



# Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

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

April 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.

In response to your expressed interest to leave these TNA brochures at your doctors' clinic TNA tri-fold brochures have been bulk sent to your Support Group Leaders (SGL). Please use the brochures provided to spread the word that support is available and for new patients to contact the Association.

It is important that we continue to grow. The strength of the Association is related to the size of its memberships. How successful we are in representing facial pain patients depend on how well we can impress with numbers. Each time you complain that your medication is too expensive because they are not on the Australian Government's Pharmaceutical Benefits Scheme (PBS) and wish the Association to appeal on your behalf – realise this - No one is going to pay us any attention because "you are only a small group." So help us to help you.

We also appeal to doctors to refer their patients to the Association for mutual support and information. It is most appreciated that you do not re-distribute our newsletters to you to your patients. When patients contact the Association we also send them an information pack with a membership form. Subscription is \$25 a year, which covers the cost of printing and postage. Please encourage your patients to contact the Association for support and further information. No one should suffer in isolation.

**“There is no exercise better for the heart than reaching down and lifting people up.”**

- John Andrew Holmes Jr., American writer and minister

## **BATTER -UP!!**

Gold Coast SGL, Andree Chenevier is stepping down due to personal health issue. We wish her all the best, and remember her in our prayers for a complete and speedy recovery.

We now need someone to pad up for the next innings. The meeting venue should still be available – all that is needed is someone willing to shoulder some responsibility to organise and schedule meetings, so that patients in your area can learn something together while being in support of each other. Reports of the meeting are sent to me to be published, so that we can have an accurate and cohesive understanding of your pain condition and management.

Some members in the Newcastle and Hunter region as well as Coffs Harbour have expressed a desire for their local support group to be revived. I too would like to see some initiative being taken to get these groups off the ground again. If you have a passion to help TN and related facial pain patients, please contact me. I look forward to hearing from you!

**Together we can make a difference.**

**“Your talent is God's gift to you. What you do with it is your gift back to God.”**

- Anonymous.

*Irene.*

From Medscape Neurology & Neurosurgery : American Academy of Pain Medicine (AAPM) 24th Annual Meeting

## **An Overview of the Decade of Pain Lecture From AAPM 2008:**

Posted 02/27/2008

Joshua P. Prager, MD, MS

### **Editor's Note:**

The American Academy of Pain Medicine (AAPM) 24th Annual Meeting took place from February 12 to 16, 2008, in Orlando, Florida. During this meeting, new information about the diagnosis, treatment, and management of acute pain, chronic pain, and breakthrough pain (BTP) was presented. Darlene Field, PhD, Medscape Neurology & Neurosurgery Scientific Director, discussed the highlights of the "Decade of Pain" keynote address with Joshua P. Prager, MD, MS, Director, Center for the Rehabilitation of Pain Syndromes (CRPS), and Immediate Past President, North American Neuromodulation Society (NANS) . Dr. Prager delivered the "Decade of Pain" lecture at the 2007 annual meeting of the AAPM.

**Medscape:** Can you discuss some important findings presented at the AAPM meeting you just attended - specifically, was any new knowledge shared at the Decade of Pain lecture given by Dr. Michael Cousins?

**Joshua P. Prager, MD, MS:** The keynote lecture at the meeting was given by Dr. Michael Cousins, who is Professor and department head of Anesthesia and Pain Management, University of Sydney, Sydney, Australia. Dr. Cousins made 3 main points in his lecture. The first point was that pain is a disease in its own right. The concept of persistent pain as a disease entity leads us toward new specific treatments aimed at physical, psychological, and environmental components of the disease, and takes into account the possibility of a genetic predisposition to experience pain. Dr. Cousins explained that persistent pain has a prevalence of 1 in 5 in the general population, and the studies conducted by the Pain Management Research Institute of Sydney, Australia, indicate that pain leads to an annual cost of \$1.85 billion per million of the population.

The second point made was that the medical community has now recognized that additional specialty training in pain management is absolutely necessary. There are too few true pain medicine specialists being trained, and many patients have limited or no access to effective pain treatment.

