



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, Townsville.

September 2010.

As well as celebrating TNA's 20th Anniversary, the National Conference theme is Facial Pain – A Global Dilemma. Both Jillie and I were asked to submit an article of about 500 words regarding our organization, and provide a background as well as information on our services & outreach. This was to be added into their commemorative program book. I thought perhaps you might like to know what I had submitted.



Trigeminal Neuralgia Association Australia Inc.

Congratulations on your 20th Anniversary.

As we celebrate this significant milestone we think of the friendships, the hard work and achievements shared by all involved in Trigeminal Neuralgia and Trigeminal Neuralgia Association. We especially acknowledge Claire Patterson and her dedicated volunteers who have worked tirelessly from Barnegat Light, and we also applaud the fantastic support we received from the TNA Medical Advisory Board. This invaluable service of information/education, support and encouragement reached even the shores of Australia.

Ten years ago, after having watched my mother wince in pain, one hand trying to shield her face while tears rolled down her cheek, I was compelled to learn what was causing this suffering. Armed with 2 words - "tri- *something* neuralgia" - I searched the Internet and thankfully found the TNA website and began learning about Trigeminal Neuralgia.

Touched by the outcry for help I could not shelve the information I had gained for it was obvious that many were suffering helplessly like my mother, in isolation and in ignorance.

In June 2000, I registered with the Trigeminal Neuralgia Association, Barnegat Light USA to start a support group here in Sydney and began the slow road of contacting sufferers throughout Australia, in particular Sydney, New South Wales. I was passionate about sharing the information. I felt that with knowledge they would cope better. There was also the need to let others know that they were not alone with this strange pain. There was no need to suffer in silence and helplessly.

On 2nd September 2000, with guidance from TNA USA, I held my first Sydney support group meeting. It was the first time any of them had met another who truly understood the pain. The following year I was able to establish support groups in Melbourne and Brisbane. By February 2002, we felt the need to reach out nationally and that it would be better served by a national organization.

In January 2003 we successfully registered Trigeminal Neuralgia Association Australia Incorporated as a non-profit charity organization and began our TNA Aus journey. Today, we have several support groups established throughout the country.

We publish a monthly newsletter which is circulated to both patients and medical and health professionals; mainly carrying patients' news of their progress and their pain management.

In keeping with the Association's goal to have a unified understanding of TN; and an improved approach to the treatment of Trigeminal Neuralgia and other related facial pain, the association holds a bi-annual conference. Our conference delegates have benefited greatly from the support of local and international pain researchers, investigators and clinicians.

It is by coincidence I am to receive the President's Pin on TNA 20th Anniversary. The President's Pin commemorates camaraderie, hard work and accomplishments shared. It is a great testimony of the global outreach and growth of the founding association & the thousands of lives we in turn have helped. I take this opportunity to pay tribute to the founder – Mrs. Claire Patterson. We are all indebted to you.

Irene

Hebrew University researchers identify gene related to chronic pain

Published: Thursday, August 5, 2010 - 08:29 in Health & Medicine

Hebrew University photo Researchers at the Hebrew University of Jerusalem and elsewhere have succeeded in identifying for the first time a gene associated with susceptibility to chronic pain caused by nerve injury in humans, signalling a significant step toward better understanding and treating of the condition. Chronic pain is a serious medical problem, afflicting approximately 20% of adults. Some individuals are more susceptible than others, and the degree of pain experienced after injury or surgery is known to be highly variable between patients, even under nearly identical circumstances.

The basis for this has remained largely unknown, prompting researchers to search for the contribution of genetics to chronic pain susceptibility. To accelerate research in this field, animal models are proving to be critical to understanding the underlying biology of chronic pain in human patients.

In a report to be published online on Aug. 5 in *Genome Research* (www.genome.org), Prof. Ariel Darvasi of the Alexander Silberman Institute of Life Sciences at the Hebrew University of Jerusalem and colleagues identified a region of mouse chromosome 15 that likely contained a genetic variant or variants contributing to pain. However, this region contains many genes, and the responsible variant remained unknown.

Darvasi and an international team of researchers that included Prof. Marshall Devor of the Hebrew University and Canadian and European scientists undertook two fine-mapping approaches to narrow down the chromosomal locus to an interval of 155 genes.

