



Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

OUR MISSION: To advocate for the awareness of Trigeminal Neuralgia and related facial pain.
OUR GOAL: To have a unified understanding of Trigeminal Neuralgia and other related facial pain resulting in better pain management.
OUR VISION: An improved Quality Of Life of a chronic facial pain patient.

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

April 2010

Do more than belong: participate. Do more than care: help. Do more than believe: practice. Do more than be fair: be kind. Do more than forgive: forget. Do more than dream: work.

William Arthur Ward

Have you renewed your 2010 Membership?

Recent increases in printing costs along with our ever growing mailing list means our average monthly operating cost now tops \$900 a month; @ \$11,000 a year.

Currently we post our newsletters to 500+ sufferers, (this does not include those receiving electronically); we also post out to 80+ health professionals; and receive an average of 18 new enquiries a month. Membership fee helps defray these expenses, however, we are behind in meeting this projected expense. We need you to pay your membership dues now.

We would also be most appreciative of any donations made to TNA Australia Inc. All donations made to TNA Aus Inc. are tax- deductible.

Health Professionals are invited to support our work with a donation instead of a subscription. Included below for your convenience a Gift Form.

Please make Cheque or Money Order payable to: **Trigeminal Neuralgia Assoc. Aus Inc.**
& send to: **P O Box 1611 CASTLE HILL NSW 1765**

Yes! I would like to support TNA Australia Inc. in their mission

Name: _____

Address: _____

Postcode _____

Phone: _____ Email _____

This is my gift to the Trigeminal Neuralgia Association Australia Inc. Support Fund to assist in their ongoing work of patients' support and education through information:

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

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

Do you have burning pain or even type 2 TN?

We are still seeking participants. If you -

- Are willing to consume the specific food type and amount on a daily basis for duration of the trial
- Are undergoing management for trigeminal neuropathic pain / Type 2 trigeminal neuralgia
- Agree to participate in the trial
- Are willing to be contacted at regular intervals for assessment

Please contact Irene Wood.

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

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

Irene.

DISCLAIMER

The information provided in this Newsletter is of a general nature only and is not intended to replace medical advice. Any views of a medical or therapeutic nature expressed are the views and opinions of the author and are not necessarily the views of Trigeminal Neuralgia Association Australia.

Before considering or undertaking any medical or therapeutic treatment described please seek advice from a Qualified Medical Professional.

Trigeminal Neuralgia Association Australia does not accept liability for any adverse consequences that may arise from following any treatment or advice described in this Newsletter.

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In December 2009, a TN member (Byril) mentioned to her Pain Specialist at POW, that she is a member of TNA Aus. The doctor interested and asked if it was possible to find out how many members were on Neurontin. *Interesting!- I thought.*

So I designed a new survey form and ran a trail at the February support meetings that I attended. The trial exposed some modification required but since I have processed the data I thought I'd share it so you can be persuaded how much we can learn from such surveys.

A total of 41 survey forms were handed out at 3 separate meetings to members in attendance. The forms were completed and collected at the meeting.

The response came from 29 Female and 12 Male. The mean age is 67.2 yrs. Youngest being 42 y.o and oldest is 82 y.o.

There were 3 with bilateral facial pain, 16 with Left sided facial pain, and 22 with right sided facial pain.

32 said that Tegretol was the first drug prescribed after being diagnosed.

75% said they responded to Tegretol. (24/32)

Epilim and Lyrica (more recently diagnosed) were the other drugs prescribed upon diagnosis.

8 /32 – were prescribed with either Gabapentin or Lyrica as adjunct medication.

Chart below shows groups with length of time suffering with facial pain.

Length of Facial Pain	Number of people	TN patients
Less than 2 years	4	3
Less than 5 years	9	5
5 years + more	8	8
10 years+ more	12	10
15 years +	2	2
20years +	6	5

In this survey, 29 years was the longest length of time suffered by a TN patient, while 6 months was the most recent.

- 33 Trigeminal Neuralgia - described their pain as sharp, shooting, electrical shocks. Some of the more common triggers are: eating, brushing teeth, cold wind, talking.
- 2 Anaesthesia Dolorosa
- 1 Glossopharyngeal Neuralgia
- 1 MS/TN
- 1 Cervical Neuralgia
- 2 with constant burning pain/ ache. (trigeminal neuropathic pain)
- 1 Post Herpetic Neuralgia

Of the 33 TN - 5 noted that their pain has changed since it first started- it now has a burning component.

This is only a small survey conducted at Sydney and Melbourne Support Group. Perhaps nation-wide the data would reflect differently. I urge you to take part in all our surveys. You hold the answer to your problems. By taking part you can help us unlock answers.

Irene.

