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.

MAY 2012

"Life presents many choices, the choices we make determine our future." ~ Catherine Pulsifer

MOVIE AND SUPPER NIGHT: 3RD MAY @ 8 PM; BALWYN CINEMA VIC.

A big THANK-YOU to Mary Zaccaria for a fantastic job in organising our MOVIE & SUPPER NIGHT. This was an effort to raise much needed funds for the Trigeminal Neuralgia Association of Australia so that we can continue our invaluable work in educating and assisting sufferers of this condition.
The movie “The way” is an enjoyable and inspirational story, based on The Camino de Santiago walking trail. I mused at the parallel one can draw with a TN journey. Mary also did very well to gather some fantastic prizes for the evening.

3 NIGHTS STAYING AT SEA WORLD RESORT

We are selling only 500 raffle tickets to raise funds for our 5th National conference. These tickets are priced at $10 each. We would like you to help by selling these tickets to your friends or workmates.
Firstly you should know that the $5,000 per annum that was provided for us by the previous government to help us host a biannual national conference has been removed by the current government. So, please pitch in to help yourselves. All money raised will lower your conference registration rate.

• First Prize is 3 nights of accommodation in a Resort room at Sea World Resort. This prize must be redeemed by 30th June 2013. Conditions apply.
• 2nd prize is a Warwick Rock bass Corvette* valued at $1049.00. Donated by Dominant Music
• 8 X Consolation Prizes = Coles Gift Cards valued at $25 each.
The chances of winning is first prize is 1 in 500.
If you think you can sell at least 5 tickets, please contact Irene. All you need is 5 friends who will buy one ticket each. I am hoping our Queensland members will support this exercise as the major prize is in your backyard.

Later in the year, I also hope to run another raffle for our members only – where the 1st prize will be 4 nights of accommodation at Sea World Resort during our conference in 2013. The aim is to raise the funds that have been taken from us. Stay Tune.

SA REGIONAL CONFERENCE – THANK YOU

I would like to express our gratitude to all presenters at the Adelaide regional meeting. All presenters had sacrificed their precious Saturday, giving up quality time with their family members to bring to you their TN knowledge.
Folks who were at the meeting said they had enjoyed themselves and had learned so much. They are all in awe of the information presented.
Now that you have an appetite for learning I hope you will make plans for our 5th national conference in 2013. I would also like to thank Graham and Liz Boyer for their assistance and support on Saturday.

~ Irene Wood ~
Abstract
OBJECT:
The success rates and side effects of Gamma Knife surgery (GKS) in patients with trigeminal neuralgia (TN) are not fully clear. A comparison of data across previous reports is hampered by differences in treatment protocols, lengths of follow-up, and outcome criteria. The purpose of this paper is to contribute to knowledge of the efficacy of GKS in TN by reviewing data in a large group of patients with this disorder, who were treated with a uniform treatment protocol and evaluated using a well-established pain scale and Kaplan-Meier analysis.

METHODS:
The authors reviewed 450 treatments in 365 patients with medically refractory TN who were treated between June 2002 and October 2009 at the Gamma Knife Center Tilburg. In all patients 80 Gy was prescribed, with a single 4-mm isocenter located at the root entry zone (REZ). In 79 patients repeated GKS was performed using a uniform dose of 80 Gy, which was delivered, in a highly standardized manner, to a spot anterior to the position of the first treatment. Follow-up was obtained by reviewing the patients' medical records and conducting telephone interviews. Outcome was assessed using the Barrow Neurological Institute (BNI) pain scale and the BNI facial numbness scale.

RESULTS:
The median follow-up period was 28 months. In the idiopathic TN group, rates of adequate pain relief, defined as BNI Pain Scores I-IIIIB, were 75%, 60%, and 58% at 1, 3, and 5 years, respectively. In the multiple sclerosis (MS)-related TN group the rates of adequate pain relief were 56%, 30%, and 20% at 1, 3, and 5 years, respectively. Repeated GKS was as successful as the first. An analysis of our treatment strategy of repeated GKS showed rates of adequate pain relief of 75% at 5 years in the idiopathic TN and 46% in the MS-related TN group. Somewhat bothersome numbness was reported by 6% of patients after the first treatment and by 24% after repeated GKS. Very bothersome numbness was reported in 0.5% after the first GKS and in 2% after the second treatment.

CONCLUSIONS:
In this study the authors analyzed outcomes of GKS in a large cohort of patients with TN; uniform treatment consisted of 80 Gy delivered to the REZ. The initial and long-term outcomes of pain relief and sensory dysfunction are comparable to recently published results at other institutions, where similar outcome criteria were used. These data should prove helpful to assist patients and clinicians in their TN management decisions.

PMID: 21121797

Dhople AA, Adams JR, Maggio WW, Naqvi SA, Regine WF, Kwok Y.
Source: Department of Radiation Oncology, University of Maryland School of Medicine, 22 South Greene Street, Baltimore, Maryland 21201, USA.

Abstract
OBJECT:
Few long-term studies of Gamma Knife surgery (GKS) for trigeminal neuralgia (TN) exist. The authors report their long-term experience with the use of GKS in a previously reported cohort of patients with TN that has now been followed since 1996.

METHODS:
One hundred twelve patients with TN were treated with GKS at the University of Maryland between June 1996 and July 2001. Of these, 67% had no invasive operations for TN prior to GKS, 13% had 1, 4% had 2, and 16% had >or= 3. The right side was affected in 56% of cases, predominantly involving V2 (26%), V3 (24%), or a combination of both (18%) branches. The median age at diagnosis was 56 years, and median age at GKS was 64 years. The median prescription dose of 75 Gy (range 70-80 Gy) was delivered to the involved trigeminal nerve root entry zone. The authors assessed the degree of pain before and after GKS by using the Barrow Neurological Institute (BNI) pain scale.

RESULTS:
In total, 102 patients took the survey at least once, for a response rate of 91%. Although not found to alter the conclusions of this study, 7 cases of atypical TN were found and these patients were removed, for a total of 95 cases
The median follow-up was 5.6 years (range 13-115 months). Before GKS, 88% of patients categorized their pain as BNI IV or V (inadequate control or severe pain on medication), whereas the remainder described their pain as BNI III (some pain, but controlled on medication). After GKS, 64% reported a BNI score of I (no pain, no medications), 5% had BNI II (no pain, still on medication), 12% had BNI III, and 19% reported a BNI score of IV or V. The median time to response was 2 weeks (range 0-12 weeks) and the median response duration was 32 months (range 0-112 months). Eighty-one percent reported initial pain relief, and actuarial rates of freedom from treatment failure at 1, 3, 5, and 7 years were 60, 41, 34, and 22%, respectively. Response duration was significantly better for those who had no prior invasive treatment versus those in whom a previous surgical intervention had failed (32 vs 21 months, p < 0.02). New bothersome facial numbness was reported in 6% of cases.