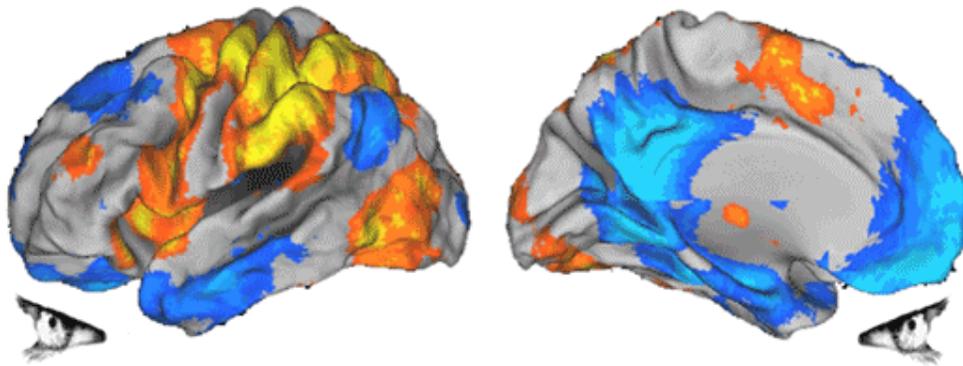
Dr. Cousins' final main point was that pain management needs to truly become a fundamental human right. To achieve this goal, we need parallel initiatives in medicine, law, ethics, and politics.

**Medscape:** Did Dr. Cousins offer any evidence to lend credence to the fact that pain itself is a disease?

**Dr. Prager:** Well we always knew that persistent pain is very different from acute pain and we can now demonstrate those differences with imaging studies of the brain. A functional magnetic resonance image (fMRI) of a patient with chronic pain will appear quite different from that of a fMRI of a patient with acute pain. For example, an imaging study just published last week in the Journal of Neuroscience demonstrated that chronic pain harms cortical areas, indicating that chronic pain has a widespread impact on overall brain function (Figure). Several areas of the brain in patients in chronic pain fail to deactivate during the attention task compared with healthy patients.

**Figure.** The pictures below are brain fMRI data (right images of the brain are seen from the head's midline, left images are from the side) showing the average brain activity during the entire task. Colors illustrate how much activation (red-yellow) or deactivation (dark/light blue) was found at each brain location during the attention task. The main result here is that brain images of patients in chronic pain exhibit a significantly smaller territory of brain deactivating (ie, in blue) during the task than healthy individuals. For more information, see [www.chialvo.net](http://www.chialvo.net). Reprinted with permission from Dante R. Chialvo, MD.

## Normals



## Chronic back pain

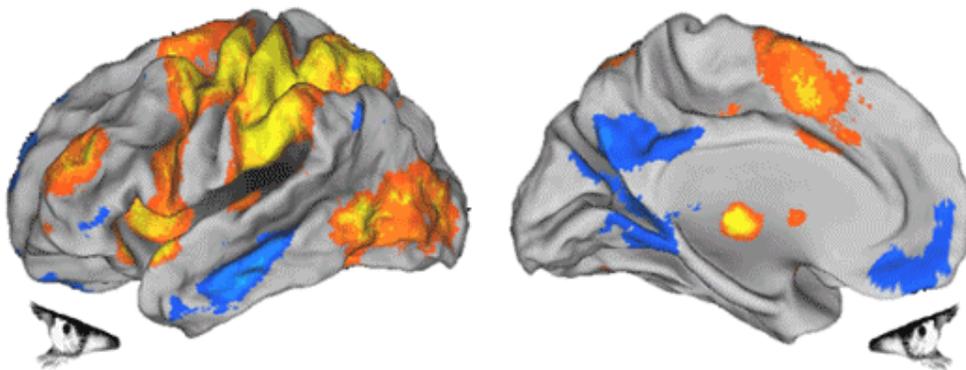


Figure 1.

If pain persists despite reasonable efforts to manage it by the patient's general practitioner and specialists, then consultation with a board-certified pain medicine specialist is absolutely necessary. Because pain is a disease, it is important to manage the pain early on to prevent the pain from becoming a persistent problem, with all of the attached disease changes that occur.

**Medscape:** After listening to the Decade of Pain lecture, what do you think is in store for the future of pain management?

**Dr. Prager:** As we look toward the future of pain management, the treatment of persistent pain will be markedly different from how we currently treat it. Instead of using drugs like morphine that only provide symptom relief, newer drugs will aim at the disease process. Dr. Cousins mentioned a new class of drugs in development, subtype selective sodium channel blockers. Pain-sensing neurons of the peripheral nervous system express several sodium channel subtypes, and pharmacologic agents that target the Na 1.8 selective small molecule sodium channel are currently in development.

**Medscape:** Was there any discussion of the role of genetics in pain medicine?

**Dr. Prager:** Yes, Dr. Cousins presented some really fascinating data that suggest that genetic analysis of patients may indicate who would be predisposed to persistent pain, for example after a mastectomy, vs who wouldn't. If the genetic analysis demonstrates a patient to be at risk for chronic pain, then more aggressive maneuvers would be necessary related to that surgery; whereas, somebody whose genetics would not predispose him or her to persistent pain wouldn't need the same intensity of treatment (prophylaxis).

