Trigeminal Neuralgia Association Australia Incorporated. ABN 33 914 644 101

Making A Difference

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

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

March 2012

Man falls through Castle Hill Post Office roof at feet of police

Hills Shire Times 31 Jan 12 @ 09:29am by BEV JORDAN

A MAN is under guard in Westmead Hospital after falling through the roof of Castle Hill Post Office.
The 31-year-old, from Toongabbie, was arrested by police at 1am this morning.
A security company who answered the alarm called police after they allegedly saw a man inside the building.
Police set up a perimeter around the building while a police dog and handler searched the premises on the corner of Old Northern Rd and Castle St . It is alleged police saw a man's leg fall through the roof in two areas before the roof gave way and the man fell onto the floor at the feet of police.
Investigations are continuing but police say both the Post Office and the neighbouring cafe, Castle Coffee Bean, had been broken into. The man is being treated for an injury to his arm.

Membership

We fear some of your cheques for membership renewal may have been lost due to the break in at the Post Office. Please check to see if your cheque has been presented. If not, please cancel it and please renew your membership ASAP.

Thank you for your membership renewal. Your membership renewal is an indication of your confidence in our work and we take heart in your continued support. Your kind words of encouragement provide us with the strength to carry on. All money collected are used in our invaluable work to promote TN.

TNA Australia 5th National Conference in 2013

After many months of searching and negotiating , I am proud to announce that TNA Australia has now signed contract with Sea World Resort in Surfers Paradise to hold our 5th National Conference from 23rd – 26th August in 2013. I have also bargained for an optional extra day for you to explore Sea World and Water Park; or other Theme Parks nearby.

This would be a splendid opportunity to bring your family, your grandchildren, and friends. We have struck a fantastic deal for you and it would be a dire shame to miss it. So start saving. We will also be celebrating our 10th Anniversary then, and we would love to mark the occasion with our loyal friends and supporters. Besides the excitement of the venue, you can expect another outstanding program from speakers and their topics - more later.

Regional Conference in Adelaide

This meeting is opened to all members of TNA Australia, and all health care professionals who have an interest in trigeminal neuralgia. Please feel free to invite your doctors to the meeting. However, as seats are limited, please book your seat/s before 30th March. We need to know numbers to cater for Lunch.
I urge those are newly diagnosed to take advantage of this wonderful opportunity.

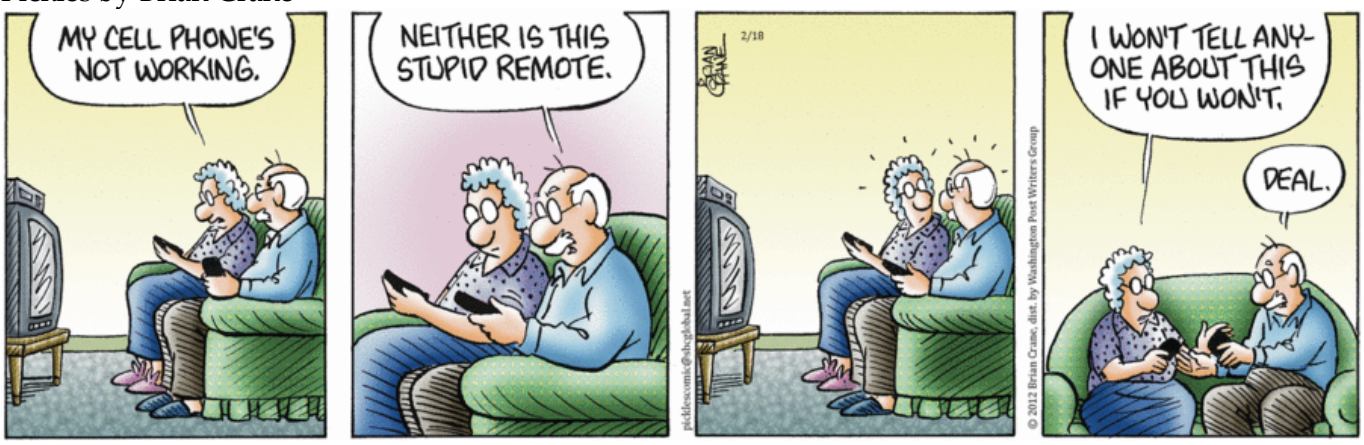
Program

Saturday 28th April 2012	Topic	Speaker
9:00 – 9:20	Registration & Welcome	
09:20 – 10:00	What is Trigeminal Neuralgia & New Classification of Facial Pain (Burchiel)	Dr Andrew Zacest
10:00 – 10:40	Pain Shield - Can it help TN?	Mr Ken Ho / - Gen Med Pty
10: 40 – 11:20	Results of a survey of clinician preferences in management of trigeminal neuralgia	Dr Ben Jonker
11: 20– 12:00 Noon	Co-morbidities of TN	A/Prof Arun Aggarwal
12:00 – 1:00 PM	Lunch	
1:00 – 1:45	Medical management of TN	A/Prof Arun Aggarwal
1.45 – 2:30	Percutaneous Procedures for TN	Dr Andrew Zacest
2: 30 – 2:45	Break	
2:50 – 3:30	SRS and outcome for TN	Dr Ben Jonker
3:40 – 4:20	MVD – The procedure, who is a candidate and the outcome	Dr Andrew Zacest
4:20 – 4:45	Q &A - Panels	Dr Zacest, Dr Jonker And A/Prof Aggarwal
4:45 PM	Concludes	

Attendance is FREE - a door donation would be appreciated. $10 for catered Lunch.
As seating is limited, please reserve your seats before 30th March 2012

~ Irene ~

Pickles by Brian Crane



Rewiring the Brain to Ease Pain

Brain Scans Fuel Efforts to Teach Patients How to Short-Circuit Hurtful Signals

By MELINDA BECK

The Wall Street Journal / Health Journal / NOVEMBER 15, 2011.

