



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.

November 2010

“Aerodynamically the bumblebee shouldn't be able to fly, but the bumblebee doesn't know that so it goes on flying anyway.” -- Mary Kay Ash

Trigeminal Neuralgia Association Australia Inc. 4th National Conference 2011 September 2nd – 4th Cypress Lakes Resort, Hunter Valley, NSW

Who should attend?

- Patients
- Care givers
- Physicians
- Psychologists
- Dentists
- Nurses
- Pharmacists
- Other health professionals.

The Meeting provides the opportunities to

Network Learn Enjoy!

A scientific program led by international and local TN & Facial Pain experts:

- * Mrs. Claire Patterson – Founder of TNA (USA)
- * Professor Marshall Devor – University Jerusalem, Israel
- * Dr. Donald Nixdrof – University Minnesota, USA
- * Prof. Andrew Danks – Monash Medical Centre Vic.
- * Dr. Mark Dexter – Westmead Hospitals. NSW.
- * Dr. Arun Aggarwal – Royal Prince Alfred NSW.
- * Dr Helen Boocock – Pain Management RNSH, NSW
- * Dr. Andrew Zacest - Royal Adelaide Hospital, S.A

T cells attack neurons in MS

Posted by Megan Scudellari [Entry posted at 23rd September 2010 05:00 PM GMT]

In a rare glimpse inside a diseased brain, researchers watch for the first time as immune cells directly attack neurons in a mouse model of multiple sclerosis (MS).

Published this week in *Immunity*, the surprising role of T helper cells in neurodegeneration may provide a novel therapeutic target for blocking neuron dysfunction in patients with MS.

"It's a beautiful paper," said Howard Gendelman, chair of the department of pharmacology and experimental neuroscience at the University of Nebraska Medical Center, who was not involved in the research. "Axonal degeneration is a big part of MS, but nobody knew until this paper what the mechanism was."

MS was first described as a demyelinating disease in which immune cells in the brain attack the protective myelin sheath around axons, tearing it apart and slowing or stopping nerve signals, leading to muscle spasms, weakness, and other symptoms of MS. Over the last decade, however, scientists have come to realize that axons are also part of the pathology of MS: Direct damage to neurons and their processes, and not just the myelin sheath, causes disability.

Frauke Zipp and colleagues at the Johannes Gutenberg University Mainz in Germany used live imaging to demonstrate how T cells cause severe, yet partially reversible, damage to axons and neuronal bodies in a mouse model of MS, mice induced with experimental autoimmune encephalomyelitis (EAE). In these mice, the team labeled neurons with green fluorescent protein and T cells with red. Then, using two-photon laser scanning microscopy, a relatively new tool that allows live imaging over several hours, the researchers observed, in real time, how T cells enter and move about the central nervous system.

The results showed that some T cells directly kiss neuronal cell bodies, forming immune-neuronal synapses, indicating communication between the two cells. The cells forming these synapses were T helper cells called Th17 cells, which have previously been implicated in MS inflammation. Indeed, time-lapse imaging showed axons falling apart at locations where synapses formed between the Th17 cells and neurons. Further experiments revealed that the Th17 cells caused an increase in calcium inside the neurons, followed by cell injury and death.

A 2001 *in vitro* study found that CD8 T cells, which predominate in human MS lesions, can also directly attack neurons, suggesting this may also be an important mechanism of neurodegeneration in human MS.

That's not to say that T cell-induced neuronal damage is the only cause of MS, said Zipp, as demyelination is obviously a significant part of the disease. "It's really not clear when and to which extent the different types of pathology take place," she said. "But what is clear is an inflammatory attack against neurons and axons is a major part [of MS] and can be reversed."

After the team determined the cause of damage, they successfully prevented it by blocking NMDA receptors, which allow calcium into a cell. When the receptors were blocked during T cell-neuron contact, calcium levels decreased.

MS symptoms do not always get worse over time, but can often get better, even without treatment, implying that there are compensatory mechanisms in the brain to regenerate areas of damage. "This was always interpreted as remyelination," said Zipp, because the myelin sheath was believed to be the main source of damage. "Now we see that these calcium changes in the neuron, induced by the T cells, can be reversed." The next step, she added, is to find neuroprotective drugs that interfere with this newly discovered mechanism of neurodegeneration.

The research also suggests a link between MS, classified as an autoimmune disease, and neurodegenerative disorders like Parkinson's disease, which are not typically linked to the immune

system, said Gendelman. In a Journal of Immunology paper published earlier this year, Gendelman and colleagues found that Th17 cells are also involved in Parkinson's disease, perhaps as an immune system reaction to the buildup of toxic proteins in the brain.

"We're finding that we may want to reexamine this whole deal," said Gendelman. "It's not just multiple sclerosis that is engaging these parts of the adaptive immune system; we're seeing it in animal models reflective of Parkinson's and Alzheimer's and possibly for ALS and Huntington's disease...[The immune system] may play a part in a broader spectrum of neurological diseases."

V. Siffrin, et al., "In vivo imaging of partially reversible Th17 cell-induced neuronal dysfunction in the course of encephalomyelitis," *Immunity*, 32(4):424-36, 2010.

T cells attack neurons in MS - The Scientist

<http://www.the-scientist.com/blog/display/57697/#ixzz10OWkRTVG>

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The below Abstract is an excerpt from <http://www.ncbi.nlm.nih.gov/pubmed/19243598>

Mol Pain. 2009 Feb 25;5:8.

Effects of removal of dietary polyunsaturated fatty acids on plasma extravasation and mechanical allodynia in a trigeminal neuropathic pain model.

