUNE & ROGER O.

DONATIONS: \$46.00. **TOTAL FINANCES TO DATE:** \$172.10.

WELCOME: Graham welcomed members with a special welcome to new member Eileen and her friend Jean. Eileen is about to undergo a percutaneous procedure and was keen to receive some support and advice.

GERNERAL BUSINESS:

Members had received their news letters and read Irene's report on B12. There was some discussion on the excellent results being achieved - in some cases sufferers were now 100% free from pain. Lisa enquired how long before patients received any benefit from B12 and the general consensus was approximately 4 weeks. Laurel said she has been taking B12 for several years now and is convinced it is keeping her TN at bay. Eileen, however, is receiving injections every 3 months but still has to take medication. Bert is going to try 1000mg B12 and Garry is taking a compounded tablet. Graham mentioned that Irene is looking for volunteers who have type 2 TN or experience burning pain, to trial certain foods and to contact Irene if they wish to participate.

MEMBERS UPDATES:

EILEEN: Has had TN for about 16 years. She used to get some months remission, however the last two years have been virtually constant pain. Her pain is in the jaw and she experiences electric shock and nagging type pain. She has difficulty sleeping as the pain can keep her awake at night. If she does sleep the pain can break through, waking her. Cleaning her teeth is a major trigger point. Fortunately she was diagnosed with TN quite quickly. As with most sufferers, she thought it was a dental problem and when the dentist could find no problem he recommended she see a doctor who was able to diagnose her and put her on to Tegretol immediately. Initially the Tegretol was helpful and she was taking 2 x 100 mg. daily which made her very drowsy. Her specialist at the time was reluctant for her to undergo any surgical procedure. Her new specialist recommends a radiofrequency rhizotomy which she is having on the 9th April. Eileen's MRI report showed no tumour, however a compression was not particularly clear. She does feel if she is engrossed in 'being busy' it helps to take her mind of her pain. The worse thing is the unpredictability of an attack. Everyone agreed. Eileen was loaned Striking Back so that she could understand more about the procedure before her operation.

Interesting information from Eileen was that her MRI was performed in a new machine with a clear "cockpit". Wonderful for those who suffer from claustrophobia. We all wished Eileen good luck for her procedure and look forward to her coming to our next meeting hopefully pain free.

GARRY: Is still awaiting a miracle. He is taking high doses of Nurontin and puts a great deal of importance on his state of mind for his coping strategies. If he is calm and lost in an activity he is much better. He also finds music helpful also burying his head in his pillow.

BERT: Takes 600 mg slow release Tegretol daily. He was up to 800 mg. He forgot his tablets one night and he suffered dreadfully. He asked if it could be damaging to take the Tegretol on an empty stomach. Joan commented she always has barley sugars with her. Bert feels constantly woozy but his pain is fairly well controlled at a level 2.

GRAHAM: After 15 years of having TN and after his MVD last July is completely pain free and off all medication. Only trouble now is he has trouble sleeping!

JOAN: Had TN for 19 years. She has had 2 MVD's and is absolutely fine. Her TN was aggravated by two calcified tumours. She highly recommends MVD. She also reported she doesn't sleep well.

Laurel asked if surgeons would perform an MVD even if the patient did not experience electric shock pain. It was thought possibly not as "electric shock" pain is indicative of type 1 TN which has a better success rate than type 2 TN. A surgeon would take this into consideration when deciding the appropriate treatment. See article by Dr. Kim Burchiel in last Newsletter. (Pain relief after MVD is strongly correlated with the lancinating pain component...)

GRACE: Reported she has undergone two glycerol injections but unfortunately still experiences some bad symptoms, stabbing pains in her temple and itching which drives her mad. She also has numbness which is continually uncomfortable. Also doesn't sleep well. She worries her TN will return one day. She prefers not to take medication. Her fall back plan is to have an MVD should her TN return.

