



Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

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

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

March 2010

Do more than belong: participate. Do more than care: help. Do more than believe: practice. Do more than be fair: be kind. Do more than forgive: forget. Do more than dream: work.

William Arthur Ward

Do you have burning pain or even type 2 TN?

We are conducting a trial to determine if natural food rich in antioxidant “X” would decrease or alleviate burning pain. Participation is voluntary. Please contact Irene Wood

If you -

- Are willing to consume the specific food type and amount on a daily basis for duration of the trial
- Are undergoing management for trigeminal neuropathic pain / Type 2 trigeminal neuralgia
- Agree to participate in the trial
- Are willing to be contacted at regular intervals for assessment

We are interested to learn if you can eat your way out of pain. The specific food type is natural food to be included into your normal diet.

Principle investigators are Irene Wood, Dr. Arun Aggarwal and Dr. Volker Neugebauer.

Unfortunately printing cost has increased. Thus comic strips, cartoons and jokes will be limited to availability of page space from now on. My priority is to disseminate TN information; however every effort will be made to add a laugh or two.

Quote of the week:

“How do we account for patients with classic (TN) syndrome who lack any detectable neurovascular compression on either high-resolution MR imaging or compulsively through surgical exploration?” Dr. Kim Burchiel.

Irene.

DISCLAIMER

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Predictors of long-term success after microvascular decompression for trigeminal neuralgia

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Object

Microvascular decompression (MVD) is an effective treatment for trigeminal neuralgia (TN). However, many patients do not experience complete pain relief, and relapse can occur even after an initial excellent result. This study was designed to identify characteristics associated with improved long-term outcome after MVD.

Methods

One hundred seventy-nine consecutive patients who had undergone MVD for TN at the authors' institution were contacted, and 95 were enrolled in the study. Patients provided information about preoperative pain characteristics including preponderance of shock-like (Type 1 TN) or constant (Type 2 TN) pain, preoperative duration, trigger points, anticonvulsant therapy response, memorable onset, and pain-free intervals. Three groups were defined based on outcome: 1) excellent, pain relief without medication; 2) good, mild or intermittent pain controlled with low-dose medication; and 3) poor, severe persistent pain or need for additional surgical treatment.

Results

Type of TN pain (Type 1 TN vs Type 2 TN) was the only significant predictor of outcome after MVD. Results were excellent, good, and poor for Type 1 TN versus Type 2 TN patients in 60 versus 25%, 24 versus 39%, and 16 versus 36%, respectively. Among patients with each TN type, there was a significant trend toward better outcome with greater proportional contribution of Type 1 TN (lancinating) symptoms ($p < 0.05$).

Conclusions

Pain relief after MVD is strongly correlated with the lancinating pain component, and therefore type of TN pain is the best predictor of long-term outcome after MVD. Application of this information should be helpful in the selection of TN patients likely to benefit from MVD.

Abbreviations used: AED = anticonvulsant drug; MVD = microvascular decompression; TN = trigeminal neuralgia

Classification of trigeminal neuralgia: clinical, therapeutic, and prognostic implications in a series of 144 patients undergoing microvascular decompression

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Please include this information when citing this paper: published online April 24, 2009; DOI: 10.3171/2008.6.17604.

Object

Trigeminal neuralgia (TN) presents a diagnostic challenge because of the variety of symptoms, findings during microvascular decompression (MVD), and postsurgical outcomes observed among patients who suffer from this disorder. Recently, a new paradigm for classification of TN

was proposed, based on the quality of pain. This study represents the first clinical analysis of this paradigm.

Methods

The authors analyzed 144 consecutive cases involving patients who underwent MVD for TN. Preoperative symptoms were classified into 1 of 2 categories based on the preponderance of shocklike (Type 1 TN) or constant (Type 2 TN) pain. Analysis of clinical characteristics, neurovascular pathology, and postoperative outcome was performed.

Results

Compared with Type 2 TN, Type 1 TN patients were older, were more likely to have right-sided symptoms, and reported a shorter duration of symptoms prior to evaluation. Previous treatment by percutaneous or radiosurgical procedures was not a predictor of symptoms, surgical findings, or outcome ($p = 0.48$). Type 1 TN was significantly more likely to be associated with arterial compression. Venous or no compression was more common among Type 2 TN patients ($p < 0.01$). Type 1 TN patients were also more likely to be pain-free immediately after surgery, and less likely to have a recurrence of pain within 2 years ($p < 0.05$). Although a subset of patients progressed from Type 1 to Type 2 TN over time, their pathological and prognostic profiles nevertheless resembled those of Type 1 TN.

Conclusions

Type 1 and Type 2 TN represent distinct clinical, pathological, and prognostic entities. Classification of patients according to this paradigm should be helpful to determine how best to treat patients with this disorder.

Abbreviations used: GKS = Gamma Knife surgery; MVD = microvascular decompression; TN = trigeminal neuralgia.

Excerpt: Editorial / Response by Dr. Kim Burchiel ~ J. Neurosurg. / Volume 110 / April 2009

... .. "Several years ago we postulated that patients with symptomatic TN secondary to MS might still be candidates for MVD. At that time, we felt that these patients might develop symptoms of TN due to a combination of demyelination in the brainstem descending tract and otherwise modest vascular compression of the nerve. In our series, all patients with MS who underwent MVD had some degree of trigeminal neurovascular conflict demonstrated by high-resolution MR imaging. Although this small subset of patients unanimously experienced improvement immediately after surgery, more long-term follow up was disappointing. It is likely that short term benefit was simply from manipulation of the nerve at the time of MVD, from a mild rhizolysis effect. **We have since abandoned MVD for patients with MS and do not consider the procedure to be indicated in these patients.**"

.... .." if we have conclusively discovered and corrected the origin of the patient's pain by decompression of the nerve, why do most MVD outcome series, including ours, demonstrate a slow, but statistically relentless recurrence of the pain? If we have "cured" the patient of pathological neurovascular compression, **why does the pain come back**, often many years after MVD? We are not convinced that the usual explanation of recurrent nerve compression is a likely explanation for this failure of surgical therapy."