CONCLUSIONS:
This study represents one of the longest reported median follow-up periods and actuarial results for a cohort of patients with classic TN treated with GKS. Although GKS achieves excellent rates of initial pain relief, these results suggest a steady rate of late failure, particularly among patients who had undergone prior invasive surgical treatment. Despite a higher than expected recurrence rate, GKS remains a viable treatment option, particularly for patients who have had no prior invasive procedures. Patients with recurrences can still be offered salvage therapy with either repeat GKS, microvascular decompression, or rhizotomy.

PMID: 19326987

BNI Pain Intensity Score: Facial pain (trigeminal nerve)

<table>
<thead>
<tr>
<th>Score I</th>
<th>No trigeminal pain, no medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score II</td>
<td>Occasional pain, not requiring medication</td>
</tr>
<tr>
<td>Score III</td>
<td>Some pain, adequately controlled with medication</td>
</tr>
<tr>
<td>Score IV</td>
<td>Some pain, not adequately controlled with medication</td>
</tr>
<tr>
<td>Score V</td>
<td>Severe pain, no pain relief</td>
</tr>
</tbody>
</table>

BNI Facial Numbness Scale

<table>
<thead>
<tr>
<th>Facial numbness (trigeminal nerve)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score I</td>
</tr>
<tr>
<td>Score II</td>
</tr>
<tr>
<td>Score III</td>
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<tr>
<td>Score IV</td>
</tr>
</tbody>
</table>


THINGS TO PONDER: CAN GAMMA KNIFE SURGERY CAUSE ANAESTHESIA DOLOROSA ?

“O, be some other name! …. What’s in a name? that which we call a rose, By any other name would smell as sweet”

Doctors who perform GK surgery for TN continue to tell us that GK does not cause Anesthesia Dolorosa (AD). Instead authors report outcome as “bothersome numbness and persistent pain” However, IF this new bothersome numbness and persistent pain is as difficult to treat as AD, then - what’s in a name?  GKS patients who now have developed bothersome numbness and persistent pain would describe their present condition as:

- Constant unremitting burning pain in an area with no feeling; (to half of their face)
- Even more incapacitating than trigeminal neuralgia; and to-date there is -
- No effective treatment.

And if this is not Anaesthesia Dolorosa, it matters not then what it is called. More importantly is that TN patients are aware of the possibility of this new condition with “no effective treatment” and not be seduced by a “non-invasive” surgery. Or that GK 75% BNI I- III is as good as MVD. Patients need to be more wary of the other 25% ~ Irene. Wood

Further reading: Review Article: Clinical Outcomes of Gamma Knife Radiosurgery in the Treatment of Patients with Trigeminal Neuralgia: International Journal of Otolaryngology; Volume 2012 (2012), Article ID 919186, 13 pages doi:10.1155/2012/919186; Ameer L. Elaimy,1,2 Peter W. Hanson,1,2 Wayne T. Lamoreaux,1,2 Alexander R. Mackay,1,3 John J. Demakas,1,4 Robert K. Fairbanks,1,2 Barton S. Cooke,1 Sudheer R. Thumma,1,2 and Christopher M. Lee,1,2 http://www.hindawi.com/journals/ijol/2012/919186/
The following report is from Dr Linskey’s slides, with my added notes. Any error is mine. - Irene Wood.

### Trigeminal Neuralgia: A Medical Advisory Board Member Perspective

Mark E. Linskey, MD  
Professor, Neurological Surgery  
Director, UCI Neurosurgery Cranial nerve Clinic  
Western Regional Director, Medical Advisory Board, TNA

Sharing What I Have Learned Serving 10 years as a Member of the TNA- Facial Pain Association MAB:

**Observation – 1**
Since > 75% of TN involves V2 and V3 divisions only, it is often assumed by the patient to be dentally related
- Dentists are often the first practitioners to evaluate the TN patient,
Despite progress over the last 10 years, most dentists are unfamiliar and/or inexperienced with TN
- ~50% of TN patients still have unnecessary dental procedures prior to correct diagnosis

**Observation – 2**
Most Neurologists are not aware that anticonvulsant medications have a high long-term failure rate
- Neurology textbook chapters do not mention this.
- All modern drug randomized clinical trials only have short-term endpoints for results (1-2 years)
- Only one published long-term follow-up study (carbamazepine) – 16 years – 44% failure rate
- This is a rare condition
- Most neurologists no longer follow patients long-term
  - Managed care constraints
  - Patients tend to change neurologists when they fail

**Observation – 3**
Most Neurologists try too many medicines before declaring medical failure
- This is a rare condition
- Their anticonvulsant treatment paradigm is epilepsy
  - In epilepsy, by convention, patients are not considered “intractable” until they have failed 2-3 medications at maximal tolerated dose
  - Sequentially and simultaneously
- Often underweight the side effects of anticonvulsants –
  - sleepiness, low energy, dulled cognition, poor memory, imbalance, falls

**Observation – 4**
Many non-neurosurgeons suffer from the misperception that they can “rule in” or “rule out” vascular compression by ordering an MRI
- Order the wrong study
- Study protocol wrong at the MR site
  - Managed care & MR site costs/work flow constrains
    - SPGR volumetric contrast acquisition
    - T2 3-D volume acquisition
    - 0.8 – 1mm secondary slicing
    - Imaged in all three planes for each technique
- Radiologist reads the study and creates a report
  - “Normal study”
- Ordering physician only reads the report
- Ultimately leads to either delay in referral or referral to a neurosurgeon who does predominantly, or in fact only does, palliative destructive procedures

**Observation – 5**
Surgeons tend to recommend what they do
- Surgical procedures are tools, and there is more than one tool in the surgical toolbox
- On the other hand “When all you have is a hammer, everything looks like a nail”
Observation – 6
Surgeons tend to quote other people’s data and statistics, rather than their own
- They may have too small an experience
- They may not know their own results
- They may not be following their patients beyond the 90-day reimbursement global period
- Managed care

Observation – 7
Too few patients do their homework.
- This involves doing Research. (He recommends reading “Striking Back, Insights and Orofacial Pain”)
- Take personal control of their care. (It is imperative that patients take personal control of their own care. If you leave it up to the doctors they are going to screw it up. You have to take control of your care and drive it forward.)

Observation – 8
Most patients see or consult with only one surgeon prior to their first surgical procedure.

Observation – 9
Post-operatively, greater than 70% of TN patients wish they had seen a surgeon much sooner
- <5% felt they saw a surgeon too soon
  - Survey 2004 was done by Prof Zak on Dr Coakham’s patients (from Bristol) after MVD or RF. Published in 2005.

