Trigeminal Neuralgia Association
Australia Incorporated ABN 33914644101

Support Groups – Sydney, Melbourne, Brisbane, Canberra, Newcastle, & Sunshine Coast.

September 2004

Support Group to meet in Sydney CBD.

The Sydney Support Group will hold its December 4th meeting at St. James Parish Hall, Level ONE, Philip Street Sydney from 11 am – 2 pm.
We are hoping to provide members living on the eastern and northern side of Sydney the opportunity to meet and enjoy the friendship of their fellow sufferers. As we prepare to celebrate Christmas it is fitting that we care and share with them. So Ye who have difficulties travelling West – the mountain is being moved closer to you. Come join us for a warm and fun filled meeting.

We thank Father Peter Kurti for giving us his permission to use the Parish Hall. We are very appreciative of his kindness and support. I am sure we will have a very special meeting on Saturday 4 December.

More Good News!

Kim Smith has agreed to co-host the support group at Winston Hills with me. I am confident that Kim will soon be able to lead the group on her own. This will then allow me to host another group in Sydney. When I wrote to the St. James Parish, I also requested permission for use of their Hall on a regular basis. I am very happy to inform you that Fr. Kurti has also generously given us permission to hold regular meetings at the Parish Hall. Therefore in 2005, we will have a Sydney CBD support group. I will lead this group in the city and Kim will take over the reins at Winston Hills.
My plans are to have the Sydney CBD meeting every second month and have the other months to keep in touch with my friends at Winston Hills. I am excited about these developments and I hope you are too.

Sunshine Coast meeting – September 18 th.

The meeting on Saturday 18th will convene at **11am -** 23 Beach Rd (Dental Surgery). Maroochydore. We have to move this meeting to an earlier time to accommodate for Irene. She has to be back at the airport by 3pm – to catch the one and only flight out of Sunshine Coast for the day.

New Support Group Leaders.

We welcome Connie Holden and Neil Westbrook, our new Support Group Leaders for Sunshine Coast. Thank you both for having the courage to accept and undertake the responsibilities of a SGL.

It ‘s a Fridge Piece.

It has come to my attention that some of you have difficulty in remembering meeting dates and venues. So for your convenience, I have published “NEXT MEETING” on the last page of the Newsletters. Simply detach it and stick it up on your fridge or by your phone or some place that you would look at daily. Hoping this would help avoid panic stage.

Thanks for the cards.

There were so many, and ashamedly I am unable to write back individually. Instead I take this opportunity to thank all of you for your kind thoughts. Thank you for caring.

Irene Wood

August 2004, Volume 55, Number 2
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CLINICAL STUDIES

Trigeminal Neuralgia Caused by Venous Compression

Toshio Matsushima, M.D.; Phuong Huynh-Le, M.D.; Masayuki Miyazono, M.D.

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OBJECTIVE: The purpose of this study is to clarify whether venous compression on the trigeminal nerve really causes trigeminal neuralgia or not, and to identify which veins are the offending veins.

METHODS: We used microvascular decompression in operations on 121 patients with typical trigeminal neuralgia. We analyzed the intraoperative findings and surgical results in these 121 cases.

RESULTS: In 7 of the 121 cases, only the vein was identified as a compressive factor on the trigeminal nerve. In 6 of these 7 cases, single venous compression was found, whereas the remaining case had two offending veins. The transverse pontine vein was most frequently found as the offending vein near Meckel's cave. All patients showed complete relief of trigeminal pain after decompression of the veins, but four of them developed facial numbness after surgery, which tended to be slight and did not require any treatment.

CONCLUSION: Our surgical experiences showed that venous compression could cause trigeminal neuralgia by itself and that the transverse pontine vein should be carefully observed because it is most frequently the offending vein.
(Neurosurgery 55: 334-339, 2004)

Key words: Microvascular decompression; Offending vessels; Trigeminal neuralgia; Vein

A re print from TNA Sydney Newsletter June 2002

What to do IF pain comes back

Video presentation - the 3rd TNA Conference.
Below is a summary - as best and as accurately as I can ..I reserve the right to be wrong!

Dr. Ken Casey :: The title implies some event occurred, perhaps a surgical one, in which the pain stopped for a reasonable period of time, and now it is back.

* It is going to be an individualised decision, perhaps more confusing than your original decision because the data on repeat operations and going back on medicines, etc is non existent. The amount of cross over between one procedure to another, does one procedure best set up another?, does one procedure help lead into another ?- is also data that is non existent.

* More often than not it is a process where the patient and physician sit down and feel their way through as to what you are going to do.

