Trigeminal Neuralgia Association Australia Incorporated ABN 33914644101

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

August 2004

12 months to go….

- It offers a wonderful opportunity to meet TN friends from around the country. It also provides you the chance to exchange TN history and management know how with international TN sufferers.
- It cost me thousands $$$ to attend one. I am bringing it to you at a lot less so that you can enjoy the advantages and benefits of such a conference.
- You pay just as much to see your specialist for 15 minutes. At the Conference you get to ask the experts, and have a chance to chat with them over lunch /dinner.
- Learn the latest information direct from both international and local experts.
- Accommodation at the Swiss Grand Bondi Beach at a special rate for Conference guests.

Conference Registration Fee

Payment made -	**Before** 30 /04/05	01/05/05 – 30/06/05	01/07/05 – 10/08/05
TNA Paying Members and spouse	$180 p/p	$235 p/p	$260 p/p
Non TNA Members	$235 p/p	$250 p/p	$280 p/p
Professionals	$280 p/p	$320 p/p	$360 p/p

Conference Registration fee includes : (for both days.) –

- T/ Coffee with freshly baked muffins on arrival (First session to start by 8am each day.)
- Morning T/ Coffee with home made biscuits,
- Lunch - with OJ and Mineral water,
- Afternoon T/Coffee with fruits etc.
- Dinner
- Local and international speakers. We are proud to have Dr. J.Zakrweska and Dr. K.Casey.

To Register Interest for the Conference : Contact Irene Wood -
Email : tna_sydney@yahoo.com Tel : 02 45796226

Fetal cells used to treat ALS July 30, 2004 *The Scientist*

Americans seek glial cell transplants in Beijing for spinal injury and other conditions | By Paul Mooney

BEIJING—From the outside, the Chaoyang Hospital looks nothing like a state-of-the-art medical facility. The pavement outside the old red-brick building is broken, while patients inside lie on hospital cots in grim, dark hallways.

Despite its appearance, the hospital has become a magnet for patients with spinal cord injuries, amyotrophic lateral sclerosis (ALS), and Parkinson disease from all over the world. They come to find neurosurgeon Huang Hongyun, who is using fetal tissue transplants in the hope of repairing neurological damage.

Over the past 3 years, Huang told *The Scientist*, he has used fetal tissue transplants to treat more than 450 patients. He now has 1000 Chinese and foreign patients on a waiting list, including about 100 Americans, who find him via the Internet or word of mouth. He has also used the procedure to treat strokes, **multiple sclerosis, cerebral palsy, and brain injuries with, he says, "equally positive results."**

The bulk of his Huang's patients are people suffering from spinal cord injury, followed by ALS, a distant second. He has only treated a few patients with Parkinson disease.

Huang uses **olfactory ensheathing glial cells** (OECs) extracted from the olfactory bulbs of fetuses aborted during the second trimester of pregnancy. These cells are thought to **have the capacity to regenerate damaged nerve fibers,** and although research groups elsewhere are conducting human trials with adult versions of the cells, Huang's group is virtually alone in using fetal tissue.

The neurosurgeon's team cultures the cells before injecting them into the patient. For ALS patients, three incisions are made, two in the frontal lobe and the third at the spinal cord around mid-neck. Spinal cord injury patients get injections in the spinal cord close to the site of injury.

"If you look at an MRI of an ALS patient, you'll see that the greatest atrophy is in the frontal lobes," Huang said. He thus injects the OECs at the point closest to the area of damage.

The transplanted cells do not replace neurons, but help the neuronal axons to regenerate, and this brings about improvements in the conditions of patients, Huang told *The Scientist*. "OECs don't replace neurons," he said. "It's the glial cells that provide an environment in which damaged neuron cells recover."

"I don't know how it works, but I know it helps patients," the neurosurgeon admitted. "But the clinical evidence shows that it can help. And if I'm wrong, we wouldn't be achieving these results."

About 1 to 1.5 million cells are injected per injection site, Huang told *The Scientist*, so patients with spinal cord injury receive a total of 1-1.5 million cells, while those with ALS receive up to 4.5 million cells. He said patients often regain some movement or feeling 2 to 3 days after the procedure. There was no evidence that injecting more cells would attain better results, he added. An Australian group had done a similar procedure on three patients, giving 10 injections and injecting 10 to 15 million cells. "I believe this is dangerous," he said. "It's a large volume and not good for the spinal cord."

Animal research using OECs for spinal cord injury is conducted in the United States, but the human transplant procedure is not available. Scientists feel the evidence is not strong enough to support human use of the technique. Plus, research using fetal and embryonic tissue is restricted.

"There's no moral majority in China ruling scientific research, and that's a big factor," said 33-year-old ALS patient Ben Byer, who was diagnosed in 2002 and operated on by Huang on July 20.

The published evidence in support of Huang's work is skimpy. No controlled clinical trials have been carried out, although Huang said he's talking with the Miami Project to Cure Paralysis about designing such studies.

"We are evaluating his work and determining what next steps would be appropriate, if any," a spokesman for the Miami Project told *The Scientist*. In fact, two physicians from the Miami Project are currently in Beijing for 10 days to gather information on Huang's procedure and to evaluate the progress made by patients.

Wise Young, a research professor at New York University's medical school, told *The Scientist* Huang's work was interesting. "His results represent a credible phase 1 trial that establishes the safety and feasibility of such transplants. Preliminary analyses of the results suggest that the procedure may produce rapid but modest sensory and motor improvements in people from 2 to 40 years after injury. These results await confirmation with more rigorous controlled trials."

Huang himself does not claim a miracle cure. With spinal injury patients, he said, neurological functions can improve, but he expects no complete recovery. With ALS, "If the process can keep them stable, that's already pretty good."

In the Chinese Medical Journal last year, Huang published a report showing results in 171 spinal cord injury patients, 2 to 8 weeks after transplantation.