Genetic analysis to determine who is prone to chronic pain vs who is not is a very new concept. It is also very costly. To do a complete genetic analysis of a patient at this time costs about a million dollars, which is much less than it used to be. As a matter of fact, James Watson recently had a genetic analysis completed on himself, being one of the first ever to take advantage of the Human Genome Project. Right now we are still a long way from determining which genes would make someone more susceptible to experiencing pain than others.

**Medscape:** Is there anything else you would like to mention? Particularly, any important take home messages from Dr. Cousin's lecture?

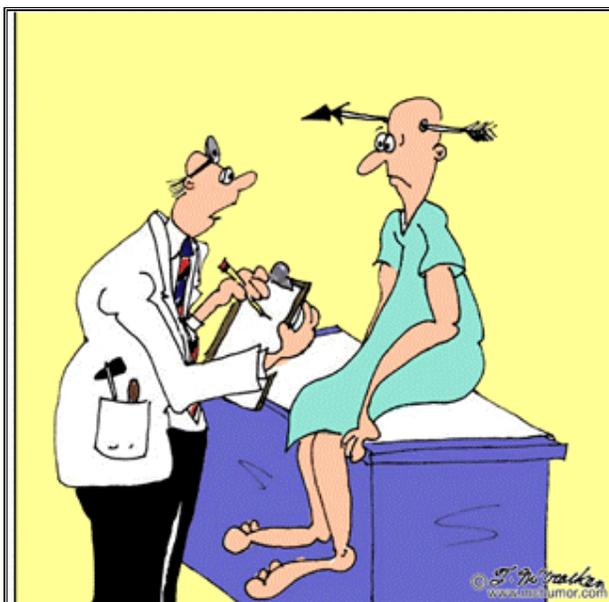
**Dr. Prager:** Yes, there were some very compelling data presented from a study done at Kaiser Permanente Northwest that I would like to mention.[2] In an analysis of 1997 and 1998 data in Salem, Oregon, Kaiser Permanente Northwest was able to demonstrate that by having a pain service (a multidisciplinary pain management group) to serve their community, they were able to reduce emergency room visits by 43%. Patients with chronic pain who think their pain is discounted by physicians often overuse medical services like emergency departments to identify the cause of their pain or to prove to physicians that their pain is real.

**TNA Australia is a self-funded charity organization** for the support of patients with trigeminal neuralgia and related facial pain.

**Your bequest to Trigeminal Neuralgia Association Australia Inc**, no matter how small, will make a difference in the search for a cure for Trigeminal Neuralgia.

If you wish to leave a bequest, you can use the following wording as a guide:

"I bequeath to Trigeminal Neuralgia Association Australia Inc. for research purposes (a specified sum, or specified items, or the residue of my estate), free of all duties. The receipt of the Secretary or other authorised officer shall be a complete and sufficient discharge for the executor(s)."



"Off hand, I'd say you're suffering from an arrow through your head, but just to play it safe, I'm ordering a bunch of tests."

## Pregabalin Relieves Trigeminal Neuralgia

By Megan Rauscher

NEW YORK (Reuters Health) Mar 07 - Pregabalin appears to be effective in the treatment of patients with trigeminal neuralgia, particularly in those without concomitant chronic facial pain, clinicians from Germany report in the February issue of Cephalalgia.

Clinical trials have shown pregabalin to be effective in relieving various types of neuropathic pain including that associated with postherpetic neuralgia, diabetic peripheral neuropathy and fibromyalgia.

Dr. Mark Obermann and colleagues at the University of Duisburg-Essen assessed the efficacy of pregabalin (150-600 mg daily) in 53 patients with trigeminal neuralgia (14 with concomitant chronic facial pain).

"The results of this one-year follow-up, prospective, open-label clinical observation are encouraging," Dr. Obermann told Reuters Health, noting that 39 patients (74%) improved after 8 weeks with a mean dose of 269.8 mg daily.

Thirteen patients (25%) experienced complete pain relief and 26 patients (49%) reported pain reduction greater than 50%. Fourteen patients (26%) did not improve.

Patients without concomitant facial pain had better response rates (32 of 39, 82%) than patients with concomitant chronic facial pain (7 of 14, 50%,  $p = 0.020$ ). "Concomitant chronic facial pain appears to be a clinical predictor for poor treatment outcome," Dr. Obermann said.

