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

February 2007

“We will open the book. Its pages are blank. We are going to put words on them ourselves. The book is called Opportunity and its first chapter is New Years Day”

- Edith Lovejoy Pierce

HAPPY NEW YEAR!

I hope your facial pain is all under control and you are enjoying a bright new year. Thank-you for your Christmas cards and encouraging words and notes to update me with your news. It is very kind of you to remember me at such a busy time of the year ...if only Santa would agree with you on how good I have been. ☺

Our thoughts and prayers are with all our TN friends especially those in Victoria we hope you are safe and not affected by the bushfires.

Thank you for your memberships and a bigger thank you to those who sent extras as gifts.

“If you light a lamp for somebody, it will also brighten your path.”

I would like to welcome a few new support group leaders; Evelyn who has taken over from Joan to facilitate for the Melbourne group; Leonie and Tony co hosting with Lesley for the Brisbane group; Teresa co hosting with Connie and Neil for the Sunshine Coast group. Thank you for taking the onus to keep your support group going. Now the rest of the support work belongs to the members. Your attendance at group meetings is necessary to keep their interest and inspire them to continue facilitating for the group.

So friends, here we are in 2007. What are your plans for this year? How are you going to fill in your pages? I wish you a fruitful and rewarding year.

-Irene

Dr. John Tew: “Every patient should have access to treatment and to study and evaluate what for you is the best result.” ... TNA 5th National Conference 2004

Dr. Al Rhoton: “A physician best ally is a well informed patient.”

Percutaneous Procedures vs Microvascular Decompression for TN

The article below is taken from Imigraine.net- http://www.imigraine.net/other/
The author of this website, Todd Troost, M.D., is the former Professor and Chairman of Neurology at Wake Forest University School of Medicine (1983-2004). He is the author of over 200 papers on Neurologic topics.

Despite the numerous drugs that are available for the treatment of trigeminal neuralgia, between 25% and 50% of patients will eventually fail to respond to drug therapy and need some form of neurosurgical treatment (Dalessio, 1981). In the series by Van Loveren et al. (1982), of 1000 patients with trigeminal neuralgia, 90% had an initially favorable response to medical therapy, but 75% failed to achieve satisfactory long-term relief and required surgical intervention.

The production of selective lesions of the trigeminal root by means of a radiofrequency electrode placed in the root under radiologic control (percutaneous radiofrequency
trigeminal rhizotomy, PRTR) is an operative procedure that has gained wide acceptance (Sweet and Wepsie, 1974; Tew and Keller, 1977; Scarfo et al., 1980; Keet, 1982; Nugent, 1982; Rushworth and Smith, 1982) (Figure 36.16). It has the advantages of relative safety and simplicity. The anesthesia used is light. The patient is awake during some of the procedure and recovers rapidly. Unfortunately, after this procedure, there is a recurrence rate of about 25% (Sweet, 1976; Nugent, 1982). In addition, trigeminal-innervated muscle weakness is a significant early side effect, occurring in 23% of the patients operated upon by Tew (1979) and 25% of the patients operated upon by Nugent (1982). The muscle weakness resolves in most patients within 6 months. Altered sensation in the face is reported by many patients who undergo PRTR, but rarely is the sensory disturbance intolerable (e.g., anesthesia dolorosa--Tew and Keller, 1977; Tew, 1979). Occasionally, corneal anesthesia occurs (Lewis et al., 1981, 1982a, 1982b; Nugent, 1982), and neuroparalytic keratitis has also been described (Sweet and Wepsie, 1974; Thiry and Hotermans, 1974; Tew and Keller, 1977).

Ocular motor nerve palsies have been reported following radiofrequency trigeminal rhizotomy. Onofrio (1975) described one patient who developed a sixth nerve palsy among 140 patients who underwent the procedure, and Rhoton et al. (1977) also reported one patient who developed an isolated sixth nerve palsy among 149 similar patients. Tew (1979) has reported transient diplopia in 3% of 500 patients in whom he has performed radiofrequency rhizotomy, and Tew and Keller (1977) documented five patients who developed sixth nerve palsies and two patients who developed fourth nerve palsies. Grimson and Boone (1981) have reported two patients who developed sixth nerve palsies following PRTR for trigeminal neuralgia. In both patients, the palsies resolved spontaneously within 4---7 months. Among the possible mechanisms responsible for these palsies are direct injury to the nerves, inadvertent penetration of the cavernous sinus by the radiofrequency needle, and indirect thermal injury during ablation of the trigeminal nerve rootlets (Onofrio, 1975; Sweet, 1976; Tew and Keller, 1977; Siegfried, 1977). That the cavernous sinus may be inadvertently penetrated during the procedure can be inferred by the reports of Sekhar et al. (1979) and Gökalp et al. (1980) describing the development of carotid-cavernous sinus fistulas following the procedure.

Finally, we are aware of one patient who suffered blindness with eventual development of optic atrophy after percutaneous radiofrequency trigeminal rhizotomy. The mechanism for this complication was thought to be inadvertent passage of the needle through the inferior orbital fissure into the orbit.

