



# Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

## Making A Difference

- 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.

## JUNE 2012

*As geese flap their wings, they create an uplift for the bird following. By flying in a V formation, the whole flock adds 71% greater flying range than if any bird were to fly alone.*

*If we share a common direction and a sense of community, we can get where we are going more quickly and easily because we are traveling on the thrust of one another!*

*The geese in formation honk from behind to encourage those up front to keep up their speed.*

*If we "honk," we need to make sure it is positive and encouraging. ~ John Murphy - 'Pulling Together'*

### TNA Australia Annual General Meeting – 2<sup>nd</sup> June 2012

We hope to have a good turn up for our Annual General Meeting which is held at St James Parish Hall from 10AM. We are legally required to hold an AGM. The business of the A.G.M. includes:

- receiving a report from the President on activities over the year
- receiving a report from the Treasurer on the finances of the Association for the year
- electing a Committee /Board members
- considering any other matter arising.

On this occasion we will also be drawing the 5<sup>th</sup> National Conference Raffles. This fund raising effort was proudly supported by:

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North Richmond NSW;  
Castle Hill NSW; Richmond NSW

We wish to acknowledge their generous support.

Thank you to those who stepped forward & helped in selling the raffles – 40 of us in total; while others contributed with a donation – thank you too. If only 20 more individuals had joined in the effort we would have achieved the desired target.

*"Individual commitment to a group effort - that is what makes a team work, a company work, a society work, a civilization work." ~ Vince Lombardi.*

The kind of person we are can be reflected by the friends we have. I was most impressed by the support of Mary and Steven's families & friends who came to support our cause at the Movie & Supper Night. They filled the whole cinema except for 7 seats - (Dr Helen Boocock, Peter and his wife, Lauren and 2 friends and myself.) Then the next day all her friends rang to say that they would definitely attend another; so Mary is planning another one for next year.

*"You don't choose a life, Dad...you live one." From the movie, "The Way"*

----- Irene -----

## Carbamazepine-induced toxic effects and HLA-B\*1502 screening in Taiwan.

Chen P, Lin JJ, Lu CS, Ong CT, Hsieh PF, Yang CC, Tai CT, Wu SL, Lu CH, Hsu YC, Yu HY, Ro LS, Lu CT, Chu CC, Tsai JJ, Su YH, Lan SH, Sung SF, Lin SY, Chuang HP, Huang LC, Chen YJ, Tsai PJ, Liao HT, Lin YH, Chen CH, Chung WH, Hung SI, Wu JY, Chang CF, Chen L, Chen YT, Shen CY; Taiwan SJS Consortium.

### Collaborators (105)

Su JJ, Lee MJ, Yen DJ, Liao KK, Hong CJ, Chen C, Su MS, Chuang CP, Chen CM, Lin KP, Lin JC, Chang CA, Yuan RY, Hu CJ, Yu CM, Shen JJ, Kuo YT, Sung JY, Lai TC, Wang KC, Wang CJ, Wang HC, Yeh JH, Hsu WC, Huang KL, Chiang TR, Chung WH, Chang YJ, Hsu WC, Lin KL, Wu YL, Huang CR, Chen YC, Chien HU, Wu TC, Sung CY, Lee YY, Hsieh MJ, Huang KL, His MS, Lee TH, Lyu RK, Yeh TH, Chuang WL, Chen CC, Huang CC, Chang HS, Wu YR, Lai SC, Chu NS, Kuo HC, Huang YZ, Weng YH, Ruy SJ, Fung HC, Chen RS, Chen ST, Chang TY, Hsieh HY, Tsai YT, Cheng MY, Yip BS, Chou PC, Kuo TM, Tsai PC, Tsai CH, Liu CH, Kuo HT, Chou IC, Yang YW, Hsu YT, Tsai TC, Lin KH, Lin JC, Liu CS, Chang MY, Wu CS, Wang HP, Hung PH, Kao YH, Lee CD, Hsiao MC, Wu CY, Wong TW, Yeh PS, Lin HJ, Ke DR, Cheng TJ, Lin KC, Chang CY, Chou CH, Tseng KY, Khor GT, Hsu CY, Liou CW, Chuang YC, Chang WN, Lai SL, Lin TK, Jen HM, Liu AB, Chen WH, Lin PY, Lee MT, Wei CY.

