



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.

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

December 2010

“What we call the beginning is often the end. And to make an end is to make a beginning. The end is where we start from.” : T.S. Eliot

As we draw closer to another new year, I take this opportunity to thank all members, friends and members of our Medical Advisory Board for your participation, support and contributions. I am proud to say that this has been another year of achievements; reflected in all areas of growth of the Association. In our quest for raising TN awareness, attribution also goes to our many support group leaders who have worked hard in reaching out to TN sufferers in their communities. We have also enjoyed more support from the medical and dental professions and there is also an increased in the number of health professionals receiving our newsletters. As the Association continues to grow in stature, our focus will always be for the support of TN patients. Your continued membership is important to us; we take heart that you are satisfied with our work and that we have served you productively. Please renew your membership by January 31st. Membership Form can be found on the last page of this newsletter. We look forward to your continued support.

On Sunday November 28 A/ Prof. Andrew Danks, Chairman of our Medical Advisory Board was guest on Radio 3AW program “ Talking Health” with Dr. Sally Cockburn.

The interview was about trigeminal neuralgia and neurosurgery; TNA Australia is very grateful for the tremendous plug we enjoyed on air.

If you wish to listen to it – click on the below link (the headphones.)

Or type this URL : <http://www.3aw.f2.com.au/Podcast/Feeds/66.xml> - then select November 28.

Talking Health, November 28

[281110_Talking_Health.mp3](#)

TNA Aus offers our congratulations to **A/Prof. Arun Aggarwal**.
Made A/Professor in May 2010 through University of Sydney.



*May the spirit of Christmas bring you peace
The gladness of Christmas give you hope
And The warmth of Christmas grant you love
Merry Christmas,*

Irene.



TNA Australia 4th National Conference

2011 September : Cypress Lakes Resort Hunter Valley, NSW

Date& Day	Events
2/09/11 - Friday	Arrival; SGL Workshop; Welcome dinner
3/09/11 - Saturday	Conference Day 1; MAB meeting
4/09/11 - Sunday	Conference Day 2 ; Gala Dinner
5/09/11 - Monday	Departure; HV winery tour

TNA Aus Members Conference Registration fee is subsidised.

Conference Registration - includes:

- 3 nights accommodation
- All meals - Friday Dinner to Monday Breakfast.
- 2 days of conference - with morning and afternoon tea & Lunch.

Accommodation Format: You will be sharing a villa.

Cypress Lakes Resort offers villas with 2 or 3 bedrooms. Each villa comes with all the creature comforts, including air conditioning and heating, private bathrooms, large living and dining rooms, a gourmet kitchen with refrigerator, tea and coffee making facilities and high tech entertainment units with satellite television.

Very much as in Yarra Valley – where it was 6 rooms in a cottage, this is a villa with 2 rooms

2 Bedroom / 2 bathroom Villa = Quad occupancy (2 couples)

3 Bedroom / 2 bathroom villa = Double occupancy (1 couple) + Twin occupancy.

Twin occupancy = 1 person per room but shared bathroom.

2 Bedroom / 2 bathroom Villa - Single Occupancy / per bedroom

1 bedroom Villa

All quotes are in Australian Dollars (AUD)

Villas	By 30/04/11	01/05/11 - 31/07/11	01/08/11 – 15/08/11
2 Bdrm + 2 Bathrms Villa Quad Share	Members Only \$425 p/person	Members Only \$550 p/person	Members Only \$650 p/person
3 Bdrm + 2 Bathrms Villa 1 Double + Twin share	Members Only \$425 p/person	Members Only \$550 p/person	Members Only \$650 p/person
1 Bedroom Villa Double Occupancy	Members Only \$635 p/person	Members Only \$685 p/person	Members Only \$750 p/person
2 Bdrm + 2 Bathrms Villa Quad Share	Non Members \$600 p/person	Non Members \$700 p/person	Non Members \$775 p/person
2 Bdrm + 2 Bathrms Villa Single person per room	Non Members \$800 p/person	Non Members \$900 p/p	Non Members \$1000 p/p
1 Bedroom Villa Sole Occupancy	\$1500 p/person	\$1600 p/p	\$1800 p/p
1 Bedroom Villa Double Occupancy	\$810 p/person	\$880 p/p	\$950 p/p

Coach Transfer from Airport to Conference Venue

We will organize a coach to take delegates from the Domestic airport to Cypress Lakes Resort Hunter Valley. An estimate quote is about \$60 per person (Return)

To ease the Treasurer's burden - Conference Registration Forms will be sent out next year. *I get into trouble when the newsletter exceeds 17 pages. It becomes too thick for 60 cents postage.*

Meanwhile, I suggest you keep an eye on Airfares to Sydney & purchase them during SALES.. It can be as cheap as \$65 each way.

What can you expect from the conference?

You will hear our **Medical Advisory Board** talk about medical and surgical treatments. A wide range of TN topics will be covered and you will leave the conference better informed and be able to discuss with your doctors your pain management plan.

I think many of you will be thrilled to meet her. **Mrs Claire Patterson** - the founder of TNA. Hear how she started TNA. She is an amazing woman who has much knowledge in support work. She will be conducting our support group leaders workshop. She has much experience to share I know you will be inspired.

Prof. Marshall Devor will again come to support our conference and will present his latest pain gene, (cacng2). Are you predisposed to pain? He will also explain how your nerve fires, why touch becomes exploding pain, how your TN medication works or why some doesn't work. If you have questions about TN peculiarity he would be one you might want to ask.

