



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, Townsville.

July 2010.

“ Dare to reach out your hand into the darkness, to pull another hand into the light.”

~Norman B. Rice

I am proud to reveal another addition to our TN family - welcome Townsville Support Group !! Sera had expressed the desire to meet and share with other TN sufferers in her region and I was only too happy to comply. After some basic groundwork we held the introductory meeting last month. We successfully appointed Sera Ansell as support group leader with Sue Macey, her able assistant. Congratulations ladies, I am sure the group will grow and benefit from your compassion and leadership.

I am only one, but I am one. I cannot do everything, but I can do something. And I will not let what I cannot do interfere with what I can do. ~ Edward Everett Hale

Do you have a desire to start a Support Group in Your Community? **You too can make a difference.**

Benefits of starting TNA support group :

- Create a network of people concerned about TN and working on the same issues.
- Bring together the collective wisdom of people who have already experienced the same challenges you are seeking solutions for.
- Create a group that can make a difference in your community, maybe even save a life.
- Motivate you to take ownership of your pain management.
- Help you rediscover strengths and humour you may have thought you had lost.
- Together there is HOPE.

The first step to beginning a group in your community is to contact the Trigeminal Neuralgia Association Australia Inc. - Irene Wood.

We do have expectations of our support group leaders, and we do assess each individual before entrusting them with the group leaders role. Amongst other criteria, support group leaders must be members of the Association.

Teresa Miller has decided to step down from her SGL role as other aspects of her health and family life demand more of her attention. It is with regret we lose her valuable service as SGL for the Sunshine Coast group but we thank her for the years of service she has provided for others in her community. We send our love and best wishes in her future undertakings. Much to my relief Jean Williams has agreed to battle on – phew! ☺

The first question which the priest and the Levite asked was: "If I stop to help this man, what will happen to me?"

But... the good Samaritan reversed the question: "If I do not stop to help this man, what will happen to him?"

~Martin Luther King, Jr.

Friends, I am quite surprised (alarmed even) that many continue to ask me when and where is the next conference. The below notice has been in the past newsletters. You need to start penciling this into your diary and start making serious plans to be there.

TNA Aus 4th National Conference 2011 September 2nd – 5th

I am very proud to announce that your subsidized conference registration fee for our next national conference at the Hunter Valley Cypress Lakes Resort in 2011 September would only be @ \$420 per person twin share. (*This deal is for TNA Aus members and their partners only.*) Your fee will as usual include 3 nights accommodation, all meals (3 breakfast, 2 lunch, 3 dinners), 2 morning and afternoon tea and 2 days of invaluable information. Just so you can appreciate the fantastic deal I have struck for you – a 2 bedroom villa with breakfast is usually \$678 per night, without dinner or conference. I hope you will be able to enjoy this package. For more details of the venue: visit - www.cypresslakes.com.au

The after Conference Social Events:

- Hunter Valley winery tour - 5th September
- 4 nights at Brampton Island - 6 – 10th September.
- Are you planning on being there? Start saving now. You would hate to miss out.

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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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:

- | | |
|-----------------------------|--------------------------------------|
| <input type="radio"/> \$25 | <input type="radio"/> \$250 |
| <input type="radio"/> \$50 | <input type="radio"/> \$500 |
| <input type="radio"/> \$100 | <input type="radio"/> Others \$_____ |

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

Trigeminal Neuralgia Association Australia

MINUTES OF ANNUAL GENERAL MEETING

Date: 5th June 2010

Location: St James' Parish Hall, Phillip Street, Sydney

Time: 10.00am

Minutes of the last AGM were read by the Secretary, and accepted by Frank M and seconded by Kim K

Treasurer's Report

Frank presented a Statement to Members under Section 26 (6) of the Associations Incorporation Act 1984, the Income & Expenditure Statement, and Assets and Liabilities statement for the year ended 31.12.2009. *(If you wish a copy of The Treasurer's Report please send request and a self addressed envelope to the Association.)*

Total expenditure for 2009 was \$60524.67. This is inclusive of Bank charges, Conference Expenses, Legal and Accounting Fees(Audits), Postage, Printing' Stationery, Insight Books Freight, Travel/fares and the Purchase of Video Camera. The major components of this was the conference expenses @ \$46500.00 and postage /printing @ \$10,000.

Presidents Report

Irene reiterated that our objective is to provide the information, the support and the encouragement to TN sufferers. Our mission is to advocate for the awareness of TN and related facial pain through information and education to both sufferers and professionals. Our goal is to have a unified understanding of TN and other related facial pain resulting in better pain management.

Year 2009 Highlight - was our 3rd National Conference at Yarra Valley held on the 27th -29th of August with 86 people attending. We enjoyed the participation of international Pain experts such as Professors Marshall Devor, Manfred Zimmermann, Volker Neugebauer and Ms Phyllis Berger. The national conference was also well supported by members of our Medical Advisory Board.