How does gabapentin relieve neuropathic pain?

Marshall Devor

Pain. 2009 Mar;142(1-2):13-6.

The question of gabapentin's analgesic mechanism, and that of its congener pregabalin, is important because both drugs have proven analgesic efficacy in a variety of neuropathic pain conditions, they are widely prescribed and their molecular target is a novel one. Knowledge of the mechanism of action can contribute to our overall understanding of pain mechanisms, and can serve as an important guide to the development of improved analgesic agents. For this reason I write to comment on a topical review of the subject published recently in Pain [3]. The review was written by Charles Taylor, a key player in making gabapentin a success and undoubtedly an authority on the topic. Specifically, I would like to point out what I consider a serious lacuna in Dr. Taylor's review, and one that also characterizes a good deal of thought in our field, well beyond the specific subject of gabapentin.

Dr. Taylor opened his review by pointing out that gabapentin binds selectively to a Ca²⁺ channel subunit, Cav α 2- δ , in muscle tissue and brain. After ruling out muscle as the analgesic site of action, he concluded that "Pharmacology mediated by Cav α 2- δ binding is confined to the brain and spinal cord ...". He proceeded to consider several possible mechanisms of action in the CNS with a strong tilt towards a fascinating new mechanism (for an analgesic drug), interference with the trafficking of Ca²⁺ channels from the cytoplasm to the neuronal membrane. The idea is that with fewer Ca²⁺ channels delivered to the membrane of synaptic terminals in the spinal cord, synaptic transmission and hence pain will be attenuated.

Pain readers should be aware, however, that gabapentin also binds to primary sensory neurons in the dorsal root ganglia (DRGs) as shown, among others, by Taylor and Garrido [4], and that it has profound effects on the electrical discharge properties of these neurons in experimental models of neuropathic pain. Specifically, gabapentin strongly suppresses the ectopic discharge that originates from the DRG following peripheral nerve injury, at doses relevant to those achieved in clinical use. The first demonstration of this suppressive effect in the peripheral nervous system (PNS) was published 10 years ago by Pan et al. [2]. This was followed by several others, including a recent study in Pain by Yang et al. [6] who explored the mode whereby gabapentin suppresses neuropathic ectopia. There are good reasons for believing that ectopic discharge originating in the PNS contributes to neuropathic pain [1]. Hence, the fact that gabapentin suppresses ectopia ought to be mentioned in a review of gabapentin's potential analgesic actions.

But my concern goes beyond the completeness of an otherwise excellent review. The issue is broader as it extends to a wide range of pharmacological studies in which agents are assumed to produce analgesia by an action on the CNS, without any consideration given to the PNS. For example, ketamine and amitriptyline are almost universally presumed to act in the CNS because they have known synaptic effects (on NMDA-type glutamate receptors and on catecholamine reuptake, respectively). However, both also strongly suppress neuropathic ectopia in the PNS (e.g. [5], [7]). The problem is even more acute when drugs are applied intrathecally. Although many authors (and journal referees) presume that this route of delivery insures that the drug is acting in the spinal cord, it is well known that the DRG resides within the intrathecal space and is accessed by drugs injected intrathecally. One cannot presume that analgesia following spinal administration of a drug is due to a spinal action without first ruling out the possibility that the

major analgesic action is in fact on the DRG. This issue is not just of academic interest. If drugs that are widely used in the treatment of neuropathic pain such as gabapentin and amitriptyline in fact act in the PNS, it might be possible to develop peripherally acting derivatives that fail to penetrate the blood–brain-barrier. This would yield analgesic agents devoid of the CNS side effects, somnolence, vertigo and nausea, that plague the drugs in current clinical use.

Article Outline : Volume 145, Issue 1, Pages 259-261 (September 2009)

REPLY: Charles P. Taylor

I would like to thank Dr. Devor for his thoughtful letter to the editor concerning my recent Topical Review in PAIN. Many of his points are important ones. I would like to reply to some of those points in detail.

Firstly, attention is drawn to the binding of gabapentin to calcium channel alpha2-delta (CaV α 2 δ) protein expressed in the cytosol and membranes of dorsal root ganglion cell bodies. Although this observation is clear, it is less clear that drug binding sites in the sensory ganglia or axons are important to the analgesic action of gabapentin and pregabalin. In particular, the recent paper by Annette Dolphin and colleagues [1] shows that allodynia in rat sensory nerve ligation is correlated with an increase of CaV α 2 δ -1 protein in the plasma membrane of sensory neurons at their presynaptic endings in the spinal dorsal horn, but increases of protein that were mostly restricted to endoplasmic reticulum of sensory ganglion cell bodies and intracellular vesicles of axons. This finding suggests that functional increases of CaV α 2 δ -1 protein associated with allodynia are restricted mostly to presynaptic regions in the spinal cord. Devor also cites the observations of Pan and colleagues [13] showing that gabapentin reduces ectopic firing of damaged sensory neurons in a partial nerve injury model. Another paper from the same group [5] demonstrated that pregabalin (but not its enantiomer) inhibited ectopic firing in neuropathic sciatic nerve. However, other investigators (e.g. Tomotoshi et al., Pfizer Nagoya, Japan, personal communication) failed to replicate this effect of pregabalin with ectopic firing caused by chronic sciatic nerve constriction and instead found no effect on ectopic firing. Therefore, the observations of Pan et al. still need additional confirmation.