Observation – 10
Patients often do not know what questions to ask surgeons
- Hammer and nail syndrome
- Learning curve
- Annual ongoing volume
- Source of quoted data/statistics – is it theirs?
- Questions specific to procedures
  - MVD – ABR monitoring
  - SR – technology utilized
  - Balloon compression – Luminal pressure, external pacer/defibrillator

* Again, you have to remember that surgeons suffer from the hammer and nail syndrome. If they have one procedure, they tend to recommend that one procedure. So you need to know what procedures they do. You need to know whether they are over their learning curve. In surgery we call the “learning curve” the number of cases you have to have done of a procedure, before your results are excellent and comparative to the best who do them; and at what point your complication rate is as low as the best people who do that. For MVD – the learning curve is generally between 50 – 100 cases. For the percutaneous procedures it is about 50 cases, GK is about 25 cases. MVD is technically the most difficult and has the steepest and longest learning curve to get to that level of excellence. But that’s not enough. If you are not doing the procedures on a regular ongoing basis your skill’s deteriorating and your outcome getting worse. We now have good data to support that looking at medical database discharged volumes in the US, and it shows that a surgeon re: MVD – needs to be doing at least 6 per year after they got over their learning curve. * Ask Questions specific to procedures you are considering e.g – MVD - it is very important to know whether or not auditory brainstem response monitoring is being utilised by that surgeon. For SRS, it is very important to know the technology being used. Is it a Gamma Knife? Is it a Cyber Knife? ( difference is in the collateral damage – says doc)
For Balloon Compression, you want to know if the doctor is measuring luminal pressure during the compression and whether they are cautious enough to have an external pacer or defibrillator in place in case you get an autonomic response to your heart.”

Observation - 11
Patients are often seduced by marketing:
- Internet - No truth in advertising
- Gimmicks, come-ons, and “buzz words/phrases”
  - “Minimally invasive”
  - “smaller incision or craniectomy”
  - “less pain”
  - “shorter length of stay”
  - “more cosmetic” (hair)
Myth 1
- **Diagnostic:**
  - A Patient with a Detectable Trigeminal Sensory Deficit Does Not Have Trigeminal Neuralgia
    - the International Headache Society (IHS) International Classification of Headache and Related Disorders (ICHD-II) 2004
    - subtle sensory deficits in up to 30% of TN cases.
      - appear to be more common in patients with a longer history of TN
      - more common in patients who remain predominantly typical, but are starting to develop minor background atypical pain features

Myth 2
- **Diagnostic:**
  - Patients Who Do Not Initially Respond to a Trial of an Appropriate Antiepileptic Drug for Trigeminal Neuralgia Do Not Have Trigeminal Neuralgia
    - The absence of response, should lead to very careful reconsideration of the other non-TN facial pain syndromes
    - up to 10% of TN patients who go on to respond to surgical TN interventions never responded to Anti-Epileptic Drug therapy

Myth 3
- **Diagnostic:**
  - A Patient with Bilateral Symptoms Does Not Have Trigeminal Neuralgia
    - much more common in the setting of multiple sclerosis (MS)-related TN
    - However, approximately 2%–4% of non-MS TN patients have bilateral symptoms

Myth 4
- **Prognostic:**
  - TN is a stable chronic syndrome
    - TN is usually a progressive syndrome
      - Increasing medication dosage required for control
      - Eventual loss of medication control
      - Increase in severity and frequency
      - Spread in trigeminal division effected
      - Development of ‘atypical’ features
      - Development of subtle sensory findings
      - Reduced response to surgical intervention over time

Myth 5
- **Age:**
  - Patients over age 65 cannot undergo safe MVD (SSA 1935)
    - It’s not the years, it’s the miles…
  - The real risk is not the surgery, it is the general anesthesia
    - MVD > 65 and <80
      - If ≤1 general anesthesia risk factor no increased risk over <65 yo

My own experience with MVD
- 19 of last 100 cases (19%)
  - Range, age 65 - 79
    - 65 – 69 8
    - 70 – 74 8
    - 75 – 79 3

- **Results**
  - No difference in outcome
  - No difference in morbidity or mortality
Seduction 1
• “There is no down-side to beginning with the least invasive procedure first and then moving on to those with increased risk if this fails” (in the US, the patients are often counseled to choose their initial therapies based on the invasiveness because you haven’t lost anything, you can always do more, you can’t do less. Sounds very reasonable, however, the truth is -
  – The longer you have TN, the lower your chances of long-term complete pain relief with no need for medications after MVD (Where the break point is - with a given patient depends on that given patient. Population data: Jannetta’s series of + 1,000 patients the statistical cut off is at 8 years)

“The important point is that there is a threshold – where you go from completely reversible damage to your nerve once you move the vessel/s away, and allow your body to heal; to a point where there is some permanent damage that can’t be healed, and when you reach that point, your success rate of getting rid of the cause go down.”

Seduction 2
• “If GKSR doesn’t work, you can always do more, you haven’t lost anything”
Unfortunately having had a prior palliative destructive procedure lowers your chances of long-term complete pain relief with no need for medications after MVD
  • The lesion created in the nerve can potentially become a source for TN independent of vascular compression
    – just like an MS demyelination plaque within the nerve

Seduction 3
• All radiosurgery is the same. The choice of delivery technology does not matter”
While this may approach truth for larger volume targets (AVM, Tumor, etc), it is not true for TN
  • TN is a much smaller target and very high dose needed to damage normal tissue, requires greater radiation focusing and more precise targeting
    – Pain control are similar. (the difference is in the damage)
    – Numbness rates much higher if not Gamma Knife
      » Up to 47% vs up to 15% (5.6% at 80 Gy)
    – Imaging changes quite different
  • GK – Precise and Focal (Gamma Knife Perfexion) –
  • “hits exactly where you targeted, and the changes are restricted to the nerve. You don’t see changes in the brainstem. Doc also discussed the differences between GK and LINAC.

Caution 1
• Beware unqualified and undefined percentages when discussing results.
  • “There are lies, damn lies, and statistics” - Benjamin Disraeli, 19th century British Prime Minister
  • “Success: TN drug trial success
    – ≥ 50% pain relief on TN medicines
  : MVD success = Pain-free, Off all TN medicines
Success is defined differently and you need to know what that means. For a drug trial, success is defined as greater than or equal to 50% pain relief but still on medicines. For MVD, success is strictly defined as zero pain, no medicine.