The study used the International Standards for Neurological and Functional Classification of Spinal Cord Injury scale, which gives a best total score of 100 for motor function and 112 for pin-prick (light-touch)

sensation. Huang did not report baseline scores, but after OEC transplantation, motor scores increased by 8.3 in patients aged 21 to 30 years and 5.7 in those aged 31 to 40 years, he reported. Light-touch scores increased by 15.5 and 12.0 in the same groups.

Jake Giambrone, 18, was paralyzed following a wrestling accident 3 years ago and has lost all ability to move his body. Just 2 days after he underwent the transplant in Huang's operating room, I watched as Jake struggled to move his thumb and as he talked about feeling muscle spasms for the first time since his injury. "It may not seem like much to you all, but he hasn't moved in 3 years," said Susan Giambrone, Jake's mother. "We're real excited about the thumb."

Cade Richardson, 31, underwent surgery on Monday for paralysis that resulted from a paragliding accident in 2001.

Richardson heard about Huang from another patient. He communicated with Young, who he says cautioned him to wait another 6 months before trying the procedure. (Young, who studies OECs in mice, also moderates a CareCure chatroom for spinal cord injuries where a lot of news about Huang's research is discussed). But when Richardson started hearing more success stories coming out of China, he decided to go ahead.

"It's going to be another 5 or 6 years before anything happens in the United States," Richardson told *The Scientist*. "I don't want to wait another 5 or 6 years."

Links for this article

Miami Project to Cure Paralysis
http://www.miamiproject.miami.edu/

Wise Young
http://www.med.nyu.edu/people/W.Young.html

H. Huang et al., "Influence of patients' age on functional recovery after transplantation of olfactory ensheathing cells into injured spinal cord injury," *Chinese Medical Journal*, 2004;116:1488-1491.
http://www.cmj.org/information/full.asp?id=959

Standard Neurological Classification of Spinal Cord Injury
http://www.asia-spinalinjury.org/publications/2001_Classif_work sheet.pdf

CareCure Community
http://carecure.rutgers.edu/spinewire/

DYING BY INCHES

Excerpt from : "Dying by inches" SUNDAY 17th July 2004 - Channel 9

They're our ultimate safety net — the intensive care units of our major hospitals. High tech and high touch, it's a comfort to know that however sick we are — wherever we are — if we need them, they're only an ambulance trip away. The dollar pressures on our public hospitals are well known. Intensive care units — costing as much as $6,000 per bed per day — are bearing the brunt of this. As Australia's population ages, we're living longer, but living sicker — the number of admissions to intensive care of people aged 80 and over has tripled in the past five years. And often when we reach that age, we've long lost the ability to say what kind — or how much — treatment we would want to receive in the event of a life-threatening illness. Many families, by default, are demanding that "everything be done" for their loved ones. We have the technology to keep many people alive indefinitely, but that robs a bed from a patient with a longer — and better — life expectancy. Some of the nation's most senior doctors are finally telling it like it is. Governments claim their pockets are empty. Neither of the major parties would dare run on a platform of higher taxation. Under these kinds of pressures, intensive care is simply too valuable a resource not to be rationed. Admissions should be prioritised. Only those likely of long-term quality survival should receive the best care that taxpayer money can buy ... more

Transcript

GRAHAM DAVIS: Fahima Sharoubim is 79 and lives in a Melbourne hostel. Her doctors evidently think this Egyptian-born grandmother would be better off dead. For when her family insisted they continue the kidney dialysis on which her life depends, the doctors tried to get a guardian appointed, arguing the treatment was no longer viable. Fahima's the face of a whole new health care dilemma for all of us - just when does life cease to be economically viable? She's still here only because her family fought back, refusing to accept the

death sentence the system had passed on her.

Do you think your mother would be better off dead, yourself?

SOBHY GIRGIS, SON: Oh, that's absolute nonsense.

FATHER DANIEL GHABRIEL, COPTIC HOSTEL, NARRE WARREN: ..I asked them for a medical reason why they wanted to end the treatment or cease the dialysis treatment. The only reason they forwarded was she didn't have a sufficient quality of life or prospect of a sufficient quality of life. They weren't able to forward me a medical reason.

GRAHAM DAVIS: To support its application, the Monash Medical Centre said Fahima's treatment: "Was causing her distress as she'd removed her needles during dialysis three times over the last one to two weeks."

SOBHY GIRGIS: If that's true, which I doubt it, that is not an excuse to end someone's life.

GRAHAM DAVIS: Yet even more disturbing is evidence that far from being voluntary, what the hospital had in mind for Fahima was against her will. Sobhy, could you ask your mother what her wishes are. Does she want to continue getting treatment?

FATHER DANIEL GHABRIEL: She's expressed no will to end her life to me or that she'd had enough. She doesn't refuse to go to dialysis when it comes about. In some ways she looks forward to going to dialysis.

GRAHAM DAVIS: Small wonder that facing such evidence before the tribunal, the Monash Medical Centre quietly withdrew its application. Did they at any stage of the negotiations mention money?
FATHER DANIEL GHABRIEL: They did mention that it was an expensive treatment and I said, "All treatment's expensive." When someone says the treatment's expensive and we want to stop it, you can only come to one conclusion.

GRAHAM DAVIS: Dialysis for those whose kidneys can no longer clean their blood is now the main reason elderly people go to hospital. And demand for these machines is expected to triple over the next 20 years as the baby boomers enter the twilight of their lives.

It costs $50,000 a year to treat the average dialysis patient. But this is just one component of an all-out assault on health budgets as ageing taxpayers demand the latest technology with scant regard for how much it all costs. Dollar pressures on our public hospitals are nothing new. But today, you'll hear some of the nation's most senior medicos break the ultimate taboo - talking openly about rationing health care.

DR BOB WRIGHT, DIRECTOR OF INTENSIVE CARE SERVICES, ST. VINCENT'S HOSPITAL, SYDNEY: We've had such wonderful advances in medicine in the last 30-odd years. But in some ways, some of us are a bit like kids in lolly shops - we haven't got the wisdom to apply it, ah, you know, appropriately. And I think it gets a bit out of hand at times.

GRAHAM DAVIS: In what sense?

DR BOB WRIGHT: I think we are doing too much for some people.