The other international presenter I have invited is **Dr. Donald Nixdorf** - Assistant Professor, Division of TMD and Orofacial Pain, Department of Diagnostic and Biological Sciences. Uni Minnesota, MN. We were chatting re: my "eat your way out of pain" hypothesis, and he impressed me with his patients pain management plan - "beginning with self care." He will also be sharing a dental aspect on pain and his latest paper "Persistent Tooth Pain and Root Canal Therapy".

Many folks when they first attend our conference come with intrepidation of the benefits of such a conference. I am pleased to say all delegates have come away with hope and a better understanding of and TN management. Here are some post conference remarks:

"It has reassured me in many ways, not the least by having the opportunity to meet others who have this condition and to learn about their treatments and reactions. I look forward to the next conference."

"I mixed throughout the attendees and got a common response from everyone present that the course content was just right, the venue was great, the food was fabulous, the presenters were informative and interesting --and that overall everyone had a great time."

"I felt that the presentations were of a high standard and realistic in content. The environment was relaxing and food hearty. More importantly, the people - presenters, organisers and delegates were all on the 'same page' which made for an extraordinary successful conference. I particularly enjoyed meeting other TN patients ...the conference provided many with the information and hope of managing TN in the best way possible."

My advice to you is to have all these information, especially when you are pain free, so you can plan while you are not in pain. Don't wait till the pain is so bad and you can't think straight, then try to figure out what to do.

No, ringing Irene whilst in tears is not the answer, nor the plan! ☺

Cool way to pain relief : Triggering cold receptors blocks off pain signals.

15/09/2006 by Kern Smith : news@nature.com

Here's a cool strategy for relieving pain: scientists have found that cold temperatures and even cool-sensation chemicals can be used to treat chronic pain. Cold wet cloths and mint leaves pressed to the temple have long been used to put a damper on pain. But aside from the general numbing effect that ice can have on nerves, how cooling treatments work has remained a mystery. Now that the mechanism has been unpicked, researchers say, it could give new hope to sufferers of chronic pain, an often intractable condition affecting 50 million people in the United States alone. Some nerve-ends in the skin are known to hold receptors that are sensitive to temperature changes as well as foods frequently described as hot (such as chilli) or cold (such as menthol).

One of these receptors, called TRPM8, can help the body to monitor temperatures between about 8 and 12 °C, as well as being activated by menthol-like chemicals, including a super-cooling chemical called icilin.

Susan Fleetwood-Walker of the University of Edinburgh, UK, decided to investigate the link between these cold receptors and pain in rats. They first induced chronic pain in their animals by tying a thread around a thigh, and then either injected a very small dose of icilin into the spinal cord or had the rats stand in a shallow bath of the chemical. They then stroked the painful limb and checked the rats' response: those treated with icilin could withstand three times as much pressure. The findings are reported in *Current Biology*.

Cool relief

Activating the cold-sensing receptors sends a signal to the nerve's terminus in the spinal cord, where it then prevents other nerves from transmitting information about pain, says Fleetwood-Walker. "The terminals are actually touching pain-transmitting nerves and stopping them from being activated," she says. The fact that the cooling message can block pain signals even those coming from elsewhere in the body wasn't known before. "If you just looked at the nerve itself you wouldn't know that it's having this gating control over all the other nerves," says Fleetwood-Walker.

"It's only by looking in the whole animal that you can see this." Similar work is being done at the other end of the temperature spectrum: earlier this year, Brian King and his team at University College London, UK, did some work on a similar receptor, TRPV1, which signals heat. They reported at a Physiological Society conference in July that heat can stop pain through similar blocking mechanisms. "We're just coming to realise that we can exploit this," he says. "There's potential at both ends of the temperature scale."

Throbbing pain

Fleetwood-Walker's team are hoping that their findings will translate to people suffering from chronic pain conditions such as arthritis, phantom-limb pain, or neuropathic pain, which can result when nerves are damaged through injury or disease. People with chronic pain show higher levels of TRPM8 receptors in nerves that are damaged, providing a target for these cool treatments. The idea wouldn't work for acute pain, however, which operates through a different set of receptors. The team recommends pursuing the idea of a chemically cool treatment, rather than, say, applying a cold cloth to the skin, because only a very specific temperature range would have the optimal effect on the TRPM8 receptors.

If the treatment works in people in the same way as it does in rats, it could cut out the side effects that plague many of the current treatments for chronic pain, such as morphine. And there will be no need to take tablets. "They could be applied directly to the skin in a cream or in a simple solution," says Fleetwood-Walker. She hopes to move into clinical trials within a year.

Proudfoot C. J., et al. *Current Biology*, /16. /1591 - 1605 (2006).

Magnesium:

*My interest in magnesium came about after a torrid day of competition. It has been getting progressively regular over the years that I would get cramps during competition. This particular day, after 2 major seizures I had to investigate why, and what I can do about it (besides praying that the cramp on the left- back doesn't come around to the front. A particular muscle in the chest cavity was my main concern.) I started reading about magnesium and my interest was raised when I read about its role in cells potential. From my understanding, magnesium would be nature's (natural) **calcium channel blocker!!** some of the drugs you take work by using this mechanism. So, I began to investigate further into magnesium's role in pain modulation. Below, for your interest are some references: Please discuss with your physician/s before embarking on any supplements.*

Efficacy of intravenous magnesium in neuropathic pain

1. S. Brill¹, P. M. Sedgwick², W. Hamann¹³ and P. P. di Vadi*¹

Abstract

Background. Postherpetic neuralgia is a complication of acute herpes zoster characterized by severe pain and paraesthesia in the skin area affected by the initial infection. There is evidence that the *N*-methyl-d-aspartate receptor is involved in the development of hypersensitivity states and it is known that magnesium blocks the *N*-methyl-d-aspartate receptor.