Caution 2
• Know your decision time frame
  • Median life expectancy

Surgical Judgment
• Recognition of the various causes of TN
• Not all patients are best served by one approach
• Eliminate symptom by curing the cause vs. Palliate symptom
  – Rare causes not “curable” - MS, lacunar infarction
  – Some patients not good candidates for general anesthesia
    • age
    • medical condition(s)
  – Individual risk tolerances differ
    • FDIC-insured savings accounts vs CD’s vs Mutual funds vs Individual Stocks vs Commodities/Junk Bonds
• Fit the approach to the patient not visa versa
Surgical Judgment
• What are the goals, priorities and expectations
  – How much relief of pain desired?
  – How long is relief needed?
  – Is it desirable or necessary to be off all TN medications?
  – Is the cause likely cause other than vascular compression?
    • >95% of patients with typical TN by history
  – Are you a candidate for safe general anesthesia?
    • Medical and functional risk factors
  – Are there special social considerations?
    • Career
    • Income
    • Family priorities

OVERALL MVD RESULTS

<table>
<thead>
<tr>
<th>Results</th>
<th>1 Week</th>
<th>1 Year</th>
<th>10 years</th>
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<tbody>
<tr>
<td>Full Relief</td>
<td>82%</td>
<td>79.7%</td>
<td>69.6%</td>
</tr>
<tr>
<td>Partial relief</td>
<td>16%</td>
<td>7.6%</td>
<td>4.2%</td>
</tr>
<tr>
<td>No Relief</td>
<td>2%</td>
<td>12.7%</td>
<td>26.2%</td>
</tr>
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N=1204 - 1972-1991

Recurrence rate over time after MVD


Effect of:
(1) Female sex
(2) Symptoms >8 yrs
(3) Venous compression only
(4) Immediate post-op relief on results

Percutaneous Procedures
• Heat damage - Radiofrequency Lesion
• Chemical damage - Glycerol rhizotomy
• Mechanical crush - Balloon compression

<table>
<thead>
<tr>
<th>Relief</th>
<th>Needle</th>
<th>Pluse</th>
<th>Anes</th>
<th>Auto-nomic</th>
<th>Subj</th>
<th>Paras</th>
<th>Obj</th>
<th>Numb</th>
<th>Motor</th>
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<tr>
<td>RFL</td>
<td>Immed</td>
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<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>-</td>
<td>&lt;1%</td>
<td>-</td>
</tr>
<tr>
<td>Balloon</td>
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<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>-</td>
<td>&lt;1%</td>
<td>-</td>
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<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>&lt;1%</td>
<td>+</td>
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<td>&lt;1%</td>
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<td>&lt;15%</td>
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Estimating the Tipping Point
• Highest rates and magnitude of short-term pain relief correlate with the degree of resulting numbness
• Numbness from nerve damage has its own problems
  – Exposure keratitis if in V1 distribution
  – Worse prognosis for repeat Rx if TN recurs
  – **Anesthesia Dolorosa - “Painful Numbness”**
    • Constant unremitting burning pain in an area with no feeling (anesthetic)
    • Pain of central origin in a denervated somatotopic area
      – Similar to phantom limb pain
    • Even more incapacitating than trigeminal neuralgia
    • No effective treatment

Comparative Surgical Trials
• Through 2008, no comparative trials existed comparing MVD to any of the 4 palliative destructive procedures, nor comparing the 4 palliative destructive procedures
  – Prospective randomized clinical trial
  – Prospective cohort study
  – Retrospective matched case-control
• Main problem was surgeon selectivity of techniques
  – Do both
  – Do both well
• In the late 90’s we thought we were in a position to do the first
  – Prospective cohort study 1999-2003 (~ 4 years)

**First Prospective Cohort Study:** A prospective cohort study of microvascular decompression and Gamma Knife surgery in patients with trigeminal neuralgia: J Neurosurg 109:160-172. 2008; Linskey ME, Ratanatharathorn V, Peñagaricano J. – Department of Neurological Surgery, University of California, Irvine Medical Center, Orange, California 92868, USA (due to space constrain – can’t publish all tables – please read online)

**Intra-operative Findings MVD**

<table>
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<tr>
<th></th>
<th>U of PGH N=1204</th>
<th>MEL N=36</th>
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<tbody>
<tr>
<td>Artery(s) Only</td>
<td>382</td>
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<tr>
<td>Artery(s) &amp; Vein(s)</td>
<td>671</td>
<td>33</td>
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<td>Veins(s) Only</td>
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**GKSR Primacy Among Palliative Destructive Procedures**
• Equivalent pain relief among palliative destructive procedures
  – Only drawback - delay in onset of pain relief
• Least risk of numbness or dysesthesia
  – Exposure keratitis
  – Anesthesia dolorosa
• Elimination of trans-foramen ovale needle
  – Significantly less pain (no pulse anesthesia)
  – Less cardiac stress (bradycardia, hypotension, arrhythmia)
  – No meningitis, carotid injury, etc
• No risk of trigeminal motor weakness
• No other SR technology with the proven accuracy, experience, safety and efficacy of Gamma Knife
Current Surgical Treatment Philosophy

- If Healthy, Not Elderly, & Willing
  - MVD
  - Trying GKSR first should be avoided
    - worsens subsequent MVD results
    - further delays the time to MVD
- If High Risk, Elderly, or Refuse MVD
  - Not in Acute Extremis
    - GKSR > Glycerol or Nugent RFL > Std RFL or balloon
  - Acute Extremis
    - Glycerol or Nugent RFL > Std RFL or balloon

Recommendations (1-4)

- 1st Line - Medical Rx
  - But do not delay beyond reasonable trial
    - Single agent (carbamazepine, oxcarbazepine, gabapentin)
    - duration of syndrome negatively correlates with MVD outcome
- Educate yourself
  - TNA website
  - Publications
  - Local TNA support group
- Take control of your health care and condition
  - “own your pain”
- Understand your own treatment result priorities and life timeline for your need

Recommendations (5-8)

- Seek care at a center with coordinated multidisciplinary approach and capability
- Seek surgical consultation early
  - Before medications clouds judgment
  - Before desperate for intervention
- Set your surgical contingency plan in advance
- Find the best
  - Volume
    - Learning curve
    - Ongoing skill maintenance
  - Results
    - Study
    - Publish

Recommendations (9)

- Please stay involved and help others.

Thank you Dr Linskey for sharing your TN perspective with us.~ Irene Wood
SUPPORT GROUP MEETING REPORTS

HOBART SUPPORT GROUP
Glenorchy Library
24 March 2012 2-4 pm


Apologies: Pauline T, Jean L, Lyn D, Julie H, and Joan A.

The meeting started with Co-Group Leader Helen T welcoming everyone and particularly Bobby M, a new sufferer. Helen T acknowledged those sufferers who have health problems in addition to TN issues, that they are also battling – and wished them good health as soon as possible.

It has been 4 months since our last meeting and Ros W urged everyone to think about volunteering to do some of the organisational tasks so that the work does not rest on the Co-Group leaders’ shoulders alone, and we can have gatherings more frequently.