**Source:** Institute of Biomedical Sciences, Academia Sinica, Taipei, Taiwan.

### Abstract

#### BACKGROUND:

Carbamazepine, an anticonvulsant and a mood-stabilizing drug, is the main cause of the Stevens-Johnson syndrome (SJS) and its related disease, toxic epidermal necrolysis (TEN), in Southeast Asian countries. Carbamazepine-induced SJS-TEN is strongly associated with the HLA-B\*1502 allele. We sought to prevent carbamazepine-induced SJS-TEN by using HLA-B\*1502 screening to prospectively identify subjects at genetic risk for the condition.

#### METHODS:

From 23 hospitals in Taiwan, we recruited 4877 candidate subjects who had not taken carbamazepine. We genotyped DNA purified from the subjects' peripheral blood to determine whether they carried the HLA-B\*1502 allele. Those testing positive for HLA-B\*1502 (7.7% of the total) were advised not to take carbamazepine and were given an alternative medication or advised to continue taking their prestudy medication; those testing negative (92.3%) were advised to take carbamazepine. We interviewed the subjects by telephone once a week for 2 months to monitor them for symptoms. We used the estimated historical incidence of SJS-TEN as a control.

#### RESULTS:

Mild, transient rash developed in 4.3% of subjects; more widespread rash developed in 0.1% of subjects, who were hospitalized. SJS-TEN did not develop in any of the HLA-B\*1502-negative subjects receiving carbamazepine. In contrast, the estimated historical incidence of carbamazepine-induced SJS-TEN (0.23%) would translate into approximately 10 cases among study subjects ( $P < 0.001$ ).

#### CONCLUSIONS:

The identification of subjects carrying the HLA-B\*1502 allele and the avoidance of carbamazepine therapy in these subjects was strongly associated with a decrease in the incidence of carbamazepine-induced SJS-TEN.

(Funded by the National Science Council of Taiwan and the Taiwan Drug Relief Foundation.)

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#### To the Editor:

Chen et al. report that SJS-TEN did not develop in subjects testing negative for HLA-B\*1502 who received carbamazepine. After genotyping HLA-B in 11 patients who had carbamazepine-induced SJS-TEN and who were of southern Han Chinese origin, we observed that 3 of these patients were negative for HLA-B\*1502.

Rather, they carried HLA-B\*1511/1511, 5401/5401, and 4001/4601. Some early studies suggested that Han Chinese persons with carbamazepine-induced SJS–TEN who lived in Taiwan, Hong Kong, or some Southeast Asian countries were almost all HLA-B\*1502 carriers. More recent studies have reported more instances of SJS–TEN among persons who were negative for HLA-B\*1502. Since it has been reported that European and Japanese patients with carbamazepine-induced SJS–TEN were negative for HLA-B\*1502, we suggest that the risk of this disorder is not nil in such patients and that physicians should be vigilant about the possibility of this disorder in patients receiving carbamazepine, regardless of their HLA-B genotype.

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Second Affiliated Hospital of Guangzhou Medical University, Guangzhou, China

<http://www.nejm.org/doi/full/10.1056/NEJMc1105467>

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Pain Pract. 2012 Mar; 12(3):202-8. doi: 10.1111/j.1533-2500.2011.00479.x. Epub 2011 Jun 16.

## **HLA-B\*1502 strongly predicts carbamazepine-induced Stevens-Johnson syndrome and toxic epidermal necrolysis in Thai patients with neuropathic pain.**

Kulkantrakorn K, Tassaneeyakul W, Tiamkao S, Jantararoungtong T, Prabmechai N, Vannaprasaht S, Chumworathayi P, Chen P, Sritipsukho P.

Source: Department of Medicine, Faculty of Medicine, Thammasat University, Thailand.

### **Abstract**

#### **BACKGROUND:**

Carbamazepine (CBZ) is one of the standard pharmacological treatments for neuropathic pain. However, its serious adverse drug reactions include Stevens-Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN). Recently, HLA-B\*1502 allele was implicated as a genetic marker of CBZ-induced SJS/TEN in some Asian epilepsy populations.

#### **METHODS:**

This is a case control study to describe the clinical characteristics of SJS/TEN in Thai patients with neuropathic pain who were treated with CBZ, and to determine the association of HLA-B\*1502 in these patients, comparing with those who exposed to CBZ for at least 6 months without any cutaneous reactions.

#### **RESULTS:**

Thirty-four SJS/TEN patients and 40 control patients were included in this study. Mean age of SJS/TEN patients was 47 years. SJS/TEN was developed in  $10.8 \pm 1.4$  days after initiation of CBZ. HLA-B\*1502 allele was found in 32 of 34 SJS/TEN patients (94.1%) but it was found only in 7 of 40 control patients (17.5%). The association was very strong with an odds ratio of 75.4. Sensitivity and specificity of this HLA-B\*1502 genotype test were 94.1% and 82.5%, respectively, while the positive predictive value and negative predictive value were 1.43% and 99.98%, respectively. Positive and negative likelihood ratios were 5.37 and 0.07, respectively.