Method. A double-blind, placebo-controlled, cross-over study was conducted in which magnesium sulphate was administered as an i.v. infusion. Spontaneous pain was recorded and qualitative sensory testing with cotton wool was performed in seven patients with postherpetic neuralgia before and after the i.v. administration of either magnesium sulphate 30 mg kg⁻¹ or saline.

Results. During the administration, pain scores were significantly lower for magnesium compared with placebo at 20 and 30 min ($P=0.016$) but not at 10 min. I.V. magnesium sulphate was safe, well-tolerated and effective in patients with postherpetic neuralgia.

Conclusion. The present study supports the concept that the *N*-methyl-d-aspartate receptor is involved in the control of postherpetic neuralgia.

Br J Anaesth 2002; 89: 711–14

Patol Fiziol Eksp Ter. 2010 Jan-Mar;(1):6-10.

Pharmacological correction of pain sensitivity threshold in magnesium deficiency

Spasiov AA, Iezhitsa IN, Kharitonova MV, Kravchenko MS.

Abstract

The purpose of this study was to compare effect of: Mg L-aspartate and MgCl₂ alone and in combination with pyridoxine (B6) on hyperalgesia in rats fed with Mg-deficient diet.

To induce hypomagnesemia, two hundred rats were placed on a Mg-deficient diet (MP Biomedicals Inc., OH) and demineralized water. To evaluate pain sensitivity, motor and vocalization threshold in response to a mechanical stimulus (Randall-Selitto paw pressure test) and tail withdrawal, simple and brief vocalization threshold in response to an electrical stimulation (algometry by electrical stimulation of the tail through intracutaneous needles) were assessed.

In our study Mg deficiency results in reduced vocalization threshold by 42% in response to a mechanical stimulus. Thresholds of motor tail response, simple vocalization and brief vocalization after discharge in response to an electrical stimulation were decreased by 32.5%, 20.5% and 23.8%.

Oral magnesium salts led to normalization of thresholds of pain sensitivity with a return to pre-deficient levels. Magnesium salts in combinations with pyridoxine tended to be significantly more effective in Randall-Selitto paw pressure test as compared with salts without pyridoxine. The effect of studied salts was comparable with those observed in Magne B6 treatment and significantly higher than in magnesium sulfate treatment.

PMID: 20731120 [PubMed - indexed for MEDLINE]

Other References on Magnesium that may be of interest:

- Journal of the National Defense Medical College(2005) : **Physiological role of magnesium ions in living cells**
- Abraham GE, Glechas ID. "**Management of fibromyalgia: A rationale for the use of magnesium and malic acid.**" Journal of Nutritional Medicine, 1992;3:49-59.
- Russell IJ, et al. "**Treatment of fibromyalgia syndrome with Super Malic: A randomized, double blind, placebo controlled, crossover pilot study.**" Journal of Rheumatology, 1995; 22:953-958.
- "**Pain medicine and management**" By Mark S. Wallace, Peter Staats
- **The magnesium solution for migraine headaches: the complete guide to using ...** By Jay S. Cohen

Krispin is a Clinical Nutrition researcher and educator, writing, teaching, and consulting from Incline Village, NV, in the San Francisco area. She has continued to study: biochemistry, psychology, exercise physiology, biofeedback, biochemical effects of child abuse; nutrition and its role in degenerative disease; toxicology, parasitology; effects and side effects of the use and abuse of legal and illegal drugs including nutrient deficiencies caused by prescription drugs; chemotherapy and radiation; nutrition and the media; nutrition and government, nutrition policies and economics; and the formulation, manufacturing and marketing of supplements. Within the last year, 2009, she has been adding the study of microbiology to her resume, in particular the study of the microbial inhabitants of humans. The notes below are taken from her website: Krispin.com.

Magnesium is a critical element in 325+ biochemical reactions in the human body.

Recent research, in France and several other European countries, gives a clue concerning the role of magnesium plays in the transmission of hormones (such as insulin, thyroid, estrogen, testosterone, DHEA, etc.), neurotransmitters (such as dopamine, catecholamines, serotonin, GABA, etc.), and minerals and mineral electrolytes.

This research concludes that it is magnesium status that controls cell membrane potential and through this means controls uptake and release of many hormones, nutrients and neurotransmitters. It is magnesium that controls the fate of potassium and calcium in the body. If magnesium is insufficient potassium and calcium will be lost in the urine and calcium will be deposited in the soft tissues (kidneys, arteries, joints, brain, etc.).

Magnesium protects the cell from aluminum, mercury, lead, cadmium, beryllium and nickel. Evidence is mounting that low levels of magnesium contribute to the heavy metal deposition in the brain that precedes Parkinson's, multiple sclerosis and Alzheimer's. It is probable that low total body magnesium contributes to heavy metal toxicity in children and is a participant in the etiology of learning disorders.

The best food sources of magnesium are chocolate, nuts, seeds, and deep, dark, leafy greens. If you regularly consume these foods you may not need extra magnesium.

Magnesium has been consistently depleted in our soils. It has been further depleted in plants by the use of potassium and phosphorus laden fertilizers which alter the plant's ability to uptake magnesium. Water from deep wells supplies additional magnesium not found in food, but surface water, our common source of supply, lacks magnesium. Food processing removes magnesium. Broiling, steaming and boiling remove magnesium into the water or drippings. High carbohydrate and high fat diets increase the need for magnesium as does physical and mental stress. Diuretic medications and insulin further deplete total body magnesium. As we age magnesium uptake may be impaired. Dieting reduces intake of already low levels of magnesium intake.