By applying bioinformatics approaches and whole genome microarray analysis, they then were able to confidently identify a single gene, *Cacgn2*, as the likely candidate.

To further test the potential role for *Cacgn2* in chronic pain, the authors utilized a mouse strain harbouring a mutant version of the gene that had previously been used in epilepsy research. In testing the mice for behavioural and electrophysiological characteristics of chronic pain, they found that, the observations were consistent with a functional role for *Cacgn2* in pain, even though it might be modest.

However, the question still remained as to whether the human version of the gene also is important for chronic pain. Analysing a cohort of breast cancer patients who experienced chronic pain half a year or more after they had undergone removal or partial removal of a breast, they found that genetic variants of *Cacng2* were significantly associated with this chronic pain. The authors cautioned that

although this association will need to be analysed further, the result is encouraging at pointing to this gene as a significant factor in experiencing pain.

"The immediate significance is the mere awareness that differences in pain perception may have a genetic predisposition," Darvasi explained. "Our discovery may provide insights for treating chronic pain through previously unthought-of mechanisms."

Source: The Hebrew University of Jerusalem.



Meeting Reports

SYDNEY CBD SUPPORT GROUP

St James Parish Hall, Sydney

7th August 2010

Present: Ben H., Ingrid K., Diane & Terry B., David R., Allaster McD., Julie & Steve C., Marjorie B., Mary K., Kim K., Irene W.

Apology: Lois & Reg W., Jocelyn S.,

Email from Lois: " I am sorry to say Reg & I will have to put in our apologies again for Saturdays meeting. I am still having trouble with episodes even though the specialist has started me on Lyrica as well as the Lamictal. I am now taking 3 x 200mg Lamictal plus 2 x 75mgs Lyrica daily. This had given me a few weeks without any bad attacks, however yesterday I had a beauty, had to leave Reg at his heart specialist and make a hasty retreat to the car. I really hope things will have settled down before the October meeting, have missed seeing everybody, even though we get a report in the newsletter."

Jocelyn: just recently become grandma for the second time sends her apology as she had to mind baby so poor mum can have a rest.

Kim stated that our opening balance on 7th Aug 2010 was \$191.40. We collected \$44.00 and \$40.00 was paid for the church hiring. Our balance is \$195.40.

We welcomed first time attendees, Julie & Steve C and David R to our CBD meeting. Also, we welcome back Diane and Terry B. They have been AWOL. ☺

Julie: TN began in April 2010 with "extremely severe" pain; within a couple of weeks it had progressed to constant severe pain. She described them as electric shock pain lasting 1 -2 minutes each episode. She

could not eat as eating triggered the attacks. She was referred to Dr. Russell Vickers who diagnosed Trigeminal Neuralgia. Dr. Vickers suggested Julie contact TNA Aus for support. Julie then attended the support group meeting at Toongabbie and learned a bit more of her options. She saw Dr. Dexter, and had her MVD on the 9th of June. Since then she is free of TN pain. As a result of her MVD, she has double vision, which the doctor assures her the double vision would right itself in time. On the whole Julie is very pleased with her MVD outcome and is confident that her double vision is transient.

David: TN began in 2007. Pain was so bad that he ended up in hospital for 10 days. While in hospital he finally saw a Neurologist who prescribed Gabapentin 300mg. By January 2008, David had his MVD. He had been pain free since the MVD surgery till about 6 weeks ago. Dental work he had seems to have set off his pain again, on the left top and bottom jaw. David is sure this pain is similar to the pain he had before his MVD. He described it as a knife digging in. The top jaw is more intense, and he has trouble eating. He copes quite well in warm weather. He finds cold weather and morning especially bad, and has a massive struggle eating breakfast. He is currently taking 1000mg of Gabapentin; 25 mg of Endep to help him sleep. David finds that if he had a decent night sleep, he copes better the next day. He also takes 700mg of Epilim AM/PM for his epilepsy. He cited that when he was in Coffs Harbour, where the weather was warmer, his pain level dropped to very low

Allaster: seems to have a relapse. He was good till about a fortnight ago. His hot knife stabbing pain is on the whole gum area and trigger points are more widespread. He is taking Trileptal 150mg AM / PM; with 30 mg Cymbalta in the morning. He still takes B12 and has been also recently been prescribed Sifrol for his Restless Legs Syndrome. Cold water also sets off pain attacks.