GRAHAM DAVIS: In the age of the ventilator, people can be kept alive almost indefinitely. But the debate doctors want is should they be sent here in the first place?

PROF MALCOLM FISHER, DIRECTOR, INTENSIVE CARE, NORTHERN SYDNEY HEALTH: A patient in intensive care, there are three things that can happen. They can get better, they can die, or a third option, which may be the worst, where they essentially become people who exist rather than live. In New Zealand they call them "warm cadavers".

GRAHAM DAVIS: And how long do you see people living like this in intensive care units?

PROF MALCOLM FISHER: Probably the longest in this unit in recent memory is about 50 days. This person, over the course of his period in the unit, would have made it necessary for us to move sick patients to other hospitals.

GRAHAM DAVIS: But this debate isn't just about stopping treatment, but starting it in the first place. The treatment train, let's call it, that sets out once an ambulance is called and wends its way inexorably through

the system. It's time, say some, to halt that train for some patients, especially before its final destination.

PROF PETER CAMERON, THE ALFRED HOSPITAL, MELBOURNE: The problem is, once they end up in a high-technology tertiary hospital with specialists running around, it's inevitable that they get on a treadmill and they go right all the way down, often end up in intensive care, of all places, you know, with machines that go ping and 20 doctors hanging around them having operations and procedures. And that's just not appropriate for some of these people.

GRAHAM DAVIS: Which is why some medicos now think we have no choice but to exclude some patients from intensive care altogether. The most radical proposal comes from a most unlikely source. For more than 30 years, Dr Bob Wright has been head of intensive care at the Roman Catholic Church's St Vincent's Hospital, in Sydney.
DR BOB WRIGHT: Intensive care is such a limited resource, I think it's got to be rationed. We're putting so much resource into people with a poor prospect of good-quality survival that people who would benefit more are getting neglected. We've only got a certain number of beds staffed and we can't take your young patient at the moment because to take them we've got to, you know...

GRAHAM DAVIS: ... take an oldie off a respirator.

DR BOB WRIGHT: Yeah.

GRAHAM DAVIS: And how do you feel when you have to say that?

DR BOB WRIGHT: Oh, I don't feel happy about that. I think it's not right. But this is something the community and government and health departments have got to talk about.

GRAHAM DAVIS: And are they?

DR BOB WRIGHT: I think they're going to start after this program.

PROF MALCOLM FISHER: Our age population is increasing. It's surviving longer and it's losing its marbles.

GRAHAM DAVIS: That debate on patient rights to treatment is already well under way in medical circles, like this gathering of intensive care workers in Sydney.

PROF MALCOLM FISHER: Our ICUs are full of old people receiving treatment that would be against their wishes, at the request of their children.

GRAHAM DAVIS: But there's frustration here that the nation's intensive care units are being left to make the hard decisions no-one else in the system is prepared to make.

PROF MALCOLM FISHER: And maybe it is time for a realistic discussion in society about what people are entitled to expect. But the politicians are certainly not going to lead this because it's something they're very afraid of.

GRAHAM DAVIS: With an election looming, we'll test that assertion with Federal Health Minister Tony Abbott as we confront him with the crisis of bed blocking in intensive care.

Do you think the frail and very elderly ought to be in there at all?

TONY ABBOTT, FEDERAL HEALTH MINISTER: We should do whatever we reasonably can to save and enhance life. I would be shocked if any significant sections of the medical profession were saying that there are some people who shouldn't be treated.

GRAHAM DAVIS: Right, well, prepare to be shocked, Minister.

We're seeking Tony Abbott's response to this - a discussion paper proposed by Dr Wright, at St Vincent's, that would exclude from intensive care patients with the lowest priority, priority three. Anyone who'd require "high-level organ support or have a low probability of long-term quality survival."

DR BOB WRIGHT: Because once you get one of these you're often stuck with them for weeks and that's one of your beds gone. And that ...

GRAHAM DAVIS: Bed blocking?

DR BOB WRIGHT: That's blocked a bed.

GRAHAM DAVIS: So priority three - people with low probabilities of long-term quality survival - are bed blocking in the system?

DR BOB WRIGHT: Yeah. Because these people usually take a long time to die.

GRAHAM DAVIS: Dr Wright specifically cites as an example "frail elderly patients, especially if there are impaired activities of daily living". Their admissions to intensive care have tripled over the past five years.

DR BOB WRIGHT: It's a bit like being a mechanic in a garage, you know, and someone comes in with an old FJ Holden, you know, the tyres are bald, only two cylinders are working, the transmissions gone and the brakes, and they say, "Look, I want you to make a new Commodore out of this," and it just can't be done. You're just doing everything you can to try and keep this machine running and you realise it is an exercise in futility. I don't think it's good for anyone to live longer than they should. You know, I think it's best, if you're going to go, to go quickly and as peacefully as you can.

If you wish to read the full article or watch the whole presentation – contact me (Irene.)

I was much affected by the above. When my father was in ICU we experienced some of those attitudes. I could not bring myself to make the decision they wanted, so they "talked" to us everyday. I like to add they did not know what was making him so ill, they only said he had an infection. They did not know what the infection was.
On the 3rd day of the "Talk", one of them said " even if he recovers he will not recover to that same level as before he was admitted." – their Holden theory. I was not expecting a new Commodore nor was I expecting to dump my old FJ Holden.

I like to know - How do you " go when you got to go and go quickly"? and go peacefully"?

Those who welcome death have only tried it from the ears up.

Wilson Mizner (1876 - 1933)

Target ?

BRISBANE SUPPORT GROUP

DATE. 31/07/04

ATTENDANCE 19

AGENDA. At this meeting we all had time to share our TN experiences before our guest from the last meeting returned to collect the magnetic samples he gave out for members to try. We all had great hopes that these would prove beneficial but none found the items relieved their pain. A few did mention they had amazing dreams though. We all appreciated the opportunity to try without having to outlay money for expensive items so we thank Don very much.