There are many conditions and diseases that are clinically tied to magnesium deficiency. **Blood tests for magnesium deficiency are irrelevant and unusable.** These levels do not reflect **total body magnesium (TBM)**. Magnesium levels of bone and intracellular levels of magnesium are what tell the true status of TBM.

Apparently, **overdose is real** but not common for most. Magnesium is water-soluble mineral and the body excretes any excess. One way of bypassing this would be to have transdermal magnesium – apply to the skin. Talk to a compounder chemist. Or maybe it is available over the counter.

I only half supplement the recommended dose, but increase my natural intake of magnesium. Yes, chocolates are my other magnesium tablets. ☺

However, if you have impaired kidney function such as kidney failure, renal failure, and on dialysis, then you have a high risk of magnesium overdose. Do not supplement on Magnesium unless under the directions of your doctor.

Other conditions that should not take magnesium are :

- Myasthenia Gravis - a neuromuscular transmission disorder
- Atrial Fibrillation - Those with current Atrial Fibrillation have the possibility of 'converting' their atrial fibrillation into a normal rhythm by taking a high dosage of magnesium. While this may seem desirable, there is a high risk of having a blood clot ejected from the heart and into the general circulation. This could cause a life threatening condition of a heart attack, stroke or pulmonary embolism. If you have atrial fibrillation, your cardiologist should be directing your magnesium supplementation.

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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Events that you might want to pencil in for 2011: All are welcome

April 30: Dr. Kim Burchiel has kindly agreed to call into Sydney and will do a talk for us.

Melbourne Support Group Meeting Dates for 2011

Saturday afternoons on the following dates:

12 February, 9 April, 11 June, 13 August, 8 October, 10 December.

All meetings are in the same venue we have always used: the Ringwood Room, Ringwood Public Library, Ringwood Street Mall (near Eastland), Ringwood.

Thank you for your invitation to join you as you celebrate your 10th Anniversary on February 12. My flights are booked and I look forward to seeing you all then. – Irene.

Correspondence Corner

Prof. Devor : I forgot to mention how much I liked Kerry Graf's TN poem. I'd like to read it in one of my classes that touches on TN. It would be a great idea to encourage your folks to write/ paint about their pain.

Irene: I am sure Kerry would be stoked to know you read her poem to your class.

Meeting Reports

SYDNEY SUPPORT GROUP

Toongabbie Public School

6 November 2010

Present: Irene W, Kim K, Kim S, Jeanette & Henry B, Vera R, Frank M, Marion A, Ann & Laurie P, Stewart & Gundel B, Ian L, Jesse T, Peter H & wife, Beryl & Max, Jean, Elizabeth & Lloyd,

Apologies: Jocelyn S, Emily S, Jan McL.

We had a bit of a trek in the rain today to gain access to the new Hall, but it was worth it! Its very comfortable. This resulted in the meeting starting a little late and the note taker being on "directional duties" so apologies for any inaccuracies! Kim S stepped in to take the meeting as Kim K was held up in traffic, thanks Kim S.

Peter: Is well, he has been trying the B12 lozenge for the last 3 months, but has not noticed any change.

Jeanette: Is eagerly awaiting Dr Dexter's report regarding her results that he is writing up in a medical journal. She hopes to see a copy next month

Marion: 2 years since MVD & all is well.

Stewart: has anaesthesia dolorosa and reports he is about the same.

Vera: Is doing well

Jesse: His TN comes and goes and he is currently pain free, thank goodness. When it does come, it thankfully doesn't seem to be as bad as his initial attacks. He has breaks of 2-3 months then bouts of about 5 weeks duration, where he takes Tegretol and sits it out. He questions the random nature of the disease and treatments and Irene explained how we are all different & there is no wonder drug that is tailored for all. What works for some may not work for others.

Beryl: We welcome new member, Beryl and her friend Max. Beryl's pain started in 2002 with a severe attack that lasted about a month. She was put on Tegretol, but it didn't agree with her. It went away for a few years, then returned, but less severe. Her 3rd recurrence was 3 months ago and is worse when she eats. It is a sharp stinging pain in her lower right side jaw. She is currently on Epilim and recently saw a neurologist who has advised she take 1 month break from it due to an adverse reaction. We wish you well, Beryl.

Jean: We also welcome Jean, who lives not far from Beryl. She had her first episode in 2007 and it was fast & furious. She was put on 800mg of Epilim and has not had an attack since! We hope you continue to be pain free, Jean.

Ann: Is well too.

Kim S: So far, so good following her second MVD, in June. She continues to be pain free, but does have numbness around the eye and inside her mouth, but reckons that is preferable to the pain. She is nearly off all meds and feels great!

Ian: Is about the same, has some pain on & off. Right side is identical to previous pain, but Left side seems to be getting a bit worse. He is not sure what is going on. He is not on any meds.

Jesse had questions to Irene regarding B12 and the different types available and the effect.

We were delighted to see Lloyd and Elizabeth at the meeting.