Irene wondered if there was a coincidence with the recent prescription of Sifrol and the recurrence of pain. It was suggested he asked his Chemist to check for drug to drug interactions.

Ingrid: last attack was in May. Since then she has been good apart from a week ago where she had 2 deep stabs followed by another occasion of 2 big stabs. These "big stabs" were not followed by episodes of attacks. They came and went out of the blue. She is now on Tegretol 100mg in the morning and 200mg at night; and 75mg of Lyrica at night as well. Ingrid is contemplating cutting back half a tablet of Tegretol while the pain is under controlled

Marjorie: has been pain free since her MVD, to be 1 year next month. She is still very much over the moon from her successful operation and has come to the meeting to support and inspire others into considering having an MVD sooner rather than later.

Ben: travels all the way from Newcastle to attend our CBD meetings. He catches the train to Sydney, and often than naught he arrives well in time for the meeting. INSPIRATION plus!!

Ben's GP is reluctant to change his TN medication so he is stuck on Tegretol... which in all fairness, is working and controlling Ben's TN. He was on 1000mg of Tegretol and has dropped dosage to 800mg ie 400mg AM, 200 PM and 200 before bed. With his pain under control, Ben is thinking of dropping the dose by half a tablet in the morning dose.

Diane: Pain has been getting more frequent, could be due to the cold/winter. Her therapy involves using a mouthguard filled with Lignocaine – absorbed through the mucosa, also a lignocaine spray for trigger point in the nostril. When pain is beyond endurance she takes Lyrica 25mg PM and another 25 mg for bedtime. She also finds that lying down helps to ease the pain.

Mary had TN for 8 years. As years rolled on, TN became more unmanageable. August last year, she had a successful MVD and has been pain free since. She found that her "high blood pressure also dropped" after her MVD, and commented that pain really affects the whole body; and that emotional stress adds to pain.

I remember there were claims made about MVD & hypertension in the early years of my TNA work... TN patients with hypertension who had undergone MVD for TN not only were relieved of their pain but a lowering of their BP too. ... so it was claimed. Mary - you are the first one that I know to testify to that. ☺

We concluded the meeting with light lunch and a cuppa. Thank you Ingrid for doing the tea and coffee. Thanks all for bringing the yummy food, and all the hands that make light work in setting up and cleaning up afterwards.

Next meeting: October 2nd: **Dr. Tony Merritt** - Pain Psychologist from RPAH
Dr. Merritt has set aside his Saturday for your benefit. Please do not let him talk to an empty room.

Reminder: December – Dr. Mark Dexter at Toongabbie SG Meeting

Irene

ADELAIDE SUPPORT GROUP MEETING

Burnside Town Hall

Sunday 25th July, 2010

PRESENT: Laurel S, Grace A, Angela M, Garry & Lisa R, Kevin S, Bert J, Joan E, Ann T,

APOLOGIES: Graham & Liz B, June & Roger O.

Ann and Bert ran the meeting as Graham and Liz were overseas.

DONATIONS: \$28 Balance on hand \$121.65

REPORTS FROM MEMBERS:

LAUREL: Laurel reported pricking, pressure in her ear and sharp pain behind her eye. It goes as quickly as it comes. She is still taking the vitamin B12 and trying to dodge the Epilem. She has an appointment with the Dr. to check it's nothing else but is fairly sure it is Neuralgia. She tends to put all her little aches and pains down to neuralgia. Otherwise she is feeling OK. She puts cotton wool in her ears when it is cold and windy. The same thing happened last winter. If ever she gets the electric shock pains back she will opt for the MVD.