* May has been unwell and came for a short time to return her magnet. Hope things look up May. Audrey was going so well with the compounded meds but has developed a reaction to the gel and has had to stop until she finds out just what ingredient was irritating her.
* Wonderful to see Beryl and Henry smiling again. I'm glad Fay could come this time too.
* Its wonderful to see someone like Margaret B, whose pain is fairly stable, always at the meeting to support and help with Col. Thank you both.
*We were happy to welcome Don to his first meeting and hope he benefited from hearing others stories that may help him to see where he fits into the TN picture.
* I was so happy that Shirley and Joan got here with out mishap after being thwarted trying to get to some recent meetings. Great to see Shirley's pain is better too.
* While I was thrilled that Fred was back after such a rough time I was not so thrilled with his experiences. When he was admitted to hospital for a really bad episode recently he was told he had to decide there and then to have his nerve CUT! He refused as the reading and information he had gathered had never advocated this. He was then told he would be the village idiot if he didn't. He stuck to his guns and is now managing the pain again using medication. Unbelievable. I can see the smoke coming out of Irene's ears to hear something like this. *Irene is very proud of Fred. If you were to decide on surgery – MVD would be wiser than having it cut.*
* Great to see Howard looking relaxed and pain free. The residual numbness is very slowly reducing. Howard would rather have this any day than have the pain and meds back..
Both Margaret O and Anne have had to adjust their meds to settle flare-ups. It's good to see that's worked.
Fred and Henry have tried to capsaicin creams formulated by the compounding pharmacists (one in Bne and the other in Sydney) Both agree that these creams do not do the same job as the Zostrix so we'll have to look into that.

FINANCES A gold coin donation was taken and $60 was collected. Many thanks everyone.

NEXT MEETING Our next meeting will be on September 11/04 at 1.30pm.
The venue is 30 Ridley Rd., Bridgeman Downs.

Lesley.

An interactive web-application for Facial Pain Diagnosis - Is Here !
http://www.ohsu.edu/neurosurgery/facial_pain.shtml

from the webpage….Although Burchiel is speaking of one type of facial pain, trigeminal neuralgia, with his new classification system and computer assisted diagnosis Burchiel is taking the mystery out of diagnosing any facial pain. These include severe, post traumatic facial pain syndromes following oral, dental, or ear, nose and throat surgery; pain accompanying multiple sclerosis; and pain after shingles infections, to name a few.
Burchiel devised a questionnaire that assesses and diagnoses facial pain syndromes and tested the instrument on dozens of OHSU patients. At a national meeting, he then had physicians interview scores of patients and compared their assessments and diagnoses to computer assisted responses. "In fact," Burchiel said, "the computer diagnosed a little better than the doctors."…..

SYDNEY SUPPORT GROUP

Winston Hills Public School
3rd July 2004

Welcome Dr Toby Newton John

Present (40) Irene W, Gary A, Pam D, Bev H, Nola W, John W, Vera.R, Kathryn. S, Frank M, Norma M, Audrey T, Thelma D, Jeanette B, Henry B, Jocelyn S, Oscar S, Gundel B, Stewart B, Hilary W, Keith W, Kim S, Stephanie R, Vern R, Ann P, Lawrie P, Norma M, Trevor, Toby N-J, John W, Bruce H, Joyce H, Judith D, Terry D, Jenny G, Bill G, Alan G, Lloyd T, Elizabeth T, Jenny W, Mark W
Apologies: Shirley C, Ray & Joan W, Doug & Margaret W, Blanch & Max S, Celia C, Gavin L, Marie H, Kim K.

Welcome to all new attendees, Alan, Jenny & Norma
*** Alan** was first diagnosed with TN in 1997. Right side ophthalmic region (V1) He commenced on Tegretol and then went in remission. He had a recurrence in February 2004 and is on 800mg Tegretol. It is not helping. He found out about the support group through the US website and is hoping for some help.
*** Jenny** has had right side pain for 12 months. She first went to the dentist, then GP then specialist. She was prescribed Tegretol. She went into remission and has had a recurrence in the last 2 months. Jenny resumed the tegretol and is still increasing the dosage to gain control. Currently 500mg
*** Norma** had a root canal on the right side and has left side Maxillary (V2) nerve pain. Norma was given a band because of teeth grinding. The pain increased. She has seen 2 neurologists. She takes Neurontin
From our caring and sharing after the presentation
*** Terry** is having increasing pain. He is on Tegretol, Neurontin & Epilim & will be reducing the Neurontin. He is seeing Dr Vickers & Dr Newton John at Royal North Shore Pain Clinic
*** Jenny** is going to Westmead Pain Clinic She is trialing Amitriptyline with Neurontin. Finds all normal daily activities difficult- eating drinking, talking. Has stinging, burning pain.
* Group discussed that it is common for patients to tell Doctors what they want to hear, sometimes feel guilty that the help they are given is not working. Difficult for doctors as we have many different trigger points and medications. There is no easy answer. It's trial and error for everyone.
Be aware that artificial sweeteners can affect pain, also grapefruit juice can react with Tegretol.

Welcome to Dr Toby Newton John –Clinical Psychologist at RNSH Pain Clinic
Dr Newton John presented his information and answered questions throughout the presentation. Please note: the following report is my own understanding of the discussion. (Kim S)

Why do we need a psychologist in a pain clinic?
The clinical Psychologist talks, the Psychiatrist prescribes.
The psychologist looks at behaviour, thinking and mood. Most people are concerned that their pain is imagined when they are referred to a psychologist. This is not the case. People tend to see a large injury as more painful and have difficulty with any pain not due to a visible injury.

Definition of Pain –an unpleasant sensory and emotional experience usually involving tissue damage
All pain includes both physical and emotional factors.
All pain is real. It is not caused by stress or emotions but is certainly exacerbated by those factors. The pain can be more intense/ harder to deal with. The pain can vary according to how you feel. This just means you are normal., Healing is also better in a person who is not stressed.