How you think about pain can have a major impact on how it feels.

That's the intriguing conclusion neuroscientists are reaching as scanning technologies let them see how the brain processes pain.

Alternative remedies for relief of chronic pain are getting new attention and respect these days. Melinda Beck has details on Lunch Break.
That's also the principle behind many mind-body approaches to chronic pain that are proving surprisingly effective in clinical trials.

Some are as old as meditation, hypnosis and tai chi, while others are far more high tech. In studies at Stanford University's Neuroscience and Pain Lab, subjects can watch their own brains react to pain in real-time and learn to control their response—much like building up a muscle. When subjects focused on something distracting instead of the pain, they had more activity in the higher-thinking parts of their brains. When they "re-evaluated" their pain emotionally—"Yes, my back hurts, but I won't let that stop me"—they had more activity in the deep brain structures that process emotion. Either way, they were able to ease their own pain significantly, according to a study in the journal Anesthesiology last month.

While some of these therapies have been used successfully for years, "we are only now starting to understand the brain basis of how they work, and how they work differently from each other," says Sean Mackey, chief of the division of pain management at Stanford.

He and his colleagues were just awarded a $9 million grant to study mind-based therapies for chronic low back pain from the government's National Center for Complementary and Alternative Medicine (NCCAM).

Some 116 million American adults—one-third of the population—struggle with chronic pain, and many are inadequately treated, according to a report by the Institute of Medicine in July.

Yet abuse of pain medication is rampant. Annual deaths due to overdoses of painkillers quadrupled, to 14,800, between 1998 and 2008, according to the Centers for Disease Control and Prevention. The painkiller Vicodin is now the most prescribed drug in the U.S.

"There is a growing recognition that drugs are only part of the solution and that people who live with chronic pain have to develop a strategy that calls upon some inner resources," says Josephine Briggs, director of NCCAM, which has funded much of the research into alternative approaches to pain relief.

Already, neuroscientists know that how people perceive pain is highly individual, involving heredity, stress, anxiety, fear, depression, previous experience and general health. Motivation also plays a huge role—and helps explain why a gravely wounded soldier can ignore his own pain to save his buddies while someone who is depressed may feel incapacitated by a minor sprain.

"We are all walking around carrying the baggage, both good and bad, from our past experience and we use that information to make projections about what we expect to happen in the future," says Robert Coghill, a neuroscientist at Wake Forest Baptist Medical Center in Winston-Salem, N.C.

Dr. Coghill gives a personal example: "I'm periodically trying to get into shape—I go to the gym and work out way too much and my muscles are really sore, but I interpret that as a positive. I'm thinking, 'I've really

worked hard.' " A person with fibromyalgia might be getting similar pain signals, he says, but experience them very differently, particularly if she fears she will never get better.

Dr. Mackey says patients' emotional states can even predict how they will respond to an illness. For example, people who are anxious are more likely to experience pain after surgery or develop lingering nerve pain after a case of shingles.

That doesn't mean that the pain is imaginary, experts stress. In fact, brain scans show that chronic pain (defined as pain that lasts at least 12 weeks or a long time after the injury has healed) represents a malfunction in the brain's pain processing systems. The pain signals take detours into areas of the brain involved with emotion, attention and perception of danger and can cause gray matter to atrophy. That may explain why some chronic pain sufferers lose some cognitive ability, which is often thought to be a side effect of pain medication.

The dysfunction "feeds on itself," says Dr. Mackey. "You get into a vicious circle of more pain, more anxiety, more fear, more depression. We need to interrupt that cycle."

One technique is attention distraction, simply directing your mind away from the pain. "It's like having a flashlight in the dark—you choose what you want to focus on. We have that same power with our mind," says Ravi Prasad, a pain psychologist at Stanford.

Guided imagery, in which a patient imagines, say, floating on a cloud, also works in part by diverting attention away from pain. So does mindfulness meditation. In a study in the Journal of Neuroscience in April, researchers at Wake Forest taught 15 adults how to meditate for 20 minutes a day for four days and subjected them to painful stimuli (a probe heated to 120 degrees Fahrenheit on the leg).

Brain scans before and after showed that while they were meditating, they had less activity in the primary somatosensory cortex, the part of the brain that registers where pain is coming from, and greater activity in the anterior cingulate cortex, which plays a role in handling unpleasant feelings. Subjects also reported feeling 40% less pain intensity and 57% less unpleasantness while meditating.

"Our subjects really looked at pain differently after meditating. Some said, 'I didn't need to say ouch,' " says Fadel Zeidan, the lead investigator.

Techniques that help patients "emotionally reappraise" their pain rather than ignore it are particularly helpful when patients are afraid they will suffer further injury and become sedentary, experts say.

Cognitive behavioral therapy, which is offered at many pain-management programs, teaches patients to challenge their negative thoughts about their pain and substitute more positive behaviors.