At The Johns Hopkins Hospital, Dr. Melvin Epstein has performed this procedure on over 300 individuals with trigeminal neuralgia. Among these patients, there have been no deaths, and there have been no cases of anesthesia dolorosa, neuroparalytic keratitis, or ocular motor nerve palsies.

Broggi and Franzini (1982) have used PRTR for the treatment of symptomatic non-neoplastic facial pain in 20 patients. Fourteen of the patients had multiple sclerosis, three had Paget's disease with basilar impression, two had untreatable intracranial aneurysms, and one patient developed chronic ocular pain following a vitreous hemorrhage. All patients had immediate pain relief following the procedure; unfortunately, there was a high (40%) recurrence rate in the patients with multiple sclerosis, requiring, in most cases, a second procedure.

An alternative procedure that is performed in patients with trigeminal neuralgia who are unresponsive to medical therapy is microsurgical decompression of the trigeminal root (Gardner, 1953, 1962; Apfelbaum, 1977; Jannetta, 1977; Rand, 1981; Klun, 1981; Voorhies and Patterson, 1981; Wilberger and Velo, 1981; Adams et al., 1982; Breeze and Ignelzi, 1982; Taarnhoj, 1982; Barba and Alksne, 1984). The neurosurgeon assumes that he will find a lesion, usually a vascular loop, compressing the trigeminal root adjacent to the
brain-stem (Figure 36.17). According to Jannetta (1979), the advantages of this procedure are: (1) an improved quality of life; (2) a decreased rate of recurrence; (3) no anesthesia dolorosa; and (4) the ability of the surgeon to perform percutaneous radiofrequency trigeminal rhizotomy should the procedure fail to achieve the desired pain relief. In Jannetta’s series of over 450 patients, the majority of patients were cured of their disease over a long follow-up period, and the majority of recurrences occurred within 6 months.

Barba and Alksne (1984) reviewed the results of microvascular decompression in 37 patients with trigeminal neuralgia. They found that patients with trigeminal neuralgia of greater than 9 years’ duration had a cure rate following surgery of only 42%, compared with an 88% cure rate in patients with symptoms less than 9 years. In addition, in this study, patients undergoing microvascular decompression as a primary procedure were cured at a rate of 91%, compared to a 43% cure rate in patients treated with destructive procedures (e.g., rhizotomies) prior to microvascular de-compression. The study of Barba and Alksne thus suggests that microvascular decompression should be performed early in the course of trigeminal neuralgia as the first procedure for it to be maximally effective.

Microvascular decompression of the trigeminal nerve does have a definite morbidity and mortality. Jannetta (1977) has reported herpes perioralis, mild hemiparesis, decreased ipsilateral hearing, and cerebellar infarction and hematoma after surgery.

Pazin et al. (1978) reported that herpes simplex virus was reactivated within a few days in nearly 60% of patients who had a history of herpes labialis and underwent microneurosurgical decompression; however, this complication can apparently be prevented by the use of human leukocyte interferon for 5 days beginning on the day of operation (Pazin et al., 1979).

With respect to operative mortality with microvascular decompression, Jannetta (1977) has reported only four postoperative deaths among over 450 patients and none in his last 200 patients. Taarnhoj (1982) reported only one death among 120 patients who underwent this procedure. Jannetta has emphasized, however, that the procedure may be difficult to perform and must be carefully learned if the surgeon is to avoid making inaccurate observations and causing unnecessary morbidity and mortality.

Several investigators (Apfelbaum, 1977; Burchiel et al., 1981; Ferguson et al., 1981; Van Loveren et al., 1982) have compared the effects of percutaneous radiofrequency trigeminal rhizotomy and microvascular decompression of the trigeminal nerve. In Apfelbaum’s (1977) series of 103 consecutive patients with trigeminal neuralgia, 48 patients underwent radiofrequency rhizotomy and 55 patients underwent microvascular decompression. Successful initial relief of pain was achieved in 88% of patients in the first group and 96% of patients in the second group. Severe recurrences occurred in 13% of patients who underwent radiofrequency rhizotomy and in only 5% of patients who underwent decompression.

Of the patients who underwent radiofrequency rhizotomy, seven developed corneal anesthesia, six developed anesthesia dolorosa or severe dysesthesia, and one developed trigeminal motor loss. In addition, one patient suffered an intracerebral hematoma, and one patient developed a temporal lobe abscess. There were no postoperative deaths.

Of the patients who underwent microvascular decompression, two developed transient fourth nerve palsies, two developed mild hearing loss, two developed a cerebellar syndrome, one patient had a pulmonary embolism, and one patient developed severe hearing loss associated with ipsilateral sixth and seventh nerve palsies. There were no operative deaths. Apfelbaum has concluded that both percutaneous radiofrequency trigeminal rhizotomy and microvascular decompression are effective procedures for the initial relief of trigeminal neuralgia that is unresponsive to medical therapy. Because micro-vascular decompression requires a craniotomy, there is greater potential risk to the procedure; however, absence of altered facial sensation, corneal anesthesia, or dysesthetic
complications in the postoperative period are definite advantages of this procedure. In addition, this approach offers those few patients with unsuspected, small tumors the advantage of early discovery and cure. Finally, according to Apfelbaum, patient satisfaction with microvascular decompression is higher than with radiofrequency rhizotomy.