National Business
1. Those attending were urged to renew their TNA Membership if they hadn’t done so – a pile of forms were at the meeting
2. Those attending were reminded they could donate to TNA Australia to support the development of the 2013 conference – a pile of forms was at the meeting. The meeting was reminded of the location on the next conference on the Gold Coast and people were urged to start putting money aside to attend.
3. Those attending were reminded they could make donations to the work of TNA – tax deductible – a pile of forms were at the meeting
4. Those attending were reminded a new Facebook site has been established for TNA Australia. Helen T explained the largest growing body of users of Facebook are grandparents and urged those present to consider opening a Facebook account if they do not have one.
5. Those attending were reminded of the Adelaide mini conference – a pile of forms were at the meeting
6. Those attending were shown the dramatic black and white A4 poster from the South Australia Support Group – a pile of these were available at the meeting

Any sufferer who was not able to come to this meeting and who wants any of these documents or related information, please contact Ros or Helen and we will post you/email you one or more. See our phone numbers at the end of this newsletter.

Local Business
1. Financial situation –Bank Statement of 30 December 2012 from Bendigo Bank showed a balance of $183.36. Taking into account this meeting’s income less expenses, our balance is now $269.36 including the float. We are planning two big meetings in the coming months and now we know we have some money behind us for promotion.
2. Since our last meeting, one of our distance sufferers Helen C made a sizeable donation. Even though she is not able to get to our meetings, she values the invitation and any other information that can come her way. (I learnt after our meeting that one who attended this meeting put a sizeable donation into our collection box. Maybe others did and do. Thanks so much because this helps cover our room hire and postage expenses. In addition, it helps cover for those people who are not as financially well off as others. Very much appreciated all round.) Thank you!
3. We have three ‘Striking Back’ books waiting to be borrowed. Who will be next on the list to borrow? Do you think your GP or dental professional might be interested to browse through some of it. Even if you have borrowed the book before, you can borrow it repeatedly. All you have to do is to ask Ros W who is waiting on your phone call.
4. Helen T reminded everyone of the ‘Planning for a medical appointment’ handout she had prepared as a result of Dr Mark Dexter’s plea at the last TN conference. She encouraged people to collect one or more copies so they could fill them in for taking to first visits with new GPs or specialists – whatever the medical reason. If you were not at the meeting, please contact Helen for one or more copies.
5. Clarence City Council has called for community organisations to apply for an entry in their annual handbook. We are submitting an application to promote our Support Group.
6. Ros W developed a package of promotional material that contained a number of information pamphlets and an A4 coloured flyer inside a plastic sleeve. When she handed these out to each person, she fervently urged everyone to give the whole pack to a medical professional (including dentists) or to break it up and give different pieces to different people. This package cost our Support Group money to prepare, so Ros stressed the need to distribute the pack as soon as possible to get our message out there. If you want one or more packages, please contact Ros for help in this regard. This is her wonderful initiative for which we are all grateful – and we assume others who hear about us through this information will be also.

7. Hobart X Ray now has the small A4 flyer and another via email because they have TN sufferers passing through from time to time (generally getting dental X ray pictures!)

8. The meeting was asked ‘what should we do about the big poster’ (from the conference)? Helen T suggested sufferers take it in turn if they are part of club such as Probus or a small group such as a quilting group, etc. The idea is to display the poster with blu-tak on a house or hall wall for the duration of the gathering. It is not necessarily the intention that TN becomes the topic of that meeting and therefore in most circumstances the poster will be background. Del L borrowed it first. Please contact Ros W if you can see an opportunity. We need to get the message out there that our Support Group exists. The poster is of no use rolled up in a tube in our houses! Perhaps you may even have a family gathering or BBQ and it could go up on the wall? Think creatively where you might use it and contact Ros soon. Jim A offered to frame the poster but this was declined for the moment – thanks Jim.

Bobby M, then Helen T reported on their MVD operations.

Bobby M was ably assisted by her partner Stu in a very informative Powerpoint presentation. Bobby (and Stu) is delighted to be pain and drug free now. Her first/only ever TN pain period was comparatively very short before and then another after her surgery. Her MVD was performed by local neurosurgeon Dr Andrew Hunn in the Royal Hobart Hospital in the second week of December. Through her presentation, we came to understand what a horrific experience her TN pain had been. We heard the sad saga of the process that led Bobby to agree to have an MVD – her TN pain had been so bad she had no alternative after spending many days as a patient in the hospital through October and November last year. Now she is happily getting back into life and hoping never again to have TN pain. Bobby expressed appreciation for the support of and information from our Co-Group Leaders during the ordeal, and Stu was so pleased that the book ‘Striking back’ existed. They were both amazed and pleased that the nursing staff at the hospital borrowed ‘Striking Back’ from them in order to have a better understanding of what Bobby was going through. Thanks so much for your very interesting talk Bobby and Stu – it was much appreciated.

Helen T explained that after many years of TN pain she had a relapse last September. It was then she realised it was time to take the plunge. A few days before Christmas, Helen had an MVD performed by Dr Mark Dexter at Westmead Private Hospital. The experience was excellent and the operation was successful so she counted herself as one of the lucky 90 odd percent of people who have successful surgery. Unfortunately, she found that after three to four weeks she was one of those 25% who have the pain return within 5 years. Now Helen is on a new medication, Trileptal and this was none of these visibly compressing the trigeminal nerve when operated on. By comparison, an artery was compressing Helen’s nerve on the MRI. During the operation it was found that Helen had an artery and vein compressing the nerve, ‘countless’ miniature veins touching it, and one vein growing through it.

A significant difference between the two speakers was that Bobby had no artery or vein pictured on her MRI and there was none of these visibly compressing the trigeminal nerve when operated on. By comparison, an artery was compressing Helen’s nerve on the MRI. During the operation it was found that Helen had an artery and vein compressing the nerve, ‘countless’ miniature veins touching it, and one vein growing through it.

Both Bobby and Helen are very happy to have had the MBVD surgery and will be very happy to talk to anyone who is considering this option. Ros W, who had a successful MVD seven years ago, reminded everyone that this option will not be suitable for everyone, and that everyone has to do their own research and make up their own minds.

3.30 pm Helen T noted that more and more wonderful food is being brought to share at the end of our meetings. Thanks so much to everyone who contributes and to Del’s continual servicing of our tea, coffee, milk, and sugar. You are all doing a marvellous job making sure our gatherings are so pleasant.

Thanks to Ros W for taking the minutes. Who would like to do these at our next meeting? The meeting concluded at 4 pm. Future meeting: To be determined

Co-Group Leaders: Helen Tyzack and Ros Wilkinson

Trigeminal Neuralgia Association Australia
ADELAIDE SUPPORT GROUP
Held On 25th March, 2012

PRESENT: Grace A, Angela M, Lisa & Garry R, Kevin S, Judy F, David N, Graham & Liz B
APOLOGIES: Ann T, Bert J, Kerryn E

WELCOME: Graham welcomed all in attendance.


CONFERENCE: Graham asked members to get their registration forms in a.s.a.p. Garry asked if it would be possible for Lisa and himself to attend for just half the day due to health issues. Graham thought will be acceptable. The Adelaide Support Group has donated $200.00 towards the conference which has been greatly appreciated. We were able to do this due to a generous donation from one of our members in March last year. TNA Australia has placed advertisements in the local media and contacted radio stations. Lunch is catered.