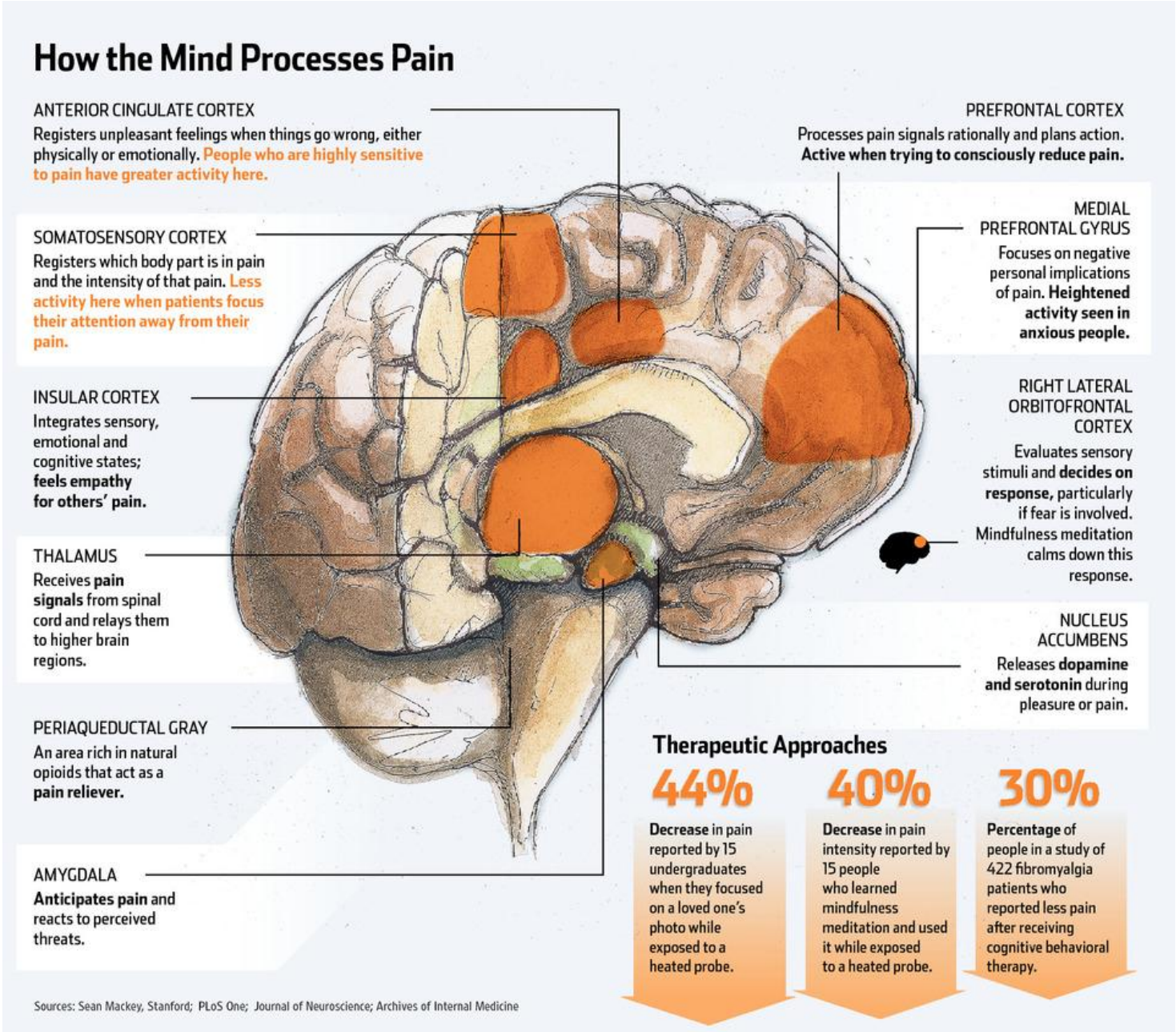
Even getting therapy by telephone for six months helped British patients with fibromyalgia, according to a study published online this week in the Archives of Internal Medicine. Nearly 30% of patients receiving the therapy reported less pain, compared with 8% of those getting conventional treatments. The study noted that in the U.K., no drugs are approved for use in fibromyalgia and access to therapy or exercise programs is limited, if available at all.

Anticipating relief also seems to make it happen, research into the placebo effect has shown. In another NCCAM-funded study, 48 subjects were given either real or simulated acupuncture and then exposed to heat stimuli.

Both groups reported similar levels of pain relief—but brain scans showed that actual acupuncture interrupted pain signals in the spinal cord while the sham version, which didn't penetrate the skin, activated parts of the brain associated with mood and expectation, according to a 2009 study in the journal Neuroimage.

One of Dr. Mackey's favorite pain-relieving techniques is love. He and colleagues recruited 15 Stanford undergraduates and had them bring in photos of their beloved and another friend. Then he scanned their brains while applying pain stimuli from a hot probe. On average, the subject reported feeling 44% less pain while focusing on their loved one than on their friend. Brain images showed they had strong activity in the nucleus accumbens, an area deep in the brain involved with dopamine and reward circuits.

Experts stress that much still isn't known about pain and the brain, including whom these mind-body therapies are most appropriate for. They also say it's important that anyone who is in pain get a thorough medical examination. "You can't just say, 'Go take a yoga class.' That's not a thoughtful approach to pain management," says Dr. Briggs.



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High-dose capsaicin patch reduces postherpetic neuralgia
Publish date: Oct 1, 2010 By: Ilya Petrou, M.D. Source: Dermatology Times

Studying Qutenza

Dr. Wallace co-authored a study (Backonja M, Wallace M, et al. Lancet Neurol. 2008;7(12):1106-1112) evaluating the efficacy and safety of the Qutenza patch over a 12-week period. The multicenter, double-blind study included 402 participants with at least a six-month history of postherpetic neuralgia who were randomized to receive one-time 60-minute application of the 8 percent capsaicin-containing Qutenza patch (206 patients) or a low concentration 0.04 percent capsaicin-containing control patch (196 patients).

The primary efficacy endpoint was percentage change seen in numeric pain rating scale (NPRS) score from baseline to weeks two to eight. Patients were followed to week 12.