In the series reported by Burchiel et al. (1981), 42 patients underwent microvascular decompression for trigeminal neuralgia, while 78 patients underwent PRTR. In this series, the success rate of microvascular decompression (90%) was higher than that of PRTR (64%). In the group of patients who underwent microvascular decompression, there were only two complications. One patient developed bifrontal chronic subdural hematomas, and a second patient developed severe systemic hypertension and a subsequent cerebellar hematoma 4 hours postoperatively, eventually resulting in death. In the group of patients who underwent PRTR, 8% developed complications including neuropahtic keratitis, anesthesia dolorosa, and significant facial paresthesias, although there were no deaths.

In the series reported by Ferguson et al. (1981), 55 patients underwent PRTR, while 24 patients underwent microvascular decompression. In neither series was there an overwhelming success rate, with only 54% of patients who underwent PRTR and 71% of patients who underwent microvascular decompression remaining free of pain over a follow-up period of about 28---30 months. In the patients who underwent PRTR, there were no deaths and no lasting complaints of numbness or dysesthesia. Anesthesia dolorosa occurred in only one patient, and corneal anesthesia occurred in only four patients, with none of the patients having any evidence of neuropahtic keratitis. Similarly, there were no major complications in patients who underwent decompression. There were no deaths, and one patient required evacuation of a small cerebellar hematoma. Several other patients experienced transient vertigo and ataxia, one patient developed a transient fourth nerve palsy, and several patients complained of mild facial numbness or weakness.

Van Loveren et al. (1982) treated 750 patients with trigeminal neuralgia who had failed on medical therapy. Fifty patients underwent microvascular decompression, of whom 84% were pain free after 3 years. Only 12% had recurrence of their neuralgia. The remaining 700 patients were treated with PRTR. Of these patients, 74% had results that were considered excellent or good, and only 20% of patients had a recurrence of their pain over a 6-year follow-up period. Van Loveren et al. concluded that there was no significance in results between microvascular decompression and PRTR, but since PRTR is a simpler procedure to perform, it is the treatment that they favor.

Not all investigators have had such excellent results in the surgical treatment of trigeminal neuralgia. Breeze and Ignelzi (1982) have reported their experience with 51 consecutive patients with trigeminal neuralgia who underwent microvascular decompression. While they had an 85% early success rate, 13% of the patients developed a recurrence of pain over a 4-year period. In addition, 60% of these patients experienced some form of transient or permanent complication.

In the final analysis, it would seem clear that neither microvascular decompression nor percutaneous radiofrequency trigeminal rhizotomy should be performed by the inexperienced neurosurgeon, but that in the proper hands, both procedures represent relatively safe and effective measures for the treatment of trigeminal neuralgia.

Adams et al. (1982) have performed posterior fossa microsurgery on 57 patients with trigeminal neuralgia. Fifty-four of these patients underwent either partial or total section of the trigeminal sensory root, two had microvascular decompression operations, and one patient had both a partial sensory root section and micro-vascular decompression. Over a mean follow-up period of 4.5 years, 52 of 54 patients (96%) had either no further pain or suffered only minor twinges requiring no treatment.

In addition to percutaneous radiofrequency trigeminal rhizotomy and microvascular posterior fossa surgery, several other procedures have been advocated for the treatment of
patients with trigeminal neuralgia. In a report from the Karolinska Institute in Stockholm, 75 patients were treated by injection of glycerol into the trigeminal cistern (Hakanson, 1981). Long term follow-up showed alleviation of pain with minimal or no disturbance of facial sensation in the majority of the patients. Injection of glycerol into the trigeminal cistern is a stereotactic procedure that may have the benefits of reduced anesthesia time, minimal complication rate, and excellent result. Hakanson has suggested that the glycerol may act primarily on partly demyelinated nerve fibers that are presumed to be involved in the trigger mechanisms that produce trigeminal neuralgia.

Mullan and Lichtor (1983) have reported their results in patients with trigeminal neuralgia whom they treated by percutaneous microcompression of the trigeminal ganglion using a balloon catheter. During a follow-up period that ranged from 6 months to 4 ½ years, 44 of 50 patients (88%) remained free of pain. According to Mullan and Lichtor, the advantages of this technique are freedom from patient discomfort, ease of performance of the procedure, absence of associated mortality, and a minimal morbidity rate. One patient developed a trochlear nerve palsy 2 days following the procedure. Although this patient was shown to have a small dural arteriovenous malformation draining into the ipsilateral cavernous sinus, the role of this malformation in the production of the palsy is unclear. The palsy disappeared without treatment after about 3 months.

Incision of the descending trigeminal tract near the cervicomedullary junction will reliably cause the loss of pain and temperature in the ipsilateral face and pharynx and usually will relieve the pain of trigeminal neuralgia (Hosobuchi and Rutkin, 1971). This procedure has been used only in patients who have failed with both medical and conventional surgical therapy.

Lende et al. (1971) have performed combined removal of precentral and postcentral cortex in two patients with severe facial pain, one of whom had trigeminal neuralgia refractory to numerous medications and surgical procedures, including frontal lobotomy! Following cortical removal that included precentral and postcentral facial representations, both patients had immediate and lasting pain relief.