He also noted that almost all patients that responded well to pregabalin reached their maximum pain reduction within the first 4 weeks "so that unsuccessful treatment attempts should not (exceed) 4 weeks if pregabalin doesn't help sufficiently."

Pregabalin, Dr. Obermann said, "is easy to use in the clinical setting due to its BID administration without the need for complex titration regimens and provides fast and sustained pain reduction."

Cephalalgia 2008;28:174-181.

**Having read the full article I am unconvinced. To start with, the study had no placebo control and no comparison group. Feed back from TNA Aus members haven't been as impressive. It stated mean effective dose as 269.8 mg daily - we have members who can't function after just 150 mg of pregabalin.(75mg B.I D). If I am not wrong, most of our TN members max daily is only 150mg. I haven't come across anyone with more than 150mg. Usually after 4 weeks - if it didn't work the patient would be in dire pain - in desperate of help. Some have developed blurred vision, put on weight, but most are zonked out at 150mg. I wonder what comatose state at 600mg? Off the top of my head, I would say it is about 50 /50 success with our members. One huge draw back is it is expensive.**

**Interestingly the article also included the use of additional medications when pain was not totally alleviated with PGB. And for those who did not respond to PGB at all, treatment was discontinued after 8 weeks and other TN drugs such as Carbamazepine (Tegretol) and Lamotrigine (Lamictal) were used.**

**Proving that IF Pregabalin (Lyrica) cannot help you – there are other drugs that can.**

## Meetings Report:

## Sydney Support Group Toongabbie March 1st 2008

Attendance (20) Irene W, Terry D, Frank M, Jeanette & Henry B, Ian & Janette L, Lorraine P, Reg & Margaret McB, Lillian B, Kim K, Jocelyn S, Elizabeth & Lloyd T, Ray C, Vern & Stephanie R, Vera R, Kim S  
Apologies Jan McL, Judith D, Anne & Laurie P

Anne & Laurie were celebrating their Wedding Anniversary with family and friends. We send them our congratulations.

Jan is recovering from her MVD a couple of weeks ago. Signs are looking very good for her so far. We wish her a speedy recovery.

Ian will have his MVD with Dr Dexter on 7th April. He is looking forward to this day as he is currently on 1000mg Tegretol, 3000 Neurontin and Endep.

Reg and his wife Margaret were here for their first meeting. Reg has had sharp pain for 12 months. His pain is on the right side, maxillary region. He is unable to take Tegretol due to Glaucoma. He also had a reaction to Lyrica and ended up in hospital. He 'seems to have had a reaction to everything'. He is currently on 100mg Dilantin and 1/2 mg Clonazepam and while the pain is not under control he is sleeping well! He is now trying B12 injections and also takes Magnesium phosphate. He has had an MRI and will go to see Dr Biggs.

Irene showed a presentation regarding the 2009 conference in the Dandenong Ranges in Victoria from 27th-29th August. It looks like a lovely venue, which should be very relaxing. I'm sure there will be more information to follow. Keep an eye out in the newsletters.

Irene then showed us a presentation of her B12 study, which has been continually updated. This covered many aspects including:  
The different forms of B12 (cobalamin) supplements available and how B12 is absorbed converted and transported by the body. The importance of gastric juice and the intrinsic factor plays in B12 absorption.

A lot of the results from the study, many covering years of follow-up, with great success. It is very important that if you decide to start B12, you contact Irene so that your results can be included in this data.

**My B12 program requires you to have your serum B12 measured before you start taking B12. and then after 4 weeks of B12 supplements, have another serum B12 measured – so we can ascertain if there is an increase in your B12 level. Meanwhile keep a record of your pain attacks and pain level per day. Include your current medication /dose.**

**The program goes for 18 months - in which you continue to supplement on B12 – record your pain and treatments ie medication/dose.**

**The aim is for remyelination and perhaps even the regeneration of damaged axons. What we have learned is that folks supplementing on cyanocobalamin at 1000mcg finds little or no significant difference in the first 4 weeks of supplementing. Their records only show lessening of pain and pain attacks after about 6 weeks.**

**Folks on sub-lingual Methylcobalamin at 4mg have a more immediate effect. Within the week itself – their record of pain level and pain attacks could go down to NIL It is important to realise I am not saying B12 is the answer to your pain. The purpose of Vitamin B12 is for remyelination. According to Professor Devor's Ignition Hypothesis – the close apposition allows for cross talk – one fibre cross exciting many**

**neighbouring fibres = cross excitation amplification. The close apposition is due to loss of myelin.**

**Pain can recur. However, it is interesting to note – when pain recurs – it is at a lower level and quite easily controlled with a low dose of medication.**

Irene then answered questions from the members.