Martin YB, Avendaño C. Department of Anatomy, Histology & Neuroscience, Autonoma University of Madrid, Medical School, Madrid, Spain.

Abstract

BACKGROUND: Neuropathic pain (NP) is partially mediated by neuroinflammatory mechanisms, and also modulates local neurogenic inflammation. Dietary lipids, in particular the total amount and relative proportions of polyunsaturated fatty acids (PUFAs) of the omega-3 and omega-6 families, have been reported to modify the threshold for thermal and mechanical allodynia in the partial sciatic nerve ligation model of NP in rats. The effects of dietary lipids on other popular NP models, such as the chronic constriction injury (CCI), have not yet been examined. It is also unknown whether dietary PUFAs exert any effect on the capsaicin (CAP)-induced neurogenic inflammation under control or NP conditions. In this study we investigated these interrelated phenomena in the trigeminal territory, which has been much less explored, and for which not all data derived from limb nerves can be directly applied.

RESULTS: We studied the effects of a CCI of the infraorbital nerve (IoN) on the development of mechanical allodynia and CAP-induced plasma extravasation in rats fed either a regular diet (RD), or a modified diet (MD) with much lower total content and omega-3:omega-6 ratio of PUFAs. In rats kept on MD, mechanical allodynia following CCI-IoN was more pronounced and developed earlier. Extravasation was substantially increased in naive rats fed MD, and displayed differential diet-dependent changes one and four weeks after CCI-IoN. When compared with basal levels (in naive and/or sham cases), the net effect of CCI-IoN on ipsilateral extravasation was a reduction in the MD group, but an increase in the RD group, effectively neutralizing the original intergroup differences.

CONCLUSION: In summary, PUFA intake reduces CAP-induced neurogenic plasma extravasation in the trigeminal territory, and their removal significantly alters the mechanical allodynia and the plasma extravasation that result from a unilateral CCI-IoN. It is likely that this "protective" effect of dietary lipids is temporary. Also, the presence of contralateral effects of CCI-IoN precludes using the contralateral side as control.

The electronic version of this article is the complete one and can be found online at:

<http://www.molecularpain.com/content/5/1/8>

Describing a novel approach to treating pain through altering body perception through the use of imagination and artificial feedback: Terry Borsook

IASP 13th World Congress On Pain: Topical Symposia: Exploring the Power of Illusions and Imagination to Achieve Lasting Reductions in Pain.

The below are my notes. Any inaccuracy is strictly mine.

Mirror therapy essential set up entails a patient place an intact limb reflective side of mirror and sits so that both the intact limb and its reflection can be seen. Performs motions with the intact limb while imagining that the resurrected limb is performing those motions.

Essentially requires visual feedback to create an artificial perception that a missing limb exists once again, and this works partially because of the dominance of the visual modality in humans and also due to the lack of sensory tactile proprioceptor input at the same time.

Mirror Therapy shown great promise but is limited to:

- Small group of pain conditions such as Phantom limb pain, Chronic Regional Pain Syndrome.
- whatever can be displayed in the mirror.

So the kind of perceptions that we can create with a mirror is also limited.

“My goal for this talk is to present a novel approach that may circumvent these limitations – while keeping 2 key features of mirror therapy.”

2 Key features: 1) **Imagination** 2) **feedback**

Both of these are fundamental to how the brain works.

Imagination allows the creation of smell, sights, taste - almost every sensation in the mind.

Imagination occurs all the time eg: we use it to practise a task before performing it, reliving experiences, imagining pleasant scenarios, stimulating in our mind how we would feel under various conditions: empathy, fantasy, time travel: reminiscing, and Pain Control

Two magical feature of imagination

1. Imagination can create an internal reality that can diverge dramatically from sensory experience
We can create a world in our mind that is completely independent of what our senses are telling us.
2. Neural activation patterns while imagining an experience or behaviour overlap considerably with those that occur during actual experience or behaviour execution.
Looking at the brain of somebody imagining their loved one in front of them & looking at the brain of somebody actually looking at their loved one in front of them – looks very similar

The brain's activity looked very similar during imagined and real pain.

Mirror Neurons

Mirror neurons activate during execution of an action or observing another individual performing a similar action. Action observation appears to induce action simulation – the simulation of motor activities in the brain of the observer that parallel those occurring in the performer.

Mirror Neurons are scattered throughout the pre-motor, primary motor cortex among many other regions; - also shown that mirror neurons occur in the insular cortex.

- Evidence that the brain can change (learn) through mere observation

So experience can be created through the imagination that is independent of sensation.

2nd feature of Imagination = Mental Simulation.

There is a lot of evidence that shows mental imagery can be very powerful eg: imagined and executed motor activities such as writing and walking show the same durations.

First Law which states that difficult tasks take longer than easier ones has been found to be applicable both to imagined movement as well as executed movement.

Imagine foot movements lead to changes in the heart rate, CO₂ pressure and respiration rates, it's as if the brain is being fooled to believe that the person is performing the activity.

Borsook then gave some examples of mental power, quoting the work of Pascuale Leone et.al (1995); and Mental Practice such as those used by experienced athletes to see, feel and fully experience mentally the action they need to take, this boosts effects of physical practice.

With the power of imagination – why not imagine away your pain?

The problem is the reality barrier. Far from being simply an instrument that dutifully records reality, the brain constructs perceptions and it does so all the time from a lot of input – based on our mood, memory, past experience proprioception, touch, sounds and sight.

We may imagine no pain but if we have tactile allodynia there's going to be tactile and nociceptive feedback going back to the brain that says "I don't care what you are imagining, there is pain."

So the question is how can we overcome the reality barrier?

Answer: Artificial feedback.