#### **CONCLUSIONS:**

HLA-B\*1502 is a strong genetic marker for CBZ-induced SJS/TEN in Thai patients with neuropathic pain. The screening for this marker should be performed prior to initiation of CBZ treatment to assess the risk of this serious side effect.

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## Common risk allele in aromatic antiepileptic-drug induced Stevens-Johnson syndrome and toxic epidermal necrolysis in Han Chinese.

Hung SI, Chung WH, Liu ZS, Chen CH, Hsieh MS, Hui RC, Chu CY, Chen YT.

**Source:** Institute of Biomedical Sciences, Academia Sinica, 128, Academia Road, Section 2, Nankang, Taipei 11529, Taiwan.

### Abstract

#### AIMS:

Compared with other categories of drugs, such as antibiotics and NSAIDs, antiepileptic therapies are associated with a high incidence of Stevens-Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN). We previously reported that carbamazepine (CBZ)-SJS/TEN is strongly associated with the HLA-B\*1502 in Han Chinese, which has been confirmed in other Southeast Asian countries where the allele is prevalent. Here, we extend the study of HLA susceptibility to three different antiepileptic drugs, phenytoin (PHT), lamotrigine (LTG) and oxcarbazepine (OXC), which have structure similarity to CBZ.

#### MATERIALS & METHODS:

We carried out a case-control association study. We enrolled 26 PHT-, six LTG- and three OXC-induced SJS/TEN patients, 113 PHT-tolerant and 67 LTG-tolerant subjects who were on the drug, respectively, for more than 3 months without the adverse reactions, and 93 normal subjects from the general population. The HLA-A, B, C and DRB1 genotypes were determined.

#### RESULTS:

We found that HLA-B\*1502 was present in eight out of 26 (30.8%) PHT-SJS/TEN (OR: 5.1; 95% CI: 1.8-15.1;  $p = 0.0041$ ), two out of six (33%) LTG-SJS (odds ratio [OR]: 5.1; 95% CI: 0.8-33.8;  $p = 0.1266$ ) and three out of three (100%) OXC-SJS (OR: 80.7; 95% CI: 3.8-1714.4;  $p = 8.4 \times 10^{-4}$ ) patients. In addition, HLA-B\*1301, Cw\*0801 and DRB1\*1602 also showed an association with PHT-SJS/TEN ( $p = 0.0128-0.0281$ ; OR: 3.0-4.3).

#### CONCLUSION:

Our results indicate that OXC, PHT and LTG, which possess an aromatic ring just as CBZ does, when causing SJS/TEN, share a common risk allele. Aromatic antiepileptic drugs causing SJS/TEN in HLA-B\*1502 carriers may act on a similar pathogenetic mechanism, although other genetic/nongenetic factor(s) may also contribute to the pathomechanism of the disease. We suggest that aromatic antiepileptic drugs, including CBZ, OXC and PHT, should be avoided in the B\*1502 carrier and caution should also be exercised for LTG.

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**Decoded:** According to the authors above folks with Chinese ancestry and carrying the HLA-B\*1502 allele is likely to develop Stevens-Johnson Syndrome (SJS) or toxic epidermal necrolysis (TEN) from Carbamazepine (Tegretol), Phenytoin (Dilantin), Oxcarbazepine (trileptal) and Lamotrigine (Lamictal). They suggest that patients should be screened for this marker before starting on such medications to avoid serious side effects such as SJS and TEN

Wei-Ping Liao, M.D., Ph.D. from Guangzhou Medical University, Guangzhou, China disputed that Japanese and European patients who had also developed SJS/TEN but do not have the HLA B\*1502 allele; and physicians should remain vigilant for such adverse side effects.

*I was beginning to think that anyone who developed or develops SJS –TEN from Carbamazepine must have some Chinese “blood” in them. ☺*



## Non-CNS Side Effects of Antiepileptic Drugs (Medscape Neurology)

**Stevens-Johnson Syndrome.** SJS is a serious immune reaction associated with drug exposure (in 50% of cases), viral infections, and malignancies but it often occurs without a known precipitating cause. Unlike hypersensitivity syndrome, SJS produces mucosal lesions, usually multiple blisters (Figures 2 and 3). SJS is distinguished from TEN in that there is detachment of less than 10% of the body surface.