"The gate theory" relates to how much pain is 'let through' to the brain. The gate opens or closes in different degrees. The gate is generally closed more when we are busy and distracted. We may not notice an injury occurring or experience pain. The gate is located in the dorsal horn of the spinal chord
The gate will be open or closed depending on 3 main factors:
physical (number of nerves in the site, extent of the injury)
psychological (calmness, distraction, focus on the pain)
medication
When treating pain:
Doctors start by treating the cause- if it can't be identified or relieved,
Treat the pain with drugs or surgery
If pain can't be treated or side effects worsen, it has an impact on quality of life and functioning leading to suffering.

Pain creates a cycle- leads to decreased activity –lose fitness –work may suffer –mood drops –frustration from failed treatments/side effects of medications–family problems/lack of social involvement –loss of support –suffering

Psychologists look at the whole quality of life to try to reduce the extent that the pain causes suffering. Patients may be worried that doctors try to blame the pain on family environment –it is not a CAUSE but may make it harder to deal with the pain.

Studies have shown that 80% of people in the western world will experience back pain at some point in their life. 20% have some form of chronic pain yet our understanding of pain is very poor.

To treat a patient at the pain clinic the psychologist would first have the patient fill in a questionnaire to give a general idea of how it impacts on your life and how to improve the quality of life. They may look at triggers, see if anything can be identified. The patient may see the psychologist for about 6 weeks and monitor the pain. Strategies may be developed to decrease flare-ups.

Strategies. Using distraction to calm you down can be one technique but there is a limit to how long you can maintain it. The higher the pain, the lower the concentration levels making distraction less effective.

We often do things to avoid pain whereas we are sometimes able to push through the pain. When we stop using a body part, the brain focuses more on the unused area. It then becomes more sensitive to the pain. It can be better to keep using the body part.

TN can be very difficult because it is unpredictable and therefore can be uncontrollable

In controlling pain;

-try to keep a balance between resting/active periods –you are usually tired after a flare-up as it uses a lot of energy

-keep a balance between ignoring the pain and totally focusing on it –try not to avoid life completely

Partners

The psychologist likes to see the partner at the same time as the patient as they have a significant role in managing the pain and coping with the effects. The partner may feel helpless, especially during an attack. Partners can be either over solicitous, over caring and overprotective or punitive and uncaring.

In both cases, this can create problems in the marriage and the management of the pain. The patient can become more disabled if the partner is overprotective, but feel less supported by a punitive partner.

A balance between the two is the best result. The couple need to talk about it when attacks are not happening to develop a plan of how to deal with flare-ups. It is important to be caring and concerned without being overprotective. It is valuable to discuss the pain with your partner.

Talking with others about the pain. What do you say to work mates? It is helpful to have a brief concise statement about the TN. Let them know you have a problem with the nerve in the face. You will experience attacks of pain, which will pass. Tell them how you will deal with the attack and what you may expect of them. Eg 'I'll need to sit quietly until the attack passes. You can't do anything to help and it is best that I be left alone till it passes.' (or whatever suits you best)

Alternative treatments –anything that calms you down is valuable. It 'closes the gate' to the pain.

Anything is worth a try if it is not invasive, reversible and doesn't cost too much.

Be conscious about the fact that you are in a vulnerable position and may be used as a guinea pig.

How do we find a GP with TN knowledge? Dr Newton John agreed it is difficult and suggested:

-You may ask for a referral to a pain clinic –they may have access to knowledgeable GP's

-Talk to other members

-See the RNS website for pain management

We thanked Dr Newton John for his very informative talk.

(Kim S)

Very Well Done Kim. Thank you also for facilitating for the group at such a short notice. I am greatly heartened by Kim's potential and look forward to taking holidays in the future.

To my Sydney members :

The weeks leading up to the July meeting were tremendously strenuous for me. My father had been ill in hospital. On that Saturday, the docs were supposedly to be reviewing his condition, and if there were no improvement, they would withdraw all the drugs and move him to the ward and then "it would be a matter of hours." I was in no state to run a meeting, and had that dreaded phone call come I would need to leave immediately. I apologize for the spillage later that day. The strain was unbearable. My father passed away the following Friday. Thanks for your condolences and sympathies, and especially to Margaret who took time to attend the service.

Please continue to pray for Margaret and Doug.

SUNSHINE COAST SUPPORT GROUP

FRED MURRAY BUILDING
NAMBOUR

26TH JUNE 2004

ATTENDANCE :
Jane K, Jean W, David and Gloria, Ed and Pat W, Sandra G, Max H, Connie H, Mark and Jacqueline H, Marcella McS.

AGENDA:-
We had a lovely day for our meeting in Nambour, we seem to be averaging around 12 people a meeting. We had a new member, Mark and his family, hope Mark got something out of the meeting. Mark has been a sufferer for approx 9 years but has only recently been diagnosed. I'm sure hearing everyone else's stories might make him feel that he is not alone.

It was decided that more advertising was needed to let people know that there is a support group on the Sunshine Coast, Connie and Mark both come from and around the Tin Can Bay area and if able will put an ad in their local paper, also Ed will be looking into an ad in his area. I have asked that we check out the community billboard in the free local paper as we don't have the funds to pay for ads, (we all know how expensive they are).

Donations of $46.50 were received for the day. Many Thanks.

I also had to let everyone know that I no longer have access to the Fred Murray Building in Nambour as I am not positioned there anymore. Ed has been kind enough to secure us a room at a Dental Surgery at 23 Beach Road Maroochydore. Our next meeting will be on the 14th August at 1.30pm. Hope this will be a long term meeting room.

Marcella.

