



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.

JULY 2012

“Nothing great is ever achieved without much enduring.” ~ St. Catherine of Siena

“With ordinary talent and extraordinary perseverance, all things are attainable”~ Thomas Fowell Buxton

A couple of support group leaders have expressed their wish to step down from their current duties come the end of the year. We are in the process of seeking suitable replacements. While we have a set of criteria for support group leaders, we also depend on individuals to express their willingness in taking on the onus. It need not be a sole custodian role; we can have co-host and hence share the responsibilities. However, if no one is willing to assist I am afraid we will just have to suspend the group. If you believe your support group is worth having, and that the support within the group is essential to TN sufferers, then please step forward or have a chat with your current SGL to see what this role entails; then contact me – Irene.

Results of TNA Conference Raffle - Drawn 2 June 2012

Congratulations to all the winners. We trust you have by now received your prize.

To all who sold or bought the raffles - “THANK YOU”. We raised a total of \$3280. (\$1720 short of the target)

| | Ticket No | Winner |
|---|----------------|---------------------|
| 1 st Prize 3 nights at Sea World Gold Coast | 12141 | R & A Beresford QLD |
| 2 nd Prize Rock Bass Guitar | 12089 | V & T Willott QLD |
| Consolation Prizes Coles \$25 Voucher | 12301 | G Gleesen QLD |
| | 12348 | R Stewart NSW |
| | 12081 | A Martin NSW |
| | 12267 | M Zaccaria VIC |
| | 12031 | R Cooper NSW |
| | 12086 | P & L Daniels QLD |
| | 12288 | Liz Savage VIC |
| | 12229 | P Woolcock ACT |
| | 12282 | S Savage VIC |
| 12355 | J Grainger NSW | |

All money raised will be used to subsidise your conference fees. We aim to raise more funds early next year so as to be able to offer you an affordable package to our 5th national conference in 2013. A similar raffle will be run early next year with the 1st prize being 3 nights of accommodation at the SeaWorld Resort during our conference. It could mean free accommodation for a TNA member and partner whilst attending the conference. ☺

“A large oak tree is just a little nut that refused to give up.” ~ David McGee

~ Irene ~

Lacosamide Good in Trigeminal Neuralgia

By Ed Susman, Contributing Writer, MedPage Today

Published: April 30, 2012

Action Points

- Note that this study was published as an abstract and presented at a conference. These data and conclusions should be considered to be preliminary until published in a peer-reviewed journal.
 - In this very small, retrospective chart review, lacosamide, which selectively enhances slow inactivation of voltage-dependent sodium channels, was associated with some response in most patients with refractory trigeminal neuralgia.
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NEW ORLEANS – The anti-epileptic agent lacosamide (Vimpat) appears to give relief to patients with refractory trigeminal neuralgia, researchers reported here.

Principal investigator Jeffrey Cohen, MD, an attending neurologist at Beth Israel Medical Center in New York City, looked at the drug in a pilot study of 11 patients – some of whom had failed to get relief even after surgical procedures.

Cohen, a member of the medical board of TNA--The Facial Pain Association, and neurology resident Shivang Joshi, MD, lead author, found that several patients achieved relief for more than a year with lacosamide and one achieved complete resolution of pain.

For seven of the 11 patients they had results from a Barrow Neurological Institute Pain scale, and five of those seven patients achieved some degree of pain relief, they reported in a poster presentation at the American Academy of Neurology meeting.

"Some of our patients had been in pain from trigeminal neuralgia for as long as 22 years, Joshi told *MedPage Today*."

"In this small case series of patients with refractory trigeminal neuralgia, a majority of the patients responded at least initially, despite multiple previous medication trials and surgical procedures in some, he said."

In addition to surgical treatments that still did not relieve pain, the patients had been treated with a variety of drugs: anesthetics, anti-epileptics, opioids, nonsteroidal anti-inflammatory drugs, triptans, tricyclic antidepressants, and other medications. "These were truly refractory patients," Joshi said.

The dosage of lacosamide was not standard, but averaged around 200 mg a day.

Four of the patients were able to take lacosamide as an add-on therapy without experiencing further adverse effects; five other patients complained of dizziness; one patient reported fatigue and the other patient complained of constipation.

Image studies were performed in 10 patients, and these were negative in eight; two patients were observed to have meningiomas that could have caused the trigeminal nerve pain.