Results showed a significantly greater reduction in pain between weeks two and eight of treatment in those patients who received the Qutenza patch compared to controls. The mean changes in the NPRS scores from baseline to week eight were -29.6 percent versus -19.9 percent for the Qutenza and control group, respectively, which slightly improved by week 12.

A 30 percent or greater reduction in the mean NPRS score was seen in 87 patients (42 percent) and 63 patients (32 percent) of the Qutenza and control groups, respectively.

"Once the three months pass and the analgesic effect of the treatment begins to wear off, another treatment can simply be applied, if necessary, to further manage the pain. Repeat treatments with Qutenza have shown an efficacy out to 52 weeks," Dr. Wallace says.

The adverse events with current treatment approaches can sometimes be difficult to tolerate and can include constipation, sedation and nausea with opioids, and cognitive impairment, vertigo and nausea with gabapentin and pregabalin. The lidocaine patch is a very well tolerated therapy and does not have any serious adverse events.

Side effects

Treatment with Qutenza proves to be safe with patients showing only mild-to-moderate and transient erythema and pain at the site of application. Transient blood pressure changes (less than 10 mm Hg) were also seen in study patients. However, these were associated with changes in pain level immediately after the application of the patch. There are no systemic toxicities with Qutenza and no systemic absorption of the drug.

"There is a distinct increase in pain at the target area where the patch is applied. Upon removing the patch after an hour, the pain will rapidly decrease. Most patients are not phased by and can easily tolerate this temporary increase in pain," Dr. Wallace says.

After the painful target area is mapped, the patch is placed directly over this area for one hour. The capsaicin penetrates the dermis to activate a receptor on unmyelinated free nerve endings, resulting in an influx of calcium into the intracellular space. The massive influx initially depolarizes the nerves, resulting in transient pain followed by a prolonged desensitization of the nerve endings and prolonged pain relief.

A biopsy of the treated skin will demonstrate a regression of the epidermal unmyelinated nerve fibers. According to Dr. Wallace, this regression of the nerve fibers explains the long-lasting analgesic effect of locally applied capsaicin.

"Capsaicin in a way causes a chemodenervation where applied. These unmyelinated epidermal nerve fibers will regress and then regrow over the course of three to four months, at which time a new treatment with Qutenza may be required," Dr. Wallace says. Qutenza, available on the market in the United States since May, requires a prescription.

Disclosures: Dr. Wallace has received research support from NeurogesX.

Support Group Meeting Reports

ADELAIDE SUPPORT GROUP

Burnside Civic Centre

Sunday 29th January, 2012

Present: Bert J, Sue & David H, Kevin S, Grace A, Pamela L, Ann T, Kelly N, Kerryn E, Angela M, Garry & Lisa R, Graham & Liz B.
Apologies – Non received**.**

Welcome: Graham welcomed all in attendance with a special welcome to Kerryn from Berri attending for the first time.

Finance: Donations $25.30; Interest $0.59c; Xmas mail out postage $29.95; Balance on hand: $539.44. Account from Burnside Council for hire of venue for $81.00 (Jan-Mar- May meetings) is due this week.

General Business: Graham reminded members that subscriptions for 2012 were now due. Subscription forms are available together with copies of the 2012 programs for those who had not received one in the Xmas mail out. We have been advised that the cost for hire of the Civic centre has been increased to $27.00 per meeting. As this includes public liability insurance and use of kitchen and video equipment it is still very good value. He advised that some expenses may need to be met for the SA Regional Conference if our offer to provide cake/tea/coffee is taken up. Caterers will supply the sandwiches for lunch. Registration Forms will be in the next Newsletter, everyone is asked to forward their registrations as soon as possible.

Member Updates:
David: Situation unchanged. He thought the high doses of Vitamin B12 had not really helped, however he has started also taking multi vitamin tablets and thinks there may be some slight improvement. His GP is not very enthusiastic regarding vitamin therapy. David has post hepatic N. He finds riding his exercise bike aggravates his pain, also stress and high blood pressure. He is still taking Endep.

(Topical Capsaicin cream may help. Zostrix can be bought over the counter. It is a chilli cream, applied several times a day can provide pain relief. Apply 4 - 5 times a day - Same time each day. Relief is usually only after a period of (4 – 6) weeks It works by depleting the substance P - a neurotransmitter - found in nerve endings and interferes with the transmission of pain signals to the brain. If you don't respond to chilli cream, try peppermint oil. Others have had success with this. ~ Irene)

Sue: Keeping reasonably well, although she feels the frequency of her attacks are beginning to increase. She still takes 50 mg Tegretol night and morning and is not prepared to increase the dose at this stage. Her pain is not as bad as it was initially when she was almost passing out the pain was so severe. Sue also suffers from fibromyalgia and also takes Endep. Sue and David are planning an overseas trip during the year and have found travel insurance with a pre existing condition a little difficult to obtain, however COTA will cover them. She is very nervous about flying as it was during a flight she experienced her first attack and thought there was a connection, however her Doctor says this should not be a problem.
(Discuss with your doctor about increasing Tegretol by another 50mg AM/PM a couple of days before, and after your flight – if you are worried.~ Irene.)