* You need to be empowered with the data, to go to your physician /surgeon and say to them - IF you are you going to do X / Y / Z , are you to do it this way? Are you going to follow these standards? Are you going to monitor me properly on these medicines? Are you going to know when to switch over?

* You have got to be a much greater participant in this.

Interventional Choices

MVD

RF Ablation

Glycerol neurolysis

Radiosurgery

Balloon Compression

* Topical Anaesthesia

* Trigger Injection

* doing 2 things at once: (2 things done through the same needle)- data on that is also very limited. - trying to treat the pain in different respects.

* **BE VERY careful** about the original diagnosis when the pain returns, **look again at some of the possible secondary mechanism**. Make sure that if a new symptom comes up, don't make the mistake of automatically assuming that what happens to you is the same thing all over again, when in fact it could be something different.

Dr.Ron Apflebaum. :* We all base our judgement on our own experience.

* Medical option is first line of treatment.

What happens when the patient has a recurrence? (the emphasis here is **Typical TN**)

* the less destruction - the better. It is easier to treat any recurrent trigeminal neuralgia than to treat any deafferentation pains of Anaesthesia Dolorosa and dysaesthesia symptoms.

* if someone has a recurrence after any procedure - **the first step is to go back on medication.** Patients sometimes say "I have tried that, it didn't work" - it doesn't mean it won't work again. Very often, a treated nerve with a touch of medication, will stop it. * every recurrence does not mean it will have a full blown pattern again - so treat that with medication first. If you cannot control it medically, then you have several options.

If it was MVD that was done a few months ago, one that I have done, and I was pretty sure I had **inspected the nerve very carefully and haven't missed anything,** then I probably would go to a percutaneous procedure; as opposed to one that comes back 5 yrs later, then you have a harder decision. A second vessel may have come up against the nerve, or one that has been done by someone else,- who may not have done as many (MVD), and may have missed things. I have re operated on some and found missed vessels. That is when the new higher resolution imaging may be very helpful in swaying you one way or the other.

Percutaneous procedures - I use Glycerol preferentially, has a higher recurrence rate but that's not a big deal. It is very easy to retreat and the patient would much prefer to do that than have more numbness.

That's the route we go - if it recurs, we retreat it. We have retreated a number of times, but the average is about 1.5 treatment per patient, the most I have ever done is about 6 on a patient - vast majority of patients never get more than 2 or 3.

Dr.Jeffery Brown : * when **it** comes back - **it** may not be the same pain that you had the first time. So my plea is that you and your physician **carefully evaluate what this new pain is** and is it the same pain that you have before or does it need a different treatment?

Dr.Ron Young : * **You must reassess your situation and your options in the event of recurrent pain** - whether that recurrence is after medical treatment or surgical treatment or something in between it (nerve block. or some other temporising procedure).

IF the pain is **EXACTLY** like it was previously, (in terms of its characteristics, where it is located, what kind of pain it is, what activates it) Classic TN tends to be very stereotyped - it's the same all the time, and it can be the same for years, same kind of pain, same location, same triggers, sometimes it moves around but not so typically.

Alot of people who have had surgical procedures, tell me that they have TN, but then they tell me that they are quite numb in the area. My view is that you cannot have TN and numbness together, (not everybody agrees with that but I don't think you can). You can have a pain that mimics TN in a numb area and that is a nerve injury from one of the procedure, then the procedures that we talk about here are NO GOOD to treat that situation.

Medical treatment : the biggest problem with medications is that physician and consequently patients don't understand how to take the medication.. The physician don't understand, and they don't take the time to describe how to properly take the medications . These medications are not like any of the other pain medicines, (it builds up in your blood quickly and it also goes out of your blood very quickly) these medications tend to gradually build up in your blood level over time.

* **Unless you are taking the medication correctly - you cannot judge its effectiveness.**

The same goes for side effects. People are started on big doses of the medications with devastating side effects.. Start on small amounts and gradually increased as needed, and then tapered off. It takes time, months probably, to find a level that's good,- it keeps the pain suppressed and it has the minimum side effects. You can't do that by taking a prescription out of the doctor's office and start taking the medications.

* Sometimes a moderate dose of one with a moderate dose of another does better that a higher dose of one alone. It's a trial and error thing - you have to patient about it and can't expect an immediate result. Then if you have a recurrence you have to re assess - do I need to add a second medication? or go up in dose? or switch to another one?. This aspect perhaps is even more important that theses decisions about reoperations.