"**TN is a continuum from purely episodic to purely constant pain**".....Perhaps divide Type 2 TN into 2 subdivisions **Type 2a** (with history of lancinating pain) and **Type 2b** (no such history).

Meeting Reports

SYDNEY CBD SUPPORT GROUP

6 February 2010

St. James Parish Hall

Present: Irene W, Nelma M; Barbara B; Ieuen R; Ingrid K, Alan M, Lois & Reg W, Linda K, Veronica B; Fran T; Victoria Q, Jeremy Q,

Apologies: Alaster McD; Aubrey K, Pam & Pat S; Margaret M.

We welcomed the new folks in the room. Our thoughts turned to members who were in hospital; remembering especially those who were recovering from their microvascular decompression surgery. Fore most in our thoughts is David who had his MVD on January 27th. We hope to learn good news soon.

We held a brief discussion about the earlier meeting time. All those present did not mind the 10Am time so it was voted we keep the venue and future meeting will start at 10 AM. The beauty of a 10 AM meeting is that there are parking spots right in front of the building.

Members update

Lois: is going well except for an episode of short sharp pain (that lasted about 5minutes) three weeks ago. Had tried to reduce her PM dosage to 100mg of Lamictal; but since the episode, she has returned to her usual dose of lamictal at 200mg X morning and night. Lois also suffers from pernicious anemia, and prior to Irene's B12 work, was only having once every three months B12 injection. Now, she has a monthly B12 injection, which has helped to keep her pain at most time under control.

Linda: has more good days than bad. She is under the care of Dr. Aggarwal; and also has help from a pain psychologist and a pain physiologist. She uses meditation to distract her from pain and learning also to recognise stress and how to ease off. She is also given exercises to do which can be performed anytime /anywhere which helps relax her neck muscles. Her pain starts around the jaw/ear area – is dull and digging; creepy crawlies sensation in the skull and when it is really bad she gets clammy in the hands.

Some of her symptoms prompted Irene to ask if she ever had any pimple like rash or rashes around her eye /ear or mouth area. Linda then showed us a cluster of rash on her leg. Irene suggested they could be herpes zoster.

FYI - Irene explained that usually prior to the outbreak of these rashes, the person may feel "odd - not quite right, may have fever or chill; and usually describe a tingling or creepy crawlies sensation." This is known as the prodromal. The idea is to recognise these symptoms and start the antiviral such as Acyclovir, famciclovir, and valacyclovir – in the hope of preventing nerve damage which could result in burning pain. Sometimes these vesicles or rash may not appear making diagnosis even more difficult.

Folks supplementing on L-Lysine attest that it inhibits or prevent the virus reactivation.

Note: a possible side effect of too much L-lysine supplements can result in gallstones.

Alan's no pain no medication lasted one week ☺! Out of the blue he had an episode of 10/10 pain which lasted 6 minutes; then another 5 minutes episode of 7 /10 pain and then it stopped. Since then Alan has resumed his medication and seen his neurologist. Currently he is on 300mg of Neurontin X AM /PM; and 200m Tegretol X AM/ PM. He has been told to increase his Neurontin if pain increases. Apparently his MRI showed "no further compression."

Irene then shared a summary of Dr. Kim Burchiel's **Classification of trigeminal neuralgia: clinical, therapeutic, and prognostic implications in a series of 144 patients undergoing microvascular decompression** : Journal of Neurosurgery December 2009 Volume 111, Number 6'

FYI - Dr. Burchiel performed MVD on 144 TN patients; who were classified into type 1 TN and type 2 TN. Of the 144 patient -

104 = TN type 1 symptoms = >50% of sharp lancinating, shocklike pain, with pain free intervals

40 = TN type 2 symptoms = > 50% of constant aching, throbbing, or burning pain.

TN type 1 was twice as likely to have arterial compression; less likely to have only venous compression.

TN type 2 was more likely to have venous compression as often as arterial compression. "And these patients were 5 times more likely than those with type 1 TN to have **no compressive vessel observed at surgery.**"

According to Dr. Burchiel the 104 type 1 TN patients were older, mean age = 57; there were more female 73/ 104; and right- sided TN = 70/ 104;

Surgical findings and post op. outcome for type 1 TN (104)

Arterial compression = 82 Venous compression = 20 No compression = 2

Pain free after MVD = 99 Pain recurred within 2 years = 14.

In "**Predictors of long term results after microvascular decompression for trigeminal neuralgia**" - Journal of Neurosurgery Volume 110 April 2009; Dr. Burchiel listed MVD outcomes as:

1. improve immediately and dramatically after surgery;
2. continue to experience some degree of pain;
3. recurrence of pain after an initial excellent result.

Dr. Burchiel said that people with type 1 TN are more likely to have immediate and long term pain relief after MVD; although recurrence of pain were observed in both TN1 and TN2.

He also pointed out that people with type 1 TN remembers exactly when/ where /what they were doing at onset of pain. (*everyone in the room nodded.*)

Please note that the above are my notes. Any error is mine.