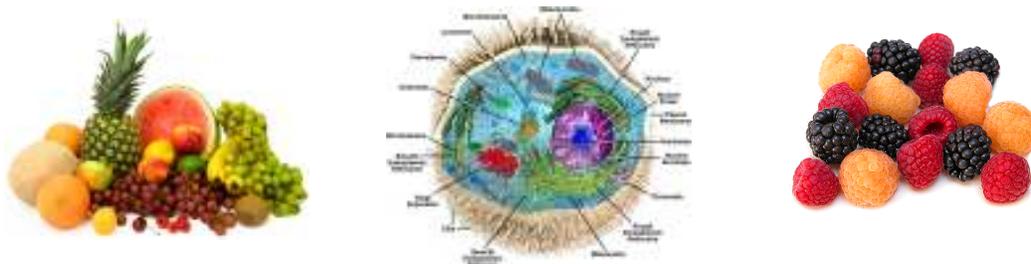
Irene said, we must all decide for ourselves if something is working for us or not and that once again, what may work for some, does not work for others.

Irene presented her informative slide show of her posters regarding her study into "Can you eat your way out of pain?"

A SUMMARY:

1. **Free Radicals cause cells to mal function, this leads to cells dysfunction and eventually causes cell death.**
2. **Neuropathic Pain is associated with ROS, oxidative stress, mitochondria, apoptosis and cell death.**
3. **Antioxidants are the body's natural defences against ROS and oxidative stress.**
4. **Your body makes natural antioxidants from various dietary food.**
5. **The most powerful antioxidant is Glutathione, glutathione also works intracellularly**
6. **For antioxidants to work properly, it depends on an all round support of other antioxidants, proteins and minerals. Glutathione supports other antioxidants.**
7. **Supplementing on a specific type of antioxidant is not recommended**
8. **Eat a variety of vegetables and fruits daily that are either rich in antioxidants or that assist in increasing the levels of antioxidants in the body.**
9. **Fresh and raw is best. Storage and cooking loses antioxidants value.**
10. **If we can prevent cells mal functioning and downstream cell death, we can prevent neuropathic pain. With cells functioning properly the body can heal itself.**

This hypothesis supports You can eat your way out of pain.



Today's door raffle was won by Beryl! We then enjoyed a cuppa and delicious treats.

Next meeting will be Dec 4th, here at Toongabbie Public School which will be our combined Christmas Function, with Dr Dexter as our guest.

Thanks Marion, for the notes from the meeting.

Irene.

Please note: There will be no newsletter in January. I need a rest.

"Look to your health; and if you have it, praise God and value it next to conscience;
for health is the second blessing that we mortals are capable of, a blessing money can't buy.

- Izaak Walton

HOBART SUPPORT GROUP

Glenorchy Library

20 November 2010 2-4pm

Present: Helen T, Ros & Ian W, Shirley B & Kay P, Del & Jean L, Julie H, Lyn D, Bernadette C, Pat W, Pauline T, David B, Betty D, Christina S, Gary H, and our special guest Dr Tim Begbie.

Apologies: Barry D, Libby C, Carol E, Iris H, and Fran B.

The meeting started with Co-Group Leader Helen T warmly welcoming everyone.

An information handout containing images of the head showing the location of the three branches of the trigeminal nerve and the common trigger points for Trigeminal Neuralgia, was distributed to everyone at the meeting.

Guest speaker

Guest speaker was Dr Tim Begbie. After years working as a GP who also practiced acupuncture, Dr Begbie now provides acupuncture services full time. He is in the process of encouraging other GPs to develop their skills in this area. Tim talked about the lack of randomised-double-blind scientific trials associated with the effectiveness of acupuncture, other treatments and some drugs such as Tegretol. Nevertheless this was not to say such treatments wouldn't work for TN sufferers. It was simply that the effectiveness of such treatments is based on anecdotal evidence and 'measured' by doctors and sufferers seeing a reduction or a stop in the pain. Also Tim explained the processes of acupuncture and spent considerable time addressing the challenges of determining whether acupuncture helps TN pain (for eg, did the pain stop because of the acupuncture or was it going to stop anyway? He talked about whether a TN attack after treatment was the result of the treatment or would have happened anyway.) Other issues, including matters of ethical interest, were raised and discussed through a very useful question time. Some people at the meeting had been or were currently having acupuncture treatment and talked of the relief it gave them. We were immensely grateful for the time and effort our guest speaker put into his preparation for our meeting and then for giving up his Saturday afternoon to inform us. He has been a champion for our cause. Thanks Tim.

Other Business

For the first time our financial situation is comfortable. We were absolutely delighted to receive a donation of \$100 from Gill Thomas at the New Norfolk Pharmacy (thanks to Pauline T's prompting) and then a donation of \$200 from the Australian Dental Association-Tas branch (thanks to the persuasiveness of our August guest Dr Tom Higgins). These monies will take some pressure off and help cover operational needs. The ADA have also offered to provide future guest speakers. Helen T noted that another dentist had joined today's meeting in response to an advert and article we had placed in the ADA newsletter - and he was welcomed.

In September an Extraordinary Special Meeting of our Support Group was held where it was agreed to set up a bank account with Bendigo Bank with Ros W, Helen T and Del L as signatories. Two people need to sign to make any withdrawal. Helen T explained that at every Support Group meeting the folders containing all records of correspondence and financial matters (including receipts) would always be available for any sufferer to read. After purchase of stationary and stamps, room hire, gifts for guests, a book (see below) and photocopying, the total surplus at the end of the November meeting was \$152.81.

A copy of the well known book that explains Trigeminal Neuralgia, 'Striking Back' was purchased from our donations to be available for loan to sufferers for a period of 3 weeks at a time. It is such an extraordinarily interesting book that if you haven't seen it then please make sure you are in line to borrow it. Co Group Leader Ros has agreed to be librarian and manage loans (see her phone number

below). In addition, Ros has donated one of the books she found useful - 'Mayo Clinic on Chronic Pain'. This is yet to be borrowed so please phone Ros and arrange to have it on loan.