GRACE: Much the same, eye itching and feels she could almost pull her skin off, also getting lots of headaches with pain behind the temple. She has been diagnosed with high blood pressure but is reluctant to start taking tablets. Ants crawling sensation and pain behind the ear sometimes, a little bit and then it goes away. (Bert asked if anyone else experienced ear pain and most did.) Grace dreads the thought of an MRI as she is claustrophobic. Lisa said there were new machines these days that were faster and less noisy

ANGELA: Has crushing pain. In June she had terrible pain after getting out of the shower. She finds if she moves her head around it sometimes can alleviate some of the pain. She dropped her head to her chest but then couldn't lift it up as the pain was so intense. She was admitted into hospital where she stayed for 3 weeks. During that time she was placed on a medication regime. Sometimes she can't lift her head because the pain is so intense. In between she gets lots of electric shocks. She has difficulty eating. She wanted to come to the meeting to talk to everyone and to see if there were any new ideas about. She is taking up to 1600mg Tegretol daily. Sleeping is difficult. Everything she does in her daily life is measured by her pain. Ann suggested Angela speak to Irene regarding B12. Angela is taking a vitamin complex and wondered if the B12 in that was sufficient. It was suggested she take concentrated B12, in injection form together with sub lingual tablets. (Ann said she has been trying magnesium and her

shooting pains were lessened. She had noticed a difference almost instantly.) Angela asked if anyone had tried Zostrix. Kevin had tried it and found it helpful at first but less beneficial after a while. Ann suggested it was time for Angela to seek further specialist medical advice. During the time Angela was speaking she had to stop frequently due to painful spasms. Ann commended Angela on making the effort of attending the meeting when she was so obviously in a great deal of pain. Angela appreciated the group listening to her and being so understanding.

GARRY: Has discontinued taking the B12. His pain is related to a slightly different problem and found the B12 unhelpful. His biggest problem is his eye and surrounding area. He is also seeing an eye specialist. He has been prescribed eye drops but not sure if they are helping. When he gets pain he finds pressing on the area helps. He still gets 2 or 3 shocks a day which only last a few seconds. He also finds a cold compress on his face helps. Lisa reported that Garry's medication has been lowered slightly. He tolerates his pain.

KEVIN: It has been 3 months since he saw his chiropractor who worked on the muscles in his mouth. He had been virtually pain free until a terrible excruciating attack overcame him. The pain lasted 20 to 30 seconds which was longer than it used to be. He went back and his chiropractor worked on him further. When he returned he was in constant zapping pain and thought it was because it had been stirred things up during the previous treatment and that it would settle after a while. It eased up after 4 weeks. He feels a little better now, although he had a zap putting a spoon in his mouth today. Kevin wondered if specialists are reluctant to do MRI scans because of the cost to the Government. The group thought this was not so. He recommends a stout at dinner time to help him sleep.

BERT: Had his radiofrequency procedure last Wednesday and he has some numbness in his face. It has only been done very recently so hopefully the numbness will reduce. He won't know how effective the procedure has been until he has come off his medication which will take 24 days. Bert mentioned the importance of having someone with you when you are discharged from hospital as often instructions on discharge are forgotten or misunderstood due to grogginess from the anaesthetic.

JOAN: Can't understand why everyone is putting up with their terrible pain when hers was fixed with an MVD. She takes magnesium. She can't recommend an MVD more highly. Joan is our group's role model everyone aspires to be as healthy and pain free as her.

ANN: Ann's TN is worse in winter. She finds "living through the pain moment" helps. She tries to eat better and more healthily. She recommends having things around you that makes you happy or gives you pleasure, listening to music for example. Having a positive attitude and enriching our lives by doing things to make ourselves feel good. We have to look after ourselves. (Joan's way of relaxing, when her husband was so ill, was to bake.) Ann remembers vividly a visit to a specialist when her husband said to the Dr. "Something has to be done because I (her husband) can't live with this anymore

Meeting closed, followed by afternoon tea with lots of lovely cakes.

NEXT MEETING: 2.00 pm Sunday 26th September 2010 at the Burnside Town Hall Civic Centre.

(Liz's note: Thank you Ann and Bert for running the meeting and taping the conversations to enable the minutes to be made.)

MELBOURNE SUPPORT GROUP

“Ringwood Room” Ringwood Library

1.30 pm. 7 August 2010

In the absence of Evelyn, who had to make an urgent trip to family in Indonesia, **Alan C.** welcomed everyone to the meeting on a sunny Melbourne winters’ afternoon, especially the (6) new TN sufferers and their guests, attending for the first time.