The Association was also able to provide full scholarship to 2 support group leaders for the 3rd national conference, while in previous conferences only one scholarship was afforded. The scholarship is an acknowledgement and appreciation of the work support group leaders do and knowledge gained from the conference would enable them to better help others. We trust that they would in turn honour the advantage and continue in their important role as the extended arms of the association. Naturally there are selection criteria, but due to the lack of funding we can only offer what we can afford. It is my hope though, that we can continue to uphold these scholarships.

Another wonderful outcome of the 3rd national conference was the birth of the Hobart Support Group on 6th of December 2009.

In 2009 we serviced 180 new enquiries, and of that only 65% subscribed to membership.

Irene thanked the committee members for their assistance in 2009/10 especially Frank who is retiring as Treasurer but will stay on as a Committee member.

Election of Office Bearers for 2010

President: Irene Wood

Vice President: Kim Koh

Treasurer: Marion Abraham

Secretary: Jocelyn Stafford

Committee: Frank Martin, Ray Cluett & Linda Knowles.

Meeting Closed at 11.00am

Moved by Kim K. Seconded by Ben H.

Migraine, Cluster, Trigeminal Neuralgia, and Mood Disorders: Common Ground for Treatment

Author: Stephen D. Silberstein, MD

Published: 10/26/2001; Updated: 10/26/2000

Trigeminal Neuralgia

Trigeminal neuralgia also causes severe, intermittent head pain. Approximately 15,000 new cases of trigeminal neuralgia are diagnosed each year, with 90% of cases beginning after age 40. The prevalence is about 12 million, with a female predominance of 1.5:1.^[51] Stabbing, shooting, electric shock-like pain in the distribution of the maxillary and mandibular nerves can be spontaneous or triggered by stimuli, such as touch, cold air, chewing, talking, facial movement, brushing the teeth, or emotional distress. Trigger zones are usually in the central face around the nose and lips and may be quite small (1-2 mm). Chronic focal demyelination and irritation of the trigeminal nerve appear to be responsible for the attacks (Figure 6).

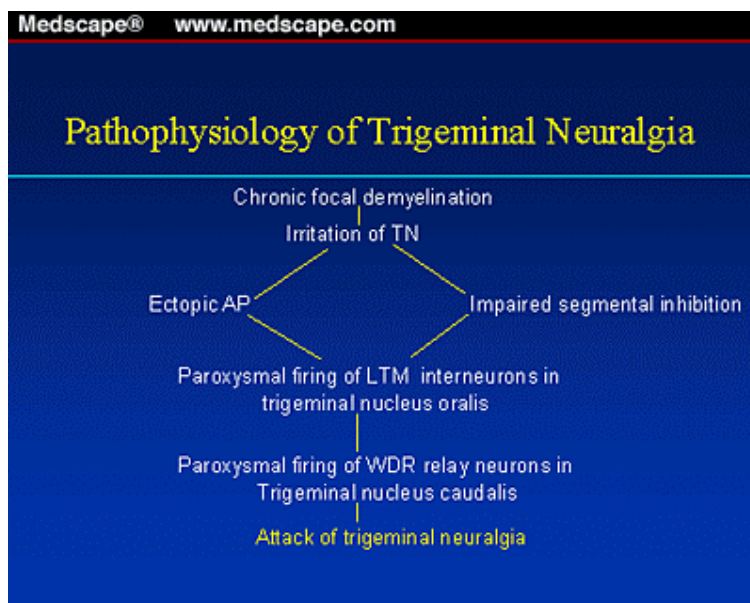


Figure 6. Pathophysiology of trigeminal neuralgia.

AEDs are the standard treatment for trigeminal neuralgia. Carbamazepine, the first-line agent, is effective in about 80% of patients in the short term.^[52] More than 94% of patients respond within 2 days. However, in the long term, only 56% respond. Most people need less than 1200 mg of carbamazepine a day. One should wait at least 20 days to measure serum levels because carbamazepine undergoes auto-induction of its own metabolism. Furthermore, the half-life of the drug changes over time; initially the half-life is about 40 hours, but with chronic exposure, it falls to around 27 hours. Carbamazepine may cause drowsiness, dizziness, and hematologic side effects.

Phenytoin was shown to be effective for the treatment of trigeminal neuralgia more than 30 years ago.^[53] The short-term efficacy rate is 60%, which drops to 30% after 2 years. Phenytoin can be difficult to dose because of zero-order kinetics. Thus, a small change in dose can result in a large change in serum concentrations.

Clonazepam is effective in 65% of patients with trigeminal neuralgia. In 1 small study, clonazepam provided pain relief to half of the patients who had not achieved relief from carbamazepine.^[54] Starting dose is 0.5 mg 3 times a day, with a target dose from 1.5-8 mg/day.