Helen T reminded everyone about the TNA Conference next September. This is an event not to be missed so all stops should be pulled out to go. Please start saving now.

Before the meeting concluded we enjoyed a wonderful Christmas break-up afternoon tea. Sufferers had come festooned with tinsel, wearing Christmassy clothes and jewellery, and Ros's knitted mini plum puddings 'took the cake' (yes there was one for everyone). Everyone shared wonderful nutritious food and the parting chatter was very happy. A wonderful way to conclude our first year as a Support Group.

Thank you everyone for all your support and care as we have established this first Tasmanian Trigeminal Neuralgia Support Group together during that time. It truly has been a team effort with everyone sharing their skills and time.

Next meeting: Late February 2011 but date and other details yet to be finalised. Further information will be posted out when available. Always feel comfortable to contact Group Leaders Helen Tyzack on 6245 0429 or Ros Wilkinson on 6234 7989.

Brisbane Support Group **Bridgeman Down** **13 November 2010**

Attendance: Henry C, Eileen C, Margaret B, Colin B, Helen W, Joan F, Alzira D, Marie K, Margaret H, Tony M

Apologies: Leonie G, Jeff & Lorraine B.

The 2011 conference was outlined and members urged to attend. The article by Terry Borsook in the recent newsletter on pain treatment through perception was discussed. Implications for TN involving the use of mirrors were suggested.

(The notes that I made from Terry Borsook's lecture were more for people with neural injury eg: Anaesthesia Dolorosa or folks who have relentless constant type of pain. - Irene.)

Following our last meeting when we spoke of frequent dental problems associated with TN, Tony outlined his talk to dentists at a recent pain management conference organised by Dr Helen Boocock. Our group sees great benefit in educating key health providers to ensure early TN diagnosis.

(Great, please encourage them to come to our national conference- Irene.)

We then shared our stories.

Henry continues to be really well. He is now down to only ½ Tegretol a day. He uses 1 Neocobalamin injection per month.

Joan also continues to be really well. She takes Magnesium and Fish Oil and 5mls of Endep daily. She has continued to be well since commencing monthly Methyl cobalamin injections.

Margaret B had a relapse five weeks ago with shocks cleaning teeth. She increased her dose to 600mg Tegretol a day. She is now back to good health and continues with Neocobalamin injection. Hubby Colin is going really well also.

Helen is now off Tegretol. She takes Fish Oil, Magnesium and B12 tablets. She continues to be pain-free following the MVD performed by Dr Coyne.

Alzira is now off all medications. She was on many meds at the start of the year to control pain and a rash resulted. She uses pure juices extracted fresh at home. She now experiences mild tingling only on the left side and 1 paracetamol a day seems to control the pain.

Marie had two tough months this year; September/ October. She had been on weekly Neocobalamin injections and initially responded really well to this treatment. The pain has now passed.

Margaret H says she is wonderfully well thanks to Methyl cobalamin. She also takes Bio-magnesium, Vitamin E, Evening Primrose Oil and high strength Fish Oil. She has experienced doubled vision with TN. She has been able to reduce her medication down to 800mg Tegretol.

As I write I continue to be really well. I have used a combination of therapies this year including monthly Methyl cobalamin injections and homeopathy. I have also found osteopathic treatment to be of some benefit along with magnesium, Flaxseed oil, lysine, olive leaf extract and an executive stress vitamin. I have returned to work part-time this year and have not missed a single day due to TN.

On behalf of our 'Brisbane Wellness Group', I extend my heart-felt gratitude to Irene and her dedicated band of colleagues who do so much for the benefit of others.

Gold coin donation: \$19

Next Meeting: Saturday February 12th 2011

Joy, Peace and Healing to all.
Tony MacPherson

SUNSHINE COAST SUPPORT GROUP
Kawana Library, Nanyina Street, Buddina.
Saturday 20th November, 1.00pm

Present; Jean W, Teresa M, Marie D, Barry F, Jean Be, Dawn & Jim S, Andrea F, Max H, Pater & Pearl R, Trixie B, & Jill Le M.

Apologies; Glenda W, Jean Bi, Sheryl M. (Jill apologized for last meeting).

A warm welcome to everyone old and new.

Business:

Care Memory Band- This band has a USB port. You can transfer your medical data to the bracelet. Should there be a medical crisis, the emergency staff can plug the band into their computer & access information. I'm not recommending this to you, only bringing this to your attention. For further information visit www.dukehillhealthcare.com.au. Apparently, when you renew your license this information will be placed on it. It will take a few years before all this is in place.

The Commonwealth Respite & Carelink Centre will ring in the next week or so. They want information regarding TN. This info will be placed on their health information board that they take around to the shopping centres, age care facilities etc.

Members update:

Glenda W: Had her operation in Brisbane, but not that successful. Glenda has been able to reduce her medication a little to 300mgX2 Gaberpentin; 800X2 Tegretol. She is still attending pain clinic.

Jill LeM; Asked the question "Is anyone putting on weight with Tegretol"? Jean suggested it may be preferable to having the pain. It is important to maintain your exercise program so as to keep the weight

gain to a minimum. Jill is too scared to stop the medication even though she isn't having pain. (a few twinges). Current dosage is 100mgX2 Tegretol.

Marie D; (First time). Marie asked a question "Why does it go away at times?"