Present (18). Joy & Alan C., Joan & Neil T., Beryl O., Rita & Chris W., Vicki M., Suzanne McC., Will. & Jean R., Alf. H., Sandra H., Barbara A., Bill P., Alan L., Doug. E., & Terry S.

New TN sufferers & Guests (8). Maree B., Wendy P., Les. & Violet C., Elaine A. & Guest., Mora S. & Marion McD.

NB. Several of our visitors today said they saw the notice of the meeting in the Victorian seniors magazine “50 PLUS”, and another at their local Church. It certainly pays to “advertise”.

Apologies. Toni B. (recovering from MVD), Evelyn & Din. D. (in Indonesia), Nita & Robert McK. (holidaying in Europe), Rob. O, Ellayne C., Bernadette G., Graeme & Sandra T.

Alan read a message to Evelyn from Toni B. that she was to have an MVD at Monash Medical Centre on 10th Aug. by Prof. Andrew Danks, a decision she arrived at after much consideration. We wish her well. Toni hopes to be at our next meeting.

Alan also gave a reminder to everyone regarding the 4th National TNA Conference to be held at the Cypress Lakes Resort, at Pokolbin in the Hunter Valley area of NSW, from 2-5th Sept. 2011. Alan urged everyone to seriously consider attending, as these Conferences are excellent value in the wealth of information available through local and International presenters, with the opportunity to speak one on one with the presenters, and also the very affordable costs for the 2 day 3 night Conference, incl. all meals and accommodation, which is heavily subsidized by TNA Aust. for the benefit of members so start saving now!!

Treasurers report. Alan donned his “Treasurers hat” to advise an opening balance at the June meeting of \$130.25, donations of \$45.10, expenses of \$16.50 for our meeting room insurance, leaving cash in hand of \$ 158.85 carried into this meeting. He also stressed the importance of a donation by those attending, as this is our only form of income, which we need to function as a Support Group, in our mission to support TN sufferers, and broaden the awareness of TN in the wider community.

Reports from members

Terry S. can now talk, having no pain for 2 weeks. Pain started in Feb. 2009. He had an MVD with slight relief, but not 100% success. Since Feb. this year he has been going backwards, with medication not being successful. He started looking for a Chiropractor or similar help, then went on the Internet and found a Dr. Joseph Ierono in Sydney, and after talking with him on the ‘phone, went up to Sydney for treatment to his head, neck and spine. He first had 6 X-rays in that area to identify the problems, then 3 treatments for 3 days running, and he is now fine with no drugs and a clear head.

Barbara A is now taking 100mcg Tegretol at night and 200 mcg during the day (down from 400) but continues to feel very tired.

Rita W. has found meditation a big help, and is now only on half a tablet (100mcg) of Tegretol.

Joy C. reported on recent developments with her TN journey. She has had MS since 1987, and developed TN in 1997. She had two unsuccessful “Radio Frequency Gangliotomy” procedures in 1999 at Epworth,

and she was resigned to a lifetime of drugs, with intermittent visits to hospital for pain relief infusion, when her drugs no longer controlled frequent pain spasms. She had been told in 2005, after viewing her MRI's, that her pain was caused by the plaque on her brain from the MS, and that there was nothing more that could be done surgically.

A recent trip to hospital in late June for a pain spasm, was delayed due to difficulty in getting access to either her Neurologist or her Pain Management... she had increased one of her medications (a recent new one) to try and "knock" the pain, but in doing so unfortunately "overdosed" and became allergic to this drug with the effects being weakness, unsteadiness, falling over, seeing imaginary things etc. She eventually gained an appointment with her Neurologist, who was shocked at her condition, and arranged to have her admitted into Monash Medical Centre, suggesting also that he would have Dr Danks see her in hospital, as he has been having success with "Balloon Compression" procedures with MS patients. Joy was subsequently admitted into Jessie McPherson Hospital (the private section of Monash Med.), as there were no beds available in the main Monash Med Centre. Dr. B could only treat her if she was in the Public section, so another Neurologist was appointed to look after her in Jessie McP. Dr Danks eventually saw Joy and she agreed the Balloon Compression be tried. He said the measure of success is that she should wake up after the op. with a numb face and head, which is what did happen. A post operation visit with Dr Danks confirmed that the numbness is normal, and that it should disappear over 6 – 12 months. She has difficulty eating on the left side of her mouth due to the numbness, and she has to be careful not to bite the inside of her mouth. She is still on her medications (not the one she was allergic to ... this was replaced with a previous drug Neurontin) at this stage under the advice of her Pain Mgt. Her neurosurgeon advised the Balloon Compression could last from 2 – 5 years, and can be repeated. We hope soGood luck Joy.