Barbara came to learn about TN so she could support her sister who attends our Sunshine Coast support group. Glad to see such a caring sister.

Nelma has up and down days – depending on pain being on or off. Her eye operation made pain worse. She has constant pain behind the eye; stabbing pain on her left cheek. She is on 25mg Endep per day. We hope you have enjoyed your first meeting.

Victoria is one of the newbies. Walking in that wind did not do Victoria any good and she was visibly suffering all through the meeting. It was great to see son Jeremy, and daughter in-law coming along to support her. Victoria's TN started in May 2009. It started as a toothache and soon developed into shooting pain up to her head. Her MRI and test were all clear. Gabapentin 300mg X TID did not help at all, instead it made her drowsy and pain was getting worse. She was not keen on taking drugs as she did not want to be drug dependent.

Irene explained what the drugs do and convinced Victoria to at least try Tegretol and give B12 a go. We hope Victoria has been able to bring her pain under control by now.

Fran has been on Tegretol 100mg as maintenance dose until her "pool attacks." She swims a lot, and recently had to increase her medication to 400mg – which has lessened the pain.

Veronica has been to see Dr. Aggarwal in January and has increased her night dose of Tegretol to 200mg. Her daytime dose stays at 100mg as she had side effects such as unbalanced gait and sleepiness.

With this we concluded the official part of the meeting and enjoyed a cuppa and chats. Thanks for the morning tea and all the yummy food; and thanks everyone for helping out with tables and chairs. I take this opportunity to ask for volunteers to help out with the morning tea. We just need you to lug the stuff back and bring them for the next meeting. And if you wish to add some delicious cake/ sandwiches etc. we all would show our appreciation. ☺ However, doughnuts are NOT allowed. I look forward to your participation.

\$65 was collected. \$40 paid to church. Leaving Kitty with \$156.00

Due to the Easter Weekend in April, meeting in April is moved forward to **MARCH 27th @10AM**

Irene.

SYDNEY SUPPORT GROUP
Toongabbie Public School
6 February 2010

Present: Irene W, Kim K, Marion A, Gundel & Stuart B, Frank M, Henry & Jeanette B, Elizabeth & Lloyd T, Bernice & Mr. R, Ann & Laurie P, Irene V., Jan McL, Marj & Ken F, Kim S, Ian L.

Apologies: Norma M. Jocelyn S.

Kim K opened the meeting and welcomed new members Marj & husband Ken.

Marj's TN started in Aug 2008, with what she thought was a bad toothache. She went to a Dentist, who found nothing wrong so was sent to a macular surgeon who diagnosed TN. He offered Tegretol, but she declined as she had heard that it had some unpleasant side effects. She had intermittent Right side pain, lasting from 1-6 mins per attack, and she managed to cope until Oct 2009. They had visitors from overseas and the pain increased (could that be stress related? She wondered.) Pain is triggered by eating, drinking, touching and it wakes her from her sleep. She went back to her GP and was offered Tegretol once more, but decided to try Lyrica first. That didn't help so she has resorted to the Tegretol. She is on 2 tablets per day 1 x Tegretol in the morning & 1 x Lyrica at night. The pain is "sort of" under control, but she finds it is bad, particularly when eating.

She asked if anyone could recommend a good Neurologist and Dentist as she has broken a tooth and her usual Dentist doesn't want to touch her until she gets her pain under control.

We had a general discussion regarding medications and what works & what doesn't. Perhaps she could try a CR Tegretol (Control Release). Marj was obviously suffering, and we wish her well & hope that she has gained some insights and information from the Members present.

Irene V. spoke next. Since last meeting she has been in hell! Attacks - pain after pain. She is on the same meds, but finds she is losing her balance, has blurred vision, particularly as she turns her head and is suffering from nausea in the mornings. She has had heaps of blood tests which showed her Cholesterol & sugar are up and her sodium level is very, very low. She thought it may be the meds, so she tried reducing the Tegretol & Lyrica as she couldn't even walk, she was so dizzy. However, that didn't help. She saw a Neurologist, who didn't seem concerned, and she

is due to see Dr Aggarwal soon, so is hoping he can help her. She takes an Executive B. Irene W. suggested 1000mcg B12 and instead of eating chips with salt perhaps try some electrolytes drink.

Kim K had to leave early so we didn't get an update from her, hope you are well Kim.

Irene W was in the City earlier this morning at the CBD meeting and was exhausted. She gave us a brief overview of studies by Dr Burchiel (see CBD meeting report) prior to going home to "collapse". Burchiel has also developed a 3D imaging which is proving extremely accurate.

Jan reports she is still the same - No pain after her MVD nearly 2 years ago, but still some numbness, although that seems to come & go at times. But she is happy to be pain free! But takes B12 1000mcg daily.

Marion also reports she is another MVD success story, with Dr Dexter performing her MVD in July 2008 and absolutely no side effects. She also takes B12, 1000mcg daily.

Elizabeth pain is off & on but she is coping. Last fortnight she had a migraine as well, so didn't know where to turn. Ouch! She takes Epilim, B12 and Acidophilus, which she feels helps her. She has a good GP, however he did say her Vitamin D level is high, but they don't know why?

Stuart reports he is on Methylcobalamin which has reduced the level of burning pain. He doesn't sleep as long or as soundly but that's ok. He tried applying the Peppermint Oil as suggested by Irene, last meeting, but it hasn't helped.

