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

**October 2007**

*What else can we talk about - but our 2nd National Conference!!*

“Begin with the end in mind” – was aimed at helping you understand the mechanisms of pain, the process of pain signals, the biochemical anatomy of pain pathways, the mechanisms of neuropathic pain, how cells/neurons behave, cell death etc. as well as to provide you with an insight to the treatments available. In short I hope the science – the “WHY” would enhance your decision in the “HOW” for your pain management.

Terminologies are only unfamiliar names but with regular use, you will eventually get the hang of it. Remember when you could not even say Microvascular Decompression? You so easily now identify with it as MVD.

**My highlight:**

“The Ignition Hypothesis” - Prof. Marshall Devor

*Ever since I read his work in 2002 I had wished for the opportunity to hear his lecture. Below are my notes. Any error is strictly mine.*

- “TN is a Peripheral Nervous System problem and not a Central Nervous System problem.”
- Anti epileptic and anti depressant drugs that are effective for trigeminal neuralgia are membrane stabilizers. Membrane Stabilizers have the ability to suppress ectopic firing (abnormal firing) of injured nerve fibers.
- The biopsy sample of MVD patient showed the nerve fibers in close apposition- nerve fibers touching one another without the insulating sheath (demyelination) - the anatomical basis for cross talk / cross excitation to take place.
- Chemical cross talk = cross excitation - occurs at nerve injury site and sensory ganglion.
- The amplification is: one fibre cross exciting many neighbouring fibres (indirectly) at the injured nerve site as well as within the ganglion. (cross excitation amplification)
- In trigeminal neuralgia, the ganglion is hyper excitable due to the vascular compression.
- The trigger therefore sets off spontaneous ectopic firing, which then leads to an explosion of activities in the ganglion (the compression site).
- The Aβ fibres (touch fibres) can activate C fibres, (cross exciting nociceptive fibers) hence why touch can cause pain.
- The firing itself turns off the firing. The nerve cells firing at high frequency cause hyper polarization & the cells become less prone to fire.
- Why electrical shock sensation? - The only thing that activates all the different kind of sensory cells simultaneously is electrical shocks.
My thoughts:
If anatomical basis for ephaptic cross talk and cross excitation is the close apposition of nerve fibres (due to the loss of the myelin) then perhaps re-myelination of these nerve fibres would minimise such phenomenon?
If membrane stabilizer reduces the tendency of a nerve cell to fire - a membrane stabilizer drug applied topically on the site of trigger should reduce more quickly such ectopic firing.
And if we minimise the ectopic firing, minimise the cross excitation, then perhaps there would not be any ignition /explosion? And if TN is a peripheral nervous system problem – there would be NO pain. And if all is so simple – I could retire tomorrow. 😊

More questions:
1. IF membrane stabilizer suppresses the tendency of peripheral nerve fibres to fire; then why do TN patients who are on daily doses of such drugs still get tic attacks? Plasma concentration? Why do pain break through?
2. And when one achieves no pain – would it be wiser to stay on a minimum dose of the drug than to come off it completely?

Irene.

Below are notes from members who attended the conference. I am proud to share their highlights with you. The reward for organising such a conference is the fulfilment of the purpose and that is, you are able to learn from it. Happier still is the fact that I don’t have to organise the conference then write all the notes for you. Deciphering my own handwriting can be a major task. 😊 Please note: these are just individual notes – not necessarily accurate.

Neurobiology of Pain: Ken Casey
Tony: Pain is fundamental to species survival. Tegretol, Neurontin etc do not cure TN. Treatment of whole person is essential. Patients seem to respond well if MVD is done in first 7 years. Medication is not useless but cells keep changing and damage continues to occur.
Kim: This talk focused on the different fibres in the nerve and what sense they control and why the messages get confused when nerve is damaged/compressed. The nerve becomes overly sensitive due to the repeated stimulation.
Irene: there are at least 8 different voltage-gated sodium channels present within the nervous system.