The Jar and the Coffee ☺

A professor stood before his philosophy class and had some items in front of him. When the class began, wordlessly, he picked up a very large and empty jar and proceeded to fill it with golf balls. He then asked the students if the jar was full. They agreed that it was.
So the professor then picked up a box of pebbles and poured them into the jar. He shook the jar lightly. The pebbles rolled into the spaces between the golf balls. He then asked the students again if the jar was full. They agreed it was.
The professor next picked up a box of sand and poured it into the jar. Of course, the sand filled up everything else. He asked once more if the jar was full. The students responded with a unanimous "yes."
The professor then produced two cups of coffee from under the table and poured the entire contents into the jar, effectively filling the empty space between the sand. The students laughed.
"Now," said the professor, as the laughter subsided, "I want you to recognize that this jar represents your life. The golf balls are the important things - your God, your family, your children, your health, your friends, and your favorite passions - things that if everything else was lost and only they remained, your life would still be full. The pebbles are the other things that matter like your job, your house, and your car.
The sand is everything else-the small stuff. "If you put the sand into the jar first," he continued, "there is no room for the pebbles or the golf balls.
The same goes for life. If you spend all your time and energy on the small stuff, you will never have room for the things that are important to you. Pay attention to the things that are critical to your happiness. Play with your children. Take time to get medical checkups. Take your partner out to dinner. Play another 18. There will always be time to clean the house and fix the disposal." Take care of the golf balls first, the things that really matter. Set your priorities. The rest is just sand." One of the students raised her hand and inquired what the coffee represented. The professor smiled. "I'm glad you asked. It just goes to show you that no matter how full your life may seem, there's always room for a couple of cups of coffee with a friend."

Correspondence Corner

Trevor H : I have had the disease for about 3 1/2 years and got to the stage last year where the pain was without letup for about 9 months 24 hours a day. I am an incredibly strong person for my age both physically and mentally but even though the specialist upped my dosage of Tegretol 1200 milligrams a day and Valpro to 400 mg a day I was still getting severe pain which was one of the reasons I never wrote or paid your annual fee.
I decided as with many things in my life to take control myself and early last September stopped all medication (the above). At the same time I would try to relax myself and get deep into my brain making it fight and stop the pain into the trigeminal nerve. I now believe I have been about 90% successful and the little pain that returns every now and then I have learned to relax instead of tensing up (very hard) and it generally goes quickly. While I am reminding my brain to stop the spasms. I have not taken any tablets since last December and have given the specialist away. If I can be of any help to anyone well it would be good, but it has not been easy especially the 1st few weeks but now I lead almost a normal life and the little pain I suffer in infinitesimal compared with before. But after such a tough time you can never be sure it won't return full blast but I am determined to fight in do my thing for an hour every morning and be positive. Thanking you for sending me your literature, I remain very thankful.

Marilyn : We now have a compounding Chemist here in Canberra at Macqurie Chemist Shop.
We got from him today 'Percutane' which was around $11 for 100gms. It has capsican in it and he said worth a try for me. He can also make up what is in Zostrix if this doesn't work.

Anne Marie(France) **:** I finally went to see this famous Dr Sindou and was very impressed. Many thanks for recommending him. He's recommended an MVD and I found out that he works with the neurologist Dr Rougemont whom I've been seeing lately. The MRIs that I've had don't show anything but the four doctors I have seen so far are saying that it doesn't mean that there is no vascular compression. So I'm booked for the MVD on 13 September. They wanted to hospitalise me straightaway as in both consultations I had quite a few attacks then. I also want to have my jaw fixed as I have one muscle that is hyperactive and adds to the pains and I'm sure is aggravating the pain from TN.

Forrest Gump Goes To Heaven.

Courtesy of Margaret W.

The day finally arrived; Forest Gump dies and goes to Heaven. He is at the Pearly Gates, met by St. Peter himself. However , the gates are closed and Forrest approaches the Gatekeeper. St. Peter says, "Well, Forrest, it's certainly good to see you. We've heard a lot about you. I must tell you, though, that the place is filling up fast, and we've been administering an entrance examination for everyone. The test is short, but you have to pass it before you can get into Heaven".
Forrest responds, "It shor is good to be here, St. Peter, sir. But nobody ever told me about any entrance exam. Shor hope the test ain't too hard; life was a big enough test as it was."
St. Peter goes on, "Yes, I know, Forrest, but the test is only three questions.
First: What two days of the week begin with the letter 'T?
Second: How many seconds are there in a year?
Third: What is God's first name?"
Forrest leaves to think the questions over. He returns the next day and sees St. Peter who waves him up and says, "Now that you have had a chance to think the questions over, tell me your answers."
Forrest says, "Well, the first one - which two days in the week begin with the letter "T"? Shucks, that one's easy - That'd be Today and Tomorrow".
The Saint's eyes open wide and he exclaims, "Forrest, that's not what I was thinking, but you do have a point, and I guess I didn't specify, so I'll give you credit for that answer. How about the next one?" asks St. Peter.
How many seconds in a year?"
"Now that one's harder," says Forrest, but I thunk and thunk about that a nod I guess the only answer can be twelve."
Astounded, St. Peter says, "Twelve? Twelve? Forrest, how in Heaven's name could you come up with twelve seconds in a year?"
Forrest says "Shucks, there's gotta be twelve - January 2nd, February 2nd, March 2nd ..."

"Hold it," interrupts St. Peter. I see where you're going with this, and I see your point, though that wasn't quite what I had in mind ... but I'll have to give you credit for that one, too. Let's go on with the third and final question. Can you tell me God's first name?"
"Sure" Forrest replied - "It's Andy."
"Andy?" exclaimed an exasperated and frustrated St. Peter. "OK, I can understand how you came up with your answers to my first two questions, but just how in the world did you come up with the name Andy as the first name of God?"
:Shucks, that was the easiest one of all." Forrest replied. I learnt it from the song –
"ANDY WALKS WITH ME, ANDY TALKS WITH ME, ANDY TELLS ME I AM HIS OWN..."