Bernice said last meeting she was on 800mg Tegretol and someone suggested she take 400mg early in the morning & 400mg with breakfast a couple of hours later and that has been working great. She has actually been able to decrease her dose over the last 8 weeks and is down to 500mg and is now free of pain, so will slowly decrease further. She has had TN for 23 years, on & off, more often off, but it flared 18 months ago and seems to follow Dr Burchiels' TN1, TN2 theory. She saw Dr Dexter & he recommended an MVD and after 6 weeks consideration, she has booked in for Friday 19th Feb! (Even though she is pain free, at the moment!) We wish you every success, Bernice & if you need anyone to talk to, we are here for you.

Ian is about the same, had his MVD about 21 months ago and still has a small amount of pain, but very mild "sparkles" and he is not on any meds. He takes sublingual methylcobalamin. He is thankful at the end of each day that "I have got through another day, pain free!" Keep up the positive thinking Ian.

KimS is Ok at the moment, on 600mg Lyrica & 10 mg Endep, which is controlling her pain. It has flared up a bit recently with her return to work, but she is feeling quite good.

Ann is fine. She advises to Marj to tell people about her TN and that the best thing they can do when she has an attack is just let her sit quietly & not fuss over her. Good advice, as friends do get concerned and the last thing you want is to be fussed over.

Jeannette: Still good, no pain. She reminded us that she had TN for 18 years and was booked in for an MVD, but prior to the op she had a stroke, which cured her.

Frank reports **Norma** is quite good at the moment and is at home looking after their 12 week old Great Grand daughter, so she is keeping busy!.

Treasurer report for the Toongabbie group:

Donations \$ 79.50 + Raffles \$159.00; + B/fwd \$ 85.60 . = \$324.10

Hall Hire (\$33 x 6) = \$198.00 and gift for speakers. **On hand = \$107.10**

Henry & Jeannette once again supplied a lovely raffle which was won by Kim K.

Next meeting here at Toongabbie Public School at 1.30 on **Saturday 6th March 2010.**

(Note: that is next month, then we will be back on the bi- monthly cycle.)

Kim S closed the meeting at 4.30pm, and we enjoyed a cuppa and chat and the usual delicious treats.

Thanks for the notes Marion - Irene.

MELBOURNE SUPPORT GROUP
"Ringwood Room" Ringwood Library
1.30 p.m. 13 February 2010

Evelyn welcomed everyone to the meeting, especially new people attending for the first time and acknowledged the traditional custodians of the land where we meet and acknowledged their elders, past and still living. We recalled also those still suffering as a result of the fires of Black Saturday one year ago.

Present:(21)Barbara & Robert A, Nancy B, Alan & Joy C, Evelyn & Din D, Bruce G; Alan L, Beryl O, Bill P,Beverley R, Terry S. Joan& Neil T, Graeme & Sandra T, Rita & Chris W; Steve& Mary Z.;

New: (6) Lesley & John B.; Diane & Ken C.; Dorothy G.; John V.

Apologies: (13) L.; Ellayne C.; Rita F.; Bernadette G.; Alf H.; Will R.; Rose M.; Rob O.; Dorothy M. & Di S.; Jenny & Kevan S.; Michelle T.; Bernice W.

Guest Speaker: Irene Wood, President TNA Australia.

Business:

Amendment to last December's report: Bernadette G. advised that she is taking 1 x 75mg Lyrica a.m. + p.m. and noted that B12 injections and sub-lingual tablets are a help in controlling her pain. Sorry for any confusion, Bernadette.

Treasurer's Report: Alan took this opportunity of Irene's visit to summarise the history of the Melbourne Support Group which has met in the same room since 2002. Alan also reported that \$64.05 was donated by attendees at the Dec '09 meeting and special donations amounting to \$25 for Irene Wood's February 2010 travel to Melbourne were gratefully received. Expenditure since then totalled \$103.25 (insurance, supplies, gift, paper/envelopes/printing) leaving a balance of \$141.20. Thanks to Alan for keeping the records. We are urged to make at least a gold coin donation at each meeting as we have no other source of funds.

Subscriptions 2010: Now due - \$25 p.a. is very reasonable considering the eleven newsletters per year with lots of valuable information for TN people.

Newsletters: Some people now receiving their Newsletter electronically. Let Irene know if you prefer this mode of delivery to save paper and costs.

Community Radio interview: Evelyn was interviewed on Community Radio on 31 December 2009 about TN; also Evelyn's interview in Waverley Leader last year was heard on a radio segment where newspapers are read to the blind! These are all ways to get the message around that there is support for Trigeminal Neuralgia sufferers. (*Congrats ladies - Irene*)

Reports from members:

Graeme has suffered TN for 2 years and in that time has reduced his daily dosage of slow release Tegretol from 600mg to 400mg, taken in two doses of 200mg. He is good now and reminded us of the importance of B12 and of blood tests to check the liver.

Nancy has been completely free of pain for six months now!

Barbara was pain free for six months but then her TN pain returned so she began taking Tegretol again. 300mg/day is not enough so she is taking 400mg daily even though this makes her tired. She was pain free during a recent short trip to New Zealand.

John did not know of the support group til this week and is glad he knows other people who suffer similar pain. He has red hot poke like pain in his eye and feels his face is wrinkled from wincing with pain. He takes 200mg Tegretol twice a day and is to see a neurologist soon.

Alan's regime of 500mg Tegretol daily was good for a year but recently he has had sharp pain in the middle of the lip which prevents him from shaving in that area. He is now taking Lyrica twice a day though it is expensive and 200mg Tegretol once a day but the pain is not under control. Capsaicin cream for the trigger point area was suggested.