Jean gave Marie a basic outline of the MVD operation. Marie has managed it for about 30 years. This was the first time that Marie had ever met anyone else with the condition. After taking Tegretol she had a toxic reaction. Now on 150 X2 Lyrica. Her chemist suggested Endep, taking 10mgX1 pd. Her pain is on the right side, stabs in her ear, then spreads. Wind and eating affects it.

If the pain is in her jaw and she is unable to drink. Jean suggested Sustagen (hospital strength), chocolate is pretty good. It can be placed in a sippy cup if you can't drink from a cup or use a straw.

Barry F; (First time). 2 years out of the blue he had his first attack. Neurologist diagnosed it. Took Tegretol for 9-10 months, but developed a reaction - swelling of arms & legs. He stopped Tegretol and the pain went away. It has since come back whilst he was shaving; he dropped to the floor from the pain. When he gets an itchy right eyebrow, he can't scratch it as it will trigger the pain.

He told his Neurologist that he wanted the operation. Was referred to a neurosurgeon. Had a MRI at the Wesley Hospital. The doctor showed him a blood vessel around the nerve; but was reluctant to operate and suggested trying other medication until he finds something that helps. He was sent back to the neurologist where Barry was placed on 400 Tegretol and 300 Dilantin. The medications are only just helping, no reports of swelling of limbs.

Jean B; (First time). 17 years ago she had Bells palsy and the TN nerve was damaged. The wind affects her face. The pain returned in July. It was a cold windy day and she got this dreadful pain at night. Jean went to the dentist, couldn't find anything wrong. Her doctor has put her on anti-inflammatory. It was recommended that Jean B. borrows the book "Striking Back" from our library as it is very informative. She has pain in her upper teeth and gums. Jean B. finds using Colgate for sensitive teeth helps with the pain and she has noticed a difference.

Dawn S; (First time). The pain started 18 months ago. Dawn was exercising for her singing lessons when the pain began. It is like pouring boiling oil into her right ear. She has triggers on her lips. Dawn went to the dentist and it was suggested that she may have TN. A Facial Surgeon confirmed the dentist's diagnosis. Dawn was sent to a Neurologist and she was started on 50 mgX2 Tegretol increasing to 100mgX2. This brought out a rash. She stopped the medication but the rash didn't go. Had to bath in a bleach solution also using a cortisone treatment. The TN pain returned, so her neurologist put her back on to Tegretol 100mgX2. Starting to get the rash back. Dawn has pins and needles on her tongue, had ear-ache and sore gland. Went to see a different doctor who put her on strong antibiotics which seems to have helped. Now Dawn is going to see her own doctor next week. Her TN is not under control but she is willing to increase her Tegretol. It was suggested for Dawn to stop Tegretol and try a new medication. Lyrica, Gabapentin, Valproate etc.

(If you refer to the product catalogue you will see that it has warnings of such rash and that Tegretol must be stopped or the rash could turn into more severe problems such as Steven Johnson Syndrome. Please discuss with your doctor for a change of medication. It is a well known side effect of AED – Irene.)

One question we have for Irene - **Can slow release Tegretol be cut in half?**

*Irene: The product catalogue states - Take Tegretol during or after a meal. Swallow the tablets with some liquid; if necessary, **the tablets may be broken in half along the line**. If you miss a dose, take it as soon as possible.*

As far as JeanW knows, the doctors use Tegretol as a diagnostic tool. 5 people at the meeting today have had reactions, from rashes, blackouts, swelling of face and tongue, to hepatitis.

(The response to Tegretol IS a diagnostic tool for TN.- Irene.)

Andrea F; It has been 8 weeks since her MVD. The operation went well. Her salt levels and blood pressure were low after the operation. Andrea was in ICU for 5 days. Dr Dexter took her off Tegretol after the operation to help restore the salt levels. Results were; she had a deep compression but she is now good. Her next appointment is on the 2nd of December, for her post operation check up. Andrea still feels a little wonky when she turns her head. Great news, she is able to drive and best of all no pain or having to take medication.

Max H; No pain for a couple of months. He has the occasional twinge and he isn't on any medication.

Peter R; 600mg Tegretol, slow release (300X2) He still has the occasional pain.

Trixie B; Had her MVD in February; it was very successful, no pain since. She went on an overseas trip 5 days after coming out of hospital. Going back to when her pain first started, Trixie first thought she had a toothache, or sinus. It was then diagnosed as TN after she saw Dr Staples at Redcliffe.

Teresa M; Teresa explained her story, since this was the first time for a few people. The doctors had a hard time diagnosing her. Her husband eventually looked up Neuralgia and came across Trigeminal Neuralgia in a Readers Digest Health book. Teresa took this information to her doctor. She eventually had MVD in 2009 - very successful; Dr Dexter was the surgeon.

Jean W; Jean told her story regarding an Arachnoid cyst. Her first operation was on the right side followed by a second on the left side. Head pain and eye pain has started again since February this year. Jean has been back to Dr Dexter and the Arachnoid Cyst is clear. It seems the problem is in the eye and she needed to go back to her Ophthalmologist. It appears that the buckles that are holding her eye together maybe causing the pain. Jean is going to the Palliative Pain Clinic at the Caloundra Hospital while waiting to get into a private pain clinic. Her medication at the moment is 800mg X2 Gabapentin.

Everybody was asked to join us for our last cup of tea for the year. We take this time to wish everybody a Merry Christmas and a pain free New Year.

Found:1 umbrella left at the last meeting. Call Jean, so you can pick it up.

Funds taken: \$30.00

Next meeting: 15th January 2011, @ 1pm Kawana Library. Guest : Irene Wood.