Pharmacologic Management of Pain Expert Column

Expanding Our Understanding of Central Sensitization

Jeffrey A. Gudin, MD
Medscape Neurology & Neurosurgery 6(1), 2004.
http://www.medscape.com/viewarticle/481798 Posted 06/28/2004

Why does local injury resulting from trauma lead to chronic, intractable pain in some patients? What is responsible for the translation of local injury with acute pain into a chronic pain state? Why does some pain respond to anti-inflammatory drugs, whereas other types require opiates?
Pain is a complex process involving both the peripheral nervous system (PNS) and the central nervous system (CNS). Tissue injury activates the PNS, which sends signals through the spinal cord to the brain, where pain perception occurs. But what causes the acute experience of pain to become an unremitting phenomenon? Can anything be done to prevent it? Evidence suggests that chronic pain results from a combination of mechanisms, including neural "memories" of previous pain.
Nociception: The Simplest Path
Acute or nociceptive pain is the everyday experience of discomfort that occurs in response to a simple insult or injury. It is protective, warning us to move away from the cause of the injury and take care of the trauma. The mechanisms that generate nociceptive pain include transduction, which converts the external traumatic stimulus into electrical activity in specialized nociceptive primary afferent nerves. The afferent nerves then conduct the sensory information from the PNS to the CNS. In the CNS, the pain information is transmitted from the primary sensory neurons to central projection neurons. When the information is transferred to those parts of the brain that are responsible for our perception, the actual sensory experience occurs. Nociceptive pain is a relatively simple response to a relatively simple, acute stimulus. But the mechanisms responsible for nociceptive pain cannot explain phenomena, such as pain that persists despite removal or healing of the stimulus, such as in phantom limb pain.

Pain and the Inflammatory Response

In cases of more severe trauma (including surgical wounds), tissue damage stimulates an inflammatory response. But other conditions, notably arthritis, are also characterized by ongoing inflammation associated with severe pain. The mechanisms for this sort of pain related to tissue damage and inflammation are distinct from early-warning nociceptive pain. Following the incision or other trauma, a cascade of hyperexcitable events occurs in the nervous system. This physiologic "wind-up" phenomenon starts at the skin, is potentiated along the peripheral nerves, and culminates in a hypersensitivity response from the spinal cord (dorsal horn) and brain.
Inflammatory cells surround the areas of tissue damage and produce cytokines and chemokines, substances that are meant to mediate the process of healing and tissue regeneration. However, these agents are also irritants and change the properties of the primary sensory neurons surrounding the area of trauma.
Thus, the major features triggering inflammatory pain include damage to the high-threshold nociceptors (peripheral sensitization), modifications and modulation of the neurons in the nervous system, and amplification of the excitability of neurons within the CNS. This represents central sensitization and is responsible for hypersensitivity, in which areas adjacent to those of the actual injury hurt as if injured. These tissues also can respond to stimuli that ordinarily do not produce pain, such as a touch, clothing, light pressure, or a hairbrush, as if they are painful (allodynia).

Other Mechanisms in the Pain Mix

Neuropathic pain results from an insult to the nervous system, such as carpal tunnel syndrome, postherpetic neuralgia, diabetic neuropathy, etc. Although some of the mechanisms that seem to

cause neuropathic pain overlap with those responsible for inflammatory pain, many of them are distinct, and thus will require a different approach to management.
The process of peripheral and central sensitization is maintained, at least theoretically and experimentally, through the excitatory neurotransmitter, glutamate, which is believed to be released when the *N*-methyl-D-aspartate (NMDA) receptor is activated.
Our nervous system includes either inhibitory or excitatory neurotransmitters. Most of what allows our nervous system to react appropriately is the fine-tuning or inhibition of many processes. The overexcitation of the nervous system is seen to be a problem in a number of different disorders. For example, overactivation of an NMDA receptor is also associated with affective disorders, sympathetic abnormalities, and even opiate tolerance.
Even normal nociceptive pain, in part, activates the NMDA receptor and may result in glutamate release. However, in neuropathic pain oversensitivity to the NMDA receptor is key.
With other types of chronic pain, such as fibromyalgia and tension-type headache, some of the mechanisms active in inflammatory and neuropathic pain may also produce similar changes in the pain system, including central sensitization, greater excitability of the somatosensory pathways, and reductions in CNS inhibitory mechanisms.

Peripheral Sensitization

Cyclo-oxygenase (COX) also plays an important role in both peripheral and central sensitizations. COX-2 is among the enzymes that are induced during the inflammatory process; COX-2 converts arachidonic acid to prostaglandins, which increase the sensitivity of peripheral nociceptor terminals. Of interest, peripheral inflammation also causes COX-2 to be released in the CNS. Signals from peripheral nociceptors are partially responsible for this upregulation, but there also appears to be a humoral component to the transduction of the pain signal across the blood-brain barrier. For example, in experimental models, COX-2 is produced in the CNS even when animals receive a sensory nerve block *before* peripheral inflammatory stimulation. The COX-2 that is expressed within the dorsal horn neurons of the spinal cord produces prostaglandins, which act on the central terminals -- the presynaptic terminals of nociceptive sensory fibers -- to increase transmitter release. In addition, they act postsynaptically on the dorsal horn neurons to produce direct depolarization. And finally, they inhibit the action of glycine receptor, which is an inhibitory transmitter. Thus, the prostaglandins produce an increase in excitability of neurons centrally.

Brain Plasticity and Central Sensitization

Central sensitization describes changes that occur in the brain in response to repeated nerve stimulation. Following repeated stimulation, levels of neurotransmitters and brain electrical signals change as neurons develop a "memory' for responding to those signals. Frequent stimulation results in a stronger brain memory, so that the brain will respond more rapidly and effectively when experiencing the same stimulation in the future. The resulting changes in brain wiring and response are referred to as *nerve plasticity* (describing the ability of the brain to change easily) or central sensitization. Thus, the brain is activated or sensitized by previous or repeated stimuli to become more excitable.
The changes of central sensitization occur after repeated experiences with pain. Research in animals shows that repeated exposure to a painful stimulus will change the animal's pain threshold and result in a stronger pain response. Researchers believe that these changes may explain the persistent pain that can occur even after successful back surgery. Although a herniated disc may be removed from a pinched nerve, pain may continue as a memory of the nerve compression. Newborns undergoing circumcision without anesthesia will respond more profoundly to future painful stimuli, such as routine injections, vaccinations, and other painful procedures. These children have not only a greater hemodynamic response (tachycardia and tachypnea), but increased crying as well.
This neural memory of pain has been studied extensively. In a review of his earlier studies, Woolf[1] noted that the enhanced reflex excitability after peripheral tissue damage does not depend on continuing peripheral input; rather, hours after a peripheral injury, spinal dorsal horn neuron receptive fields continued to expand. Investigators have also documented the importance of the spinal NMDA receptor to the induction and maintenance of central sensitization.[2]