Kelly: Underwent an MVD in October. She had a post -operative leakage but this rectified itself after a short time. She has a "crawly" sensation in her face and slight pain in her jaw, but generally feels well. She does not require any medication. She had a satisfactory recovery from her surgery and was back at work after six weeks. *Hurrah!*

Bert: Is very well, life is good. Does not require any medication. He says he "only comes for the cake". *(bless, him!!. we do appreciate Bert's cheeriness at our meetings).*

Ann: Has pretty awful days like everyone. Her quote for the day "Pain is inevitable, misery is optional". Ann has pain on both sides which is relatively unusual. She has been told that further surgery is not an option. She experiences twitching eyes. Where ever Ann goes she makes sure she is in safe surroundings and is loved. She works in a very caring environment and has a very supportive family. *(Ann is an inspiration despite her extreme suffering.)*

Kevin: Still takes Lyrica and has experienced some very nasty pain episodes. He has been in touch with Professor G and his GP and is now waiting for an appointment at the RAH Pain Clinic. Kevin's problem is caused by a worn disc in his jaw affecting the trigeminal nerve. From the top of his head to his chin, the temple in particular is very sensitive and he has electric shocks. Speaking and smiling often produces shocks. He is looking forward to the Pain Management appointment. Kevin's family are concerned about his Lyrica medication as they have heard it can cause dementia. He takes 4 x 70 mg. daily. He would like to decrease the dose because of his concerns. Discussion ensued about reactions to various drugs and generally Tegretol seems still to be the most effective but there are several new drugs becoming available, however they all seem to be very expensive. Graham said we would probably learn more about these at the April Conference. (*Kevin could try Zostrix too.~ Irene.)*

Angela: Doing really well. She had TN for 27 years. She underwent an MVD in Sydney. Her pain returned and she had a radio frequency procedure in April 2010 by Dr. Z which has proved very successful. If she is stressed or really busy she experiences "strange" sensations and she still cannot lie on her affected side. She takes multi vitamins and B12.
27 years ago nothing was offered to her except larger and larger doses of Tegretol. Her mother also suffers from TN.

Pamela: Has Atypical TN. She was diagnosed in 2011. She experiences pain all day, every day. Burning and ants crawling which is worsening. She has been told her pain is a cross over between TN and migraine but she states it is nothing like a migraine. She has also been told no surgical procedure will work. She has also tried B12 injections. Her neurologist advised he can do nothing more for her. She is taking 400 mg. Tegretol which does not seem to help and causes unpleasant side effects. Dr. Z is sending her to the Flinders Hospital Pain Clinic. Pamela has other health issues and feels "she has been cast adrift with no help". Her GP will not prescribe Endep as he "doesn't believe in it." Graham suggested Pamela seek advice from her chemist regarding the various medications she is taking. Pamela has read Striking Back and Insights but found these books did not really relate to her problems.

The term "Atypical" and a typical can be quite confusing. Atypical means out of character, or not conforming; so if you have "Atypical Trigeminal Neuralgia "- it means your symptoms do not conform to the classic TN; and usually tricyclic antidepressants such as amitriptyline (Endep) is used as first line treatment for "Atypical trigeminal neuralgia." Sometimes these "Atypical TN" are also referred to as "Trigeminal Neuropathic Pain"; more recently, IASP new terminology "Persistent idiopathic facial pain (PIFP)." In my opinion - this should not be confused with Burchiel's TN 1 and TN2 – where TN 2 is a continuum of TN1- in other words, you have to have classic TN first ~ Irene.

Grace: Still has intense itching and cannot lie on her affected side. She has undergone two glycerol procedures which has left her face very numb. She takes 25 mg Endep to help her sleep. She takes medication for high blood pressure but does not take any drugs for her TN. She does not sleep well and suffers badly with restless leg syndrome.

Garry: No change in his condition. 4 – 5 electric shocks daily also burning. He finds applying pressure on the painful sites helps. He finds it difficult to describe his pain. He has been taking Endep for years. He also takes 600 mg Nurontin three times a day together with 2 Oxynorm. He is having hormone injections for prostate cancer which gives him hot flushes. Garry has Atypical TN due to damage from a stroke.

Kerryn: Our new member who travelled all the way from Berri. She is a friend of Kelly and has suffered from TN for 3 years. Her skin specialist diagnosed her TN. She had an MVD last May at Flinders Hospital. Three blood vessels were involved. A sling made from her tissue was used during the operation. Unfortunately her TN returned after only 4 months. She has been told nothing more can be done. She feels as though her head is being pulled apart. She also has swelling at the operation site, a black eye and facial swelling. Wearing glasses is too painful. Kerryn has visited 21 different doctors for help, also psychiatrists. She is now awaiting an appointment for a further opinion at the Royal Adelaide Hospital.

Ann was able to relate to Kerryn's story as many of their symptoms are very alike.

Graham: Very well. No pain or medication after his MVD 2½years ago.

The meeting ended at 3.45 p.m. and all present enjoyed delicious cakes, tea and coffee and lots of chat.

NEXT MEETING: 2.00 pm **Sunday 25th March** 2012 at the Burnside Town Hall Civic Centre.

Graham and Liz Boyer

SYDNEY SUPPORT GROUP

Toongabbie Public School

28th January 2012

Present: Irene W, Kim K, Kim S, Jeanette & Henry B, Frank M, Marion A, Stewart & Gundal B, Peter & Rose H, Marj & Ken F,Ann & Laurie P,Vera R.
Apologies: Elizabeth & Lloyd, Beryl T, Jocelyn S

Irene opened the meeting at 1.45 and welcomed us all after a relaxing Christmas & New Year.
Kim S has agreed to co-host this support group along with Kim K. This would give Irene time to visit other support groups. Thanks Kim S.
We need to continue to spread the word about this support group and everyone is asked to do their bit. Marj participates in a choir in Blacktown and is willing to put our flyer on their notice board. Kim K will send Marj some flyers so Marj can leave these flyers wherever she goes with her choir.
Kim K asked if we have any particular topic or speaker we would like to have during the year? She has approached a dietician without much luck, however Peter Cowie (Chiropractor) has indicated he would like to attend a meeting and give a talk. Marion suggested a Nutritionist could be of benefit especially for those in pain who cannot eat, finding out what is the easiest way to obtain necessary vitamins & minerals could help. Kim S said she had received some valuable info from a friend when she was at her worst, so would approach her for more info.
Irene said she was proposing a ½ day at SMSA with 2-3 guest speakers in or around June, so hopefully more on that later. We will probably hold our CBD & Sydney combined meeting in Dec here, due to St James Church not being available in Dec.