Lesley's TN pain started two years ago following a trip to Afghanistan. She has pain in the left side of her head and had dental work done on that left side. She has seen up to 15 professionals – dentists, chiropractors, neurologists etc. Lesley takes Tegretol but suffers some short/long term memory loss. She can now identify some triggers to her pain: altitude (lifting the head from a lower position e.g. head on the pillow, bending to the floor), cold, stress e.g. she lives half the week in Bendigo and half in Melbourne. She has been busy all her life and still is in retirement. Lesley wants to find ways to manage her pain other than Tegretol. Her pain is now about level 2 and comes and goes.

Bruce has been taking Tegretol for 2 years and is now trying to reduce this. He takes 1x11mg a.m., 3x100mg p.m. on different days. He suffers some memory loss.

Rita had a very bad start to her TN experience: starting 7 years ago she had 56 days of non-stop pain until she began taking Tegretol. This is not a pain killer so it cannot be reduced or increased quickly. Now she is down to ½ tablet i.e. 100 mg p.m. For a while she took this dosage only every other night but now has resumed this as a daily dosage. Rita said that physical and mental stress play a huge part in TN pain. Meditation has helped Rita greatly. Now she is trying to reduce the dosage of Tegretol again until but there are twinges of pain.

Diane started having TN pain 5 years ago. A few months ago it was terrible then the pain went away, then it returned. It's on and off. She experiences pain in the back of her head and takes pain killers for this. Diane takes 4 x 200mg Tegretol/day and is considering an MVD after something was found on her MRI. She also has Lupus. Diane's daughter is a nurse in pain management at St V's.

Beryl had an MVD 10 years ago and is now pain free. She was told of the possible disadvantages of an MVD but the pain was so bad she had an MVD. She urged those considering an MVD to go into all the details.

Bill had TN really badly but was lucky to have a GP who was sympathetic to TN since the GP's father-in-law suffered TN. Bill was referred to a neurologist who prescribed many medications including Tegretol – these helped for a while but the pain returned. It was SO bad that Bill returned to the neurologist and was referred to neurosurgeon. Although his pain lifted at the

time of Bill's appointment, he was encouraged to ring back whenever it returned, which he did and received a fast appointment for an MVD. That was in 1998 and he has been pain free since.

Irene W then addressed our group, thanking us for inviting her to be at the 9th anniversary meeting of the Melbourne Support Group. The aim of the Association is to have a unified understanding of trigeminal neuralgia; eg the diagnostic criteria for TN - pain must be in the distribution of the trigeminal nerve, sharp or lancinating electric shock pain, have remission, trigger spot/s and the response to antiepileptic drugs such as Tegretol. Dr Kim Burchiel said every TN patient will remember where and when their first TN attack occurred! The description of pain for TN 1 is usually "sharp, striking" pain and for TN 2 has more than 50% "constant burning".

When considering surgery, Irene pointed out the whole purpose of MVD is to move the blood vessel/s away from compressing the nerve; and she warned that an MRI is not a diagnostic tool for TN. This is because there are some TN with no compression, and some people with vascular compression but no TN symptoms. Burchiel's 3D constructed image shows more accurately the vascular compression.

Some advice re: taking your TN medication: try taking your meds the same time each day to avoid peaks and troughs. Aim activities such as brushing teeth, about an hour after taking meds. An alternative to taking oral medication is to have your meds **compounded into a topical application**. The base can carry up to 4 drugs through the skin, allowing at max. a 4-prong attack on the mechanisms of pain. It uses less drugs and also by passes the systemic side effect. Get your compounding chemist to talk to your doctor to work out what is the best formula for you! Different drugs have different mechanism of action.

People taking Tegretol: it is good to have an annual test blood for sodium, liver function and white blood cell count. Irene then gave a Power-point presentation of her studies in the role of B12 in TN management.

Book borrowing: members were reminded of books available for borrowing on payment of \$40 refundable deposit. Irene brought some new copies of Striking Back (\$39) and Insights (\$35) which are available for purchase from Evelyn.

Thanks to all who attended and those who helped this afternoon – Joan and Neil for collecting the key, arranging insurance and collecting afternoon tea items from Rose and all who helped setting up the chairs, tables and loudspeaker; Alan for looking after our finances; Joan, Rita, Beryl and helpers for looking after afternoon tea and to all who brought goodies to share, Neil on the front desk and all who helped clean up; Din on the loan desk and Alan for bring a data projector and Din for helping with the PP presentation. Most of all thanks to all TN patients and those who accompanied them to the meeting – your attendance is very important.

Special thanks to Irene for making the effort to visit the Melbourne Group and for so much information and advice. Evelyn presented Irene with a small gift of thanks and people acknowledge their gratitude. *(I do enjoy visiting and catching up with members. All it takes to get me to your meeting is an invitation. ☺ BTW - thanks for the chocolates –they were nice but not the laps I had to run afterwards – Irene.*

Next Meeting: Saturday 17 April 2010, 1.30 – 4 p.m. Guest speaker to be advised, if available.

Evelyn.

Feedback : T.

“ Some feedback in appreciation of your time and work. Last Saturday I gained a better understanding of the place of Cobalamin in dealing with Tn and the trauma.

I had been taking B12 injections weekly for the previous 6 weeks but had little idea of how often and what to expect. From your presentation, and that you put forward the possibility of some reduction in pain in three days by daily ingestion of 4 mgs of methylcobalamin gave me some possibility of what one might expect. So I immediately took what I had on hand i.e. 1000mcg cyanocobalamin 4 times a day with the probiotics. Also I had the Methylcobamin injections continue every 5 days where possible. Towards Thursday my head was beginning to attain to some level of normalcy because I have been able to space out the Trileptal back to around 5 hours apart. The 'viciousness' of the electric stabbing has been reduced. By this weekend I have been able to taste food rather than fight pain simply to eat it first time in most of the last year.