Valproate has a 65% efficacy rate in the treatment of trigeminal neuralgia, but it can take several weeks before patients respond. Because of the severe nature of trigeminal neuralgia pain, most patients will not want to wait this long.

Two studies suggest that gabapentin relieves the pain of trigeminal neuralgia. In the first,^[55] two 80-year-old women became pain free within a week of starting gabapentin. In the second study,^[56] 6 of 7 patients with multiple sclerosis (MS) and trigeminal neuralgia became pain free, and the other experienced significant relief. This effect was maintained for the year they were studied. In a third study,^[57] low-dose gabapentin proved effective when used as an adjunct to lamotrigine or carbamazepine in 11 patients with MS and trigeminal neuralgia.

Oxcarbazepine, a keto analogue of carbamazepine, appears to be as effective as carbamazepine, or better, for treating trigeminal neuralgia.^[58,59] Patients who have failed carbamazepine may respond to oxcarbazepine, and achieve relief within 24 to 72 hours.

The effectiveness of lamotrigine in treating trigeminal neuralgia has been evaluated in 2 studies.^[60,61] In the first study,^[60] when lamotrigine was added to carbamazepine and phenytoin, 85% of patients improved. In the second study,^[61] 73% of patients improved and 53% became pain free on lamotrigine monotherapy. Doses in both studies were titrated up to 400mg daily.

Topiramate is the newest drug to be evaluated for the treatment of trigeminal neuralgia. In an open-label study^[62] of 5 patients with MS and trigeminal neuralgia that was refractory to combination therapy with a variety of conventional treatments, all became pain free. Doses ranged from 200-300 mg/day. One patient continued concomitant treatment with carbamazepine, but the other 4 patients were able to discontinue all other medications for trigeminal neuralgia. Pain relief was maintained at 6 months follow-up.

Because many patients with trigeminal neuralgia are older, they are more susceptible to neurotoxic side effects from medications, therefore, overtreatment must be avoided. A pain diary can be quite helpful in this regard. If the clinician determines the patient has become pain free, he or she should begin to taper the drug, and restart or restore the dose if pain returns. Side effects can be minimized by titrating doses throughout the day and avoiding high peaks. Although monotherapy is preferred, polytherapy may be necessary to treat trigeminal neuralgia. Patients may tolerate the newer AEDs better than carbamazepine or phenytoin.

These are classified ads, which were actually placed in a U.K. newspaper:

FREE YORKSHIRE TERRIER.

8 years old. Hateful little bastard. Bites!

FREE PUPPIES

1/2 Cocker Spaniel, 1/2 sneaky neighbour's dog.

FREE PUPPIES.

Mother, a Kennel Club registered German Shepherd.

Father, Super Dog... able to leap tall fences in a single bound.

COWS, CALVES: NEVER BRED.

Also 1 gay bull for sale.

JOINING NUDIST COLONY!

Must sell washer and dryer @100.

WEDDING DRESS FOR SALE.

Worn once by mistake.

Call Stephanie.

*** And the WINNER is... ***

FOR SALE BY OWNER

Complete set of Encyclopedia Britannica, 45 volumes.

Excellent condition....£200 or best offer.

No longer needed; got married last month.

Wife knows f#%##%#g everything!

Study Finds Vitamin D Deficiency Common in People With Diabetes

By Kathleen Doheny

WebMD Health News

Reviewed By Laura J. Martin, MD

June 21, 2010 -- Vitamin D deficiency, long suspected to be a risk factor for glucose intolerance, is commonly found in people with poor diabetes control, according to a new study.

"Our study could not show cause and effect," says Esther Krug, MD, an endocrinologist at Sinai Hospital of Baltimore and assistant professor of medicine at Johns Hopkins University School of Medicine, Baltimore, who presented the findings at ENDO 2010, the annual meeting of The Endocrine Society, in San Diego.

But she did find that vitamin D deficiency was common in her study, with more than 91% of participants deficient. As the deficiency worsened, so did diabetes control. Only eight of the 124 participants took vitamin D supplements, she found.

About 18 million people in the U.S. have been diagnosed with diabetes, according to the American Diabetes Association, and about 6 million more are believed to have the condition but are undiagnosed.

Low Vitamin D, Poor Diabetes Control: The Study

Krug and her colleagues decided to look at vitamin D deficiency in the wake of reports suggesting that vitamin D has an active role in regulating pancreatic beta cells, which make insulin.

So they evaluated the medical charts of 124 people with type 2 diabetes (in which the body doesn't make enough insulin or the cells ignore the insulin) seen at an outpatient clinic from 2003 to 2008. The charts contained information on the patients' age, race, vitamin D levels, calcium intake, family history of diabetes, and results of their hemoglobin A1c blood test. The A1c provides an average measurement of blood sugar control over about a 12-week span. (For people with diabetes, the goal is 7%; for people without, the normal range is 4%-6%.)