The trick for crossing the reality barrier is to coax the brain into constructing as perception the scenario being simulated in the mind – make the feedback match what it is we are imaging.

Feedback is a critical component is the operation of almost every system.

- is the signal that is fed to the system that tells the system how it is doing. Almost every single system no matter how simple or complex relies on feedback.

There is **negative feedback** which limits the activity of the system eg: baroreflex, body temperature, blood pressure, stress response.

And **positive feedback** eg: Contractions in childbirth (contractions causes release of oxytocin which stimulates further contractions); Pain chronification (pain causes anxiety and depression which makes pain worse).

The Power of Feedback

Feedback is very important on how the brain works. Feedback has the power to change the behaviour of the system without changing the system itself.

- Consider a car /driver with the goal of driving forward – this is the system.

The driver uses feedback about location within lane to make steering changes accordingly.

- What if we want to get the car to veer to the left? In other words we want to change the behaviour of the system so that it veers left – instead of going straight?
- One way of accomplishing this would be to convince the driver to change his goal
- Alternatively, make the driver **believe** that he is too far to the right, if the driver believes he is too far to the right, he will correct, and steer a bit to the left – so he can continue straight.

But what if we want to change the behaviour of the system? ie get the driver to go left to turn left?

Simply make him believe that he has drifted too far to the right.

Executing his goal he would turn his car to the left, keeping his car going straight. The change we have done here is change the feedback to the driver, nothing has been done to the system itself.

Artificial Perception: use whatever technological means possible to produce feedback that leads to the perception we wish to create.

1. Virtual reality
2. Augmented reality
3. Haptic feedback
4. Proprioceptive feedback

An example Borsook used was that of simulation rooms or rides operated with hydraulic lifts. The simulation of moving through space with what you see on the screen (visual input) as visual feedback is convincing. This becomes more convincing with additional feedback such as shaking that occurs at the same time. So the idea is to give feedback that we want, to create the perception that we want to achieve.

Approaches:

- Attribute pain to cause that can be manipulated
- Break connection between ordinary painful stimuli and the pain response
- Prevent imagination of pain.

Goal – we can't change nociceptive signals but we can change the interpretation of these signals. We can change the interpretations to something that can be manipulated.

Eg: Normally if we have arthritis in the hand the brain perceives arthritis and the person knows they have arthritis and they feel it. But what would happen if we attribute the arthritis pain to fire? Fire is something we can manipulate.

If the arthritis pain is associated with fire, then we can diminish pain through fire decreasing in intensity.

By using Augment Reality System we can super impose a computed generated graphic onto a photo or video or on an actual thing; eg: real arm with super imposed flames.

Tell the person to imagine the flames and that these flames are the cause of the pain in the joints or hand and to feel the pain. Once they do that we get them to link the pain to the fire, we can then reduce the fire and as a result reduce the pain.

The 2nd strategy: Break the connection between stimuli and pain response.

Goal: link behaviour that would typically result in pain with the absence of pain

Example he used was touch produces pain (allodynic pain). Super impose the computed generated paint brush animation on top of the image of the real arm so that it looks like the arm is being brushed (but in fact is not) . Then have the person look on a screen at their arm with a virtual brush. The arm is real, but the brush is virtual. They can see the arm is being brushed, so the virtual feedback is "arm being brushed" but at the same time they are not experiencing any pain. This breaks the connection between the senses that normally contribute to the feel of pain and the pain.

In conclusion: treatments such as mirror therapy shows that perception is malleable and that artificially created perceptions can have very real effects of cortical organization and neurophysiological responses. Rapid developments in virtual augmented reality as well as other technologies such as haptics and robotics permit ever expanding possibilities for the construction of artificial feedback and perception.

Following talks in this topical symposium -

2. Describing research on the treatment of pain through altering one's sense of body ownership: Henrik Ehrsson
3. Describing research on the use of cognitive illusions to induce top down physiological responses that lead to analgesic effects: Lorimer Moseley

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I believe that imagination is stronger than knowledge -- myth is more potent than history -- dreams are more powerful than facts -- hope always triumphs over experience -- laughter is the cure for grief -- love is stronger than death. -- Robert Fulghum

Meeting Reports

MELBOURNE SUPPORT GROUP at the "Ringwood Room" Ringwood Library 1.30 p.m. 2 October 2010

Evelyn welcomed everyone to this first meeting of Spring – especially those who might prefer to be watching the Grand Final take 2! Particularly welcome also are those attending for the first time. Welcome also to Chris Mahon, our guest speaker for the day.

Present: (18) Barbara & Robert A.; Maree & Glenn B.; Alan & Joy C.; Ellayne C.; Evelyn D.; Doug E.; Suzanne McC.; Nita McK.; Vicki M.; Chris M.; Beryl O.; Bill P.; Terry S.; Joan & Neil T.

New: (3) Filomena C and her sister Teresa; Teresa E.

Apologies: (12) Bruce G. (also apologised for last meeting); Rob O.; Robert McK.; Din D.

Business:

Books for sale and books for borrowing: Please see Evelyn during afternoon tea to borrow Striking Back, Manage Your Pain or Insights - \$40 refundable deposit required. Evelyn has Striking Back and Insights for sale at \$39 and \$35 respectively.

Treasurer's Report: The balance coming into this meeting was \$158.85. Donations in August were \$50.00 and there was income of \$30.00 for sale of one book that had been on extended loan. Expenditure since August totalled \$16.50 (insurance) leaving a balance of \$222.35.

Next meeting: will be on 4 December with a Christmas theme and Alan has kindly offered to take the meeting if Evelyn is unable to be back from travels in time.