VISITOR REPORTS

Maree B. has had face pain for 34 years. In 2006 she visited a dental surgeon, and was on 400mcg of Tegretol. May 2007 a blood infection hospitalized her in Geelong. She was transferred to the Alfred where an MVD was performed. She has suffered lots of stress and found us by searching on Google, contacting TNA Aus, who sent her information. She is medicine free at the present.

Wendy P. Found out while in Tasmania that she had TN, which started in 1998. An Osteopath in Ringwood has been a great help, as she also has a bad back and neck from heavy lifting during her working life. She is currently on 100mcg per day of Tegretol.

Les. C. Is on 200mcg of Tegretol per day, and has had pain for a number of years. The TN was diagnosed by his GP. He is also on Trammel and Endep at night, and the pain is presently under control.

Elaine A. Has suffered Neuralgia for 3 years. Last Sept. was diagnosed with TN. She has seen several Doctors and a Neurologist, with no real relief, and has had 3 MRI's which showed nothing. We suggested to her that she get a referral to see Dr Danks and ask for a 'Thin Cut' MRI. We hope he can help her.

Marion McD. A sufferer for 30 years. She was told she had irritated nerve endings. A local Physiotherapist gave her electric stimulation for 25 yrs. Marion swears by the success of this method of treatment for her.

Alf. H. gave his apology for this meeting.

Thanks to those who brought food for afternoon tea, Rita & Chris for serving and washing up, Neil & Joan for the meeting set up, and the greeting and sign-in process for all present. Many thanks to Beryl for taking the meeting notes. We are amazed at how Evelyn is able to do that and run the meeting as well!!!!

Alan C.

Victorian members are urged to attend the
next meeting of the Melbourne Support Group
at 1.30 on Saturday 2 October 2010 in the Ringwood Room, Ringwood Public Library near Eastland.

Our guest speaker will be **Chris Mahon, a nurse who suffered TN and had a successful MVD**. Chris wrote in a Newsletter of her experience from a nurse's point of view but by coming to the meeting you will have the opportunity to hear her in person and discuss TN issues with her. I look forward to seeing you at the meeting.

Evelyn Diradji, Leader, Melbourne TN Support Group.

HOBART SUPPORT GROUP

Glenorchy Library

21 August 2010 2-4pm

Present: Helen T, Ros & Ian W, Shirley B & Kay P, Del & Jean L, Julie H, Lyn Y, Bernadette C, Pat W, Barry & Janet D, Pauline T, and our special guest Dr Tom Higgins.

Apologies: From many because of the elections or ill health.

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

Thanks were given, with individuals being singled out for mention, to everyone who made the May meeting so successful.

Guest speaker

Guest speaker, Periodontist Dr Tom Higgins was introduced as one of the important contributors to the success of the May meeting. He persuaded the Australian Dental Association (Tasmanian Branch) to inform all those in the dental profession across Tasmania about Dr Aggarwal's visit, and as a result we had many additional visitors that day.

At this August meeting, Tom volunteered his time to answer our questions. Firstly, he explained in simple, easy to understand language the difference between a periodontist and a dentist. He went on to explain the work of other specialists in the dental profession. We learnt that the periodontist supports the supports for our teeth; as Tom explained, a periodontist looks at everything around our fangs, and particularly the gums.

Dr Higgins talked about the power of anti-depressant drugs to dry the mouth. If your mouth is dry and you are in pain, you often drink sugary or alcoholic fluids for comfort. But this may lead to ring barking of your teeth with bacteria working at the neck of one or more teeth. Once the pain starts from there, a visit to a periodontist may be on the cards.