Acupuncture has been used in some areas of the world in the treatment of trigeminal neuralgia. Yiu and Tam (1976) reported that of 378 patients who underwent acupuncture for this disorder, 88% achieved initial (over 6 weeks) "excellent improvement" in pain although these investigators did not report long-term results. The reader interested in a more complete discussion of trigeminal neuralgia is encouraged to obtain the excellent publication concerning this entity edited by Hassler and Walker (1970).

The success of these procedures and the rate of complications are very much influenced by the experience of the surgeon. **Dr. Peter Jannetta emphasised** the importance of having your chosen surgical treatment performed by a neurosurgeon who is well experienced in the procedure. According to Dr. Jannetta, **an experienced surgeon is one who does 30 – 50 (ops) a year.**

*The above article is for your information. It is not to replace your treating doctor’s advice.*

**Things you don't want to hear during surgery:**

Better save that. We'll need it for the autopsy.

Wait a minute! if this is his spleen, then what’s that?

Hand me that...uh...that...uh.....thingie.

Oh no! I just lost my Rolex.

Oops! Hey, has anyone ever survived 500ml of this stuff before?
Meeting Reports:  

BRISBANE SUPPORT GROUP  
11 November 2006  
Guest Speaker: Dr. Robert Campbell.

ATTENDANCE 27.
Dr. Robert Campbell, Colin, Margaret, Joan F, Joyce, Max, May, Neil, Shayne, Vonnie, M.H., F.H., Eileen, Henry, Doug, Jennifer, Lesley, Fay, Amit, Thandie, Shirley, Joan Mc, Mei, Fred, Audrey, B.J. and Tony.
A warm welcome to Amit, Thandie, MH & FH and Mei. You are very welcome to attend our future meetings.

APOLOGIES: Thanks to all those who offered their apologies including Leonie and Beryl.

AGENDA
Guest Speaker Dr. Robert Campbell. Dr Campbell is a respected neurosurgeon in Brisbane. Today he joined us for a relaxed question and answer session, beginning with a brief overview of TN. Some of the questions he answered are as follows:

* How many MVD's have you done?
His experience in neurosurgery spans 10-12 years in a number of different hospitals. The condition is more common than many believe. In the last seven years he has done about 15 MVD's and thirty injection procedures for TN. He also assisted with TN surgeries prior to coming to Brisbane.

* At what stage do you know you really need surgery?
He usually sees people when they fail to get relief from simple or complex meds. He does not push one treatment over another but decides what to recommend after assessing each patient. It depends on the person’s pain, its management and what options have been explored already. He would find it loath to operate on a person who is well controlled by medication just for the sake of getting off the medication. He said his approach to TN surgery is a conservative one.

* When would you NOT do a MVD?
When the patient was not fit for a General Anaesthetic, had any other serious illness or condition that would exclude such surgery, if the skin had be irradiated or had some other problem that would cause concern in the healing process. There had been no MRI to confirm the compression.

* Is it any use doing surgery for other neuralgias, occipital etc?
In his experience - no. He usually restricts the surgeries to Trigeminal Neuralgia. He mentioned that some work was being done at Greenslopes hospital using electronic implants to treat Occipital Neuralgia. Perhaps we could look further into that.

* How long before you are back on your feet after a surgery like MVD?
Usually it is 3 months. Dr. Campbell then gave us a step by step account of the MVD surgery.
1. You have a MRI scan the night before surgery so Dr has the most up to date images of your compression to work with.
2. You are put to sleep.
3. He makes an incision behind the ear. His description was – a lazy S.
4. He removes a small disc of bone about the size of a 20 cent piece.
5. He opens the membrane.
6. Some fluid is removed so he can see and work in the area.
7. The blood vessel is located.
8. It is delicately peeled away from the nerve.
9. The nerve is padded to protect it from being compressed by the blood vessel again.
10. Everything is closed up again and the patient is monitored closely for the next 24 hours and stays in hospital for up to a week depending on their recovery rate.

We all greatly appreciated Dr Campbell’s contribution to our support group and hope he will visit again. We presented him with a copy of Striking Back to thank him.

Thank you to the many helpers on the day. Our group could not survive without you.

FINANCES
A gold coin donation was taken and $45 was collected. Many thanks everyone.

NEXT MEETING
Our next meeting will be on January the 13th, 2007 at 1.30pm. Please note we are moving to the third Saturday of the month for the January meeting only. The meetings for the rest of the year will be on the second Saturday of March, May, July, September and November. The venue is 30 Ridley Rd., Bridgeman Downs.

Lesley Curtain

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SYDNEY CBD SUPPORT GROUP
St. James Parish Hall
11 AM - 2nd December 2006


Apologies : Joan C, Allaster McD, Pixie M, Jocelyn S, and Fae M.

This is our usual Christmas combined gathering of the 2 Sydney Support groups. I must admit I was very tired and conducted a short and quick meeting and left members to catch up with each other whilst sampling the array of Christmas goodies.

We talked about the conference and I am very encouraged that many members from this group will be coming to our national conference. I am sure this is a reflection of the benefit members have enjoyed with the guest speakers at our CBD meetings. Being exposed to good presentations and information could only lead to wanting more and the appreciation a national conference can provide.