My review was written prior to the appearance of the recent report of reduced ectopic firing and reduced sustained sodium currents in dorsal root ganglion neurons by Yang et al. [18]. I agree that this is potentially an important finding. It will be of particular interest to determine whether gabapentin in Yang's model acts indirectly via binding to CaV α 2 δ proteins in sensory neurons, or instead acts by some other unknown mechanism that secondarily influences voltage-gated sodium channels. It appears that the site of drug action in this case must be other than "normal" voltage-gated sodium channels, since a previous paper [3] demonstrated that gabapentin had no effect on voltage-clamped sodium currents in sensory neurons, unlike lidocaine, mexiletine and carbamazepine.

Surprisingly little work has been focused on the anatomical site(s) of analgesic action of gabapentin and pregabalin within the neuraxis. One study [10] differentiated gabapentin responses in sciatic nerve constricted rats between vocalization to paw pressure (a supraspinally mediated behavior) and paw withdrawal (a spinally mediated behavior). Interestingly, vocalization (although produced by stronger paw pressure stimuli) was reduced at systemic doses of gabapentin that were 100-fold lower than those needed to suppress paw withdrawal

responses, suggesting a potent and important drug action in the forebrain. On the other hand, a study by Carlton and Zhou [4] showed that local injection of gabapentin or pregabalin into the rat footpad attenuated late-phase behavioral responses in the formalin footpad test, indicating a peripheral site of drug action. Additional work is needed to determine whether CaV α 2 δ -1 protein is localized at the peripheral tactile and pain-sensitive endings of sensory neurons in the periphery.

It appears that compounds related to gabapentin by structure and pharmacology fail to act as analgesics if they are poorly penetrable across the blood–brain barrier via system L transport [2]. In particular, one potent CaV α 2 δ binding compound was inactive as an anticonvulsant when given systemically (it was also inactive as an analgesic, data not shown) but the same compound prevented seizures when administered intracerebrally to mice [14]. This observation suggests that the brain is an important site of action for CaV α 2 δ drugs, but additional experiments comparing intracerebral and spinal administration in pain-related models are needed. It is certainly possible that CaV α 2 δ drugs act in the periphery (for example to reduce ectopic firing in sensory neurons) but that they also act in the spinal dorsal horn, where neuropathic rats have increased density of CaV α 2 δ -1 protein at presynaptic endings [1] and where pregabalin decreases the frequency of glutamate miniature synaptic potentials in neuropathic rats when applied locally [16].

Furthermore, gabapentin acts when applied directly to isolated neurons of the rostroventral medulla [7], [8], and gabapentin and pregabalin reduce synaptic currents and presynaptic neurotransmitter release when applied directly to neurons of isolated entorhinal cortex [6], hippocampus [12], [17] and perhaps other forebrain areas. An additional possibility not mentioned in my recent review is that gabapentin and pregabalin promote slow-wave sleep both in animals [11] and in humans [9], presumably by an action within the brain. This could have important implications for emotional stress, anxiety and pain perception in pain patients who are partially deprived of sleep by their discomfort.

Unfortunately, it is not immediately clear which of these various sites of action of gabapentin and pregabalin are the most important for their clinical use in chronic pain. I completely agree with Dr. Devor's point, suggesting that several papers have shown gabapentin or pregabalin to have analgesic action following intrathecal administration without proving where the drugs act. Intrathecally administered drugs could potentially act in the dorsal root ganglia, the brainstem, or even the neocortex. It will be interesting to see whether future investigations are able to shed more light on the anatomical sites of action that are most relevant to the clinically important actions of gabapentin, pregabalin and related compounds.

Reply to: How does gabapentin relieve pain? (Marshall Devor) , 01 July 2009

Charles P. Taylor

PAIN® : September 2009 (Vol. 145, Issue 1, Pages 259-261)

FYI : voltage-gated calcium channel alpha2-delta proteins (CaV α 2- δ); voltage-gated calcium channel (CaV); calcium (Ca²⁺); Dorsal Root Ganglion (DRG); central nervous system(CNS); peripheral nervous system (PNS).