Over almost an hour and a half, Tom covered a huge amount of ground in a lively conversational style which encouraged everyone to ask questions. He was very accessible, and the bag of products he brought with him was very informative – we wanted to know what TN sufferers could do to cope when opening the mouth or popping a brush inside was a shocking experience. He distributed products and we were able to

feel tooth brushes with brushes of different levels of softness from one almost as soft as velvet to other firmer examples. In addition there were brushes with very, very tiny heads which would be very useful on those days when a sufferer has great difficulty opening their mouth but must try and clean their teeth. The brand was one we hadn't heard of before; TePe Special Care. In terms of other products, Tom particularly took the view that fluorides are the best protection for our teeth against bacteria.

He alerted the meeting to the Federal government's Enhanced Primary Care Program where a number of visits to particular dental, medical and health professionals are free. If you don't know about this Program and think it might be relevant to your circumstances, then please talk with your GP.

Dr Tom Higgins reminded us that people in pain always step back from looking after themselves, but his message was that there are tools to help us. I guess this means we should do everything we can so we do not need his specialist services; we need to clean our teeth properly so we don't end up with gum disease or ringbarking of our teeth. It was an inspiring contribution to our knowledge, and all those attending the meeting were very pleased to have been present.

Other Business

Helen T alerted everyone to TNA President Irene Wood's forthcoming trip to two international conferences and the possible benefits to the Association. She went on to remind everyone of the value of membership and, as a result, two attendees collected application forms. Those attending today's gathering agreed they were happy with the content of meeting reports published in previous TNA newsletters.

Helen T then talked about the TNA Conference next September and suggested some savings strategies that might help people get the funds together. There is one year to save and the total cost from Hobart to the Hunter Valley is likely to be around \$700-750 return per person (for the heavily discounted \$420 registration fee for accommodation, all meals, and the expertise from the conference; and approx \$250 return airfares). We may need to plan for a bus fare to transport us to and from Newcastle – not sure about that. This is an event not to be missed so all stops should be pulled out to go. Please start saving now.

Next the meeting moved to a discussion about operational matters. The two Co-Group Leaders raised the issue of not having sufficient funds from the gold coin donation to cover the costs associated with having our meetings. The meeting agreed that a \$5 donation will be asked for at future meetings, but that no-one should feel embarrassed or not attend for the want of that money. We were so grateful when our guest speaker suggested some possibilities to supplement our funds. These will be followed up in the coming weeks. Everyone left prepared to think of other options.

Missing a plate or a fabric scone holder from the May meeting's lunch spread? Let Ros or I know ASAP.

Our November gathering will be our special Christmas meeting. Please bring a plate for afternoon tea, and wear anything that gives the look of Christmas if you wish. And please come even if you aren't feeling well.

Next meeting: Saturday 20th November 1.45pm for 2pm start at the Glenorchy Library as usual. Finish time will be 4pm. We will be inviting another special guest. Further details will be posted out to members when available. Always feel comfortable to contact Group Leaders Helen on 6245 0429 or Ros on 6234 7989.

FROM: Co-Group leaders Helen Tyzack and Ros Wilkinson

TOWNSVILLE SUPPORT GROUP

21 August 2010

Present: Mary C, Jill S, Sue M, Phil M, Sera A, Peter A and Jean T.

Apologies: Joan B (Ingham), Jim K, his wife and daughter.