SJS usually occurs 1 to 3 weeks after a drug is initiated. Often preceded by a prodrome of fever, sore throat, chills, and malaise, the rash usually consists of small blisters on purpuric macules, producing target lesions. These lesions may become bullous, then rupture and become infected. Corneal scarring is a common

complication of SJS. Mucosa in the respiratory and gastrointestinal tracts may also be involved.

**Figure 2.** A more severe, nearly confluent, morbilliform skin eruption with bullae. The patient did not have fever or organ involvement but did have minor mucosal bullae, which are features of Stevens-Johnson syndrome (erythema multiforme major). (Courtesy of Ira Skolnik, MD, Department of Dermatology, Johns Hopkins University.)



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**Toxic Epidermal Necrolysis.** TEN is a severe rash characterized by major skin exfoliation (sheets of peeling skin) usually involving over 30% of the body surface area (Figure 4). TEN is triggered by a drug exposure in more than 80% of cases and is fatal in 30% of patients.<sup>[9,10]</sup> The rash usually appears 1 to 3 weeks after a drug is initiated. Individual skin lesions are similar to those of SJS, and TEN can progress from SJS; however, unlike SJS, TEN causes shedding of the outer layer of epidermis. The treatment for TEN is similar to burn therapy.



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Recently I was alerted to Lyrica causing muscle pain and weakness and injury. It then dawned on me that members have complained of overwhelming fatigue and even developed Myasthenia Gravis. So I wondered ...

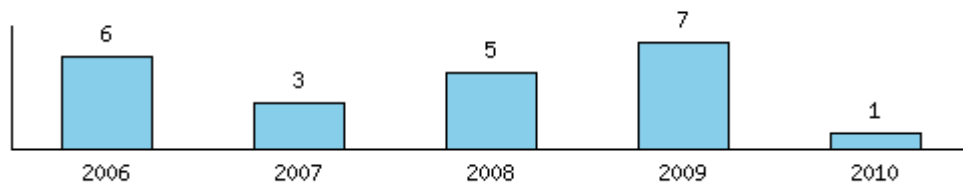
## Could Lyrica (or similar TN medications) cause Myasthenia gravis?

<http://www.ehealthme.com/ds/lyrica/myasthenia+gravis>

This is a [post-marketing study of Myasthenia gravis among people who take Lyrica](#). The study is created by eHealthMe based on 22 reports from FDA and user community.

On May, 20, 2012: 34,830 people reported to have side effects when taking Lyrica. Among them, 22 people (0.06%) have Myasthenia Gravis.

Trend of "Myasthenia gravis in Lyrica" reports



Time on Lyrica when people have Myasthenia gravis \* :

	< 1 month	1 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10+ years
Myasthenia gravis	100.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%

Gender of people who have Myasthenia gravis when taking Lyrica \* :

	Female	Male
Myasthenia gravis	54.55%	45.45%

Age of people who have Myasthenia gravis when taking Lyrica \* :

	0-1	2-9	10-19	20-29	30-39	40-49	50-59	60+
Myasthenia gravis	0.00%	0.00%	8.33%	0.00%	0.00%	8.33%	16.67%	66.67%

Their study of 1,627 people who have Trigeminal neuralgia did not find any Myasthenia gravis. However the study is created by eHealthMe based on reports from FDA and user community.

## pregabalin, Lyrica (cont...)

Pharmacy Author:  
Omudhome Ogbru, PharmD

Medical and Pharmacy Editor:  
Jay W. Marks, MD

**SIDE EFFECTS:** The most common side effects of pregabalin are dizziness, drowsiness, dry mouth, edema (accumulation of fluid), blurred vision, weight gain, and difficulty concentrating.

Other side effects include **reduced blood platelet counts**, and increased **blood creatinine kinase levels**.

Increased creatinine kinase can be a sign of muscle injury, and in clinical trials three patients experienced rhabdomyolysis (severe muscle injury). Therefore, patients should report unexplained muscle pain, tenderness or weakness to their doctors, especially if associated with fever and malaise (reduced well-being). Pregabalin has rarely been associated with angioedema (swelling of the face, tongue, lips, and gums, throat and larynx).

Antiepileptic medications have been associated with increased risk of suicidal thinking and behavior. Anyone considering the use of antiepileptic drugs must balance this risk of suicide with the clinical need. Patients who are started on therapy should be closely observed for clinical worsening, suicidal thoughts, or unusual changes in behavior.

## Could Gabapentin cause Myasthenia gravis ?

This is a [post-marketing study of Myasthenia gravis among people who take Gabapentin](#). The study is created by eHealthMe based on 8 reports from FDA and user community.

On May, 27, 2012: 21,533 people reported to have side effects when taking Gabapentin. Among them, 8 people (0.04%) have Myasthenia Gravis.