One 25-year-old man with right side trigeminal neuralgia did not receive any relief from treatment with lacosamide. An 80-year-old man and a 77-year-old man said that the treatment provided pain relief for two months; a 47-year-old woman reported 9 months of pain relief, and an 88-year-old woman reported 11 months of pain relief. The other six patients reported they have had relief of pain from 2 months to 12 months, and that relief is ongoing.

The median age of the patients in the study was 63; the mean duration of neuralgia was 10 years.

Shirin Issa, MD, assistant professor of neurology at the Montefiore Medical Center in Bronx, N.Y., told *MedPage Today* that lacosamide might be helpful for some of these patients who have no treatment options available. The use of lacosamide is attractive, she suggested, because the side effects are minimal. "We are interested in trying it in our patients," she said.

Cohen and Joshi believe their results deserve to be pursued in a larger study. "Lacosamide was well tolerated and should be considered as a treatment option in chronic trigeminal neuralgia," Joshi said. "The positive results in a small case series such as this justify designing a clinical trial to determine safety and efficacy of lacosamide in trigeminal neuralgia."

The researchers had no disclosures. Shirin had no disclosures.

Primary source: American Academy of Neurology

Source reference: Joshi S and Cohen J, "Lacosamide as adjunctive therapy for refractory trigeminal neuralgia" AAN 2012; Abstract P03.224.

<http://www.medpagetoday.com/MeetingCoverage/AAN/32429>

Successful Treatment of Refractory Postherpetic Neuralgia with Topical Gallium Maltolate: Case Report

1. Lawrence R. Bernstein PhD*

Article first published online: 8 JUN 2012

DOI: 10.1111/j.1526-4637.2012.01404.x Wiley Periodicals, Inc.

Abstract

Introduction. Postherpetic neuralgia is a common sequela of herpes zoster (shingles), in which chronic pain may last for weeks to years. Currently, available treatments include systemic opioid analgesics, tricyclic antidepressants, corticosteroids, and anticonvulsants, as well as topical capsaicin and lidocaine. These treatments are commonly unsatisfactory, with fewer than half of treated patients experiencing more than a 50% reduction in pain.

Case. A 99-year-old woman had a 4-year history of severe postherpetic (trigeminal) neuralgia on the left side of her face. During those 4 years, numerous treatments were tried, including systemic opioid analgesics and anticonvulsants, and topical lidocaine and capsaicin, all with unsatisfactory results. The topical application of gallium maltolate, at a concentration of 0.5% in an emulsion of water and hydrophilic petrolatum, was found to relieve the severe pain within about 10 minutes, with the relief lasting for about 6–8 hours. The patient has been using this treatment for more than 5 years, with no adverse effects and a highly significant improvement in her quality of life.

Discussion. Gallium has significant anti-inflammatory activity, inhibiting the activation and proliferation of pro-inflammatory T cells. Because gallium is chemically similar to zinc, it can interfere with the activity of matrix metalloproteinases (zinc-bearing proteases), which have been implicated in the etiology of neuropathic pain, and it may suppress the secretion of substance P. Gallium may also inhibit viral replication and the inflammatory activity of viral proteins. This case provides rationale to study topical gallium maltolate in patients with refractory peripheral neuropathic pain.

Full Article maybe viewed at <http://onlinelibrary.wiley.com/doi/10.1111/j.1526-4637.2012.01404.x/full>