2011 meetings: Thanks to Joan who has submitted our preferred dates for next year to Council and we await the outcome of allocation of the meeting room. 2011 will be the 10th anniversary of the Melbourne Support Group so there will be some discussion in December about ways to mark this significant milestone.

Thanks to all helpers who give of their time and effort to prepare for each meeting, greet people and help with afternoon tea and clean up. After some discussion it was decided that we will each take our own name badges home and thus eliminate the need for the person on the front desk – usually Neil – managing tags as well as welcoming people signing in. Beryl will look after emergency stick on name tags for newcomers or those who forget to bring their own.

Reports from members:

Terry S told of his treatment from Dr Joseph Ierano, a chiropractor in Sydney, who took x-rays and then used a special technique/tool to subtly move the upper cervical vertebrae. This treatment took 2-3 seconds and was done 4-5 times. It changed the posture of his neck and he was immediately pain free and does not need to return for further treatment. That was after an MVD earlier this year that was successful for only a short time and a long period of intense TN pain before that. Terry now has a clear head and feels as if he's back to normal. This treatment is available in Sydney and Brisbane but no chiropractors do it in Melbourne.

Filomena: attended a support group meeting last year but felt she had a downturn after hearing all the stories and was in denial of her own condition. She has now come to terms with it and has seen Dr Andrew Danks. She is taking 1200mg Tegretol/day and Epilin before going to sleep rather than more Tegretol which was intoxicating her. She has been pain free for 2 months now and is starting to wonder about surgery but is scared of an MVD so was interested to hear of the chiropractic procedure Terry just

spoke of. An MRI showed no obvious compression so being young with a family she is trying to manage the pain without surgery and without the side effects of medication.

Bill: told of his MVD 10 years ago with Dr Peter McNeil who was very experienced in MVD surgery. Prior to that Bill had chronic pain but he has been pain free since and has not even had an aspirin!
Beryl: said that she had taken 4 years to pluck up the courage to have an MVD but the surgery was successful and she has been free of TN pain in the ten years since then.

Maree: said she is the one in 200 who has complications after an MVD. At age 34 she began having massive TN attacks and was sent by her dentist to an oral surgeon and then to a neurologist. In Nov 2007 Dr Wade performed an MVD at the Alfred. She left hospital 1 day after the surgery and drove herself back to Geelong! (We all gasped at such treatment.) 2 weeks later problems began with fluid build-up at the site of the incision followed soon after by Bells palsy that sent her back to hospital. Not long after that a clear white gel discharge meant another return to hospital and later still further hospitalisation to remove the plate that had been inserted over the site. Maree's TN has not returned but as recent as June this year the scar suddenly re-opened and infection set in. She would not have survived without her husband Glen who is her rock! She is to see her surgeon later this month and is scared he will want to do more surgery – at this point Evelyn urged she see another neurologist for a second opinion. She has a good GP. Two other people in her workplace with 200 workers have TN – one is in denial but Maree will try to get her to come to meetings.

Joy: due to her MS Joy cannot have an MVD so in recent months she had a balloon procedure which left the left side of her face numb immediately following the procedure. 10-14 days later the numbness gradually began to wear off except in some areas. Now her face is not so swollen and she is able to eat and speak a little more easily. The benefits of this surgery should last 5 years. Joy is keen to reduce her medication. Thanks for sharing your experiences, Joy, even when you did not feel very well today.

Teresa: had a creeping numbness over the right side of her face for three years. An MRI found she had a "spot" on the fifth cranial nerve but she was told it would go away. In August '09 she had a severe fall at work. Shocks to her right eye followed 3 weeks later. She went to neurologist and again had an MRI. She was told she had TN but was given no information. Teresa was prescribed Tegretol – up to 600mg/day but still has pain and at times can hardly speak and can't eat til after midday when the medication has controlled the pain enough to allow this. Later she contacted Irene who recommended she see Andrew Danks. She is disappointed her 13 October consultation has been postponed and she will see Danks' assistant. Teresa is seeking answers to the questions of how and why TN?

It was suggested she ask for Trileptol, said to be better than Tegretol which she does not like – she feels quite different if she does not take her tablets. Barbara said she takes 200mg Tegretol morning and only 100 at night – others find a larger dose at night is better because then side effects are not as problematic. Other discussion: wearing bi-focal glasses while doing computer work tends to lead to bad posture. Wear special computer glasses if possible. People spend far more time at computers now than people did at typewriters in the past. We agreed that TN is more commonly diagnosed nowadays. Evelyn spoke of a recent phone call – a lady with MS had advice from a pharmacy assistant and found great relief from severe TN pain after taking Schusslers Tissue Salts – the combination for neuralgic pain.

Guest Speaker, Chris M:

Chris is a nurse and she experienced TN over the ophthalmic and maxillary area for three years. For this she took Lyrica in increasing amounts but now feels controlled release Tegretol is a better medication. She had an MRA (different from MRI) – thin cut 8 mm slices in 3D with an injection half way through to show up contrast. (There are MRA machines at Cabrini, Epworth and Melbourne, to name a few.) There was convincing evidence of compression of the trigeminal nerve by a cerebellar artery. Since medication was no longer an effective means of managing her pain, Chris decided to have an MVD. She chose a

neurosurgeon who has had a lot of experience, who averages one MVD a week, and a medical centre with a low infection rate. Chris was at a toxic level by the time she saw Dr Danks. She had the MVD 2 weeks later in May 2009 and immediately after the surgery she touched her trigger area and felt no pain! Since then she has been so well she had forgotten how bad the pain was until asked by Evelyn to talk to the group.