Krug's team divided the vitamin D levels they found into four groups: normal (defined in the study as above 32 nanograms per deciliter), mild deficiency, moderate deficiency, or severe.

In all, 113 of the 124 patients (91.1%) were vitamin D deficient -- 35.5% severely, 38.7% moderately, and 16.9% mildly.

The average A1c was higher in patients with severe vitamin D deficiency compared to those with normal levels of vitamin D. Those with severe deficiency had an average of 8.1%; those with normal vitamin D levels averaged 7.1%.

Krug found racial differences. "In people of color, vitamin D levels were even lower than in Caucasians and they were associated with even poorer diabetes control," she tells WebMD.

Only 6.4% were on vitamin D supplementation. This was true, Krug says, even though they had medical coverage and saw their doctors. She suspects a lack of awareness on the part of the physicians partly explains the frequent deficiencies she found.

Aggressive screening of vitamin D levels is crucial for people with diabetes, Krug says. Once a supplement is recommended, she says, the blood levels should be rechecked to see if the supplement sufficiently increases vitamin D levels.

Vitamin D Facts

Vitamin D is crucial not only to maintain bone strength, but research also suggests it plays a role in immune system functioning, cancer prevention, and cardiovascular health. It is produced when ultraviolet rays from the sun strike the skin and is also found in fish, eggs, fortified milk, cod liver oil, and supplements.

Adequate intakes, set by the Institute of Medicine of The National Academies, are 200 international units (IU) a day for adults up to age 50, 400 IU for people aged 51-70, and 600 IU for people 71 and older. But some experts say much more is needed; the recommendations are under review, with an update expected in 2010.

Second Opinion

The new study lends support to a growing body of scientific and clinical data linking vitamin D with insulin and glucose, says Ruchi Mathur, MD, an endocrinologist and assistant professor of medicine at Cedars-Sinai Medical Center, Los Angeles, who reviewed the study for WebMD.

Other research has shown that supplementing with vitamin D and calcium slows the progression to type 2 diabetes, Mathur says. Even so, she tells WebMD, "At present, a direct link between vitamin D and type 2 diabetes is not conclusively established."

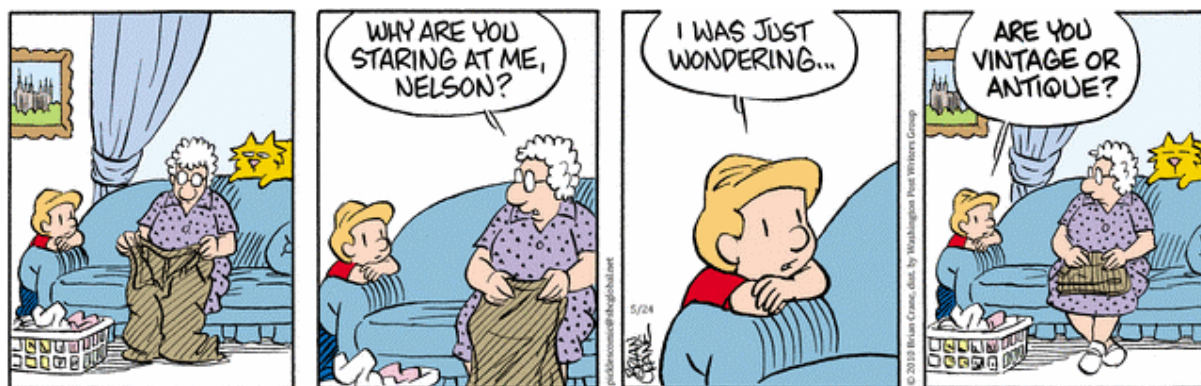
She has another caveat. "One important point that is missing ... is the prevalence of vitamin D deficiency in the general population" compared to those in the study. As vitamin D deficiency is being noted with "an alarming increase in frequency" overall, she says, "it may shed doubts on the authors' conclusions."

It's also possible, she says, that people with poor glycemic control have it because of a general unhealthy lifestyle, not just their low vitamin D status. They may engage in less outdoor exercise, for instance, or have unhealthy eating habits.

Because of the possible link, however, she agrees that screening for vitamin D deficiency in people with type 2 diabetes may be warranted.

This study was presented at a medical conference. The findings should be considered preliminary as they have not yet undergone the "peer review" process, in which outside experts scrutinize the data prior to publication in a medical journal.

SOURCES: Esther Krug, MD, assistant professor of medicine, Johns Hopkins University School of Medicine; endocrinologist at Sinai Hospital of Baltimore.



Meeting Reports

SYDNEY CBD SUPPORT GROUP St. James Parish Hall 11:00 am - 5 June 2010

Present: Irene W, Frank M, Kim K, Jocelyn S, Linda K, Ingrid K, Fran T, Alistair McD, Ben H.

Apologies: Pam & Pat S, Lois & Reg W, Margaret & Alan M, Marion A.