Radiosurgery (Gamma knife / Linac) can be used for recurrences. whether it's a recurrence of one of the other procedures. Repeats of any of the surgery tend to be not quite as successful as the first time around, but SRS is also an option .

Dr John Tew. :* the first thing to do is medication .but when you have reached an intolerance for medications there are several options

* recurrences can occur with every type of treatment, and that includes medications

TN Pain Recurrence :.

Procedure	(Mean) Follow Up	Pain Free (= without medication)
MVD	7 yrs	77% (the best result)
PSR	6 yrs	75%
Glycerol Rhiz	3 yrs	55%
Balloon Comp.	3 yrs	76%
RadioSurgery	1.5 yrs	55%

for this to be an equal study - all pts should be followed for the equal period of time.

Repeat MVD is Frequently Unsuccessful

Series	Pts	Success
Yamaki 1992	7	2 (29%)
Cho 1994	31	11 (35%)

Rath 1996	16	12 (75%)
Jannetta 1996	**132**	**55 (42%)**
Pagura 1998	10	0 (0%)
Total	196	80 (41%)

* the pain usually recurs in another division, indicating a progressive chronic disorder.

*Repeat operation of any type is more dangerous and less likely to be as successful

- (Dr.Tew's opinion) - PSR is choice after MVD or Glycerol failure

  MVD is choice after PSR or Glycerol failure

* **There is no easy answer but there are multiple options** Your challenge is to find a physician, or a group of physicians who will work with you to find the very best choice for you.

Q: Is there a limitation on the number of times any of these procedures may NEVER be repeated?

Casey: Not sure if the word NEVER is accurate but I think most people practising MVD, would seriously question the advantage of a 3rd trip. The 3 percutaneous procedures are the most repeatable ones.

Q : Patients now comes back with a recurrence that's different and it's worse. It's a burning and continuos pain. (non classic tic) that has come back, who is willing to do another re op - to get closer to AD?

Brown : do a very careful evaluation, bring in the McGill Pain Questionnaire - evaluate what this pain is, hopefully I have been compulsive in having them fill it out before they did the first operation, so now I can compare. (Documenting what it was we were treating before and what it is we are thinking of treating afterwards. We can have an idea about whether it is the same pain , whether it is a pain that has leaked out to another division or whether it is a progression to this neuropathic pain.) *If it has now gone from an electric shock like pain in the cheek to burning pain in the cheek - then NO if I were treating with a Balloon - I am not confident that I would want to treat pure burning pain in the cheek,*

Casey : I would not repeat an MVD on a patient you described.

Apflebaum : In patients with deafferentation pains, destructive procedures make things worse**.**

Q: What are the rates of recurrence for Glossopharyngeal Neuralgia

Aplfebaum : In my experience, I don't think the glossopharyngeal nerve recovers as well from decompression. Sectioning the nerve, has resulted in very minimal discomfort or problems with the patients.

Recurrent Trigeminal Neuralgia Attributable to Veins after Microvascular Decompression

February 2000, Volume 46, Number 2

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OBJECTIVE: To demonstrate the cause of and optimal treatment for recurrent trigeminal neuralgia (TN) in cases where veins were observed to be the offending vessels during the initial microvascular decompression (MVD) procedure.

METHODS: An electronic search of patient records from 1988 to 1998 revealed that 393 patients were treated with MVD for TN caused by veins. The pain recurred in 122 patients (31.0%). Thirty-

two (26.2%) of these patients underwent reoperations. Clinical presentations, recurrence intervals, surgical findings, and clinical outcomes were analyzed.

RESULTS: Analysis of 32 consecutive cases of recurrent TN initially attributable to veins revealed a female predominance (female/male = 26:5), with one female patient exhibiting bilateral TN caused by venous compression. Patient ages ranged from 15 to 80 years, with a prevalence in the seventh decade. The V_2 distribution of the face was involved more frequently than other divisions. For 24 patients (75%), recurrence occurred within 1 year after the initial operation. At the time of the second MVD procedure, development of new veins around the nerve root was observed in 28 cases (87.5%). After successful subsequent MVD procedures, the pain was improved in 81.3% of the cases.

CONCLUSION: The recurrence rate for TN attributable to veins is high. If pain recurs, it is likely to recur within 1 year after the initial operation. The most common cause of recurrence is the development and regrowth of new veins. Even fine new veins may cause pain recurrence; these veins may be located beneath the felt near the root entry zone or distally, near Meckel's cave. Because of the variable locations of vein recurrence, every effort must be made to identify recollateralized veins. Given the high rate of pain relief after a second operation, MVD remains the optimal treatment for the recurrence of TN attributable to vein regrowth.