Abnormal Peripheral and Central Excitability as Mechanisms of Neuropathic Pain:
Prof. Manfred Zimmermann
Tony: Apoptosis is programmed cell death. Lidocaine could be a very useful topical agent to apply to face to reduce pain and studies on this ought commence. Botulin toxin and capsaicin to trigger zones may also be of benefit. Stay active and maintain your potential to enjoy life. DA UT DES-Give to others and you will receive rewards.
Kim: Looked at how nerve injury causes excitation of the nerve. The nerve may stop firing due to repetitive stroking. Lidocaine increases the refractory period and reduces length of attack. The reflex action of the nerve impulse causes the cycle of pain fibres activating. Also discussed the research into male & female HRT
Irene: Peripheral damage signals may reach the central nervous system to form central pain generators. Lesions of peripheral nerves result in apoptosis in the peripheral nerves and in the spinal cord. Microglial mechanisms and also immune system are involved in neuropathic pain - early treatment to prevent progression.
Genetic Analysis of Neuropathic Pain Mechanism : Prof. Marshall Devor

Tony: Over 10% of population have a lesion that should be causing TN pain, yet only 1 in 1000 of these report pain. Perhaps a genetic reason and identification of such a gene would lead to early treatment.

Kim: Looked at variability in pain responses between different patients. Some can have same injury and different pain. Looked at genetic differences. Also how psychosocial factors can change pain.

Nagu: Variability to pain sensitivity depends on genetic factors as well as environment (family, ethnicity, culture, etc.)

Irene: variability in pain response among individuals - traditionally explained in terms of socialization i.e. “environment”. Genetic polymorphisms and mutation plays a role - gene identity can inform pain mechanism eg: genes affecting susceptibility to disease states that may be painful vs genes affecting susceptibility to pain - a uniform pathology – predisposition for pain?

Dental and Orofacial Pain: Dr. Russell Vickers

Tony: TN pain ranks as highest pain level. It is impossible for a doctor to understand months or years of pain in a 15 to 30 minute consultation. Hormone treatments will be of benefit - estrodiol enhances pain, progesterone relieves. 50% of patients on Tegretol report serious complications.

Kim: Tn patients have highest level of pain. The oestrogen in the pill can increase pain. Need progesterone only.

Trigeminal Neuralgia Diagnosis and Medical Management: Dr. Arun Aggarwal

Tony: Tegretol CR has a response in 65-80 %. A Lyrica study showed 55% of people on a placebo improved, compared to 80% on actual drug (20%+ of these though reported side effects such as dizziness). Oxcarbazepine is Tegretol without the side effects. Tricyclic antidepressants can control pain with quite low dosage, side effects come with higher doses. Capsaicin works, but burns. Norspan, a weekly patch, gives a good baseline pain relief. Ketamine is useful but has side effects including hallucinations and unsteadiness. Vitamin B12 has been used since 1940. It is required for myelin production. Deficiencies lead to nerve damage.

Kim: Looked at different medications and their effects. Wind up pain can be reduced with ketamine - intravenous trial and then move to lozenges if effective. Lignocaine can be added.

Teresa: Wind Up – Caused from prolonged response to noxious stimulus. can reduce with Ketamine (intravenously), oral is available, but not effective as high dosage is needed.

Irene: Oxcarbazepine = Trileptal

Other Neuralgias: Glossopharyngeal, Geniculate, Occipital: Dr. Mark Dexter

Tony: 20% of post herpetic neuralgias involve TN nerve. Herpes zoster resides dormant in ganglion until immune system is weakened. Often after operations cold sores erupt.

Kim: Many similar pain to TN – Importance of accurate diagnosis for correct treatment.

Geniculate neuralgia involves ear pain and deep face pain and triggered by noise.

Is it Trigeminal Deafferentation Pain or is it Anaesthesia Dolorosa? What then?: Dr. Andrew Danks

Tony: begin "lightly" with surgical approach so as to avoid numbness. His view is that early treatment with MVD may not necessarily improve outcomes.

Kim: When pain returns – is it same pain. Is it a new pain caused by surgery or unrelated problem. Possibly repeat previously tried treatments eg medications & try new ones. Prevention of damage to nerve is best – avoid further denervation.