We discussed the importance of accurate information. You as a consumer needs to evaluate the information, even when it had been sent out by TNA. An example given was the “pain pen.” Folks were testifying to this magic pen in the beginning, but when it stopped working, no one cared enough to write to say it doesn’t work anymore. Irene urged that all information shared are for the benefit of sufferers – let us know even when had it stopped working so that members are not left with the misconception that this “magic” pen is still helping you.

Members Update:
Aubrey’s pain started about 2 years ago. His GP reckoned it was some sort of neuralgia, and at the ENT, he had all sorts of X-rays. He said it felt like a terrible toothache. The Cardiac specialist was the one who referred him to a neurologist who then diagnosed the condition as TN, and prescribed Neurontin. Talking triggers the attack.

Fran is pain free and had reduced her Tegretol from 300mg to 200mg per day.

Nola had an infection in the hair roots, according to her doc, which was magnifying the pain. Her doctor prescribed he with 2 doses of antibiotics.
Diane has been to see Dr. Joe Ierano from Atlas Orthogonal Chiropractic for her neck pain. She achieves complete pain relief almost immediately after each treatment.

Lois has pernicious anemia has resumed B12 injection once every 3 months. After her B12 injection her pain was under control but in the last fortnight her pain returned and she is now back on Lamictal.

Mary gets the odd break through pain. She is taking 1000mg Tegretol and 50mg of Endep.

We wondered what long-term effects these medications could cause. One particular paper discussed epilepsy patients on long-term anticonvulsants showed lower level of B12 in their CSF, compared to people who don’t take anticonvulsant drugs.

The Art Group under the care of Diane Brown is working towards an art exhibition during our Conference in September. She reported that all is going well. They have had 3 meetings already and the input from the group has been very productive. The workshop will re start in February 2007. Diane also brought some mini masks to show at the meeting and it was hoped that folks would take a mask home, paint it and returned to Diane for exhibition.

Anyone interested in the Art group please contact Diane – 02 9772 2574.

We concluded the meeting and members took the opportunity to catch up with their friends with a cuppa.

Irene.

Melbourne Support Group
At "Ringwood Room" Ringwood Library,
1.30 p.m. 2nd December 2006.

Present: (20) Barbara & Robert A; Nancy B; Joy & Alan C; Evelyn D; Edmund & Irene F; Gisele H; RoseM; Dorothy M & niece Di S; PatO’G; Beryl O; Peter & Freda Rigby; Joan & Neil T; Rita & Chris W..

Apologies: (3) Alma E; Jenny & Kevan S; Gillian W.

Treasurer's Report: The current balance is $215.60

General Business:
• Five more raffle books were available - prize document box.
• General information about speakers for 2007 and possible visit of Irene Wood.
• Resources available for borrowing: Evelyn found "Striking Back" very helpful.
• Joan is looking for another copy of the same book not yet returned.
• Evelyn asked if any more volunteers are interested in helping the work of the group -
• Beryl is happy to continue doing follow up phone calls and Nancy will help with typing.

Members' experiences:
• Evelyn has been able to reduce medication and eventually stop taking Valpro altogether after a course of acupuncture and advice from a prosthodontist. This is to be followed up with a visit to local dentist to have a broken tooth in right jaw repaired and to adjust lower partial plate that was putting extreme pressure on upper right jaw/bite. Meditation has been helpful in periods of low level pain - no further extreme pain episodes.
• Dorothy (new member) has been a sufferer on and off for twelve years and of late has had some relief from severe pain when Tegretol dosage was raised to five a day. She is anxious to speak to others who are on the same level of medication but does not want to consider surgery at this stage. She was supported in seeking information and coming to the group by her niece.
Closing: Irene F spoke on behalf of the group to thank Joan for her enormous contribution in setting up the support group and her commitment over the five years since. Irene described Joan as the face, the voice and the hands of TNA Melbourne Support Group. Irene said a copy of Insights might be given in Joan’s name to the Group’s resources. Joan responded by thanking members for their assistance and support over the years and especially her husband. She regrets that since her stroke she is unable to carry on in the same role but hopes to be able to still attend meetings and be involved. Evelyn wished everyone a happy and pain free Christmas and New Year and thanked all who had helped set up and clean up and especially thanked those who had provided the refreshments with a touch of Christmas which were enjoyed by everyone in a friendly atmosphere. Next Meeting will be on Saturday 10th February 2007 at 1.30 p.m. in the Ringwood Room. Evelyn.

Congratulations! I am very happy and proud to see all of you taking part in keeping your support group alive and functioning and I am sure the group will continue to grow under the leadership of Evelyn. – Irene.

Sunshine Coast Support Group
16th December 2006 1.00pm
Fletcher Dental Surgery
23 Beach Rd Maroochydore


Apologies: Pamela Christmas

Meeting opened by Neil.
Welcome back to Connie. (Thank you for the card and concern, much appreciated). Conference 2007 was discussed with info and registration forms now available. For Conference Registration Forms please contact Irene Wood.

A quick discussion on Lyrica found Jean having seizures lasting up to 2½ hours not to ever take again, however Dianne is finding it useful without that type of side effect.