MINUTES OF ANNUAL GENERAL MEETING

| | |
|---------------------------|---|
| Date | Saturday 2nd June 2012 |
| Location | St James' Parish Hall, Phillip Street, Sydney |
| Time | 10.00am |
| Present | Irene W, Kim K, Jocelyn S ,Peter Huby, Marion A, Ieuen R, Margaret & Allan M, Nola & John W, C. Mahdu |
| Apologies | Frank M, Mary Z, Ingrid K, Kim S. Mary K. |
| Previous Minutes | Read by the Secretary, accepted by Marion A and seconded by Peter H |
| Treasurer's Report | <p>A Statement to Members under Section 47 (2) of the Associations Incorporation Act 2009, the Income & Expenditure Statement, and Assets and Liabilities statement were presented for the year ended 31/12/2011 with total equity of \$78,255.60. This includes funds invested as The Silvia Whitworth Research Fund of \$56,212.41. Accepted by Kim K and seconded by Peter H.</p> <p>The Depreciation Schedule shows a total of \$3,762.25 to 21.12.2011</p> <p>Marion noted that the TNAA 2011 accounts reflect the increased costs for printing & postage of the monthly newsletter which are not being covered by membership fees alone.</p> <p>The accounts have been audited by an independent Accountant in accordance with Australian Auditing Standards for the 2009 & 2010 financial with 2011 audit to be completed in the coming months. All books have been found to be in order. (See Treasurer's Report attachment)</p> |
| President's Report | <p>Irene reiterated that our <i>aim</i> is to provide the information, the support and the encouragement to TN sufferers. Our <i>mission</i> is to advocate for the awareness of TN and related facial pain through information and education to both sufferers and professionals.</p> <p>Our <i>goal</i> is to have a unified understanding of TN and other related facial pain resulting in better pain management.</p> <p>Our <i>vision</i> is to focus on patients and improve their quality of life with assistance to understand there are things they can do to manage the pain better.</p> <p>In 2011 we provided service to 140 NEW enquiries - down from last year's number of 145. We have helped almost 2000 people (not all are current members). We are all unpaid volunteers, and the Association depends on willingness of members to help, and donations for financial support. Due to the increased demand on her time, priority of response is given to subscribed members and new enquiries.</p> <p>Activities: National conference in 2011 in the Hunter Valley. We realized our aim in providing information through education – folks said they learnt a lot and enjoyed networking with other members. Movie night and fund raising was held by Mary Zac in Melbourne and was a great success. The recent regional conference in Adelaide was another activity we completed in meeting our Aim.</p> <p>Support Group Leaders are an important arm of our work and all our Support Group Leaders</p> |

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|-----------------------------|---|
| | <p>are assessed before we entrust the role to those who can retain and disseminate information accurately.</p> <p>Irene thanked the committee members for their assistance in 2011/12 and also the Support Group Leaders and Medical Advisory Board members.</p> |
| Election of Officers | <p>President: Irene Wood Vice President: Kim Koh Secretary: Jocelyn Stafford Treasurer: Marion Abraham Executive Committee: Peter Huby, Mary Zaccaria.</p> <p>All members re-elected unopposed. Frank Martin did not stand. An official acknowledgement was made for Frank's 10 years of serving on the committee and being one of the founding members.</p> |
| Matters Arising | <p>The conference fund-raising raffle was drawn and the 3 nights at Sea World was won by R & A Beresford. There was also a second prize and 10 consolation prizes.</p> <p>No other matters arising</p> |
| Meeting Closed | <p>11.00am - Moved by Irene Seconded by Allan M</p> |

TRIGEMINAL NEURALGIA ASSOCIATION AUSTRALIA INC ABN 33 914 644 101

**STATEMENT TO MEMBERS UNDERS SECTION 47 (2) OF
THE ASSOCIATIONS INCORPORATION ACT 2009**

- (A) Income and expenditure of the Association during it's financial year ended 31-12-2011 is attached. (Annexure 1)
- (B) The assets and liabilities of the Association as at 31-12-11 are listed on the attached balance sheet. (Annexure 2)
- (C) The Association does not own any property and accordingly there are no mortgages, charges or other securities of any description affecting the Association as at 31-12-2011.
- (D) The Association was not trustee of any trust.

NOTES TO MEMBERS - ANNUAL GENERAL MEETING 2-06-2012.

1. TNA 2011 accounts reflect the increased costs for printing & postage of the monthly newsletter are not being covered by membership fees alone. We are reluctant to increase membership fees and have endeavoured to cull the mailing list to current financial members for the 2012 year.

2. Depreciation for the years 2002 – 2011 has been calculated at \$3,762.25. Depreciation rate used is 20% per annum, using the straight line method. Pro-rata calculation is made in year of purchase based on number of days held in that year as per Annexure 3. Future years will be smaller amounts.

3. Accounts have been audited by an independent Accountant in accordance with Australian Auditing Standards for the 2009 & 2010 financial years with 2011 Audit to be completed in the coming months. All books have been found to be in order.

Marion Abraham
Treasurer

SUPPORT GROUP MEETING REPORTS

ADELAIDE SUPPORT GROUP BURNSIDE CIVIC CENTRE, SUNDAY 27th MAY, 2012

PRESENT: Faye D, Roy H, Bert J, Kerryn & Rob E, Kevin S, Ann T, Judy F, Jan B, Kelly & Mark, Graham & Liz B,

APOLOGIES: Sue & David H, Grace A, Garry & Lisa R, Angela M.