Motor cortex stimulation will become more widely used in next 5 years.
Pathophysiology of Trigeminal Neuralgia: The Ignition Hypothesis: Prof. Marshall Devor

**Tony:** TN is rare—5 cases per 100,000 per year. Membrane stabilizing anti-convulsants work.

**Kim:** Treatments that work are those which stabilize the membranes—anti-convulsant, slows down the excitability of the peripheral nerve—antidepressant—silences the ectopic firing of nerve, reduces hyperexcitability. Pain is like electric shock because all the senses are affected.

**Irene:** Barbiturates do not silence the abnormal firing. Amitriptyline in addition to acting on the synapse, also act to suppress ectopic firing.

Chronic Pain and Depression: Neurochemical Connection: Dr. Russell Vickers

**Tony:** Depression in 75% of TN patients. Pain produces fear and helplessness, sleep deprivation, anger and anxiety. Drugs and cognitive behaviour are of benefit.

**Kim:** Pain experiences are encoded with negative emotions. Face pain emotionally disabling due to the way it affects our image of ourself. Learn to recognise negatives behaviours that indicate depression. Important to look after the whole person not just the pain.

Individualisation of Surgical Treatment: Introduction: Dr. Andrew Danks

**Tony:** TN is different to other neuralgias in that disturbance of nerve leads to pain reduction. Percutaneous Procedures Goal is minimum disturbance.

Balloon Compression: Dr. Andrew Danks

**Tony:** Expect numbness. 64% pain free at 10 years. Blood pressure soars in procedure.

**Kim:** Sensory loss indicates the procedure’s success. Severe numbness may settle to acceptable level. What is acceptable?

**Irene:** Inflate balloon with 0.75 mL contrast for 1 minute, observe shape to verify position and amount of inflation.

Glycerol Rhizotomy: Dr. Mark Dexter

**Tony:** Initial success 90%, but sensory changes in 50% (18% moderate or severe)

**Kim:** Aim to damage pain fibres but preserve touch fibres.

**Irene:** 0.2 ml of sterile anhydrous glycerol. Patient sit up for two hours.

Radio Frequency Rhizotomy: Dr. Ken Casey

**Tony:** One day, Early success 65%, 50% at 5 years.

**Kim:** Difficult to get the right level of “burning” all nerves have different vulnerability.

**Nagu:** RF rhizotomy (burning of nerve) and MVD result in highest rates of initial pain relief. Numbness is a problem with RF rhizotomy.

**Irene:** Unmyelinated pain fibers can be irreversibly affected at 55°C to 75°C.

Motor Cortex Stimulation for Trigeminal Neuropathic Pain: Dr. Mark Dexter

**Kim:** Has a role in many types of face pain including AD and TN 2. Still under trial, and is reversible.

Thin Cut MRI: Operative Outcome Correlation: Dr. John Alksne

**Tony:** 3.5 mm cuts are OK for tumours & MS, but 8 mm needed to look at TN nerve. All hospitals do not have the Protocol. If 4 out of 5 successive cuts show nerve artery contact, then MVD is best. If no contact, use stereotactic radiosurgery.

**Irene:** Not a diagnostic test!! - a reliable predictor that a vessel will be found at Surgery, assists patients in decision making, suggest that patients with non-classical TN may benefit from micro-vascular decompression!

Microvascular Decompression and Prognostic Factors for success: Dr. A. Danks.

**Tony:** MVD widely regarded as best surgical option as it treats the cause of the problem. 70%+ pain free at 10 years. If relapse, can repeat. Death in 0.4% of cases.
Long Term Outcome for Microvascular Decompression for Trigeminal Neuralgia;  
Second MVD Findings and Results : Dr. Mark Dexter  
**Tony:** patients on repeat MVD - 89% pain free at 10 years  
**Kim:** Recurrence of pain higher risk if female, vein compression, over 8 years pain.

**Prognostic Factors for Recurrence: Dr. John Alksne**  
**Tony:** No procedure is 100% effective. MVD has 15-20% failure over time. Duration of TN >8-10 years increases risks. Enjoy being pain free while it lasts!!  
**Kim:** Initial failure to respond to AED, Vein more likely to adhere to nerve.