Carl had a motorcycle accident years ago and suffers pains to the head, migraines, etc. We discussed causes and symptoms of TN and what it is and does.

Stanley mentioned Chinese mushrooms for detoxing, he found them to be very effective. (on a note of caution do not detox too fast)

Teresa reminded everyone about the raffle tickets for the document box, this being our last chance to purchase them before the draw.

Introduction for our guest speakers Heather Irvine and Nancy White practising Cranio Sacral Therapists

An explanation was given describing our spinal and brain fluid being as one that pulsates every 6 - 12 seconds, similar to a hydraulic system. They use a very light touch to improve flow and possibly adjust any cranial bone or spinal misalignment.

For anyone interested there are practices at Caloundra and Nambour if you didn’t get details, please contact Connie.

Thank you to our guest speakers, we enjoyed their open and frank discussions regarding Cranio Sacral Therapy and health in general.
Reminder membership fees are due, bulk payment can be arranged with Connie as last year for those interested.

Gold Coin Donation raised $37.00 plus the money collected by Neil and Teresa less expenses $28.60, bringing our grand total to $224.90

A big thank you to Teresa for assisting Neil in my absence I do hope you will stay on with Neil and I, as this is what group support is all about, here to assist one another. Indeed I hope Teresa continues to co facilitate the group - many hands make light work.

We followed this with a cuppa and some delectable nibbles, not to mention the sharing of information and experiences. Thank you to all who contributed and for cleaning and restoring the centre prior to leaving.

Hope everyone has a wonderful Christmas. Look forward to re-grouping in the New year.

Next Meeting 17th February 2007 at 1.00pm,
Fletcher Dental Surgery, 23 Beach Rd, Maroochydore.

Meeting report: Connie
Photo courtesy of Teresa. – Sunshine Coast Support Group Members

BRISBANE SUPPORT GROUP
DATE. 13.1. 2007

ATTENDANCE: Neil, Howard, Janet, Beryl, Colette, Noela, Fay, Margaret, Colin, Vonnie, Tony, Joan, Lesley, May, Leonie, Fred, Audrey, Irene, Joan, Shirley, John, Henry and Eileen.

APOLOGIES: Thanks to all those who offered their apologies including Max, Joyce, Doug and Jennifer.

AGENDA Today we celebrated our 5th anniversary. Irene Wood, the Australian TNA President, came and gave a presentation on the role Vitamin B12 plays in the condition and the conclusions of her study on increasing B12 and it’s absorption in a group of TN sufferers. Irene presented this at the most recent TNA Conference in Oregon. The details of this will be available in the conference papers which I hope will soon be in our library for you to read. (DVD should be available soon; had published in past newsletters)
Irene also briefed us on the upcoming 2007 Australian Conference, encouraging us all to join the fun on South Mole Island with some world-renowned TN experts. As I am handing over the Group Leadership, Irene facilitated a discussion on how we can work together to keep our group alive and vibrant through 2007. Thank you to those who stepped forward and offered their services. Many thanks to Irene and the members present for their input. Our next meeting will be a planning meeting. Things to be discussed at the March meeting include:

- Venue Management
- Discussion/meeting facilitator
- Note/minute taker
- Report writer
- Librarian
- Afternoon tea facilitator
- Treasurer
- Publicity/ Guest speaker coordinator.

In the past I have attended to these tasks with your support. Split up between the group members they are small jobs and I can be called on to guide and assist. The systems are already in place and need only to be duplicated. I’m sure there will be better systems that could be implemented and welcome that wholeheartedly.

FINANCES  A gold coin donation was taken and $75 was collected. $50 of this was given to Irene to help pay for the data projector hire for the presentation. Many thanks everyone. We start the year with $28 in our petty cash after making a $100 donation for the use of the venue throughout the year.

NEXT MEETING  Our next meeting will be on 10th March at 1.30pm. The venue is 30 Ridley Rd., Bridgeman Downs.

Lesley Curtain

Thank you for inviting me to join in your support group’s 5th anniversary celebration. As with all support groups I am very happy to attend if and when invited. It is always a pleasure to catch up with old friends and meet new ones.

My trip north also involved sorting out the group leader’s position. Lesley had informed me that due to personal problems she would not be continuing as support group leader for 2007. I am happy and proud to announce that Leonie Gall and Tony MacPherson have both stepped forward to take on the support group leader’s role; and together with Lesley Curtain will co lead the Brisbane Support Group. Congratulations Leonie and Tony.

It was thus agreed that these 3 would co lead the group but would rely on members’ assistance for smaller task. I am sure the group will now thrive with this injection of new energy, new system and new ideas. However a word of advice –3 chiefs having a powwow is plenty, no good having too many chiefs and not enough Indians.

A personal thank you to Tony for the lift to and from the airport and the lovely lunch at the Nursery. It was indeed an experience having lunch with big fat lizards (water dragons). They were huge! And were crawling everywhere. Irene was petrified they would make lunch with her ankles!

Irene.

Looks Ain't Everything
A doctor examined a man, took his wife aside, and said, "I don't like the looks of your husband at all."