As advised in the last newsletter the next National Conference will be held 23rd – 26th August, 2013 at Sea World Resort on the Gold Coast. This is a great venue and if we get 10 persons from SA interested in attending Graham will look into Group Travel. Give it some thought.

Graham informed the meeting that he has advised Irene he intends to stand down as Support Group Leader at the end of the year. He and Liz plan to travel in 2013 (while he can afford the travel insurance) and will not always be available to run the meetings. Hopefully Irene will find someone to take over, if not Graham and Liz will continue but the meetings will need to be on an ad hoc basis.

REPORTS:

SUE: Doing well. She is still taking 100 mg. Tegretol and 50 mg. Endep. She feels she is a little worse but is managing on her present medication. Sue also has fibromyalgia and has difficulty sleeping.

DAVID: Has post hepatic TN. He cannot tolerate Tegretol due to adverse side effects. Lyrica has not helped him. He takes 50 mg. Endep which has dulled his pain slightly. He has been told his system will repair itself over 5 years at which time his TN should go. He has found multi vitamin tablets helpful. He tried lowering the amount he took but found his pain worsened, experiencing strong jolts. He tried vitamin B12 tablets but on their own they were ineffective, however, in conjunction with the multi vitamins has proved beneficial.

GARRY: His TN has been due to a stroke. An MRI indicated that a nerve had been damaged. He takes 1800 mg. Neurontin. He is not confident enough to try lowering the dose. Fortunately Garry sleeps well. His pain is more constant lately and mainly affecting the eye area. His eye is very dry and his specialist has recommended he use eye drops. He also has pain inside his nose and mouth and the gentlest of touch brings on an attack. He has tried vitamin B12 to no affect. Garry has other health issues for which he takes other medication.

KEVIN: Is the best he has been for many years. Only a few months ago he was in tremendous pain. He saw Professor G, an oral surgeon. He takes Lyrica 150 mg x 4 times a day. Kevin now attends the RAH Pain Clinic and has found them very helpful. He gets his Lyrica from the RAH which is less expensive. Kevin has been diagnosed with TMJ and while not strictly TN he experiences similar symptoms. He is very sensitive from the top of his head to his chin. His constant pain has gone which he attributes to the Lyrica.

GRACE: Has had TN for about 12 years. Her first attack she remembers clearly. She was having dinner with the family when she was struck with horrendous pain and was unable to speak. She has had two glycerol procedures both only lasting a few months. She experiences numbness and ants crawling on her face. She cannot chew on the affected side as she has no feeling and can choke. Should the excruciating pain return she is prepared to have an MVD. Her son, who is a doctor, worries about the amount of drugs she is taking. At the present time she is uncomfortable, but coping.

ANGELA: Has had TN for 26/27 years. Over the years she has had three glycerol injections. The first was a disaster, the second lasted 2 years and the 3rd 12 months. She went to Sydney to have an MVD, full of hope she even threw away all her pills. However the operation was unsuccessful. The nerve was being contacted by a blood vessel and not an artery and she was told MVD’s were not as successful in such cases. She returned to heavier and heavier drugs, Tegretol, Neurontin, Endep then Lyrica which affected her badly. Angela saw Dr. Z and underwent a radio frequency procedure last April and has been pain free ever since. She experiences numbness and sensitivity, particularly when stressed. The intense mind blowing pain in her eye has gone. She is happy at this time but has been told there is no guarantee her pain will not return.
GRAHAM: Had an MVD nearly three years ago and has been pain free ever since. Prior to the MVD he had a glycerol procedure which lasted a eighteen months. He was reluctant to have a further glycerol injection due to a serious attack of shingles he suffered after the first procedure. If he gets a little stressed he has “feelings” in his face but no pain.

DAVID: David joined our group today. He happened to be visiting the library adjacent to our meeting room and noticed the TNA signs in the foyer. He has had TN for 10 years. Pain struck after eating an ice cream. A dentist diagnosed TN. An MRI indicated a problem. He was prescribed increasing amounts of Tegretol which caused confusion. He had difficulty at his work. Neurontin was prescribed and the pain went but returned six months later. His pain radiates from the side of his nose to his teeth. He has difficulty shaving and brushing his teeth. He has been given a sample of Lyrica but has not taken any at this stage. Graham informed David about slow release drugs being helpful. Graham loaned David “Insights”.

JUDY: Has had TN for 7 years, the pain is on her left side jaw area. Originally, she visited a dentist and had numerous treatments. She experienced electric shocks. Eventually she was sent to a specialist who sent her to Professor G, the oral surgeon who diagnosed her problem immediately. A scan showed no tumour. She could not tolerated Tegretol and now takes Neurontin irregularly. She still has pain but not the strong shocks. She feels burning and numbness and has difficulty sleeping on the affected side. Endep causes severe drowsiness.

MEETING ENDED AT 3.50 p.m. followed by coffee, biscuits and a chat.

SA REGIONAL CONFERENCE: Saturday 28th April 2012 9.00am – 5.00pm Hetzel Lecture Theatre, State Library of SA, North Terrace, Adelaide.
NEXT MEETING: 2.00 pm Sunday 27th May at Civic Centre Burnside Town Hall.
Graham & Liz Boyer

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SYDNEY CBD SUPPORT GROUP
St James Parish Hall
31st March 2012

Present: Fae M; Jocelyn S; Ingrid K; Ieuen R; Kim K; Kim S; Alan M; Margaret M; Fran T; Graeme McA & Mrs McA; Gundel B; Stewart B; Vicky B; Gary B; Paul D; Heather H; Bertha M; Ross M; CV Madhu; Gill D; Allaster McD; Jeanette B; Henry B; Irene W. Guest: Dr Mark Linskey.

Apologies: Nina D; Cheryl B; Ben H (open heart surgery) Lois W; Reg W; Jean W. Dr B. Jonker, Dr M. Dexter; Dr A Collins; Dr G McKellar.

Irene welcomed Dr Mark Linskey to the meeting and also greeted members who have come from interstate. Brilliant sunshine was the order for the day. Without much a do Irene introduced Dr Mark Linskey from University of California, Irvine. His talk is as reported on pages 4-10.

After a quick Q&A round, we had to stop the meeting for cuppa and it was good to see folks take time to share and care with each other. For some newcomers – I do apologise that we didn’t get to know you better – but the important thing is there is a next meeting; This will be 2nd June. We hope to see you then.

Irene Wood

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MELBOURNE SUPPORT GROUP
Ringwood Public Library
14 April 2012

New attendees: (6) Gail A.; Kate & Maria M.; Diane O’B.; Peter & Vera R.;
Apologies: (6) Audrey B.; Ellayne C.; Din D.; Nita & Rob McK.; Lauren S. (Lauren’s e-mail about her Facebook page was read out - thanks Lauren.)

Welcome to all members and a special welcome to those attending for the first time.