**Neuro-protective and antinociceptive mechanism of B Vitamins: Prof. Manfred Zimmermann**  
**Tony:** Consistently, animals tolerate more pain with methyl cobalamin. B12 seems very potent in neuropathic pain conditions as it protects nerve cells against apoptosis (cell death)  
**Kim:** B12 protects nerve cells against secondary damage due to apoptosis. B12 has important role in Neuropathic pain conditions – B1 & B12 major anti- allodynia.  
**Irene:** B1 – Thiamine is involved in metabolism and energy provision in nerves. B6- involved in the synthesis of serotonin and GABA in CNS. B12 plays a role in myelin formation. Role of Vitamin Bs – Analgesia, Neuro-protection and advanced glycation.

**Transdermal Medication: Ms. Marina Holt.**  
**Tony:** Topical treatments are available from compounding pharmacists.  
**Kim:** Works deeper into the systemic circulation. Largest portion goes into first area of application.

**Why the medication/s did not work: Dr. Arun Aggarwal**  
**Tony:** Neurontin generic is available at less than half the cost. Not the same drug- try it. If it works stay on generic, otherwise switch back.  
**Kim:** Incorrect diagnosis, wrong medicine type, wrong dosage, patient compliance, financial  
**Nagu:** Start with low dose and increase dosage gradually - takes a couple of weeks for the medication to take effect.

**Role of Acupuncture in Pain Management: Dr. Chin Chan**  
**Tony:** used for 2000 years. Serotonin levels & other good chemicals rise after treatment.  
**Kim:** Takes 5-6 treatments for body to realise what acupuncture is trying to achieve and to “switch on” to the treatment

**What to expect at a Pain Management Clinic: Dr. Helen Boocock**  
**Tony:** An integrated approach to pain management linking advice from a group of professionals.  
**Kim:** Multidisciplinary program – How to get patient back to being “you” after interviews, professionals have meeting to come up with master plan. Lists can be long for attending pain clinic.

**Your pain management is a joint decision with your health care professional: Dr. A. Danks**  
**Tony:** Teamwork is best approach. The doctor who treats himself has a fool for a patient!!  
**Kim:** Patients vary in the relationship to Doctor – some are Dr led, others Patient led, teamwork approach – informed patient – many factors involved including knowledge, prior beliefs, trust, social support, personality.
Feed back from the conference:

Graham: What a wonderful weekend it was. Even for people suffering with TN – as many were. The Trigeminal Neuralgia Association Australia 2nd National Conference on South Molle Island had everything. A spectacular location, eminent speakers, a comprehensive range of topics, a host of like minded friendly people, efficient organisation – great atmosphere.

What did we get at South Molle?
- The opportunity to learn about TN from some of the worlds leading surgeons and medical professionals and the latest treatments and resources available to help us cope. The chance to ask experts questions relative to our own situations, not just in the lecture hall but also in a one on one discussion over breakfast or dinner. Amazing.
- The chance to meet and make friends with fellow sufferers (and the cured) who understand what TN pain is like, to share experiences, compare treatments and gain support for the future.

What outcomes from South Molle?
- A better appreciation of the nature of the beast (TN). The importance of confirming whether it is classical TN or other facial pain.
- An understanding of the wide range of treatments and medicines available including natural therapies. The pros and cons of the different options and the possible risks involved.
- Now able to have informed discussion with doctors and surgeons. Able to make a better decision as to the most appropriate treatment relative to ones own circumstances having regard to previous treatments, age, health etc.
- Recognising the importance of support groups and the sharing of knowledge to all sufferers so that informed decisions can be made and support given to both sufferers and their carers.
- A network of new friends and support. The knowledge that we are not alone.
- Anticipation for the next conference in Victoria in 2009 – start planning.

MJ: First of all my compliments for a GREAT job, organizing the Conference. It has been a real help to me hearing all the Doctors and scientist and speaking to other sufferers. You can already book me in for the Next conference.

B&PW: Our thanks for a superb conference. Your choice of venue, papers and presenters gave us a most enjoyable and informative experience. We look forward to 2009! Hard to give specific highlights for such a superb conference with an impressive selection of high quality speakers. Personally I was particularly interested in the references to recurrence probabilities which were well covered by several speakers. Not that I want or expect to suffer a return of TN, but it helps to know the odds. Just having that information before the event makes it easier to make the right choice, without rushing the decision at a time when it’s difficult to think clearly. Congratulations and best wishes.