"Me neither doc," said the wife. "But he's always been good to the kids."
ACT Support Group  
Weston Creek Community Centre  
Saturday 20th January 2007

Present: Constance, Barbara & Colin B., Jane, Marilyn & Adrien W

Apologies: Jan G., Susan C.

Marilyn led the meeting as Jan G. was unable to attend because of family commitments. Adrien helped out with taking notes which was much appreciated.

Congratulations to Susan C. on the announcement of her impending marriage.

Constance spoke about her continuing bad spell and is now taking 2 Dilantin morning and night, 2 Kaponol morning and night, 1 Neurontin at night and Panadol when needed, which is often at the moment. Constance said she starts to feel very tired about 24 hours before she gets an attack. Marilyn said she had experienced the same. Constance is going to attend the Conference at South Molle Island with some members of her family.

Barbara spoke about her recent visits to a Neurologist Dr Arun Aggarwal in Rozelle in Sydney. He has changed her medication – she was on very high doses of Gabapentin and Epilim – but now slowly changing over to Lyrica 75mg twice a day working up to 150mg, and ensuring they are taken at the same time every day. He did another procedure by inserting a syringe up her nose (without the needle) to “quieten down” the nerve endings in the region of the Trigeminal nerve. Barbara felt she had benefited for about four days from the procedure – she felt it was worthwhile trying it out. Dr Aggarwal said if the procedure was effective it could be repeated, when required by an anaesthetist in Canberra.

Jane rang in the morning as her husband had seen our notice in The Canberra Times and asked if we would like her to come and talk about her operation. Jane had a MVD in 1998 in England and has not had any trouble since. A real success story. She had really suffered for four years beforehand. We really enjoyed hearing all about what led up to the operation. She was living in a small village in the Lakes District and the local GP sent her across country to Newcastle Hospital to have the operation.

Marilyn is still taking Epilim and Baclofen and has been able to reduce Epilim to 200mg at lunchtime instead of the 300mg.

Our next Meeting will be at Weston Creek Community Hall at 10.30am on 17th March. We will just book the hall for the hour and then go for a coffee at Cooleman Court afterwards if anyone wants to. By putting in a small donation it covers the hire of the Room which has now gone up to $11.00 for the hour.

Marilyn

Correspondence Corner

M (USA): I am just taking over the support group leadership for our small group and have been reading past issues of newsletters from different groups to get a handle on how they function. I have found your newsletters amazing to read and commend you on all of your hard work! We are a small group of 12 that attend meetings on really good months. Usually it is around 4-6 but we keep trying. I would like permission to photocopy the Black Mold information out of your Dec-Jan issue. We have one member that made a major life change when he and his wife thought mold in their house was one of his TN problems, along with plastic bags, newspapers and a number of other things. I know I have a problem with mold also. I read this to my husband and he too was just amazed at what you had written. I love it when I "finally" find someone else who has had the same
problem as I have. Thank you for all you do in Australia-keep up the good work!

- I love it too when I get mails like yours – Irene.

V: I sent an e-mail to you in December 2005 in regard to my mum who was visiting me in Queensland. You promptly replied with certain good advice and consequently, I joined mum up with the Trigeminal Neuralgia Association. Mum is unable to attend any meetings but the newsletters have been a great help. Mum was taken to hospital while staying with me as the pain was so intense, she was unable to catch her breath. Mum recovered somewhat prior to her return to the Central Coast

Over the past 12 months mum has been prescribed and taken nearly every drug for her TN without much relief. In late November, mum was again taken to hospital. The pain this time was excruciating on the r/h side of her face, including, nose, eyes mouth. Mum was unable to speak, drink, eat, clean her teeth, blow her nose and brush her hair. At the time, mum’s Neurologist was on leave and a Heart and Lung Specialist took care of her! The Neurologist team was not even notified. Mum was given Morphine for a whole week, even when she was not in pain. I went down to NSW to care for her upon her return home from hospital. I was never advised that Morphine was a drug which should not be stopped abruptly. Consequently, I had a few frightening days caring for her. During that time I telephoned you and you advised me of the Vitamin B12 in the "gel" form. I ordered this B12 from the pharmacist and started mum on it immediately. By now, her Neurologist had returned from leave and was horrified by the treatment received in Hospital. The Neurologist wanted mum to have an MRI and then see a Neurosurgeon for an operation. I was not at all happy about this considering mum’s age and other problems. Mum made her own decision not to have the operation which I was happy about. The Neurologist advised me to increase mum’s Neurontin which I did. Mum now takes 2,400 mg Neurontin, 6 Panamax and the gel Vitamin B 12 daily. After I increased the Neurontin and added the Vitamin B 12, and the effects of the morphine had worn off, mum seemed to recover before my eyes. After 2 weeks I felt confident to leave her. Mum continued to get better each day, so much so, she was able to fly from NSW to Queensland and arrived yesterday. Mum has gained weight and looks so good. She has had only a few spasms since mainly in the nose, mouth area. I ordered more Vitamin B12 to be sent to me while mum is visiting.