A patient must prepare well for an MVD – eat good food, sleep well, walk, maintain a positive attitude. For the first 24 hours after the surgery expect to be in the high dependency ward, then in general care in hospital for 3-4 days before being discharged with carer. It is a major event so it is not uncommon for some people to be extra sensitive to noise, to be a little off balance etc – but pain free! For the first two weeks the patient can expect to be tired and sleepy and in need of rest from household chores and visitors. Take care of the surgical incision with Betadine for example. Four weeks later there is a follow up visit to the surgeon – take a list of questions and go with a carer. Chris was told not to drive yet – and not to go bungy jumping! Make sure your concerns are answered. The last consultation is 12 weeks after surgery – usually the person can drive to this. Chris referred to Dr Janetta who pioneered this modern MVD in America as being 4/10 in neurosurgery.

Terry who spoke earlier, never had convincing compression. Chris addressed some questions and spoke of TN as a rare disorder that is frequently misdiagnosed. She provided hand-outs: Micro Vascular Decompression – a Personal Experience as well as Suggested Questions to Include with your Questions for Surgeon.

On behalf of the group, Evelyn thanked Chris for her personal account of TN and MVD and her valuable advice from a nurse's point of view.

Thanks to all who attended and shared and those who helped this afternoon.

Please note: during October and November when Evelyn is away, all TN enquiries to Irene please. Thanks to Irene for being prepared to take enquiries and to Alan for offering to take the December meeting if necessary.

Please note date of the last meeting for this year: Saturday 4 December 2010, 1.30 – 4 p.m.

Evelyn, 2 October 2010.

ADELAIDE SUPPORT GROUP

Sunday 26th September 2010

PRESENT: Eileen P, Elizabeth S, Kate N, Dina G, Garry & Lisa R, Ann T, Kevin S, Bert J, Grace A, Joan E, Laurel S, Graham and Liz B.

APOLOGIES: June and Roger O.

FINANCE REPORT: brought forward: \$121.65. Donations: \$30.00. Payment of \$78.00 to Burnside Council for hire of room for July, Sep. and Nov. meetings. Balance: \$73.65.

WELCOME: Graham welcomed all, especially first time visitors Elizabeth and daughter Kate, both TN sufferers, and their friend Dina. Graham thanked Ann and Bert for running the meeting in July while he and Liz were overseas. He pointed out that TNA Australia has been going for 10 years now and the Adelaide Support Group for 4 (since 18th February 2006). Graham has spoken to Barbara S recently, who was the first Adelaide Group Co-ordinator, and she hopes to visit the group in the near future.

MEMBERS REPORTS:

KEVIN: Has suffered TN pain in his jaw for about 15 years and attended the very first TN Support Group meeting in Adelaide. Initially he wasn't sure if it was a medical or dental problem. His dentist

ground down one of his fillings which gave him some relief. Eventually he experienced electrical pain and it was a chemist who mentioned it could be TN. His GP prescribed Tegretol but this produced a rash. Over the years he has tried various medications, none of which were particularly helpful, the pain would come and go. He went to a specialist dentist who gave him exercises to do. He was then referred to a Neurologist who diagnosed TN and was prescribed Endep and various other drugs, which again did not help. He recently visited a Neurosurgeon after one of our members had gained relief from a radiotherapy procedure but the surgeon diagnosed a problem with a pinched nerve in his temporal mandibular joint. An MRI showed a problem with his jaw. Valpro (Epilim) is controlling his pain at the moment. Previously Kevin had undergone Chiropractic treatment which initially helped, and this, he believes, ties up with a temporal manipular problem rather than TN. He has an appointment with Professor G. who will perform a procedure to inject cortisone which he hopes will fix the problem. The procedure will be done in day surgery. We wish Kevin good luck with his procedure and hope to get successful feedback at our next meeting.

GARRY: Garry's TN began due nerve damage following a stroke. No operation will benefit him. He has tried all the usual TN drugs and now takes 1800 mg. Nurontin daily and 5 mg Oxynorm twice daily. He experiences 3 – 4 electric shocks per day together with burning pain. He sometimes has pain in his eyes.

JOAN: Has hurt her back, but TN wise she is well and pain free. She has undergone two MVD's and thoroughly recommends the operation.

ANN: Is quite well, she thinks the warmer weather helps. She believes that the people who come to the support group meetings are more informed and proactive with their illness and manage their problem better than others.

EILEEN: Has been a TN sufferer for 15 years. Underwent a radiofrequency procedure in April 2010 and is no longer in pain. She does have numbness in her tongue and lips which effects her eating and has to be careful not to bite the inside of her mouth. This is taking a bit of getting used to. She was warned that numbness could occur as a result of the procedure and advises that before anyone undergoes such procedures they take into account the possibility of numbness resulting. She hopes to have 4 – 5 years pain free and has not regretted having it done. The procedure can be repeated in the future if necessary.

GRAHAM: It is now 15 months since his MVD and he is very well. He is completely pain free although still experiences slight facial numbness which is the result of a previous glycerol procedure.

ELIZABETH: started with TN pain in June last year. For six weeks she kept returning to her GP not knowing what was happening to her. Her pain attacks would last for 15 minutes at a time. She was in the throes of a serious attack, having tics and spasms, so went to a hospital requesting pain relief. She was told that she had earache and sent home. She also saw her GP during a severe attack and he diagnosed TMJ. (Elizabeth also suffers rheumatoid arthritis). After four ineffective cortisone injections she was eventually diagnosed as having TN and prescribed Tegretol. After a week of intolerable side effects - constant vomiting and rash - she was given Lyrica and this finally helped. She has been pain free for 7 months. She also experiences numbness in her arm which her Dr. thought was due to a brain tumour however this was discounted after a CAT scan and MRI. The Drs. are looking at the possibility of MS.