KEVIN: Had TN for 10 – 15 years off an on. Unfortunately a root canal procedure stirred up Kevin's TN 12 months ago. His worse pain comes at night. He has pain and aching in his jaw. He saw a Neurologist who prescribed 200 mg Valpro (Epilem). An MRI did not reveal any compression of the nerve. His Neurologist thinks Kevin has TN and asked if it was "liveable". He said Kevin can return for a further visit when it was necessary. Kevin tried Zostrix cream which helped for a while but not any more. Kevin went to a chiropractor who worked on his neck and muscles inside his mouth at the back right hand side. He has had 3-4 treatments and feels much better. The Chiropractor taught Kevin how to massage inside his mouth and he is now free from pain and his chewing has improved.

LAUREL: Still taking B12. Has continual feeling of numbness in her face and ants crawling sensation. Touching her face triggers the "ants". Laurel does not sleep well either. She keeps a prescription of Epilem on hand "just in case".

JEAN: Eileen's friend and supporter just felt she had to comment on her admiration for the group. Thank you Jean, it's nice to know we are providing some assistance and a friendly, sympathetic ear.

ANN: offered an apology for today, however she telephone to tell us that she is now taking Magnesium and can fully recommend it. She takes 400 mg at night which helps her relax and reduce muscle spasms.

MEETING CLOSED AT 3.45 p.m. followed by the usual cuppa and chat.

NEXT MEETING: 2.00 pm SUNDAY 30th May 2010 at the Civic Centre - Burnside Town Hall.

Our guest speaker will be **Mr. Andrew Zacest** - Neurosurgeon Royal Adelaide Hospital. Andrew's talk will cover the various surgical options available to TN sufferers.

If you are not a regular attendee but are intending to come to this meeting, please advise Graham on 8392 2781 so we can arrange sufficient seating.

Graham & Liz

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Ruth and Golda were walking along Hendon High Street.

Ruth says, "My son Irving is getting married. He tells me he is engaged to a wonderful girl, but... he thinks she may have a disease called herpes.

Golda says, "Do you have any idea what this herpes is, and can he catch it?"

Ruth replies, "No, but I am just so thrilled to hear about Irving's engagement - it's time he settled down. As far as the herpes goes...who knows?"

"Well," says Golda, "I have a very good medical dictionary at home. I'll look it up and call you."

So Golda goes home, looks it up, and calls Ruth. "Ruth, I found it. Not to worry. It says herpes is a disease of the gentiles."

Correspondence Corner

Don C: I have suffered from TN for about seven years, after three years and becoming dysfunctional I went on Tegretol 200 mg per day, which enabled me to function again. Over the next three to four years the pain got gradually worse until I was taking 600 - 800 mg per day to try to stay functional and try to continue with my part time job.

As the TN was getting worse I began to search your monthly reports for the best solution. I am unable to attend your regular meetings as my weekends are preoccupied. However I came to the conclusion that the only real solution was to have the MVD procedure. After visiting a couple of Drs in Brisbane who wanted to treat me with the facial injection to deaden the nerve, which I was not happy with, I decided to have the MVD with Dr. Sara Olson at the P A Hospital in Brisbane. That took place on the 17 / 2 / 2010. with instant relief and I have not had a twinge since. I am in my 80Th year and I have fully recovered and able to carry on with my part-time job with plenty of energy and vitality, so I owe you a great depth of gratitude for supplying me with the relevant information in your monthly reports. A very big thank-you to you and all of those people who attend your meetings and help provide this vital information.

Ron: I would like to thank you for your support and advice when I rang you over a year ago now. I would also like to thank the Trigeminal Neuralgia Association's newsletter, which I found informative and somewhat comforting through the months of pain I went through.

I look back and believe I had the symptoms of TN for probably 4-5 years. Feeling I had problems with my teeth I had a couple of trips to the dentist early on, which found no reason for the slight pain in that area. Eventually the pain got worse and my local GP diagnosed TN in 2008. He really did not give me very much information and just medicated me with Tegretol. Not long after starting the Tegretol I started to get a rash. I went back to the GP and he prescribed Dilantin. This only escalated the rash and I started to get other reactions, like itching and swelling, to this medication.