Some interesting info from the discussion;

- Tinnitus was noted as being present in one third of TN sufferers who took part in the B12 program.
- There were 2 papers that showed people on long term anticonvulsants had lower level B12 in their cerebral spinal fluid compared to those not on anticonvulsants; therefore it makes sense to boost B12 if you are taking anticonvulsants.
- The most specific test for B12 status is methylmalonic acid (MMA) testing. The amount of vitamin B12 that comes out in the urine is measured by the Schilling test.
- Vitamin B12 is considered safe and non-toxic vitamin. There are no perceived side effects of this vitamin and for this reason, no Tolerable Upper Intake Level for Vitamin B12 has been prescribed by The Institute of Medicine of the National Academy of Sciences.
- too much Vitamin B6 can result in nerve damage.

If your pain is returning, you could consider increasing your B12 as well as your meds.

**Vitamin B12 cannot be absorbed on its own: it must first combine with another substance called 'intrinsic factor' which is produced by your stomach lining. B12 from foods is released from its protein complex by the action of hydrochloric acid and enzymes. The secreted intrinsic factor then binds to B12 and this complex (IF-B12) travels to the end of the small intestine where it crosses the intestinal wall into the bloodstream. B12 is stored in the liver after it is absorbed, and any excess is excreted in the urine. The body contains roughly a 3-year supply and 30% of that found in food is typically destroyed by cooking.**

Vitamin B12 sources:

**Meat, dairy, eggs, seafood. [Vitamin B12 is only found in animal products, but has been obtained through insect / faeces-contaminated grains, fruits, or vegetables],**

**Typical food sources for all other B-Vitamins:**

**Brewer's yeast, unrefined whole grains, liver, all meats, eggs, green leafy vegetables, nuts, seeds. ☒**

**- extra calcium, may improve B 12 absorption.**

We appreciate Irene coming to talk to us. It was very informative and interesting.

We enjoyed a lovely afternoon tea and the usual chatter!

Thanks everyone for all your help with organising everything.

**KimS**

**Guest Speaker for meeting in May - Dr. Marlene Yee on Acupuncture**

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An aged farmer and his wife were leaning against the edge of their pig-pen when the old woman wistfully recalled that the next week would mark their golden wedding anniversary.

"Let's have a party, Homer," she suggested. "Let's kill a pig."

The farmer scratched his grizzled head. "Gee, Ethel," he finally answered, "I don't see why the pig should take the blame for something that happened fifty years ago." ☺!!

**Brisbane Support Group**  
**30 Ridley Rd., BRIDGEMAN DOWN**  
**Saturday March 8**

Attendance: Leo L, Niel F, John L, Jeff B, Lorraine B, Margaret, Roberta, Anne P, Collette, Beryl, Dorreen T, Henry C, Eileen C, Margaret S, Margaret B, Colin B, Joan F, May G, Noela W, Fred L, John, Leonie G, Keith Tony M

Apologies: Audrey C, BJ Stokes, Bev, Bob G

Donation:\$106.65 Total in kitty:\$265.40

Tony opened the meeting welcoming our new members. Our guest speaker Dr Helen Bocock was unable to attend today, but will speak at the July 12 meeting.

Tony urged all to consider attendance at the next conference. He stressed the importance of as many of us as possible going as we each bring another story to the table, whether it be about a successful remedy or a failed procedure.

We again discussed the four forms of B12 that group members are using

-1000mcg cyanocobalamin tablets readily available at supermarkets and health food stores

-4mg methylcobalamin lozengers made up by compounding pharmacists

-1 mg/ml neo B12 injection (hydroxo cobalamin) Often sold very cheaply in a pack of three – as cheap as \$3 per vial

- the more concentrated injection of methyl cobalamin. More expensive, but an effective form of B12.

He again briefly spoke of Professor Zimmerman's work with B Vitamins and pain management and urged us to sign up with Irene's B12 trial.

We agreed that we would make a significant contribution from our funds to Irene so as to assist in her travel costs to our May 10 meeting.

Leonie spoke of future possible guest speakers including Dr Robert Campbell and Anthony Kingston.

We then shared our stories.

Leo spoke of his MVD which ended his TN but left him with anaesthesia dolorosa, a condition that is nearly as annoying.( the Italian film star he keeps reminding us!!) He has visited the Greenslopes Pain Clinic for a very brief consultation. He takes a lot of tablets including clonazepam to assist with sleep.