KATE: Is Elizabeth's daughter. Seven weeks ago while on holiday in New York her attacks began. Initially she thought it was toothache. She described her pain as crushing, stabbing, sharp. It gradually worsened particularly in the lower jaw. Her mother recognised the symptoms as similar to her own TN. She has been home for two weeks and now has pain in both top and bottom jaws, and it has spread into her neck and to the top of her head. Her face draws up in a tic. Her pain attacks last up to 2 hours. Her Dr. has prescribed 1200 mg. Tegretol together with Valium. Kate is awaiting an appointment with a

Neurologist. She has been told her problem could be inherited because of the vein mapping in her brain. It was suggested that Kate have photographs taken during an attack showing her tics and swelling, also to keep a pain journal. Kate was in extreme distress with her eyes almost swollen shut during the meeting. We wish her well. Graham mention that as tegretol had not been effective in reducing her pain the problem may be something other than TN. Kate and her mother will buy a copy of "Striking Back" to be prepared for future consultations.

BERT: Has had TN for 10 years. In June he underwent a radiofrequency procedure which has been successful and he has no more TN pain. He has a few problems however which he believes stem from pressure being applied to his left temple during the procedure. (During the alertness stage of the procedure he was aware of someone pressing on his head, presumably to keep him immobile). He continues to experience bruising pain to his forehead and cheek and discomfort in his jawbone. His lips are sore and dry and his gums and palate have shrunk. He cannot tolerate cold water. He was advised to take Tegretol but was not prepared to (that was the reason he had the procedure in the first place). He was prescribed Movalis 15 mg. for inflammation. It was considered he may have a sinus infection and prescribed Clamoxyl. This appears to have worked even though a sinus CAT scan proved negative. He still can only manage to eat soft foods but finds shaving easier.

GRACE: has had two glycerol procedures, the last one two and a half years ago. She still has pain and sensitivity on touching her face near the eye and itching on her face is almost intolerable. She experiences numbness in half her nose, tongue, teeth and throat and like Eileen has to be careful not to bite the inside of her mouth.

LAUREL: It is eight years since her glycerol procedure. She still experiences "ants crawling" and numbness in her face. She visited a chiropractor recently who used a KST instrument on her face which she feels has helped.

JUNE: although absent had phoned in an update on her condition. Her TN is back, fairly badly. She has visited a Neurosurgeon at the Royal Adelaide and has an MRI booked for early December. She is unable to take Tegretol and Lyrica seems to have no effect. She is taking anti-inflammatory tablets at the moment which seem to be helping a little.

MEETING CLOSED: 3.50 p.m. The group then spent time chatting and partaking in some tasty goodies that members had supplied. Ann had generously supplied tea, coffee, sugar, biscuits and disposable cups, serviettes, etc. plus a wheelie bag to keep it all in. (Thanks Ann! From Liz).

NEXT MEETING: 2.00pm SUNDAY 28th NOVEMBER, 2010, at Burnside Town Hall.
This will be our final meeting for the year so bring a party plate if you are able.

Graham and Liz

CANBERRA SUPPORT GROUP

Canberra Labor Club Belconnen

Saturday 25th September 2010

Present: Angela K-L, Christine R, Barbara B, Colin B, Beth C, Kerry G, Richard M, Susan M, Jan G.

Apologies: Brian W

Jan opened the meeting by welcoming two new members, Angela and Kerry. Beth is Kerry's daughter and had driven her to our meeting.

A letter from Irene had been sent to Jan suggesting members consider attending the December meeting at Toongabbie as Dr Dexter would be guest speaking.

Most members expressed interest and it was decided to finalise details at our next meeting. Jan to attempt to book the room for mid-November so that we would have time to workout who was attending and transport there. On contacting the Club a mid November date was not available but the earlier date will give us more time to make arrangements.

Canberra Members please note: the meeting at Toongabbie will be on 4th December at 1.30pm.

Jan asked if members had read in the May newsletter about the gel developed in Melbourne. She had referred **Devi** to this article and had since heard that the compounding chemist would only produce this if a script was available from her G.P. Jan suggested speaking to her doctor. To date Devi has not been in touch as to the result of this.

In the meantime Jan saw her own G.P. who gave her a script. Unfortunately the compounding chemist could not prepare the gel for a few days but when she trials it she will report back to members.

Angela was asked how her TN was identified and she replied that after dental surgery she was in constant pain. She had tried drugs but became very tired when taking them, so much so that she fell asleep when in her car at traffic lights. She had ceased all drugs and was trying pain management. It has been suggested that Passionflower could help so she had just started on that.

Barbara suggested that both Angela and Kerry consider consulting Dr Aggarwal as he had been such a help to her. Kerry was given details on how to contact him. Among other things Dr Aggarwal tried antidepressants and this reminded Jan that she had recently been told that Endep was an antidepressant. Other members were aware of this and that drug companies were now looking at first generation antidepressants to discover if they were could be used to treat other diseases.

Kerry has had her symptoms for 2 years and thought it was a dental problem but her dentist sent her to her G.P. Tegretol made her so sleepy that she could not drive any long distance. She had found that medication affected her work so much that she was in danger of losing her job.

Chris wondered if the TN Assn. could find a way of informing employers of the problems caused by TN. She had retired early because of her TN and Kerry is considering doing the same.

(To do anything at all TNA Aus needs numbers to impress. Meanwhile we are promoting TN awareness via whatever media, and rely on members to do their bit too. We would be happy to provide TN information to the employers, but we would need the employee / TN patient to be willing to stand up and say "I have trigeminal neuralgia and this is my problem.") Irene.