A scan and a consultation with Dr Dexter confirmed I had TN, which he was confident he could fix with MVD. I deferred the MVD for a few months but the TN got worse, deteriorating from being tolerable before Christmas to finally stopping me from working by early May 2009. In the end I could hardly talk, I found eating terribly difficult, and I had lost about 14 kilos.

I had the MVD on the 1st June 2009 and have had no pain from TN ever since. I am very thankful that my GP was able to diagnose TN as soon as I described all the symptoms. I thank my wife for finding the TN website so I could confirm what I had and encourage me to contact the Association. I thank you (Irene) that you were there to give me information and great advice, and Dr Mark Dexter - a compassionate doctor who has given myself and many others a new lease on life free from TN.

If your oral TN medication isn't working too well- try this topical Amethocaine gel - discuss this with your doctor - any compounding chemist should be able to compound this.

FYI : Amethocaine gel for topical anaesthesia: a stability study using HPLC

White B 1, Titchen T1, Bakalova M 2, Finnin B 2

1 Pharmacy Department, Royal Children's Hospital, Parkville, Vic

2 Pharmaceutics Department, Victorian College of Pharmacy, Parkville, Vic

Amethocaine base 4% in methylcellulose gel is currently manufactured by the Royal Children's Hospital pharmacy. Amethocaine gel for topical anaesthesia is effective and has minimal side effects. It is used as an alternative to EMLA[®], the proprietary preparation containing lignocaine and prilocaine. It has a number of advantages over EMLA[®]; it is considerably less expensive and has a faster onset and longer duration of action. Additionally, application of the amethocaine gel produces vasodilation enabling easier cannulation. A similar product has been used extensively in the United Kingdom for many years.

This study was undertaken to assess the stability of the gel and allow an appropriate expiry to be assigned. **The current shelf life is six months if refrigerated** or one month if kept at room temperature.

- THE ROYAL CHILDREN HOSPITAL MELBOURNE - PHARMACY DEPARTMENT

2010 Meeting Dates

State	GROUP	Date & Time	Venue	Group Leader/s
ACT	Canberra	24 July 10.30-12.30	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 62474508
NSW	Sydney	3 July 1:30pm – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Irene Wood ☎ 0413 363 143 Kim Koh ☎ 02 97431279
	Sydney CBD	5 June 10:00am –12:30 pm	St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413 363 143
QLD	Brisbane	8 May 1.30-4.00pm	30 Ridley Road BRIDGEMAN DOWN Guest: Chiropractor	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	15 May 1:00 pm	Kawana Library, Nanyima Street, Buddina	Teresa Miller ☎ 07 54912487 Jean Williams ☎ 07 54911978
	Townsville	19 June 1.00 pm	Carville Senior's Villa 35 – 37 Diprose St PIMLICO	☎ Irene Wood ☎ Sera 07 47516415
S.A	Adelaide	30 th May 2:00pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Road Guest : Dr. Andrew Zacest	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	16 May 12:30 – 2:30 pm	Glenorchy Library Enter via Barry and Cadell Streets Guest: Dr. Arun Aggarwal	Helen Tyzack ☎ 08 6245 0429 Ros Wilkinson ☎ 08 6234 7989
VIC	Melbourne	12 June 1:30pm – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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TRIGEMINAL NEURALGIA ASSOCIATION AUSTRALIA INC.

359 Terrace Road, NORTH RICHMOND NSW 2754

ABN 33 914 644 101

NOTICE TO MEMBERS

The Annual General Meeting of Trigeminal Neuralgia Association Australia Incorporated will be held at 10am on Saturday 5th June 2010 at St James Parish Hall ,Level One, 169 - 171 Phillip Street, SYDNEY

Agenda:

To confirm minutes of previous AGM held on 6th June 2009.

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 2137 by 30/5/2010

Cut here =====

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 5th day of June 2010 and at any adjournment of that meeting.

.....
Signature of member appointing proxy

Date.....