I had already booked in to have a MVD next Tuesday 23rd Feb. One of the weird experiences of this disease is that one can have short periods of feeling quite okay, quite normal, and there is no evidence that anything was wrong. However I think to realistically continue because the possibility of the full violence coming back needs to be dealt with. And the damage, retardation of the drugs is not worth living with.

My heart felt admiration and appreciation to you I mention again Irene. A place in heaven. I have now a better idea to continue to rebuild the nerve before and after the operation using B12. I wanted to let you know that the three day improvement seems to have worked for me as well whereas many other things didn't.

Irene's Response:

Sorry to learn that you have been suffering so badly most of last year. Your email has shown me my folly in not aggressively staking my work. If only you had asked me about the B12 ...if only..... it is after all my work; 3 months of solid reading from nerve to B12 to probiotics; followed by 2 years of data gathering and another couple of years of follow up work. Today, we have many in the Association who are controlling their TN with B12 - with or without medication.

PS: I think it is fair to say I am the one who would know most about B12, and its efficacy on TN management. If you have any query feel free to ask me. ~ Irene.

FYI - Vitamin B12 in TN management : Irene Wood 2004 – 2008 - Please see page 15 – 16.



HOBART SUPPORT GROUP

Glenorchy Library

20 February 2010; 2-4pm

Present: Helen T, Ros & Ian W, Shirley B, Del & Jean L, Julie H, Margaret C, Patricia W.

Apologies: Fran & Bill B, Judith B, Betty & Otto D

The meeting started with Co-Group Leader Helen T warmly welcoming everyone including two new sufferers.

Helen T talked about the

- intention of the Hobart Support Group and the sharing of tasks such as looking after the tea and coffee;
- the national Trigeminal Neuralgia Association including the value of the newsletter and the conference;
- the need for the sign-in sheets and obtaining everyone's permission to use their Christian name in the TNA newsletter.

Shirley B reported she has been receiving a number of phone calls from more sufferers – we are so pleased that people now have someone and somewhere to turn to for support for their TN.

I hope they were directed to contact the support group if not the national association for support and information. ~ Irene.

Then the meeting asked each person to tell their current stories.

Shirley B, was on Gabapentin at the December meeting but because she had been giddy and found it difficult to drive her car, she is now on Lyrica (one at morning and one at night each day) and quite happy with the results. She stressed the need to persevere with doctors.

Margaret C used to have pain in the left side of her face but these days is feeling well and has been very pleased with acupuncture. She takes 2 Endep every night without side effects.

Pat W's pain is in the right side and affects the upper nerve strand. She takes an ultra B12 tablet which she dissolves slowly under her tongue. She has tried Tegretol and Lyrica but was unhappy with both. Pat has been very satisfied with acupuncture. While she still has some pain in the nose area the stabbing and sharp pains have gone.

Julie H has used acupuncture and had some success. Currently, she is on Tegretol but getting quite forgetful and fuzzy headed. Recently, Julie had an MRI and is waiting on the report.

Del L was free of pain for 12 months but late last year the pain returned to his eye. He has tried Tegretol. However, the side effects of not being able to drive a car and his becoming increasingly very confused recently, has helped him to persuade his doctor to change the drug. Del is now on Valpro 200. He has been advised to take two a day for 10 days and already the pain is not as sharp.

Co-Group Leader **Ros W's** pain started 14 years ago, and after trying everything with no good effect, she had the MVD operation 5 years ago. It has been a wonderful success and she is now pain free. There is some residual tightness and numbness in her face but this is merely discomfort and does not stop her living a very happy life.

Ian W was the carer of his suffering wife. He talked about the stress that carers take on, and the importance of these support groups for carers as well as sufferers.

Ros and Ian have relocated to Tasmania from the mainland where they were long term members of the Perth WA support group. Despite being pain free, Ros values the Support Group as so very important and she believes she must continue to be a TNA member. So, we are very lucky to have her support. Already she is motivating and educating us from her experiences.

Helen, who was full of pain at the December meeting, was happily pain free. In January, she travelled to Sydney to meet with pain management (drugs) Dr Arun Aggarwal who prescribed Epilim 200mg. His instructions were that the tablets were to be taken in an increasing pattern over 8 weeks, starting with one a day taken at night for the first fortnight. On day 16, Helen was without pain, and with no side effects. Helen also reported on a visit to neurosurgeon, Dr Mark Dexter. He confirmed that an artery rests along her trigeminal nerve and if the drugs and a few other options don't work then the MVD surgery is an option.

After individual reports, the meeting heard that both Dr Aggarwal and Dr Dexter have agreed to come down to Hobart and talk to sufferers and as many of the medical and dental profession as can be mustered. Dr Aggarwal's visit is locked in for Sunday 16th May. Methods of promoting this extraordinary event were discussed. The publicity and lobbying is expected to connect with local medical and dental associations, to use free newspaper feature articles, radio talkback shows, posters and flyers, and any and every possible method. All Support Group members left the afternoon meeting feeling very excited.

Everyone enjoyed a cuppa and social chat before leaving.

Next meeting: Will be at lunch time and into the mid afternoon on **Sunday 16 May**. Actual time and venue to be confirmed. Information will be posted out to everyone but information is available from Group Leaders Helen on 6245 0429 or Ros on 6234 7989.