[Muscle Nerve](#). 2000 Aug;23(8):1204-8.

## Gabapentin may be hazardous in myasthenia gravis.

[Boneva N](#), [Brenner T](#), [Argov Z](#).

**Source** - Department of Neurology, Hadassah University Hospital, Jerusalem Israel.

### Abstract

A patient with painful neuropathy developed ocular, facial, and masticatory weakness and fatigue after 3 months of gabapentin (GBP) treatment (400 mg/day). An elevated level of serum acetylcholine receptor antibodies (AChR-Ab) was detected. The patient recovered following pyridostigmine therapy and withdrawal of GBP and, 2 years later, is practically asymptomatic despite positive AChR-Ab. Because of this clinical observation, we gave 150 mg/kg GBP to rats with experimental autoimmune myasthenia gravis (EAMG). Repetitive nerve stimulation at 3-Hz was performed, and the 5th/1st amplitude ratio was used to calculate the decremental response. In all EAMG rats, GBP induced a transient, abnormal decrement (7-20%) 90 to 240 min after administration. No decrement was induced by GBP in normal rats. Thus, GBP aggravates the decrement in EAMG. The mechanism involved in the hitherto unreported possible unmasking of myasthenia gravis (MG) by GBP is unknown. Gabapentin should be used with caution in this disease.

Copyright 2000 John Wiley & Sons, Inc.

## Gabapentin-induced exacerbation of myasthenia gravis - Volney L. Sheen MD, PhD<sup>1</sup>,

Article first published online: 25 JUN 2010

DOI: 10.1002/mus.21708

Issue **Muscle & Nerve**





## SUPPORT GROUP MEETING REPORTS

### Sydney Support Group

Toongabbie School

5<sup>th</sup> May 2012

**Attendance:** Kim K, Marion A, Frank M, Ann & Laurie P, Elizabeth and Lloyd T, Cecelia C, Angela R, Doug M, Stewart B, Gundal B, Kim S, Irene W, Val & Tony W, Peter & Rose H, Jeannette B and Henry Jr.

**Apologies:** Marj and Ken F, Jocelyn S

We welcomed 2 new members today. Angela lives locally and Val and Tony are visiting from the Gold Coast. Before hearing from Angela and Val, we gave everyone the opportunity to update us on their current progress.

**Anne** is going fine

**Doug** went to the Conference in Adelaide and found it very informative. He is seeing Dr Aggarwal about changing his medications and is also having a needle in his spine to relax him. He has had TN for 12 years, multiple procedures including MVD, balloon compressions and 2 motor cortex stimulators. He has had a stroke and now suffers from Anaesthesia Dolorosa

Doug encourages everyone to stay positive and well educated. At meetings, listen carefully, be encouraged and most importantly everyone is different.

**Jeanette** is still free of TN pain but is suffering from a bad back.

We missed Henry who always looks after our front desk and raffles. He cut his foot with the lawn mower.

Jeannette and Henry's son came to look after the desk. Thank you very much for your help.

Jeanette updated us on some of the members she is contacting by letter and phone.

- Neville from Coffs Harbour attended the conference at the Hunter Valley and takes Tegretol SR.
- Shirley M had a recent agonising attack and now knows why TN is called "The worst pain known to man."
- Marjorie from the Gold Coast has suffered from right side pain with an MVD in 1989. She had no problems until 1996 when she started getting left side pain. She has had another procedure.

It was lovely to see Lloyd and Elizabeth, who have absent due to health difficulties.

**Elizabeth** has been coping with Lloyd! She is also having problems with glaucoma in the eye as well as her TN pain. She is finding visits to an osteopath very helpful. She is taking Epilim for TN.

**Stewart** had some severe pain after some physical movement 4-5 days ago.

**Peter** has Post Herpetic Neuralgia from shingles. He has a nerve stimulator above and below the eye. The pain has worsened from a recent haircut.

It was also lovely to see Cecelia who is going very well since her MVD in June 2010. She has no pain.

**Marion** has also had no pain since her MVD in 2008.

**Kim K** is on 800mg Tegretol per day. Her pain returned 15 months after her MVD. She now has burning pain. She had acupuncture for 2 months and is now pain free. Her next goal is to slowly try reducing the medication.

**Kim S** pain returned in March after a second MVD in June 2010. The pain has been controlled with a low dose of 200mg Tegretol per day. A clear MRI means Dr Dexter is confident this is just a short lived flare up related to some recent illness.

We then heard from our **new members**.