Irene mused – AGMs are as effective as citronella oil – it keeps folks at bay. ☺

Lois: have been very sick with pneumonia for the last two and a half weeks; and have been having a very bad time with my T.N. since the 17th. (may be triggered by all the coughing,) I have had attacks most days since then some times twice a day and once three times. Reg has been keeping tabs on the attacks, when they were and for how long. Mostly 35mins.

We have sold our house, (a man just walked in off the street and asked would we sell), a good price was offered so after a lot of persuasion we agreed. Moving out on the 30th of June. It has all been trying to say the very least. (*Irene wonders if unbeknown to Lois& Reg - some loot - X marks the spot - is under the house ☺. We hope you have recovered from your pneumonia and your TN is all under control again.*)

Pam S. wrote to say all is well.

Alan M. is well and no pain. He and Margaret are on a road trip to north western Australia.

Linda: Is much better but she still has pain and stabbing in the jaw and teeth as well as creepy crawly pain all over her face. She also receives muscle skeletal related therapy which also relieves her neck pain. Learning not to be anxious has also helped her manage her pain.

Ingrid: Had no pain for 2 months then a “warning” pain started 3 weeks ago at night with about 10 minutes between each stab. She is taking methylcobalamin, fish oil, glucosamine, calcium and Vitamin D as well as low dose of Tegretol and Lyrica.

Fran: Pain has been on and off since Christmas. 3 weeks ago she started having attacks where she couldn't talk which lasted a week. She increased the Tegretol from 100 to 700gr per day. Irene suggested that medications such as Tegretol should be titrated, and she should give 48 hours between increase. Sometimes when such meds are increased too much too soon, they can cause adverse side effects. Fran is scheduled for both knee replacement and is most concerned that her TN would flair up while in hospital. Irene assures her that she would be in a comatose state with morphine after her op. to feel anything. We wish Fran a speedy and full recovery.

Alistair: has burning pain in lower jaw. Is taking Trileptal twice a day and also Methylcobalamin and Cymbalta @ 30mg.

Ben: Caught the train down from Newcastle to attend the meeting. Ben's TN started about 4 years ago, it got so bad that he contemplated walking to NZ with the hope he drowned before he gets there. *Irene asked – why? Doesn't he like NZ? ☺.* Ben has been on high dose of CR Tegretol (1200 mg per day) and suffers nausea with that. His doc had tried him on Trileptal but it was not effective. Irene suggested perhaps he could try Epilim or Neurontin.

We concluded the business part of the meeting and enjoyed a cuppa with all the goodies and chatted.

Next meeting: 7th August (hoping to have a guest speaker - hypnotherapist)
Thanks Jocelyn for the meeting notes. *Irene.*

MELBOURNE SUPPORT GROUP MEETING
“Ringwood Room” Ringwood Library
1.30 p.m. 12 June 2010

Evelyn welcomed people to the meeting – a long weekend in winter is often not a popular date for a meeting so it was good to see everyone who attended, especially two new people attending for the first time.

Present: (17) Barbara & Robert A.; Toni B.; Alan & Joy C.; Evelyn & Din D.; Marjory & Murdoch F.; Bruce G.; Alan L.; Beryl & Rob O.; Will & Joan R.; Joan & Neil T.

New: (2) Sandra H.; Sandra M.

Apologies: (12) Ellayne C.; Doug E.; Alf H.; Nita & Robert McK.; Vicky M.; Bill P.; Dot M & Diane S.; Carol S.; Graeme & Sandra T.; (Sorry Beryl & Rob O's apology did not appear in the April Report.)

Doug has just regained his driver's license and noted he only takes up to 8 Panamax or Panadeine a day when necessary; **Vicky** had a niece's wedding to attend but reported her TN is under control since her first meeting in April after a combination of strategies e.g. changing to controlled release Tegretol which she tolerates better so has been able to increase her dosage, Endep at night and 400mg sub-lingual B12 daily; **Graeme** made contact with several organizations for TN publicity before his holidays – many thanks.

Business:

Books for sale and books for borrowing: Please see Din 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 in April were \$65.00. Expenditure since then totalled \$33.45 (insurance, white board markers and gift for guest speaker in April) leaving a balance of \$130.25.

Evelyn informed the meeting of a very generous donation of \$500.00 being forwarded to TN Australia, from Rob & Beryl O. - specifically to support the Conference 2011. Rob's accompanying letter acknowledged the high level of organization and quality speakers and presentations at the 2009 Yarra Valley Conference which he attended.

Newsletters: Good article on Trigeminal Neuralgia in the recent June newsletter.

Maroondah Festival – Croydon November 2010 probably not suitable for TN promotion.

Reports from members:

Toni is taking 200mg CR Tegretol a day and 2 x 1000 mcg B12 x 3 times a day. Toni tried the diet / vitamin regime in Striking Back and is less vegetarian now than previously. Her pain is on and off and changes location between upper lip and eye. She is hesitating having an MVD as she hears good and bad stories of outcomes. A running nostril is another symptom she sometimes has - others have also experienced this.