The problem of cleaning teeth was shared by all. Jan mentioned the orofacial pain practitioner who had spoken at the last conference and mentioned some of her tips to cope with this.

Richard said had to increase his Epilim to 800mg per day as winter and the cold winds had their usual effect. Apart from some drowsiness in the afternoon he has no other problems, Angela asked members in the group how long they had suffered TN and was thus informed.

The meeting closed at 11.40am.

Next meeting will be at 10.30am on **6th November** in the Barbara Byrne Boardroom Canberra Labor Club, Belconnen. *This was later changed to the 30th October due to room being unavailable*

Jan

I am assuming that a short meeting would have been held on the 30th of October and some decisions would have been reached regarding travelling to Sydney on the 4th of December. I suggest if you have missed that meeting, please ring Jan for travel details. ph : 6254 6640

SYDNEY CBD SUPPORT GROUP

St James Parish Hall

2nd October 2010

Present: Beverley L, Catherine L, Veronica B, Allaster McD, Kim K, Lois and Reg W, Nelma M,
Nola W, Irene W.

Guest speaker: Tony Merritt

Members Update:

Bev: Had TN for 13 years before her MVD in 2009. She now has 60% numbness on the right side of her face, with a tingling sensation - "little things running up the nerves" and she takes 300mg of Neurontin 4 times a day; and the heads gets tighter as the days goes on. She manages by not thinking about it, but some days are worse than others. She is now under the care of Dr.R. Vickers.

Nelma also has tingling, and pins pricking sensation. Nelma has had TN for many years, but now experiences burning sensation behind the eye and in the left cheek. She takes 25 mg of Endep twice a day, however the side effect "the spaced out" feeling is not desirable.

Mary K. also had her MVD in August 2009 and is still beaming brightly. Her successful MVD means she is totally pain free but commented on the itchy feeling near top of her ear.

Reg reports that all is well with him, and that his trip to the heart specialist was a routine check.

Lois has had 3 episodes of attacks a day last month, that lasted 20 minutes. She gets electric shocks and then burning to half of the face. She found that increasing her Lamictal by another 200mg did not help, so went back to her normal 200mg X 3 and her doctor started her on Lyrica @ 75mg once a day. This seems to bring things under control. She continues to have her once a month B12 injection.

Allaster said Trileptal made little difference to his pain and so his doctor has started him on a new anti-epileptic drug called VIMPAT Lacosamide @ 50mg twice a day. He reckons the strikes pain level used to be 9 out of 10 but now reduced to a level of between 3 – 4.

Von takes on half a tablet of 100mg Tegretol twice aday. She feels her glossopharyngeal neuralgia is in remission. She commented that higher dose of Tegretol makes her to lurch to the right.

Nola's facial pain is very much under control, which she describes as "only a little bit of a bother." She uses the compounded topical (medicated) cream once a day only. But being off her oral pain medication, Nola has a clearer head and was even able to travel to the meeting by herself.

And for those at the meeting who were wondering about Ben:

Ben wrote: Have been laid up literally as I have severely injured my back and unable to leave my bed until today for a few minutes. Doctor says it will be about 6-8 weeks before I'm back to my old self again and I can't wait. Very sorry I missed the meeting on 2 Oct. Tried to get there by other means other than the reliable train but sadly arrived in Sydney to late to attend. Apologies.

We welcome our guest Tony Merritt, Clinical Psychologist from Sydney Clinical Psychology and Eastern Suburbs Pain Clinic. Tony has worked 10 years in various pain clinics and has also worked with a number of trigeminal neuralgia patients.

Chronic Pain is typically defined as pain that last for more than 3 months. Because pain is an experience, your emotions, your thoughts, your physiological responses, your behaviour, influence the way you feel. There is hope and ways to improve your quality of life to help you cope. Behaviour changes are important tool.

Strategy

With a group or on your own, take an inventory of all the things that have changed since you developed TN. Include as many things as possible. Make this the basis of your coping plan.

For each change develop a plan that:

- (a) is active and connected to change;
- (b) is based around accepted and practical ideas;
- (c) will give you an increased sense of control;
- (d) is about what you can do for yourself

A general approach to coping with chronic pain

* Education

The condition, chronic pain, evidence-based treatment

(Research shows that people who have knowledge of their condition manage their condition better)

* Engagement

Interested involved treatment professionals with whom you can have a long-term relationship, esp. GP and specialist

(Need to have a relationship with someone you can work with- your GP)

* Meditation/relaxation skills

* Managing fear and anxiety

Including acceptance

* Dealing with unhelpful thinking

* Re-engaging with values and goals

* Staying realistic

Three key areas: Anxiety

* The fear of pain is more disabling than pain itself

* The fears involve one or more of:

- (a) Fear of activities
- (b) Fear of movement
- (c) Fear of the actual sensation

* Increased fear of pain is associated with

- (a) Reduced physical functioning
- (b) Poorer return to work outcomes
- (c) A more restricted life
- (d) Unemployment, relationship problems, sexual problems

Coping with fear of pain

* Accept that thoughts and feelings are not facts

- o Possibilities and extra information

* Develop relaxation/meditation practice

* Develop of 'hierarchy' of fears to confront

* Start with the things at the bottom of the hierarchy and gradually work up

- o Reward yourself for progress

* Recognise and challenge 'fearful' thinking

* Catastrophising, black and white thinking, generalising

Values and goals

- People with chronic pain or illness lose sight of what matters to them
- Refocusing on values is associated with better coping with chronic pain, less pain, less depression and anxiety, better sleep, less medication use

- Values provide general life direction, goals the means of getting there

Staying realistic

- Develop reminder cards for your wallet/bag
- Use mindfulness and other strategies to 'ride the waves'
- Be informed about your condition
- Be kind to yourself
- Enlist a friend to 'remind you' of where you are
- Recognise that a lapse is not a relapse
- Reduce but do not stop activity
- Focus on activities that are either valued, pleasurable, necessary

Tony commented that while the Internet is great and can provide valuable information, he cautioned that the information should be credible, or has researched evidence. He said there are a lot of people out there who prey on people with chronic pain and try to make money out of them with ridiculous unhelpful claims that has no evidence at all.