Helen & Ros

ADELAIDE SUPPORT GROUP
SUNDAY 31 January 2010 AT 2.00 p.m.

PRESENT: Ann T, Garry & Lisa R, Kevin S, Bert J, Laurel S, Joan E, June & Roger O, Marie F, Graham & Liz B.

FINANCES: Donations \$35.00. Total to date: \$126.10

WELCOME: Graham welcomed everyone to the meeting. Nice to see Marie and appreciated her travelling all the way from Murray Bridge.

GUEST SPEAKER: Graham introduced David and Meagan Crisci to the group. David and Meagan are Specialist Formulating Pharmacists specialising in compounding and holistic medicine. David defined and spoke at length on aspects of pain and the benefits of an holistic approach to treating illness. Pain is loneliness, pain is universal and sufferers describe their pain in many different ways. Pain may be relieved but not always resolved. Acute pain is an alarm system, e.g. touching a hot iron creates pain producing an automatic response to move the hand away, this is short term pain. Chronic pain lasts longer and can create a dependency on medication, can influence our lifestyle, can cause sleeplessness and depression. There needs to be a systematic approach to dealing with chronic pain. Anti-depressants are not necessarily

prescribed for pain but can be effective, neurotransmitters, anti-convulsants, anaesthetics, anti-inflammatories, fish oils (from which heavy metals have been eliminated), can be beneficial in controlling pain. They can be delivered in various ways to suit a patient's particular need and/or to avoid unwanted side effects e.g. topically, sub lingual, rectally, by nasal spray, etc. Site application for transdermal medicine is important and David believes transdermal application is the next big thing in medicine. A patient may require 5 different drugs and these may be able to be compounded into one cream. Chemists are continually being trained in health and wellness and are able to create a team approach with Doctors and naturopaths.

David stressed the importance of Chemists and Doctors working together. Many drugs taken orally contain fillers and sometimes contain only 15% of the actual drug required. These fillers may cause allergies, particularly if the patient is taking numerous different tablets. David then spoke about the effectiveness of alternative medicines – magnesium can assist with sleep problems, in muscle relaxation, restless legs syndrome and depression. B12 is proving helpful for autism and vitamin D can help with thyroid problems. Some health funds are now giving rebates on natural medications. David provides consultations and is happy to work in conjunction with a patient's GP.

David's talk was most informative. He distributed several leaflets and showed samples of various vitamins and products. Graham thanked him and Meagan for taking the time on a Sunday to talk to us and presented them with a small gift.

MEMBERS HEALTH UPDATES: (Kept brief due to time restraints).

Ann: Has good days and bad days but is very happy taking her Topiramade which controls her background pain.

Laurel: Quite well, applies capsicain ointment when she feels pain.

Marie: Quite well. Her pain covers her left temple and eye. Her symptoms worsen in an air conditioned environment and with strong wind.

Kevin: Going well; has great faith in Zostrix cream.

Joan: Really well.

Bert: His pain is being controlled by taking 400 mg. Tegretol in the morning.

Garry: No change; continues to take 1800 mg. Nurontin.

June: Has been prescribed anti-depressants and her pain has stopped. She has also recommenced taking B12 tablets. She is seeing the Dr. this week and is having an X-ray.

Graham: Really well.

Ken: Ken is unable to attend our meetings but Graham gets an update on him regularly. He is taking 1400 mg. Tegretol but does not have much relief. He believes at 80 years of age he is too old for surgery and recently cancelled his appointment to see a Neurosurgeon.

MEETING CLOSED AT 4.00 p.m. We all enjoyed our afternoon tea and friendship.

NEXT MEETING: 2.00pm SUNDAY 28TH MARCH 2010. Burnside Town Hall – Civic Centre

Graham & Liz

Have fun with PUNs ☺

- Teachers who take class attendance are absent-minded.
- The criminal dumping showed a won-ton disregard of the law
- The lights were too bright at the Chinese restaurant so the manager decided to dim sum.
- The young man quit dating the telephone operator because he felt disconnected. Besides, she had too many hang-ups. ☺

Vitamin B12 in Trigeminal Neuralgia management: Irene Wood.

In 2002, after having read Devor M, Amir R, Rappaport ZH. : Pathophysiology of trigeminal neuralgia: the ignition hypothesis. [Clin J Pain. Jan-Feb 2002;18(1):4-13.]; and seeing the biopsy specimens pictures, I wondered if trigeminal neuralgia patients were B12 deficient. From serum B12 data gathered over a 12 month period, 84% of TN sufferers were below the healthy level of B12 - the level when serum Methylmalonic acid(sMMA) is at an acceptable level. MMA and homocysteine levels increase in vitamin B12 deficiency. An elevated MMA level is said to be a more specific marker for vitamin B12 deficiency.

Having established that there is a B12 deficiency syndrome amongst TN patients, I wondered Could it be that –

- a low B12 would fail to sustain the demand of repair to the myelin of a nerve that is continuously being pounded by a compressing vessel?
- Would improving the supply of cobalamin (methylcobalamin) assist in the rebuilding of the nerve sheath ?
- Would that then make any difference to TN pain?

Volunteers were invited to participate in a 4 weeks program and were required to complete a specially designed questionnaire, the McGill Pain Questionnaire and the Brief Pain Inventory prior to starting on B12 supplements.

The Aim of the program was **to raise the sB12 level** and maintain at / above the healthy level.