MM: Thought I’d just drop you a quick note to thank you so much for all the effort you put into organizing such a great conference. The venue was just perfect – so relaxing and tranquil – and it all went too quickly.

LG: Peter and I would like to thank you for all the work you must have had to do for the excellent South Molle conference. The mind boggles when we think about co-ordinating speakers etc. and congratulate you on being able to arrange for such excellent speakers etc.etc.etc. I am still considering my options and will consult my local G.P before making any decisions. Heartfelt thanks once again .

AD: Well done Irene, this was a great success, even better than last time!
MZ: Great thanks to you, for arranging all of the meeting and selecting this lovely place, with a remarkable efficiency and strength. I am admiring your great personal power - it will reach much beyond your activity for the patients in TNA and might initiate new border crossings in the understanding and treatment of TN....

MD: Congratulations on a fabulous conference. It was excellent and even better than the Bondi meeting.

MH: As usual you did a stellar job in organizing the conference. It was a wonderful event to be part of, and I thank you for the opportunity to be involved. I particularly enjoyed the opportunity to meet so many researchers in the field, as well as the relaxed setting which enabled us to all speak to TN sufferers and their families in an informal yet very productive way. As always, I learnt a lot, and was excited to see so many professionals sharing ideas and learning from each other.

BG: Thank you for the wonderful experience you provided for us neuralgians and partners and friends.

JS: Because my main interest is what could I do if the pain comes back, the highlight for me was the 3 different types of Percutaneous Procedures. (Drs Danks, Dexter & Casey).
Dr Casey said that in the USA before they do the Radio Frequency Rhizotomy they suggest that the patient be injected with a pain killer that will numb the side of the face for approx 3 weeks to see if the patient could stand to have that numbness permanently.

AM: Many thanks for the TN conference which has been very informative and beneficial. I'm very impressed how professionally run it was and the quality of the speakers. Well done!!! Can't wait to attend the next one.

KS: Wow! What a great Conference. The speakers were excellent and provided a wide range of information. The scientific aspect of the talks were interesting, although harder to grasp at first, but showed a completely different perspective on the study of pain.
It was such a fantastic venue and encouraged a lot of mixing between patients and doctors. I felt like I met so many people and probably spoke to almost everyone at some stage, either over breakfast, tea breaks, lunch and dinner.
Most of us had a chance to speak to at least one doctor or speaker, one on one. They were so helpful, and very happy to help, as they have such concern for all of us.
It was great to get different perspectives from the different speakers. I have learnt so much more. My find is filled with information and my heart filled with the new people I have met. I now feel a connection to people all over the country and can put a face to names I see in the newsletters all the time.

ED: We enjoyed our time at South Molle and the chance to learn more about TN and meet so many who share the experience.

H&KW: It was like the Olympic Games – a rare collection of the experts in their field – and truly “the best ever.” It was a wonderful conference ......er... too modest to type the rest but Thank you for your lovely card. Very much appreciate the words in the card “for the sunlight you’ve brought to our days.”

Our 3rd national Conference will be held in Victoria in 2009. Start putting your penny aside so that you can join us and enjoy a wonderful experience.

No great or good things are ever achieved alone... it is from the support that uplifts the achievement. My personal thank you to all – speakers, conference delegates, volunteers for making this a great success.

Irene.
On the Lighter Side:
We were impressed that the Resort Manager personally greeted us at the jetty and everyone received a welcome drink…. only it was not alcoholic. All the Resort staff always had great big happy smiles. I was impressed that the chef took time to learn about trigeminal neuralgia.

The island has bush turkeys, wild pheasants, besides pythons. I also discovered those lorikeets have very long and sharp talons. Some of us were lucky enough to see the whales breaching.