We thanked Tony for an interesting and informative lecture and for giving up his Saturday morning to join us. We then presented him with "Striking Back" and hope he learns a bit more about trigeminal neuralgia.

We concluded the meeting at 12 noon; followed by tea and coffee and all those delicious food.

Kim's Report: Donation collected at door = \$35.

After paying Hall's rent and Striking Back book – there is \$155.40 in the Kitty.

Irene.

Reminder - No CBD meeting in December. We will have a combine Christmas meeting at Toongabbie. Meeting starts at 1:30pm. Guest Speaker: Dr. Mark Dexter.

If you need transport from Westmead Railway station to Toongabbie School please contact me **prior** to meeting day – so arrangements can be made.

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.

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Correspondence Corner

Mira Z: " I contacted you about 1 year ago regarding my Mum who has multiple sclerosis, is wheelchair bound and suffers with T.N. She was in incredible pain & you gave wonderful support & suggestions (eg Zostrix cream). Thankyou!!! You also sent newsletters for which I am very grateful. The last newsletter I received was Oct 2009, in which "Kay M" described "My TN journey". This lady's journey is exactly what my Mum has gone & is going through. The 'barb wire' pain, electric shocks in the mouth... G.P's, Dentists, Endodontists and Neurologists - These Health Professionals are unaware or lack information about TN. They seem to have a "Quick fix it" response. Increase the dosage...change medication...have an MRI...Its all in your mind !!!!!"

Irene - *Hence my newsletters. They are aimed at empowering you with information so you can better travel your pain journey. Educating your doctors could sometimes be as simple as sharing our newsletters with them.*

Mum was on Tegretol (100mg twice daily) then 200mg twice daily, now Sodium Valproate 200 mg twice daily, and finally Sodium Valproate four times daily. It is all very confusing, and it seems like no-one can help. Mum's GP and Neurologist are away on holiday until 04 Oct 10 . Once again, no-one can help ...suffer and wait. Mum has been in terrible pain in the last 3 days (crying & screaming) with very sudden TN attacking her without warning. I went to a chemist & she suggested SCHUESSLER TISSUE SALTS...NERVE TONIC...COMB 5. Mum has taken this, and I am very surprised to say that it has completely eliminated Mum's pain...IMMEDIATELY.

Irene - *Anyone interested in this Tissue Salt should Google it. Part of it contains magnesium. Due to space constrain I'll share some magnesium facts with you next newsletter.*

Jennifer D: I spoke to you around two years ago regarding my condition. You were kind enough to give me some advice. I exhausted a number of avenues regarding my condition and did not have a lot of luck. I ended up having an MVD endoscopically and that was of no success, so went in again, with no success. With not getting any satisfaction, I started again with my condition. I had another MRI to show I still had loops but the TN nerve had been separated for the artery. I also have a compression and loops on the left.

Irene - *MRI is not a diagnostic tool for TN and not all compression causes TN.*

To cut a long story short as I am sure you have heard it all, I visited a Dr. Sandstrom in Brisbane and he has done Botox on me, with really good results. I thought I would let you know for other sufferers of TN maybe this is an option for them.

Irene - *Yes, studies have shown Botox can provide relief for TN but only for 3 months. However there is no long term study - what happens if Botox is done 4 times a year and 5 years later? Financially it is \$500 X 4 X 5 years.*

Graeme T: I have been taking a modest one level teaspoon of Lecithin per day. On that level I have been able to reduce my Tegretol dose progressively over an 18 month period from 600mg/day to a current 200mg/day. The 600/day was necessary to control the then frequent and very severe TN attacks but since using Lecithin during this gradual dose reduction regime I have suffered no attacks.

Irene: *People take lecithin supplements due to the popular beliefs of the benefits they provide but there is no scientific evidence to support any of these claims. Most lecithin supplements are derived from soya beans; & be very aware of the side effects. Eating a healthy, varied, balanced diet would give you all the lecithin you need - around 50mgs a day for most people & to enable normal body function. Natural sources of lecithin include foods such as soybean, egg yolk, wheat germ, legumes, yeast, peanuts and fish.*

However, I suspect it is more due to Choline (found in lecithin) for the healthy cells and also a key component of acetylcholine, a neurotransmitter. Beef liver, chicken liver and eggs are all excellent sources of choline. Other sources of choline include soybeans, egg yolk, butter, peanuts, potatoes, cauliflower, lentils, oats, sesame seeds and flax seeds and whole wheat bread. High doses (10 to 16 grams/day) of choline have been associated with a fishy body odor, vomiting, salivation, and increased sweating.

2010 Meeting Dates

State	GROUP	Date & Time	Venue	Group Leader/s
ACT	Canberra	30 th Oct 10.30am-12.30pm	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 6254 6640
NSW	Sydney	4 December 1:30 – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Kim Koh ☎ 02 97431279
	Sydney CBD	4 December 1:30 – 4:00 pm	Combined Meeting at Toongabbie	Irene Wood ☎ 0413 363 143
QLD	Brisbane	13 November 1.30-4.00pm	30 Ridley Road Bridgeman Down	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	20 November 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	28 November 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 Sts	Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989
VIC	Melbourne	4 December 1.30 – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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