Studies Reveal Benefits of Omega-3 Fatty Acids for Dogs with Osteoarthritis

Monday, March 29, 2010 by: Katherine East.

(NaturalNews) Osteoarthritis is a painful degenerative joint disease that affects many canines, especially geriatric dogs. Studies published in the January 2010 and March 2010 issues of the Journal of the American Veterinary Medical Association (JAVMA), report the possible benefits of feeding foods high in omega-3 fatty acid concentrations to dogs with osteoarthritis. Dogs that were fed the foods experienced less pain associated with the disease and greater mobility.

A contributing author and director of research at a leading pet food company said: "Many of us write off mobility problems in dogs as a part of the aging process. These studies demonstrate that feeding a food containing omega-3 fatty acids to a dog with osteoarthritis significantly improves mobility and quality of life. All three studies showed significant mobility improvement as assessed by either pet owners, veterinarians, or both."

274 dogs with osteoarthritis took part in clinical studies at a number of privately owned veterinary clinics and two university veterinary clinics.

The three areas of focus were:

1. The effects of omega-3 fatty acids on clinical signs of osteoarthritis in dogs.
2. The effects of omega-3 fatty acids on weight bearing in dogs with the disease.
3. The effects of omega-3 fatty acids on non-steroidal anti-inflammatory drug (NSAID) dosage in dogs with osteoarthritis.

In the first study, dogs with chronic pain associated with osteoarthritis showed improvements in their ability to play and get up from rest at six weeks after being switched to a diet containing high concentrations of fish oil omega-3 fatty acids. The second study showed that limb strength in dogs improved with omega-3 dietary intervention.

In the third study, veterinarians were able to reduce the dosage of a common NSAID used for pain relief in dogs with osteoarthritis. This was possible while still maintaining pain relief in dogs that were fed food supplemented with omega-3 fatty acids.

Osteoarthritis is caused by the progressive inflammation and deterioration of the cartilage, bone, and soft tissue of one or more joints. It is often mistaken in its early stages as "slowing down" due to old age. Canine osteoarthritis can be a silent and unrecognised problem that affects both the pet's and the owner's quality of life.

Non-steroidal anti-inflammatory drugs (NSAIDs) are commonly used to increase joint mobility and control pain in severe cases. The down side is that long-term use can result in side-effects such as kidney damage, ulcers, etc.

The relevance of the findings in this study is important because complications that may arise from pain relief medications could be reduced when the medications are used in combination with proper nutrition.

Other Health Benefits Of Omega 3 Oils For Dogs

- Omega 3 oil is very effective in controlling allergies and skin disease.
- Maintain mental alertness in older dogs
- Maintain a healthy, shiny coat.

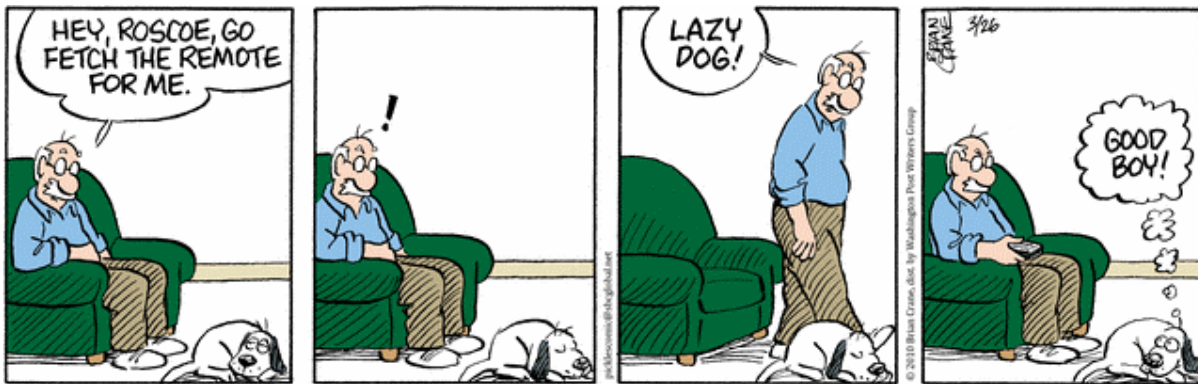
- Controls the growth of *Malassezia pachydermatis* which causes yeast infections in both cats and dogs.

Other natural treatments that can help control the progression of osteoarthritis are:

- Weight control - excess weight can cause additional pain and increased damage to dogs' joints.
- Regular gentle exercise - Improves strength and mobility of joints
- Hydrotherapy - some dogs are very fond of swimming; this is a low impact exercise that promotes joint movement without aggravating joint pain.