(Neurosurgery 46: 356-362, 2000)

Sydney Support Group

Winston Hills Public School
Meeting for 7th August 2004

Attendance(40) Irene W, Kim K, Roy and Joan W, Dororthy P, Terry and Judith D, Lesley B, Carole McD, Kim S, Jocelyn and Oscar Stafford, Allan G, Celia C, Gavin and Mum L, Stuart and Gundal B, Audrey T, Judy McM, Henry B, Barbara and Max S, Elizabeth and Lloyd T, Vern and Stephanie R, Vera R, Frank and Norma M, John and Nola W, Ann and Laurie P, John and Chrissy L, Hilary and Keith W. Glenn T.

Apologies: Margaret W, John W, Thelma D, Maree H, Jeanette B.

September will be our 4th Birthday. We asked that everyone bring a plate of goodies to share.

Welcome to everyone including our new members. Also welcome back to Alan for his second meeting.

Gavin told us about his MVD (microvascular decompression) . He described the experience to us all in all its gory detail! After a 1 week delay it was all go. He had an MRI before the surgery to match up markers. He was in recovery for 5 hours after the operation. He described the pain as horrendous. He describes the recovery as difficult. After a week in hospital he went home to recover with his parents. He is now off all his medications and very happy with the results. He still has some balance problems which should correct in time. All the best Gavin
Post MVD - Gavin experienced post operation pain, nausea, vomit and balance problem.

Roy described his very different experiences to Gavin. He had his first MVD at 70 years. He had 4 ½ perfect years before a recurrence. His second MVD was at 76 years old. He has had perfect results for the past 4 years. He wanted to reassure members that we don't all have the some experience with the surgery. He felt very well 12 hours after surgery. Thanks Roy.

Lesley started with what she thought was a toothache. She saw a dentist who thought she was grinding her teeth. Her pain is right side V3 (jaw and chin) Her attacks became longer, lasting ½ hour, continuously.
The pain was excruciating. She went to her GP during an attack. He actually put the specialist on the phone to hear her screams! He started her on Epilim. When the pain came back, he added Tegretol. The dosage has been increased continually to 800mg Epilim and 800mg Tegretol. She describes problems with memory loss and balance. Lesley also has Meniere's disease. Not keen on

taking meds. Lesley wants to try the MVD and is keen to learn from the other members' experiences. She expressed concern about driving, due to the balance problems. Irene suggested a high resolution MRI, also advising that the MVD only works with classic TN.
Lesley was horrified how those who are no longer in pain stop coming to meetings. "Oh they need to come back to provide the support and hope for others!" Lesley exclaimed. YOU tell them!!

Jocelyn feels well today. She takes Baclofen and an antidepressant. She is now off Dilantin but back on Tegretol after having reactions of dizziness and itchiness when taken before. Jocelyn has been to RNS Pain Clinic. She is taking 'Capsicum Capsules' available from 'Healthy Life' stores. When the pain is in the mouth, she breaks the capsule directly into the mouth.

Chrissy & John are here to find help for Chrissy's mum, **Maria.** Her pain started in 2000 with shooting spasms from the shoulder to the scalp. Both a CT scan and MRI revealed nothing. In April 03 she had 3 trips to ER with 'fits' and was discharged with Valium – with no effect. Maria was diagnosed with MS in 1992. It is not degenerative. She is currently on Endep, Neurontin and another med. Pain lessened, now worsening. Unlike other members, she has pain in the shoulder, hand and leg. Glenn Turner suggested this may be muscular-the sternocleidomastoid muscle, which could be helped with acupuncture. Irene suggested an MRI to check if the pain is related to the MS.
I think the stats are 5 % of MS have TN and 2% of TN have MS.

We welcomed Glenn Turner from In Golden Health

Glenn spoke to us about 4 self-help techniques to manage pain. They may help to reduce the amount of medication for some people. We were given a handout describing each technique, and then practiced each procedure ourselves. Glenn advised that different techniques work for different people and problems. We can use them to get rid of other contributing factors to reduce the pain of the actual problem.

Bowen Technique encourages blood through the muscle by 'plucking' the muscle. It is useful for most face problems, including Meniere's disease, Bells Palsy, TMJ (*release TMJ)* and paralysis. Glenn demonstrated with Irene. Each session usually takes about 30 mins and involves 1-min periods of movement followed by important 2-min rest periods to allow the muscle to settle.