Alan reported that B12 as methylcobalamin from a compounding chemist, is more effective for him plus 200mg Tegretol during the night. The very sensitive spot on his upper lip has gone so now he can shave - since using Zostrix. He is pain free and hesitant to have an MVD.

Barbara has sensitivity around the eye causing weeping at times and is continuing slow release Tegretol and sub-lingual B12..

Sandra H has TN on the left side of her face – she didn't know anyone who had TN nor did she know about the group until she saw the meeting notice in the local paper. She was “normal” til 2 years ago when she lost a front tooth – then attended an implant seminar followed by lots of expensive root canal

work and crowns and saw a maxillofacial surgeon. At St Vincent's Pain Clinic her pain was finally diagnosed as trigeminal neuralgia by Dr. Nina Boremeo. She had also been told it was dry mouth syndrome and to eat pineapple. Joy said Tic Tacs were just as good; some medicos tried to link it to a brain tumour that had been removed. Chiropractic treatment with a spinal adjustment tool relieved a little of the pain. Sandra experienced a loss of faith after such confusing diagnoses and treatments that didn't relieve the pain. She has taken Lyrica for approx 2 yrs and is very happy to have found the group and be able to listen to others' experiences. Some members mentioned a thin cut MRI if she is thinking of an MVD. (In an e-mail since the meeting Sandra has expressed gratitude for her welcome and all the information she was given at the meeting!)

Sandra M's TN was diagnosed in March 2010 by oral pathology and oral medicine in Ivanhoe after jaw x-rays & a blood test. She also has a dry mouth. Sandra had a month of no pain but the cold weather has triggered a return at times. Sandra had dental work over a 3 year period; after one visit the pain was so debilitating she could not drive home from the dentist. She is not taking any medication and is wary of Tegretol and its side effects. The pain is worse at night and notes that stress is a factor. Joan said that a blood test before beginning Tegretol and one after a period of taking it would reveal changes.

Beryl was happy to announce that on 4 July it will be 10 years since her MVD and she has been pain free ever since! The MVD was done at Melbourne Private after TN pain for 4 years.

Joan had an MVD 8 years ago and is pain free on that side but still has pain at times on the other side (bi-lateral TN is rare). She still uses the external Capsaicin cream Zostrix but warned care must be taken not to allow this near the eyes or inside the mouth. Her Croydon dentist knows about TN.

Alan reported for Joy - she recently went to a dentist for the first time in 50 years (has had dentures) thinking there was gum shrinkage but it was an ulcer. The dentist knew about TN.

Will admitted to being a somewhat newer MVD graduate having had his 2 years ago this month after TN was diagnosed at his first visit to his GP. It was triggered by cleaning his teeth. The neurologist prescribed Epilim but this led to weight gain and a neck brace did not relieve the pain. He began to get short of breath and had to have a blockage in the aorta attended. A web search revealed that the American Dental Association saw a link between root canal therapy and TN but other groups claimed no definite link could be established. Will had a reaction to Tegretol and 3600 mg a day of Gabapentin was no help. The unpredictability and severity of the pain were hard to deal with and he had to remain absolutely still to avoid pain. Finally at 82 years of age, he decided to have an MVD. After the operation he was out of hospital in 3 days. He is pain free now and takes Fibroplex for magnesium.

Marjory said Will was the reason she is now a happy woman! Will's story of having an MVD at 82 years old inspired her to go ahead although she was warned that at 78 she was too old. She has been absolutely pain free ever since.

Evelyn first had TN four years ago this month, took anti-epileptic drugs for a short time then acupuncture and laser acupuncture and now is taking up to 4000mcg sub-lingual B12/day and is pain free.

Thanks to - Joan and Neil for collecting the key, arranging insurance and setting up the chairs, tables and loudspeaker; Alan for the financial report; all who helped with afternoon tea and to all who brought something to share; Neil ensuring everyone sign in; and all who helped clean up. Most of all, thanks to all TN patients who shared their story, especially the two new people for coming today.

Please note date of **next meeting**: Saturday 7 August 2010, 1.30 – 4 p.m.

Evelyn

Inaugural meeting of the Townsville Support Group
Saturday 19 June 2010 at 1:00 pm at
Carville Senior's Villa – Unit Hall, Pimlico.

Present: Sera and Peter A, Phil and Sue M, Irene W, Jill S, Louis and Anthony B, Joan B, Jim, Eileen and Kerren K.

Irene opened the meeting and said to thank the owners of the venue for the free of charge use of the room. Irene talked about the history of the association, its goal and mission.

Irene explained the great benefits of our national conference. The Association subsidize members registration conference fees and if possible, it is certainly worthwhile to attend and experience one.