Nutritional supplements - some are specifically designed to reduce pain and inflammation as well as for prevention and treatment of disease.

Thought some of you might be interested- old dogs and all! ☺



Dog Logic

The reason a dog has so many friends is that he wags his tail instead of his tongue.

-Michael Combs

Puns Intended

1. The roundest knight at King Arthur's round table was Sir Cumference. He acquired his size from too much pie.
2. I thought I saw an eye doctor on an Alaskan island, but it turned out to be an optical Aleutian.
3. She was only a whiskey maker, but he loved her still.
4. A rubber band pistol was confiscated from algebra class, because it was a weapon of math disruption.
5. No matter how much you push the envelope, it'll still be stationery.
6. A dog gave birth to puppies near the road and was cited for littering.
7. A grenade thrown into a kitchen in France would result in Linoleum Blownapart.
8. Two silk worms had a race. They ended up in a tie.
9. A hole has been found in the nudist camp wall..The police are looking into it.
10. Atheism is a non-prophet organization.
11. Two hats were hanging on a hat rack in the hallway. One hat said to the other:
'You stay here; I'll go on a head.'
12. I wondered why the baseball kept getting bigger. Then it hit me.
13. A backward poet writes inverse.
14. The short fortune-teller who escaped from prison was a small medium at large.
15. In a democracy it's your vote that counts. In feudalism it's your count that votes.

Meeting Reports

SYDNEY SUPPORT GROUP

6 March 2010

Present: Irene W, Jocelyn S, Hilary & Keith W, Peter & Rose H, Ravi & Usha K, Kim S, Ray C, Marion A, Stewart & Gundel B, Frank M, Henry & Jeanette B, Ann & Laurie, Irene V, Jan, Marj & Ken F

Apologies: Elizabeth & Lloyd, Kim K, Ian L

Irene W opened the meeting at 1.45 and reminded everyone that meeting start time is 1.30, please, not arrival time! She welcomed new members, Peter & Rose and Ravi & Usha K.

Marion reports she is one of the MVD success stories, with Dr Dexter performing her MVD in July 2008 and absolutely no side effects. She just takes B12, 1000mcg daily.

Jocelyn reports, she is another Dr Dexter, MVD success story, having had her MVD 4 years ago. She also has no pain.

Ray was busy trying to operate the fans but he is yet another of Dr Dexter's MVD success stories.

Hilary now suffers Anaesthesia Dolorosa (AD). Her TN management included the Glycerol Rhizolysis and Stereotactic Radio Surgery (SRS). Recently she is also suffering from neuropathic pain in her back and wanted some feedback on Lyrica as her GP has prescribed it for her. She is on many meds and has a B12 injection every 5 weeks.

Irene explained that from her observation in her B12 studies, once every 5 weeks injection is not sufficient for pain management. Also according to the NZ Vet Journal, the B12 decreases each day, whereas a daily dose of oral methylcobalamin tends to keep B12 elevated 24 hours. She suggested Hilary would be better off taking the compounded sublingual Methylcobalamin. Irene also explained that there are many disputes regarding injected B12. Much has been debated over intramuscular, intravenous, and subcutaneous injections – and even in the subcutaneous - there seems to be a difference between deep subcutaneous, and shallow subcutaneous injection. Rather than being a pin cushion an oral route is proven effective.

Ann is fine. She continues to take B12.

Irene V. - Since last meeting she has improved, then last week she had 2 or 3 days of really bad pain, but she seems to have stabilised again. Last month she reported she was getting very dizzy & feeling unbalanced, so she tried the "sports drinks", to replenish some electrolytes back into her system & she feels there has been a noticeable improvement. She mentioned later that a recent blood test has shown she is very low in Iron and wonders why this wasn't picked up before, and if that is the cause of her dizziness as well?

Peter suffered from Shingles in his left eye in 2006 at age 44 and 9 months. He developed pain and was told it would be a permanent condition, known as Post Herpetic Neuralgia . He tried Tegretol, but was allergic to it so went on to Lyrica, which was working but over time, seemed to lose potency. He has 2 nerve stimulators implanted in his face, one above and one below his left eye, which he kindly showed us by moving the skin. (You would never know they were there). These are connected by wire under the skin to a battery pack below the stomach.

He is still having dull, annoying pain and is currently taking 1 x 10 mg Endep, Paracetamol & Codeine as required. Triggers are light, sun, wind, cold air etc.

He saw a pain specialist on Thursday and was advised that nothing more could be done. He was given 2 migraine tablets at cost of about \$10 per tablet (yikes!), and advised if they work, to get another script from his GP. He couldn't recall the name of them. He leaves his stimulator on during the day, but wondering if he should turn it off & only turn it on when needed? He does turn it off when he sleeps.