Neil continues to use exercise to control his TN as best he can and finds the elevation of the heart rate is essential in pain management. Stress is a trigger for the condition. Neil finds that when heading out for a run, he suffers shocks in the early part but then they soon pass.

**One of the effects of exercise is its effect on the brain - through several mechanisms, including neurogenesis, mood enhancement, and endorphin release. Endorphin-binds to opioid receptors in neurons, blocking the release of neurotransmitters and thus interfering with the transmission of pain impulses to the brain. – Irene.**

John also exercises to assist controlling TN and does weight resistance training at the gym. John first got it 10 years ago. It returned one and a half years ago and went back on Tegretol. He now manages it really well with regular neo B12 injections and no Tegretol.

Lorraine suffers from glossopharyngeal neuralgia which has caused lesions of the tongue and which makes speaking difficult. She is on Tegretol and Lyrica. Acupuncture cupping was initially helpful in reducing pain. Our group warmly welcomes you, Lorraine, as well as supporters Jeff and Margaret.

Anne had her very successful MVD two years ago by Dr Mark Dexter. There is slight numbness in the top lip.

Beryl has had TN for 11 years. She is on 400 mg Tegretol and 800 mg Neurontin. Beryl has recently had two neo B12 injections and feels much better.

Doreen has occipital neuralgia .She was on 200 mg tegretol and now on only 100mg a day and a blood thinning agent with the neo B12 injections each month. Doreen also gets flashes at times in each eye.

Henry is now also on neo B12 injections each fortnight. He was on 600mg tegretol and now only 100mg.He is now pain free. Eilleen continues to enjoy his wellness as she can now “punch him up” and enjoy bus trips together!

We welcomed Margaret S who has suffered with TN for 9 years. She has tried everything and now has an ANS installed by Dr Baker with wires under the skull. This battery-operated device must be charged weekly. There is still pain She has been on Lyrica, and Gabapentin and found the latter of some assistance. She will go back on gabapentin soon. Margaret has also tried B12 three times.

Joan offered the encouraging account of the deep brain stimulation performed by Dr Coyne on a patient who was unable to move her legs. Within 6 weeks of the procedure, she can now walk. Margaret, we hope our group can help and support you along the road to wellness.

Margaret B is now going well. She has had TN since 96. It got really bad in Feb 07 and continued into this year. She is now on 600 mg tegretol and 20 mg nexium along with neo B12 injections. Margaret is suffering from a rash all over the body and would love to go on Neurontin. Husband and constant supporter Colin B has neuropathy of the feet. He is currently on 1800mg neurontin and still in pain. He will soon commence with a group at the Pain Management Clinic.

Joan continues to be well, and cheerful! She had been on tegretol, dilantin and epilan. She is now pain free on 3 monthly methyl cobalamin injections, half a zolofit daily, magnesium, glucosamine and fish oil.

Noela's pain was stirred up with a bout of shingles. Pain was with jaw movement and affected eating. Noela is now off tegretol and has found acupuncture helpful. She continues with B1& 12 and magnesium tablets.

Fred continues to be well, 4 years this Melbourne Cup after Dr Scott Campbell's MVD. Fred's garden produce continues to be well also. Thanks for the beautiful strawberries and pumpkins.

We welcomed John who has experienced constant pain in R top teeth area since September 2003. Air conditioning can be a trigger for pain. Though he doesn't get the lightning bolts, he was diagnosed with TN .He has had Xrays. Prosiadin made him ill, tofrinol made him sun sensitive. Valium eliminates the pain. ( probably his TN = Trigeminal Neuropathic)

Leonie spoke of mum Corry's ongoing struggles. Corry has had most procedures including an MVD and 3 glycerol injections. She experienced a bad reaction to tegretol and is now on gabapentin and slow dose morphine. The pain diary helps. Pain comes in cycles. Longest time pain free has been 5 months. Corry commenced B12 injections in January and is finding that this cycle is bearable. Corry, again the Banana benders up here send our best wishes and hopes for good health ahead.

Keith has experienced neuralgia with stabbing pains in both sides of the head. He is now pain free and considers a parasite or combination of parasites the cause of TN. He also suffers from MS.

**(2% of patients with multiple sclerosis (MS) have trigeminal neuralgia and 18% of patients with bilateral symptoms of trigeminal neuralgia have M.S.. - Irene)**

Tony recently suffered a very severe cycle that was the worst in 18 months. He has trialled the four forms of B12 listed above and is currently on fortnightly injections of methyl cobalamin. He has commenced Neurontin at 400mg daily. He uses prayer, magnesium, fish oil, folic acid and continues to say to himself after horrible shocks with a bit of a smile "You haven't got me yet, ya bastard!!"(Can we say that,Irene?)