Implications for Pain Management

Once central sensitization is established, larger doses of analgesics are required to suppress it. Preemptive analgesia, or treatment before pain progresses, may reduce the impact of all these stimuli on the CNS. Woolf[3] demonstrated that the morphine dose needed to prevent central hyperexcitability, given before brief noxious electrical stimulation in rats, was one tenth the dose required to abolish activity after it had developed. This translates to clinical practice. In a clinical trial of 60 patients undergoing abdominal hysterectomy,[4] those who received 10 mg of morphine intravenously at the time of induction of anesthesia required significantly less morphine for postoperative pain control. Furthermore, pain sensitivity around the wound (secondary hyperalgesia) was also reduced in the morphine pretreated group.

Preemptive analgesia has been used with similar success in a variety of surgical settings, including prespinal surgery[5] and postorthopaedic surgery.[6]

A single dose of 40 or 60 mg/kg of rectal acetaminophen has a clear morphine-sparing effect in day-case surgery in children, if administered at the induction of anesthesia. Moreover, children with adequate analgesia with acetaminophen have less postoperative nausea and vomiting.[7]

NMDA receptor antagonists have imparted postoperative analgesia when administered preoperatively. Various reports exist in the literature supporting the use of ketamine and dextromethorphan in the perioperative period. In patients undergoing anterior cruciate ligament reconstruction, 24-hour patient-controlled analgesia opioid consumption was significantly less in the preoperative dextromethorphan group vs the placebo group.[8]

In double-blind, placebo-controlled studies, gabapentin has been suggested as a premedicant analgesic for patients undergoing mastectomy and hysterectomy. Preoperative oral gabapentin reduced pain scores and postoperative analgesic consumption without difference in side effects as compared with placebo.[9,10]

Preoperative administration of nonsteroidal anti-inflammatory drugs (NSAIDs) has shown a significant reduction in opioid use postoperatively. COX-2s are preferable because of their relative lack of platelet effects and significant gastrointestinal safety profile as compared with traditional NSAIDs. Celecoxib, rofecoxib, valdecoxib, and parecoxib (outside the United States) administered preoperatively reduce postoperative narcotic use by more than 40%, with many patients using less than half of the opioids as compared with placebo.[11,12]

Blocking nerve conduction in the perioperative period appears to prevent the development of central sensitization. Phantom limb syndrome (PLS) has been attributed to a spinal wind-up phenomenon. For patients undergoing lower-extremity amputation under epidural anesthesia, none of the 11 patients who received lumbar epidural blockade with bupivacaine and morphine for 72 hours before surgery developed PLS. For those who underwent general anesthesia without prior lumbar epidural blockade, 5 of 14 patients had PLS at 6 months and 3 continued to experience PLS at 1 year.[13]

Woolf and Chong[14] have noted that ideal preoperative, intraoperative, and postoperative treatment includes "NSAIDs to reduce the activation/centralization of nociceptors, local anesthetics to block sensory inflow, and centrally acting drugs such as opiates." Decreasing perioperative pain with preemptive techniques improves satisfaction, hastens discharge, spares opioid use (decreased constipation, sedation, nausea, and urinary retention), and may even prevent the development of chronic pain. Anesthesiologists and surgeons should consider incorporating these techniques into their everyday practices.

When pain occurs as a consequence of injury or surgery, the spinal cord can reach a hyperexcitable state wherein excessive pain responses occur that may persist for days or weeks (or even years).

Conclusion

Why does local injury resulting from trauma lead to chronic, intractable pain in some patients? Tissue injury leads to a constellation of changes in spinal excitability, which includes elevated spontaneous firing, increased response amplitude and duration, decreased threshold, enhanced discharge to repeated stimuli, and expanded receptive fields.[3] The persistence of these changes, which are collectively termed central sensitization, appears to be fundamental to the prolonged enhancement of pain sensitivity that defines chronic pain. Various medications and local anesthetic

neural blockade may limit the magnitude of this CNS windup, as evidenced by diminished pain and reduced opioid consumption in the preemptive analgesic models.

References -

Medscape Neurology & Neurosurgery 6(1), 2004. © 2004 Medscape
http://www.medscape.com/viewarticle/481798

NEXT MEETING : 2004

Newcastle : **14 August**. *1:OOPM - 4:OOpm*
Guest Speaker: LORETO WHITNEY, kinesiologist and homeopathy
TUTORIAL ROOM, LEVEL 6 MATER HOSPITAL
Lorna Street (Off Maud St.) Newcastle. Meet at Daffodils Cafe
Support group leader Phil Leaver: 49387361 or 0427571700.

Melbourne : **14 August** 1:30-4pm "Ringwood Room"
Ringwood Library
Support group leader: Joan Thompson - 03 9725 3808

Sunshine Coast : 14August 1:30 – 4:00pm
23 Beach Rd (Dental Surgery)
MAROOCHYDORE
Support group leader : Marcella McSweeny

Sydney : **4 September** *2 - 4:30pm Winston Hills Public School* Junction Rd, WISNTON HILLS.
Celebrate with us- 4th our Anniversary
Support group leader: Irene Wood 45 796226

Brisbane : **11 September** *l:30-4:00pm*
30 Ridley Rd., Bridgeman Downs.
Support group leader: Lesley Curtain 32642838

Sunshine Coast : **18 September** 1:30pm at
Maroochydore
Guest : Irene Wood.

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

GOD BLESS

Contact: Irene Wood
359 Terrace Rd, Nth Richmond, NSW 2754 Australia
Tel : 0245796226
Email: tna_sydney@yahoo.com
Website: http://tnasydney.freeservers.com
Trigeminal Neuralgia Association Australia is affiliated with TNA USA, 2801 S.W. Archer Rd, Gainesville Florida 32608