**Val** started getting pain in October 2011. She first tried Tegretol and is now taking Lyrica. She has also tried acupuncture and takes B12. Her doctor also suggested Panadol Osteo, which reduces the pain by about 10%. Her pain is worse with cold weather, vibrations in the car, wind and cleaning her teeth. The pain feels like a red hot poker up her nose or a sharp knife. She also has some numbness in her gums. The face feels like it is



burning, prickling like all the hairs are standing on end. When pain is stabbing she may have 5 stabs in 30 seconds once an hour. She also mentioned the scans have shown she has two small aneurysms. She will try to seek an appointment while she is in Sydney.

*Update on Val: Since our meeting she has been able to get an appointment with Dr Dexter and had her MVD on the 23<sup>rd</sup> of May. Tony wrote to say Val is very sleepy but "alright". We wish her a complete recovery and no more pain.*

**Angela's** pain started like a toothache which increased to a migraine. She also mentioned pain within the ear. She tried medication and heat packs before seeing her dentist. While still in the dentist she had a major attack with shooting and stabbing pain. She also feels an ache in the shoulder area. She was admitted to hospital and treated for a migraine but diagnosed with TN and referred to a neurologist. Her GP started her on Tegretol (400mg SR 1 per day) while waiting for the appointment. Her pain improved within a week. As she was not coping with the side effects of being drowsy and forgetful she wanted to reduce the medication but unfortunately halved the dose in one go, resulting in full blown attacks within 4 days. After going back on a full dose the pain subsided. Her pain is right side lower jaw and teeth.

It is important that you are very clear with the description of the pain, how it starts, position of the pain and what the triggers are, as this is the only way to diagnose TN or other facial pain. It is a good idea to write this all down before going to the appointment.

**Douglas M** gave a presentation on his work as a Biomedical Engineer.

He wants the main message to be that we have some hope for the future. There are many innovations being made in medical fields and hopefully something may be there for sufferers of TN.

Any inventions made in the medical field are shared around the world so that everyone can benefit from them.

Doug showed us some masks he was involved with, which help children going through radio surgery. By painting the masks according to the children's individual interests, the children are more relaxed about the treatment and they have been able to reduce the need for general anaesthetic for children as young as 3. Not requiring anaesthesia has many benefits for the children and their parents. The masks bring a bit of fun and light into the children's lives at a very difficult time.

Doug showed us photos of many other inventions which help with treatment for breast cancer, prostate cancer and braces for brain surgery.

Irene told us that we are no longer receiving Government Grant which was helping to run our Conferences. We now need to find a way to raise an extra \$5000 each year. We have a raffle of 500 tickets at \$10 each which will be drawn at the AGM in June. Good luck everyone and thank you for your support.

We enjoyed a lovely afternoon tea and the opportunity to talk to each other and share our experiences. We hope everyone stays well as the weather starts to cool down.

Kim K and Kim S

**Margaret Spicer** is a Bowen Therapist, Bowen Instructor and also a naturopath will give the talk at our July meeting. We hope as many of you will come and hear and learn from Margaret.

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**NOTICE: Melbourne Support Group moving in August**

The June meeting of the Melbourne Support Group will be the last meeting we have in the Ringwood Room at Ringwood Public Library. The Library is being re-located for demolition of that building and we have been offered for the remaining three meetings of this year, a meeting room, address as follows:

**Maroondah Federation Estate,  
32 Greenwood Ave.,  
Ringwood. 3134  
~Evelyn**

# SUNSHINE COAST SUPPORT GROUP

Kawana Library, Nanyima Street, Buddina.

Saturday 19<sup>th</sup> May 12

**Present:** Jean W, Amanda W, Dorrie H, Jean B, Jill L, Barry F, Max H, Peter & Pearl R.

**Apologies:** Sherryl M, Ellen B, June H, Josef A

**New Members:** Joanne & Geoff B, & Dorothy G. Welcome everybody.

## Phone reports:

Val W rang from the Gold Coast. The medication she was taking at the time is Lyrica 2/75mg, Endep 1 per night. At the time of the phone call Val was having problems with a numb lip, her lower eye lashes and top of the lip is extremely painful. Wind and air conditioning are some of her triggers. I wished Val all the very best and hope that if she is up on the Sunshine Coast to pop in and see us. Val rang later on and said that she had an appointment with Dr. Dexter to get his opinion.

Ellen B gave me a ring to say that June had been operated on at Brisbane Private Hospital. Jean followed with a phone call to the hospital and had found that she had been discharged. Jean had missed her by ½ hour.