Not only am I writing to thank you for your advice regarding the Vitamin B12 and other questions I asked, I feel mum’s history could contribute to your endeavours to find relief for the many sufferers of TN. Mum has had shingles quite a few times in her life and her teeth have never been good. Mum had shingles and dental work approximately 12 months prior to her first TN attack. I am no doctor, but I do feel that teeth have something to do with TN. I also feel that mum is in remission at the moment and the TN could return with a vengeance. If that is the case, we choose to enjoy each day without pain. Mum’s next appointment with the Neurologist is 23 January 2007 when she will advise him that she chooses not to have an operation. I hope some of mum’s history helps.

Another nice e mail. Glad to learn “MUM” is getting better each day and enjoying each day. Blessings!

M.C – I very much appreciate the information TNA (Australia) is able to provide and although I don’t have TN, I’m still able to find relevant advice along the way. I have trigeminal neuropathic pain which is very difficult to control. Recently I was given a Ketamine infusion and I am pleased to say it is still working its magic. I have acquired Ketamine lozenges and want to know if there is any kind of trial or information being collected from people like me? Many thanks for your hard work for our benefit.

- The use of Ketamine is not a secret. Dr. Aggarwal spoke about the use of Ketamine infusion and Ketamine lozenges during our 1st National conference in 2005. Patients are the walking answers to these pain problems – it is from patients we learn invaluable information. So yes, we appreciate any feedback.
Laughter is the best therapy.

Following a romantic dinner, the elderly widower finally gathered up his courage to ask his dear elderly widow friend, "Will you marry me?"

She smiled happily and answered. "Yes. Yes, I will!"

The next morning, the old man was troubled. "Did she say 'yes' or did she say 'no'?"

He couldn't remember. Try as he would, he just could not recall. Not even a faint memory. With trepidation, he went to the telephone and called her.

First, he explained to her that he didn't remember as well as he used to. Then he reviewed the lovely evening past. Gaining more courage he inquired, "When I asked if you would marry me, did you say 'Yes' or did you say 'No'?"

He was delighted to hear her say, "Why, I said, 'Yes, yes I will' and I meant it with all my heart."

Then she continued, "And I am so glad that you called, because for the life of me I couldn't remember who had asked!"

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Child Custody

A child custody case was held in court. The judge felt that the mother and father were both fit to be parents and therefore couldn't decide who he should grant full custody to. So he asks the little boy, "Would you like to live with your mother?"

"No." said the boy.

"Why not?" said the judge.

"Because she beats me."

The judge says "Okay, then you'll go live with your father."

"Oh No," cried the boy, "He beats me too."

Dumbfounded, the judge asks "Okay who do you want to live with?"

"I want to live with the English Cricket Team" 😊

"Why?" asks the judge.

"They don't beat anybody!"

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Hard of hearing

Two deaf men were in a coffee shop discussing their wives.

One signs to the other, boy was my wife mad at me last night!

She went on and on and wouldn't stop!

The other Buddy says when my wife goes off on me I just don't listen.

How do you do that? Says the other.

It's easy! I turn off the light! 😁
NEXT MEETING: 2007

NSW

3 February  11:00am – 2:00 pm - SYDNEY CBD SUPPORT GROUP
St. James Parish Hall, Phillip Street, SYDNEY.
Support Group Leader: Irene Wood  02 45 796226

3 March  2:00 pm – 4:30pm – SYDNEY SUPPORT GROUP
Toongabbie Public School,
Cnr. Fitzwilliam and Binalong Rds, TOONGABBIE

T B A  10:00 am – 1:30 pm  COFFS HARBOUR SUPPORT GROUP
Sawtell Uniting Church, 24 Elizabeth Street, SAWTELL
Support Group Leaders: Ailsa Braid  02 6658 3051

NEWCASTLE SUPPORT GROUP
Meeting - suspended till further notice

QLD

17 February 1: 00pm  SUNSHINE COAST SUPPORT GROUP
Fletcher Dental Surgery, 23 Beach Rd, MAROOCHYDORE.
Support Group Leaders: Connie Holden: 07 54833939
Neil Westbrook: 07 54451700 ; Teresa Miller: 07 54912487

10 March 1:30pm - 4:00pm - BRISBANE SUPPORT GROUP
30 Ridley Rd., BRIDGEMAN DOWN
Support Group Leader: Leonie Gall 0407 55 44 07, Lesley Curtain 07 32642838,
& Tony MacPherson 07 3822 2286

31 March 10:30 am – 1 pm - GOLD COAST SUPPORT GROUP
The Palm Beach Neighbourhood Centre, 16 Third Avenue, Palm Beach.
Support Group Leader: Andree Chenevier  07 55200228

VIC

10 February 1:30 pm - MELBOURNE SUPPORT GROUP
"Ringwood Room" Ringwood Library, RINGWOOD
Support Group Leader: Evelyn Diradji

S.A

Sunday 18 March  2 pm  ADELAIDE SUPPORT GROUP
Kensington-Marryatville Bowling Club.
Corner of The Parade and East Terrace, KENSINGTON GARDENS
Support Group Leaders: Graham/ Liz Boyer: 08 83334363
& Barbara Stentiford 08 84452019

ACT

17 March  10:30 am  CANBERRA SUPPORT GROUP
Venue: Weston Creek Community Centre
& Marilyn Whiddet.

Contact: Irene Wood,  P O BOX 1611, CASTLE HILL, NSW 1765 Australia
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