Frank: Funds held for Sydney group is $180.00 with hall hire $33 per meeting.

Members Update:

Kim S: Is continuing to be pain free, however, still has some numbness and has been getting these very spasmodic tingles right up her right side, but she is trying to disregard them. Irene suggests Kim keeps a record of the frequency, triggers etc to see if they fit a pattern or are related to any movements, or there are any common causes. Kim said they are comparable to her very initial sensations, so Irene suggests she should discuss with her doctor & maybe discuss low dose of medication to keep nerve calm. As Kim S is to see Dr Dexter soon for a follow up, so will start recording these sensations & discuss with Dr Dexter. Irene suggests: It is not wise to ignore symptoms and & "hope it goes away

Marion: 3 ½ years since MVD & all is well, however discussion came up re "scar tissue" and she said she sometimes finds it "aches" and Kim S agreed, she cannot sleep on that side as it feels like a "lump". **Kim K** said her op. wound area is numb. It was interesting to compare these post MVD effects.

Laurie: is good, and busy looking after Number 1…Ann…for which he thinks he deserves a medal.! Ann agrees as he is wonderful.

Ann: is still having trouble with the inside of her mouth, bottom lip area. Her Dentist has changed her dentures on the right side so that they don't clamp together to stop the problem of her biting the inside of her cheek, which has helped, but she needs to get the front adjusted as her lip is the problem now. She had Radiosurgery in 1990 & an MVD 18 mths before that. She has very little sense of taste & smell but has learnt to cope. It is the annoying problems of not being able to chew things like lettuce & tomatoes that gets to her, and the biting of the lip.

Gundel suggested a chopping machine that swishes the food up, yet preserving all the taste and nutrients. She will bring this "chopping "machine next meeting for "show & tell".

Jeanette: wanted to say thanks to Dr Dexter for showing what has gone on in her head at the last meeting. She would like to see the Medical Journal that he has published his findings in. Irene said she would make sure Jeanette gets a copy.

Jeanette then gave us an update on her telephone contacts. Out of the 7 Christmas Cards she sent she heard back from only 3 people. **Emily** said she is doing well following recent radiation therapy from Dr Smee. **Beryl T** said her TN is up & down but she is continuing with the Acupuncture; and **Verna McC** who share their villa at the last conference has sent copies of photos she took during the conference. Irene thanked Jeanette for doing this important follow up work.

Frank: Is not sure how he is really, he is still short of breath and just not feeling quite right. Kim asked how his heart was & he said he is due to see the Specialist again this week so hopes to find out more.

Norma: is the same, with occasional pain. She also suffers from lumps inside her mouth and lately has had pins & needles in her left foot & leg, which is annoying.

Irene: Is fine, thanks for asking.

Vera: Is well, she brought a long a card from her Bowen Technique therapist and thought it would be interesting for us to learn a bit more about Bowen Therapy. The card was then given to Kim K who noted the contact details. Vera finds the treatment has been helping her with her general well .

Rose: has some issues with stomach pain, but she is working through that. She is busy "keeping out of Peters way"

Peter: had to stop using the chilli cream as he had an outbreak of hair follicles. It may have helped slightly, but not so you would really notice. He is under a lot of stress at work which doesn't help, so his pain level has been quite high.

Gundel: Is fine. She also does a brilliant job of taking care of number 1.

Stewart: He tried the Vimpat for 6 weeks, increasing it gradually to a top level of 3 per day, but didn't feel it had any effect on his pain, and he started getting blurred vision, so he gradually decreased it again until he was off it Two days after he finished the Vimpat he had a day of severe surges of pain, which came in waves. He is not sure what caused it He is now back on Amitriptyline, 25mg, 1 hour before bed which helps him sleep, for which he is grateful.

Ken: is a wonderful support for Marj.

Marj: suffered a really bad attack in early January. For the last 2 years she has been on 300 mg Tegretol, night & morning along with 200 mg Epilim night & morning. In Dec her Dentist advised she needed a tooth extracted, but wouldn't do it because of her TN, so referred her to a Specialist. Marj increased her Tegretol to 400 & 400 & her Epilim, for 4 days prior to the tooth extraction and had no problems with the procedure. Afterwards she went straight back to her previous doses and BANG, she had terrible attacks of pain. She tried to ring Irene, but she was away and she tried ice, but that didn't help. She managed to get relief using wheat packs, until Irene phoned and said she should have decreased her doses, gradually! She is now slowly reducing the doses and is feeling much better. In a couple of weeks she will be back to her usual dosage.
She noticed on the increased Tegretol she suffered blurred vision and had problems with her balance. She finds she also has to sit up straight now as sitting back in her recliner increases the pain.
She recently had a 6 month check-up and her B12 is down, so she is on to some B12 tabs.

Kim K: Is fine, but is in pain and has increased her Tegretol to 700 mg. She continues on her special diet & B12. Prior to Christmas she fell off the ladder 3 times! She thinks the Tegretol affects her balance, so be careful everyone. She also had some floaters in her eye and lightning like flashes in her eye…she has seen a Dr and hopes that is starting to settle. She took her 80 year old Mum, who is also a sufferer to see Dr Dexter. He advised as her TN is under control, he would not recommend surgery, which was a relief to her Mum, she will continue with her meds.