## General business:

- Jean had asked the group if anyone lived in the Maroochydore, Coolum and Northshore area to keep an eye out for the local paper. Please advise her of their email address for local events, as their email address has since changed. Max will get the Coolum information to Jean.
- **Positions that need filling.**
  - Advertising-** Teresa M will help with that position.
  - Beverage Superintendent-** Pearl has stepped forward to help when Trixie needs assistance.
  - Door Greeter-** Still not filled.
  - Sign Supervisor-** Still not filled.

Jean reminded everybody that she does work 5-6 days a week as a floor sander. "It isn't light work". Burning the candle at both ends will end up with a burnt out lump of wax, no good for anything.

- Raffle tickets for sale. If anyone can take a book to try and sell the tickets to your family and friends, it would be appreciated. Although the tickets are \$10.00 each there is only 500 tickets printed so the odds are pretty good. Proceeds help in running the next conference that is being held on the Gold Coast. 1<sup>st</sup> prize is: Three nights accommodation at Sea World Nara Resort for 2 adults with 1 breakfast supplied for one morning. Travel isn't included in the prize. Good luck to everybody that purchased a ticket.

## Reports:

**Peter:** he reports that he went to Sydney at the end of December and had a second MVD on the right side, which ended in a slight heart attack. Peter is on the mend now and is looking amazing. Stay well Peter.

**Dorothy:** Recently diagnosed with TN (left side). Another doctor has diagnosed her with Atypical TN. She took Tegretol & found that it made her sick. She is now taking Dilantin.

**Max:** Was on Tegretol for a long time but recently a rash developed. He has tried Lyrica and Endep. Taking no medication at present, his pain is only minor at the moment. Sometimes it takes many trials, before we find a solution to the problem of TN. It's not a one-week only, turn around solution. There is a need to be pro-active to try and stay in control of your own destiny.

**Jean B:** Can't get rid of the pain around her mouth. Taking Gabapentin 600X3 and 1 Endep before she goes to bed as it helps her sleep. It would be best to get another opinion from another doctor to see what else can be done.

**Jill L:** Jan/Feb her condition got unbearable. Her doctor wasn't very helpful. Jill was able to get an appointment to see Dr. Dexter in Sydney. After meeting with him, his response was, he'd be able to do it

straight away. Jill was in hospital for a week. During the operation there was 1 artery and 2 veins touching the nerve. Jill is now able to sleep on the left side again.

**Barry:** Still on 200mg of Tegretol at night. Considering taking another 200 because the pain is still there. After he took Lyrica, Endep etc. he found that he got aggressive so he went back to Tegretol slow release. He isn't ready to have a MVD.

**Dorrie:** Has had TN for about 2 years now. She was taking Lyrica, now on Tegretol and Gabapentin. Dorrie didn't have any facial pain when she went on the flight to Canada. Going again this year. She is fine as long as she takes her tablets.

**Amanda:** Her pain is always there. Taking Gabapentin 900mg & Tegretol 600 and 900 mg. at present. It has been 17 months since finding out she had a problem. Amanda uses a distracting tool to try and occupy her when the pain comes. Her history is, she had an accident and her brain was swollen. Her world turned upside down. Between her and her husband they have had quite a few operations. Jean reminded the group of the face/book site that Lauren Smith has set up. Amanda felt that sort of forum wasn't for her.

**Joanne:** About June last year she went to her doctor and it was thought that maybe it was a sinus condition. When that was treated and still no change, the doctor changed the diagnosis to TN. Joanne had an MRI and it showed that there was a blood vessel pressing on the Trigeminal nerve. Taking Tegretol 300X2, may need to take more. It may be worth asking if she could get in slow release so the medication is in her system longer and on an even keel. Joanne seems to think that she has the condition in all 3 nerves, eye/nose/teeth, on her left side. She may try acupuncture as her next plan of attack.

Keeping a pain diary is considered a benefit. By writing things down you can see if there are certain triggers that exacerbate the condition. Also sometimes writing things down help in the management of the pain and may give your family a bit of a break. Some of the group agreed with this option but others found that thinking about it made the condition worse.

**Next meeting: Saturday 21st July, 1pm.**

Close of meeting followed by afternoon tea. Sorry about not having any teaspoons but we an industrious lot and we made do. The spread looked and tasted fantastic. Thanks for all the effort everybody and appreciations to Pearl for taking report. Special thanks to Jean B although she is in great pain she is always there to help set up the room and help with putting everything back in it's place.

Stay pain free everybody.

Jean W.

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**Some Thoughts:** from Hilary. Thanks for sharing.