**(say what you like as long as it controls your pain and out of my earshot - ☺ Irene.)**

Our meeting again closed with a happy chat over some beaut naughty but nice goodies. Thank you to all who have shared stories –the trials and the joy of extinguished pain. All stories offer illumination and sometimes hope to others. To our friends who couldn't make it, we are thinking of you and hope to again see you soon.

Next meeting May 10 with Irene Wood as our guest speaker.

### **Tony & Leonnie**

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### **Gold Coast Support Group NEIGHBOURHOOD CENTRE, PALM BEACH 29th March 2008**

**PRESENT:** Marjorie D; Allan F; Denise M; Nancy A; Andrée C.

**APOPLOGIES:** John M; Pip B.

It was pleasing to see Marjorie looking so well and happy having had another "Inter Ocular Nerve Section" only a few weeks earlier. This keeps her free from pain for up to 18 months. Her partner Allan told us she was in hospital for only 6 hours.

Denise feels she is turning the corner now but is still taking large doses of drugs morning & night. Her Neurologist is reluctant to reduce the amount just yet as SUNCT is such a difficult condition to treat.

Nancy also suffers with SUNCT although her symptoms are slightly different; she is seeing a Chiropractor and Acupuncturist and is pain free without drugs. She and her husband are off to Canada in May. We wish you both a fabulous holiday.

**SUNCT is SUNCT. If your symptoms are slightly different – perhaps you should consider getting another opinion. There are many similar short lasting headaches.**

Unfortunately this was my last meeting – I'm stepping down due to ill health. My very best wishes to you all and keep reading your newsletters for information about another Gold Coast group starting up again in the future.

### **Andrée**

Thank you Andree for your volunteerism facilitating the Gold Coast group for the past 2 years. I am sure all our TNA members join me in wishing you well and that soon you will be up to par, and doing what you want to do.

Our thoughts and prayers are also with Pip, her husband Jack has been very ill.

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Hope is the companion of power and the mother of success,  
For those of us who hope strongest have within us the gift of miracles.

- Sydney Bremer –

Reflect upon your present blessings - of which every man has many - not on your past misfortunes, of which all men have some.

- Charles Dickens

## **Laughter is the Best Medicine**

### **Painful Experience**

The pastor asked if anyone in the congregation would like to express Praise for answered prayers. A lady stood and walked to the podium.

She said, "I have a praise. Two months ago, my husband, Jim, had a terrible bicycle wreck and his scrotum was completely crushed. The pain was excruciating and the doctors didn't know if they could help him."

You could hear an audible gasp from the men in the congregation as they imagined the pain that poor Jim experienced.

She continued, "Jim was unable to hold me or the children and every move caused him terrible pain. We prayed as the doctors performed a delicate operation. They were able to piece together the crushed remnants of Jim's scrotum and wrap wire around it to hold it in place."

Again, the men in the congregation squirmed uncomfortably as they imagined the horrible surgery performed on Jim.

She continued, "Now, Jim is out of the hospital and the doctor's say, with time, his scrotum should recover completely." All the men sighed with relief.

The pastor rose and tentatively asked if anyone else had anything to say. A man rose and walked to the podium.

He said, "I'm Jim and I want to tell my wife, the word is sternum."

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### **Coffee Argument**

A man and his wife were having an argument about who should brew the coffee each morning.

The wife said, "You should do it, because you get up first, and then we don't have to wait as long to get our coffee".

The husband said, "You are in charge of cooking around here and you should do it, because that is your job, and I can just wait for my coffee".

Wife replies "No, you should do it, and besides, it is in the Bible that the man should do the coffee".

Husband replies "I can't believe that, show me".

So, she fetched the Bible, and opened the New Testament and showed him at the top of several pages, that it indeed says... **"HEBREWS"**.

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### **PUNS**

A panda walks into a restaurant, sits down and orders a sandwich. He eats the sandwich, pulls out a gun and shoots the waiter dead. As the panda stands up to go, the manager shouts, "Hey! Where are you going? You just shot my waiter and you didn't pay for your sandwich!"

The panda yells back at the manager, "Hey man, I'm a PANDA! Look it up!"

The manager opens his dictionary and sees the following definition for panda: "A tree dwelling marsupial of Asian origin, characterized by distinct black and white colouring. Eats shoots and leaves."

## Correspondence Corner

**Karyle (USA):** I just wanted to let you know that after 2+ months of taking IM B12 injections (as cyanocobalamin 1 mcg daily) , I have significant improvement in my atypical TN pain. I have attempted to reduce the injections to 3x per week, but did have an increase in pain so I went back to the daily schedule.