Jean Williams

CANBERRA SUPPORT GROUP

Canberra Labor Club Belconnen

Saturday 30th October 2010

Present: Kerry G, Richard M, Susan M, Brian W, Jan G. Apologies: Nil

Meeting opened at 10.35am. At this time of the year the Club had many bookings so Jan had accepted the earlier date and had phoned around so that members currently attending meetings were aware of this date.

During this process she had been informed that Devi was not well (not her TN) and probably would not attend. We hope she has improved by now.

Richard had now been able to reduce his Epilam from 800 to 600. Good news.

Kerry was now on 600 Tegretol, which had eased her pain. She was not on CR Tegretol as her doctor did not seem to be aware of them.

Jan introduced the main reason for the meeting - attendance at the Toongabbie meeting to hear Dr Dexter speak.

Kerry and some family members will attend. Others were unable to do so for various reasons.

Brian felt it was time to attempt to place information on TN with Doctors, Jan suggested dentists as well and Kerry would ask the Lions if they would accept leaflets to make available to the public. Jan to copy more of the leaflets used last year and bring to the next meeting for those who could attend to this.

Kerry had found a soft toothbrush which she was able to use, also Piksters which she could use even during a painful period. Brian knew of these as his wife found them better than dental floss.

Jan will book the **next meeting** for January. This has now been done and the date booked is **15th January at 10.30am.**

The meeting then closed at 11.00am.

Jan Goleby

Townsville Support Group

Saturday November 20 2010

Present: Sera A, Peter A, Joy K, Jill S, Mary C.

Apologies: Joan B and Jean T.

Sera: Welcome and thank you for coming on a miserable day. She reports that Joan B was seeing flashing lights, and Sue said Joan needs urgent referral to an eye specialist.

Sera: Read the wonderful poem from a previous newsletter. Everyone agreed that it was very apt.

Sera: pain has increased. Anything done to face sets it off. She has increased by one Epilim.

Sue: Pain level is pretty good – not getting out of control or requiring more medication. She puts it down to the B12. She takes 1000mcg a day unless she is sick when she takes 2 a day. Sue needs to inform everyone that she will be following her husband to Mt Isa at the end of the year but will come back every second month for work in her home office based at her house which her son will be renting. When she comes back in for about 10 days at a time she will keep coming to the meetings to take the minutes. Therefore both need to be timed together.

Jill: is on B12 too. Her tongue is very sore described as dull ache – especially at lunchtime. Sometimes she doesn't take her lunchtime tablets as she has trouble eating. She asked her doctor to look at the tongue because she thinks that there is a cancer there but he says that it is fine.

Mary: is also on B12. Her pain in on the Right side – from the ear and up into head – this affects her vision and hearing. In July, Mary went to the chiropractor who took her blood pressure and said that her BP was very high. The doctor gave her tablets immediately and said she needed hospitalisation. Eventually he said that she was between anxiety and depression and prescribed Cymbalta (duloxetine). Cymbalta is an antidepressant used to treat major depressive disorder and general anxiety disorder. It is also used to treat a chronic pain disorder.

Jill: Stated that Lyrica was helpful but very expensive.

Sera: Says that she might ask the doctor about the medicine (Cymbalta) as her vision is affected as well. She also said that you can get cheaper medications by being referred to the neurologist in the hospital. Sera asked Sue whether she has had a new scan after the operation failed.

Sue: said that Dr G had said that he would do one if she was not satisfied with the medication.

Notes from Sue M.

Thanks Sera.



The Christmas Gift

It isn't the flowing ribbons,
draped and curled with extra care,
or the fine and fancy bows
tied with ornamental flair.

It isn't the label on the box,
the sum of money spent,
or anything that shows the length
to which you obviously went.

The beauty of a Christmas gift
cannot be seen at all.

For the loveliness of giving
is a feeling, grand and tall.

It's the genuine offer of love,
the yearning to make a connection,
a show of honest gratitude,
a display of sincere affection



**Christmas was coming
The goose was getting fat
So I put it on the Atkins diet
And now it's had a heart attack.**



My Christmas wish to you.

Here is my Christmas wish to you
Hold it close and it may come true
Receive that special Christmas glow
Perhaps even some Christmas snow
Find Christmas spirit in your heart
That's where Christmas has to start
Find joy in the love that you share
Giving at Christmas shows we care
Enjoy the day with family and friends
A heartfelt Christmas that never ends
Keep Christmas each and every day
You may smile more but that's ok
May Christmas live inside of you
And show in all you say and do
Find joy in all that you receive
It's possible when you believe

(Poet - Will Curl)



2011 Meeting Dates

<u>State</u>	<u>GROUP</u>	<u>Date & Time</u>	<u>Venue</u>	<u>Group Leader/s</u>
ACT	Canberra	15 January 10.30am-12.30pm	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 6254 6640
NSW	Sydney	29 th January 1:30 – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads, Toongabbie.	Kim Koh ☎ 02 97431279
	Sydney CBD	5 th February 1:30 – 4:00 pm	St. James Parish Hall Level One, Phillip Street	Irene Wood ☎ 0413 363 143
QLD	Brisbane	12 February 1.30-4.00pm	30 Ridley Road Bridgeman Down	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	15 January 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	Sera Ansell ☎ 07 47516415
S.A	Adelaide	TBA 2pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Rd	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	TBA February 2:00 – 4:00 pm	Glenorchy Library Enter via Barry and Cadell Sts	Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989
VIC	Melbourne	12 February 1.30 – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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