Irene W asked **Rose**, (Peter's wife) how she coped when Peter was having an attack? She said she knows when he is in pain and doesn't interfere but just tries to be there for him. The other partners in the room were all nodding their heads in agreement! Irene mentioned generally that's how most pain sufferers prefer it – Just be there, and let them ride out the pain.

Jeannette is still good! For the benefit of our new members, Jeannette had TN for 18 years and was booked in for an MVD, but prior to the op she had a stroke, which cured her.

Jan is also good, no pain. She had TN for 10 years and in 2007 it got very bad. She had her MVD in 2008 and apart from getting a "crawling" sensation & some numbness, she is fine.

Ravi got his first TN attack about 9 years ago, however it took a couple of years to diagnose, he did the usual rounds with Dentists etc. His attacks would last 30-40 mins, but he was coping Ok on 1-2 tablets per night of Tegretol. He came to one of our meetings about 3 years ago and also saw Dr Dexter. Because his TN was under control with medication he chose not to have surgical intervention. The thought of having an operation was scary enough.

However, in December last year the pain got out of control, starting in the centre of his bottom lip, and travelling along the lower right jaw. He couldn't eat, drink, talk, move his tongue, touch his lip and found it hurt to swallow and spit. It was a piercing, pinching plus throbbing constant pain. He got in touch with Dr Dexter and was lucky enough to get in to see him straight away & on the 4th Feb (barely 4 weeks ago), he had an MVD, which he proudly showed his "very hard to see" scar! He is now pain free and has reduced his meds to nil and is very grateful and very optimistic for the future. He decided to come to the meeting to share his good news. (*Hooray!*)

Kim S is still on the same meds, 600mg Lyrica & 10 Endep and is feeling good. In the last month she has been 3 weeks pain free, and just a few tiny niggles this last week.

Stewart reports he is not too bad. He has changed to Nortriptyline (25mg) from Amitriptyline. He has noticed this has reduced his pain level; however prolonged talking intensifies pain. He also notes the Nortriptyline isn't conducive to sleep...but reckons he can handle that. He stopped the Methylcobalamin and the pain has come up a bit, so he will go back on it.

Marj said she is doing well today! And she did look to be a lot brighter than last meeting. She is on the same meds except she has increased her Tegretol to 200mg per night & 200mg in the morning, plus 75mg Lyrica morning & night and she started on B12. Her pain level is OK, except when eating. She also noticed last week if she is sitting doing something & doesn't move her face, she gets a shooting pain, so she tries to do constant facial movements. She finds talking & moving her face helps ease the pain. She confirmed the need for support from husband Ken, just being there and providing a cuddle is worth more than anything.

Irene then showed a short slide presentation of Dr Burchiel's work, which was interesting.

Henry & Jeannette supplied a yummy looking Easter Egg raffle which was drawn by Rose and won by Ray. (That will make him a favourite when he gets home!)
Meeting closed at 2.45pm, and we enjoyed a cuppa and chat.

Next meeting here at Toongabbie Public School at 1.30 on Saturday 1st May 2010.

Thank you, Marion for writing the meeting report.

Irene.

**BRISBANE SUPPORT GROUP
MARCH 13 2010**

Attendance: Jill L, Lorraine G, Peter G, Lorraine B, Jeff B, Chris C, Patrice C, Marie K, Noela W, Henry C, Eilleen C, Leonie G, Tony M, Dianne H, James H.

Apologies: Margaret and Colin B, Doreen T, Mary M, Margaret H, Audrey C, Anne P, Helen W, Joan M, Shirley P

We extended a warm welcome to Jill, from the Sunshine Coast.

Our meeting began with a presentation by guest speakers James and Dianne Hermans outlining the use of quadrapolar magnet therapy in pain management.

James showed us samples and said a quadrapolar (or Q) magnet has four alternating poles or quadrants within the one magnet, rather than just two poles in the common magnet. They are able to produce an extremely strong magnetic flux density with a steep magnetic field gradient. The main applications are for acute and chronic pain.

Their development followed ten years of research by Vanderbilt University neurologists. Research shows that the most likely mechanism of action is that the steep field gradients alter nerve excitability as a result of change of sodium and calcium ion flow. Normal bipolar magnets have no effect on the firing of nerves. Correct placement of Q magnets is essential in pain control. Q magnets were first described in Australia at an Adelaide pain management conference in 1990. Many elite athletes are now using them and report considerable success, including the Queensland Reds, Titans and Brisbane Lions.