Other Things that were discussed:
If a coconut had just landed behind you, practically missed you by a whisker, **DO you for the rest of your time on the island walk with your eyes upwards looking for the next coconut bomb?**
The answer is NO. Because:
1. If one hit you and you didn’t see it coming, you wouldn’t know what hit you.
2. And if it hits right on the noggin, there is a chance of the coconut bouncing off.
3. Also we simply cannot afford another face pain condition: “coconuted face pain”; whereas a chronic headache is OK – it is quite common.

**DO those skinny legs of the Curlew have any nerve fibres? If one was to create a lesion on one of its leg, would it feel pain?**
Can’t give you the answer - the bird would not stay still. However we did see one that had a broken left leg, and it did not seem to be too bothered. These birds possess a horrible high pitch scream perhaps it’s from the agony in their legs?

- Some of us can play table tennis – some of us can only try. Alas! Graham and I got whipped by a pair of amateurs. 😊
- The Resort organised nightly activities and one of them was a trivia night. We soon found out we were not very good in trivia concerning some local TV productions. We wanted them to ask nerve or pain questions – but they wouldn’t. 😞 Just so unfair!
- One night they held horse races in the bar, I landed a horse with the flu, it died half way through the race. But luckily, it was Dr. Aggarwal’s money.

The Art Group had some splendid work for display. Congratulations to the participants for their accomplishments.

Thank- you Pat for minding our desk and helping out each day with the sales of books, hats/visors and collecting all the money. Below - Our volunteer at work.

Below - Our volunteer at work.
Meeting Report:  
Sydney Support Group  
Toongabbie Public School  
1st September 2007

Apologies: Audrey T, Keith & Hilary W, Norma M, Lilian B.

We welcomed everyone to the meeting and especially to Jan for her first meeting. The group also send their best wishes to Audrey as she recovers from back surgery.

Irene spoke about the Conference this week. It is an amazing opportunity to gain a huge amount of information. You would need to spend a fortune on consultations to learn this much about the condition. Irene hopes everyone would take up the chance of attending a conference if they are able to.

Jan: Jan’s daughter found the association on the internet. Jan has had TN for 10 years. Her pain is right side lower jaw up to the eye. Her dentist diagnosed after removing tooth. She has worn a splint for a misaligned jaw. After she got electric shocks the GP gave her Tegretol and sent her to Neurologist. Has been taking Tegretol SR which controlled the pain till March – her head felt like it was on fire when washing her hair. Started Neurontin in increasing doses and the pain was coming week on and week off. Now on 1800 Neurontin and Baclofen twice a day, was in control but now flaring up. Pain is often burning. Jan also experiences a prickling pain in the back of the head, which needs to be explored further.

Lorraine asked about taking B12 –Irene gave a quick rundown on B12  
NOTE: Anyone interested in taking part in the B12 program, please contact Irene.

We had a short discussion on spreading the word about the support group. Suggestions were putting ads in as many local papers as possible prior to the meeting. Also putting flyers up in libraries, community centres and Doctors surgeries. A member also suggested approaching local libraries to purchase a copy of the books. We also discussed sending contact details for our Health professionals so they may be added to the database to receive a newsletter.

We discussed what we need in a doctor  
*to know they care about you  
*to feel supported  
*to know they will be prepared to look further for information if they don’t know the answers  
*to refer members to the Association

When you visit the doctor: BE PREPARED.  
• Don’t rely on memory.  
• Write down any questions you have.  
• Describe your pain very specifically, What the pain feels like, how long it lasts, where the pain is etc. Keep a pain diary  
• It is a good idea to write it down if you will be unable to talk to the doctor due to the pain.

Jeanette told us about a card she keeps with a list of all her medications. It includes dosages and schedules. This is updated once a month. She is able to hand this to the doctor which then saves lots of time asking questions.

Thankyou, Frank for coming to the rescue with afternoon tea for us all. Also thanks to Lorraine for your beautiful caramel slice and Jeanette for the birthday cake. Everyone enjoyed the chance to catch up and share info over this lovely food.

Take care - Kim S.
For Your Information

Link Healthcare has advised that Zostrix and Zostrix HP are both available now in Australia and that “the recommended retail price has been significantly reduced on previous levels.”