The raffle was won by Ken.
Meeting closed at 3.30pm and we enjoyed some delicious sandwiches, cakes and slices and a cuppa. Thanks to all for the food and supporting our group.

Next meeting will be on the 3rd of March Thank-you Marion for the meeting report.

Irene.

MELBOURNE SUPPORT GROUP

Ringwood Public Library

11 February 2012

Present: (16) Barbara & Bob A.; Alan & Joy C.; Evelyn & Din D.; Bruce G.; Alf H.; Verna & Richard H.; Beryl & Rob O.; Bill P.; Neil & Joan T.; Jo Z.;
New attendees: (4) Lauren S.; John and Natalie S.; Michelle ?;
Apologies: (9) Audrey B.; Toni B.; Ellayne C.; Sugi & Lenny H.; Nita & Rob McK.; Will & Joan R,;

Apologies to Nita & Rob who were present at the December meeting and reported on in the meeting report but not listed as being present!

Evelyn acknowledged that we meet on the traditional lands of the Wurundjeri people and welcomed everyone to the first meeting for 2012, especially those attending for the first time.

Report: Treasurer Alan reported that there was a carry forward balance of $304.35, expenses of $38.05, a special cash donation gratefully accepted from Bruce G. and donations at the last meeting of $51.90 leaving a balance of $418.20. Evelyn reported that a very generous donation of $500 had just been made to the Melbourne Support Group by Sugi H. whose wife Lenny G. has been pain free since attending a meeting last year and taking sublingual Vitamin B12! The cash was handed to the treasurer.

Lost property: a small black zip purse with a few coins in it was left on the library table last year still unclaimed – contents will be put in kitty.

Newsletter: received recently thanks to Irene and the Sydney team of helpers. Reminder about annual memberships due now to be paid directly to Sydney as per Newsletter; reminder also about the regional conference in Adelaide on 28 April.

Lauren S. was invited to tell us about her recent initiative of setting up a Facebook page, encouraged by Irene, aimed at younger people suffering TN. There is a lot of general information about TN, a disclaimer, and the opportunity for an on-line community of sufferers. Lauren first suffered TN at 26 yrs old after dental work and was on very heavy levels of medication (over 200 Tegretol a day at one stage!) and she had developed a variety of ways of concealing the dizziness that caused in order to keep working. She finally collapsed and had surgery before she knew anything about support groups or TN information. Her neurologist at the Epworth knew she was in a very awful situation only checked by morphine, so an MVD was finally done by neurosurgeon at the Epworth. She has had no pain and is on no medication since and has a gradually reducing area of numbness. She is interested in knowing how long she can expect the effect of the MVD to last – see later comments.

John S. Is almost 35 yrs old and is with his wife Natalie today. They have an 11 ½ mth old son. In 2012 John had dental surgery to remove a wisdom tooth in the lower right jaw. This was followed by numbness, then TN pain. Since he has seen many, many specialists to have an accurate diagnosis and has been prescribed many different medications – Tegretol, Dilantin, Ketamine. His body breaks down medications very quickly. He had a nerve block with a pain anaesthetist. Prof Teddi is treating his atypical TN. He had a temporary trans-dermal neuro-stimulator and then a permanent one was implanted and that worked for a few weeks but is to be removed as it is no longer effective. His only option now seems to be medication – hypnotherapy did not work – nothing helps. He is in constant pain – hot aching pain or electric shocks. Members told him about Capsaicin cream for the sensitive area on the side of his face, acupuncture and Vit B12 and wondered if he's explored Botox treatment. The cold increases his pain. John still tries to work but is gradually having to reduce the number of working days. We encouraged him to keep exploring options and to be as well informed as possible about options available, though we could appreciate it's been a particularly painful journey for him.

Jo Z. is still in the midst of her very difficult legal process with Workcover. Good to see Michelle is staying with her to help especially with the many appointments and accompanying her to this meeting.

Verna H. has botox injections around her eye and is now on Tegretol. Some discussion took place about the need to have liver function tests to assess the effect of Tegretol – before starting and then at intervals.

Joan T. found 200mg Tegretol helped but now she has other strategies. She had an MVD on the right side 10 yrs ago and no pain since but also has TN on the left side. Two tablets/day of Vit B12 has helped as also the use of Capsaicin cream sold under the trade name Zostrix. She has suffered some small strokes which caused some brain damage but she feels the Vit B 12 might even be helping in that area – she feels better than before!

Bruce G. takes 200 gm of controlled release Tegretol at night and that lasts til late the next day. He was taking an extra tablet of non controlled release Tegretol if there was a flare up but that caused double vision so now he does not take the extra one.

Bill P. had a successful MVD done at Mercy Private 12 years ago. His TN started some time after he suffered a broken neck in an accident. He has had no TN pain since and takes no medication. He has noticed just a slight tingle in one small area when shaving and hopes it's not TN returning.

Beryl O. had a successful MVD 10 years ago – no pain, no medication since. Claire Patterson in US was one of the earliest to have an MVD and for 24 years has had no pain.

Various people noted that major life events can precede the onset of medical conditions, in this case often dental work precedes TN.

Members were reminded that there are books available for borrowing on $50 refundable deposit. Evelyn to follow up on outstanding loans.

Evelyn thanked the faithful work of Neil and Joan in paying insurance and picking up the keys, opening up and setting up the room, Alan for keeping the books, Beryl and Neil on the front desk, Joan and Beryl in the kitchen and all who help pack up.