Dianne H is a physiotherapist and has been trained by a neurologist in the US. She has since trained many health professionals in Q magnet use. She said the magnets produce a static field and are listed with the TGA as a Class 1 Medical Device. They work well on stress fractures and disc herniation. They should not be used if you have a pace maker, but are fine for use near titanium.

Dianne said Q magnets work best on unmyelinated fibres, unlike a TMS machine, which works best on myelinated fibres. The two key areas for TN treatment are at the top of the spine and on the face near the ear on the affected side.

Of the eleven TN cases they are treating, they have four cases with complete or almost complete cessation of pain. The best results were with MS induced TN pain.

Another three cases showed reduced pain with reduced medication. (eg 6 tegretol tablets down to 2). The remaining four cases had some effect, but insufficient to say conclusively that the Q magnets were of benefit. In terms of safety, the WHO has said there are no known side effects using static magnets to 2 Tesla. The ones used for TN are 1.3 Tesla.

Dianne gave a demonstration as to positioning of the magnets for TN treatment. Testimonies from TN sufferers who had found relief were cited, including that of Bob D who had recently attended our Brisbane meeting.

We thanked Dianne and James for the very informative presentation.

Tony reminded our group that our association does not offer endorsement for this, or any other treatment that is described by a guest speaker.

Further to recent discussion of the book *The Brain that Changes Itself* by Doidge, Tony outlined autism treatment developments described therein.

He also spoke of the widespread use of frequent methyl cobalamin injections for this condition, often given to young children.

Leonie said that her mum was now off gabapentin completely and is about to start methyl cobalamin injections following a quite successful period with hydroxy cobalamin.

She also said a couple of people from Townsville have been in contact and are now meeting together up there to help one another out. We wish you well!!

Time did not permit us to share our stories.

Thank you to all who again assisted with our afternoon tea goodies-delicious as always.

TN is a real shocker, but a great way to meet very nice people over a cuppa!!

To our dear friends who can't be with us, you are very much in our thoughts. We hope the burden of your struggles can be lightened. Colin, we trust you are on the road to recovery after your recent hospital visit.

Father John at the parish here is really interested in our plight and will have the church congregation pray for our group. Thank you, John.

Gold coin donation: \$24

Next meeting: Saturday May 8, 1.30 pm

Tony.

SUNSHINE COAST SUPPORT GROUP

Saturday 20th March, 2010.

Attendance: Teresa M, Jean B, Patricia O, Peter & Pearl R, David & Gloria G, Lloyd K, Jim K, Andrea F, Jill L.M

Apologies: Jean W, Sherryl M, Trixie & Keith B, Kay C, Max G, Glenda W.

Trixie had her MVD last month. Keith called from Sydney after her op to say the operation was a great success, Dr Dexter was pleased and Trixie was recovering well. Teresa spoke to Trixie the week after her operation, she was feeling great, no pain, no numbness, no problems with eating. Trixie and Keith left for an overseas trip two weeks after her operation, we hope she is still keeping well and is enjoying being pain free.

Max is unable to attend today as he is not well – (not TN). Max has gradually reduced his medication to 200g Tegretol p.d, and is feeling good.

Lloyd: Still no pain whatsoever since his MVD 15 months ago. However, he is still afraid of going swimming as that is what set off the first TN shocks.

Jim: Pain free as far as TN, but has neck trouble. Saw a program on SBS to do with pain that was very helpful to him. Jim was led to believe that his TN pain was due to mental illness, it was many years before he was actually diagnosed as having Trigeminal Neuralgia.

David: He has some eye trouble, but no bad shooting pains. David is still having medication for an eye problem but is on no medication for his TN.

Jean B was pain free for almost 12 months. She ate a couple of biscuits without her dentures and the next day got pain in her gums and up to her ear. It is not as bad as the pain she had before, but is a different type of pain, more like a pumping pain.

Andrea was pain free since July. She then got a toothache on her right side which only lasted for a day (her TN is on the left side). The next day the pain on her right side returned. Her previous attacks were different. The pain is now shooting from the side of her nose right up to her head – like a red hot poker. Pain is triggered by touching her head. Andrea is on 200mg Tegretol p.d and does not want to increase that dosage due to adverse side effects she has experienced previously. She is also being treated by her son with naturopathic remedies. She is going to see a “young” dentist who has an understanding of TN.

Trish: Has had ongoing problems with pain in her teeth and jaw over many years. She has had numerous extractions and root canals. Trish asked the group if anyone knew of a doctor and a dentist that was experienced in the treatment of trigeminal neuralgia. She is also considering a consultation with Dr Dexter. Trish has written down what she wants to say so she doesn't forget anything.