Reset Procedure encourages blood flow wherever the hands are placed.
Glenn took us through the procedure, which usually takes about 30 mins. In Chinese medicine, it is believed that the kidneys store energy. The hands are warmed and then placed in sequence on parts of the body, first the kidneys, the face, jaw, head, cheekbones. This can be used as a preventative measure and with minor pain.

Gentle touch procedure
This involved using the two hands to transfer energy. The left hand is used to touch the head. The index finger is placed in the depression above the ear. The index finger of the right hand is then placed on the site of pain and contact is maintained until a pulse is felt.

Relaxation Drill for pain
This is a relaxation technique, which can be used on any pain. Begin with minor pains, headaches etc to train the body to respond when more severe pain is felt. The body will take over as it becomes conditioned to use this response. It is basic self-hypnosis/ meditation.

Kim Smith.

Meniere's disease = recurrent vertigo accompanied by ringing in the ears (tinnitus) and deafness. A dysfunction of the semi-circular canals (endolymphatic sac) in the inner ear. Symptoms include dizziness, hearing loss (one-sided), vertigo, nausea, vomiting and abnormal eye movements.

Newcastle Support Group

Mater Hospital
14 August 2004

In Attendance : Phil & Raelene, Laura, Eileen, Jim & Beryl, Heidi, Neil, Margaret.
Apologies : Phyllis, Thelma, Monica.
Meeting opened at 1315.
Collected $17 as donations. Thank you, this money goes toward postage and the tea / coffee at the meetings. If any one would like to see a breakdown of received and spent, it is available on request.
We had a very windy day in Newcastle and I assume that the wind probably kept a few of our group indoors.
We had two new faces at this meeting and welcomed Neil and Margaret.
Margaret has had TN pain for about 15 years and generally keeps it under control with Gantin (Gabapentin).
Neil suffers right side face pain the majority of the time. Unfortunately, Neils pain is the result of a severed nerve during surgery to remove a lump in his neck. He is on Neurontin and Endep but there are times where he needs to visit the pain clinic for a nerve block.
Heidi has had an unusual experience in that her pain has transferred from her face to her legs. She says at times it is quite unbearable and can alternate from one leg to another.
Eileen was a little concerned that she possibly should not be attending as her condition does not appear as bad as the others. Anyone that comes along or toys with the idea of coming along to a meeting should be aware that our group *(as well as the Association)* is here to assist anybody who wants assistance. Face pain comes in many forms and if there are no rules about who should attend. Even if we can help someone only once, then we have achieved what we set out to do. *Hear! Hear!*
We had a guest speaker this meeting, LORETTO WHITNEY.
Loretto runs a health clinic in Lochinvar and specialises in KINESIOLOGY. Loretto struggled with asthma for many years and looking beyond mainstream medicine, she discovered kinesiology. Kinesiology was developed from chiropractic base by Dr John Thie in the 1970's, and is a powerful system of stress management and healing via muscle testing that detects physical, emotional, mental and spiritual imbalances.
Loretto has been instrumental in setting up the DOLPHIN HEALING and TRAINING COMMUNITY COLLEGE in the grounds of CALVARY RETIREMENT COMMUNITY in Cessnock. The centre now has ten volunteer receptionists and 15 therapists.
One of the most important points Loretto emphasised was that our bodies operate on electrical impulses, conducted through our nervous system. We are all well aware of the results of problems with nerves. One point she made is whilst we are trying to resolve problems with the nervous system within the body, we should be assessing the electrical interferences outside the body.
Think about this - Wristwatches were traditionally worn on the left hand so that the right handed person could wind it up. These days most of our watches have batteries that do not require winding. One view of the kinesiologist is polarity of energy in the body; the battery on the left wrist is in conflict with the body's polarity. Loretto suggested that we all should wear our battery powered watches on the right wrist.
She showed us an amazing demonstration - I laid on the floor with no watch on. Loretto tried to shift my legs sideways but could not. She placed the watch next to my left hip and I was powerless to stop her shifting my legs. I can be sceptical but this demonstration was quite amazing. We talked about electrical appliances around the home and particularly the bedroom. Any of you who wake up and do not feel rested, have a look at what is around your bed and consider moving it - see what happens.
Loretto talked about meridians in the body and how manipulation of different parts of the body can reduce pain. Again we saw an amazing demonstration where just holding the forehead and concentrating on your pulse can reduce pain. Neil said his pain was about 8 out of 10 when he walked into the meeting. After this simple manipulation, his pain was about 6 and was gob smacked at the difference. After a few more manipulations (right foot would you believe) Neil's pain was at about 4 out of 10. To all the sceptics; laugh all you like but to this man the relief was very real.