Report: Treasurer Alan reported that there was a carry forward balance of $418.20, expenses of $16.50, donations at the last meeting of $51.90 and a special donation of $500, leaving current balance of $953.60.
Newsletter: received recently thanks to Irene and the Sydney team of helpers. Attention was drawn to 2012 membership dues, the regional conference in Adelaide on 28 April and a film fundraiser in Balwyn on 3 May (flyer tabled).

Correspondence: Volunteers luncheon hosted by Mayor of Maroondah Council will be on 17 May in East Ringwood—please see Evelyn if you would like to represent our group.

Books: Evelyn has contacted people with outstanding books – most intend to return them and were urged to do so promptly in order for more people to have access to them.

**Reports from members:**

**Verna H.** has botox injections around her eye, done every 12 weeks by a GP who bulk bills. This stops the constant blinking she was having. Still taking Tegretol.

**Diane O’B.** has facial pain in the jaws, around her face and neck. Jaw grinding was suggested as a cause. Now her Cranbourne doctor suggests Botox treatment so she wanted to hear of others’ experiences to get more of an idea of the possible dangers. Some said the injections deliver such a small amount of the toxic substance that it insignificant. Others reminded her that many women especially are freely opting to have Botox treatment for cosmetic reasons. One said Aspirin possibly contains as many harmful substances but people take the risk in order to gain the benefits. Diane takes Cerepax and Panadol Osteo and will see Dr Andrew Danks in a couple of months.

**George G.** spoke for his wife Lyn who has been pain free for just over a month now. Under Doctor E, she was using morphine patches and a high dosage of Baclofen. Now she is not using the patches and is on a lower dosage of medication including Tegretol twice a day (down from 400/day to 200/day). Now Lyn is just about back to her old self which was good news to hear!

**Jo Z.** said her pain was much the same but this weather is great for her – not too hot or too cold. Tests showed that kidneys & liver function and cholesterol levels are not good. She has a mix of medications including Endep and Lyrica – too high a dosage of Tramadol results in itchiness. She is in waiting mode as her further court case against Workcover is due in early June. We certainly wish her well and hope for a positive outcome. Jo wanted to know if anyone was familiar with the nerve conduction test (Alan and Evelyn had had this for carpal tunnel) but no one could help with such tests for damage to the occipital and trigeminal nerves. She has to prove that the condition of severe pain she suffers was caused by a workplace fall when her face crashed into a desk. No one could help with information on electromyography either. Dr Danks has diagnosed her condition as post traumatic neuropathic pain syndrome but Workcover does not recognize diagnoses of pain – they look for physical, measureable conditions.

**Kate M.** Had an MVD 4½ weeks ago and is still recovering but things are looking good. She started getting TN 4 years ago after having some wisdom teeth removed at 24 years old. Kate’s pain was at first thought to be TMJ but later atypical TN was diagnosed – atypical because there was a constant ache as well as TN attacks when the pain level was 8 or 10. After her mother took her to the emergency department because the pain was so bad, Kate was given Lyrica and Tegretol but she had an allergic reaction. She was referred to a neurologist who prescribed Neurontin 2400mcg then 3600 mcg a day. When that failed to control the pain she opted for a glycerol injection and eventually an MVD. Eight small compressions of a blood vessel on the trigeminal nerve were found and treated. She does not feel 100% yet and is on 900 Gabapentin/day. Her doctor has advised it will take 9 months to wean off this and feel the full benefits of the surgery. She hopes to return to work soon. If anyone wants to watch an MVD procedure, it can be seen on U-tube. Kate has read the new book Facing Face Pain.

**Will R.:** was 82 when he first experienced TN when brushing his teeth. Medications caused side-effects and the pain worsened so much that food eaten cautiously on the non-TN side caused trouble on the TN side. The situation progressed with different medications until finally he was referred to a neurosurgeon who arranged surgery and had a fine-cut MRI a few days beforehand. He was out of hospital in three days, was a bit unsteady at first but when he saw his neurosurgeon 2 weeks after the operation he was told there was an artery looped around the trigeminal nerve – Dr Gavin Fehini saw the nerve relax when the artery was removed from impacting on it.

**Peter R.** Had TN on the left side – he has never known pain like it. There were sharp flashes of pain around the eye. His local doctor referred him to Dr Danks who performed an MVD when a blood vessel was found pulsating on the nerve. He was on Tegretol but found the side effects very bad so started taking Trileptal and he was okay until one morning very severe pain returned. He returned to Dr Danks for surgery on the glossopharyngeal nerve. Then Trileptal worked for him immediately (he obtains this for $5.80 with an authority script whereas Verna pays $69.00 for the same – people suggested she ask for an authority script). Peter self-medicates now with Trileptal and he now has it sorted out! When he is nervous or anxious or in stress he feels different or when very hot.
Gail A. was diagnosed with MS in 2002 after she experienced numbness and icy coldness. Later she had TN shock pain on the left side—small riggers could start very distressing, horrible pain. On one occasion of pain her husband took her to Box Hill emergency where her daughter a nurse was on duty. She was treated with morphine and allowed home and recovered enough to travel alone to beyond McKay to holiday with her other daughter and enjoy many activities—even going on a water slide. However, two days later she had the worst TN episode ever. She could not eat easily at all—lost 10 kgs during that time. A few weeks before seeing the doctors she had more attacks in public places. In January 2012 she had a small rhino... surgical procedure. She has right side facial numbness. Now Gail is not taking any medication for TN but continues with medication for her MS and blood pressure.

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 helped clean up and pack up. Evelyn advised that she will relinquish the role of Melbourne Support Group Leader at the end of this year so our group will need to consider a replacement.

Next meeting: Saturday 9 June 2012 – same time and place! Come with ideas for better informing the community about our group and professionals about TN (e.g. George related how a GP was not interested in our 2012 flyer since she only had 1 TN patient, Lyn!).

Evelyn Diradji

BRISBANE SUPPORT GROUP

30 Ridley Rd, Bridgeman Down
Date: April 14, 2012

Present: Margaret B, Helen W, Rod W, Dorreen T, Tony M, Henry C, Eileen C.

Apologies: Colin B, Mary M, Margaret H, John H, Jeff B, Lorraine B.

Our meeting began with yet another reminder of the national conference next year to be staged at the Gold Coast. Tony again praised the outstanding quality of the venue, speakers, company and organisation of the past three conferences he has been able to attend. He has urged us to attend the next one and to start saving now. It really is a great opportunity for partners to meet other partners (and share stories about our many and varied impediments.) Our group again agreed that we would aim to again financially support the next conference by way of donation.

The article in the recent newsletter regarding use of eye drop anaesthetic was discussed. Tony again showed the drops that are used for this procedure. A local GP has been using this method to control severe TN for years, and he was trained in this method by an old bush doctor. A member in our group is currently trialling this method and will keep us informed. (The Amethocaine is not meant to be used as a regular therapy, similar caution should be exercised as with proparacaine eye drop – prolonged use can cause permanent eye problems.- Irene.)