Jill: Is thankful that she attended her first meeting two months ago and heard of other members experiences with TN as well as borrowing “Striking Back” from our library. This prepared her for the shock of her worst attack to date. She is getting shooting, hot poker pain from her ear down to the side of her mouth. She started on Lyrica, 2 x 75 mg each night, but found it difficult to get out of bed in the morning due to dizziness. Now taking 10mg Endep in the morning and 75mg Lyrica at night. Jill attended the Brisbane support group meeting and was interested in the presentation on magnetic therapy.

Teresa: Still doing really well since MVD two years ago. In the last 6 month or so has some sort of fluttering in the right ear.

Teresa gave a brief presentation on the three “through the cheek” procedures, Glycerol injections, Balloon Compression and Radiofrequency lesioning.

Our next meeting is on the 15th May, 1pm at Nanyima Street (Kawana Library). We have a **guest speaker next meeting – Drew Glendining**, a chiropractor specialising in upper cervical care.

A special thanks to Pearl for taking the minutes today and to all those who helped with setting up as well as cleaning up after the meeting

Teresa

SYDNEY CBD meeting report for 27th March will be deferred to May Newsletter

Next meeting: June 5th @ 10 AM.

Irene.

Correspondence Corner

Do you have a dentist who understands the situation with TN patients so that she can consult with him/her with confidence? (Sydney area). Nagu has been suffering from a bad toothache for the last few days. She is afraid to go to the regular dentist as he has little experience with TN patients.

Please contact Irene – to pass info to TN member.

Trish (QLD): For me, Lyrica has affected my senses of taste and smell, and has increased my sensitivity to hearing especially high-pitched sounds. The worst side effect is the function of my brain, which has become quite slow and I find it difficult to understand and comprehend new concepts. I find this disability frustrating, but the relief of chronic tooth and head ache more than makes up for it.

Finally I have a question: When my eyetooth was removed, it seeped muck for months, but I finally had no pain in that area. When the gap closed over I noticed I began to have a sensation in the cavity area that feels like a raw sore full of gravel and I cannot touch the spot with my tongue, it is excruciating. Some days it is not there, but more often it is. **Has anybody else experienced this and if so what have they tried?**

Try this:

Alwyne (NSW): So I soldiered on without treatment until June 30 when I mentioned it my doc. He suggested Gabapentin 3 x 300mg per day and suggested I consult the Pain Management Center. I saw Dr P. who prescribed a gradual increase of Gabapentin to 6 tabs per day plus local anesthetic cream – **Amethocaine** (very effective). Pain eased and eventually disappeared for over a week.

FYI : Amethocaine gel for topical anaesthesia: a stability study using HPLC

White B 1, Titchen T1, Bakalova M 2, Finnin B 2

1 Pharmacy Department, Royal Children's Hospital, Parkville, Vic

2 Pharmaceutics Department, Victorian College of Pharmacy, Parkville, Vic

Amethocaine base 4% in methylcellulose gel is currently manufactured by the Royal Children's Hospital pharmacy. Amethocaine gel for topical anaesthesia is effective and has minimal side effects. It is used as an alternative to EMLA[®], the proprietary preparation containing lignocaine and prilocaine. It has a number of advantages over EMLA[®]; it is considerably less expensive and has a faster onset and longer duration of action. Additionally, application of the amethocaine gel produces vasodilation enabling easier cannulation. A similar product has been used extensively in the United Kingdom for many years.

This study was undertaken to assess the stability of the gel and allow an appropriate expiry to be assigned. **The current shelf life is six months if refrigerated** or one month if kept at room temperature.

- THE ROYAL CHILDREN HOSPITAL MELBOURNE – PHARMACY DEPARTMENT

2010 Meeting Dates

State	GROUP	Date & Time	Venue	Group Leader/s
ACT	Canberra	TBA July 10.30-12.30	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 62474508
NSW	Sydney	1 May 1:30pm – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Irene Wood ☎ 0413363143 Kim Koh ☎ 02 97431279
	Sydney CBD	5 June 10:00am –12:30 pm	St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413363143
QLD	Brisbane	8 May 1.30-4.00pm	30 Ridley Road BRIDGEMAN DOWN Guest: Chiropractor	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	15 May 1:00 pm	Kawana Library, Nanyima Street, Buddina	Teresa Miller ☎ 07 54912487 Jean Williams ☎ 07 54911978
	Gold Coast	No date set	The Palm Beach Surf Club,	Ann Papandreas ☎ 07 5522 6892
S.A	Adelaide	TBA May 2:00pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Road	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	16 May @ 12:00 noon	Venue to be announced Guest: Dr. Arun Aggarwal	Helen Tyzack ☎ 08 6245 0429 Ros Wilkinson ☎ 08 6234 7989
VIC	Melbourne	17 April 1:30pm – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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