The Objective was for **remyelination of damaged neurons.**

Choice of B12 supplements

- a. **Cyanocobalamin, 1000mcg, and supported with Probiotics @**
- b. **Sublingual Methylcobalamin(compounded) @ 4 mg.**

Choice of route was left to the individual. After 4 weeks of B12 supplements, another serum B12 test was done to ascertain for increase. Pain level was recorded at the end of each week. Long term follow up was 30 months.

What Did We Learn?

- a. **Cyanocobalamin @ 1000mcg per day** - in 4 weeks there was marginal difference in pain level
Difference was more noticeable at about 6 weeks.
- b. **Sublingual Methylcobalamin @ 4 mg** - has more immediate results; benefits noticeable within 3 days onwards.

Many have achieved no pain / no medication. However, occasionally a low level 1 - 2 pain may recur. It may require a low level of medication for a short period to bring pain back to 0.

Vitamin B12 is also known as cobalamin - **B12 Supplements** comes as

- **Cyanocobalamin** usually found in tablet forms
- **Hydroxocobalamin** usually in injection form
- **Methylcobalamin** can be compounded in a sublingual form and also as injectable.

* Most of the B12 naturally circulating in the blood plasma is in the methyl form.

The problem with cobalamin is any defect in its absorption / conversion or transportation can lead to B12 deficiency. You need a healthy gastro- intestinal system: an acidic stomach, gastric acid and pepsin to release cobalamin from animal proteins, parietal cells to produce intrinsic

factor (IF); then binds to IF to form an IF-cobalamin complex. In the upper small intestine pancreatic enzymes with an alkaline pH digest the R protein-cobalamin complex. The IF-cobalamin complex attaches to membrane receptors in the ileum (small intestine) and is absorbed through endocytosis. Any defect in any of these steps would cause malabsorption.

* Injection or sublingual administration bypasses this process of conversion & absorption.

What Is Myelin?

Myelin is the insulation (sheath) usually around the axon of a neuron; made up of 80% lipids and 20% protein. Schwann cells supply myelin to the peripheral neurons. About one quarter of the axons in the peripheral nervous system are myelinated.

Sublingual Methylcobalamin

- sublingual - placed under the tongue and it then melts away and is ingested directly into your blood stream. (absorbed through the mucosa membrane.)
- **“Blood levels of B12 indicate that sublingual B12 becomes available as early as 15 minutes after administration and are still elevated at 24 hours, suggesting that a once-daily dose of 2,000- 4,000mcg would be an effective preventive measure.”**

[Bhat N.K. - Presentation at the 43rd Annual Meeting, American Academy of Allergy and Immunology, 1987]

vs. B12 Injection

- given to you with a needle - a more invasive method of receiving B12.
- These injections are sometimes very painful as they are given deep under the skin, known as a deep subcutaneous injection, or into a muscle, called an intramuscular injection.
- It could be expensive especially if you rely on your doctor to inject.

There are many side effects that patients may experience from injections of vitamin B12.

Common side effects are: Mild diarrhea; Upset stomach; Nausea; A feeling of pain and a warm sensation at the site of the injection; A feeling, or a sense of being swollen over the entire body; Headache; Joint pain.

Serious side effects but not common: A rapid heartbeat; Heart palpitations; Chest pain; A feeling of tightness in the chest; Rapid weight gain; Muscle weakness; Muscle pain; Muscle cramps; A feeling of extreme thirst; Frequent urination; Leg pain ; A sense of confusion; Numbness; Dizziness; A tingling sensation; Difficulty breathing; Difficulty swallowing

A paper published in NZ Vet Journal – showed that the serum Vitamin B12 concentrations of B12 treated lambs (injected B12), peaked at day 2, decreased rapidly to day 8, and then decreased more slowly until day 24 when there were no longer differences between the groups. They concluded that a subcutaneous injection soluble Vitamin B12 was effective in increasing and maintaining the Vitamin B12 status of lambs for about 24 days.

(This supports my findings, that B12 injection once a month is needed, after initial boosting, to maintain B12 benefits in TN management. ~ Irene.)

Since my studies in 2004, there have been many exciting new Methylcobalamin findings:

1) Methyl-B12 **protects cortical neurons against** NMDA receptor-mediated glutamate cytotoxicity. 2) a high concentration of methylcobalamin in spinal fluid is highly **effective and safe for treating the symptoms of diabetic neuropathy**. 3) Ultra-high dose methyl-B12 **promotes nerve regeneration** in experimental acrylamide neuropathy. 4) methyl-B12 **promotes regeneration of motor nerve terminals** degenerating in anterior gracile muscle of gracile axonal dystrophy (GAD) mutant mouse.

2010 Meeting Dates

State	GROUP	Date & Time	Venue	Group Leader/s
ACT	Canberra	20 March 10.30-12.30	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 62474508
NSW	Sydney	1 May 1:30pm – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Irene Wood ☎ 0413363143 Kim Koh ☎ 02 97431279
	Sydney CBD	27 March 10:00am –12:30 pm	St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413363143
QLD	Brisbane	13 March 1.30-4.00pm	30 Ridley Road BRIDGEMAN DOWN	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	20 March 1:00 pm	Kawana Library, Nanyima Street, Buddina	Teresa Miller ☎ 07 54912487 Jean Williams ☎ 07 54911978
	Gold Coast	No date set	The Palm Beach Surf Club,	Ann Papandreas ☎ 07 5522 6892
S.A	Adelaide	28 March 2:00pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Road	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	16 May @ 12:00 noon	Venue to be announced Guest Speaker: Dr. Arun Aggarwal	Helen Tyzack ☎ 08 6245 0429 Ros Wilkinson ☎ 08 6234 7989
VIC	Melbourne	17 April 1:30pm – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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