Members' news

· Sera's pain started 11 years ago. It started as little twinges around the V2 area then became lightning bolts that "twisted@ and wouldn't let go. She also experienced creepy crawlies on the top of her head. Pain eventually got worse, while dental exploration found nothing. The pain got so bad that she couldn't talk, eat or smile. Her GP diagnosed TN. The first drug did not work and she was given Gabapentin started at 300mg. By the beginning of last year, Gabapentin was no longer helping her control her pain – so her GP suggested it was time for surgery. She had an MVD, but just before Christmas her pain started again and Gabapentin was reintroduced. She has been taking 2400mg of Gabapentin a day, and aims to taper off one tablet a month with the help of her neurologist.

Joan B. has been contact with Irene since 2000. That was when she was struggling with her facial pain. Joan said that it was a blessing she could communicate with Irene during that time and keep her sanity. Joan's pain started when she was 10, after a bout of chicken pox in her abdomen. She is now 82. Ever since then her chicken pox, she has always experienced facial pain which was made worse by wearing her glasses. She also mentioned that she has always been a fainter all of her life. (*Irene asked if it was the pain that made her faint but Joan can't quite recall*)

Some years ago she saw a locum here in Townsville who refused to accept her description of pain (Joan described it as a sharp twisting cramping sensation that winds up (like a corkscrew) from her cheek area to the top of her head. The doc. insisted that it was a dull throbbing headache and did nothing to help Joan in her face pain. Her eye cancer also exacerbated her facial pain but has since had the eye removed. Joan used to have frequent herpes infection esp. cold sores and finds that taking L-Lysine supplements has helped in decreasing these herpes outbreak, and keeping her facial pain at bay. She also uses a "migraine stick" – a roll-on herbal ointment stick – smells of the lavender and peppermint – gets relieve almost immediately.

Jill's TN started 15 years ago. Her first medication was Tegretol. She described her pain as electric shocks. During the 15 years period her TN attacks were bearable and controlled by Tegretol. She also enjoyed long periods of remission. But 18 months ago she had a severe attack and Tegretol was no longer helping. She was then started on Neurontin and eventually was taking 16 X 300mg per day!! (Irene commented that according to literature 3600mg is the max. - anymore after that makes very little difference.) Jill is now on 75mg of Lyrica X AM/PM - which controls the pain. Jill also finds that the other side of her tongue has developed a burning sensation.

Jim: Jim is in a nursing home, and it is great to see Aileen (wife) and Kerren (daughter) coming along to share in Jim's support group meeting. Jim s pain is on the right side of his face. He recalls when he couldn't shave, and going to the dentist, thinking it was something wrong with his teeth. The dentist having confirmed it was not a dental problem referred him to the neurologist. In the early 90's Jim had his MVD but only enjoyed 2 weeks without pain. After pain recurred, he was placed on Tegretol and is still taking CR Tegretol 400mgX AM/ PM. He also takes 300mg Gabapentin – perhaps for his other neuropathic pain condition as he also wears a morphine patch. Bending forward triggers his TN pain.

Jim was having a grand ole time telling us all of his operations re: hip replacement and details. Aileen and Kerren, horrified deterred him from painting the explicit details. Jim mentioned he keeps himself busy and gets on with it.

Louise's pain started in her teeth and face. It got so bad that she was taken to hospital in ambulance. Tegretol was prescribed but she developed undesired side effects. She was then prescribed Endep and gabapentin. Had an MVD recently but that was not successful, in fact it is now worse. Now her pain is constant and burning. She now takes Lyrica 75mg twice a day and Endep.

Sue's · TN began about 9 years ago as irritating electrical shocks (when driving mainly). She has been not given a diagnosis at this stage. She has tried Tegretol but reacted with massive rash and headaches on Christmas day 2000. The pain then went away for a while but returned more painful. Sue went to dentist (nothing), went to ENT who diagnosed it as TN and prescribed Endep. The Endep made her feel very dopey; then pain went away for another 6 months and came back full bore. All types electric shocks, mild and severe, severe burning and constant – felt like being 'kicked in the side of the face by a donkey' pain. She was put on Epilim but pain broke through and was given Gabapentin as well. Dosage was as high as 6X400mg day. Pain broke through yet again. Had severe headaches at times with the pain. Set off by warm, cold air, talking (meetings), car vibrations when driving and stress. Referred to the pain clinic to get Gabapantin cheaper. Eventually they suggested an MVD. Had it in April 2008. Took a while to get over it but it lasted for 20 months without pain. Pain returned late December 2009 after Dad died and husband lost his job. Mother-in-law was also ill. Went back onto 2 x 20mg Epilim, then increased to 3. More pain. Saw neurosurgeon who stated that probably a vein had been missed and put her back on 2 x 10 mg Endep at night. Travel by road to Victoria. It got worse. Saw mother-in-law's doctor and he put the Epilim up to 4 a day and gave samples of Lyrica and said to take 2 on a day of severe pain. Travelled back and normal GP gave more Lyrica samples and said to take 2 a day. He was not happy that the operations were not working. Lyrica makes Sue feel very dopey.