FINANCE: Opening Balance \$285.92; Income: Donations: \$38.40 Interest: \$0.21. Conference expenses: \$53.80; Closing Balance: \$270.73.

WELCOME: Graham welcomed all in attendance with a special welcome to Faye and Roy, attending for the first time. Roy and Faye were asked how they heard about our support group. Roy found us through the internet and Faye was referred by her health fund. Graham explained that the group members have no medical expertise, just firsthand experience as TN sufferers. We share our experiences and the success, or otherwise, of medications and treatments undertaken. It gives sufferers the opportunity to talk about their TN with others who really understand what they are going through. Partners and supporters of sufferers are encouraged to participate.

UPDATE: The recent Regional Conference held in Adelaide was very successful. The speakers were excellent and gave attendees a very good appreciation of the latest drugs and treatment options available for treatment of their TN. The feedback has been very positive.

MEMBERS UPDATES:

JAN: Has had to increase her control release medication but is managing. She has breakthrough pain from time to time. Cold, windy weather and washing her face exacerbates her TN. She learned from the Conference that it is OK to add other types of TN medicines rather than continually increasing the one drug. She found Dr. Aggarwal (R.P.A.Pain Clinic) particularly interesting. Jan was unsure as to whom she should go to in Adelaide to help her manage her drug regime. She took notes at the Conference and has given them to her GP. Kerryn informed the group that Dr. Aggarwal has a questionnaire on his web site and will send the address to Graham. Kerryn has offered to approach her Specialist at the Flinders Pain Clinic to see if he will come to one of our meetings to speak.

KERRY: Since her MVD in October Kerry's "zaps" have ceased. She does, however, get bad 'migraine' type headaches on one side of her face, particularly if she gets cold. She has the feeling that "something is trying to get started again". *We hope not!* She is seeing her neurosurgeon in June.

KERRYN: Since her second MVD Kerryn has developed pain at the operation site resulting from scar tissue. She takes Panadol for an aching eye, particularly in the morning. She also experiences numbness in her face.

KEVIN: Going well. He has a constant ache but it is not severe. He doesn't have any zaps. As an outpatient of the RAH Pain Clinic he is able to get Lyrica at a reasonable cost. Unfortunately there is a very long waiting list to get in to the Pain Clinic.

BERT: Going well after his radio frequency procedure. However, earlier in May he sneezed and got two hefty jolts of TN pain. He finds that wind affects him badly so has bought a 'hoody' which helps. He continues to have numbness but has become used to the sensation (or lack of it). He would much rather have numbness than have to rely on medication. He also suffers from dry eyes. Discussion then ensued regarding dry eyes as several members also experienced the same problem - possibly caused by medication? Warm flannels over the eyes help, together with gentle massage under the eye, this activates and stimulates the tear ducts.

ANN: Thought the Conference was brilliant. She is going to a physiotherapist for help with her neck.

FAYE: Her TN began in July 2009 when she thought she had a tooth abscess and visited a dentist. Her initial pain was excruciating. She was unable to clean her teeth or apply make-up. She was sent to different neurologists then hospitalised. She underwent a Glycerol procedure which cured her pain. She was, however, not informed that her TN could return and when it did she again thought it was an abscess and had 8 teeth extracted. Faye has a friend who also has TN and has undergone a successful MVD. At the moment Faye is pain free and does not really understand why it can go away for a while and then return with a vengeance. Faye has experienced severe pain in her tongue and asked if other members had that problem and couldn't talk during an attack. Graham explained the nature of TN and that it tended to have periods of pain free but over time the pain free periods became shorter with an increase in the severity. He also spoke about the benefits of taking vitamin B12 which was thought to help repair the myelin nerve covering and the positive results some members have had while taking B12. Faye has borrowed the book *Insight*.

ROY: Roy's first attack occurred in the mid 1990's. He had a pain above his eye while washing his face. He was living in Brisbane at the time and was quickly diagnosed with TN. He had pain for a couple of years and then it went away for 14 years. His pain returned intermittently in his eye and down to his lips. His pain is worse when washing his face and chewing. He saw Dr. Z who prescribed medication and told if it returns he can have an injection. An MRI ruled out tumours or aneurism and showed a blood vessel on the nerve. He takes medicines for a sleep disorder and is worried about side effects from mixing his drugs. Ray already takes B12.