- **After eating** – soften 1 pellet of sugar free chewing gum under tongue, then roll it around mouth & teeth. This removes “left overs”. Spit out before cleaning teeth with super soft brush using Neutrafleur 500 Pharmacy only toothpaste. Try not to eat or drink for ½ hour. Then put fresh pallet of sugar free chewing gum under tongue to increase saliva flow.
- **Dry Eye** - Apply Optive (or similar ) at least 3 times daily. Buy product specifically for **dry eye** and choose brand which has a life of **6 months after opening**.
- **For Burning Pain** - Apply a little “**ICE GEL** “ Menthol content will cool burning feeling. Avoid contact with eyes. (*Ice gel is very good for badminton injuries too! & all the “...itis” injury*).  
*We have been advocating peppermint oil for the same purpose / result, except Ice Gel is cheaper. However, I have no idea in terms of how long the cooling effect of Ice gel would last in neuropathic pain – Irene.*

## LAUGHTER IS THE BEST MEDICINE

### Things you would never know without the movies

- 1) During all police investigations, it will be necessary to visit a strip club at least once.
- 2) When they are alone, all foreigners prefer to speak English to each other.
- 3) If being chased through town, you can usually take cover in a passing St. Patrick's Day parade - at any time of year.
- 4) All beds have special L-shaped cover sheets which reach up to the armpit level on a woman but only to the waist level on the man lying beside her.
- 5) The Chief of Police will almost always suspend his star detective -- or give him 48 hours to finish the job.
- 6) All grocery bags contain at least one stick of French Bread.
- 7) It's easy for anyone to land a plane providing there is someone to talk you down.
- 8) The ventilation system of any building is the perfect hiding place -- no one will ever think of looking for you in there and you can travel to any other part of the building undetected.
- 10) The Eiffel Tower can be seen from any window in Paris.
- 11) All bombs are fitted with electronic timing devices with large red readouts so you know exactly when they are going to go off.
- 12) If you need to reload your gun, you will always have more ammunition, even if you haven't been carrying any before now.
- 13) You are very likely to survive any battle in any war unless you make the mistake of showing someone a picture of your sweetheart back home.
- 14) Should you wish to pass yourself off as a German officer, it will not be necessary to speak the language -- a German accent will do.
- 15) If your town is threatened by an imminent natural disaster or killer beast, the mayor's first concern will be the tourist trade or his/her forthcoming art exhibition.
- 16) A man will show no pain while taking the most ferocious beating but will wince when a woman tries to clean his wounds.
- 17) When paying for a taxi, don't look at your wallet as you take out a bill -- just grab one at random and hand it over. It will always be the exact fare.
- 18) Kitchens don't have light switches. When entering a kitchen at night, you should open the fridge door and use that light instead.
- 19) If staying in a haunted house, women should investigate any strange noises in their most revealing underwear.
- 20) Mothers routinely cook eggs, bacon and waffles for their family every morning even though their husband and children never have time to eat it.





## 2012 Meeting Dates

<u>State</u>	<u>Group</u>	<u>Date &amp; Time</u>	<u>Venue</u>	<u>Group Leader/s</u>
ACT	Canberra	TBA	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 6254 6640
NSW	Sydney	7 <sup>th</sup> July 1:30 – 4:00 pm	<b>Toongabbie Public School</b> Cnr Fitzwilliam & Binalong Rds Guest Speaker:	Kim Koh ☎ 02 97431279 Kim Smith
	Sydney CBD	4 <sup>th</sup> August 10am 12:30pm	<b>St. James Parish Hall,</b> Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413 363 143
QLD	Brisbane	9 <sup>th</sup> June 1.30 -4.00pm	30 Ridley Road <b>BRIDGEMAN DOWN</b> Guest Speaker: Naturopath	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	21 <sup>st</sup> July 1:00 PM	<b>Kawana Library,</b> Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	30 <sup>th</sup> June 1.00 – 4:00pm	<b>Carville Senior's Villa</b> 35 – 37 Diprose St <b>PIMLICO</b>	Sue Macey; Sera Ansell ☎ 07 47516415
S.A	Adelaide	29 <sup>th</sup> July 2:00 – 4:00 pm	<b>Burnside Town Hall</b> <b>Civic Centre</b> Cnr Portrush/Greenhill Rd	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	TBA 2:00 – 4:00 pm	<b>Glenorchy Library</b> Enter via <b>Barry and Cadell</b> <b>Streets</b>	Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989
VIC	Melbourne	9 <sup>th</sup> June 1.30 – 4:00pm	<b>"Ringwood Room"</b> <b>Ringwood Library,</b> <b>RINGWOOD</b>	Evelyn Diradji ☎ 03 9802 6034

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