Next meeting: Saturday 14 April 2012 – same time and place!

Evelyn Diradji

Correspondence Corner

Robert T from Armidale, NSW rang to share his news that his acupuncture treatment has provided him with pain relief and that he was able to reduce his Tegretol down to 200mg AM/PM.
He happily recommends his Acupuncturist from Armidale.

Heather H wrote I am emailing to share some information in the hope that it may help someone with this debilitating condition.
My 79 year old father developed this condition about 18 months ago. He was in excruciating pain for the episodes and it was so bad that he couldn't even chew his food. He went to specialists and was prescribed drugs. He was on so much Epilim that he could barely function. He was encouraged to visit the local acupuncturist. Dad went along with no expectations. He had a number of treatments in quick succession over a series of weeks, and then these visits became less regular as he responded positively to the treatment. Then the visits were just occasional, and now he is pain free and the doctor has reduced his Epilim to 2 tablets and he doesn't need any acupuncturist visits anymore.

Jan K wrote Thank you so much for the newsletters I have read them all and found them helpful. My reaction to Tegretol was so severe it was stopped immediately- the rash lasted almost 3 weeks and I also suffered an extremely sore throat and then mouth ulcers and I now am taking Gantin which so far seems to be working with no side effects, not even drowsiness which I had with Tegretol.

Jillie L wrote … I suffered such bad pain and vomiting for hours that I had to go to the hospital. They gave me injections of morphine and kept me in over night. I went to see my doctor when I got out and he put up my dose of Tegretol to 800mg. I have very little pain now but I can't stay awake. I am sleeping 10 hours a night and 6 hours a day and not steady on my feet, I have totally lost my desire to eat though I am trying to eat. I also feel nauseated.

Irene: Sorry to learn of your bad spell. Firstly, is your Tegretol – controlled released (CR)? I am assuming they are CR. How much Tegretol were you taking before you increased it to 800 mg? Sometimes the reaction you are feeling is due to "too much too quickly" When you see your doctor tomorrow you might also ask for a blood test for sodium. Tegretol has a way of affecting that – a condition call hyponatremia, and esp. so in diabetics. (so it seems).

Jillie L: Thanks Irene, yes I think I increased the dose too quickly. I was on 200 morning and night and went straight up to double.

Paraprosdokian is a figure of speech, which little known by the general public, but is well understood by satirsts. The key feature is that the final words make the listener reinterpret the first part of the sentence.

Do not argue with an idiot. He will drag you down to his level and beat you with experience.

Going to church doesn't make you a Christian any more than standing in a garage makes you a car.

The last thing I want to do is hurt you. But it's still on the list.

Light travels faster than sound. This is why some people appear bright until you hear them speak.

If I agreed with you we'd both be wrong.

We never really grow up, we only learn how to act in public.

War does not determine who is right - only who is left.

Knowledge is knowing a tomato is a fruit; Wisdom is not putting it in a fruit salad.

The early bird might get the worm, but the second mouse gets the cheese.

Evening news is where they begin with 'Good evening', and then proceed to tell you why it isn't.

To steal ideas from one person is plagiarism. To steal from many is research.

How is it one careless match can start a forest fire, but it takes a whole box to start a campfire?

Some people are like Slinkies ... not really good for much, but bring a smile to your face when pushed down the stairs.

Dolphins are so smart that within a few weeks of captivity, they can train people to stand on the very edge of the pool and throw them fish.

A bank is a place that will lend you money, if you can prove that you don't need it.

Whenever I fill out an application, in the part that says "If an emergency, notify:" I put "DOCTOR".

I didn't say it was your fault, I said I was blaming you.

I saw a woman wearing a sweat shirt with "Guess" on it...so I said "Implants?"

Why does someone believe you when you say there are four billion stars, but check when you say the paint is wet?

Women will never be equal to men until they can walk down the street with a bald head and a beer gut, and still think they are sexy.

Always borrow money from a pessimist. He won't expect it back.

Hospitality: making your guests feel like they're at home, even if you wish they were.

Money can't buy happiness, but it sure makes misery easier to live with.

Some cause happiness wherever they go. Others whenever they go.

I used to be indecisive. Now I'm not sure.

A bus is a vehicle that runs twice as fast when you are after it as when you are in it.

2012 Meeting Dates

State	Group	Date & Time	Venue	Group Leader/s
ACT	**Canberra**	**31st March** **10.30am- 2.30pm**	**Barbara Byrne Room** **Labour Club, Belconnen**	Jan Goleby ☎ 02 6254 6640
NSW	**Sydney**	**5th May** **1:30 – 4:00 pm**	**Toongabbie Public School** Cnr Fitzwilliam & Binalong Roads	Kim Koh ☎02 97431279
	Sydney CBD	**31st March** **10am –12:30pm**	**St. James Parish Hall,** Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413 363 143
QLD	**Brisbane**	**14th April** **1.30-4.00pm**	**30 Ridley Road** **BRIDGEMAN DOWN**	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	**10th March** **1:00 PM**	**Kawana Library,** Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	**TBA** **1.30 – 4:00pm**	**Carville Senior's Villa** 35 – 37 Diprose St **PIMLICO**	Sue Macey; Sera Ansell ☎ 07 47516415
S.A	**Adelaide**	**25th March** **2:00 – 4:00 pm**	**Burnside Town Hall** **Civic Centre** Cnr Portrush/Greenhill Rd	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	**Hobart**	**24th March.** **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**	**14th April** **1.30 – 4:00pm**	**"Ringwood Room"** **Ringwood Library,** **RINGWOOD**	Evelyn Diradji ☎03 9802 6034

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