We then shared a few stories.

Henry continues with monthly neocobalamin injections and his turnaround in health has been amazing. Almost all pain vanished, and has stayed away. He just comes to the meetings to skite, his usual cheerful comment. He thinks he may soon just throw his remaining tegretol away. He did comment that some time ago, while on tegretol, he took Panadol Osteo-eze and this triggered an attack.

Margaret B has continued to suffer some attacks, but was so thankful only two last night. She recently had some dental work and said the drilling seemed to never stop. She thought they were drilling to China!!! Her experience has often been that dental work causes an increase in TN pain, so this time increased the tegretol dose prior to the work being done. She also took two paracetamol prior and noticed this time that she then had three good weeks following this procedure. During a recent rough patch, Margaret was again unable to even drink water. She remembered we had spoken about how effective cocktails of drugs can be for some patients and added low dose gabapentin to her usual medication of tegretol, with success. She is currently also taking folic acid, 1g Vit C, multi B Vit, magnesium, fish oil, lecithin, flaxseed oil, Vit E, the neo cobalamin injection, Deptran and ¼ Valium.

Colin couldn’t be with us today and we wish him a speedy return to his usual cheerful cheeky form!

Dorreen has had a number of operations recently including one for cancer on the jawbone. She has done really well in the recovery and is TN pain free on 100 mg tegretol. Her blood pressure is perfect, but she occasionally suffers cluster migraines and tinnitus. She has found gingko helpful in relieving the tinnitus. She commented that when her TN began in 2007, her doctor told her to put frozen peas on it.
Helen continues to be well. It is two years since her MVD. She did have a minor stroke in August, but recovered quickly. She is currently on warfarin, B12 tablets and magnesium.

Tony was on trileptal last year for seven weeks. Pain disappeared almost immediately on the first day of use. He discontinued it when a rash developed. He then began using supplements prescribed by a naturopath who successfully treats MS patients. Pain has not returned and he has now returned to work. He continues with methylcobalamin injections. The naturopath, herself an MS sufferer, will be our guest speaker at our next meeting.

Best wishes to all who couldn’t be with us today. And don’t be too hard on your dentists—remember that they have fillings too!!

Next meeting: Saturday June 9

Tony MacPherson

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**CANBERRA SUPPORT GROUP**

Meeting: 26th May is cancelled due to lack of interest. - Jan G

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**ST CLOUD SUPPORT GROUP MINNESOTA**

We had our support group meeting yesterday with 12 people in attendance. Had a wonderful speaker, Jesse Rolfes, who is a new acupuncturist in town. She grew up in St Cloud so is returning home to practice. She wowed us with her knowledge of Chinese Acupuncture telling us about the approximately 2,000 different acupuncture points the body has. She was questioned quite extensively about how she would treat a TN patient and she said if the patient was in pain at the time of treatment she would not put any needles on the face but rather approach the points through the legs. She said before any treatment starts she goes over extensive medical history, the medications the patient is on, looks at the tongue and feels the different pulse points along the arm. She hasn’t treated any TN patients herself yet but during schooling she was able to see a number of TN patients being treated and was able to also talk to them afterwards about their experience with acupuncture. She did mention that since she received her license she has been treating a number of pain patients with a variety of pain issues and feels confident that she can help us also.

She handed out an interesting worksheet for each of us to take with us to find out what Element we were. There are 5 elements in acupuncture, Water, Wood, Fire, Earth and Metal. We thanked her for her time by giving her a copy of Striking Back which she was thrilled to receive.

She said she would read it because it would help her understand us better and what we are dealing with.

After Jesse spoke and we ran out of questions we talked together about how everyone was doing.

Allan M said he had a great winter pain wise and is decreasing his dosage of Trilepal. He is still considering having his 2nd MVD on his other side but right now since the pain isn’t bad and he is reducing medication he is holding off as long as he can.

Ann N came with her daughter and she is doing fairly well as long as she takes her meds. 2 of her friends have gone to Jesse Rolfes so she came to see her presentation and ask her some questions. She is thinking strongly of calling her to make an appointment. Her daughter said she hopes that she does, she thinks it would help her a lot.

Bea A woke up to a jolt this morning but after taking her meds she was fine. She is doing quite well overall she said.

Dick T came with his wife. He had an MVD a few years back. He and his wife started to come to meetings to see if
anyone has had problems afterwards. He has been numb since the surgery and wondering if it will ever go away. He is on a lot of medication and scheduled to have MVD surgery done May 17 at the University of Mn. She said if it wasn’t for her husband around all of the time she wasn’t sure what she would do. I suggested that she carry a little notebook with her to jot down notes. We all laughed when she said problem with that is I would forget to look at the notebook or if I did I wouldn't understand what the note was about. We all wished her well on her surgery.

Mary H came with her husband. She has been having increased pain so has increased meds again. This coming week she will be talking with her neurologist about taking a drug holiday with the Tegretol and going on Trileptal for a while. Even though they are cousins she has been taking a little of it to see if she would have side effects. So far seems to be working. She is going to start acupuncture April 30th with Jesse and hopefully that will help. She has done it in the past with someone else and had good results.

While chatting we had coffee and tea with banana bread.
Next meeting isn’t until July 7th due to lack of interest. Greetings to everyone in Australia!

Mary Hall

2012 Meeting Dates

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<td></td>
<td>Sunshine</td>
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<td>Coast</td>
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<td></td>
<td>Townsville</td>
<td>TBA</td>
<td>Carville Senior’s Villa</td>
<td>Sue Macey;</td>
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<td></td>
<td></td>
<td>1.30 – 4:00pm</td>
<td>35 – 37 Diprose St</td>
<td>Sera Arsell</td>
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<td></td>
<td>PIMLICO</td>
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<tr>
<td>S.A</td>
<td>Adelaide</td>
<td>27th May</td>
<td>Burnside Town Hall</td>
<td>Graham/ Liz Boyer</td>
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<td></td>
<td></td>
<td>2:00 – 4:00 pm</td>
<td>Civic Centre</td>
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<td>Cnr Portrush/Greenhill Rd</td>
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<tr>
<td>TAS</td>
<td>Hobart</td>
<td>TBA</td>
<td>Glenorchy Library</td>
<td>Helen Tyzack</td>
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<td></td>
<td></td>
<td>2:00 – 4:00 pm</td>
<td>Enter via Barry and Cadell Streets</td>
<td>Ros Wilkinson</td>
</tr>
<tr>
<td>VIC</td>
<td>Melbourne</td>
<td>9th June</td>
<td>&quot;Ringwood Room&quot;</td>
<td>Evelyn Diradji</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.30 – 4:00pm</td>
<td>Ringwood Library, RINGWOOD</td>
<td></td>
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</tbody>
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