JUDY: Judy was in considerable pain at the meeting and finding it difficult to communicate. Her pain is in her tongue. Unfortunately she has had to resign from a committee of which she was a member because of her inability to talk during attacks. She has an upcoming appointment with a neurologist. She is taking Neurontin and because of thyroid problems has been told she should not have Tegretol. She was interested in Dr. Aggarwal's comments on taking more than one drug. Dr. Aggarwal suggested at the Conference that 800 mg. Tegretol would be the most he would use and if that doesn't work, add other drugs. Sufferers should not persevere too long with a drug if it is not effectively controlling pain.

Graham said that people should keep a record of the medications they are taking together with the times, amounts and effectiveness. This will help when discussing treatments with their doctors. Bert suggested we compile an information sheet to help people get the most out of visiting their doctor or a specialist.

RAFFLE TICKETS:

Graham informed the group that TNA have recently lost the \$5000.00 Government support which helped TNA to host our National Conferences. Irene has organised a raffle to offset the loss of that income. Details are in the May Newsletter.

POSTER:

Bert would like to borrow the poster SA displayed at last years' Conference. Graham will take it to July's meeting.

MEETING CLOSED AT 3.55pm followed by coffee, cake and friendship.

NEXT MEETING: SUNDAY 29th JULY, 2012 AT 2.00 p.m. At the Civic Centre, Burnside Town Hall Corner of Portrush and Greenhill Roads, next to the Library.

Graham & Liz

MELBOURNE SUPPORT GROUP

RINGWOOD PUBLIC LIBRARY

12 JUNE 2012

Evelyn welcomed those present and commended them for coming despite the cold and the long weekend.

Present: (13) Gail A.; Alan & Joy C.; Ellayne C.; Evelyn & Din D.; Beryl & Rob O.; Bill P.; Will & Joan R.; Neil & Joan T.;

Apologies: (10) Barbara A.; Audrey B.; Bruce G.; Alf H.; Alan L.; Nita & Rob McK.; Diane O'B.; Lauren S.; Jo Z.; To those who have just had surgery of various kinds we send our best wishes and also to those holidaying in warmer places. Thanks for news of your legal case Jo – all the best when it resumes and let's hope consultations your new neurologist will culminate in an effective plan for pain management. Glad previous support group meetings proved helpful when you met the new neurologist.

Evelyn noted that there have been some important events for some members since the last meeting: Joan and Neil T have downsized to a new abode; Beryl and Rob celebrated their golden wedding anniversary and Beryl a significant birthday. We noted also that Ellayne C is attending for the last time – she will move back to Sydney to be closer to family so we wish her all the best and thank her for her support while in Melbourne for the past three or so years.

Report: Treasurer Alan reported that there was a carry forward balance of \$953.60, expenses of \$16.50, donations at the last meeting of \$60.00, leaving current balance of \$997.10. There was some discussion about application of these funds with some worthwhile ideas presented. Further group discussion is anticipated when more members are present so a decision can be made.

Newsletter: received recently thanks to Irene and the Sydney team of helpers. Good to see our change of venue for future meetings was advertised.

Details of new venue: Maroondah Council will be demolishing the building where we have met since the beginning of the Melbourne support group so for the remaining meetings this year we will meet at Maroondah Federation Estate, 32 Greenwood Ave., Ringwood. Mel 49 H10. (copies of Melways map and the address available for members). After meeting there and seeing the facilities we will make a decision about next year's venue. Also the new support group leader replacing Evelyn in 2013 might have some ideas about a suitable venue. We hope to have Irene visit before the hand-over to an as yet unknown volunteer leader!

Correspondence: Notice of the Maroondah Festival on 11 November in Croydon was tabled. Our group will not be represented there as it has proved unproductive in the past.

Reports from members:

Diane O'B. (by phone) contacted Dr Danks after attending our last meeting and is happy to report she'll see him on 18 June.

Evelyn D. is still pain free and takes 1 B12 daily.

Neil reported that **Joan T.** has been doing it tough lately, with TN pain on her second side (left), worse at meal times. She is taking 2 sublingual B12 tablets a day. Soon after starting B12 she noticed some relaxation of the TN area but now she wonders what to do next as Zostrix is not working. She is frightened of Tegretol as she feels she has never been the same since taking it when she first suffered TN on the right side. We suggested she see a neurologist. Winter and the stress of moving house may be contributing to the recurrence.