- Everyone quickly introduced themselves and Sera suggested that we quickly review what we said last time to catch the newcomers up to date.
- **Sera:** Pain began about 11 years ago – lightning bolt. Her teeth were checked and found to be fine. Pain got very severe but there was no outward sign and so Sera thought that she was going mad. Dr McG knew what it was straight away. He put Sera on Gabapentin – up to 5 X 800mg over 9 mths. The pain gradually got worse. Added Sodium Valproate (Epilim) 200mg X 2. Dr said it was time for the operation. Had it on 8/09/2009. Afterwards weaned off tablets slowly and the pain returned – went back on Gabapentin 400mg x 6 and now 2 Epilim as well. Very disappointing.
- **Sue:** Pain began 9 years ago as irritating zaps – very irritating when highway driving. Trialled Tegretol – had allergic reaction. Zaps went away for 6 months. Came back as shooting pain – trialled Endep - made her very dopey before it worked. Stayed on it for 6 months, then reduced it slowly and came off it. About 6 months later the pain returned as very bad lightning bolts. Started with Epilim – got up to 4 x 200mg, then added Gabapentin 200mg – up to 8 a day prior to operation in March 2008. After weaning off the drugs gradually had no pain until January 2010. Now on 4 x 200mg Epilim + 2 x 10mg Endep + 2 x 75mg Lyrica. Trialling 1000mcg Sublingual B12 daily (Cyanocobalamin). Appears to have made an improvement – less breakthrough pain. Very cheap.
- **Jill:** On Lyrica and Endep. Trialling B12 1000mcg – not sublingual. Trying to relax more. Jill says the tummy breathing and yoga helps. Believes that stress definitely linked to the pain.
- **Mary:** New attendant. Not on medication but has had an on-going joint problem – TMJ. Dr L would adjust her joint inside her mouth. Had pain through the top of her head and down through her neck – only on one side.
- **Sera:** Said that Irene could assist with working out what type of problem was causing Mary's pain.
- **Mary:** Suggested certain neck exercises to assist with the pain – she demonstrated them. Carlisle Gardens runs yoga classes. She stated that massage is great – will give the name of her practitioner.
- **Joan B:** from Ingham (absent) asked if anyone else had worse pain and bruising from acupuncture. Hers got much worse during the 3rd visit.
-
- **Sue:** Stated that she had tried acupuncture for TN once as she had used it before for arthritis. This time it made her pain much worse and she only had the one treatment.
- **Mary:** Had also tried acupuncture.

- **Jean:** New attendant. Has had problems since the 1960's – stressful job in Myers in Toowoomba (new job in new shop). Left side pain straight to the top of her head – like a lightning bolt. Went to a neurosurgeon in Brisbane. Jean was injured by a bomb during the war in England. She had a shrapnel injury on top of her head. Trouble began then from post-operative scarring. Used medication but it got better with age. When she told the neurosurgeon about it in Brisbane, he thought that she had a brain tumour. He operated and she hovered between life and death for about 6 weeks. The neurosurgeon kept apologising and he told her that the operation would cause her increasing pain.
- **Jill:** She wondered aloud what causes TN. Is it a stressful life?
- **Everyone:** We all agreed.
- **Sue:** She stated that she has the book 'Striking Back' and will bring it along to the meeting for anyone to borrow. When asked to clarify about how she got her Gabapentin at PBS prices before the operation, she stated that she was referred to the Pain Clinic at the Townsville hospital and was able to receive scripts to be filled at the hospital. Her chart did not state that she was an epileptic but no other assistance was given apart from that they suggested she try acupuncture which had already failed and a psychologist for self-hypnosis lessons which Sue had tried and had given up on because it was not any use when in a classroom. They suggested she change jobs.
- **Sera:** Stated that she goes to Dr R (a neurosurgeon) at the hospital to get her Gabapentin cheaper.
- **Jean:** Was on Tegretol – not really any good. After a while her pain went away. She has not had any pain for about 10 years now. It stopped about the time that she stopped work and moved to a warmer climate. Still cannot sit in a room with fans going full tilt.
- **General discussion:** About whether cooler weather affected anyone or not. Some it did and others it didn't.
- **Finished with afternoon tea.**

Next Meeting Date: Set for November 20 (Saturday) 1:00 pm.

Sera to confirm the hall. It will be a Christmas breakup.

Bring eats, Christmassy poems etc.

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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2010 Meeting Dates

State	GROUP	Date & Time	Venue	Group Leader/s
ACT	Canberra	25 September 10.30am-12.30pm	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 6254 6640
NSW	Sydney	6 November 1:30 – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Kim Koh ☎ 02 97431279
	Sydney CBD	2 October 10am –12:30pm	St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413 363 143
QLD	Brisbane	11 September 1.30-4.00pm	30 Ridley Road BRIDGEMAN DOWN	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	18 September 1:00 pm	Kawana Library, Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	20 November 1.00 – 4:00pm	Carville Senior's Villa 35 – 37 Diprose St PIMLICO	Sera Ansell ☎ 07 47516415
S.A	Adelaide	26 September 2pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Rd	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	20 November 2:00 – 4:00 pm	Glenorchy Library Enter via Barry and Cadell Streets	Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989
VIC	Melbourne	2 nd October 1.30 – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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