I think the most important result of the meeting today was that people must open their minds to the possible alternatives to relief BUT bear in mind that not everything works for everyone and for some people mainstream treatment may be the best option.
We finished the meeting with a cuppa and everyone thanked Loretto and left with more than a little to think about.
Next meeting is Saturday 13th November. We will need to discuss the frequency of meetings, whether everyone is happy with quarterly and I would like to hear from anyone who may have a health professional or someboady inspirational that can present something to the group.
Best wishes to all
Phil
CONTACT
Phil 02 49 387 361 or 0409 072571
Laura 02 49 684 873

Great report. Thanks for sharing this with us all.

MELBOURNE SUPPORT GROUP MEETING

At "Ringwood Room"
Ringwood Library, 1.30 p.m.

14th August, 2004

Present: (14) Bernadette & Les B.; Kay B.; Leah C.; Alma E.; Helen F.; Joe I.; Pat O'G.; Bill P.; Leanne S.; Karin S.; Sharyn S.; Joan & Neil Thompson.

Apologies: Nancy B.; Joy & Alan C.; Beryl O.; Jean & Tom P.

Treasurer's Report: Cash in Hand: $162.70.

I want to thank some members who make an extra commitment – we do appreciate very much all the donations, we cannot operate without meeting some financial obligations. *(Absolutely! how much more so for the national Association.)* However, it is noticeable that donations are indeed larger from some who shall remain anonymous. Thanks to everyone!

We have been successful in our application to Maroondah City Council for some funding. A grant of $335 has been made, for a Trigeminal Neuralgia Awareness Program, and must be used by April, 2005. I shall need lots of help to distribute flyers, etc., over this period. ??????????

We welcomed five new attendees, and one guest, and while it is sad to hear their stories of their facial pain, at least they all went home feeling more positive about managing their condition after the interaction with other members, and the extra knowledge they gained.

Kay wakes up with pain, mostly a dull ache, but a sharp pain is triggered by washing face and brushing hair. Pain on Right side, from temple to side of nose, cheek and upper jaw. Kay is managing without meds, but keeps out of the cold.

Leah first had pain 8 yrs ago, 1st MVD 6 yrs ago, and pain returned 2 yrs ago. 2nd MVD nine weeks ago. Still some pain, not stabbing, a constant aching, burning, sometimes on both sides. Not on meds as they give a bad reaction, and Leah has her small baby to look after. She has help at her workplace, by attending an occupational doctor when pain is severe.

Sharyn's pain commenced 15 yrs ago. Bilateral, atypical. Meds: Neurontin, Epilim, Rivitril, Cipritol, and also attends a pain clinic. Sharyn was a teacher, now on pension because of the pain. Her sister, Helen, who has permanent pain after radiation treatment, came to support her.

Leanne has MS, and her TN pain commenced 2 yrs ago. She is taking Tegretol 200 Mg p.d. Considering using Zostrix, as she'd like to come off Tegretol.

Karin – pain commenced 18 months ago, suspects TN, dentist inclined to agree and recommended Tegretol, but Karin believes good nutrition should keep us healthy, and takes no medication, only Vit.B Complex tablets, incl. B.1. She has less pain now, than at first.

Two of the above ladies are also coping with cancer.

Joe is still managing his pain without Tegretol. He gave us his recipe for a Zostrix substitute: He uses Dencorub Arthritis Cream (odorless) + Masterfood Chillies, ground, hot. He mixes ¾ portion of ground chillies with few drops hot water to a thick paste, then add ¼ portion of Dencorub, and combine to a smooth cream. Then he applies it in the same way as Zostrix, keeping it away from eyes and broken skin. This keeps Joe's pain down to a tolerable level.
Thanks, Joe. I, for one, would try this if my supply of Zostrix ceased.

Please note that at our December 4th meeting, we will be having Mr. Mark Feldschuh, a compounding chemist, for our speaker.

Many thanks to all for contributions towards afternoon tea, - much appreciated on this very cold and windy day.

Next Meeting: Saturday, 9th October, at 1.30 pm in the Ringwood Room.

Joan

SUNSHINE COAST SUPPORT GROUP

23 BEACH ROAD
MAROOCHYDORE

14TH AUGUST 2004
ATTENDANCE:- David & Gloria, Max, Jane, Sandra, Peter & Pearl, Connie, Marcella and Neil.