Joy C has had MS for 25 years – she is stable now but suffers some side effects. She has had TN for 15 years – it is less severe now the drugs are working. She will see her neurologist and a pain management professional soon. Joy takes Gabapentin, Endep, Topomax and one other medication. Her eye condition was recently taken as a case study by a doctor in training.

Will R. is happy that he is still pain free 4 years this month after his MVD.

Bill P. has been pain free for 13 years since his MVD in 1999 – he takes no medication.

Gwen A. showed us an article about TN help in a recent MS magazine. She had a rhizotomy procedure at Melbourne Private – she was pain free at the one month follow-up and is still, though she has a numb face and numbness slightly affecting the eye. Now she is experiencing a very difficult itch.

Beryl O. has been pain free for the 12 years since her MVD on 4 July 2000!

Being a smaller number of people, we had time to linger over afternoon tea after the last meeting in this venue.

Thanks to all who have ensured the meetings continued to happen over the years by their volunteer work in so many ways.

Next meeting: Saturday 11 August 2012 –1.30 – 4 00 pm at the new address:

Maroondah Federation Estate, 32 Greenwood Ave Ringwood Mel 49 H10!

Evelyn Diradji

BRISBANE SUPPORT GROUP

30 Ridley Rd, Bridgeman Down

Date: June 9, 2012

Present: Christine M, Sue R, Margaret H, John H, Jeff B, Lorraine B, Glenda H, Neil F, Tony M, Margaret and Colin B, Mary M, Doreen T, Ken and Kay

Apologies: Henry and Eilleen C

We welcomed new members Christine, Kay and Ken, and our guest speaker, Eliane Lee-Schneuwly. Eliane is a naturopath and has suffered from MS, and was able to improve her health significantly by altering diet and lifestyle.

Eliane spoke of similarities between TN and MS, and then began telling us her story. At 21, she first experienced electric shocks and numbness in legs. She was leading a high stress lifestyle as a Uni student and getting about 4 hours sleep each night.

Her next serious bout came at age 24 and she then was unable to walk more than a metre. Writing was impossible and tremors were frequent. She was diagnosed with MS and told to expect to eventually be wheelchair bound. She read a book “MS is Curable” and this changed her life. It details many case studies where symptoms disappear following significant diet and lifestyle changes.

Since that time, some thirty years ago, Eliane has had some relapses, but she has always been able to recover. She knows that she has to watch out for triggers such as mental stress, too much wine, coffee and even talking.

Eliane says genetics alone does not determine the extent of a disorder that we might experience. Other features play a big part. Our emotions and anxiety levels affect our immune system. She quoted Bruce Lipton who claims that genes only express themselves under certain circumstances. Certain viruses, otherwise dormant, become active when the body is stressed.

Eliane also spoke of the power of the mind. She was determined to beat the illness. She ensures her Vitamin D levels stay high by being in the sun 15 minutes each day. She commented that MS is on the rise and wondered if this rise is related to more people covering up.

Eliane also spoke of the importance of Vitamin B12, particularly methylcobalamin. She also said deep sleep is needed for myelin regeneration and is essential for the nervous system. Myelin degradation is caused by inflammation and antioxidants play a big role in reducing inflammation.

Eliane spoke about the importance of an excellent diet and cited the typical Asian diet which supplies small quantities of red meat. She said many things are hidden in so many of the packaged foods we eat and we

should move towards raw foods and soups. Slow cooked stews are good and assist digestion. Boiled vegetables have lost nutrients.

Fresh fruit and vegetables are essential as they produce an alkaline effect. Stress leads to acidic tissues which enhance inflammation, so alkaline foods counteract this.

An alkaline diet will also counteract osteoporosis.

Eliane suggested we avoid GM oils. The best to use are cold pressed. Extra virgin olive oil is good for salads, but not for cooking. Coconut oil is a good oil for cooking, as is rice bran oil. We need oils as our myelin sheaths are made of fats. Protein is also important in our diets, but we need to avoid excess red meat.

Refined wheat has an inflammatory effect on the body. Eliane suggests oats are a good source of carbohydrate. She said that even wholemeal and multigrain breads can still be 70% white flour. She said Kamut bread is a good choice and can be purchased at health food shops. Another is Rye and Spelt. Of all dairy, yoghurt is the most alkaline. Eliane suggests Greek as one of the best forms. Organic soy, almond and rice milks are good alternatives to standard packaged milk. UHT products are not the best choice.