We discussed a variety of alternative therapies – such as compounding topical applications, the use of Zostrix (chillie cream sold over the counter), Vitamin B12.. She related her B12 studies and found that 85% had a low B12 syndrome. The following study involved folks supplementing on B12 and this saw a reduction of the participants pain – to the point where some were able to be pain free and medication free. Today many in the association are on B12 therapy and controlling their pain.

We also discussed that it is important not to let the pain take control of your life. You need to take ownership of your pain and be proactive in your pain management. Distraction can also help in controlling your pain – an example given was music therapy.

- Sue said music gives her pain, and Irene asked what type of Music was that ?
- Phil (husband) explained that it didn't take much sound to set Sue off.

Surgical treatments were also discussed. Irene warned that TN surgeries are only good for classic TN symptoms. More specifically percutaneous procedures (damage the nerve slightly to cause numbness) could cause irreversible damage if it was constant burning pain.

Irene: the purpose of her visit is to officially launch the group under the auspices of the National Association. It is great when patients are prepared to volunteer and facilitate for the group, but Irene emphasize that the success of the group depends on the members involvement. You need to support it. Sera and Sue will co-facilitate the group.

Meeting concluded with cuppa and afternoon tea. Everyone was still buzzing with the thrill of finally meeting another TN patient and empathise.

Sera and Sue

Peter and Sear - Thanks for showing me around Townsville. **Irene.**

Correspondence Corner

Annemieke: I use an injection of 1 mg hydroxycobalamin (Neo B12) about every 4 weeks since late 2007. I've had TN since 2002. It became unbearable in 2007. I believe the B12 has been extremely helpful - far more than Tegretol (which I hated) and acupuncture. Since getting the B12, I can cope with my TN. I don't take anything else for TN but I am on amitriptyline 25 mg nocte for other neuropathic pain. B12 has been a godsend. Thank you.

Joan C: Irene and the Association have been a great help to me as I had TN for at least 25 years, and have been more or less pain free for the past 4 years except for the occasional strong 'twinge'. I have B12 injections every three months plus B12 tablets (2) each day. Also, Tegretol 100mg twice a day. These seem to be working for me. Thank you for the very informative Newsletters.

Joan T: I want to let you know how helpful the newsletters are. I would like to be attend some of your meetings but is too difficult for me to get to Toongabbie, so I rely on the newsletters. I would also like to tell you that I had an MVD last year, and so far it is successful except for numbness on the side of my face.

Beryl O : we had both attended the 2009 National Conference at the Yarra Valley Conference Centre. We were both so impressed with the quality of the organisation that went into running that event, the very high standard of the specialist speakers and the general program, quite apart from a great venue and their excellent service and meals.

Both of us (from our own experiences) are very conscious of the huge amount of work that goes into organising such Conferences and the funding necessary to support these projects, including the need to subsidise attendance costs - particularly for those with major travel expenses. We appreciate the need for a flow of donations to make it all happen!

We are, therefore, pleased to attach a cheque for \$500.00 as our donation and ask that this be channelled specifically to the funding pool for the next National Conference. Our very best wishes to you and the organising committee and may this upcoming event be as stimulating, informative and enjoyable as that we attended last year. *Your kind gift is much appreciated.*

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Two Irishmen making a letter bomb

Paddy- Do you think I've put enough explosives in?

Mick- Dunno open it and see.

Paddy- But it will explode.

Mick - Don't be daft Paddy its not addressed to you.

Answer to Riddles:

1. Though not a plant, Has leaves. Though not a beast, Has spine.
Though many wouldn't need this thing 'Tis more valuable than wine.
What is it? **A book**
2. Around the corner there is a tree. Under the tree there is a school. In the school there is a desk.
Behind the desk there is a bell. Behind the desk is a teacher.
What is her name? **Isabelle**
3. What has a foot on each side and one in the middle? - **A yard**

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 6254 6640
NSW	Sydney	4 September 1:30pm – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Kim Koh ☎ 02 97431279
	Sydney CBD	7 August 10:00am –12:30 pm	St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413 363 143
QLD	Brisbane	10 July 1.30-4.00pm	30 Ridley Road BRIDGEMAN DOWN	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	17 July 1:00 pm	Kawana Library, Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	21 August 1.00 – 4:00pm	Carville Senior's Villa 35 – 37 Diprose St PIMLICO	Sera Ansell ☎ 07 47516415
S.A	Adelaide	25 th July 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	14 August 12:30 – 2:30 pm	Glenorchy Library Enter via Barry and Cadell Streets	Helen Tyzack ☎ 08 6245 0429 Ros Wilkinson ☎ 08 6234 7989
VIC	Melbourne	7 August 1:30pm – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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