Multiple Sclerosis Gene Discovery First Major Genetic Advance in 30 Years
Caroline Cassels

July 30, 2007 — The discovery of a new gene linked to multiple sclerosis (MS) marks the first major genetic advance in the disease in more than 30 years and may pave the way for future research and treatment options. Two separate but related studies published online July 29 in Nature Genetics and the New England Journal of Medicine report the discovery of the interleukin 7 receptor (IL7R) alpha chain gene. According to investigators, this is the most significant MS genetic breakthrough since the 1970s and only the second MS genetic risk factor confirmed through research.

Second Gene in 30 Years
"Although there are no immediate clinical implications, this is a great breakthrough on the research side of things. This discovery opens up an entirely new avenue of research and provides us with a new set of genes and proteins that will ultimately lead us to new targets for drug therapy and better diagnostic approaches," Jonathan Haines, PhD, principal investigator of the Nature Genetics study and senior corresponding author of the New England Journal of Medicine paper, told Medscape.

Correspondence Corner

MH: Was reading your wonderful September 2007 newsletter and you had a question on pg 10 about Lyrica. I have 2 different people in my group who were on Neurontin and were switched to Lyrica - they were first switched to Tegretol and then Lyrica was added later. Now for how Lyrica worked - both said it made them gain weight, clumsy and stupid. One lady who is 77 found she lost her balance sometimes and she dropped I don't know how many correll plates. We had a good laugh over that after awhile since she ended up breaking so many plates she would often send her email saying she needed to run to the store and get a couple new plates. She is now off of the Lyrica after having successful surgery and doing much better. She also did not drive during this time.

Other then these 2 ladies I do not know of anyone else on Lyrica. Hope it helps a little. I feel so badly for the person writing to you and the doctor who wasn't willing to help. Doctors like that I wish TN pain on them just for an afternoon so they can see how non fun this disease is.
NEXT MEETING: 2007

ACT
13 October: 10:30 am  CANBERRA SUPPORT GROUP
Venue: Weston Creek Community Centre
Support Group Leaders: Jan Goleby – 62474508

NSW
1 December: 11:00am – 2:00 pm  SYDNEY CBD SUPPORT GROUP
St. James Church (crypt), King Street.
Support Group Leader: Irene Wood 02 45 796226

3rd November: 2:00 pm – 4:30pm  SYDNEY SUPPORT GROUP
Toongabbie Public School,
Cnr. Fitzwilliam and Binalong Rds, TOONGABBIE

TBA
COFFS HARBOUR SUPPORT GROUP
Sawtell Uniting Church, 24 Elizabeth Street, SAWTELL
Support Group Leader: Ailsa Braid 02 6658 3051

NEWCASTLE SUPPORT GROUP
Meeting - suspended till further notice

QLD
22 September: 1:30pm - 4:00pm  BRISBANE SUPPORT GROUP
30 Ridley Rd., BRIDGEMAN DOWN
Co- Support Group Leaders: Leonie Gall 0407 55 44 07;
Tony MacPherson 07 3822 2286

29 September 10:30 am – 1 pm  GOLD COAST SUPPORT GROUP
The Palm Beach Neighbourhood Centre, 16 Third Avenue, Palm Beach.
Support Group Leader: Andree Chenevier 07 55200228

20th October: 1:00pm  SUNSHINE COAST SUPPORT GROUP
Fletcher Dental Surgery, 23 Beach Rd, MAROOCHYDORE.
Support Group Leaders: Connie Holden: 07 54833939
Neil Westbrook: 07 54451700; Teresa Miller: 07 54912487

S.A
7th October: 2:00pm  ADELAIDE SUPPORT GROUP
Corner of The Parade and East Terrace, KENSINGTON GARDENS
Support Group Leaders: Graham/ Liz Boyer: 08 8392 2781
& Barbara Stentiford 08 84452019

VIC
13 October: 1:30pm  MELBOURNE SUPPORT GROUP
"Ringwood Room" Ringwood Library, RINGWOOD
Support Group Leader: Evelyn Diradji 03 9802 6034

Contact: Irene Wood, P.O. Box 1611, Castle Hill, NSW 1765 Australia
Tel: 02 45796226, Email: tna_sydney@yahoo.com or irene.wood@tnaustralia.org.au
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