Eliane also suggests starting the day with some lemon juice in warm water as this has an alkalisating effect also. Apple cider vinegar has a similar effect.

During relapse, Eliane tells us it is essential to keep away from sugar, alcohol, caffeine and wheat. If we still want a cuppa, make two cups with the one tea bag. The second one will have a lot less caffeine.

She suggests supplements including magnesium powder, flaxseed oil, broccoli sprout powder (highly alkaline) and B12. She also suggests we monitor our alkalinity state by using pH strips available from chemists.

We thanked Eliane for her informative and entertaining talk. Our interest was such that she spoke with us for two and a half hours!!

She left just before we brought out the cakes, Tim Tams, and coffee!!

Good wishes to all our friends who couldn't be with us today.

Gold coin donation: \$35

Next meeting: Saturday August 11, 2012

Tony MacPherson

Sydney CBD Support Group

SATURDAY 2nd JUNE 2012

Attendees: Irene W, Kim K, Jocelyn S, Peter H, Marion A, Ieuen R, Margaret & Allan M, Nola & John W, Mr Mahdu .

Following the AGM, we had a group discussion and update on members.

- We heard from Ieuen that Ingrid is doing well, and has reduced her Tegretol to 500mg a day and Lyrica 300mg a day. Ingrid was unable to attend but sent her husband with the tea/coffee unit. He said her pain is under control and is looking at perhaps reducing her meds further if possible.
- Allan still takes 300mg of Lyrica and 200mg of Tegretol twice a day; as well as 60mg of Cymbalta per day. He said his trigger points seem to move through the 3 divisions. Pain level is presently around a 2 or 3 out of 10. Allan reckons that when it is bad – it is intolerable, but when it is not so bad – it is great! On further discussion, we learned that the Allan has been taking the same level of medications for more than 12 months, and Irene suggested that perhaps he should be seeing a doctor to reassess the effectiveness of his medications and perhaps to even change to SR Tegretol.

- Peter has a peripheral nerve stimulator implant to help reduce his post herpetic neuralgia pain –normally a persistent burning pain. Although the pain sensation is beginning to be more bothersome, he said the nerve stimulator still makes a difference. The difference is very obvious when he turns it off to go to bed and when he wakes up in the morning – an hour before the stimulator is fully functioning. Itch is also a problem Peter suffers from due to PHN.
- Kim went to an acupuncturist for 3 or 4 months twice a week which has helped control her pain. She has managed to reduce her Tegretol back to 400 mg a day, and if all continues to be good, she will try reducing it further – but slowly.
- Nola said that although her pain has worsened lately, she is coping. A broken foot as well as stress did not help matters. She uses compounded topical application instead of oral medications and still enjoys a cup of camomile tea a day. (It was good to see Nola and John again. Thank you for making the effort to attend the AGM)
- Marion and Jocelyn: Still good. No pain since their MVD.
- Mr Mahdu said his wife (Nagu) had MVd 14 years ago, but pain returned 12 months later. She has been on 2 mg of Methylcobalamin a day to help control her pain, but pain has been getting worse since last week. She has also been to a dentist in Maroubra – who understood TN and was very gentle during treatment. Nagu is on 25 mg Endep per night and has an appointment to see Dr Dexter.
- We then discussed alternatives such as the use of magnesium, which then brought to the discussion of Schuessler Tissue Salts. A long time term TN patient had recently rang Irene to share the news that consistent application of Schuessler tissue salt **cream** has provided complete pain relief.
- We talked about the beauty of compounding medication into topical applications and this led to the discussion of the side effects such as Myasthenia gravis (which as published in June Newsletter.) Irene was interested to see if anyone else who is taking Lyrica or Gabapentin has any muscle or joint weakness or pain. Ingrid and Allan were the only 2 in the room who takes Lyrica:
Ieuen said Ingrid has developed burning sensation on the tip of her nose as well as burning on her left foot. She feels very tired in the afternoon (I can't recall if Ieuen said she needs a nap).
Ieuen reckons he has to massage her foot to help relieve the soreness.
Allan said he feels very sleepy too, comes mid-afternoon and that he has some twitching on the hand.
Irene suggested peppermint oil, or as suggested by Hilary the "Ice Gel" that could help with the burning pain. Then Irene discussed the use of her ICE GEL on muscular and joints pain – due to inflammation after hours on the badminton court. (I think everyone left the meeting intent on buying this fantastic tube of ice).