AGENDA:-
Our meeting was held at Fletcher Dental, hopefully our permanent new meeting venue. I have unfortunately had to resign as Group Leader due to personal issues and Connie and Neil are going to co-host the meetings from now on.
Jean is having an operation in Sydney on the 18th August, our thoughts and prayers are with her.
Ed brought along a video on TN, operations and such, it is to be lent out to anyone interested. It was interesting to watch and hopefully of assistance to any one contemplating surgery. However the results cannot be guaranteed and your options should be weighed up very carefully. There is no reversing some of the side effects.
Our kitty from donations last meeting now totals $166.20.
It was suggested we have a phone tree, to advise people of any changes to time or venue etc. Need to know the legalities for privacy laws.
We hope that Marcella, can resolve her personal issues satisfactorily and rejoin our group, in the near future.

Next meeting: 18th September 2004 11:00am
23 Beach Rd, Maroochydore.

Marcella & Connie

Special Issue – Phenylalanine - Be Careful!

Our last newsletter highlighted an amino acid supplement called D-Phenylalanine. While it is an important amino acid for most people, for some it can be very dangerous.

On August 19, 2004 one of our Newsletter articles described the benefits of D-Phenylalanine (Elevates Endorphin Levels). One of our readers pointed out that D-Phenylalanine "Has been

known to increase blood pressure so should be used with caution in persons with that problem." Thank you!

I did some research into this point and I "re-discovered" some of the serious problems associated with this amino acid. Sure, phenylalanine is an important amino acid - for most of us. However, some people are born with a genetic difficulty that makes it dangerous to consume most protein material. They have a condition known as phenylketonuria (PKU). Without a doubt, those who HAVE PKU know it and avoid things that contain phenylalanine. They also avoid aspartame (aka, NutraSweet®), because one of the major components of that artificial sweetener is phenylalanine.

Here's something that Dr. Joe Mercola wrote about aspartame in one of his newsletters;

Phenylalanine is an amino acid normally found in the brain. Persons with the genetic disorder phenylketonuria (PKU) cannot metabolize phenylalanine. This leads to dangerously high levels of phenylalanine in the brain (sometimes lethal). It has been shown that ingesting aspartame, especially along with carbohydrates, can lead to excess levels of phenylalanine in the brain even in persons who do not have PKU.

This is not just a theory, as many people who have eaten large amounts of aspartame over a long period of time and do not have PKU have been shown to have excessive levels of phenylalanine in the blood. Excessive levels of phenylalanine in the brain can cause the levels of serotonin in the brain to decrease, leading to emotional disorders such as depression. It was shown in human testing that phenylalanine levels of the blood were increased significantly in human subjects who chronically used aspartame.

What does this mean for The Compounder? We have decided to remove D-Phenylalanine from our catalog. The risk of harm is just too great in my opinion to offer this product.

We also offer this warning to anyone who suffers any symptoms of depression. Do not use phenylalanine supplements. Furthermore, stop using any product that contains aspartame (NutraSweet®). Approximately 50% of this sweetener is phenylalanine. Every diet product you consume could be making your depression worse.

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Drug-Food Interactions

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Summary
Interactions between foods and drugs can have profound influence on the success of drug treatment and on the side effect profiles of many drugs. The interactions are not always detrimental to therapy, but can in some cases be used to improve drug absorption or to minimize adverse effects. These interactions have received more attention recently, especially drug interactions with grapefruit juice. As new drug approvals occur with ever-increasing speed, there is less information available about their adverse effects and interactions when the drugs reach the market.
A second area of concern is the use of herbal medicines and dietary supplements. These products are not rigorously monitored, and may contain little if any of the substance indicated on the label. Some of the herbs used can interact adversely with prescription drugs. Two notable examples are ma huang (ephedra) and feverfew. Ma huang is a stimulant that can cause hypertensive crises in patients taking monoamine oxidase inhibitors. Feverfew has anticoagulant properties that can augment the effects of warfarin.
Most food-drug interactions occur through three mechanisms: reduced rate or extent of absorption, increased rate or extent of absorption, or through chemical/pharmacologic effects.

With some drugs, the presence of increased amounts of stomach acid results in the destruction of acid-labile drugs, such as penicillin G, ampicillin and dicloxacillin. In other cases, the components of the food, such as calcium or iron, may form complexes with the drug that are less easily absorbed. Examples include tetracycline, sodium fluoride and ciprofloxacin. The absorption of alendronate is impaired by food, calcium and almost everything, including orange juice and coffee. It should be taken with plain water and nothing else should be consumed for at least 30 minutes. In many cases, the actual mechanism by which food interferes with absorption is not known. Delayed absorption does not necessarily reduce the total overall exposure to the drug; the area under the curve (AUC) may be equivalent regardless of how the drug is taken. A reduced rate of absorption may sometimes be useful in reducing the side effects of a drug, as in the case of ibuprofen, without reducing bioavailability.