I do still try to avoid my triggers (cold food and drinks, crunchy foods, cool breezes, the frozen food section at the grocery store, etc), but when I am taking the injections daily, my significant pains have been limited to 2-3 x per week. However, those pains that I do have do have an identifiable trigger; I can't recall the last time I experienced a truly spontaneous episode.

I don't know if the B-12 is really helping or if it is all psychosomatic – either way, I don't care. At least for now, it seems to be working and I don't have to resort to the awful anti-seizure meds.

**Pam:** ...just to tell you that overnight the neuralgia has disappeared and has done so almost 12 months. I just wanted to thank you for your support. **We are delighted to learn of your good news.**

**Neil:** I have been on Tegretol CR 400 (2 x 800 mg. per day) for about 2 years and was totally pain free so I decided to wean myself off the dosage.

What with blood pressure tablets, cholesterol tablets and trigeminal neuralgia tablets I was taking 91 tablets a week so you can't really blame me for wanting to 'cut down'.

After stopping the Tegretol I was completely pain free for about 3 months but then I begun to have that familiar small pain in the 'jaw hinge area'.

Not wishing to have one of those terrible full on attack again, I weaned myself back onto the Teretol 2 x 800 mg per day dosage as before, and again had to endure that lousy spaced out feeling until my system got used to them. My hands still tremble occasionally and sometimes jerk when I'm trying to write.

This time however that small pain in my jaw has stayed with me and lurks just below the surface so to speak and feels about to come back with a vengeance if I miss a dosage.

I have trouble eating, shaving and saying words that start with 'P' that make my cheek puff out.

There is absolutely no question that your excellent newsletter has helped me as I know it must have helped so many others.

You're correct in saying that when one has that first attack we feel so confused and alone, the pain being so unlike anything we have endured previously. I went to my GP and he scratched his head and said that he didn't know who to send me to. Luckily he did send me to a neurologist at St. George Private Hospital who gave me that camera up the nose examination then ordered an MRI of my head. The result was no tumor etc so he sent me to a neurologist in the office next door. This chap didn't seem to know a great deal about the problem and prescribed something (I've forgotten what). This didn't help and I phoned for another appointment. Luckily, I was to see another doctor in the same group who knew all about TN and was able to treat the problem and gave me a great deal of comfort.

It was there that I was given the information about you association. Reading in your newsletter about other sufferers I have nothing to complain about, but always in the back of my mind is the thought that any moment it will fully return.

The full on pain is not so much like an electric shock as an extremely painful crawling, stretching upwards feeling of the entire right hand side of my face. This seems to be brought on by any loud screeching noise (like dragging sheets of corrugated iron over each other). Cold wind doesn't seem to worry me, however my son has a soundproof room and this also seems to affect me.

**Davi:** heat, wind and stress brings on the pain, or when eating food at certain temperature - it sets off a pulsating pain. During my cannot speak moments – I scribble messages to indicate my situation. Davis also reported she had 2 falls. – We hope you are fully recovered.

## 2008 Meetings

### **ACT**

**12 April 10 :00 am CANBERRA SUPPORT GROUP**  
Venue: Weston Creek Community Centre, Room2  
Support Group Leaders: 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

**3<sup>rd</sup> May 1:00 – 4:00 pm SYDNEY SUPPORT GROUP**  
Toongabbie Public School,  
Cnr. Fitzwilliam and Binalong Rds, TOONGABBIE  
Support Group Leaders: Kim Smith 02 9769 1947.  
& Kim Koh 02 97431279  
Speaker: Dr. Marlene Yee - Acupuncture

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.

**TBA 10:30 am – 1 pm GOLD COAST SUPPORT GROUP**  
The Palm Beach Neighbourhood Centre, 16 Third Avenue, Palm Beach.  
Support Group Leader: Andree Chenevier 07 55200228

**19 April : 1: 00pm SUNSHINE COAST SUPPORT GROUP**  
Fletcher Dental Surgery, 23 Beach Rd, MAROOCHYDORE.  
Support Group Leaders :Teresa Miller: 07 54912487  
Jean Williams : 07 5491 1978

### **S.A**

**Sunday 6<sup>th</sup> April: 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**

**12<sup>th</sup> April 1:30pm MELBOURNE SUPPORT GROUP**  
"Ringwood Room" Ringwood Library, RINGWOOD  
Support Group Leader: Evelyn Diradji 03 9802 6034  
Guest Speaker : Irene Wood

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