We closed the meeting at 12 noon but stayed to enjoy our morning tea and chat generally.

Next meeting : 4th August, 10 AM at St James Parish Hall.

Update from Members:

Just a short note to advise I have at last had my MVD. After two false starts, one my end as I ended up in Wyong hosp. for six days with pneumonia which overlapped my first call up, the second was RNShore end with equipment problem right at the op time. Third time lucky, I went in last Monday, op. on Tuesday, home Saturday morning.

They found- Trigeminal nerve identified, loop of superior cerebellar artery noted to be impinging root entry zone of trigeminal nerve - carefully dissected. All went so very smoothly in the end. I am not off my meds yet, this will be happening over the next three weeks. So far so good. Hope to return to the next meeting all things being equal. See you then, **Lois**

A belated Apology was also received from **Allaster McD**.

He wrote: "Had every intention of attending (the AGM) but on the night before, my wife had something of a panic or anxiety attack, so that was that.... " Mary is now under the care of a psychogeriatrician; and Alzheimer's has been ruled out, and chemical imbalance test are now on-going.

MVD Experience to share with an elderly member.

We have a new member in her 80's who would like to speak with someone about their MVD experience. She is contemplating MVD – but I guess – needs some encouragement from folks esp. around her age. I am writing to ask if you would be agreeable for her to contact you, or conversely for you to contact her... If you can help, please let me know. (NSW only). ~ Irene.

Please pencil in **the 3rd of November**. We are organising a combined support group meeting at the Mechanic School of Arts with guest speaker Prof Phyllis Butow School of Psychology | Faculty of Science THE UNIVERSITY OF SYDNEY . Prof. Butow will be presenting "**Doctor-Patient Communication: The Key to Patient Care and Adherence (PL 02)**" at the IASP Congress in Milan –August 2012. I believe we will benefit greatly from her talk and will learn how to better work with your treating physicians.

I will be away August – September, grabbing a holiday before and after the IASP Congress in Milan. I will be checking my email periodically. Please use the tna_sydney@Yahoo.com email to avoid jamming up the "tnaaustralia.org.au" account – as it only has 10MB storage space.

The best bit is Jocelyn will doing the newsletters during my absence. ☺ ~ Irene.

Laughter is the Best Medicine

I was out walking with my Grandson. He picked up something off of the ground and started to put it in his mouth. I took the item away from him and I asked him not to do that.

'Why' my Grandson asked.

"Because it's been on the ground; you don't know where it's been, it's dirty, and probably has germs," I replied.

At this point, my Grandson looked at me with total admiration and asked, "Grandma, how do you know all this stuff?? You are so smart."

I was thinking quickly and said to him, "all Grandmas know stuff. It's on the Grandma Test. You have to know it, or they don't let you be a Grandma."

We walked along in silence for 2 or 3 minutes, but he was evidently pondering this new information.

"Oh....I get it! he beamed, So if you don't pass the test you have to be the Grandpa".

'Exactly,' I replied with a big smile on my face.



2012 Meeting Dates

| <u>State</u> | <u>Group</u> | <u>Date & 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 | 1 st September 1:30 – 4:00 pm | Toongabbie Public School Cnr Fitzwilliam & Binalong Rds Guest Speaker: | Kim Koh ☎ 02 97431279 Kim Smith |
| | Sydney CBD | 4 th August 10am 12:30pm | St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD | Irene Wood ☎ 0413 363 143 |
| QLD | Brisbane | 11 th August 1.30 -4.00pm | 30 Ridley Road BRIDGEMAN DOWN | Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286 |
| | Sunshine Coast | 21 st July 1:00 PM | Kawana Library, Nanyima Street, Buddina | Jean Williams ☎ 07 54911978 |
| | Townsville | TBA 1.00 – 4:00pm | Carville Senior's Villa 35 – 37 Diprose St PIMLICO | Sue Macey; Sera Ansell ☎ 07 47516415 |
| S.A | Adelaide | 29 th July 2:00 – 4:00 pm | Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Rd | Graham/ Liz Boyer ☎ 08 8392 2781 |
| TAS | Hobart | TBA 2:00 – 4:00 pm | Glenorchy Library Enter via Barry and Cadell Streets | Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989 |
| VIC | Melbourne | 11 th August 1.30 – 4:00pm | Maroondah Federation Estate, 32 Greenwood Ave RINGWOOD | Evelyn Diradji ☎ 03 9802 6034 |

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