The bioavailability of some drugs may be enhanced by food. For example, an acid environment is necessary for the absorption of ketoconazole. The absorption of griseofulvin is increased by fat in a meal. Fenofibrate, mebendazole, isotretinoin, tamsulosin, carbamazepine and labetalol are examples of drugs that will be better absorbed when taken with food. Improved absorption of a drug may or may not have a significant effect on the drug's efficacy.

Chemical or pharmacologic interactions occur through a wide variety of mechanisms. A very common interaction is that between beverage alcohol and drugs that have sedative effects. The effects of sedative drugs will usually be potentiated by the consumption of alcohol. Opiates, benzodiazepines and antihistamines are well-known examples of this phenomenon. Another alcohol-related interaction is the competitive inhibition of the enzyme aldehyde dehydrogenase, often called the "Antabuse®" reaction. Nausea, vomiting, flushing, dizziness and tachycardia may occur with exposure to alcohol in patients taking some cephalosporins, ketoconazole, metronidazole and sulfonylureas. In addition, chronic alcohol overuse can increase the toxicity of some drugs, as with acetaminophen and methotrexate, or reduce the drug's efficacy, as with phenytoin.

Components of food may antagonize the desired effect of the drug, as in the case of warfarin. Foods which are high in vitamin K, or which enhance vitamin K production by intestinal microorganisms, can reduce the effectiveness of warfarin in diminishing the body's supply of vitamin K, which is needed to activate clotting factors. Changing to a diet with increased consumption of leafy and/or dark green vegetables, such as spinach and turnip greens, could lessen the degree of anticoagulation made possible by warfarin by supplying additional vitamin K.

Perhaps the most feared food-drug interaction is that between monoamine oxidase inhibitors (MAOIs) and the amino acid tyramine, which is found in a variety of aged, fermented, overripe or pickled foods and beverages and, to a lesser extent, chocolate and yeast-containing foods. Tyramine is indirectly sympathomimetic. When its metabolism is suppressed, as it is by MAOIs, it can cause a significant release of norepinephrine, resulting in markedly increased blood pressure, cardiac arrhythmias, hyperthermia and cerebral hemorrhage.

The interaction between grapefruit juice and a variety of drugs has been widely reported. It appears that one or more flavonoids found in grapefruit juice inhibit some of the enzymes in the cytochrome P450 system. This results in reduced metabolism of drugs that are cleared by the same system; bioavailability may increase by as much as 200%. Patients should avoid drinking grapefruit juice for two hours before and four hours after taking drugs in this category. If the drug is in an extended-release dosage form, patients should wait until six hours have passed before drinking grapefruit juice.

NB. The absense of a drug on the text above does not necessarily mean that it has no drug-food interactions.

NEXT MEETING : 2004

Brisbane : **11th September** l:30pm - 4:00pm
30 Ridley Rd., BRIDGEMAN DOWN
Support Group Leader: Lesley Curtain 07 32642838

Sunshine Coast : **18th September** 11am – 2 pm
23 Beach Rd, MAROOCHYDORE
Guest : Irene Wood.
Support Group Leaders : Connie Holden : 07 5486 7055
Neil Westbrook 07 54451700

Sydney : **2nd October** 2 pm - 4:30pm Winston Hills Public School
Junction Rd, WISNTON HILLS.
Support Group Leaders: Irene Wood 02 45 796226
Kim Smith 02 9769 1947

Melbourne : **9th October** 1:30pm - 4pm "Ringwood Room"
Ringwood Library, RINGWOOD
Support Group Leader : Joan Thompson - 03 9725 3808

Canberra: **16th October** l:00pm -3:30pm -
Weston Creek Community Centre
Contact : Irene Wood. 02 45796 226

Sydney : **6th November** 2 pm – 4:30pm Winston Hills Public School

Newcastle : **13th November** 1:00pm – 4:00pm
TUTORIAL ROOM, LEVEL 6 MATER HOSPITAL
Lorna Street (Off Maud St.) Newcastle. Meet at Daffodils Cafe
Support Group Leader: Phil Leaver: 02 49 387 361 or 0409 072571
Laura Moodley 02 49 684 873

SYDNEY: **4th December** 11am – 2 pm
Level One, St. James Parish Hall
Philip Street, SYDNEY.

GOD BLESS

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